Bangor University

DOCTOR OF PHILOSOPHY

Living with Stroke
a Wales context

Heyworth-Thomas, Elizabeth Mary

Award date:
2018

Awarding institution:
Bangor University

Link to publication

Living with Stroke: a Wales context

PRIFYSGOL
BANGOR
UNIVERSITY

1884

PhD Sociology and Social Policy

Thesis submitted to

The School of Social Sciences

Author: Elizabeth Mary Heyworth –Thomas

Executive Summary

This thesis reports the findings of a doctoral study which sought to explore the everyday lives of survivors of stroke and their caregivers, who live in Wales, UK. Through an exploratory multi-method approach to research, data collected from survivors of stroke, their caregivers, and Stroke Club observations provided in-depth insight into the participants' lives, and the contribution of Stroke Clubs to the personal support networks of the study participants. The findings of this study provide an insight into post-stroke life in Wales. The findings also highlight the value of social enterprise (Stroke Clubs) in the context of supporting survivors of stroke and their caregivers, in the months and years after stroke. The key conclusions of this study are that survivors and caregivers benefit from life-long support. Furthermore, the social enterprise sector provides an avenue of informal support and has the potential to meet the aims of policy makers, by filling the gaps in existing service provision. This thesis contributes to the fields of sociology, social policy, social enterprise, and research methods for research involving vulnerable adults. Recommendations for practitioners, policy makers, and social entrepreneurs are underpinned by the study findings and include suggestions for effective collaboration between the sectors. The limitations of this study are that the sample consisted of eight (of nine) participants who engaged with Stroke Clubs. Therefore, a contrast between those who attended Stroke Club and those who did not could not be established. However, this thesis does form the basis of such study in the future as it highlights what the participants perceive to be benefits of Stroke Club.

Table of Contents

List of Figures

List of Tables

Acknowledgments

I would like to aknowledge the support of the academics at Bangor University for their support and guidance throughout my studies. The support and guidance of supervisors Professor Catherine Robinson and Dr Diane Seddon throughout the completion of this thesis has been greatly appreciated. I thank my family and friends for their everlasting support in all I have done. I wish to dedicate this thesis to my husband, parents and grandparents, who have supported me throughout my studies, and to those family members who did not get to see me complete this achievement.

For Dad, Nanna, Nan, Aunty Siân, Grandpa and Linda.
May you be forever at my side.

<div align="center">**Declaration and Consent**</div>

Details of the Work
I hereby agree to deposit the following item in the digital repository maintained by Bangor University and/or in any other repository authorized for use by Bangor University.

Author Name: Elizabeth Mary Heyworth-Thomas

Title: Living with Stroke: a Wales context

Department: School of Social Science

Supervisor(s): (1st.) Professor Catherine Robinson (2nd.) Dr Diane Seddon

Qualification/Degree obtained: Thesis in submission for PhD Sociology and Social Policy
This item is a product of my own research endeavours and is covered by the agreement below in which the item is referred to as "the Work". It is identical in content to that deposited in the Library, subject to point 4 below.

Non-exclusive Rights
Rights granted to the digital repository through this agreement are entirely non-exclusive. I am free to publish the Work in its present version or future versions elsewhere.
I agree that Bangor University may electronically store, copy or translate the Work to any approved medium or format for the purpose of future preservation and accessibility. Bangor University is not under any obligation to reproduce or display the Work in the same formats or resolutions in which it was originally deposited.

Bangor University Digital Repository
I understand that work deposited in the digital repository will be accessible to a wide variety of people and institutions, including automated agents and search engines via the World Wide Web.
I understand that once the Work is deposited, the item and its metadata may be incorporated into public access catalogues or services, national databases of electronic theses and dissertations such as the British Library's EThOS or any service provided by the National Library of Wales.
I understand that the Work may be made available via the National Library of Wales Online Electronic Theses Service under the declared terms and conditions of use (http://www.llgc.org.uk/index.php?id=4676). I agree that as part of this service the National Library of Wales may electronically store, copy or convert the Work to any approved medium or format for the purpose of future preservation and accessibility. The National Library of Wales is not under any obligation to reproduce or display the Work in the same formats or resolutions in which it was originally deposited.

Statement 1:
This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree unless as agreed by the University for approved dual awards.

Signed: *E Heyworth-Thomas*   (candidate)

Date: 01/02/2018

Statement 2:
This thesis is the result of my own investigations, except where otherwise stated. Where correction services have been used, the extent and nature of the correction is clearly marked in a footnote(s).
All other sources are acknowledged by footnotes and/or a bibliography.

Signed: *E Heyworth-Thomas*   (candidate)

Date: 01/02/2018

Statement 3:
I hereby give consent for my thesis, if accepted, to be available for photocopying, for inter-library loan and for electronic storage (subject to any constraints as defined in statement 4), and for the title and summary to be made available to outside organisations.

Signed: *E Heyworth-Thomas*   (candidate)

Date: 01/02/2018

Statement 4:
Choose **one** of the following options

a)　I agree to deposit an electronic copy of my thesis (the Work) in the Bangor University (BU) Institutional Digital Repository, the British Library ETHOS system, and/or in any other repository authorized for use by Bangor University and where necessary have gained the required permissions for the use of third party material.	x
b)　I agree to deposit an electronic copy of my thesis (the Work) in the Bangor University (BU) Institutional Digital Repository, the British Library ETHOS system, and/or in any other repository authorized for use by Bangor University when the approved **bar on access** has been lifted.	
c)　I agree to submit my thesis (the Work) electronically via Bangor University's e-submission system, however I **opt-out** of the electronic deposit to the Bangor University (BU) Institutional Digital Repository, the British Library ETHOS system, and/or in any other repository authorized for use by Bangor University, due to lack of permissions for use of third party material.	

Options B should only be used if a bar on access has been approved by the University.

In addition to the above I also agree to the following:

1. That I am the author or have the authority of the author(s) to make this agreement and do hereby give Bangor University the right to make available the Work in the way described above.

2. That the electronic copy of the Work deposited in the digital repository and covered by this agreement, is identical in content to the paper copy of the Work deposited in the Bangor University Library, subject to point 4 below.

3. That I have exercised reasonable care to ensure that the Work is original and, to the best of my knowledge, does not breach any laws – including those relating to defamation, libel and copyright.

4. That I have, in instances where the intellectual property of other authors or copyright holders is included in the Work, and where appropriate, gained explicit permission for the inclusion of that material in the Work, and in the electronic form of the Work as accessed through the open access digital repository, *or* that I have identified and removed that material for which adequate and appropriate permission has not been obtained and which will be inaccessible via the digital repository.

5. That Bangor University does not hold any obligation to take legal action on behalf of the Depositor, or other rights holders, in the event of a breach of intellectual property rights, or any other right, in the material deposited.

6. That I will indemnify and keep indemnified Bangor University and the National Library of Wales from and against any loss, liability, claim or damage, including without limitation any related legal fees and court costs (on a full indemnity bases), related to any breach by myself of any term of this agreement.

Signature: *EHeyworth-Thomas*

Date: 01/02/2018

"Stroke patients may spend several days or weeks in hospital, but it is in the months and years after discharge that they, their families and carers, experience the full impact of stroke."

(National Audit Office 2010, 24)

1.0   Introduction

This thesis reports the findings of a qualitative study funded by Bangor University under the 125th Anniversary Scholarship Scheme. The study explored the everyday lives of survivors of stroke and their caregivers in Wales, and the ways in which social enterprise initatives contribute to post-stroke life.

Everyday life is a broad phrase which is used by academics in the existing knowledge base to explore various aspects of sociology. Everyday life is considered by Heller (2016) to be a social contract and made up of social interaction in society. This includes the behaviour of individuals, and situations that occur in daily life, which Karp et al. (2016) feel individuals may take for granted. For the purpose of this thesis, the author defines everyday life as the behaviours of, and situations experienced by the study participants. This included situations which occur regularly, perhaps on a daily basis and experiences which have been significant for the participants and may have impacted on their daily lives in some way. By doing so, this thesis explores the participants' post-stroke lives; that is, their feelings towards life situations, their behaviours towards life situations, their levels of social participation, and the support they receive.

To explore the phenomenon of interest in its entirety, data collected from Stroke Clubs through observational research informed how social enterprise initiatives provided support to the participants, while interviews using the Biographic Narrative Interpretive Method (BNIM) allowed the author to consider the participants' perspectives on such support. To fully ascertain the support that the participants received and their feelings about it, the thesis reports on health and social care policy initiatives and whether they are deemed effective in providing a contribution to the participants' lives.

The findings of this study contribute to academic literature within the Social Sciences, and Business Studies disciplines, and have implications for health and social care practitioners, policy makers, service providers and social enterprise organisations. Through in-depth insights into the everyday lives and experiences of individuals who have experienced a stroke and their caregivers, service responses and policy development, this thesis informs a greater understanding of how to provide effective support to people who are living with stroke in their everyday lives.

1.1 A Note on Terminology Adopted within this Thesis

Throughout this thesis, the participants who have experienced stroke are referred to as 'survivors'. This phrase is not only prevalent in the existing literature; it is the term that the individuals who had experienced stroke used to describe themselves. Furthermore, in this study, the term 'caregiver' is used to refer to those people who provide care for the survivors of stroke, who are adult children of the survivors, their spouse, or partner.

1.2 Development of the Research Questions and the area of interest

The research questions were:

- What is everyday life like for people living with stroke in Wales?
- What is everyday life like for caregivers of survivors of stroke?
- How are survivors of stroke and their caregivers supported in their everyday lives?

These questions prompted the development and exploration of substantive areas of interest presented in Figures 1 and 2, underpinning the review of the existing literature in Chapters 2 and 3. By having two separate elements to the model presented in Figure 1, the author highlights the dyadic nature of the study of carers and the cared-for which allowed consideration of multiple perspectives. This approach ensured the findings of this study provided as full a picture as possible, making the findings robust and reliable.

The review of the literature helped the author further develop the research questions. To draw valid research conclusions, the author then defined the research aims and objectives. There were three research aims to this study which are outlined overleaf, along with the research objectives set to meet each aim.

The research aims and objectives were as follows:

Aim 1:   To explore the everyday lives and experiences of survivors of stroke and their caregivers by:
- Gaining an insight into everyday life with stroke;
- Identifying key aspects of everyday life, such as challenges faced and changes experienced.

Aim 2:   To identify the key avenues of support for survivors of stroke and their caregivers by:
- Identifying the key actors who provide help and support to survivors and their caregivers;
- Exploring the role of the (identified) key actors and their contribution to the everyday lives of survivors and caregivers.

Aim 3:   To explore how the social enterprise sector supports survivors of stroke and their caregivers by:
- Defining social enterprise in this context;
- Exploring how the social enterprise sector can support policy initiative and statutory sector provision (from the participants perspective);
- Exploring the contribution of social enterprise (Stroke Clubs) to the everyday lives of survivors of caregivers.

These aims and objectives along with the review of the existing literature influenced the exploratory research design and the inductive, qualitative methodology of the study.

1.3   Research Rationale

There are over 1.2 million survivors of stroke in the UK (The Stroke Association 2016), 66,000 of which are said to reside in Wales (Welsh Governent 2017). Stroke is recognised as the largest cause of adult disability and the third most common cause of death after heart disease and all cancers in the UK (Kumar et al. 2015; The Stroke Association 2016; Welsh Government 2016a; Williams et al. 2008). Stroke remains a key area for Welsh health and social care policy. There are approximately 7,600 strokes in Wales each year (Welsh Government 2017), 6,000 of which are new stroke incidences (Welsh Government 2016a). Much previous academic research and health and social care policy have had a strong focus on prevention strategies, as healthcare professionals and policy makers are increasingly aware of the risks of stroke. Advances in medical research have led to more people surviving stroke. With the rate of stroke incidence staying the same, more people are living with the impact of stroke in their everyday lives (Ashton et al. 2010; Glasby 2017; Kim et al. 2015; Lee et al. 2011). This trend also suggests that there is an increase in the number of family members becoming caregivers of stroke survivors. This assumption is justified by the research of Bäckström and Sundin (2009), Cameron et al. (2013), McPherson et al. (2011), and The Stroke Association (2016) who state that when survivors return home from hospital, they are (typically) cared for by family members. As there are more survivors of stroke, there is a stronger need to support survivors and caregivers in their everyday lives. To do this effectively, academic researchers and policy makers need to understand the lived experiences of both the survivors and their caregivers. The findings of this study contribute to the existing literature by discussing these perspectives, through a methodology which will allow for reflection and the consideration of any change over time. This research is particularly important, as there is a gap in the existing literature which focuses on survivors and their caregivers (experience combined) in the months and years after stroke.

1.4   Reviewing the Existing Body of Knowledge

Chapters 2, 3, and 4 report the existing research in the fields of sociology, health and social care, policy, and practice. The focus of this study meant that this review of the existing literature considered predominantly qualitative and narrative research. However, quantitative data streams were also considered, as no specific data stream or approach was excluded from the search criteria.

When deciding keywords used, the author referred to terminologies used by other authors and a thesaurus to consider alternative terminologies; beginning each search area with an initial keyword or phrase. To narrow the search results down, the author refined the search parameters by considering further limiters such as the year of publication and descriptors. The author broadened the parameters again when the search became too narrow. Further possible linkages were also explored with use of Boolean operators such as 'AND' and 'OR' within the search parameters, allowing exploration of the core topic and the interrelationships which surround it (Finfgeld-Connett and Johnson 2013).

The search was conducted using online public bibliographic databases such as Web of Knowledge, PsycINFO, and Medline (CSA), as well as private bibliographic databases such as the Applied Social Sciences Index and Abstracts (ASSIA); and, the Cumulative Index to Nursing and Allied Health Literature (ACINAL). The search also utilised specialised bibliographic databases consisting of government reports, Census Data websites, and online search engines.

Academic research papers, books, and journals consulted throughout the review, as well as a 'by hand' search, allowed backward tracking where the author referred to reference lists used by other authors.

Figure 1 overleaf presents the conceptual framework which underpins the review of the existing literature discussed in Chapter 2 and 3.

Figure 1:   Areas of Exploration: Chapters 2 and 3

A Priori Themes
Everyday life: Survivor

Living with the outcomes of stroke
Survivor need
Coping with post-stroke life
Emotional and psychological wellbeing
Personal support network
Social participation
Quality of life

Emerging Themes

Positive perspectives
Perception of the self
Identity
Stigma and discrimination
Specific coping strategies
Participation in activities

The Survivor – Caregiver

Relationship between themes

The literature reported in Chapters 2 and 3 was revisited as themes emerged from the primary data collection.

A Priori Themes
Everyday life:Caregiver

Defining the caregiver
Preparing for the caregiving role
Caregiver need
Coping with post-stroke life
Personal support networks
Social participation
Quality of life
Emotional and psychological wellbeing

Emerging Themes

Positives of caregiving
Perception of the self
Identity
Specific coping strategies
Participation in activities
Intellectual fulfilment

As Figure 1 illustrates, the review of the existing knowledge base on everyday life and stroke was inclusive of the following key themes:

- Stroke - to gain an understanding of the causes of, prevention of, results of, and rehabilitation;
- Living with Neurology, cerebrovascular disease, and vascular conditions - to gain a deeper understanding of stroke and related conditions;
- Everyday lives (of survivors and caregivers) – with a focus on chronic disease;
- Quality of Life – to learn of those key elements of everyday life referred to by professional practitioners, and academics; and,
- Social Participation, with a focus on living with physical disability and neuro-disability.

Figure 1 presents, in blue, the a priori themes. These themes formed the basis of the literature review and the basis of this study. As the primary data was analysed, new themes began to emerge from the data. These themes are presented in green. As Figure 1 shows, the author revisited the literature and conducted a futher review of the existing knowledge base as themes emerged from the research. This ensured that the literature reported in Chapters 2 and 3 of this study is current, and that all key themes from the study were thoroughly explored. Therefore, figure 1 not only informs the development of Chapters 2 and 3, it also shows key themes which surround the everyday life and lived experience concept, in the context of survivors of stroke and their caregivers. Finally, Figure 1 also presents to the reader, the themes which impacted on the participants' everyday lives as found in this study.

Figure 2 overleaf presents the areas of interest explored within Chapter 4: Supporting Survivors and Caregivers. The overlap of the circles represents the focus of the literature search. Similarly to Figure 1, the a priori themes are presented in the colour blue, and those themes which emerged from the data analysis are presented in green.

Figure 2:   Areas of Exploration: Chapter 4
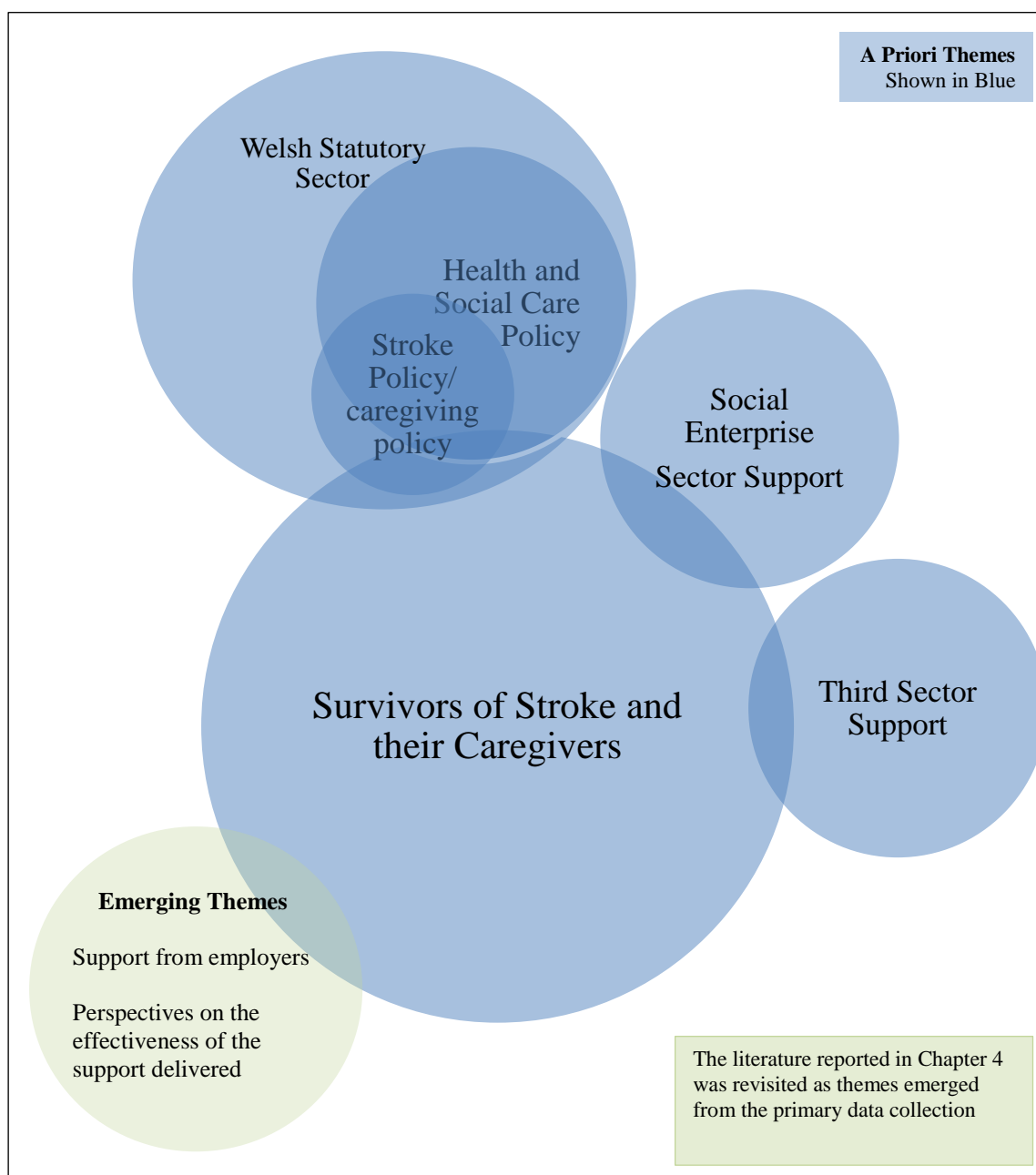
As Figure 2 illustrates, the author explored the literature surrounding supporting survivors and their caregivers, focusing on the following themes.

While reviewing the existing knowledge base the author drew on advice by McGivern (2013), Gray (2013) and Silvernman (2013), and considered the appropriateness of each resource by:

- Its validity – were the methods robust? Was the sample adequate?
- Its credibility – where was the source from? Which journal is it in? Is it cited? Has it been critiqued by another author?
- Its reliability – were the methods reliable? Is the data reliable? Are there any supporting or conflicting articles?

The author stored each citation reviewed into an online RefWorks database. This strategy ensured that all references were stored and readily retrievable, when appropriate, adding efficiency and rigorousness to the reviewing process. This phase was on-going throughout the whole study. The search parameters were revisited towards the end of the study, to ensure that all findings, discussion, and literature searched was up to date, current and relevant.

1.5 Thesis Structure

Here the thesis structure is presented. Chapters 2, 3, and 4 provide a review of the existing literature. Then, Chapter 5 presents the research design and methodology, Chapter 6 introduces the study participants and Chapters 7, 8, and 9 present the research findings. Chapter 10 closes the thesis, through its conclusion and recommendations.

Chapter 2: The Impact of Stroke, first explores the existing body of knowledge of the impact which stroke can have on a survivor's post-stroke life. This discussion includes topics such as living with physical and neurological disability, emotional and psychological wellbeing, the transition into the caregiving role, and identified survivor and caregiver need.

Chapter 3: Post-Stroke Life, continues the discussion from Chapter 2, with a focus on the survivor and caregiver relationship, personal identity, stigma, and discrimination, coping, social participation and perceptions of quality of life.

Chapter 4: Supporting Survivors and Caregivers, explores the existing literature on the ways in which survivors and caregivers receive support from the statutory, third, and social enterprise

sectors. The chapter describes health and social care policy and practice in Wales and discusses the development of Welsh stroke-specific policy.

Chapter 5: Research Design and Methodology, describes and provides a rationale for the research approach, design, and methods chosen in order to collect, analyse, and interpret primary data, and meet the research aims and objectives.

Chapter 6: Setting the Scene: An Introduction to the Study Participants, provides a context to the research findings by giving an overview of the study participants and the details of their stroke, case by case.

Chapter 7: Findings: Living with Stroke, reports the experiences of living with stroke as reported by the study participants, both survivors and caregivers, with a focus on various elements of their everyday lives as highlighted in the existing literature and the narratives told.

Chapter 8: Findings: Intellectual Fulfilment, Hobbies, Interests and Social Participation, continues from Chapter 7 and discusses the participants' perspectives of intellectual fulfillment in their post-stroke lives, and discussion on hobbies, interests and social participation since the participants experienced stroke, or became caregivers.

Chapter 9: Findings: Supporting Survivors and their Caregivers, reports of the ways in which caregivers and survivors are supported by the statutory, third, and social enterprise sectors.

Chapter 10: Conclusions, Recommendations, Implications, and Reflections, synthesises the research findings, presenting the author's concluding thoughts, reflecting on the research process, providing recommendations for Welsh policy makers and practitioners, and highlighting the implications for future health and social care policy development and avenues for future research.

1.6   Chapter Summary

This chapter has introduced the thesis and has detailed the thesis title, the research questions and the aims and objectives of the study. With the methodology deployed explained and justified, and the reader provided with a summary of each chapter contained within the thesis, the next chapter, Chapter 2 discusses the existing literature on living with stroke, considering both the survivor and caregiver perspective.

2.0   The Impact of Stroke

Chapter 2 is the first of three chapters which report a review of the existing knowledge base. Chapter 2 reports the existing knowledge of living with stroke; highlighting the emotional and physical impact of stroke. Chapter 3 reports of post-stroke life inclusive of social participation and coping, and Chapter 4 reports of supporting survivors and caregivers of stroke, and discusses support avenues and personal support networks. The research questions required a broad range of literature to be considered. The author acknowledges that there is a depth of literature in each area discussed in the literature review. However, for the purpose of this study the author reports a wide range of interconnected literature which explores the breadth of inconnection in this context. This provides an overview of key aspects and provides a context for the study and shows the breadth of existing knowledge which the findings of this study contribute to and build upon. The findings of the review are reported across the literature review chapters (Chapters 2, 3, and 4).

This chapter provides an overview of the extisting knowledge of the everyday lives and experiences of survivors of stroke and their caregivers. First, this chapter reports of the existing knowledge of living with stroke and the caregiving experience. This discussion includes living with and caring for people with physical and/or neuro-disability. In doing so, this chapter provides an insight into the lives of those who are living with stroke in their everyday lives. The author then highlights the identified needs of survivors of stroke and caregivers as reported in the literature, followed by the caregiver perspective on their transition into the caregiving role and the caregiving experience, as reported by the existing knowledge base.

Conducting a review of the literature provides the reader with background context to this study by giving insight into the lives of survivors and their caregivers, as reported in the existing knowledge base. In doing so, this chapter provided a platform for this study, which allowed the author to explore the concepts reported in the existing knowledge base, in the context of the participants of this study.

2.1   Living with Stroke

Stroke is a life-changing complex condition, and those who survive it often do so with physical and/or neurological challenge as well as an impact on brain functionality. Neurological damage to the brain caused by a stroke can result in a variety of bodily changes. These changes can have a psychological impact on the survivor. Stroke can also lead to a wide range of neurological and physical disabilities and impairments which can affect survivor and caregiver emotional and psychological wellbeing (Nelson et al. 2016; Starosciak et al. 2016). This section discusses the literature on living with a physical and/or neurological disability, followed by emotional and psychological wellbeing.

2.1.1   Neurological and Physical Disability

As acknowledged in Chapter 1, stroke is the leading cause of adult disability in the UK (Kumar et al. 2015; The Stroke Association 2016; Welsh Government 2016a; Williams et al. 2011). Nelson et al. (2016) assert that 80 percent of survivors across the UK live with an average of five other health conditions (such as those discussed below) and a wide range of psychological issues as a result of their stroke. The World Health Organisation (WHO) (2016) describes disability as an umbrella term which refers to a person's impairments, activity limitations, and/or participation restrictions. Rather than being defined as a health condition, the WHO (2016) considers disability to be reflective of interactions between a person's body and features of the society in which they live. Therefore, it is important to consider the context of the person's everyday life when researching participants living with a disability.

Post-stroke physical disability may present itself as paralysis of one side of, or across the whole body (The National Institute of Neurological Disorders and Stroke 2008). In some cases, sensory deficits and central pain syndrome may be experienced, which may result in an inability to feel touch, or experience pain, numbness and/or tingling in the paralysed limb (The National Institute of Neurological Disorders and Stroke 2008). Post-stroke neurological disability may present itself as cognitive impairment, visual impairment, post-stroke fatigue, incontinence, or epilepsy (also considered a physical disability). These conditions can lead to limitations to a person's post-stroke physical ability (Cumming et al. 2013; Sarre et al. 2014; WHO 2016).

Those who live with a disability in their everyday lives may need more time to complete, and in some cases, require assistance with, everyday tasks compared to those without (Lawrence et al. 2016; Thompson and Ryan 2009). Such assistance may be required when completing physical tasks such as housework, getting dressed, personal grooming, preparing and eating meals, washing clothes, driving, food shopping, and transport, inclusive of transportation to health services. Those survivors who are living with a physical disability may also require assistance toileting, getting out of and into bed, as well as help with food and drink consumption (Brogan et al. 2015; Camron et al. 2013; Thompson and Ryan 2009).

Furthermore, survivors may find themselves needing to make changes to their everyday lives such as finding alternative transport such as a taxi or a bus, to driving a car. It is possible for some survivors to have an adapted car. However, some disabilities such as epilepsy may prevent them from obtaining a driver's licence. Such changes may impact on a person's social participation, which is defined by Stiers et al. (2012) as a person's involvement or participation in their home (internal) environment, and/or wider society (external environment). The concept of social participation is discussed later in Chapter 3, Section 3.5. The remainder of Section 2.1.1 continues to discuss cognitive impairment and considers other outcomes of stroke such as communication and expression difficulties, incontinence, epilepsy, and post-stroke fatigue.

2.1.1.1 Cognitive impairment

Cognitive impairment is a common outcome of stroke and often impacts upon a person's quality of life and independence. Quality of life is defined and discussed in more detail in Chapter 3, Section 3.6. Cumming et al. (2013) define cognitive impairment as an umbrella term which refers to a person's inability to hold attention or focus, execute, plan, organise or visualise a task. A person with cognitive impairment as a result of stroke may be unaware of their level of impairment, and the impact their stroke has had on them which can lead to a distorted perspective of the self post-stroke. Survivors may experience memory difficulties (Cumming et al. 2013; Hilari 2011; Kalaria et al. 2016; Pasi et al. 2012; The National Institute of Neurological Disorders and Stroke 2008). The nature of post-stroke memory deficits has led to cognitive impairment being linked to post-stroke dementia (Kalaria et al. 2016; Pasi et al. 2012). However, Pasi et al. (2012) exert caution with this phrase as despite being widely used, the terminology merely describes dementia which has occurred after stroke. Therefore the phrase

post-stroke dementia does not isolate dementia as a result of stroke from dementia as a condition in its own right.

Post-stroke cognitive impairment may mean that survivors struggle to express and understand language in both written and oral form which can affect a survivor's ability to learn something new, or relearn a skill they had pre-stroke (Cumming et al. 2013; Hilari 2011; The National Institute of Neurological Disorders and Stroke 2016). An example of this is that a survivor may be able to form grammatically correct sentences, but with no meaning. More commonly the ability to conduct thought processes may be lost. Furthermore, survivors with cognitive impairment may also experience difficulties in expressing and identifying appropriate emotions which can result in a lack of confidence when communicating with people (The National Institute of Neurological Disorders and Stroke 2008). Because of the way in which cognitive impairment presents itself, post-stroke cognitive impairment has been linked to a negative impact on rehabilitation as it can affect the ability to understand, remember, and be aware of deficits (Barman et al. 2016; Pasi et al. 2012). Cumming et al. (2013) and Wei et al. (2016) assert that some of these aspects overlap into one another and can be affected by 'mood'; expressed by post-stroke fatigue, emotional, and psychological wellbeing.

Communication and expression difficulties affect at least 25 percent of all people who survive stroke (The Stroke Association 2012a). In their studies, McKevitt et al. (2010) report that 23 percent of respondents reported difficulties reading. Furthermore, survivors diagnosed with speech disorders such as aphasia (inability to speak, or be understood), dysarthria (difficulties in forming the right words due to muscle weakness in the mouth), apraxia (where signals from the brain to muscles required to perform a specific task are affected), or dyspraxia (the ability to control and co-ordinate the movements that are needed to talk are affected) (Dyspraxia Foundation 2017). Arntzen and Elstad (2013) and Eriksson et al. (2012) found that stroke not only impacts on daily functioning, but also on social participation which includes a person's employment, socialising, and family life. This change can also have an impact on self-perception, and how survivors view their post-stroke lives; impacting on their perceived quality of life. Arntzen and Elstafd (2013) also assert that identifying the traits and diagnosing survivors with conditions such as apraxia early on may assist professionals in implementing therapies and rehabilitation to focus on improving communication with and identifying the needs of aparatic patients and improving their everyday life. Furthermore, Forsberg-Warleby et al. (2007) report that those caregivers who care for survivors with aphasia often express lower levels of life satisfaction and wellbeing, than those who did not, even though overall relationship satisfaction

itself had not changed. Perhaps this is due to the communication challenges that aphasia presents.

2.1.1.2   Visual impairment

Visual impairment may be experienced post-stroke (Rowe 2013; Wolter and Preda 2015). Rowe (2013) asserts that vision impairment affects between 37 percent and 66 percent of survivors in the UK each year. Having an impact on survivors' everyday lives, vision impairment affects their ability to drive, read, write, and participate in a social activity, and also brings many emotional challenges. With the impact that visual impairment has on a person's everyday live, Ribeiro et al. (2015) identified that those who experience visual impairment are more likely to report feelings of isolation, loneliness, a poor quality of life, and depression than those without.

2.1.1.3   Incontinence

Incontinence is also reported as a common outcome of stroke (Mani et al. 2015; Pizzi et al. 2009). A reversible yet common effect of stroke, incontinence may occur when sensory controls in the bladder are affected, or the bladder and/or bowel muscles are weak. Incontinence increases the risk of a fall and results in feelings of depression (Mani et al. 2015). Brogan et al. (2015) and Cai et al. (2015) explain this link, stating that incontinence leads to an increased risk of urinary tract infection which can leave survivors with reduced body balance.

Pizzi et al.'s (2009) study of survivors of stroke found that 76 percent of their sample of 106 participants experienced incontinence. They concluded that those survivors who were incontinent reported a more negative impact on their functional ability post-stroke than those who were not. Olsson and Berterö (2015) further assert that people who experience incontinence more often report feeling a sense of guilt and shame, as well as feeling that incontinence has a negative impact on their quality of life due to the lack of control of their bodily functions. Incontinence itself, as well as an increase in falls, can lead to anxiety and reluctance to socialise; resulting in self-built barriers to social participation (Brogan et al. 2015; Cai et al. 2015).

2.1.1.4   Epilepsy

Epilepsy is said to impact on the surivior's confidence and self-esteem and inhibit the ability to drive which affects a survivor's level of independence in their everyday lives (The Stroke Association 2012b). Jungehulsing et al. (2013) report stroke to be the leading cause of seizure and epilepsy in older populations. Epilepsy can have a negative impact on a person's quality of life and yet there are limited treatment options (Tanaka and Ihara 2017). Furthemore, Chang et al. (2014) report that stroke *type* was a risk factor, as they found that the participants of their study who had experienced a hemorrhagic stroke were at significant higher risk of epilepsy than those whose stroke was ischemic. However, Chang et al. (2014) also found that epilepsy also increased the risk of further (recurrent) stroke.

2.1.1.5   Fatigue

Emery (2015), Larson et al. (2008) and Thompson and Ryan (2009) report that post-stroke fatigue is under-researched and underestimated in clinical practice. Presenting itself as a lack of energy, lack of motivation, boredom, lack of strength, or physical and/or psychological weariness (Ikemoto et al. 2015), post-stroke fatigue often contributes to depressive states in survivors (Emery 2015; Jaracz et al. 2015; Larson et al. 2008; Thompson and Ryan 2009; Wei et al. 2016).

Highlighting the value of post-stroke fatigue research, White et al. (2014) go so far as to claim that post-stroke fatigue in itself is 'disabling'. They rationalise this by explaining that in their research, they found that those who experienced post-stroke fatigue were easily exhausted and felt physically and mentally drained. White et al. (2014) found that this contributed to feelings of hopelessness, which resulted in reduced motivation and participation in rehabilitation and social activity. Supporting this, Larsson and Mattsson (2016) assert that post-stroke fatigue impacts on a person's social participation inclusive of their engagement in society and employment. Survivors living with post-stroke fatigue may also have to find ways of adapting in their daily lives. They may change activities they participate in or give up activities completely. Larsson and Mattsson (2016) also assert that those living with post-stroke fatigue may feel as though they are more dependent on support from other people than they were pre-stroke. This feeling of increased dependency can lead to decreased confidence and may evoke feelings of guilt for being dependent.

2.1.2   Emotional and Psychological Wellbeing

Living with stroke can be challenging for survivors and caregivers alike. The physical and neurological effects of stroke as discussed earlier in this chapter (Section 2.1.1) can impact upon survivor and caregiver emotional and psychological wellbeing. The existing literature reports of survivor and caregiver depression and anxiety (Alajbegovic et al. 2014; National Institute of Neurological Disorders and Stroke 2008; Thomson and Ryan 2009), fear and uncertainty (Gosman-Hedström and Dahlin-Ivanoff 2012; Lawrence 2010; Schmid et al. 2011; White et al. 2014), frustration and anger (Barskova and Wilz 2007; Jaracz et al. 2015), and of caregiver burden and strain (Boosman et al. 2011; Denno et al. 2013; Gosman-Hedström and Dahlin-Ivanoff 2012; Kumar et al. 2015; Yoong and Koritsas 2012) being common post-stroke. Notably, Bastawrous (2012) asserts that caregiver burden is a multi-dimensional concept which (for that reason) hosts no single definition. Linked with stress and strain, caregiver burden as a term relates to the challenging elements of the caregiving role. More specifically, the literature describes caregiver burden as an umbrella term which encompasses the physical, psychological, emotional, social and financial stresses that individuals experience due to providing care and the caregiving circumstance and impacts upon caregiver quality of life (Jeong et al. 2015).

In it not uncommon for caregivers to experience similar psychological and emotional challenges to those of the people they care for (Kumar et al. 2015). Caregivers need to be supported in their everyday lives as the caregiving role can have an adverse impact on the psychological health and wellbeing of the caregiver which may lead to a decline in the caregiver's physical health. Furthermore, where there is emotional and psychological distress placed on the caregiver, caregiving can result in adverse outcomes such as stress and anxiety, for both caregivers and their survivors (Davies and Honeyman 2013; Snyder and Keefe 1985; Forsberg-Warleby et al. 2007).

Also, Dahlberg et al. (2007) identified a correlation between the number of hours a person provides care and caregiver ill health. They found that the more hours a person spent caregiving, the more likely they were to experience either physical or psychological ill health. Therefore, the time commitment to caregiving can impact on caregiver self-perceived quality of life which further highlights the importance of caregiver time out from the caregiving role. Also, the challenges resulting from the caregiving role can lead to further challenges, in maintaining a good life balance and overall wellbeing (Rochette et al. 2007).

2.1.2.1   Depression and Anxiety

Depression is the most common outcome of stroke for survivors (Godwin et al. 2013; Hackett et al. 2005; Hayhow et al. 2014; The National Institute of Neurological Disorders and Stroke 2008; Wilson et al. 2007) and is linked to increased risk of experiencing another stroke, death from stroke and is related to poor post-stroke outcomes (Starosciak et al. 2016). One-third of survivors are diagnosed with a form of depression (Alajbegovic et al. 2014; The National Institute of Neurological Disorders and Stroke 2008). Post-stroke depression impacts upon a survivor's social life and can take the form of a generalised anxiety disorder, major depression, and post-traumatic stress disorder in survivors of stroke, which can have a negative impact on social participation (Kitzmuller et al. 2012; McKevitt et al. 2011).

In their research, Alajbegovic et al. (2014) report depression to be more common in female survivors and younger survivors. They, along with Hayhow et al. (2014), highlight a link between the level of depression and post-stroke disability. Depression is more prevalent when there is increased dependency, and there has been a long-term hospital stay (Hayhow et al. 2014). Furthermore, Wei et al. (2016) report that post-stroke depression was more common among their study participants when there was low social participation.

Anxiety, frustration, anger, sadness and a sense of grief for the change to their physical and mental capabilities post-stroke can contribute to feelings of angst (National Stroke Association 2017). Such feelings can also lead to symptoms of depression such as feelings of hopelessness, self-loathing and anger or irritability (Ayerby et al. 2013; Lewin-Richer et al. 2015; Wei et al. 2016). Those survivors who are living with depression may also experience disturbed sleep patterns, fatigue, a change in eating patterns or sudden change in weight, feeling lethargic, feeling irritable and desire to isolate themselves (Lewin-Richter et al. 2015; Wei et al. 2016). As well as impacting negatively upon levels of social participation, depression can also lead to survivors feeling discouraged, which may lead to reduced motivation to participate in rehabilitative activities, reducing the overall speed and effectiveness of recovery (Ayerby et al. 2013; Wei et al. 2016). These feelings can also contribute to an unwillingness to accept rehabilitative treatment, perhaps preventing recovery completely (Wei et al. 2016). Although these emotions are responses to psychological trauma, some emotions are a result of brain damage caused by stroke (Wei et al. 2016). Impacting on the survivor's perception of their post-stroke life, such feelings are associated with an increased desire to commit suicide, requests for euthanasia, poorer outcomes of stroke overall, and lower reported perceptions of quality of life

(Harmandayan et al. 2012; Pompili et al. 2015). However, despite these outcomes and the posed risk of harm, depression is often undetected and is not treated adequately by professionals (Flyckt et al. 2014).

There are also some links between the survivor's personal circumstance (such as their home environment, whether they are in a committed relationship, whether they have children and/or whether they have a wide circle of friends) and depression. Therefore, it is important to consider the personal circumstances of the participant survivors and caregivers when conducting research for this study. Grav et al. (2012) discovered a link between social support (inclusive of financial contributions) and depression. They found that where social support was low, feelings of depression and negativity were high and participant health and wellbeing was low. Supporting this, Yoong and Koritsas (2012) also found that reduced financial support resulted in poorer health.

It is not uncommon for caregivers to also experience similar emotional difficulties as the person they care for, such as depression and anxiety (Barskova and Wilz 2007; Jaracz et al. 2015). As previously stated, Forsberg-Warleby et al. (2007) identify lower feelings of wellbeing for those caregivers of survivors who had communication difficulties. They report that one-third of caregivers experience depression when caring for someone with complex communication challenges. In their research, Bäckström and Sundin (2009) found that caregivers felt depressed that they were dependent on other people for time away from the caregiving role, stating that they felt selfish for doing so. Such feelings can lead to caregivers isolating themselves within the caregiving role and prevent them from seeking opportunities for respite, or 'time out', leading to feelings of isolation, depression, and loneliness. Therefore, caregivers may unintentionally create their own barriers to respite by not engaging in support and opportunities offered and actively avoid seeking support from others (Bäckström and Sundin 2009; Johnson and DeSouza 2008). However, admittedly engaging in such opportunities and seeking support may present a psychological challenge for caregivers, leading them to be considered 'hard to reach' in the eyes of social policy and statutory sector support provisions. The participants of Bäckström and Sundin's (2009) study do identify that support in the home from paid caregivers can allow for time away from the caregiving role. Therefore, caregivers feel less guilt from obtaining support from professional paid services and are more likely to ask for respite from such services.

2.1.2.2   Fear and Uncertainty

Wren (2013) defines fear as a heuristic device and states that it is not socially constructed, but instead, it is a self-contained response to trauma and a developmental result of activity. Post-stroke fear can be felt by both survivors and caregivers. One fear is that the survivor may experience a physical fall. The fear of falling is said to reduce over time as confidence increases (Schmid et al. 2011; White et al. 2014). A fear of reoccurring stroke can also be expressed (Girgis et al. 2013; Lawrence 2010; White et al. 2014), or a fear of confinement within the home (Gosman-Hedström and Dahlin-Ivanoff 2012; White et al. 2014). Although it is reported by Gosman-Hedström and Dahlin-Ivanoff (2012) and White et al. (2014) that survivors and their caregivers may fear being confined to the home, Sklenarova et al. (2015) report that fear can result in anxiety, and/or a reluctance to engage with the external environment, that is, the environment outside of the home, inclusive of community, due to feelings of perceived public stigma (stigma is discussed further in Chapter 3, Section 3.3). Therefore, although survivors and their caregivers may not wish to feel confined, their anxiety and fear may create barriers to them engaging outside of their home. Caregivers also report feelings of fear, of what the future may be for themselves or the survivor they care for (Bäckström and Sundin 2009; Sklenarova et al. 2015) as well as financial insecurity, and future health and wellbeing (Gosman-Hedström and Dahlin-Ivanoff 2012; White et al. 2014). These feelings can stem from the perceived pressures (by the caregiver) of the caregiving role (Gosman-Hedström and Dahlin-Ivanoff 2012).

Yoong and Koritsas (2012) report that caregivers often feel restricted in their caregiving role due to a lack of alone time and reportedly value and look forward to time outside of the home to pursue their interests (Boosman et al. 2011). These feelings can impact on the caregiver's social life, the ability to plan ahead for activities such as holidays, and is a challenging aspect of the caregiving experience (Bäckström and Sudin 2009). This also lead to caregiver participants from Bäckström and Sundin's (2010) study feeling that their life lacked spontaneity.

An explanation for the reported lack of spontaneity in the lives of the caregiver is that of uncertainty. The levels of uncertainty vary from the acute stage of stroke, into the longer term. While at a hospital there are uncertainties in the outcome for the survivor and the demands of the caregiving role, as well as thoughts about the survivor and caregiver's perceived life. This uncertainty also relates to changes which could be experienced by both the survivors and caregivers in their post-stroke lives. Therefore, the anticipated outcome and what might happen contributes to feelings of uncertainty. After being discharged from the hospital, uncertainty

continued to present itself as the caregivers developed concerns and fears that the survivor may fall, experience further stroke, experience an epileptic fit, or that the survivor's post-stroke health may deteriorate further. These concerns highlight that caregivers' fear and anxiety are not dissimilar to the survivors' themselves. Furthermore, Girgis (2013) highlights that uncertainty was present in the months and years after survivors were discharged from hospital. Participants of Girgis's (2013) study (both survivors and caregivers) reported that feelings of uncertainty related to the stroke itself and how to prevent a further stroke. Furthermore, Gosman-Hedström and Dahlin-Ivanoff (2012) and Thompson and Ryan (2009) report of caregivers feeling uncertain about the effectiveness of healthcare interventions and therapies which can increase feelings of worry and concern - contributing to overall caregiver strain. This suggests that there needs to be better provision for reassuring survivors and caregivers, improving communication with them and keeping them informed of their progress.

2.1.2.3   Caregiver Burden, Stress, and Strain

Caregiver burden impacts on the psychological and emotional wellbeing of caregivers (Kumar et al. 2015). Godwin et al. (2013), Jeong et al. (2015), and Ostwald et al. (2015) observe that spousal caregivers often feel they have a strong sense of burden depending on their personal circumstances such as their financial situation, employment status and level of health. Kumar et al. (2012) define caregiver burden as negative thought and strain experienced by a person who is caring for someone who is chronically ill.

Denno et al. (2013) observe that high levels of caregiver burden and heightened feelings of anxiety and depression are connected. Kumar et al. (2015) assert that there is a link between self-reported caregiver burden and support received in the caregiving role. They claim that where caregivers receive support from friends, family, or professional services, they typically report lower levels of burden than those without. However, regardless of any third party support received, caregivers often still felt constrained as to when they were able to leave home themselves, and report feelings of entrapment; always having to be ready to help (Gosman-Hedström and Dahlin-Ivanoff 2012; Thompson and Ryan 2009). Gosman-Hedström and Dahlin-Ivanoff (2012) report that these feelings contribute to fatigue, exhaustion, and stress, as a result of feeling as though the survivor needed them nearby all of the time. Furthermore, those caregivers with dependent children expressed concern that their children were turning away from them. They explained that their dependent children felt that their parent (the survivor's

caregiver) could not spend as much quality time with them as they could pre-stroke, that they were now less important than the survivor who required care (Gosman-Hedström and Dahlin-Ivanoff 2012). This notion demonstrates how the caregiver role can impact upon other family members and the caregiver's relationships, and could potentially lead to feelings of isolation and loneliness in the caregiving role and contribute to feelings of guilt.

The impact of caregiving can often lead to feelings of burden, stress, and strain, which may place a further demand on the caregiving role (Hassan et al. 2011; Jaracz et al. 2015). These feelings were amplified when the survivor's experienced communicative difficulties post stroke as those feelings became harder to communicate due to a lack of expressive ability. Spousal caregivers of survivors with communication difficulties are at highest risk of caregiver strain due to feelings of distress and upset at witnessing their partner's communication difficulties (Fatoye et al. 2006; Bäckström and Sundin 2009; Barskova and Wilz 2007; Jaracz et al. 2015; Palmer and Glass 2003; Vincent et al. 2009) which, as previously mentioned, can impact on caregiver wellbeing.

However, the caregiver participants of Gosman-Hedström and Dahlin-Ivanoff's, (2012) and White et al.'s (2014) study informed that their stress was caused by their frustrations at the statutory sector support system and getting the support they needed. Jones and Morris (2013) and Haley et al. (2009) report the most stressful element of caregiving is associated with the survivor's behavioural mood, presented as depression, loneliness and/or anxiety. Caregiver stress was reported to be heightened where survivors experienced memory problems and/or physical care needs, specifically where the survivor experienced fecal incontinence. However, Jones and Morris (2013) report that the greatest challenge for caregivers was achieving a balance between supporting survivor dependency and encouraging survivors to try for themselves to support and promote independent living.

Stajduhar (2013) researched caregiver experience and identified that some caregivers would prefer to make alternative arrangements to care at home, primarily because of the associated burdens. Those caregivers who lived with the people they provided care for often dream about being 'set free' from their caregiving role while wishing for improvement in the survivor's health. However, they also held concerns about being alone in the instance of mortality; a concept deemed less frightening for those spousal caregivers with offspring (Boosman et al. 2011). The desire to be set free emphasises the perception of the burden that caregivers are under.

2.2   Defining the Caregiver and the Notion of Kinship Obligation

Stroke not only impacts on the everyday life of the survivor; it also impacts on the everyday lives of their family, friends, and their caregivers (who are usually also family members) (Burholt and Dobbs 2014; Davies and Honeyman 2013; Gaugler 2010; The Stroke Association 2015a). It is common practice for the caregiving role often becoming the responsibility of a family member (where present) when a survivor returns home from hospital (Bäckström and Sundin 2009; Hassan et al. 2011; McPherson et al. 2011; The Stroke Association 2015a; Toule et al. 2015).

Supporting this, The Stroke Association (2016) identify that one-third of the 1.2 million survivors in the UK receive assistance from caregivers in their everyday lives, of which one in five are cared for by a family member and/or friend (Toule et al. 2015). In their research, Bäckström and Sundin (2011) found that where survivors were married or living with a partner, they would typically be cared for by their cohabiter, while those survivor participants from their study who lived alone received care from their adult children, siblings, friends, or neighbours. They also found that those survivor participants who were children or young adults would tend to be cared for by their parents, friends, or neighbours.

The notion of family members becoming caregivers is particularly common in rural geographies where poorer access to services compared to more urban geographies mean that informal care structures and support networks are common (Williams 2008). Johnson and DeSouza (2008) found through their research that when there were several adult children in a family, and the survivor was a parent, the caregiving responsibility would typically rest on the eldest child. In turn, the eldest sibling (the now caregiver) would receive support in their caregiving role from their younger siblings. However, those adult children who were an only child and became caregivers for their parent(s) did so without such support, emphasising the importance of other family members and friends in supporting single adult children in their caregiving role.

Notably, there was no age range or consideration of caregiver circumstance reported in Johnson and DeSouza's (2008) study. This highlights a further avenue of exploration. By identifying the adult children's caregiving experience and exploring the circumstances which surround their caregiving role, the author may ascertain the full impact of the caregiving role on the adult child caregivers' everyday lives. The author notes it cannot be assumed those eldest adult children of survivors are willing to become a caregiver or become the primary caregiver when another parent is not present, nor must it be assumed that they receive support from their siblings.

The notion of caregiver obligation is not new. In 1989, Qureshi and Walker (1989) claimed there was a hierarchy of caregiving obligation. In order from highest to lowest: the spouse, daughter, daughter-in-law, then members of the same household. This trend shows that traditionally females of the family ranked higher up the hierarchy than male family members.

Twigg and Atkin (1994) contributed to this research and referred to the concept as kinship obligation. They described that society had opinions as to who should take on the responsibility of the caregiving role when a family member became unwell. This view is said to be varied and guided in part by cultural assumptions (Burholt and Dobbs 2014), gender and marital status (Schales and Schneider 2012). More recently Seddon and Robbinson (2015) report that caregiver participants of their studies indicated that they felt a moral obligation to take on the caregiving role. Reflecting on the influence of culture upon caregiving obligation, Burtholt and Dobbs (2014) contribute to the notion by describing that in independent cultures such as those typically found in Western populations, kinship obligation to provide care would occur where there is a need such as ill health. Whereas in contrast, cultures, where there are typically multigenerational households such as those typically found in Eastern populations, kinship obligation, occurs between younger and older populations on an age qualifying basis. This demonstrates how culturally derived assumptions continue to underpin the informal support networks presented globally.

Demonstrating this, Katbamna's (2004) study of South Asian families who lived in the UK identified a fundamental cultural difference in the caregiving role compared to that of a family of British culture. In South Asian families' physical touch between adults who are unmarried is prohibited. Therefore, in South Asian families, survivors may only receive assistance in personal care from their marital partners. For caregivers, this means that they are more constrained in their everyday lives as they are the only adult allowed to provide such assistance to their partners. Therefore, unlike British families, South Asian families are not able to delegate some of their caregiving responsibilities, regardless of another adult family member being present and willing to take on the caregiving role (or provide support), or a paid caregiver being available to them. This lays more reliance of the marital partner as caregiver and means that the caregivers themselves, in this situation, cannot access support from professional services such as that offered by the statutory sector.

This creates a challenge for policy makers and practitioners within a multi-cultural nation as they need to ensure they understand ways in which they can offer support to families across a multi-

cultural society while respecting the cultural norms within it. Effective caregiving has been identified by Ekstam et al. (2011) and Jones and Morris (2012) as being a key contributor to successful rehabilitation. Therefore, it is important to understand the caregiving role fully, and what it is which makes caregiving 'effective'. By understanding the caregiving role in its complexity policy makers and practitioners become better informed as to how to support caregivers in their everyday lives. This may then have a positive impact on survivor recovery.

2.3   Preparing for the Caregiving Role

Caring for someone who has experienced stroke can be a life-changing commitment. The existing literature informs that many caregivers feel that they have not been given sufficient support or guidance from professional services (such as statutory sector services or third sector organisations) for them to prepare for the caregiving role, and understand how to best support the survivor they care for. This contributes to increased caregiver stress and can result in the caregiver experiencing poorer health (Ostwald et al. 2015).

Glendinning et al. (2009) state that caregiver support should include a combination of practical help and psychosocial support and be tailored to the survivor and caregiver needs, easily accessible and low cost. However, White et al. (2014) report that caregivers do not receive sufficient information about stroke, and what their caregiving role entails. Ostwald (2014) asserts that caregivers of stroke survivors are often confused and uncertain about what stroke is, and inform that caregivers seek information about stroke and what it means for them, as well as what the outcomes of stroke may be for the survivor to be more prepared for the caregiving role. Describing caregivers as active seekers of information, Johnson and DeSouza (2008) and White et al. (2014) report that caregivers will often proactively search a range of sources. Such sources include books and the internet; and observe, and listen, to see if they can gain any further information from professional while visiting their survivor at a hospital (White et al. 2014).

However, caregivers from Carlsson et al.'s (2012) and Gallacher et al.'s (2014) studies reported that the information they retrieved from paid professional caregiver services was unusually inadequate as it was generic and therefore not particularly relevant to their personal circumstance. This further supports the importance of understanding the participant's personal circumstances to support them in their caregiving role. However, Carllson et al. (2012) and Gallacher et al. (2014) did acknowledge that this may be a by-product of poor communication

between the parties involved. Their studies also highlighted that caregivers sought to learn how best to provide care, and gain skills to support them in their caregiving roles before discharge, as they did not feel as though they could take on the caregiving role. This can only impact negatively on caregiver confidence and thus their self-esteem.

Furthermore, caregivers from Thomson and Ryan's (2009) study expressed that they wanted to be prepared for when the survivor returned home from hospital. They also wanted to have any adaptions to the home which were required to be completed in advance of the survivor's return. However, a lack of support from the statutory sector in preparing the home environment was felt (Thomason and Ryan 2008). In addition, caregivers from studies in the existing literature also report feeling as though their ability, age, physical health or willingness to care for someone else has not been assessed appropriately by professionals (Duthie et al. 2015).

Duthie et al. (2015) and Lutz et al. (2011) report that a core challenge for caregivers transitioning into the caregiving role was that of balancing the expectations of family members such as dependent children and the person they were providing care for. This resonates with Gosman-Hedström and Dahlin-Ivanoff's (2012) earlier claim, that caregivers could feel the strain as dependent children may feel though they have become less important. Duthie et al. (2015) and Lutz (2011) found this to be particularly challenging where family expectation differed from the expectations of health professionals as those professionals in charge of organising rehabilitation and discharge did not necessarily take into consideration the family's expectation of the reality of what might happen when the survivor returned home. This meant that family members were not properly prepared for the survivor's return as they were not aware of the survivor's full ability which often differed from their expectation.

2.4 Positive Perspectives and Caregiving

The majority of the caregiving literature reports upon negative caregiving experiences (Kruithof et al. 2012). Kruithof et al. (2012) consider a caregiver's perspective of their everyday life and their caregiving role, to be reflective of their caregiving experience. Therefore, if the caregiver has a positive experience, they are likely to reflect on the more positive aspects of caregiving and feel as though they find caregiving a more positive experience than those caregivers who may struggle to cope with the caregiving role and feel more negative about the caregiving experience. Furthermore, Quiping and Loke (2013) found that caregivers were more willing to provide care

if they had positive perceptions or experiences of the caregiving role. Caregivers from Quiping and Loke's (2013) study described such positive perspectives as a result of a good relationship with the cared for person, feeling a sense of reward or personal growth for the caregiving role and personal satisfaction.

Such personal satisfaction could be felt if the caregiver can combat the challenges they perhaps felt they would not manage prior to their caregiving role. This, in turn, may also result in increased self-esteem. Then this could act as a 'buffer' against negative aspects, which then become outweighed. Furthermore, Kruithof et al. (2012) consider positive caregiving experiences to be intertwined with perceived life satisfaction, and recommend that rehabilitation; both research and practice should focus more upon positive caregiving experiences. This would support caregivers in feeling a sense of wellbeing in their everyday lives, and also contribute to a positive self-perception of their quality of life. This would also support them in their caregiving role; contributing towards improving caregiver self-esteem. Such positive perception is reported by Quiping and Loke (2013) to be a by-product of daily enrichment events and self-efficacy. Therefore, caregiver support should focus on encouraging caregivers to explore opportunities to include enrichment activities into their daily lives and improve efficiency in their everyday life.

Reflecting upon positive caregiver experience, 90 percent of the caregiver participants from Haley et al.'s (2009) study reported that they felt that caregiving enabled them to appreciate their life more. Caregiver participants from Boosman et al.'s (2011) study indicated that caregiving gave them a renewed confidence - in both their abilities as a caregiver, and in the reliability of friends', family, and/or professional paid carers who offered support and assistance. Similarly, Yoong and Koritsas (2012) found that caregivers sometimes felt a sense of personal satisfaction and gave a more positive appraisal of their lives. They assert that the caregiving role has a positive influence on a caregiver's quality of life as the caregiving role granted caregivers with opportunities to receive support, develop relationships, and participate in leisure activities. Supporting this perspective, Davies and Honeyman (2013) suggest that the caregiving experience can encourage families to gain a deeper cohesion and provides opportunities to strengthen the family unit. They also report that some caregivers may experience an increase in personal growth and development; increasing their knowledge, self-esteem, confidence and greater opportunities to form new friendships through support groups. However, the author reflects that as experience is subjective and that positive or negative feelings about the caregiving role are influenced by many factors such as the caregiver's circumstance, more

specifically their stage of life, their perspectives of their pre-stroke life, as well as their life goals and expectations.

2.5   Identified Need

Hassan et al. (2011) identify that while health-related unmet needs may be met over time, they remain doubtful that psychological health and emotional wellbeing needs will ever be fully addressed. Girgis et al. (2013) suggest that there is a decrease in the prevalence of unmet caregiver need over time; however, they found that approximately one-third of caregivers who reported an unmet need still claimed that the need had not been met 24 months later. They also discovered that after 24 months, the unmet needs were about the wellbeing and relationships of the caregivers themselves.

Both caregivers and survivors identified a desire for more support surrounding occupational therapy (Duxbury et al. 2012) and a need for people to understand stroke (Bäckström and Sundin 2009). Caregivers also report sharing the stress of the survivor, in feeling that there is a lack of understanding from friends and other family members about their lives with stroke. They report that other friends and family did not understand that they were committed to being physically near the survivor. However, primary caregivers do tend to conceal the true demands of their role in order to avoid compassion and pity from others and avoid the perception that they are complaining (Bäckström and Sundin 2009). This supports earlier comments, which identify a reluctance to take on support from friends and professionals.

2.5.1   Survivor Need

Here, the identified needs of survivors of stroke as highlighted in the literature are identified. The support services which aim to meet those needs are discussed further in Chapter 4 (Section 4.3.4).

McKevitt and Fudge (2012) conducted a study of stroke survivors who had experienced a stroke in the last five years. Participants were asked to complete the Stroke Association's 'Daily Lives Survey', and did so between September and December in 2011. The number of unmet needs reported by the participants varied between one and 13, with the average number being three per

person. All of the study participants reported at least one unmet need. McKevitt and Fudge (2012) suggest that this emphasises that meeting the needs of stroke survivors is an on-going concern. More specifically, 54 percent of the participants reported that they felt they needed more information about stroke, highlighting a key area for future development.

This was also identified in a previous study conducted by McKevitt et al. in 2011. In this study, McKevitt et al. (2011) identified that more respondents from Wales and Northern Ireland reported a lack of information about stroke than in England and Scotland. This not only emphasises that the issue has not improved over time but also highlights an inconsistency with health and social care policy delivery, relating to stroke, between UK regions. Therefore, there needs to be more of a focus on information delivery in Wales and Northern Ireland, and perhaps a comparative strategy review could be conducted in future research to highlight the key areas. Breaking this down further, 37 percent of respondents reported that they did not receive adequate information on their diet, 21 percent sought more information on holidays for people with a disability, and 16 percent wanted more information about which benefits they are entitled to and how to access them.

Furthermore, 15 percent of respondents sought information on aids and adaptions for the home, and 12 percent reported that they required more information and advice about driving. The survey also identified that 73 percent of those which reported emotional problems post-stroke informed that they didn't receive the help they needed to deal with their emotions. Also 43 percent of respondents who experienced post-stroke fatigue reported that they did not receive support in this area (McKevitt et al. 2011).

Mckevitt et al. (2011) reflect that they were not surprised that lack of information was a key issue emerging from the survey, but acknowledge that they found it surprising that there was no differentiation between those who had experienced stroke one year ago, to those who experienced stroke five years ago. Therefore, there has been no substantial improvement in this area over the last five years. They also found that those people who had disabilities, were from ethnic minority groups, or lived in deprived areas, reported higher levels of unmet needs.

It is also assumed that adults with chronic conditions are more likely to report an unmet need than those without, due to their increased level of identified needs (Ronksley et al. 2012:2013). Ronksley et al. (2012) suggest that where needs are unmet, it is due to accessibility or availability rather than the provision being non-existent. Therefore, service provision and

delivery can have a significant influence on the level of unmet needs of a survivor and their caregiver.

To further identify the unmet needs of stroke survivors, the Greater Manchester Stroke Assessment Tool - GMSAT - has been developed. This is an evidence-based assessment tool which covers 38 common areas of stroke, assisting with the six-month review. Using closed questions which require yes or no answers, the assessment aims to quickly and efficiently identify the areas in which the survivor or caregiver might have an unmet need. These requirements range from medicine management to general health, such as smoking and diet, to employment, hobbies, and activities, and travel, and can be discussed at the survivor's own home (The National Institute for Health Research 2014). The Stroke Association collaborated with the National Institute for Health Research (NIHR) (2014) to review of the GMSAT National Pilot Project in 2010. This study assessed the unmet needs of 137 patients.

Supporting McKevit et al.'s (2011) findings, this review identified that the sample produced an average of three unmet needs, with the frequency of reported unmet needs ranging from 0 to 14 across 34 different areas. The most frequent reported unmet need was fatigue, which was reported by one-third of participants. Furthermore, approximately one-quarter of the participants reported unmet needs in the areas of memory, concentration and attention (26 percent); secondary prevention (non-lifestyle) (22 percent); and depression (19 percent). As a result, 464 actions were noted. 50 percent of participants were to access provisions where they would be provided information and advice, 21 percent were advised to make an appointment with a primary care team, 20 percent were signposted to other services, and 9 percent were referred to other services such as social services, speech, and language therapy, continence advisory services, and occupational therapy. To date, this assessment tool has been implemented in the English regions of Merseyside, London, Norfolk, Greater Manchester, the North of England, Nottingham, and Yorkshire (The National Institute for Health Research CLAHRC for Greater Manchester 2014).

2.5.2   Caregiver Need

Johnson and DeSouza (2008) recognise that (non-professional) caregivers do have some needs in common with professional caregivers; they acknowledge that some of the identified needs vary considerably due to caregiving occurring in an already existing relationship; unlike other forms of caregiving relationships such as those between survivor and professionals.

Caregivers from Johnson and DeSouza's (2008) study reported they felt as though they were 'going it alone', highlighting that there was a lack of awareness of the needs of people who provide care across the statutory sector.   Supporting this, Tseng et al. (2015) and White et al. (2014) highlight that there needs to be an improvement in the way information is provided because, as identified previously, a lack of information can cause uncertainty among survivors and caregivers. Furthermore, as previously stated in Section 2.2, there was a perceived lack of support in preparing the home for the return of the survivor from hospital. This meant that on occasion, adaptations were not made to the home before the survivors came home (Thompson and Ryan 2009).

Survivor unmet need and dissatisfaction with caregiver support are said to have a negative impact on the caregiver. Taking into account the caregiver's perspective, Palmer and Glass (2003) found that many family members feel that they would benefit from psychosocial services; despite them not being accessed. Reporting on the benefits of psychosocial support, supporting caregiver mental, emotional, social and spiritual wellbeing, Cheng et al. (2014) assert that psychosocial support provides caregivers with caregiving skills and advice which allowed them to cope with stress more effectively than they did before they received the support. Furthermore, caregivers who received psychosocial support reported a more positive wellbeing and had reduced reliance (of the survivor and themselves) on statutory sector provisions.

In addition, Gaugler (2010) considers that the timing of clinical interventions could be improved by better understanding of the psychosocial changes that family members experience. Denzl et al. (2013) and Hassan et al. (2011) report that caregivers as well as survivors would benefit from more information, particularly in regards to learning caregiving skills relating to the physical aspects of caregiving and preparation for the caregiver role as well as advice of how to promote the survivor's functional ability and how to sustain themselves, the survivor and the family life within this role would also be beneficial. This would help address some of the issues identified in this chapter thus far. Furthermore, caregivers also report that they sought assistance with

finance (Duthie et al. 2015; Greenwood et al. 2009a; Bulley et al. 2010), with participants from Johnson and DeSouza's (2008) study informing that they discovered they were able to claim Attendance Allowance on the off-chance; help with dealing with feelings of anxiety and distress; help with coping and adapting to life after stroke; and better support provisions (Denzl et al. 2013; Hassan et al. 2011). These aspects correlate with earlier comments on the psychological aspects being more challenging than physical aspects as these reported needs express a desire to gain more support from emotional strain. Furthermore, caregivers feel that improvement in these areas would help improve the post-stroke experience and improve the perception of quality of life (Denzl et al. 2013; Hassan et al. 2011).

Davies and Honeyman (2013) report that the families of those with intellectual disabilities and challenging behaviour often do not receive the practical support, training, and information they need. This highlights an area of weakness in support provision. Due to the complexity of the caregiving role when caring for a survivor of stroke, there is a need for caregiver-specific strategies to be developed to assist them in finding ways to cope and support them in their caregiving roles, (Hassan et al. 2011; Simonič et al. 2012). This could potentially help caregivers to experience positive associations with the caregiving role and improve their self-perception of their quality of life. Quality of life is discussed further in Chapter 3 (Section 3.6).

A correlation between unmet need and the level of interruption in the caregiver's daily life is shown by Girgis at al. (2013). They found that where there was a higher level of interruption the caregiver tended to report unmet needs which related to anxiety, depression, avoidant and active coping, and out-of-pocket expenses. In contrast, caregivers who experienced lower levels of interruption experienced increased levels of wellbeing and also received social support and so fewer unmet needs were reported. Supporting this, Boosman et al. (2011) report caregivers also felt they needed more personal time. Social support contributes to reduced interference of the caregiving role in everyday life and provides the caregiver with more personal time. This leads to better levels of wellbeing and reduced unmet needs. Girgis et al. (2013) also acknowledge that unmet needs such as depression and anxiety became more dominant over time highlighting the importance of these needs being met.

2.6   Chapter Summary

This chapter reports of the complex and unique nature of post-stroke life for both the survivors and caregiver. The varying outcomes of stroke, survivor care needs and the impact of the carer's circumstance on the caregiving role are unique to each individual. This is an important consideration when providing support for survivors and caregivers in their everyday lives.

The existing literature reported throughout this chapter highlights how experience can contribute to survivor and caregiver wellbeing. As identified earlier, caregiver self-esteem is a key element of a caregiver's perception of their quality of life. Therefore, it is important to effectively support caregivers in their caregiving role as this may give them a better self-perception of their everyday lives, and also impacts on the perceived quality of life for the survivor. This chapter also highlights the importance of supporting caregivers in their caregiving role and developing policy which focuses upon providing caregivers with positive experiences to enable them to have a more positive perspective on their caregiving role. In turn, this could provide the survivor with more effective care and give them a better perspective of their everyday life.

3.0   Post-Stroke Life

This chapter provides further context to the study. Following on from Chapter 2, it continues to explore living with stroke. First, the nature and quality of the relationship between the caregiver and survivor is discussed. Then, the concept of a changed identity post-stroke, followed by the literature which identifies coping strategies adopted by survivors and caregivers will be explored, along with those aspects which make up survivor and caregiver personal support networks. This is followed by a discussion on post-stroke social participation. Finally, post-stroke quality of life is discussed, along with identification of the key indicators which are used by medical professionals and researchers to evaluate a person's quality of life.

In doing so, this chapter provides an insight into a person's sense of post-stroke life, for both survivors of stroke and their caregivers. It discusses changes in everyday life and coping strategies which may be adopted. By reviewing the literature on quality of life, the author also highlights the ways in which better perceptions of survivor and caregiver quality of life may be achieved.

3.1   The Survivor - Caregiver Relationship

The relationship between a survivor and their caregiver cannot be defined simply as a relationship between an 'active' caregiver and a 'passive' care recipient. Instead, this relationship is best described as a relationship between two social actors (Alexander and Wilz 2010). This relationship is complex and unique to the social actors and can host many changes in the relationship itself, and the everyday lives of both parties (Morris 2011).

Stroke can lead to changes within the family unit and the relationships and roles within it (Gosman-Hedström and Dahlin-Ivanoff 2012). Where survivors with disabling outcomes of stroke may not be able to fulfil or respond to their partner's wishes or unuttered expectations, a caregiving spouse may have to learn to withdraw any expectations and desires they have for their partner in their marriage or partnership (Alexander and Wilz 2010; Thompson and Ryan 2009). Despite this, Boosman et al. (2011) report that spousal caregivers who loved their partners pre-stroke continued to do so in their post-stroke lives. This love gave the participants of Boosman et al.'s (2011) study the will to continue in their relationship, despite them claiming that the marital relationship had become more like that of friendship. This emphasises that caregivers

may experience changes in their relationship with the survivor, which may also present a psychological and/or emotional challenge (Gosman-Hedström and Dahlin-Ivanoff 2012; White et al. 2014).

The caregiver participants of McKevitt et al.'s (2010) study expressed feelings of concern about the change in the nature of their family relationship, and the change in roles within the family unit. In their study, McKevitt et al. (2010) found that 26 percent of the survivor participants reported negative changes in their family relationships in general, whilst 42 percent of caregivers reported a negative change in their relationship with the spouse they cared for. Thompson and Ryan (2009) reported a similar trend in their studies as they found that some of their survivor participants became less tolerant of their caregiving spouse. Despite the participants of Satink et al.'s (2016) study stating that survivors found their caregivers empowering, some reported feeling contrained by their caregivers. Furthermore, the survivor participants of Thompson and Ryan's (2009) study expressed feelings of anger and frustration which they would take out on their caregivers because they disliked feeling dependent on them. This irritability resulted in increased stress and strain on the relationship between the survivor and their caregiver participants of their study which led to frequent arguments, spousal friction, and disagreement.

Supporting this, Auton et al. (2016) and Jaracz et al. (2015) also found that the caregiver participants of their studies expressed feelings of anger, which Auton et al. (2016) identified to be especially relevant when the survivor had communication difficulties. Such difficulties in communication and understanding, as discussed in Chapter 2, were found to create emotional distance between survivors and their families and friends (Schepers et al. 2006). This led to spousal caregivers of Schepers et al.'s (2006) study feeling as though mutuality within the relationship had been lost. Furthermore, participants from Booseman et al.'s (2011) study reported that they felt that they could not share their feelings with their spouse (the survivor) and missed having someone to share everyday problems with, as well as the physical closeness of their marital relationship pre-stroke (Boosman et al. 2011). This led some caregiver participants of Boosman et al.'s (2011) study to report feelings of unhappiness regarding the marital relationship, and about the marriage itself (Boosman et al. 2011). This was also found in Visser-Meily et al.'s study in 2005, demonstrating that this is an on-going issue.

Feelings of anger from the survivors towards their caregivers were also observed by Thomson and Ryan (2009) during their interviews. This occurred when caregivers attempted to answer the questions on behalf of the survivor when the survivor had struggled to finish off sentences. This

is one way in which caregivers may become overprotective. Further to this, caregivers may also unintentionally inhibit stroke recovery and limit the effectiveness of rehabilitation by intervening and not allowing the survivor to try and push themselves to realise their full potential. This can be due to a fear of the survivor falling (as discussed previously in Chapter 2), and not wanting to see them struggle, or be in discomfort (Morris et al. 2014; Oswalt et al. 2009). Perceived by caregivers as an act of support and helping, this could reduce the survivor's confidence in their ability and lead them to feel discouraged from attempting the task at hand, in a sense, enabling them to give up trying. This can contribute to conflict within their relationship, and have a negative impact on the relationship overall (Thomson and Ryan 2009).

Adding to this, Jones and Morris (2013) identified that survivors do not always easily adjust to being cared for, with participants from their study expressing that they sometimes felt that they were positioned in a 'child's role' within the home. This can contribute to feelings of irritability, stress and anger. Such changes contribute to a change in personality (discussed later in Section 3.2) which may become more pronounced over time and can put pressure on the caregiver-survivor relationship, particularly as everyday conflicts may not easily be discussed between the caregiver and survivor. Such discussions may also lead to confusion for the survivor, as well as feelings of sadness and guilt (Boosman et al. 2011).

80 percent of the caregiver participants recruited by Long et al. (2009) reported that they felt they maintained a good relationship with the survivor they cared for. However, the caregivers in the study are not defined. There may be a difference between those caregivers who are friends, adult children and spouses. Furthermore, the outcomes of the survivor's stroke were not identified. As Boosman et al. (2011), Thompson and Ryan (2009) and Gosman-Hedström and Dahlin-Ivanoff (2012) assert in Chapter 2, caregiving for someone living with cognitive impairment is found to be more challenging than caregiving for survivors with a physical disability. This emphasises the importance in understanding the context of the survivor and caregiver's circumstances when researching daily lives and relationships.

However, McPherson et al. (2011) found that there was no significant relationship between the caregiver or survivor demographics and perceived relationship satisfaction. Furthermore, relationship satisfaction and the rewards gained through caregiving were found to be significant predictors of positive perspectives of the caregiver role, such as those discussed in Chapter 2 (Section 2.4). Those caregivers whose relationships in which each party did not feel they had an equal part were found to have significantly greater caregiver burden (McPherson et al. 2011).

This suggests that those caregivers who feel they have a less equal role within their relationship with their spouse (the survivor they care for) may be more likely to report feelings of caregiver burden, and will be more perceptive to the positive rewards of caregiving. Supporting this, adult daughters of Bastawrous et al.'s (2014) study also report feeling overloaded by the caregiving role. This inequality in the role can be determined by who the caregiver is and role attitudes within the home, or as a result of the outcomes of stroke. It cannot be assumed that these role differences are purely stroke-related.

3.2   A Changed Perception of The Self and Identity

Both practice professionals and academic researchers alike consider the perception of the self as a key aspect in ascertaining quality of life. Therefore, a person's perception of themselves post-stroke can influence their perception of their quality of life. Human beings have the ability to consider themselves as *"objects of their own thought"* (Scott 2014, 589) as it is human nature to objectify the self (Best 2005; Goffman 1967). The tendency to objectify the self post-stroke can be a result of the survivor seeking the meanings behind the physical changes to the body that they experience as a result of their stroke. This experience can be described as 'living with an altered perception of the self', as survivors often consider their bodies to be unfamiliar 'objects' which are unreliable and/or fragile (Kitzmuller et al. 2012).

Best (2005) recounts Goffman's (1967) interactionalism perspective, which considers identity to be subjective in that it is reflective of, or reactive to, the social interaction. Therefore, a person's perception is made up of the combined meanings of multiple social interactions, rather than from one reality (Best 2005). Thus combined, these interactions make up a sense of a person's everyday life, a life whereby people resemble actors in a theatre; only there is no script. This perspective is supported by Meijering et al. (2016) who considers material objects, collected by a person from their interactions and experience such as visual, tangible items, on our person or around the home, to reflect our perception of our reality. This suggests that where a survivor's home may need to be adapted, their home environment, which consists of our identity forming objects, will be inclusive of our new objects which reflect a post-stroke way of life.

Furthermore, Mead (1934) informed that the self takes two forms; 'me', a self-concept where the perceptions of others are considered, and 'I' which is subjective and refers to the inner being. Considering identity, the perceptions of others, and the concept of the 'real me'; true identity is

thought to remain the same, in essence, throughout life (Best 2005; Goffman 1967). Similarly, Cooley (1902) reports of 'the looking glass self', where a person considers how they are 'seen' by others. This can vary from person to person. For example, a parent may see their child in a different light to say, a friend or neighbour. Cooley (1902) argues that we as humans imagine how we seem to 'appear' to others, we then imagine the judgements that others make based on our appearance. This then leads us to consider our appearance, as we may then change our appearance to improve the perceived judgement, in a sense, developing ourselves based on the perceived judgement of others. Therefore the 'real me' as coined by Mead (1934) may differ from the 'me' that others see.

A lost sense of identity is a common outcome of stroke (Anderson and Whitfield 2013; Sarre et al. 2014). This may lead to changes in a person's sense of 'me' and 'real me'. Meijering et al. (2016) claim that there are many aspects of post-stroke life which can contribute to a change in identity. This can even include changes to the home, which are often made to make it easier for survivors with disabilities or limitations to be more independent around the home. Meijering et al. (2016) explain that this is because the home is a space that many people tend to make reflective of their identity. The home is also someone's sanctuary, where they invite friends and family to visit. Therefore, the home is representative of the person who resides there and so when it has been adapted with objects which aid assistance, those objects become a key aspect in the home for many. This can lead to a reluctance to invite people to visit and becomes a reminder to the person who lives there that their identity has changed as they cannot escape that reality. Anderson and Whitfield (2013) found that those survivors who experience a loss of identity after stroke may find themselves struggling to form what they perceive to be, a valued social identity (a person's sense of who they are within society) without support from other people.

Anderson and Whitfield (2013) consider this to be a key area which should be focused on when helping survivors come to terms with post-stroke life. They consider that:

> *"Social relationships are the foundation upon which survivors rebuild skills to engage with the world."*
>
> (Anderson and Whitfield 2013, 820)

They consider that if survivors feel as though they have lost their sense of 'self', then they would struggle to form social relationships and engage in the social world. Reporting some of the

descriptors survivor participants used to describe themselves, Thompson and Ryan (2009, 1806) report that survivors often described themselves as 'useless' or 'lazy', and refer to themselves as a 'nuisance' or a 'burden'. This was a result of them expressing fear and anger at feeling dependent on others. Feeling as though they are a burden on their family may encourage the survivor to decide to reside in a residential care home, rather than be cared for at home. This suggests that these feelings and self-perceptions outweigh the survivor's own wishes, as they aim to reduce the burden on their families, and is damaging for the survivor's self-esteem and their emotional and psychological wellbeing.

Also, Brewin (2003) considers the effect of trauma on self-identity and informs that the experience of trauma and the common outcomes of feelings of guilt, powerlessness, and emptiness can affect the foundation of a person's self-identity. This is because negative feelings of abandonment, shame and weakness are supported by the 'negative self' and tend to undermine the 'positive self' (Chaplan et al. 2016). Furthermore, if the survivors are not satisfied with their level of rehabilitation, the thought produced by the negative self may be further supported. This can result in reduced motivation, 'giving up' and symptoms of depression.

Norris et al. (2012) summarise that western literature (Alaszewski et al. 2004; Becker 1998; Dowswell et al. 2000; Ellis-Hill et al. 2000; Faircloth et al. 2004, Kaufman 1988; Wiles et al. 2004) presents stroke as a:

> *"Disruptive event that challenges the known self through the multiple losses of physical capacity, role and identity."*

(Norris et al. 2012, 826)

This loss of identity often results in survivors exhibiting a change in personality. As previously stated by Boosman et al. (2011) and Gosman-Hedström and Dahlin-Ivanoff (2012), caregivers may consider this change in personality to be so great, that they may feel that the survivor is a different the person due to a change in personality post-stroke, with some caregivers feeling as though they are grieving for the person they once knew, even likening the feelings of loss to that of bereavement.

Thompson and Ryan (2009) assert that survivors have a unique perception of the self post-stroke. However, they report that when survivors begin to compare the pre- and post-stroke self, they often are faced with feelings of anger, irritability, agitation and intolerance at the changes which

stroke has brought into their everyday lives. This can also pose challenges in accepting that roles within the family home may have changed (Briggs 2014; Thomson and Ryan 2009).

Survivors may find that their post-stroke self-perception can also be influenced by feelings and emotions associated with changes in their family role, personal identity, self-image, sexuality, social functioning, and feelings of fear, frustration, anger, and anxiety, as well as the physical outcomes of stroke (Thompson and Ryan 2009). Furthermore, survivors will often test their body's boundaries in various ways to regain familiarity and strengthen their self-concept by managing tasks by pushing themselves to assess their capability (Kitzmuller et al. 2012). This suggests that motivation and a desire to try are a key aspect of coming to terms with stroke and developing a post-stroke identity.

Garcia-Calvente et al. (2012) also considered survivors who were women to be more vulnerable than men, expressing feelings of exhaustion, whereas the male participants were identified as being weaker at dealing with the illness but hid behind a 'tough guy' stereotype. Garcia-Calvente et al. (2012) compare that in relation to coping with illness women were 'weak but strong' and men were 'tough but weak' suggesting that gender constructions influenced the perception of the self for both genders. This study identified the preferential target groups for health and social care interventions as 'exhausted women' and 'tough men' and considers that gender differences are in permanent interaction which shapes an individual's social reality (Garcia-Calvente et al. 2012).

A person's attitude also influences their perception of themselves and their quality of life. For instance, if a survivor reflects Berges et al's (2012) theory of positive attitude, they may express that they feel 'lucky' regarding aspects of their lives. In contrast, if a negative attitude is portrayed, a survivor may express feelings of loss, lowered self-esteem, and reduced self-confidence. In addition, interventions from external actors must be considered, as should the quality and effectiveness of support provisions from the statutory and third sectors, and the level of positivity exhibited by said external actors.

Bulley et al. (2010) considers caregiver identity and explains that the emotional burden of stroke can impact on their perception of the self and their identity. Adopting the caregiver role may change a person's identity within a family unit, and in wider society (Johnson and DeSouza 2008). However, it cannot be assumed that the caregiver would identify themselves as 'caregivers'. As asserted in Chapter 2, caregivers are often identified as wives and carers; sons

and carers, and so forth. Therefore, those family members who care for survivors may also experience a change in family dynamics and relationships, as they take on the caregiving role. Caregiving in the ordinary sense (such as caring for a young child) is often taken for granted as part of a traditional family role. However, when the recipient of care is someone who has suffered a trauma (such as stroke), it is considered to be an 'extraordinary' caregiving responsibility (Briggs 2014; Presho 2008) in that it can often mean role switching between being a family member or a friend, and being a caregiver. There are also attempts to spare the discomfort of the survivor and their relatives as well as maintain the survivor's dignity, sense of independence, and sense of family life (Boosman et al. 2011). Notably, a change in personality is considered by caregivers as hard to deal with as it often led to feelings of isolation, depression and loneliness (Gosman-Hedström and Dahlin-Ivanoff 2012).

3.3   Stigma and Discrimination

Forming a post-stroke identity based upon perceptions of how others view them may lead survivors to experience self-stigma relating to self-identity. Van Brakel (2012) and Stevelink et al. (2011) identify that stigma takes two forms: (1) self-stigma and (2) public stigma. The former, self-stigma, refers to a person's perception of how others see them. This describes an individual's level of self-esteem or feelings towards themselves, whereas the latter describes the person's perception of how they feel the general public sees them. This highlights how self-esteem may contribute to self-stigma. These forms of stigma reflect earlier works by Goffman (1967) who highlights that both forms of stigma can impact on the way in which a person will perceive themselves in their everyday life. Anticipated negative judgements from others can impact on a survivor's perception of themselves within their internal and external environments. The potential (perceived) loss of roles and positions within the family and social society can impact on the vulnerable self and contribute to feelings of depression, anxiety, and isolation which can also impact on recovery (Corrigan et al. 2009; Fung et al. 2007:2008).

Public stigma is associated with discrimination and can impact on a person's level of social participation (Reeder and Pryor 2009; Sanuade and Agyemang 2014; Weiss 2008). Stigma in both forms not only impacts on social participation, but can also lead to anxiety, depression, isolation, problems in family relationships and friendships, and can impact a person's motivation to participate in rehabilitation activities; ultimately impacting on recovery (Corrigan et al. 2009; Fung et al. 2008; Sanuade and Agyemang 2014).

Survivors who experience impairments such as weakness, fatigue, disorientation and speech difficulties comment that they feel that they only those disabilities which are visible are taken seriously and understood by society (Lorenz 2016). Lorenz (2016) and Simplican et al. (2015) report that disabled people view the idea of disability as a socially constructed phenomenon. Furthermore, where survivors anticipate stigma, they feel less inclined to participate. The latter statement tells us that perceived discrimination is a barrier to social participation. Initiatives aimed at reducing such barriers would need to adopt interventions which aim to widen participation, psychologically and physically, at home and in wider society.

Van Brakel et al. (2012) suggest that improving income support, participation in activities, and addressing physical impairments as part of the rehabilitative process should be considered at both a personal and at the societal level. This may help to reduce perceived stigma. Reduction of stigma in the community through education, interventions, and addressing environmental barriers could potentially help reduce stigma and discrimination in wider society. This could be a step towards building survivor confidence both inside and outside of the home, contributing to improved quality of life by opening up further avenues for fulfilment in life.

Being powerful in society, stigma and discrimination affect millions of people worldwide who live with stigmatised health conditions or disability (Van Brakel et al. 2012; Weiss 2008). Such stigmatising attitudes are related to feelings of shame (considered the most predominant), difficulties in maintaining a marital relationship, problems in the marriage, and problems with employability (Van Brakel et al. 2012). Suggesting that these effects were a result of self-stigma, respondents interviewed in a study by Van Brakel et al. (2012) informed that they did not feel stigmatised by others. Their study concludes that people living with disability feel burdened by social stigma, which promotes a cycle of poverty, caused by unemployment, social discrimination and threats to mental health (Reeder and Pryor 2009). Furthermore, Reeder and Pryor (2009) and Van Brakel et al. (2012) highlight that stigma reduction activities and rehabilitation into society which compliment current strategies, are urgently needed as current strategies tend to focus on the prevention of further physical impairment after discharge from treatment. This recommendation should be incorporated into long-term rehabilitation strategy, as well as community development and support structures.

Barskova and Wilz (2007) and Ekstam and Borell (2008) comment that a caregiver's perception of disability and its effects on everyday life can be negatively influenced by the more limiting outcomes of stroke (such as physical disability), and suggest that caregivers tend to concern

themselves with things that the person affected can no longer do. This has been found to discourage caregivers from encouraging survivors to participate in daily tasks (Barskova and Wilz 2007). This also can potentially help to reduce the effectiveness of rehabilitation and contribute to preventing the survivor and caregiver in returning to a pre-stroke way of life; creating a barrier to recovery.

3.4   Coping with Post-Stroke Life

McPherson et al. (2011) recommend that professionals should consider the influence of stroke on the health and wellbeing of the caregivers, as well as survivors. This statement is supported by Barskova and Wilz (2007). They found a correlation between recovery from stroke (both cognitive and emotional) and caregiver acceptance of the outcome of stroke for the person they care for, inclusive of the impact that the caregiving role has on their post-stroke life.

Both survivors and caregivers must find ways in coping with stroke (Kumar et al. 2015). Lazarus and Folkman (2000) consider that for caregivers, coping is integral to managing an increase in demand or stress which comes with the caregiving role. The level of demand or stress felt by the caregivers is 'out of the ordinary' and therefore taking on the caregiving role can result in changes within a person's everyday life. The way in which a person 'copes' is influenced by a cognitive and behavioural process which helps them to find ways of managing their post-stroke lives (Lazarus and Folkman 2000).

Frankl (1963) and King and Hicks (2009) assert that when a person acquires a disability as a result of a life event such as stroke, it is instinctive for them to attempt to rationalise their experience in order to come to terms with the event. They do this by seeking to apply meaning to the life event itself (to understand), and in doing so, they attempt to establish reason (to justify) to the uncertainties they face as an outcome of the event in order to come to terms with their new life.

The way in which people cope with life events can have a major impact on their everyday life in both the short and longer term. For the survivors themselves, how they learn to cope with the impact of stroke can impact on how well they have accepted the impact which stroke has had on their everyday life, and how they perceive their post-stroke life. Cecil et al. (2011) also note that caregivers often show angst about both their own future and that of the person they care for.

Kumar et al. (2015) acknowledge that coping strategies are categorised in different ways for different research purposes. However, there are three main types which can be considered generic across the research field. They are (1) task focused, where a person may actively seek to perform a task in order to improve the perception of the situation. An example of this may be a change in the way a survivor carries out a daily task, or perhaps taking on a new task in order to compensate for not being able to carry out a specific action post-stroke. The second, (type 2) emotion focused, is where a person may attempt to manage or control their emotions, perhaps by counteracting negative thoughts with positive ones. They may be reflective or fantasise about positive events in their lives. Finally, (type 3) avoidance focused, describes where a person may seek to avoid the realisation of their experience. Perhaps they are in denial or they practise social diversion, which is a strategy whereby the individual attempts to busy themselves, in order to distract themselves from the reality that they have experienced a stroke (Donnellan et al. 2013; Kumar et al. 2015).

As stroke recovery is uncertain, survivors tend to develop coping strategies to help them to deal with the uncertainty of recovery. This may include shortening time horizons whereby they focus on the present and near future, with plans and events in the months and years after the stroke ceasing to exist, or only being discussed in vague terms (Greenwood et al. 2009b). However, the Stroke Association (2015a) is exploring ways in which to incorporate goal-setting into rehabilitation and so this may be a positive step in not only improving the outcome of rehabilitation but also allowing the survivors to gain confidence in planning ahead.

As previously mentioned in Chapter 2, research shows that caregivers found cognitive difficulties (Boosman et al. 2011), and the emotional outcomes of stroke, along with feelings of frustration and anger (Johnson and DeSouza 2008; Thompson and Ryan 2009) to be harder to cope with than physical impairment. Studies in the existing literature also report of uncertainty being hard to cope with for caregivers (Bäckström and Sundin 2009; Greenwood et al. 2009b; White and Barrientos et al. 2014).

Caregivers, as well as other family members and friends, go so far as to express that seeing someone they knew before their stroke now living with severe cognitive impairment makes them feel as though the person has changed. As previously asserted in Section 3.2, this change is so great that they are said to find themselves grieving the loss of the person they once knew; the person before stroke (Boosman et al. 2011; Gosman-Hedström and Dahlin-Ivanoff 2012). This emphasises how the emotional strain of seeing a change in the life of the family member who has

experienced stroke contributes to the emotional burden of the caregiving role. Supporting this, caregiver participants from Gosman-Hedström and Dahlin-Ivanoff's (2012) study reported that they felt as though they were living with someone else, describing that their mutual intellectual fulfilment had gone, and that the survivor exhibited a different personality.

To try and reduce feelings of uncertainty, survivor and caregiver participants of Girgis et al.'s (2013) study expressed a desire to understand stroke, to ascertain what it meant for them in their everyday lives. The desire to understand is also exhibited in the context of other diseases such as cancer (Girgis et al. 2013). Here, the coping strategies adopted by survivors and caregivers are discussed as well as support networks which help survivors and caregivers in their post-stroke lives, as reported in the existing knowledge base.

3.4.1 Coping Strategies

Academic researchers (Bäckström and Sundin 2009; Berges et al. 2012; Boosman et al. 2011; Cecil et al. 2011; Franze´n-Dahlin et al. 2007; Godwin et al. 2013; Gosman-Hedström and Dahlin-Ivanoff 2012; Greenwood et al. 2009b; Kumar et al. 2015; Lazarus and Folkman 2000; Saban and Hogan 2012; White et al. 2014) discuss various coping strategies in the existing literature. Despite them using different terminology to describe coping strategies, the coping strategies discussed have been categorised into three categories below: adaptive, positive, and avoidance. These categories resonate with Kumar et al.'s (2015) suggested three types of coping (task focused, emotion focused and avoidance focused) discussed previously.

3.4.1.1 Adaptive Strategy

Lazarus and Folkman (2000) assert that the cognitive and behavioural process of coping may lead to survivors and caregivers adapting their normal behaviour patterns and cognitive process in order to find a way of 'managing' their post-stroke lives. Bäckström and Sundin (2009), Boosman et al. (2011), Greenwood et al. (2009b), Franze´n-Dahlin, et al. (2007), and Godwin et al. (2013) reflect upon adaptive strategy and consider that survivors and caregivers will tend to take each day, one day at a time. This allows survivors and caregivers to adapt to post-stroke life gradually, inclusive of any routines and support mechanisms in place, and learn to deal with the uncertainty around stroke whilst they gain confidence (Bäckström and Sundin 2009; Cecil, et al.

2011; Greenwood et al. 2009b; White et al. 2014). Greenwood et al. (2009b), and Saban and Hogan (2012) consider this gradual acceptance of the reality of the caregiving role and the stroke survivor's functional status as an important part of the adaptive coping strategy.

Caregivers are particularly challenged when it comes to finding ways in which to adapt to the changes posed in post-stroke life, and the changes to everyday life as experienced by the survivor (Franzen-Dahlin et al. 2007). Because of this, as well as taking each day, one day at a time, in some cases survivors and caregivers disregard any thoughts that they may return to their pre-stroke way of life (Bäckström and Sundin 2009; Jones and Morris 2013).

Over time, survivors and caregivers often feel as though their knowledge about stroke has increased (Carllson et al. 2012; Franze´n-Dahlin et al. 2007). This may result in a decrease in uncertainty and fear, and reduced stress (Ostwald et al. 2009; Vincent et al. 2009; Visser- Meily et al. 2008: 2009), depression (Menlove et al. 2014; Visser-Meily et al. 2009), and anxiety (Menlove et al. 2014). Furthermore, caregiving may become more efficient and social participation may also increase (Parag et al. 2008). However, due to the complexity of stroke, this cannot be assumed for all. By taking one day at a time, survivors and caregivers can be reflective and notice such reduction of negative feelings, particularly as they are not focusing on a short or long-term goal. This contributes to an improvment in quality of life perception (Larson et al. 2008; Schlote et al. 2006). There is, however, the possibility that over time conditions deteriorate and therefore strain, anxiety, depression and fear could increase, having a negative effect on survivor and/or caregiver quality of life.

However, adopting an adaptive strategy does not mean that the survivor or caregiver is either one extreme or another. Bäckström and Sundin (2010) recognise that despite the initial challenges experienced taking on the new role, over time, can result in caregivers, spouses and relatives finding equilibrium in their everyday lives, as they begin to feel a sense of relief as they come to terms with their post-stroke lives. Furthermore, Wallengren et al. (2008) suggest that even though burden may reduce over time, and caregivers may begin to adapt to their changed circumstances, they would not be completely relieved of caregiver strain, even in the longer term.

When a survivor of stroke returns home, caregivers aim to maintain former routines in an attempt to retain a sense of normality and restore family life. However, this can host many challenges (Bäckström and Sundin 2009). An adaptive coping strategy also provides an

opportunity for caregivers to schedule private time into their daily schedule, as well as support from professional caregivers; allowing survivors and caregivers to maintain a sense of 'normal', pre-stroke family life (Bäckström and Sundin 2009). This highlights how professional caregivers can contribute to post-stroke life, allowing relief from the psychological burden and allowing time for the caregiver to be a family member, retaining a version of the pre-stroke relationship and role; as exists beyond the identity granted by the new caregiving role.

A survivor or caregiver may opt to face their experience and take on board an adaptive strategy, and learn to adapt to post-stroke life, or they may choose to avoid the realisation of the outcomes of their stroke and the impact that their stroke has had on their everyday lives. It is thought that the latter strategy is practised when survivors and caregivers have not fully accepted the stroke, or have had difficulty in adapting to post-stroke life (Wallengren et al. 2008). This highlights that it is possible for survivors and caregivers to alternate between coping strategies.

Kumar et al. (2015) assert that an adaptive coping strategy encompasses positive thought, learning from experience, seeking social support, advice from others with the same experience, taking action to deal with a problem, and active coping whereby the survivor or caregiver takes purposeful action to enable them to cope with post-stroke life. This process is guided in part by self-restraint as survivors may make a conscious decision to take their time and not rush into taking action too soon, often deciding on a plan of action. This can be presented as acceptance as they acknowledge the things they cannot change. Practising this, people may find alternative ways of doing things or compensate some activities for others they are more able to do (Kumar et al. 2015). Therefore, adaption to post-stroke life is a process which occurs over time as survivors and caregivers learn to adjust and adapt to new challenges.

For some this may mean adapting to new roles within the family or even a change to living arrangements. In some instances, spousal caregivers may choose to live apart from the survivor due to feelings that they have no alternative, other than divorce (Bäckström and Sundin 2009). This provides the caregivers the personal space they need. However, the caregiver participants from Bäckström and Sundin's (2009) study who chose to reside separately from the survivor were unable to disconnect from thoughts about the survivor and their caregiving responsibilities; emphasising the psychological and emotional burden experienced by caregivers. This then results in feelings of fear and guilt when the caregiver is not physically with the survivor (Boosman et al. 2011). Furthermore, those who sought divorce did so, claiming that they sought

more to their life and a place for them to feel good, stating that life should have a value and substance to them (Bäckström and Sundin 2009).

3.4.1.2   Positivity Strategy

Berges et al. (2012) assert that a positive attitude can have a positive effect on the individual self. The 'positive effect' phenomenon is a mental health perspective which focuses on minimising negativity in rehabilitation (Berges et al. 2012). Berges et al. (2012) discovered that a high level of positive effect during rehabilitation correlated with a high level of social participation when measured three months after discharge. Furthermore, Berges et al. (2012) found positive behaviour to be linked to better physical and psychological outcomes post-stroke. This suggests that a positive attitude can increase the level of social participation in everyday life, and enable survivors and caregivers to adapt to life with stroke. Also, positive attitudes can impact positively on confidence, self-esteem and thus on motivation, which can impact on participation in rehabilitative activities.

In fact, caregivers typically perceived this 'new' post-stroke life, as a new phase, and portrayed a constructive attitude which allowed them to remain optimistic and showing gratitude for their situation compared to that of others who perhaps were learning to cope with more complex outcomes of stroke (Boosman et al. 2011). This supports Berges et al.'s (2012) positive attitude theory as the positive drive they exhibited prepared them for facing new challenges as they emerged. This supports the work of Folkman (2013) who found that the positive emotion can help to counteract the negative 'distress' emotion which helped in coping.

3.4.1.3   Avoidance Strategies

Gosman-Hedström and Dahlin-Ivanoff (2012) found in their studies that survivors and caregivers would often seek to live their post-stroke lives avoiding the reality of their experience. Their participants would also use this strategy by avoiding situations they were unsure of and cope with uncertainty by avoiding planning for the future or making long-term plans. Kumar et al. (2015) extend on this by asserting that avoidance strategy is sometimes coined as the distraction strategy which is linked to mental avoidance behaviours. Such behaviours are present where survivors or caregivers are disengaged in rehabilitative activity and try to take their minds off

their current situation by focusing on other things. As a result of seeking to distract, this coping strategy is often linked to an increase in alcohol consumption and/or alcohol and drug abuse (Kumar et al. 2015).

Smith et al. (2009a) and Cecil et al. (2011) interviewed caregivers who cared for family members who had experienced a stroke; Smith et al. (2009a) one year post-stroke, and Cecil et al. (2011) eight years post-stroke. The avoidance strategy was adopted by both of the studies' samples. This could mean one of two things. One argument could be that the avoidance strategy is adopted regardless of whether the caregiver has come to terms with the new reality, and that fear and uncertainty prohibit the caregiver from planning ahead. Alternatively, this could mean that it can take many years to adapt to life with stroke before the caregiver considers the future (Bäckström and Sundin, 2009; Greenwood et al. 2009a; White et al. 2014).

3.4.2 Personal Support Networks

Personal support networks are valuable in helping survivors and caregivers cope with stroke in their everyday lives (Kruithof et al. 2012). Burholt and Dobbs (2014) consider support networks to be made up of three elements: social, emotional, and instrumental. They define social support as support provided by family and friends, the local community, and the third and statutory sector initiatives such as day centres, clubs, and societies. Kruithof et al. (2012) consider social support to be key to satisfaction in everyday life and comment that a good level of social support has been found to show improvement in survivor perceptions of their quality of life. Burholt and Dobbs (2014) define instrumental support as that which is practical. This is typically provided by people who have experienced stroke themselves, either as a caregiver or survivor or by professional statutory or third sector services (Cameron et al. 2013). Emotional support is that which is often provided by family and friends. However, emotional support can also be provided by professional services such as statutory sector and private sector counselling services (Burholt and Dobbs 2014). Avenues of support are discussed further in Chapter 4.

Wenger (1989) established five network typologies which are presented overleaf in Figure 3. Through her research, Wenger (1989) noted a number of intervening variables while exploring support networks. These were gender (as women tend to have larger networks than men), marital status (assuming the marriage was between a man and a woman - as men's networks can be made larger by their female counterpart, and so the husband's network would compliment his

wife's), social class (as resources available such as finance and travel opportunities can have an influence), and health (being physically and psychologically able to engage). These variables can also affect network size, with dense 'close knit' networks being less likely to seek support from more formal means such as the statutory and third sectors. Furthermore, Wenger (1989) identifies that family dependent and locally integrated support network typologies are popular in Western populations where nuclear or single person households are common.

Figure 3:   Wenger's Network Typologies

The Local Integrated Support Network:
Typically includes close relationships with local family, friends, and neighbours; usually based on long-established residence and active community involvement in the present or recent past.

The Local Self-Contained Support Network:
Typically have arms-length relationships or infrequent contact, if any, with local kin, relying mainly on neighbours. Respondents are characterised by a retiring nature and largely privatised household-centred lifestyle. Community involvement, if any, is low key.

The Wider-Community-Focused Support Network:
Typically including distant kin, with high salience of friends, some neighbours; characterised by high level of community activities and involvement, usually associated with absence of local kin.

The Family-dependent Support Network:
Having primary focus on close local family ties with few peripheral friends or neighbours. These are often based on shared household with, or living close to, adult child (usually a daughter).

The Private Restricted Support Network:
Characterised by absence of local kin, other than spouse in some cases, and limited contact with local community. No local friends and superficial contact with neighbours.

(Extracted from: Wenger C. *in* Jefferies M. 1989, 171-172)

Wenger (1989) argues that people may change from one category to another over time. She goes so far as to suggest that it is possible for typologies 4 and 5 to develop from typologies 1, 2, or 3. In her work, she found such changes to a person's typology description was not reflective of any change in the support network itself, but rather as part of the innate ageing process. Therefore, suggesting that as people grow older, their support network typologies may change. This leads the author to consider this in the stroke-related context. Perhaps the onset of a stroke may change the support typology a person would be categorised to. This is not to say that having a stroke may (in a sense) speed up the natural ageing process, or even mean that the survivor would portray support network typologies as an older person would. Instead, a life changing event such as stroke could be a factor which may or may not impact on a person's support network typology. Perhaps this change would be a result of the outcome of stroke, i.e. if the survivor is living with disability in their post-stroke lives.

3.5   Social Participation and Participation in Activities

Social participation is defined as a person's involvement in a life situation. That is, the involvement in family life (within their internal environment), the community, and employment (within their external environment) (Stiers et al. 2012). Stiers et al. (2012) and Van Brakel et al. (2012) claim that social participation is individualistic and depends on three factors; the level of disability, the type of disability, and the stage of rehabilitation. Jeong et al. (2015) also state that rehabilitation should consider the caregiver as they play a key role in survivor wellbeing, which impacts on the survivor's willingness to participate in the wider environment. This correlates with earlier discussion, in that these three factors may also have an impact on a person's perception of their everyday life, and their quality of life. Stiers et al. (2012) state that it is worth considering the implications of the physical or neurological ability; elements of which are measured by the quality of life scales presented in Appendices A and B. Quality of life itself is discussed later in Section 3.6.

Fallapour et al. (2013) assert that there are three dimensions to post-stroke participation in everyday life: (i) the survivor feels they cannot participate in activities as before; (ii) the survivor feels as though they are not the same person; (iii) the survivor feels they are not living their life. In some cases, long-term and often permanent outcomes of stroke may turn survivors 'inwards', meaning that they may recluse themselves away from the external environment and withdraw from participative activities and relationships with others (Kitzmuller et al. 2012). This can

contribute to feelings of isolation, depression and loneliness. Therefore, in this context social participation can be described as a by-product of the survivor's acceptance of stroke. Such acceptance is influenced positively by a positive attitude and a realistic appraisal of one's own ability; rather than focusing on what they cannot do (Stiers et al. 2012). This highlights that positive thinking is beneficial in reducing barriers to social participation due to its ability to reduce negative thought (Berges et al. 2012).

3.5.1 Social Participation in the Internal Environment

Social participation in the internal environment considers a person's engagement in the following elements of daily life: engagement in domestic roles and family life; as a caregiver, a family member, or as a friend (Stiers et al. 2012). The National Institute of Neurological Disorders and Stroke (2008) report that 13 percent of survivors found their perceived levels of social participation within the family unit had decreased since their stroke, and they missed playing games with their children or grandchildren. This reduction in social participation within the home contributed to feelings of isolation and loneliness and may stem from feelings of uselessness, and guilt that they may be a burden on their family (Tsang 2003). In particular, guilt that they are unable to carry out their usual role within the family unit (Thompson and Ryan 2009). Such feelings impact on the relationships within the family and the survivor's perception of their satisfaction in their everyday lives. Furthermore, the change of role within the family unit as discussed previously by Gosman-Hedström and Dahlin-Ivanoff (2012) may also impact on the level of social participation within the family unit and internal environment.

3.5.2 Social Participation in the External Environment

Social participation in the external environment considers a person's engagement in wider society and includes their involvement in education, employment, engagement with community groups and clubs, and social engagement (Stiers et al. 2012). The National Institute of Neurological Disorders and Stroke (2008) found that 25 percent of survivors missed their pre-stroke daily routines such as driving their car or going for walks. They also found that 50 percent of survivors claimed that their social activities had reduced. Of this, 19 percent claimed to no longer have a social life, and 25 percent stated that they were no longer able to go on holiday (The National Institute of Neurological Disorders and Stroke, 2008). Furthermore, The

Department of Health (2007:2008) and Satink et al. (2016) assert many survivors would like to go outside of their homes more often than they are able too, highlighting how stroke can impact significantly on many aspects of everyday life.

As stroke affects people of all ages, changes in occupation and employment can occur. The Stroke Association discovered that 75 percent of young people affected by stroke sought to return to employment (The Stroke Association 2016). McKevitt et al. (2010) found that 52 percent of those employed prior to stroke were either unable to return to employment or had to reduce their work activities which suggests a potential income reduction. This resulted in a reduction of self-esteem and changes to life goals, as survivors faced a change or loss of career.

3.5.3   Influential Factors of Social Participation

Grigorovich et al. (2015) report that the caregiving role, combined with employment, and other commitments, can act as a barrier to social participation for caregivers. However, those caregivers employed alongside their caregiving role, often perceive their employment as breathing space away from their caregiving role (Bäckström and Sundin 2009). Despite this statement, as discussed previously the caregiving role may also lead to challenges in engagement in leisurely activities (Gosman-Hedström and Dahlin-Ivanoff 2012; White et al. 2014) and result in caregivers feeling socially excluded from wider society (Gosman-Hedström and Dahlin-Ivanoff 2012; White et al. 2014; Yoong and Koritsas 2012).

Furthermore, the impact that stroke has had on the survivor can also make a difference. Where a survivor is living with physical and/or psychological impairment, barriers to social participation may be created. Such barriers include accessibility, communication and engagement (Van Brakel et al. 2012). However, where barriers to social participation are reduced, fewer restrictions to participation are present (Van Brakel et al. 2012). This highlights the importance of reducing such barriers to participation through home support, policy, and practice.

The three dependable factors of social participation (the level of disability, the type of disability, and the stage of rehabilitation (Van Brakel et al. 2012)) discussed in the opening paragraph of Section 3.5, could suggest that people with severe communication difficulties may find it harder to participate in general conversation compared to someone whose communication has not been affected. However, such assumptions cannot be made as other factors need to be taken into

account. Such factors include the availability of the social outlets in their geographical region, or online, and any communication or mobility aids in place. For example, it could be assumed by this definition that someone living with a physical disability or paralysis could be less able to participate socially within the external environment. Notably, with the advancement of mobility transport and opportunities for engagement in online communities, this may not be the case. In addition, the residency of the individual should also be considered as well as their local infrastructure; do they live in a rural or an urban region? Are services accessible to them? Factors such as bus routes need also to be considered, and also the possible opportunities to interact in both their internal and external environments.

3.6   Quality of Life

The phrase quality of life has different definitions across various professional and academic fields (Fayers and Machin 2013). For the purpose of this thesis, the author will adopt the WHO's definition, as this shapes the current quality of life literature, policy and practice in the health and social care discipline. The WHO defines quality of life as a person's own perception of their own life, in relation to their goals, their expectations, their own standards, and their concerns (WHO 2014). Quality of life is defined in health-related (perceptions of quality of life in relation to one's health status) and non-health-related (quality of life in relation to living standards) contexts. The latter guides professionals, practitioners, and academics to consider a person's own perception of their self. This includes an element of reflection where the person considers how they aim to live their life, and whether they feel that they have lived what they perceive to be a fulfilled life, that is, whether they feel they have met their life goals, aspirations, and/or expectations.

Quality of life is a broad and complex concept in that it is reflective of a person's own perception of their physical and psychological health, their level of perceived independence, their social relationships, and their relationships with salient features of their internal and external environments (Frankl 1963; Krančiukaitė and Rastenytė 2006; King and Hicks 2009). Perception as a concept in its own right differs from person to person, as it is underpinned by an individual's unique experience or life expectation regarding their personal life goals. Therefore, a survivor's perception of their own quality of life after stroke will take into account their individual interpretation and evaluation of the changes which they have experienced since their stroke - inclusive of the impact of which they feel this has had on their everyday life and their

ability to meet their life goals if they have not yet been met. This includes whether they feel they have learned to cope with their post-stroke lives and how well they have come to terms with the impact which stroke has had on their everyday lives; their relationships, social life, and their physical and mental ability. Thus, Health Related Quality of Life (HRQOL), as perceived by the survivor, not only reflects the physical, neurological and psychological outcomes of stroke, but also the survivor's own evaluation of how stroke has impacted on their everyday lives (Frankl 1963; King and Hicks 2009).

It may also be suggested that caregiver quality of life can be met by the same self-perception - whether they have met their aspirations in life, and whether the caregiving role impacts on the caregiver's ability to live, what they perceive to be a fulfilling life. That is, whether they can meet any life goals or expectations, which may have not yet been met, and whether they feel that the caregiving experience impacts on their ability to meet said expectation or goal. They also consider the impact of the caregiving role on their everyday lives inclusive of their relationships and social life. The caregiving experience itself can influence the caregiver's self-perceived quality of life, their relationship with the survivor, the extent of care needed by the survivor, managing other commitments such as employment, and the support provided for the caregiver themselves, and the cared for person (White et al. 2004).

However, as perception is subjective, it is influenced by a person's own lived experiences. Therefore, the survivor or caregiver perception of pre-stroke life must also be considered in order to ascertain whether their post-stroke perception is as a direct result of the stroke itself, or whether they feel they had a poor quality of life prior to stroke or the caregiving experience. This can then attempt to identify the full extent of the impact which stroke has had on a person's everyday life; the ways in which a person may typically act, think, and feel on a daily basis, especially when survivors or caregivers may have been diagnosed with depression, anxiety, a psychological disorder or a physical disability, prior to stroke. However, this is not without its complexities. As self-perception is reflective of experience, when a survivor or caregiver is asked to reflect on their pre-stroke life, their reflection will naturally consider the present day. This means that even if they were dissatisfied with their life pre-stroke, in hindsight (taking into account the new experience), they might feel as though it was not as bad as they felt it was at the time. If this was to occur, this could lead survivors and caregivers to report inaccurate reflections of their perceptions of post-stroke life. This highlights the importance of considering the context of the survivors and caregivers in assessing the impact of stroke in everyday life research.

Furthermore, to assess quality of life, professionals need to consider the physical, psychological, and societal impact of stroke, in order to assert true post-stroke 'quality of life'. These definitions highlight that there is no one-size-fits-all category, and there are a variety of aspects to consider which makes each survivor and caregiver have unique post-stroke life experiences.

3.6.1   Measuring Survivor Quality of Life

Professionals and academics alike currently assess quality of life for survivors of stroke and caregivers by using both generic and stroke-specific scales. These scales aim to provide consistency across the medical research and practice field. The more common quality of life scales used to assess survivor and caregiver quality of life are discussed further in Appendices A and B consecutively.

The assessment of post-stroke quality of life has become increasingly common over the past 15 years. Professional practitioners and academics concern themselves with improving the quality of survival as well as survival rates, due to the increase in people surviving stroke (Ashton et al. 2010; Glasby 2017; Kim et al. 2015; Lee et al. 2011). However, a criticism of the measures presented in Appendices A and B is that they do not consider the full psychological and emotional effects of stroke. The scales provide a physical assessment of a person's ability; the 'ability to' live a fulfilling life. However, as highlighted previously, a person's perception of public stigma and emotional and psychological wellbeing can impact on their engagement in social participation and therefore their perception of their quality of life.

Krančiukaitė and Rastenytė (2006) assert that professionals, within the non-health-related context typically focus on the patient's functional, physical, cognitive, psychological, and social elements of everyday life. This is considered to be fairly accurate to the survivor's own self-perception of their overall health and ability (Fayers and Machin 2013; Krančiukaitė and Rastenytė 2006). This suggests that an individual's own perception of their quality of life is also reflective of these aspects, and that quality of life assessment tools in this context are at the core of enabling professionals to understand the survivor's self-perception and assist them in providing person-centred care. In addition, reports of the survivor's own perception of their own health and abilities are recorded and integrated throughout the course of post-stroke evaluation and treatment. This takes into account the survivor's own feelings and perception over the course of the treatment.

Boosman et al. (2011) researched self-perceived life satisfaction three years post-stroke using the generic Life Satisfaction nine-question Survey (LiSat-9) and found that typically those participants who were less active post stroke (50 percent) also reported that they were less satisfied with their everyday day lives. Boosman et al. (2011) assert that active daily living and social activity influenced self-perceived life satisfaction for more than three years post stroke; highlighting that survivors experience on-going dissatisfaction with various aspects of their everyday of life in the months and years after stroke.

However, assumptions such as those above cannot be made, and other factors must also be considered. For example, survivors who are physically disabled and have come to terms with their stroke may feel less satisfied in their everyday life due to other outcomes of stroke. Perhaps they also have depression, lowered self-esteem, perceived self-burden, feel a level of dependency, have not come to terms with a change in ability, or harbour feelings of guilt; rather than a lack of social interactions.

Similarly, those who are struggling to come to terms with stroke may be finding it hard to come to terms with due to a change in ability, or as previously suggested, not feeling as though they have met their life goals or expectations.

3.6.2 Measuring Caregiver Quality of Life

Caregivers and their multiple roles (of caregiver and wife and so forth) are increasingly being recognised by professionals, academics and policy makers. Furthermore, it has been identified that there is a negative impact on the health-related quality of life of primary caregivers (Davies and Honeyman 2013) which is reflective of the challenges associated with the caregiving role. Such challenges can result in many emotional, psychological, and physical strains (Davies and Honeyman 2013). Yeon-Gyu et al. (2015) described such challenges as elements which contribute to caregiver burden in their definition cited earlier in Chapter 2 (Section 2.1.2). Yeon-Gyu et al. (2015) report that caregiver burden is closely related to caregiver quality of life, stating that the greater the perceived burden of the caregiving role (for caregivers of survivors of stroke), the more negative a perception of caregiver quality of life. This in part is due to the impact of these emotional, psychological and physical strains, such as sleep disturbances, mental health issues and depressive symptoms (Smith et al. 2009a: 2014).

Authors such as Seddon and Robinson (2015) acknowledge that quality of life measures do identify key aspects of caregiver everyday life, however they also report that caregiver assessment protocols fail to consider the complexity of the caregiving role in its entirety, and therefore do not take into account possible support networks which may surround them; potentially easing caregiver burden. Furthermore, researchers Kruithof et al. (2012) assert that the caregiver participants of their study who experienced both high levels of burden and self-esteem as a result of the caregiving role also presented much higher life satisfaction scores than those who experienced high levels of burden and low self-esteem. This suggests that self-esteem rather than burden is also an important factor to consider when assessing perceived quality of life. This supports earlier notions of self-perception as burden is subjective, and self-esteem is reflective of a person's confidence in their own abilities. Therefore, policy makers and professionals should focus on improving caregiver self-esteem in their policy and practice as it is beneficial to improving perceived quality of life.

Spousal caregivers tend to feel a strong sense of burden and a low quality of life due to a reduced state of emotional and psychological wellbeing (Draper and Brocklehurst 2007; Franzen-Dahlin et al. 2007; Kaizik 2017; Larsonet et al. 2008; Parag et al. 2008). Further to this, Yeon-Gyu et al. (2015) found greater levels of caregiver burden were reported when the survivors being cared for endured a longer stay in hospital. However, the author acknowledges that other factors need to be considered here, for instance, it could be that the longer the hospital stay, the worse the impact of the stroke itself. This could lead to multiple factors which could impact caregiver burden such as uncertainty or survivor dependency. Emphasisng the importance of continuous support in the caregiver role, McCullagh et al. (2005) assert that there is no improvement of self-perceived quality of life for caregivers after one year, despite there being a perceived improvement reported by survivors. This suggests that over time, as survivors come to terms with their post-stroke self, their perception of their quality of life increases, whereas the caregivers perceived quality of life may remain the same.

The quality of life scales report that caregiving for survivors of stroke impacts negatively on caregiver quality of life (National Stroke Association 2010; Persson et al. 2015). Persson, et al. (2015) also discovered a direct correlation between caregiver quality of life, and the caregiving situation itself; inclusive of the level of dependency and need of the survivor. This was evident in Persson et al.'s (2015) study during the first years of post-stroke life, and in the long-term; in the months and years thereafter, with Godwin et al. (2013) stating that caregiver health-related quality of life declined as time went on.

Furthermore, authors Ski and O'Connell (2007) and Yeon-Gyu et al. (2015) recommend that the caregiver's personal characteristics should also be considered; inclusive of their own personal attributes, circumstance (such as financial security and income) and perceived level of health and burden. Alternatively, supporting Berges et al's (2012) theory of positive attitude, Kruithof et al's (2012) research discussed previously suggests that where caregivers are more confident in their caregiving role; they report a better perceived quality of life, and a good level of vitality, and mental health; supporting earlier comments.

3.7   Chapter Summary

This chapter further informs of the complexity of everyday life for survivors and caregivers. Along with Chapter 2, this chapter draws upon literature and provides further context for the remainder of the thesis.

The coping strategies discussed are key in understanding post-stroke life. The discussion within this chapter highlights how factors such as self-perception, identity, and perceived stigma, can influence a person's coping strategy and their level of engagement in social participation. The quality of life section added to this by highlighting how quality of life is assessed by professionals. However, what is clear from this chapter is that there is so much more depth to defining quality of life than the measures can provide. This supports the qualitative, exploratory, case study approach to this study as this research strategy provides context and in-depth insight into the participants' lives.

Chapter 4 follows, which discusses the ways in which the community, statutory, third and social enterprise sectors support survivors and caregivers in their everyday lives.

4.0   Supporting Survivors and Caregivers

Survivors of stroke are often supported in their everyday lives by their family and friends (Burholt and Dobbs 2014; The Stroke Association 2015). As Chapter 2 establishes, caregivers of survivors of stroke are typically identified as their spouse, parent, child, sibling, or friend (Toule et al. 2015). This chapter explores how the statutory sector, third sector, community services and social enterprise offer support to survivors and their caregivers in their everyday lives.

Welsh policy sets a platform for collaborative approaches between the statutory, third, and social enterprise sectors in supporting people in their everyday lives. This chapter defines social enterprise in this context, and discusses what distinguishes them as different from other sectors.

First, this chapter begins by defining the study site, Wales, UK. This provides a context to this chapter's discussion of Welsh policy and policy delivery in the health and social care sector, as well as the study itself.

4.1   Establishing the context, Wales UK

Alcock et al. (2016) and Williams (2008) describe Wales as a small nation with a unique identity, and its own language and culture, which exhibits a sense of local community. Wales has a growing and ageing population (Office for National Statistics 2016; Williams 2008; Statistics Wales 2013) of approximately 3.1 million people (Welsh Government 2016b), which has increased gradually over the past 50 years (Office of National Statistics 2004). More recently, Wales's population was predicted to increase by just under 100,000 people between 2011 and 2015 with further projections continuing this slow, yet steady trend for many years to come (Office for National Statistics 2016; Statistics Wales 2013).

Since May 2005 Wales has also experienced an increase in immigration. This trend resulted from the accession of eastern European countries into the European Union (EU) (Office of National Statistics 2009). This led to a major demographic change as Polish, Lithuanian, Estonian and other migrant groups began to gain employment and/or reside across Wales, particularly in rural and deep rural regions (Wales Rural Observatory (WRO) 2009). The change in population led to the evolution in elements of Welsh culture and/or ways of life. Therefore, in

recent years Wales has become identified as an ethnically diverse and multicultural country (Cura 2011; Statistics Wales 2013; Williams 2008). There have also been changes to Welsh communities as they move away from their traditional structure, whereby communities were defined by their distinct collective identity, with their own set of distinct symbols and language (Cura 2011). Nowadays, Welsh communities are categorised by policy makers as regions which are north or south, urban or rural, Welsh-speaking or non-Welsh speaking, and/or anglicised or non-anglicised (Statistics Wales 2012).

However, despite the increase of diversity in Wales, Wales retains its strong Welsh national identity through its cultural heritage which is supported by an increase of Welsh language speakers, particularly within the younger age groups (Office for National Statistics 2013). However, only 19 percent of Welsh language speakers in Wales are reported to reside in the North, with the Welsh language being more predominant away from the English border; in the North West regions (Statistics Wales 2012). Therefore, with Welsh health and social care policy needing to consider a multitude of language and culture within its implementation and delivery, this diverse population makes the impact of devolution (discussed later in Section 4.1.2) and Wales gaining its own decision-making powers in 2011 more pertinent.

Wales has also seen younger generations migrating out of Wales to live in more urban areas of the UK, seeking employment and/or further education. This trend presents a further threat to traditional rural Welsh culture and communities, as those younger generations would perhaps continue Welsh traditions within their localities (Greenwood et al. 2009; Williams 2008). With survivors typically being cared for at home by family members (Burholt and Dobbs 2014; The Stroke Association 2015a), those families where younger family members move away from home may become more reliant on neighbours, friends and support provisions provided by the community and the statutory sectors.

4.1.2 Devolution of Policy Making Powers

Policy makers and social welfare professionals are shaping Wales as a devolved identity (Williams 2008). The devolution of Wales from other UK countries began in 1999. This process was incremental and saw the National Assembly for Wales gain legislative powers from England in 2011. Since then, Welsh policy grew in strength through support fromWelsh legislation (Chaney 2016).

There is no one-size-fits-all approach to devolution (Lord Bourne 2015; Pugh 2011). The intertwined economic and social boundaries between England and Wales made Welsh devolution complex. The economic and social boundary between England and Wales differs from the boundaries between Scotland and England as Scotland has its own established parliament with independent policy which is completely separate from England. Lord Bourne (2015) of Aberystwyth (a Conservative member of the House of Lords) describes the Welsh border as porous, stating that people move across the border on a daily basis, perhaps without even realising they are doing so.

> *"Since the advent of political devolution in the UK, it has been widely reported that markedly different health policies have emerged."*

> (Smith et al. 2009b, 216)

Smith et al. (2009b) state that devolution has led to Wales-specific health policies emerging. An example of this is the 2012 Stroke Delivery Plan (Welsh Government 2017) which is discussed later in Section 4.2.4. In the Welsh Government (2014a) report entitled 'Devolution, Democracy and Delivery: Improving public services for people in Wales', the Rt Hon Carwyn Jones AM states that devolution has allowed the Welsh Government to develop distinctive services, and provide effective solutions to issues in Wales. This has allowed the Welsh Government to better meet the needs of the Welsh population (Welsh Government 2014a). Regionalisation can be viewed as a by-product of devolution. Regionalisation across Wales has led to localised policy development, with decision-making powers being devolved to local authorities (LAs). This is said to have made local authority services more responsive to local need, which has contributed to feelings of community solidarity among the Welsh population (Pugh 2011; Williams 2008:2011). This can contribute towards supporting those traditional community structures which Williams (2008) feared may be eroding.

In 1998 the Government of Wales Act devolved the majority of powers and functions of the Welsh Office to the National Assembly for Wales. As mentioned previously, the Welsh Government and the Welsh Assembly later obtained law-making powers following the 2011 referendum, coined the 'yes vote referendum' by Wales's population. This saw the National Assembly for Wales become a decision-making organisation, forming policy based on the mantras of 'doing things the Welsh way' and finding 'Welsh solutions for Welsh problems' (Lord Bourne 2015; Morgan 2012). This gave the National Assembly for Wales responsibility

for the key policy areas of health and social care, agriculture, the environment, economic development, tourism, town and country planning, and education and training. And so, the National Assembly for Wales gained a great amount of financial and non-financial accountability (National Assembly for Wales 2016).

This move in Welsh policy development is an improvement on policy implementation across Wales as the previous centralised policy system did not meet the needs of Wales's local communities (Lord Bourne 2015). By acknowledging that there is no 'one-size-fits-all' solution for Welsh policy, the Welsh Government's decentralisation and localism agenda has enabled decisions to be made within local communities, in consultation with the people whose lives it affects.

There have been significant divergences in Welsh social policy (Drakeford 2006). However, devolution has made Wales's policy distinct (Welsh Government 2014a) in its pragmatic response to social issues, based upon a set of ideological beliefs about Welsh welfare delivery and citizenship. This has led Welsh social care policy to reflect a 'Welsh way' of doing things (Lord Bourne 2015). This included helping people to learn to help themselves, be as independent as possible, and to support each other in their local communities. This highlights an expression of self-determination based upon ideologies about Wales's national culture, national distinctiveness and its national identity within the statutory policy sector. These perspectives are interrelated and underpin the rationale for devolution, which has been said to have made Wales a stronger nation (Lord Bourne 2015; Welsh Government 2014a; Williams 2008). This provides a platform for community-based and social enterprise initiatives across Wales, both of which are defined and discussed in Sections 4.3 and 4.5.

Welsh social care strategies are informed by policy which has been developed by the Welsh Government. Wilson (2006) considers that:

> *"Policy influences practice in at least two ways: it can determine which service models and initiatives are funded; and, it provides a standard monitoring and compliance framework to which funded services are accountable."*

> (Wilson 2006, 24)

This ensures that policy makers are focused on shaping policy to meet the specific needs of the Welsh population.

Describing Wales as:

"A dynamic entity that is constantly in the process of change and remaking."

(Williams 2008, 3)

Williams (2008) questions what it is that makes Wales different from other countries, and answers that Wales is its own entity with its own characteristics, which requires its own specific responses. Therefore, Welsh policy makers should seek to innovate policy for Wales (Williams 2008). The Welsh Government (2014b) acknowledge this, and the National Assembly for Wales has been commissioned to carry out its own research, strengthening the evidence base which underpins policy development, in a bid to make it more efficient (Lord Bourne, 2015). This has enabled Wales to form its own Welsh-specific evidence base, upon which to inform its policy development, therefore taking Wales's geography and rural structures into account. An example of this is the Stroke Delivery Plan (Welsh Government 2017) and its aim to strengthen localised support in the community (discussed further in Section 4.2.4).

4.2 The Welsh Statutory Sector

With 10 percent of the poorest areas of the UK cited in Wales, Wales is considered one of the poorest regions in the UK (Statistics Wales 2014). Bochel (2016) reports a trend that poorer regions tend to be more reliant on statutory sector support as people who reside in regions which are typically less likely to afford private health care. The Welsh Local Government Association (2017) asserts that statutory sector social care services support over 125,000 vulnerable people across Wales. These statutory sector services were introduced to help safeguard and support adults and children in times of need in the short and/or long-term (Welsh Local Government Association 2017).

Working with other initiatives such as housing departments and welfare services, the overall demand for statutory sector care services is increasing due to the high incidence of chronic conditions in Wales, and an increase of in the number of people surviving stroke (Glasby 2017). This is further amplified by the ageing population in Wales and younger generations moving away from their Welsh communities (Williams 2008). Therefore, Welsh communities are populated by comparatively older people, with whom statutory sector social care services exhibit a significant amount of community involvement (Bäckström and Sundin 2009). The Welsh

Government (2007) acknowledges that these demographic trends result in an increase of vulnerable adults requiring local authority support, inclusive of the approximate 340,000 people who are providing care for family members.

4.2.1 Policy Development

In November 1998 the Minister for Wales created a rural partnership for Wales. This rural task force became responsible for diverse rural issues and brought together a variety of organisations and special interest groups which contribute to policy and programme development in rural Wales. The partnership focused on economic, social, environmental and cultural issues and in 1999, began to focus on several key areas in order to contribute to a vision of a 'sustainable future for rural Wales'. To meet this vision, the partnership focused on the key areas such as economic and business development as well as strengthening communities, improving access to rural services, and investing in the rural infrastructure (WRO 2004).

In June 2011 the Welsh Assembly called on the Health and Social Care Committee in order to examine legislation and hold the Welsh Government to account by scrutinising expenditure, administration and policy matters which included the physical, mental and statutory health of Welsh citizens (National Assembly for Wales 2011), contributing to the review of Welsh policy. Furthermore, the Welsh Government devolved powers to quasi-autonomous non-governmental bodies (quangos), giving them the task of policy delivery and the development of programmes. Quangos, despite having their own infrastructure of accountability and governance, act on behalf of the Welsh Government, typically in relation to specific services relevant to their specialist area of expertise; providing advice to the Assembly and serving a judicial role. Quangos in the health and social care sector include the Care Council for Wales and Care and Social Care Inspectorate Wales.

The most significant non-elected bodies which serve rural Wales are Welsh Government Sponsored Statutory Bodies (WGSSB) which receive direct funding from the Welsh Government as sponsorship but remain independent from the Welsh Government. They serve the Government with their own legal powers and constitutions and are key actors in policy delivery (Welsh Government 2011). The Care Council for Wales is branded the most executive WGSSB for health and social care and consists of an advisory committee made up of specialists in areas

such as dentistry, medicine, nursing and midwifery, which aim to provide local authority support through community provisions. However, this provision has been described by stroke survivors and their relatives as inadequate and poorly tailored to individual needs (Bäckström and Sundin 2009; Welsh Government 2011).

Osmond (1998) once cited that:

> *"The generosity and self-interest associated with a health service free at the point of delivery remain common sense, as did a native sense of community solidarity founded on attachment to locality, people and a shared landscape and culture. All these things were mutating back more to what it meant to be Welsh* [rather] *than British."*
>
> (Osmond 1998, 3)

Here, Osmond considered how the notion of free healthcare at the point of delivery contributes to Welsh identity and sets Wales apart from the rest of Britain. This concept was introduced to meet the needs of people in Wales, with the intent on improving healthcare opportunities for people living in Wales; improving accessibility and contributing to a better health and wellbeing of people in Wales. This has been said to be Wales's key strength in health and social care policy (Alcock et al. 2016).

As Lord Bourne (2015) states previously, the help and support provided by the health and statutory sector social care services for relatives of stroke survivors has often been found to be inadequate and poorly tailored to individual needs. The person-centred approach has been adopted to better meet the needs of survivors and caregivers who are supported by public policy in Wales.

> *"The move away from the traditional model of disease management, whereby patients were often passive recipients of care, is supported by government policy."*
>
> (Fitzpatrick 2008, 1)

As Fitzpatrick (2008) states, there has been a change in the way that 'need' is identified by policy makers who, rather than relying on expert and scientific definitions, also consult with the public; integrating the public into policy development (Alcock et al. 2016). This supports the notion of services for disabled people being informed by disabled people, integrating public opinion into policy development across Wales (Alcock et al. 2016; Gray and Birrell 2013; Johnson and

DeSouza 2008).

Effective partnerships between health and social care services which run parallel to other services such as employment, transport, housing and leisure services can help provide consistency in policy delivery (Baldock et al. 2012). It is also fundamental that rehabilitation is focused on the needs of the stroke survivor and their relatives or/and their caregivers, as good quality of rehabilitation can have a positive impact on the recovery of the stroke survivor in the long term; possibly even reducing disability (Jeong et al. 2015). Jeong et al. (2015) and the Intercollegiate Stroke Working Party (2008) also recommend that a family centred or caregiver approach should be adopted when designing policy delivery which takes into account the needs of caregivers as well survivors from the point of discharge and in the longer term.

4.2.2   Welsh Health and Social Care Policy

Before devolution, there was an absence of Welsh-specific stroke research, and Welsh stroke policy. Before the development of the 2012 Stroke Delivery Plan, health and social care for survivors of stroke was guided by national frameworks in England such as the National Service Framework, and the Older Peoples National Service Framework (Department of Health 2001; Nazarko 2004). This was founded upon an evidence base of combined Welsh and English data. Thus, early Wales-specific health and social care policy was founded upon a weak evidence base as it was not Wales-specific. This resulted in gaps within the policy, amounting to inadequate policy and insufficient delivery (Lord Bourne 2015; Williams 2008). Over time, Wales strengthened its data set and has been able to develop more Wales-specific strategy.

Since the devolution of Wales, Welsh policy has primarily focused on improving the health and wellbeing of the Welsh population. Gray and Birrell (2013, 203) describe devolved health and social care policy in Wales as:

> *"A service with close connections to the principles of social justice and equality, and strong traditional value components for Welsh politicians."*
>
> (Gray and Birrell 2013, 203)

The Welsh Government allocates almost half its annual budget (£15.3 million) to health and social care development (Chaney 2016; Gray and Birrell 2013). Life-long conditions are a key

focus of all health and social care policy, particularly as the advancement in the health sector means that more people are surviving conditions such as stroke (Glasby 2017). As discussed previously, this means that more people are living with post-stroke disability, be it physical or neurological, in their everyday lives (Glasby 2017; Kim et al. 2015; Lee et al. 2011). Therefore, the number of family members or friends taking on the caregiving role has also increased. Policymakers have recognised the impact that caregivers have in supporting people with life-long disabilities or limitations in their everyday life. This led to the advance in caregivers being acknowledged in Welsh health and social care policy (Alcock et al. 2016).

Table 1 provides an overview of the main policy development in Welsh Health and Social Care Policy over the last ten years, prior to the 2012 Stroke Delivery Plan.

Table 1: An Overview of Welsh Policy Development 2007-2012

Year	Policy/Legislation	Main provision/Developments
2007	Strategy document *Fulfilled Lives, supportive communities: a strategy for social services over the next decade*	Set out Welsh Government approach to social care based on welfare, social justice and inclusion.
2010	*From Vision to Action*: *The report of the independent commission on social services in Wales*	Public engagement exercise. Proposals emphasised preventative services built around service users, families and caregivers.
2011	*Sustainable Social Services for Wales: A framework for action*	The strategy rejected retrenchment approach and set out priorities for action linked to renewal and innovation with focus on user involvement.
2012	Social Services (Wales) Bill	Seen as an attempt to set a national care system for Wales. Proposed eligibility thresholds, a national contract for care home and regionalised commissioning arrangements.

(Extracted from Gray and Birrell 2013, 41)

In 2007 the Welsh Government created strategies and policies in a bid to reform health and social care across Wales (Gray and Birrell 2013). The reform began with the 2007 strategy 'Fulfilled Lives, Supportive Communities: A Strategy for Social Services in Wales over the next decade'. This was produced in collaboration with its Procurement and Training and Qualifications Sub-groups with advice from the Oxford Brookes University's Institute of Statutory Care. The framework for this initiative primarily focuses on social care for adult and children's services and supports other initiatives (Welsh Government 2007).

The Fulfilled Lives framework aims to encourage independent living. This is being implemented by self-directed care initiatives - by providing direct payments to people, allowing them to pay for their own care. The framework also encourages resource sharing throughout the statutory sector care homes and aims to support cross-sector cooperation and support for minority groups; inclusive of disabled people. Gray and Birrell (2013, 13) describe this strategy as *"distinctly Welsh"* in its approach to welfare, social justice and social inclusion as its focal point is the service user and their rights. Although this strategy is not caregiver-specific, it did identify caregivers as potential service users. This strategy also seeks to improve access to services through simplification, increase the profile of local authority support, and promote social inclusion. Furthermore, the framework aims to address issues around continuity of care and support for vulnerable people. The Welsh Government (2007) aims to achieve this by providing a better qualified workforce at the core of Welsh health and social care services, and ensuring the local authorities remain both commissioners and providers of health and social care across Wales (Gray and Birrell 2013; Schales and Schneider 2012).

In 2010, the Independent Commission on Social Services in Wales engaged with Welsh communities and sought to identify what service user need and challenges were presented by the current system. The Independent Commission on Social Services in Wales (2010) proposed more collaboration between service departments and a stronger emphasis on preventative services, to be focused on the service user, the caregiver and their family (Gray and Birrell 2013). This led to the development of the white paper: 'Sustainable Social Services for Wales: A Framework for Action' (Welsh Government 2011a).

This framework focuses on strengthening public voice and control, encouraging support of each other in communities, enhancing the safety of the population, prevention of disease, support in adjusting to new circumstances, providing stability and simplicity in the service provisions, and enhancing professionalism across the services offered (Gray and Birrel 2013). As a response to

this white paper, the Welsh Government (2015) developed the 2014 Social Services Wellbeing Act, implemented in April 2016 in response to White Paper 'Sustainable Social Services'. This Act sets out the Welsh Government's vision for transforming social care across Wales which was inclusive of the Welsh population (Gray and Birrell 2013; Welsh Government 2011a). The key focus being to develop high quality and responsive services which have a strong public voice, through better collaboration between partners. The aims of the Act include more effective support, allowing service users to make decisions about their care, equal rights to assessments for caregivers and preventative approaches to care and support. The Act also aims to support wellbeing by supporting people in being physically, emotionally and mentally happy, protected from harm and given opportunities for education, sport and training. Wellbeing is also supported through this Act by its aims to support positive relationships with friends and family, provide opportunities for social life and promoting engagement into the community. This was a move away from the former model where the 22 councils across Wales acted as independent entities and saw the seven Local Health Boards across Wales working across the country. The Nuffield Foundation study completed in 2014 (Roberts and Charlsworth 2014) shows that the transition to seven Local Health Boards led to an improvement in the effectiveness of Welsh social care since 2009.

The Welsh Government's approach to national strategy differs to that of England as it is less market-driven in that it does not focus on 'consumer choice', but rather making the services it can offer accessible to all (Gray and Birrell 2013). However, Lord Bourne (2015) expresses that he feels the current Welsh social care system lacks equality, is unsustainable, and is inadequate. He states that, while it is public knowledge that the system is inadequately funded, there is a reduction in funding from the Government into social care while the demand for social care services continues to increase.

The Welsh Government aims to address this issue with the 2014 Social Services Wellbeing Act through stronger partnerships between local authority services departments and the National Health Service (NHS). It is anticipated that this will result in better-integrated services through more effective collaboration. Such service improvements include better provisions for obtaining information for service users, assistance in finding out about services available to them, giving service users more say, and extending services where direct payments options are available if the service user wishes (Alcock et al. 2016; Gray and Birrell 2013). The bill has also provided the Welsh Government with the legal rights to implement a Welsh National Outcomes Framework and Standards for Social Services (Gray and Birrel 2013; Social Services Directorate 2012).

Health and social care policy aims to address social problems and improve public health and wellbeing (Alcock et al. 2016). Within this context, social policy aims to support people in their everyday lives. Whereas health services focus on providing medical care; social care services aim to support people in their everyday lives, providing assistance where needed. This highlights how the health sector provides support for policy initiatives. This ranges from support in the home in getting out of bed and washing to care home provisions and drop-in centres. Such care is provided by the local authorities on a means-tested basis ensuring that the services are provided to those who are classified as having substantial or critical needs (Age UK 2017). However social care can also be provided via the private sector for those who wish to pay, regardless of the level of their needs.

Whereas England has had a stroke-specific strategy since 2007 (NHS Wales 2014), The Health Wellbeing and Local Government Committee (2010) reflect that Wales was unlike any other UK country as it had no stroke-specific strategy. There was no Welsh Stroke Register and no systematic way of evaluating the effectiveness of stroke services. Prior to 2012, Wales's health service was adhering to the Streatgy for Older People in Wales, implemented in 2003 (Welsh Government 2003), and the NSF for older people in Wales implemented later, in 2006 (NHS Wales 2006). These frameworks were aimed at managing chronic conditions such as stroke, diabetes, heart disease and asthma, the development of the National Service Framework (NSF) and the Strategy for Older People in Wales took a person-centred approach and were concerned with improving health and emotional wellbeing (Welsh Government 2003; NHS Wales 2006). These frameworks focused on making positive contributions to improving quality of life; providing choice, providing more control, ensuring freedom from discrimination, ensuring economic wellbeing and ensuring personal dignity. However, they did not fully address the complexity of post-stroke life.

More recently stroke policy in Wales has been addressed by two health circulars: 'Implementation of National Standards for Stroke Services in Wales' and 'Improving Stroke Services' which underpins the National Service Framework (NHS Wales, 2014). These strategies were introduced to improve stroke services across Wales as the services provided were falling behind those implemented across other UK countries (All Wales Stroke Service Improvement Collaborative 2009; Welsh Government 2007a). As part of the Stroke Improvement Plan for Wales, The All Wales Stroke Service Improvement Collaborative (AWSSIC) set about data collection and evaluation of 18 acute stroke hospitals across Wales and found that interventions such as learning tools and guidelines for improvement, resulted in a

steady improvement of service delivery.

Social welfare professionals are key actors of health and social care policy in Wales. However, the move away from combined policy for England and Wales, to Welsh-specific policy has increased the opportunities for Welsh stakeholder and interest groups, such as the Care Forum Wales and Hywel Dda University Health Board, to be involved with their own agenda on policy priorities (Care Forum Wales 2017; Hywel Dda University Health Board 2017). However, it is worth noting that some stakeholder and interest groups may be stronger than others and therefore may have more (or less) influence in shaping policy (Williams 2008).

Stroke is a priority for the NHS and social services in Wales, which has led to a partnership being formed between the National Public Health Service for Wales and the National Leadership and Innovation Agency for Healthcare in 2008. The All Wales Stroke Services Improvement Collaborative launched in September 2008, bringing together management and clinical teams from Welsh acute hospitals and seeking to utilise each department's expertise, skills and resources, and further develop stroke services (National Leadership and Innovation Agency for Healthcare 2009).

NHS Wales (2014) is focusing on long term provisions which aim to prevent stroke, increase survival rates, and improve post-stroke quality of life for survivors. The prevention objective is complemented by strategic initiatives such as 'Ask First – to prevent stroke later', 'Health Challenge Wales – Stroke: don't let it happen to you', and the nutrition network for Wales's 'The National Exercise Referral Scheme', 'Stop Smoking Wales', and, 'Health Challenge Wales – Alcohol'. Primary care providers across Wales are supportive of the prevention objectives, and target such strategies at those who are at risk of stroke due to other health conditions such as hypertension and diabetes. Supporting the increased survival initiative, NHS Wales and the Welsh Government are focusing on improving public awareness and education about stroke and urgency required in accessing health care and recognising stroke. An example of this is the 'FAST' advertising campaign (The Stroke Association 2017a). Media distributed by the Stroke Association (a third sector organisation) also support this campaign.

Dewar (2010), a Consultant Stroke Physician, recommended that a Stroke Strategy for Wales be developed together with The Welsh Stroke Alliance. He suggests that this would support the need for an 'all Wales stroke strategy' which, in contrast to Williams' (2008) recommendation for innovative policy, the National Assembly for Wales recommend be developed from the existing

national stroke policy. This policy would include targets, deadlines and standards which were monitored efficiently by a strategic system (Dewar 2010). These systems provided a period of policy evaluation and development which helped to shape Welsh policy for Wales.

4.2.3 Welsh Stroke Strategy

Stroke policy in Wales has traditionally focused on prevention, the acute sector, care in hospital and the early stages of discharge. More recently, policy makers have recognised the importance of supporting people living with stroke and their caregivers in the months and years after stroke. The statutory sector has also recognised the value of collaboration between the third, and social enterprise sectors as an avenue for creating effective community support. This is evident in Wales's 2012 Stroke Delivery Plan (Welsh Government 2017), discussed in Section 4.2.4.

Before 2007, a common focus for stroke strategy in the UK was the care of stroke patients while in hospital and early stages of discharge, with much of Welsh health and social care policy and strategy focusing on general health and social care. In 2007, the Welsh Government began to focus on stroke-specific services within its statutory health sector, recognising the importance of swift admission for patients suspected of experiencing stroke. The Welsh Government invested £2.5 million in improving patient services with the aim of developing a national protocol and quality regulator by 2010. This shift increased the availability of in-hospital and community rehabilitation, and rehabilitation services, inclusive of the following: outpatient therapy; family and caregiver support and information; specialist long-term support services; community and in-home support and/or adaptions through Social Services departments, and; education and support promoting self-help, secondary prevention, hygiene, and medicine management (The Stroke Association 2012c).

4.2.4 Wales's Stroke Delivery Plan

Wales's first Stroke Delivery Plan, implemented December 2012 – 2016 (Welsh Government 2012), sought to support people who experience stroke, of any age, wherever the lived in Wales (NHS Wales 2014). Support was to be delivered by the NHS, third sector organisations and local government through stroke-specific services in all communities. This action aimed to tackle factors such as access to services which made some communities much more deprived

than others. The plan focused on long-term prevention and sought to increase awareness of stroke and its causes, encouraging people to take responsibility for their own health and wellbeing. The aim of prevention is justified. However, there was little focus on supporting people living with stroke in the months and years after discharge from hospital. The plan does identify the need to support this population, noting that there are to be services provided using the local health board and the NHS as a framework for integration and collaboration of stroke services across Wales, yet does not set a framework for providing such support. The aim of the plan is to assist the NHS in meeting the needs of people who have either experienced stroke in the early (acute) stages who have been admitted to hospital or are at risk of experiencing stroke. The aims of the Stroke Delivery Plan have been carried over to Wales's new Stroke Delivery Plan, implemented in 2017 until 2020 (Welsh Government 2017).

Supporting other strategies such as the five-year NHS plan 'Together for Health' and the Quality Delivery Plan for the NHS in Wales for 2012-2016, the 2017-2020 Stroke Delivery Plan identifies that stroke services are of top priority for the Welsh Government, it also acknowledges that stroke outcome varies geographically across Wales, with more severe stroke outcomes being reported in deprived areas of Wales (Welsh Government 2012a). The Stroke Delivery Plan 2017-2020 aims to support survivors through living well, preventing further stroke, early recognition of a transient ischemic attack, fast effective care for rapid response to suspected stroke, rehabilitation, recovery, life after stroke, and end of life care (Welsh Government 2017). The majority of survivors need long-term support and rehabilitation from health sectors, local government and the third sector. The plan aims to deliver immediate, comprehensive interdisciplinary assessment, acute care, and early stage rehabilitation. It also recognises that the local multi-professional service and planning structures which are currently in place are in need of growth and maturity. Regarding supporting life after stroke between 2012 and 2016, the plan aimed to put people at the centre of stroke care and address their individual needs to assist them in managing stroke. This has been carried forward in the new 2017-2020 strategy. Therefore, there is a focus on integration between health care and social care services with a regular review of its service users; survivors or stroke. This included those survivors with residual impairment and psychological needs and included them, along with heir caregivers, in the development of future services and, planning and delivery of local palliative care.

The plan also aims to support survivors of stroke and keep them informed by improving information and targeted research. This action is in response to acknowledgement of key factors of a positive experience of healthcare, such as communication, coordination of care, access to

care and support at home or close to home, respect of dignity, provision of information, access to psychological support and access to financial assistance. This correlates with the identified need for information as discussed in Chapter 2. Furthermore, the plan suggests that integration between Local Health Boards, secondary and community care and local authority support will enable care plans to be put in place to allow for efficient and effective discharge of survivors from hospital (Welsh Government 2017).

4.2.5 Meeting the Needs of Survivors in Wales

Survivors of stroke require the use of statutory health services in medical care, mental health and re-enablement. However, their needs can also be met by voluntary organisations, community groups and community transport (Fallapour et al. 2010).

The delivery of strategies developed to support people living with long term conditions such as stroke is a key element of strategic development and person-centred policy, which are both priority areas in Wales (Guarneros-Meza et al. 2014). Fitzpatrick (2008) argues that the primary element is to establish community resources within the infrastructure of the NHS.

Furthermore, Fitzpatrick (2008) categorises three key areas of health policy intervention as: case management, disease-specific care management, and supported self-care. These areas are supported by initiatives which aim to support people in making healthier lifestyle decisions and are focused on disease prevention and disease management. The Welsh Government (2007) supports the notion of self-care and reports that the increasing demand on local authority support departments across Wales could potentially decrease if statutory sector services were successful at helping people live in their own homes, as independent a life as possible.

4.2.6 Meeting the Needs of Caregivers in Wales

The Carers (Equal Opportunities) Act 2004, sought to improve caregiver support across the UK. Described as *"making a cultural shift in the way caregivers are viewed"* (Russell 2007, 3), this act demonstrates a turning point in policy where caregivers are considered as people in their own right, with their own needs (Russell 2007). In doing this, the act denotes that caregivers should be made aware of their right to request an assessment of their ability to provide, and to continue

to provide, care for the person cared for. This act was superseded by the National Strategy for Carers 2010, the revised 'Recognised, Valued and Support: Next steps for the Carers Strategy' 2010, and the NHS Outcomes Framework 2014/15 (Department of Health 2013). These strategies set out priorities for carers between 2010 and 2014 and aimed to provide caregivers with training opportunities, practical support and advice to support caregivers in their everyday lives. However, there were still areas to be improved for caregivers in Wales.

More recently, the Welsh Government's (2013) Carers Strategy for Wales recognised the unique needs of caregivers in Wales and aimed to meet those needs on an individual basis by providing person-centred support and information. The plan's five key priority areas were: health and social care; identification, information and consultation; young carers and young adult carers; support and a life outside off the caring role; and carers and employment, aiming to support caregivers in balancing their caregiving role within their everyday lives. The strategy aimed for caregivers to be better informed of the range of integrated and personalised support services and that they be treated as expert care partners. Such aims sought to promote caregiver health and wellbeing, encourage self-care, and ensure that caregivers manage to avoid financial difficulties (Welsh Government 2013).

This was later superseded by the 2014 Social Services and Wellbeing Act (Welsh Government 2014b). This act aimed to provide equality for caregivers, giving them the same rights as the people they care for and supporting them in living what they perceive to be a fulfilled life. This act aimed to support caregivers in maintaining a good quality of life by ensuring that those who sought employment or education are given the opportunity to do so. Furthermore, the act (Welsh Government 2014b) seeks to ensure that the caregiver's knowledge of the person they care for is treated with respect and they are made aware of their rights to a needs assessment by the LA. The act also seeks to ensure that assistance is provided to help carers understand decisions taken if required. Also, it is ensured that their age and any disability and cultural needs are considered and that carers are aware of the support available from voluntary organisations and that training on consulting with caregivers is provided to staff regarding caregiver support. This is provided in the local community by stroke clubs (in the third and social enterprise sectors) which are open to those who have experienced stroke and their family and friends.

The Carers Strategies (Wales) Measure 2010 focused new legislative requirements on the NHS and LA, seeing stronger support for caregivers. Furthermore, the Social Services and Wellbeing (Wales) Bill also added strength to caregiver support; giving caregivers and survivors equal

rights and entitlements (Welsh Government 2012b). The King's Fund (2015) views the recent Care Bill to be significant in reforming care and support; supporting these initiatives. However, the Department of Health (2014a) acknowledges that Carers Strategies (Wales) Measure 2010 requires partnership between the statutory and third sectors. They describe that the Welsh Government will collaborate with local authorities and Local Health Boards across Wales, and assert the contribution they can make to achieve the outcomes of the plan. The third sector will collaborate with the Welsh Government, NHS, and Local Health Board to effectively implement the plan; with the third sector being key to developing and delivering innovative not for profit organisations across Wales (Department of Health 2014a).

The Welsh Government also supports third sector organisations; helping to fund organisations such as Carers Wales, and Carers Trust, who identify and support caregivers, and can inform of caregiver need and effective ways of supporting caregivers in their everyday lives. They also fund the Royal College of GPs, providing training and support for GPs in identifying caregivers and assessing their needs and to provide training and support to community nurses (Welsh Government 2014a). As discussed previously, through its 2014 Social Services and Wellbeing Act, the Welsh Government (2013) aims to provide caregivers with the legal right to support which they are eligible for and plans to simplify caregiver assessments, allowing their needs to be easier to identify. The Welsh Government has also allocated £400 million to the NHS to provide respite care; giving caregivers a break from their caregiving role (Welsh Government 2014). However, the implementation of this needs to be thought through to ensure that this support is practical for caregivers and survivors, as Johnson and DeSouza's (2008) stated in Chapter 2 previous, there are difficulties in the practicalities with such respite provisions.

Authors such as Bäckström and Sundin (2009), Johnson and DeSouza (2008) and Jones and Morris (2013) identify caregivers (particularly family caregivers) as 'patients' with their own problems and unique needs. Therefore, it is important for policy makers and practitioners to take caregiver health and wellbeing into account, and support them in maintaining a good level of physical and emotional wellbeing, and support caregivers in their caregiving role (Jeong et al. 2015). This aids caregivers in being effective care providers, thus improving the support provided to the survivor. This in turn helps towards caregivers in maintaining a good self-perceived quality of life (Jeong et al. 2015; Jones and Morris 2013).

Highlighting the importance of improving caregiver quality of life, Baumann et al. (2012) state:

> *"Enhancement of a caregiver's quality of life can help maintain the patient's life satisfaction, particularly in a rural setting."*
>
> (Baumann et al. 2012, 219)

However, Baumann et al. (2012) assert that what is required to 'enhance' caregiver quality of life, is dependent on the caregiver and survivor's personal circumstance. Although, a key challenge here is that caregivers don't often identify themselves as caregivers (Bäckström and Sundin 2009). Therefore, caregivers may not recognise their own needs in order to actively seek support from professionals. Furthermore, caregivers often do not identify themselves as caregivers within a family unit due to feeling as though the caregiving role is a moral obligation (Johnson and DeSouza 2008). This highlights potential challenges for policy makers, and contributes to Johnson and DeSouza (2008) descriptor of caregivers being active seekers rather than passive recipients; however of support, not merely information.

McKevitt et al. (2010) report that there are few services designed to help families of stroke survivors. Effective support for family members who become caregivers helps to minimise the negative impact which the caregiving role may have on their everyday lives (McKevitt et al. 2010). Deacon et al. (2008) assert that:

> *"Campaigns hosted by caregiver organisations, research, and recent government legislation should, in theory, be improving the prospects for carers."*
>
> (Deacon et al. 2008, 77)

The Social Services and Wellbeing (Wales) Act recommends that caregiver needs are routinely assessed as the emotional wellbeing of caregivers should be identified and adequately supported (Welsh Governmnet 2015). This is due to the contribution that caregivers make to care in the months and years after stroke, and the rehabilitation of the survivor. Such support from the caregiver to the survivor is critical for those living their post-stroke lives to be able to address day to day challenges, retain relationships at home, and maintain a good sense of wellbeing (Drummond et al. 2013; Meijering et al. 2016; Steultjens et al. 2013).

Highlighting the proportion of caregivers who access support, Snyder and Keefe (1985) discovered that less than 50 percent of the caregivers who participated in their study had family

or friends who could assist in their caregiving role. They also found that 80 percent of the caregiving participants accessed at least one form of Social Service (Snyder and Keefe 1985). Not only should support help caregivers learn to cope with a highly stressful mood, provide physical care, and cope with cognitive problems which survivors may experience, but it should also attend to highlighting the perceived benefits of caregiving (Haley et al. 2009).

Despite Bäckström and Sundin (2009) reporting in Chapter 2 that caregivers are reluctant to seek support in their caregiving role, Lee and Mok (2011) report that caregivers often establish social support by asking for help and support from friends, families and any other available resources. This suggests that their reluctance to seek support does not prevent them in doing so as such support is typically depended on (Buschenfeld et al. 2009; Saban and Hogan 2012).

A key focus for the Welsh Government is to improve caregiver support, as well as improve the access to information and support services carers may be eligible for. This includes the provision of information for carers and full engagement with family and carers at all stages in the discharge process (Welsh Government 2016a). It is therefore fundamental that service providers ensure that different components of the service are coordinated with one another in order to improve the effectiveness of health and social care services. Such an approach should not be limited to health and social care services delivered by statutory organisations, but should include those services which may be provided by third sector organisations and other departments of a local authority, such as housing.

4.2.7   Challenges facing Policy Makers in Wales

There are many challenges facing policy makers in Wales. Here, three key challenges are discussed; identifying caregivers, defining Wales's geography, and access to services.

4.2.7.1   Identifying Caregivers

As Chapter 2 reports, defining the caregiver is a complex task. Identifying the caregiver is a primary concern for policymakers and community support services (Deacon 2008; Fitzpatrick 2008; Presho 2008). Johnson and DeSouza (2008) question: why it is still difficult for carers to obtain the help and support they need?; and answer that 'yes' the needs of caregivers are better

understood, however, there are conflicts and contradictions in the ways in which policymakers, service providers, and caregivers themselves identify caregivers, and their respective roles.

Caregivers are considered a hard-to-reach population as they do not always identify themselves as caregivers. This emphasises the importance of accurately defining the caregiver in their multiple forms, to ensure that appropriate support can be developed and properly implemented (Johnson and DeSouza 2008). Furthermore, Johnson and DeSouza (2008) identify that caregivers may even be reluctant at accessing support as they feel guilty that they are not coping with the caregiver role. There may also be pressures as the cared for person may resent the phrase 'carer' as it makes them feel that they are dependent on other people. Further complexity in delivery of support services is that professionals are often not trained in accurately identifying caregiver need which means that carers often feel misunderstood. In addition, lack of resources mean that professionals cannot always provide an effective service.

4.2.7.2 Wales's Geography

As Welsh health and social care policy seek to meet the needs of people in their local communities, policymakers need to identify the key differences between the regions across Wales. The WRO (2009) conducted a study of Welsh rural communities which found that 36 percent of their participants reported poor or very poor service provision; 63 percent rated provision of hospitals as poor or very poor. Furthermore, 51 percent stated that they received broadband. This has an impact on the implementation of initiatives such as telecare, online knowledge acquisition and accessing online support, suggesting that such support may not always appropriate in rural regions. Telecare packages may also be deemed inappropriate due to older people perhaps not having the skills to use such technology and the limited internet connection and mobile phone signals in rural and deep rural areas of Wales. For those areas where such provisions can be connected, these typically incur a greater charge from the installation company and network provider. Therefore, the Welsh Government needs to identify which regions are considered rural or urban and define classifications for each. That way they can fully explore how to target such populations. However, with a rural geography and no defined definition of rurality, semi rurality and deep rurality, Welsh policymakers have faced challenges when implementing policy across Wales (Williams 2008).

Researchers and organisations define rurality by different definitions depending on the nature of the topic under research, and the purpose of the document. While dictionaries define rurality regarding countryside; geographers define rurality by land use, population density and terrain. In some instances, rurality is defined by 'distance to services', such as the public transport system or the nearest shop (Williams 2008).

When considering rural geography, Radcliffe (2011) refers to The Organisation for Economic Co-operation and Development which defines rural areas, as areas with a population of fewer than 150 people per square kilometre. By this definition, nine of the 22 unitary authorities (the Isle of Anglesey, Carmarthenshire, Ceredigion, Conway, Denbighshire, Gwynedd, Monmouthshire, Pembrokeshire and Powys) are categorised as rural (Radcliffe 2011; Williams 2008), highlighting that these older definitions are still used by policy makers today. Furthermore, Statistics Wales (2015) reports the population density of Wales by LA and shows that population density has increased gradually from 1991-2014, particularly in the North and North West regions, with the North West being least dense.

Notably, the Welsh Government Rural Development Plan and the WRO (Radcliffe 2011) adopt the Office of National Statistics (ONS) (2004) classification which defines Wales by sparse and less sparse counties and further defines rurality by settlement and population characteristics. Furthermore, the Welsh Government (2007) and Radcliff (2011) state that these classifications are defined through consultation with local authorities and with typically no primary statistical data. However, accessing the services sought can promote further challenges due to the rural geography.

4.2.7.3   Access to Services

McGrail and Humphreys (2015) state that access to services in rural regions is a key issue which underpins much of health and social care policy. With Wales being made up of many rural regions, accessibility is something Welsh policy makers must consider. The WHO (2016) states that people living with disabilities often encounter barriers when accessing health and social care services. There barriers are not necessarily physical or tangible (Meijering et al. 2016). The WHO suggests that such barriers can be environmental or social, and require interventions to

overcome them. Such environmental and social barriers are discussed in Chapter 3 and include perceived stigma, fatigue, and depression.

The dimensions of access in relation to services include availability and supply, adequacy, distance and travel time, travel cost, transport availability, accommodation, and the degree to which services are tailored to meet consumer need; such as opening hours, waiting times, procedure, affordability of service, and the delivery of the service (WRO 2009). It is worth noting that these issues regarding stroke service accessibility in rural regions are consistent with the experience of those living in urban regions. However, rurality compounds the issues of accessibility to services.

Different services are available across different regions which can limit accessibility regarding cross-boundary access to services (Schuurman et al. 2010) as rural geography can create greater distance to health and social care services (The National Statutory Health Service for Wales 2005). This may result in a delay in diagnosis, and access to rehabilitative and support services; aspects which are crucial for people who experience a stroke. This can lead to poorer outcomes for people who reside in rural regions (WRO 2009).

McGrail and Humphreys (2015) identified that the increased travel time to GP surgeries and hospitals in rural regions also had an impact on the number of cases where diagnosis of cancer and other chronic conditions were being delayed, resulting in a poorer prognosis. This issue is taken into key consideration in public policy development (Welsh Government 2009: 2015). Rurality is a key issue across Wales. The distances to specialist health services is shown to affect the survival rates for some cases, in addition, travel time to specialist services can be costly in terms of time, energy, finance and emotions (McGrail and Humphreys 2015). This highlights a key concern for people who experience a stroke, or recurrent stroke, who reside in a rural infrastructure. This also highlights that the issue is not that the service is not there, it is that the rural infrastructure makes it hard to access. In some cases, emergency time to a district general hospital is 60 minutes. These health boards also report that accessibility issues need further financial analysis to be considered (Welsh Government 2009).

The WRO (2009) found that 92 percent of participants considered access to a car as essential in rural regions of Wales; with 4 percent stating that they had no access to independent transport. 11 percent of participants from White et al.'s (2007) study also reported that they had no independent transport; with 22 percent stating that they were reliant on other people. White et al.

(2007) also note that poor transport in rural areas of Wales results in higher need to own a car. Therefore, someone living with stroke who resides in the rural North may feel a need to be more reliant on independent transport. However, this is a potential issue for someone living with the outcomes of stroke, and their outcomes may mean that they are medically unable to drive a car.

McGrail and Humphreys (2015) observe that rurality clearly impacts on service delivery and the ability of service providers in meeting the needs of the rural population, a core issue being the lack of transport provision. This lack of access has created difficulties for 16 percent of rural residents in accessing local GP practices and 11 percent in accessing local hospitals (White et al. 2007; McGrail and Humphreys 2015). The Welsh Government supports this, and also reports that integration, community cohesion and engagement are also key issues which need addressing in relation to service provisions in rural geographies such as that of Wales (Welsh Government 2009). Accessibility to services includes access to services by patients, friends and family, through more sustainable local transport, sensitive appointment systems, and local service provision in addition to accessing local people through innovation; for example, use of IT (Welsh Government 2009). Furthermore, Green (2016) comments that the services provided within rural communities may employ a lower skilled workforce, suggesting that the quality or standard of service provided may not be as advanced as those in more urban regions. This is considered symptomatic of Wales being a country with migration trends of younger people moving to more urbanised areas, and the growing and ageing population (Green 2016; Williams 2008: 2011).

Accessibility to services is a key theme in rurality literature in the health and social care sectors. Schuurman et al.'s (2010) study conducted in Canada identified that people living in larger urbanised areas such as Vancouver had greater choice in hospital and hospice-based care; such service choice deteriorates the more rural an areas people live, and the larger the geographical distance. This is amplified further when there is poor weather and terrain. Schuurman et al. (2010) affirm it may take a professional caregiver one full day to visit a single client in a remote area, whereas urban communities sometimes have access to more diverse support teams and better transport links which make the service provision run more efficiently.

Furthermore, a correlation between a lack of access to services and feelings of isolation has been identified by the WRO (2009). They assert that residence of rural regions in Wales are more than twice as likely to report issues with access to community services such as the post office, bank, community centre, bus stops and doctor's surgery, and three times more likely to report that they

had difficulties in accessing a grocery store. This suggests that rural residents' ability to access basic services and their sense of remoteness and seclusion are closely correlated (White et al. 2007). This can result in greater feelings of reduced social participation for survivors and caregivers who reside in rural regions, compared to those who report reduced social participation in more urban geographies. However, participants of Denzl et al.'s (2013) study of rural living reported that they felt a sense of rural community, and addressed that the main isolation was from the healthcare system and statutory support, not from family and friends.

Pugh (2011) reports that the scarcity of support services accessible in rural regions has resulted in poorer health and mental and emotional wellbeing. However, Pugh (2011) states that it is important to note that literature is not stating that people living in rural areas have a lower quality of life, and/or worse outcomes of stroke; it states that rural geographies make accessing support more difficult for people residing in rural areas. However, considering the importance of accessing hospital within three hours of a stroke, it may be suggested that people living in rural regions, with weaker infrastructure, may experience a delay in receiving acute emergency treatment (Hagen 2013; Korner 2007).

Approximately one-third of Wales's population is rural, which highlights the importance of rural health for all seven of the Local Health Boards. Notably, the rural health issues are inclusive of the social, economic, transport, housing and social care matters which are also apparent in rural Wales. Beumann et al. (2012) found that people living in sparsely populated areas (of a population of one-five per square mile) were heavily reliant on informal sources for help in general, including health care.

The Welsh Rural Observatory (2009) conducted a survey on deep rurality which identified that 94 percent of respondents reported a very good or fairly good perception of quality of life; expressing a feeling of community and enjoying the peace and quiet. However, 36 percent of respondents reported poor or very poor general service provision, connectivity was considered poor with only 51 percent being in receipt of broadband and only 20 percent considered the mobile telephone network as being good. Furthermore, 92 percent considered that access to a car was essential with 4 percent having no access to independent transport. Statutory transport was also rated as poor. Additionally, 30 percent reported no central heating in their houses, and there was widespread concern about the sustainability of deep rural community with 18 percent of respondents reliant on help to access services of which 26 percent of those over age 65. Generally, they were happy with GP provision but less so with dentists, and they had major

concerns about hospital provision and ambulance services, with 63 percent stating that hospital provision was poor or very poor (WRO 2009).

The Institute of Rural Health (2009) recognised access to services as a key issue and integrated it as a theme for its plan for improving service delivery across Wales. It found that older people who live in rural Wales typically received support from informal social support structures, the availability of which helped to support positive perceptions of a good quality of life. However, new evidence shows that such structures are eroding due to increased migration, changing the structure in rural communities (Willims 2008). Also, people are living longer, which makes older people more likely to experience loneliness and bereavement as well as reduced independence through loss of transport and reduced mobility (Welsh Government 2009). These issues are more apparent in rural and deep rural areas across Wales due to poor statutory transport and isolation, leading older people viewing ageing as 'terminal tragedy' (Wales Rural Observatory 2009).

White et al. (2007) found, that when asked about their satisfaction with their local GP service, 8 percent of the respondents were dissatisfied; 45 percent were very satisfied, 46 percent considered the services satisfactory. This informs that where the services were accessible; they were considered satisfactory. Affirming that the issues with rural healthcare provisions are focused around availability; White et al.'s (2007) participants stated that they would make recommendations themed around availability and scheduling of appointments, particularly during evenings and weekends.

However, as Chapter 3 (Section 3.6) highlights access to services is not a complete measure of life satisfaction in rural regions (Romans et al. 2006). The rural residents of their study in Canada were expressed fewer symptoms of depression and anxiety than urban residents due to them reporting a good sense of community. This highlights the importance of community in rural regions. Pugh (2011) states that the reported issues for service users in rural areas are the same as those in urban regions, however it is the geography and infrastructure of the rural regions, the current infrastructure of statutory services (including transport services) and, the absence of alternative delivery provisions which result in rural residents facing further difficulties in access. Furthermore, the characteristics of communities such as those in rural regions of Wales, mean that people are familiar to one and other. Although this is reported earlier as a positive aspect of community life, there is also potential for members of the

community to feel that they are unable to use local services confidentially due to staff being local, and/or people seeing them enter or leave the facility (Pugh 2011).

4.3   Community Delivered Support

Community care services are provided by the statutory, third and social enterprise sector, and aim to meet the care needs of vulnerable people in society, where those needs are met outside of institutional care, in their own homes (Alcock et al. 2016; Johnson and DeSouza 2009; Welsh Government 2011). As it is integrated within the statutory sector, community care overlaps with health and social care policy in terms of responsibility for care and funding care.

Community support services are those services such as primary health care services (GP, dental, pharmacy and optometry services); generic community services (district nurse, health visitor, community midwife, community psychiatric nurse, school nurse, and community therapy services); specialist clinical or outreach services; and local authority services provided by the independent sector (day centre services, respite care, home support, residential and nursing home services), and aim to support health, independence and wellbeing. This can be carried out by initiatives such as telecare, web-based information services, and targeted health promotion support (Johnson and DeSouza 2009; Joubert et al. 2013).

As discussed previolyus, collaborative approaches to health and social care mean that policy makers are encouraging Local Health Boards to support community health services in supporting independent living and keeping people 'fit and healthy'. They support the local communities by introducing community services which are effective in meeting their aim, or improve the efficiency of existing services; innovate primary care contracts in order to further develop local services; monitor targets and coordination of services; maximise resource potential, and plan and manage services to ensure full integrated care for service users (Health Wellbeing and Local Government Committee 2010).

Drinkwater (2011), Williams (2008), and Johnson and Desouza (2006) report that the availability of GPs and district nurses varies across geographical regions. Therefore, they are supported by community matrons in their roles, who specifically focus on people living with long term conditions.   This emphasises the importance of collaboration in meeting the Government's vision for long-term condition management. Reed et al. (2010) consider community support to

be invaluable for survivors. Their study, which explored a community stroke scheme, found that the scheme enabled survivors to create a social self-identity and encouraged participation within the community by implementing informal support networks. The community stroke scheme also found that the needs of Reed et al.'s participants were met by exercise, goal setting, peer group interactions inclusive of social support and knowledge acquisition. Reed et al.'s study identified that a variety of internal and external resources enabled stroke survivors to rebuild their lives positively post-stroke. They considered that a 'stroke-specific' community-based scheme which focused on exercise, life-centred goal setting, peer support and knowledge acquisition as a valuable external resource which would contribute to meeting the needs of the stroke survivor. Furthermore, Patterson et al. (2010) report of the successes of peer support and exercise groups on supporting survivors in their everyday lives and improving levels of social participation.

There are limited stroke specialist medical and therapy follow-up services in the community due to severe shortage of funds. This has led to many NHS organisations using generic therapy staff to deliver treatment for survivors of stroke. This highlights that investment in stroke-specific services are needed in order to develop stroke appropriate services in the local community. However, by supporting organisations in the third sector and social enterprise sector, the Welsh Government (2015a) is supporting community initiatives which share the same aims in supporting people living with stroke and their caregivers in their everyday lives. This was also a stated aim of the Stroke Delivery Plan (Welsh Govenrment 2017). However, the plan did not state how such support would be delivered.

4.4   Third Sector Support

Third sector organisations are independent non-governmental organisations which typically consist of voluntary and charity organisations. They are value driven; focused on societal, cultural, and/or environmental objectives (Welsh Government, 2015a). The Wales Council for Voluntary Action (2013) asserts that there are 978,000 voluntary and 51,000 paid employees within the Welsh third sector; with 600,000 people volunteering independently within their local communities; complementing statutory sector services in their local communities.

Third sector organisations in this context aim to improve the health and social wellbeing of people living with the outcomes of stroke, and their caregivers. Third sector organisations typically provide lifelong support to stroke survivors and caregivers through voluntary support

and outreach centres (Schure et al. 2006; The Health Wellbeing and Local Government Committee 2010).

Community-based service support groups within the third sector offer help and support to those who are living independently to ensure they are not experiencing isolation (Drinkwater 2011). The Stroke Association affiliated stroke clubs are a community-based service which aims to support people who have been affected by stroke. Being the dominant stroke support provider in Wales, their community-based groups aimed to help improve accessibility to a range of quality and innovative services such as stroke clubs while focusing on the needs of its members (The Stroke Association 2017c). The Stroke Association's (2015c) Life After Stroke campaign has been integrated to increase public awareness of the realities of the effects of stroke and promote the support that The Stroke Association provides to people who have been affected by stroke across the UK. The Stroke Association's (2015b) stroke strategy for 2015-2018 entitled 'Together we can conquer stroke' aims to reduce the number of people who have a stroke, improve acute care provisions, support self-management for survivors, build a stroke community by supporting stroke clubs, and ensure that professional staff are trained to meet the needs of survivors. Notably, the Stroke Association's stroke strategy does not refer to supporting the caregiver. Furthermore, the strategy document does not state how the support to stroke clubs will be delivered. There is also a weakness in emphasis of cross-sector collaboration.

Figure 4 overleaf presents the life after stroke services provided by the Stroke Association. The model highlights how the services, like those in the statutory sector, are person-centred, and focus on prevention, information, communication, re-enablement and inclusion as well as caregiver support (Health Wellbeing and Local Government Committee 2010; The Stroke Association 2016; Rowe 2013).

Figure 4: The Stroke Association's Life After Stroke Services

The Stroke Association's Life After Stroke Services

Person affected by stroke

Information, Advice and Support Co-ordinator

Goals and needs assessment

Information, advice and support	Stroke prevention	Communication support	Re-ablement and social inclusion	Carer support
• Information, Advice and Support Service • Emotional support • Representation and advocacy • Black and Minority Ethnic Service • Befriending • Economic wellbeing • Information Prescription Service	• All clients • Stroke Prevention Services • Local awareness campaigns	• Communication Support Service • Carer training	• Back to Life Services • Arts • Younger People's Service • Return to Work Support Service • Long-term support • Peer support • Personal Budget Support Service	• Carers' Groups • Carer training

Reassessment

Discharged, no support needs, encouraged to volunteer

Long-term support or stroke club

(Extracted from: The Stroke Association 2011: webpage)

The Stroke Association has also been involved in the stroke awareness campaign's (such as The Stroke Association's (2017a) 'FAST' campaign, mentioned previously), and has also developed the Keep in Touch service which provides information, advice, and support in innovative ways. This scheme is driven by survivor need (The Stroke Association 2017b).

The British Red Cross (2017) is another third sector organisation which provides support for survivors of stroke in their everyday lives. The British Red Cross is not a stroke-specific charity. It supports health issues and social support overseas, however here in the UK the British Red Cross helps support independent living by providing support and care at home after discharge from hospital. This is done via its hospital from/to home scheme, focusing on rebuilding confidence, collecting prescriptions on behalf of patients, providing companionship, therapeutic hand and arm massage and assistance with shopping. In addition, the British Red Cross provides transport and/or an escort service which is funded by charitable donations providing support for essential daily activities such as attending medical appointments to support the independent living initiative. Furthermore, the British Red Cross has a voluntary-led mobility hire service, allowing people to hire equipment such as wheelchairs in the short term (British Red Cross 2017).

Survivors and caregivers may also receive support from non-stroke-specific third sector organisations such as independent living centres or carer groups such as Carers UK, and the Carers Trust; a merger of the former Crossroads: caring for carers, and The Princess Royal Trust for Carers (Williams et al. 2010). Supporting caregivers, Age UK provide information for people and carers seeking advice for support and finance, health and wellbeing as well as travel and lifestyle advice. It also provides information on work and learning, and information on products and services such as gas and electrical services, dealing with death and end-of-life provisions such as power of attorney and care home provisions, and informs people how to access help using real life stories (Age UK 2017). Also supporting caregivers in Wales, Carers Outreach covers North West Wales and the Isle of Anglesey. Its services support people who care for people with complex care needs through local outreach centres.

Focusing on caregiver needs, Carers Outreach provides information and advice about entitlements, services, social opportunities and support groups. Recognising caregiver needs as highlighted in Chapter 2, Carers Outreach also helps caregivers plan for the future and the unknown. For example, planning for care provisions at home for the dependent person if the caregiver was admitted to hospital. It also offers a benefit-checking service to ensure that the

carers are claiming for all that they are entitled to, and also support in grant and benevolent funds applications. Recognising that caregivers also need to maintain their own quality of life, Carers Outreach also assists in access to breaks, education and employment while providing information and acting on the carer's behalf at local and national levels to ensure that they receive the services and support they need (Carers Outreach 2017).

Carers UK, funded by membership, lobbies the Government on behalf of its members, and the people in its care. It represents its members nationally, and aims to promote high standards of care and to provide practical advice and support to itsmembers surrounding caregiving policy and assessment. It seeks to access carers in need of support by collaboration with GPs to provide a service and signpost carers to the services that will best support them or assess needs as in line with national carer's strategy (Deacon 2008; Fitzpatrick 2008; Presho 2008).

4.5   Social Enterprise

In this context, we explore social enterprise by the definition provided by the European Research Network which considered key categories under two dimensions. The categories within the social dimension state that a social enterprise will have an explicit aim to benefit the community, be an initiative launched by a group of citizens, have decision-making powers not based on capital ownership, be a business of a participatory nature which involves the persons affected by the activity, and have a limited profit distribution. The economic dimension of social enterprise describes social enterprise as a continuous activity which produces goods or sells a service, with a high degree of autonomy, a significant level of economic risk, and a minimum amount of paid employment or compensated labour (Welsh Government 2015).

There are multiple definitions in the extisitng literature for what constitutes social enterpese and entrepreneurship. Each of these shares the notion that for an enterprise ot entrepreneurial form to be considered 'social', it must be addressing a societal need. Bjerke (2013) considers social entrepreneurship to be all entrepreneurial activity which aims to benefir society through social aims. Whilst, Ridley-Duff and Bull (2016) expand and define social enterprise as a business which is not primarily driven by financial return, but instead, primarily focuses on social objectives, and any profit made is reinvested into the company to further work towards the social objective. Martin and Thompson (2010) describe that social enterprise harnesses a triple bottom line: social aim, income generation, and economic impact. This makes social enterprises a good

strategic partner for policy makers to consider. By supporting social enterprise, policy makers have identified potentially sustainable avenues for support in the community, which are run by the community themselves. This would meet the aim of the 2014 Social Services and Wellbeing Act (Welsh Government 2014b) and the Stroke Delivery Plan (Welsh Governent 2017) by providing a platform where people can help themselves, and support each other in their communities. This would fit into Lord Bourne's (2015) and Morgan's (2012) addenda to support Welsh people in a Welsh way, as a social enterprise has the potential to underpin local communities, whilst supporting their target population.

In order to define the social entrepreneur in this context, the sociologist perspective can be considered, whereby entrepreneurs are defined as a creative innovator in the business sphere (Ridley-Duff and Bull 2016). Here, we discover where the notion of social enterprise has evolved, and traditional characteristics differ from that of a traditional 'entrepreneur'. Social entrepreneurs are thought to be found across private, third and public sectors (Bjerke 2013) and are often described as a product of the development of the third sector and 'grey' area of cooperative and non-profit trading practices; or the result of the integration of the independent sector into the third sector (Ridley-Duff and Bull 2011: 2016). However, social enterprise can also be considered an outcome of various attempts to introduce independent sector management styles into the statutory sector; further influenced by the contributions of local politicians and community entrepreneurs with societal perspectives (Ridley-Duff and Bull 2011:2016). The change of economic theory in 1970 impacted on entrepreneurship worldwide. There was an increase in small firms and innovations in leadership and the social economy, suggesting the social enterprise expanded out of liberal capitalist ideas which founded the principles of the 'new statutory management' and market socialism (Chandler 2008; Ridley-Duff and Bull 2011:2016). The cross-sector model of entrepreneurship (Figure 5 overleaf) identifies the red shaded area, the cross over area, as the 'ideal' social enterprise sector. Edited by Ridley-Duff and Bull (2011:73), Figure 5 shows the views of Ridley-Duff and Bull (2011:2016) and Bjerke (2013), that social enterprise operates in all sectors and that there are entrepreneurial activites deemed 'social' in each sector.

Figure 5: The Cross-Sectional Model of Entrepreneurship
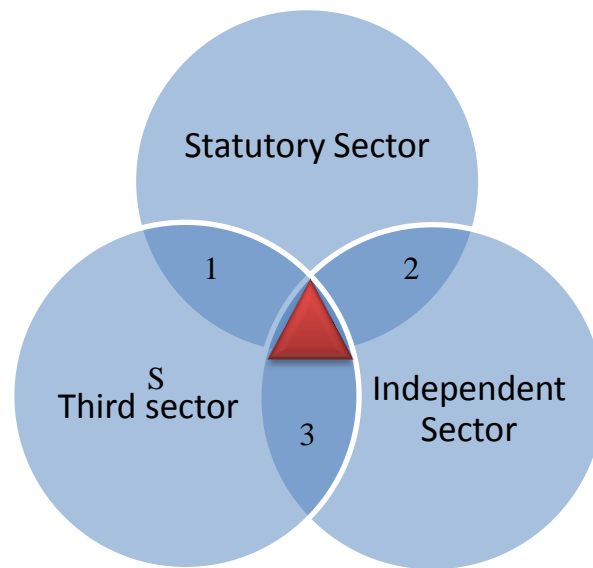
(Edited from Leadbeater 1997 *in* Ridley-Duff and Bull 2011, 73)

Figure 5 shows that social enterprise can be considered a 'bridging sector' between multiple sectors which provides an opportunity to utilise skills, abilities and knowledge; as such, a triple helix (Bjerke 2013; Leadbeater 1997; Ridley-Duff and Bull). Ridley-Duff and Bull (2011) describe that the overlap at point 1 shares public interest, and so lays the foundations for non-profit enterprise. At point 2, there is an element of corporate responsibility, where they don't consider the third sector as a viable business partner in delivering statutory service. Point 3 then identifies the overlap between the independent sector and the third sector as a 'more than profit' spectrum. Here, there is antipathy to the state and this position is considered the driver for these businesses to meet the needs of disadvantaged groups, seeing them as being realistic about the state's capacity to oppress minorities. The red shaded area is the overlap of all sectors. Being 'idealist', it replaces independent, statutory and voluntary competition with a democratic multi-stakeholder model where all interests in a supply chain are acknowledged to break down barriers to social change.

This model also suggests that social enterprise in the third sector can be supported by the independent sector and/or the statutory sector. With more traditional forms of statutory sector funding being cut, becoming a social enterprise creates opportunities for voluntary and third sector organisations to be sustainable and continue by producing collective benefits, whilst operating similarly to an independent sector business by being innovative, being driven, and

being disciplined financially (Ridley-Duff and Bull 2011; Yu 2011). This suggests that by being a social enterprise rather than being based in the third sector, groups which rely on charitable donations and voluntary staff would begin to run like an independent sector organisation in that they would have the drive and determination at what they can achieve. Furthermore, Bjerke (2013) asserts that those people who are entrepreneurs in the third sector, are defined as citizen entreprenurs; distinguishing citizen entrepreneurship from broader social entrepreneurship definitions, Bjerke describes citizen entrepreneurial practice to be identifiable as projects run by citizens, or those who seek to 'just be citizens' rather than claimining any other business practice (Bjerke 2013). Bjerke (2013) goes on to explain that the activities run by citizen entrepreneurs are typically innovative in nature and take place in either private places such as nursing homes, or public places such as public squares. This informs of a third sector-specific stream of social entreprise which looks different from typical business practice. Citizen enterprises are also commonly known as community enterprises. These forms of businesses appear to exhibit low structure and are managed by cohesive citizen (or community) decision-making processes as opposed to typical social enterprise, or indeed enterprise in general, where more structured approaches to management may be visible.

Although Bjerke's (2013) work supports the model presented in Figure 5, he asserts that citizen entrepreneurs, despite being entrepreneurial in their mannerisms and seeking to benefit society, are somewhat different from 'typcial' social entrepreneurs. They do not enter other sectors, they do not seek to be businesses or publicly employed. Instead they *"act as if they just are citizens"* (Bjerke 2013:64). Furthermore, Bjerke (2013) emphasises that social entrepreneurs inclusive of citizen entrepreneurs must not be limited to typically entrepreneurial logic as reported in business literature, as they are developing their businesses in different ways with different objectives.

Much of social enterprise literature reports of social enterprise supporting society and community. The Welsh Government (2015a) acknowledges the importance of social enterprise organisations in supporting people in their everyday lives, and in supporting survivors of stroke and their caregivers. This is evidenced in its Stroke Delivery Plan (Welsh Government 2017) and the Social Services and Wellbeing (Wales) Act (Welsh Government 2014b). It aims to support social enterprises in Wales; helping them to be sustainable and helping them to grow. The Welsh Government (2015b) states that it wishes to 'integrate social enterprise into the mainstream', and enroll collaborating agencies to support 'the creation of a thriving social enterprise sector in Wales'; however, the author suggests vagueness by the Welsh Government

in The Stroke Delivery Plan and its statements of how it wishes to support social enterprise. There is slightly more detail in the Social Services and Wellbeing (Wales) Act (Welsh Government 2014b), however there is a vague definition of social enterprise which does not take into account those social enterprises which are set up out of necessity, as the Stroke Clubs are. More recently the Welsh Government states that social enterprise sector should be integrated with 'the mainstream'; without defining the sector or business areas it considers to be mainstream. However, the Welsh Government (2015b) informs that it has supported the Wales Co-operative Centre by awarding it with Convergence and Competitiveness funding, in order to provide social enterprise development support. With a £8 million budget and £3.6 million match funding, the Wales Co-operative Centre is to meet the Government's aims of raising awareness of social enterprise and the ways it supports society and provides support by way of mentoring, training and signposting to other support agencies (Wales Co-operative Centre 2017).

4.6   Collaborative Approaches to Providing Support

As previously stated, the 2014 Social Services Wellbeing Act aims to encourage collaboration between local authority social care services and the NHS in delivering integrated services to strengthen partnerships (Gray and Birrell 2013). The Welsh statutory sector funds social care initiatives across multiple sectors. In doing so, it encourages the funded organisations to illiterate their public service values as set out in the report Sustainable Social Services for Wales: A Framework for Action (Welsh Government 2011a), into their practice across the health and social care sphere. At the heart of communities, social services departments are supporting an increasing number of people, in the short and longer term (The Welsh Government 2015b).

Support for survivors of stroke begins with emergency care such as that provided by paramedics. Then, the stroke patient receives acute care in stroke units. This is where stroke rehabilitation begins (The Stroke Association 2016). Once discharged from hospital rehabilitation and support is still provided by the statutory sector through statutory funded community local authority support services; often with follow-up rehabilitative hospital appointments. At this stage, professionals focus on assisting the survivor in returning home, implementing a support plan for the survivor in the months after stroke which aims to support survivors and close family members (Williams et al. 2010; The Stroke Association 2016). Third sector organisations can offer support at hospital, and when the survivor returns home. However, unlike hospital support post-discharge, the support they provide is life-long. Effective discharge planning relies on good

communication between the hospital and community services (Alcock et al. 2016; Jeong et al. 2015; Intercollegiate Stroke Working Party 2008) and is crucial for wellbeing and maximum recovery (Intercollegiate Stroke Working Party 2008). However, Alcock (2016) states that there are challenges for each party involved in the discharge process; hospital staff are pressured to conduct a prompt discharge; patients and their families may overestimate their ability to manage at home; and there are a limited community support services available. These are sparser in more rural regions such as Wales and vary county to county (Williams 2008). In the UK, survivors of stroke receive support from statutory services if they have extensive care needs; most manage with informal care and domestic support which is arranged and paid for by themselves (Williams et al. 2010).

A key goal in long-term support is the prevention of a reoccurring stroke and associated complications (NHS Wales 2014; Welsh Government 2017). The support needs of survivors are assessed individually by primary health services six weeks after discharge, and again within six months, then annually. This allows for change over time, such as deterioration or improvement of health and also allows a specialist review to be conducted in cases where hospital discharge may not have met the needs. This would include treatment of risk factors and secondary prevention advice (Intercollegiate Stroke Working Party 2008) and provide an opportunity for survivors, carers and professionals to consider on-going needs and partnership.

The key actors and bodies from the statutory and third sectors share the common aim of promoting person-centred care, promoting independence, and improving statutory health. However, the two sectors can approach the aim through differing strategies and practices which suggest that they work well in collaboration. Stroke-specific support is provided through Wales's recently implemented Stroke Strategy Plan (Welsh Government 2012), and with caregiver support being provided through general carer strategies and third sector organisations; again, with stroke-specific support being provided through the Stroke Association. As identified in Chapter 2, the outcomes of stroke vary greatly, with the needs of the survivors ranging greatly. Therefore, in order to meet the needs of a survivor as an individual, person-centred care may include resources drawn out in policy and practice for people living with mental health-related outcomes and physical and learning disabilities.

Third sector organisations support survivors and caregivers in their everyday lives post-discharge from statutory sector provision. Community support and third sector organisations help to reach people in hard-to-reach communities, contributing to support often given by friends, family and

neighbours. Recognising the necessity for support using the third sector, the 2012 Stroke Delivery Plan (Welsh Government 2017) proposed that long-term support of people living with stroke needs to integrate and collaborate between sectors. This affirms the importance of co-operation and collaboration between statutory, independent and the third sector in meeting the aims of improving public health and the everyday lives of people who have experienced stroke, which is to promote and support independent living and self-directed care.

In addition, the statutory sector can also provide financial support in the form of Disability Living Allowance (DLA) for those that are unable to work due to the results of their stroke. A carer's allowance is also available, as well as subsidies for a number of social care services. However, this funding is changeable, and it does not take into account increased transportation and living costs for people living in rural areas. Furthermore, caregivers have only been identified as a category of social concern since the late 20th century. The Griffiths Report (1988) and the 1990 NHS and Community Care Act was significant for caregiver recognition in health and social care policy as they identified caregivers as the primary means of care (Schales and Schneider 2012).

Furthermore, Alcock et al. (2016), Johnson and DeSouza (2006), and Glendinning (2009) assert that despite a range of policies to support caregivers, the intended results were not always achieved. However, Deacon et al. (2008) consider that in more recent contemporary society, the gender boundaries are still blurred. Norman Lamb (2014), Minister of State for Care and Support at the time, commented that the Government is dedicated to supporting caregivers in their caregiving role; to help them to care effectively, maintain their own health and wellbeing, to fulfill their education and employment aspirations, and provide them with a life away from caregiving. Reflecting upon everyday life and quality of life as discussed in Chapter 2, in doing this, the Government can potentially improve the quality of life of caregivers.

The Stroke Delivery Plan (Welsh Government 2017) discussed earlier in Section 4.2.4 identifies that cohesion between the statutory health and social care sector and third and social enterprise sector organisations would address the identified need of supporting community groups. However, the plan lacks depth in the description of the delivery of the action.

There is also a suggestion that the policy will only be as effective as the collaboration between relevant departments. Baldock et al. (2012) state that despite policy aims being clear, the cooperation required to meet those aims often results in disagreement or uncertainty between

relevant service departments such as central government and LAs. This can result in vagueness and ambiguity. Overall resulting in ineffective policy, delivery and service provisions - but ultimately leaving gaps in service provision for the potential service users. This means that without effective collaboration between sector services, a policy may be ineffective and result in the policy aims not being met.

4.7   Chapter Summary

The development, implementation, and delivery of support for survivors of stroke and their caregivers is clearly a collaborative effort, with a variety of input from many perspectives. Devolution has allowed Wales to strengthen its policy through development of its own evidence base, to better meet the needs of survivors and their caregivers across Wales.

Wales has been defined by this chapter as a rural region with a strong sense of community. This chapter suggests that support for survivors and caregivers in Wales is provided by the statutory, third, and social enterprise sectors. The Welsh Government's (2015b) Sustainable Social Services framework sets out its vision for transforming social care across Wales. The key focus being to develop high quality and responsive services which have a strong public voice, through better collaboration between partners. The King's Fund (2015) supports Lord Bourne's (2015) claims that the current Welsh social care system lacks equality, is unsustainable and is inadequate. It states that while it is public knowledge that the system is inadequately funded; there is a reduction in funding from the Government into social care, whilst demand for social care services continues to increase

Cross-referencing this with the literature in Chapter 2, the possible outcomes of stroke suggest that in some instances, face-to-face support would be essential in order to communicate effectively with the surviors of stroke. Furthermore, survivors of stroke and their caregivers in rural regions are potentially more reliant on their local community; their family, friends and neighbours for support and care. Furthermore, those who reside in rural regions consider that living in rural areas provides a good quality of life, yet the literature confirms that these rural Welsh communities are heavily reliant on informal support and help in general, which is provided in Wales by an informal community network of friends, family and neighbours.

5.0   Chapter Five: Research Design and Method

This chapter presents the research design and methods deployed to achieve the research aims and objectives of the study. The research aims, as previously outlined in Chapter 1, were to:

(1)   Explore the everyday lives and experiences of survivors of stroke and their caregivers;

(2)   Identify the key support actors involved in the everyday lives of the study participants; and,

(3)   Explore how Stroke Clubs support survivors of stroke and their caregivers in their everyday lives.

The research methodology underpinned by an inductive, qualitative approach, explored the phenomenon of interest through a multi-method design. Primary research collected data from multiple case studies which allowed for in-depth research. Two of the case studies focused on survivor participants. Seven case studies focused on survivor participant and their caregivers. The case study profiles are presented in Chapter 6.

The data collected from the case study participants addressed research aims 1, 2 and 3 by allowing in-depth exploration into the participants' everyday lives (Yin 2013). Stroke Clubs were identified as an avenue of participant recruitment as this allowed for further exploration into their role in supporting their members (and study participants) in their everyday lives. The work in the Stroke Clubs included observation of the Stroke Clubs, participant perspectives through their interviews, and semi-structured interviews with Stroke Club hosts. This triad of perspectives enhanced the research study by providing a better understanding of how support is delivered through the Stroke Club initiative.

The Research Process Model presented in Figure 6 (page 104) shows the primary data collection method process adopted for the study. Overleaf from Figure 6, Table 2 shows the primary data collection intervention in tabular form and includes. Both Figure 6 and Table 2 inform of the the month and year of the intervention. This informs the reader of the timeframe of this study. Non-participant observation of the Stroke Clubs, semi-structured interviews with the Stroke Club hosts, and BNIM (Biographic Narrative Interpretive Method) interviews with the case study participants (informed by Wengraf 2009) ran parallel to each other throughout the primary data collection stage of this study.   These primary data collection methods were synergistic, complementary, and allowed for triangulation of the data through cross-referencing of the data

collected, and the literature review. This helped validate the data, ensuring that robust, reliable data added strength to the research findings (McGivern 2013).

The BNIM interviews primarily addressed research aims 1 and 2, while contextualising the observational data in addressing research aim 3, through developing deeper knowledge and understanding of each participant's perspective.

A review of the existing literature was conducted in the first instance to gain an understanding of the study context and existing knowledge, and support the semi-structured element (phase 2) of the BNIM (McGivern 2013; Gray 2006; Russell 2013; Silvernman 2013, Thomas 2011). Development of the interview templates is discussed later in Section 5.3.

As Figure 6 overleaf shows, the review of the existing literature was continuous and revisited throughout the study. The review of the current literature synthesised key findings reported and allowed for an in-depth exploration into the existing knowledge surrounding the key areas of everyday lives literature. This allowed the author to gain an understanding of the study context, identify areas where further exploration was needed, and identify areas of interest. By conducting continuous desk research, the author was able to explore further concepts and areas of interest as they became explicit through primary data collection. Therefore, desk research and a continuous literature review provided a reference point, but also added depth and understanding to the research findings. The author continuously explored themes within the data at different stages which contributed to the overall rigour, validity and depth of the study. The research approach, design and methods are discussed in more detail throughout the remainder of Section 5.1.

Figure 6: The Research Process Model
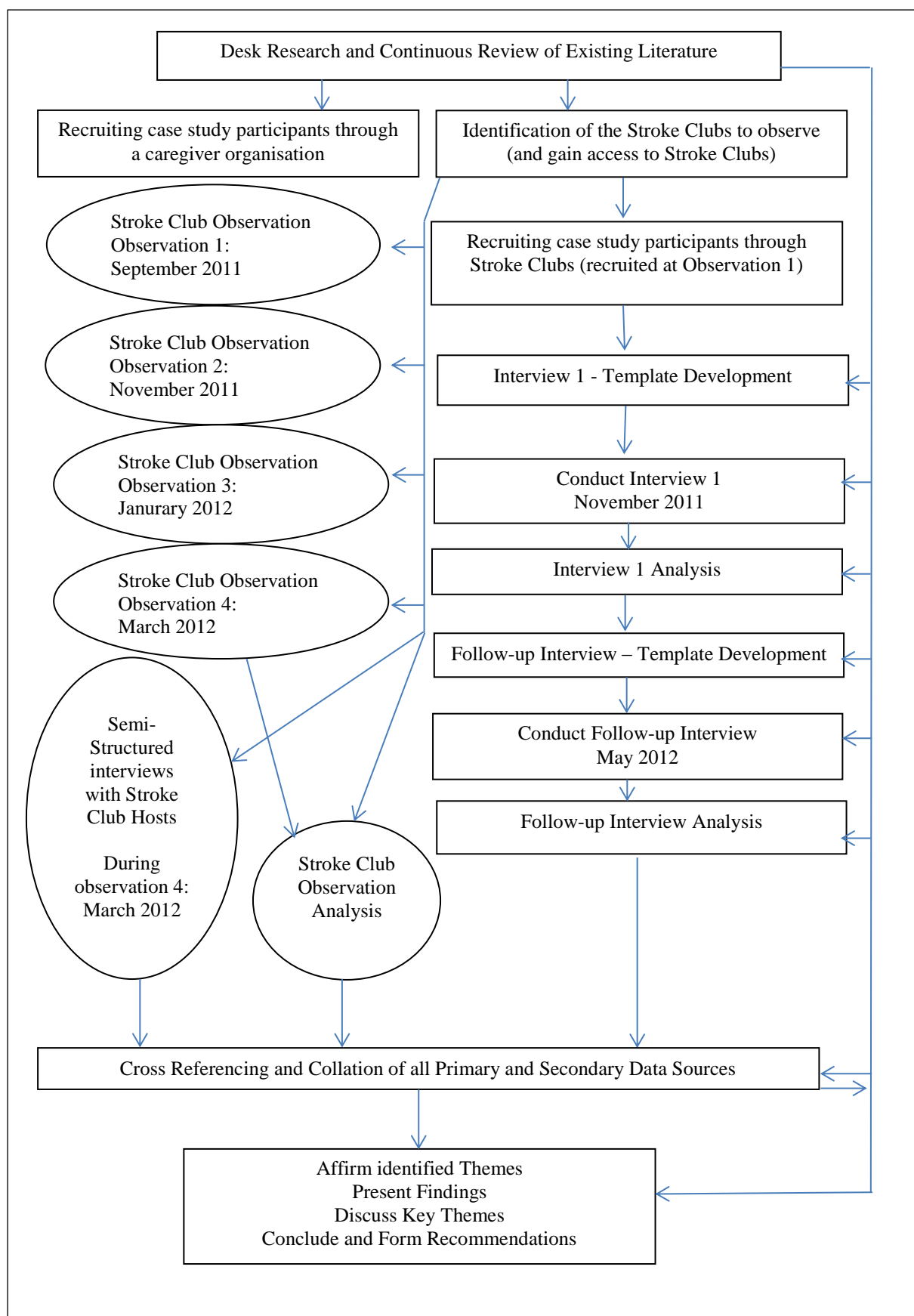
Table 2: Primary Research Intervention

Intervention Type	Description	Date	Frequency
Observation	Non-participant 6 Stroke Clubs Observed (please refer to table 4 for Stroke Club profiles)	September 2011	Bi-monthly for 8 months (total of 4 occasions)
Case Study Interview	Biographic Narative Interpretive Method with stroke survivors and caregivers (please refer to table 5 for case study profiles)	November 2011	Twice. Follow-up interview commenced 6 months later in May 2012
Stroke Club Host Interview	Semi-structured interview	March 2012	Once

5.1   Research Methodology

When deciding the research methodology, the author considered various approaches and designs. Throughout Section 5.1 the research approach, design and strategy adopted for this study are discussed, along with underpinning justification and rationale.

The observation of Stroke Clubs both in an organisational sense, and the cultural sense; that is, the beliefs, behaviours, and attitudes, of the Stroke Club members, was supported by the case study interviews. The BNIM interviews facilitated participant reflection upon Stroke Club experience (for those recruited via Stroke Club) and their post-stroke lives. This strategy enabled the author to learn how the participants perceived themselves within their everyday contexts. The interview data informed of the participants' perceptions of themselves as members of the Stroke Club community, as a family member, and/or society as a whole. Observation and interview data combined; the primary data collection methods enabled the author to explore, make sense of, and understand the subjective meaning of the participants' lives (Silvernman 2013; Wengraf 2009). Thus, learning what people 'do', and how they 'feel' through qualitative data collection; producing rigorous findings, conclusions and recommendations for policy makers and support providers (McGivern 2013; Gray 2006; Russell 2013; Silvernman 2013; Thomas 2011; Yin 2013).

5.1.1   The Research Paradigm

A humanistic approach allowed for *"an appreciation of a unique human experience"* (Bernard 2013, 22) within this research context, while an interpretivist approach enabled the author to explore:

> *"Culturally derived and historically situated interpretations of the social life-world."*
>
> (Gray 2006, 21)

Taking a humanistic interpretivist stance supported inductive enquiry and exploratory investigation into this complex area of research. This supported a focus on the participants' own unique and individual interpretations of their everyday lives (Bernard 2013; Crotty 2011; Denzin and Lincoln 2011).

Furthermore, this supports the notion that there is no:

> *"Interpersonal relationship with the world, but that the world is interpreted through the 'classifications of the mind'"*
>
> (Crotty 1998, 67).

This suggests that an individual's own interpretation of their life is subjective as it is unique to the individual and their own perception of the world around them (Bernard, 2013; Crotty 1998; Smith 2014).

As Chapter 2 asserts, stroke can result in a varying range of physical and neurological disabilities in those who survive it (The Stroke Association 2016; Williams et al. 2010). Therefore, the author considered those research methods which were adopted by others when conducting research which involved participants who were living with a disability. Two alternative paradigms, transformative and emancipatory, were identified. The author is not claiming that this research is transformative, nor is it emancipatory. The research is interpretive. However, due to the complexity of research into vulnerable adults who may be living with 'disabling' outcomes of stroke, it was important to consider the ethical conduct and practice reported within these alternative paradigms. A key difference between this study and the transformative and emancipatory paradigms is that unlike these approaches, this research was not seeking to implement a strategy for social change. Rather, the research sought to explore the everyday lives

of the study participants. However, as an outcome of this, the findings do offer recommendations for change at a policy level. However, in part, this research encompassed elements of the two approaches, or at the very least shared the same values in the way the research was conducted. This is explained further in the next two paragraphs.

Arguing that the traditional author-led stance is 'disabling' for research involving participants who are living with disability, the emancipatory approach encourages a change in the researcher-participant relationship (Denzin and Lincoln 2011; McColl et al. 2013; Oliver 1992). This gives research participants power and control of the participant-author relationship (Denzin and Lincoln 2011). By using Wengraf's (2009) Biographic Narrative Interpretive Method (BNIM) of interview (discussed later in Section 5.3) to collect primary data from the case study participants, the author gave control of the interview, in part, to the participants, allowing them to control the narrated content. This allowed them to tell their story the way they wished to tell it while sharing only the information which they wanted to share (Alleyne 2014; McGivern 2013; Gray 2006; Silvernman 2013; Wengraf 2009). This was important when collecting data about a sensitive topic. The methods used, both observation and BNIM interview, reinforced the message that the author sought to learn from the study participants. This was important throughout this study, as there was a feeling among the participants that their stories were not being heard by policy makers and practitioners. Consideration of the emancipatory paradigm also emphasised the importance of focusing on the strengths and coping skills of the participants, rather than, or equally to, the more negative outcomes of stroke (Oliver 1992 in Denzin, and Lincoln 2011, 229). This was incorporated into the interview templates and produced rounded data as participants focused on both the positive and negative aspects of their experience and post-stroke life.

The transformative paradigm claims that there is one reality, of which there are many viewpoints. This approach asserts that each viewpoint can be influenced by a range of differential factors (Mertens 2009). This emphasised that it was important to consider the factors which may influence a participant's perception or viewpoint. Such factors provided a context to their perceptions and included (but were not confined to) perceived public stigma, the impact of their stroke, and their engagement in the community. This further supports the use of the BNIM in this context as this interview approach allowed discovery of such insights which may have been overlooked by other interview types. Similarly, this also supports the previously discussed notion of the appropriateness of a change in the participant-research relationship. In doing so, more dominant research structures were challenged to achieve equality within social research,

recognising diversity within different communities (Denzin and Lincoln 2011). The author acknowledged this within the stroke survivor community through the development of the multi-method research design and a multiple case study approach.

5.1.2   Adopting a Qualitative Methodology

"Our interest in the social world tends to focus on exactly those aspects that are unique, individual and qualitative."

(Crotty 1998, 68)

The above quote by Crotty emphasises that research into unique and individual aspects to understand the social world is not a new phenomenon. A qualitative approach to this study facilitated descriptive, exploratory research while adopting a subjective approach allowed a focus on the unique and individual aspects of the participants' everyday lives (Bernard 2013; Crotty 1998; Gray 2006; Silvernman 2013). Policy makers and practitioners often focus their attentions on large quantitative studies which present mass statistical data (Hammersley 2008). Although there is value in quantitative studies, they only provide part of the story such as rates of incidence. Qualitative research, being typically smaller in size:

"has come under increasing external pressure to demonstrate its value, and in particular, its practical value for policymakers and practitioners of various kinds."

(Hammersley 2008, 1)

Much publicly funded research is heavily dominated by mixed methods and quantitative research due to its ability to produce measurable outcomes (Denzin and Lincoln 2011; Hammersley 2008). However, the value of qualitative research in this context is that it allowed the author to present research findings which told a story. By gaining insight into the participants' daily lives, the data provided information concerning feelings and emotions experienced and provided a background context to each case which highlighted reasons why some feelings may have been expressed. This added greater depth and meaning to the findings than a purely quantitative study could.

The qualitative methods chosen not only provided a great depth of understanding about this particular phenomenon but also provided rich and detailed descriptions (Cronin 2014;

Hammersley 2008; Punch and Oancer 2014; McGivern 2013). The data collection methods also allowed the author to engage with the study participants (Russell 2013; Gray 2006), gaining their trust and allowing for participant reflection and, a more open response to the interviews. This evidence gathered will help policy makers further understand survivors and their caregiver and better understand their needs.

5.1.3   Reliability in Qualitative Research

Often discussed as validity and reliability of sources (Seale 1999), trustworthiness of research is crucial in ascertaining its reliability (Golafshani (2003). Whilst authors such as Stenbacka (2001) dismiss reliability in qualitative research, Straus and Corbin (1990) claim that quantitative terminology such as reliability has been redefined to fit the realities of qualitative research. Authors such as Patton (2001) cite that both quantitative and qualitative researchers need to ensure reliability and validity when designing research methodology, emphasising that although there are arguments regarding terminologies used, researchers from all disciplines should seek to ensure their research is reliable (or dependable), valid and trustworthy. In particular, qualitative researchers seek to maximise trustworthiness, rigour and quality in their research to ensure credibility (Davies and Dod 2002; Lincoln and Guba 1985; Golafshani (2003); Maxwell 1992; Mishler 2000; Seale 1999; Stenbacka 2001).

Gray (2006) and Thomas (2011) critique qualitative research, commenting that it often lacks reproducibility and generalizability due to its typical focus on one particular context. They argue that qualitative research is often so personal to the author that if another author were to look at the data, they might arrive at different conclusions (Gray 2006; Russell 2013; Thomas 2011). Reproducability helps to validate the research as transferable, which the author sees as being a key aspect of data trustworthiness, along with credibility, dependability and conformity. However, Thomas (2011) asserts that reliability is not an essential criterion when it comes to selecting a qualitative case study sample, as the aim of the research may be to explore that one particular or multiple case(s), although these views are not shared by all (Silvernman 2013).

A multi-method strategy combined with a multiple case study approach goes some way in addressing these criticisms, allowing an opportunity for repetition across multiple 'cases' and observational field sites.   Furthermore, with qualitative research being aimed at engaging *"in research which probes for deeper understanding rather than examine surface features"* (Johnson

1995:4), the multi-method design provided academic rigour. This means that the multi-method design presented in Figure 6 can, therefore, be proven to be a rigorous design which creates credible and trustworthy data and can be replicated by other researchers in other studies and other contexts. An example of this within the sociology and social policy context would be a study which sought to explore everyday life with other conditions such as cancer or multiple sclerosis, or exploring social enterprise or business support networks across business disciplines. This emphasises methodological rigour of the research and the value of the qualitative methodology adopted for this study.

Holloway and Jefferson (2000) consider that:

"Meanings can be controlled and made identical in successive applications."

(Holloway and Jefferson 2000, 79)

Therefore, where meanings are unique, sufficient evidence is needed to defend the interpretation of the data. This was addressed by the adopted research approach and design. By collecting data from multiple sources, there was an opportunity for data checking and triangulation (Silverman 2013), not only between cases but also between the first and follow-up participant interview, between the multiple case studies and observational data, and the observation and semi-structured interviews with the Stroke Club hosts. This triangulation strengthened the study by combining methods and highlighted similarities and differences; allowing the author to ascertain which themes were deemed common, and which were unique to the individual case (McGivern 2013; Patton 2001; Yin 20134). This ensured trustworthiness of the data through credibility due to triangulation providing a more complete picture from multiple sources of the findings (Mathison 1988; Patton 2001).

In choosing a qualitative methodology, the author has not sought to disregard quantitative methodologies or the contribution of quantitative research to the existing knowledge base (Silverman 2013). Instead, by conducting a qualitative inquiry in this way, the study presents rich, in-depth data, a valuable contribution to existing literature by reporting in-depth findings, and a platform for further study.

5.1.4   An Inductive Approach

A distinctive feature of qualitative research is its inductive nature. Applying an inductive approach to the study allowed a flexible and open exploration into the participants' everyday lives, providing the opportunity for the author to follow interesting leads as they are discovered throughout the research (Gilbert 2008; Hammersley 2008; Russell 2013). Such leads included social participation and the positive perspectives.

However, it would be false to claim that this inductive research was based on no existing theory or underlying principle (Gray 2013). This is because the literature reported earlier in Chapters 2, 3 and 4 helped to frame the study aims and objectives and therefore contributed to the development of the study design, methodology and methods used. However, there was an element of deductive inquiry when conducting the preliminary literature search (McGivern 2013). This assisted in 'narrowing down' the research focus to define the research aims and objectives as ideas which become explicit from secondary (McGivern 2013).Similarly, Gray (2013) describes a literature review as a preliminary literature search which highlights important aspects which require further research.

5.1.5   An Exploratory Design

The author considered the various designs adopted in qualitative enquiries. An exploratory design allowed fresh insight into the area of interest. Descriptive designs typically seek to increase knowledge in regard to specific areas of interest, where as explanatory research atempts to explain 'cause and effect. That is, why particular occurances exist. Although both explanatory and descriptive research designs would have provided rich descriptions of everyday life, an exploratory design took a slightly different emphasis in that it allowed the author to adopt data collection methods which provided in-depth 'fresh' insight, from the study participant perspectives. This also minimised the risk of any preconceived ideas to be considered in the process of data collection (Bernard 2013; Gray 2013).

However, despite the research being explorative in nature, cross referencing of data with the existing literature for data analysis did allow the author to describe particular themes which are produced by the data, and seek to explain why some instances might be, by using the evidence collected through exploraroty primary research. Therefore, although the primary data collection

of this study is exploratory, there are elements of descriptive and explanatory design through the data analysis process as relationships are explored.

Figure 7 below shows the areas of exploration throughout this research. The methods used to explore these areas are illustrated by the arrows on the diagram.

Figure 7: The Model of Exploration
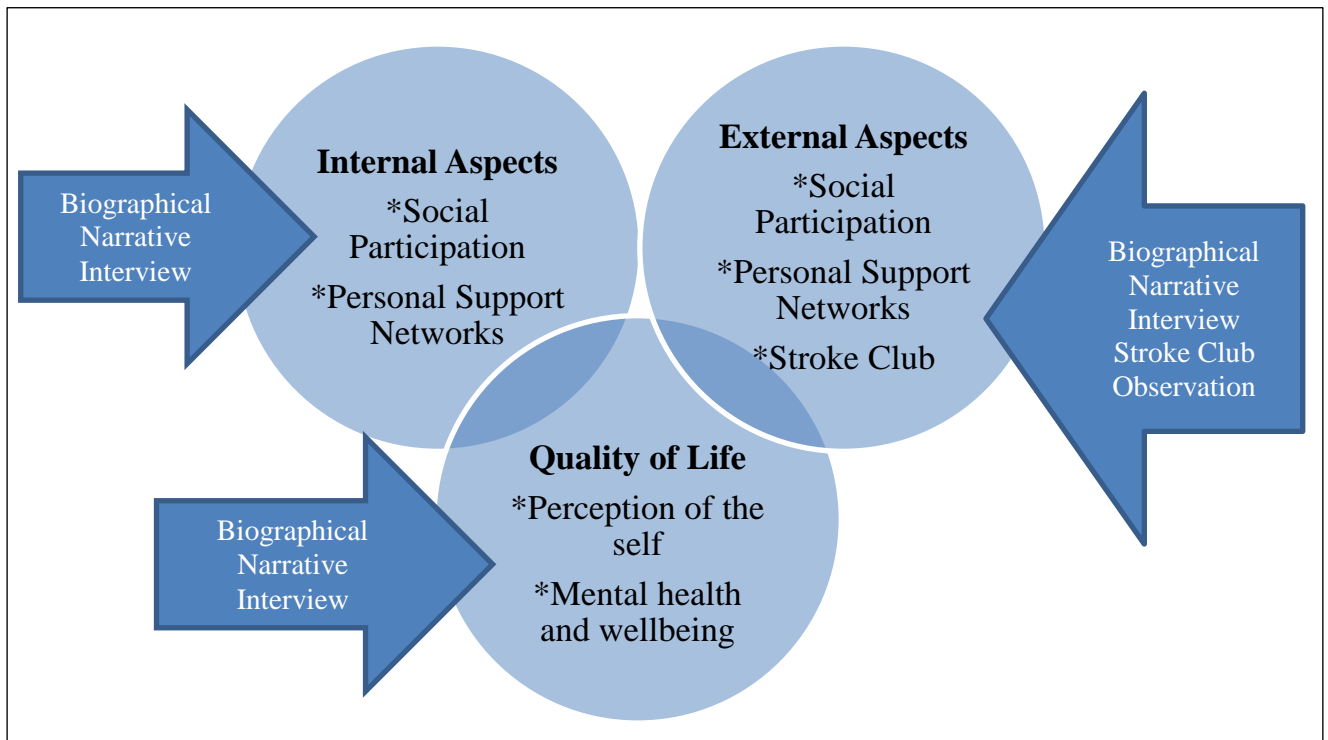
Each area of exploration provided an insight into the everyday lives of the survivor and their caregiver within each of the nine case studies. The internal aspects explored were those aspects which are present in the internal environment for the participant and included those aspects which were personal to the participants and within their home and family unit. The external aspects refer to those present within the external environment; the community and wider society. Finally, the quality of life indicators are those aspects which contribute to the overall perception of an individual's quality of life, as previously defined in Chapter 2 of this thesis. This included those aspects which are psychologically based, as well as those aspects which existed within the participant's external (outside of the home; engagement in the community, social relationships with friends, wider family and neighbours) and internal environments (inside of the home; family roles, home relationships, housekeeping).

5.1.6   A Multiple Case Study Approach

There is no set definition for case study research. Defined by the methods adopted in its implementation (Creswell 2009; Denzin and Lincoln 2011; Yin 2013), in this context, a multiple case study approach allowed investigation of each case within its own real-life context (Cronin 2014; Walsh et al. 2000; Woodside 2010; Yin 2013). This provided a small specific purposive sample of participants with their own unique perspectives. The author was able to identify (1) what was common between each case; and (2) what was unique about each case, allowing in-depth exploration into the complexities which occur in everyday life (Cronin 2014; Gray 2013; McGivern 2013; Silverman 2013; Yin 2013). This produced data which highlighted the unique and individualistic nature of the participants' everyday lives. This methodology enabled the author to consider whether elements of the descriptions were unique or common, case by case (Yin 2013). This allowed the context, and its impact, to be understood.

5.1.7   A Multi-method Strategy

Through adopting a multi-method strategy, the author was able to select research methods which complemented each other and provided a rich insight into the lives of the participants. As there is no *"clear window into the life of an individual"* (Denzin and Lincoln 2000, 12), this strategy enabled data collection at two separate interview intervals from multiple participants, and longitudinally through observation (McGivern 2013; Yin 2013).

Furthermore, Denzin and Lincoln (2000) assert that:

> *"No single method can grasp the subtle variations in ongoing human experience"*.
>
> (Denzin and Lincoln 2000, 12)

Supporting this, Silverman (2013) highlights that although participant experiences are valued in social research; supporting interviews with other methods of data collection provides a broader range of data, resulting in richer insights. This also supports the need for triangulation of data.

5.2 Participant Recruitment

The author initially aimed to recruit three Stroke Clubs for observation as well as 12 case studies. This figure took into account that interviews were to be conducted with the same participants at two separate intervals. This was an important consideration as the time between the two interview sessions meant that the participants may not wish to, or may not be able to, be interviewed at the second interval.

In total, nine case studies were recruited; one through the caregiver organisation and eight through the observed Stroke Clubs, of which six were revisited for the follow-up interview. As Figure 6 shows, six Stroke Clubs were observed bi-monthly, totalling four times over a seven-month period. This longitudinal element of the research design provided an opportunity for exploration of change over time. Such changes were attributable to either external factors such as a change in service provision or internal factors such as a change in group demographic or dynamics (of the observation) or a change in family life related to the case study participants (Green and Thorogood 2013; Gray 2009; McGivern 2013). Furthermore, the recruitment of case study participants through the Stroke Clubs provided an opportunity to explore stakeholder views relating to a specific initiative (Tummers 2013). This included how stroke support clubs contribute to the participants' everyday lives inclusive of their personal support networks, contributing towards research aims 2 and 3. The actual sample size attained allowed collection of sufficient data, which was focused and relevant, allowing the findings to address research aims and objectives (McGivern 2013).

5.2.1 Selecting a Purposive Sample

A purposive sampling strategy ensured that the Stroke Clubs observed provided an opportunity for the author to explore a specific community and that the case study participants recruited were appropriate to meet the study aims (Paanalahti 2013; Russell 2013). Having a sample of participants who were predominantly recruited through the Stroke Clubs observed also allowed collection of rich data which informed of how Stroke Clubs contributed to their everyday lives. This data supported observational data and contributed to the overall rigour in meeting the research aims and objectives.

5.2.2   Stroke Club Recruitment

The author identified a third sector organisation as a core reference point for finding out about Stroke Clubs across the study region. The author contacted the national charity stating the aims and objectives of the study and asked if the Stroke Clubs across a region in Wales would be interested in participating. Due to the confidentiality of the charity's database, a representative from the third sector organisation distributed the Stroke Club information packs (Appendix C) to all 33 Stroke Clubs affiliated with them across the selected region in Wales on behalf of the author. These packs were written in both English and Welsh, and included:

- a letter of invitation;
- an information sheet; and,
- a consent to observe form.

Six of the 33 Stroke Clubs invited to participate contacted the author by email or telephone to arrange an observation date. The host signed a consent to observe form (Appendix C) before the first observation took place and made the Stroke Club members aware that the author was there to observe. The members were given the opportunity to object if they wished, and were informed that the author would not record any personal details.

5.2.3   Recruiting the Study Participants

The case study participant information packs (Appendix D) which were distributed to the potential participants through the Stroke Clubs and consisted of two envelopes – one for the survivor and one for the caregiver. Each envelope consisted of:

- a letter of invitation;
- an information sheet;
- a consent for interview form; and,
- a postage paid envelope for return of signed forms to the author.

Ten information packs were distributed via the caregiver's organisation which generated one response. In an attempt to provide an equal response between the observed groups, the author took ten packs to each to the six Stroke Clubs being observed, regardless of the number of members each group had. Table 3 overleaf shows the distribution of envelopes to each Stroke

Club. Fifty-six information packs were then distributed across the six observation sites, making the total number of information packs distributed 66.

Table 3: Information Pack Distribution Rates (through Stroke Clubs)

Stroke Club	Number of Members on the day of case study recruitment (inc volunteers)	Packs Given Out	Packs Received Back	Invitees who Participated
A	43	10	2	2
B	15	10	2	2
C	52	10	0	0
D	21	10	2	2
E	35	10	2	2
F	6	6	0	0

*8 of the 9 case studies were recruited via Stroke Club.

A total of eight Stroke Club members aged between 36 and 92 responded to the information packs and took part in the study. The case study profiles are presented in tabular form and introduced in Chapter 6. The participants were aware their participation was voluntary and that their personal details would remain confidential (the ethical considerations of this study are discussed further in Section 5.5). Each case was unique; the commonality being that the participant survivors had experienced stroke and that they reside in Wales. This recruitment strategy provided a sample which consisted of both male and female survivors and represented a broad age range. This strategy also recruited caregivers who were spouses, partners, and adult children of the survivor participants, providing an opportunity to explore a variety of caregiving circumstances. Distribution of the information packs by hand meant that participants had the opportunity to talk to the researcher about the study before making their decision to take part. It was felt that this helped recruit for the study and helped build trust with the study participants.

5.3   Primary Data Collection

With reference to The Research Process Model presented earlier in Figure 6, here the data collection methods are discussed.

5.3.1   Stroke Club Observation

Table 4 presented overleaf shows a breakdown of each of the six clubs observed. The Stroke Clubs were of mixed ability and varied considerably in size. Despite the clubs being stroke-specific, it was noted that two members of Stroke Club D had not experienced stroke; one had dementia, and the other had lifelong disabilities. They both reported that Stroke Club supported them in their everyday lives. This highlights that the Stroke Clubs also met a social need for people who are living with a non-stroke related disability, and also suggests an area of potential growth. The majority (four) were English speaking, with the remaining two consisting of some members who conversed in Welsh on occasion. Each of the observed Stroke Clubs had a happy social atmosphere, Stroke Clubs A and F met monthly, E fortnightly, C, B and D weekly. Furthermore, five of the six Stroke Clubs consisted of mixed genders with Stroke Club F consisting of females only at the time of observation. Four out of the six clubs consisted of a mix of individuals who have experienced stroke and caregivers; Stroke Clubs B and D consisted of individuals who had experienced a stroke. Notably, two members of Stroke Club F were widows but used to attend with their husbands as they had experienced a stroke. This highlights an avenue of support for caregivers after the death of a spouse, showing how Stroke Clubs aim to support not only survivors but also caregivers. Regarding member recruitment, Stroke Clubs A, C, and D recruited members via newspaper advertisements and word of mouth, however Stroke Club B received members with communication difficulties on referral from hospitals and local GP practices.

Table 4: Stroke Club Profiles

Stroke Club Coding	Meeting Frequency	Meeting time	Number of Members (including volunteers)	Estimated age of Members (excluding Volunteers)	Cost to Members (excluding transport and raffle)	Transport to and from (survivors only)
A	Monthly	12.00 pm – 3.00 pm	39 - 47	50+	-	Car, Taxi, Charity mini bus
B	Weekly	2.00 pm – 4.00 pm	12 - 20	35+	-	Taxi
C	Weekly	10.30 am – 3.00 pm	41 - 60	30+	£1.50	Car, Taxi
D	Weekly	10.30 am – 3.00 pm	17 - 21	35+	£5.00	Car, Taxi, Walk
E	Fortnightly	2.00 pm – 4.00 pm	24 - 37	45+	50p	Car, Taxi, Walk, Own mini bus
F	Monthly	1.30 pm - 3.30 pm	3 - 6	45+	-	Taxi

Each Stroke Club was observed by the author once every other month to ensure consistency in data collection as some of the clubs were weekly, others fortnightly, and others monthly. This approach allowed for the identification of any 'one off' scenarios, and identification of common themes (Bernard 2013; Punch and Oancer 2014; Silverman 2013).

Stroke Clubs are set apart from typical social groups such as common interest groups, as they aim to provide support for people who have experienced a stroke as well as their families and friends. Conducting observational research provided insight into the activities held at the Stroke Clubs and allowed the author to learn about the ways in which the Stroke Clubs deliver their service to their members (Gray 2013; Punch and Oancer 2014). The author took an unstructured approach to research in this context and a non-participant observer role in order to consider an outsider's perspective (McGivern 2013; Green and Thorogood 2013; Saunders et al. 2015). This approach was particularly beneficial as the observer had little or no prior experience, or preconceived ideas regarding the topic of observation (Green and Thorogood 2013). Therefore, this approach also allowed themes to emerge, giving the author fresh insight. Such themes included: support from volunteers, support from other members, rehabilitative activities and the notion of shared environment. The data collected within the thematic data sets were collated and triangulated with the thematic data from caregiver and survivor interview in order to draw conclusions form the research (discussed further in Section 5.4, Data Management).

The layout of some of the buildings where the observation took place and format of the sessions meant that a non-participant approach also allowed the author to move around public areas and observe the numerous activities taking place. This approach ensured minimal intrusion and/or disruption to the observational setting. However, as the author became familiar to the observed participants, it was necessary for the observer role to change. The observed participants sought more engagement from the researcher and requested that she took part in the activities and engaged in conversation. The researcher took this invited opportunity and transitioned into a participant observer role which allowed more engagement within the research setting. This provided the author with a different perspective; the perspective of a new person joining an existing group and the experience of the encouragement in participation, provided by the Stroke Club members. However, the researcher is not claiming here that her feelings can be matched to those of a survivor joining the Stroke Club, but that she observed how the Stroke Club members welcomed new people into the group.

The author started each session as non-participant, only when she was requested to join in an activity did she participate, not wanting to offend the members who had asked for her inclusion. In this case engaging with participant research by invitation provided new opportunities for research, as members shared further stories of how they had improved physically and psychologically since going to the club and how they came to be there. The author found that the more she entered the observational site, the more comfortable the Stroke Club members were with her presence. The invitations to engage in sessions suggest that the author had built trust with the Stroke Club members. Building trust aided with data reliability as the observation took place in the natural setting and was uninfluenced by the observer's presence (Yin 2013).

5.3.2   Recording the Observation

An unstructured approach to observation allowed the researcher to observe each Stroke Club in its own setting (Green and Thorogood 2013). This was important because each Stroke Club was run independently. Field notes were collated by hand and were used to note the activities which took place within the Stroke Club and the behaviours (such as providing support to one another) of the Stroke Clubs members. Care was taken to only record data which was relevant to the Stroke Clubs and how they delivered services to their members. Collating field notes by hand ensured that the Stroke Club members were not distracted by digital recording equipment. Furthermore, background noise would have also affected the recording quality. This method, labelled 'jotting' by Bernard (2013) provided the author with brief notes which allowed her to fully observe the observation field with minimal distraction from taking notes. The author made more detailed notes of the observation session once she had left the observation site.

Visiting multiple clubs at regular intervals enabled the author to be reflective and decipher those events and behaviours which were unique to each individual Stroke Club and those which were not. For instance, if the author had visited one Stroke Club then the data could be representative of that particular Stroke Club. Similarly, if the author had visited each Stroke Club only once, they would have data to inform of the one 'snap snot' of the Stroke Club. Neither of these scenarios would have produced the depth of information provided by observing multiple Stroke Clubs, on multiple occasions.   Multiple observations also allowed for observing changes over time and specific events such as birthdays and Christmas, as well as occasions where members became unwell. By revisiting the clubs simultaneously, the author began to note themes of interest which could be investigated and cross-referenced across the observational sites, making

the observational data a valuable contribution in terms of increasingly content validity of the findings.

The author ensured that she was present at the observational site before the start of each observation to observe the members arriving, and to see how they accessed the session. During the observation, the author recorded notes by hand throughout, taking into account the number of attendees, the gender of participants, and approximate age of the participants. The author also recorded how the attendees interacted with each other, the general atmosphere and morale of the group, participation in activities within the group, the activities which were going on within the session and the actions of the host and volunteers throughout. The author noted the times that each activity began and closed, and during the session recorded notes at 10-minute intervals. The observational notes were reflected upon and typed up at the earliest opportunity to ensure that the observer's own reflections could be taken into account and recorded.

5.3.3 The Biographic Narrative Interpretive Method of Interview

Wengraf's (2009) BNIM consists of three phases; (1) a framing generative open-ended question which seeks a narrative response, (2) a semi-structured interview, and (3) closed questions (Wengraf 2009; Gubrium and Holstein 2002; Seidman 2013). Seidman (2013) defined phase 1 as a focused life story, phase 2 as a reconstruction of the details of experience, and phase 3 as a reflection of the meaning of the experience.

During phase 1 the interviewer made notes of significant statements which were to be further explored in phase 2 of the interview, being careful not to distract the participant by taking too many notes. The participants terminated the end of this phase explicitly when they were ready to do so; when their uninterrupted narrative had come to a natural close (Gubrium and Holstein 2002; Wengraf 2009). The author clarified by asking if there was anything else they wished to add before moving onto phase 2 of the interview, taking a short break in between.

Narrative approaches to interview have been documented as valuable and effective in the fields of health and sociology research due to their reflective and inductive nature (Alleyne 2014; Chamberlin 2012; Mazanderani et al. 2013; Suarez-Ortega 2013; Skinner 2014; Svašek and Domecka 2012). Personal narratives are not just a story of someone's life, told from one person to another. They are accounts which portray an identity; fashioned by the things a person may

emphasise or omit (Rosenwald and Ochberg 1992). In fact, Riessman (1993) considers narration or storytelling, as a mechanism for the story teller to tell the listener about a past 'world', *"recapitulating what has happened to make a point, often a moral one"* (Riessman 1993, 3). The participants of this study engaged with Biographical Narrative Interviews which allowed them to narritivise their experience of life after stroke, allowing them to provide detail of real and ideal, self and society (Reissman 1993). With the underlying meaning of words used to provide an experiential narrative being guided, whether consciously or subconciously, to portray an expression of real or ideal self in context, the audience must be an influencial factor as to the way in which the story is told and the words used to describe the experience, as *"without interpreting audiences, without social affirmation, stories wither"* (Hurwitz et al. 2004). The author of this thesis here, was the listener of the story told; and therefore, the audience. The author, through disemenation of the participant information packs (Appendix D) and introduction of herself at Stroke Clubs ensured that the research was independent, and made clear that she wished to find out about the lives of people who had experienced stroke, and their caregivers. The particicpants were aware that this was for the purpose of completing a thesis, and also disseminating research findings which told their story. This meant that the participants were narrating their story for this purpose. One participant, Mark, explicitly stated that: *"I am telling you this, as clearly and as truly as I can, as I know that you want to make a positive difference, and I am hoping that by telling you about my life, you will be able to make that difference, to somebody else's life"*. This informs the purpose of the narration provided by Mark. It also emphasises the strength in BNIM in enabling the narrative to naturally flow and not be influenced by the audience (the author). By employing the BNIM, the narrative was not focused on any one particular aspect of post-stroke life. This ensured that the narrator, the participant, was able to tell their story and emphasise those key points which were significant to them in their everyday lives.

Phase 1 of the BNIM required the author to be an active listener. Throughout this phase, the participant's narrative remained uninterrupted, creating explicit knowledge which was individual and personal to the participant, giving the participant conscious control of how they told their story, control of exactly what they did and did not share (Brannen 2013; Wengraf 2009).

This narrative phase of the BNIM not only consisted of the telling of a story, it also aided the process of critical reflection of each participant's own life experience (Skinner 2014; Suarez-Ortega 2013; Svašek and Domecka 2012). Reflectivity through this method meant that the participants considered their everyday life, and how stroke impacted upon it (Suarez-Ortega

2013). Chase (2011) observes that when people have survived an experience such as stroke, they are keen to let their stories be heard. Gubrium and Holstein (2002) also found this and reflected that in their research their participants were very willing to share their life experience, commenting that the majority of people who have experienced a significant life event just seek someone to listen or show interest. This was evident in this study as the research participants (both survivors and caregivers) were keen to share their life story and expressed that it was good for them to have the opportunity to talk about their experience:

"It has helped me to talk to you, about it."

(Mark, survivor participant: interview 1)

"It has been really good to talk about my experience; it has done me good to talk about it with someone."

(Sarah's daughter, caregiver participant: interview 1)

Through narration, the participants on occasion did not realise that they were imparting significant events or key information. This was evident as the some of the participants stopped themselves and apologised, stating that they had gone off on a tangent, or, that they were not sure if the information they gave was helpful or answered the question asked. This suggested that participants were more willing to share information through this method than if they had been interviewed using a more structured methodology, which would have meant the questions were being asked in a more direct manner. The reflective element of the narrative phase also assisted in memory recall as the participants were starting from the beginning of their post-stroke lives. This was key as the participant survivors often reported that their memory had been affected by their stroke.   The varying communication abilities of the participants of this study meant that some participants were able to provide more narrative, and thus more depth of information than others. This is where phases 2 and 3 of the BNIM assisted in gathering data, as these phases allowed the author to ask the participants direct questions which they could answer with a brief statement or gesture such as nodding or shaking their head.

The notes taken by the author informed phase 2 of the BNIM. During this phase, the author sought more detail from the participants relating to areas of interest which had been imparted during phase 1. This gave the author the opportunity to clarify information and seek further explanation of areas of interest. Finally, phase 3 of the BNIM interview gave the opportunity to ask direct questions in a semi-structured format covering pre-defined topics and areas of interest

which were drawn out of the review of the existing literature. This ensured that all pertinent topics were covered.

Combined, all three phases of the BNIM ensured that key topics of interest were covered, and any further insights into the participant's experiences were reported. This allowed for new insights to be considered and ensured validity in the data, with the key strength of the BNIM being the first phase; the uninterrupted narrative element (Gray 2006). The narrative phase informed of each participant's perception of their life, personal histories, and the society in which they live (Chase 2011; Skinner2014; Svašek and Domecka 2012).

The researcher was aware that similar to other interview methods, responses via the BNIM provide the opportunity for participants to present themselves, how they want to be perceived. For example, participants may present themselves as someone who is coping, when in fact, the reality is that they are not (Wengraf 2009). This presents issues of validity in the way that participants reconstruct a memory of 'past history' which can become a retrospective illusion influenced by the past, present and foreseen future as they perhaps talk about someone they 'were' or 'aim to be' and not their present self. In this instance, the narration can become:

> *"A self-image serving to protect the identity of the subject in question, an ontology of self-mythology."*
>
> (Osterland 1983, 285 cited in Wengraf 2009)

However, as the author gained trust from the study participants through the data collection methods, this reduced the likelihood of a false story being told. The author noted this as a potential issue and tried to negate this risk by not disregarding a situation where a participant may be living in an ideological state, where they believe that their told self-image (even if not accurate) to be a true reflection of their post-stroke life. Phases 2 and 3 of the BNIM deliberately allow for more direct questioning. This provided an opportunity for the author to ensure the predetermined questions she had to ask had been answered, seek clarification from the narrative phase 1 where needed, and prompt for further discussion relating to specific topics told in the narrative phase 1, to be explored further.

5.3.3.1   Template Development

The participants' narration is determined by a single generative question. During phase one of the interview, the interviewer's interventions were restricted to provide just facilitative noises and non-verbal support, with any other type of intervention terminating the session (Wengraf 2009), allowing the participant to narrate their experience of everyday life since they experienced their stroke, including any events and experiences which were important to them.

The BNI template for the survivors of stroke (Appendix E) began with the generative question:

> *"Can you please tell me about your everyday life since you experienced your stroke: all the events and experiences that are important to you personally."*

This generative question, along with the remaining phases in the template, was developed to identify themes relating to:

- Information about the participant's stroke;
- Their everyday lives and experiences after they experienced their stroke;
- Any challenges they may face;
- Support they receive/ unmet need; and,
- Who is involved in their everyday lives – identification of their personal support networks?

The BNI template for the interviews with caregivers (Appendix F) began with the following generative question:

> *"Could you please tell me in your own words your experience of caring for (survivors name) since they experienced their stroke?"*

This generative question, along with the remaining phases in the template, was developed to identify themes relating to:

- Their everyday lives and experiences since becoming a caregiver;
- The challenges faced as caregivers of people who have been affected by stroke and coping strategies adopted;
- Relationships – with person affected by stroke and with professionals;
- Experiences and perceived effectiveness of services; and,
- Unmet needs for help and how these might be met.

By interviewing the caregivers, the author gained a broader insight into 'life with stroke'. The majority of the caregivers were the spouses of the survivors, however, in some cases, it was younger generations of their immediate family. In doing this, the author gained not only the perspective of the stroke survivors but the perspectives of the primary caregivers about everyday life.

5.3.3.2 An Alternative Template

"Research involving people with communication difficulties requires authors to focus on the priorities and needs of the people with communication disabilities in their locality."

(Jones et al. 2013, 1)

This was especially important given that the existing literature highlighted that survivors of stroke might live with communication difficulties. The author developed an alternative interview technique which sought to meet the needs of participants who may experience communication difficulties (Jones et al. 2013). The author met with a speech and language therapist from a local hospital who informed her of the ways in which the rehabilitation unit communicates with people who have communication difficulties post-stroke. The author then developed an alternative way of interviewing study participants, in preparation of this instance occurring (Appendix G). The template allowed the participant survivors to read specific questions as they were being asked. Different coloured text highlighted the key elements of the question and helped to separate the question into separate parts. Pictures also helped to provide the participant with the context in which a question was being asked. For instance, where a participant is being asked about the help they receive, there is an image of a handshake gesture. These images were selected by the author for their similarity to those pictures used by the speech and language

126

therapist. Participants could then answer using their own words, or selecting pictures which represented what they wanted to say in response. This provided flexibility in how the interview could be conducted and ensured that the author prepared for instances where those with aphasia, dysarthria, or dyspraxia would wish to participate, ensuring full inclusion.

Three of the participants experienced communication difficulties in terms of verbal communication. The survivor participants from case studies 3, 5, and 6 were offered the opportunity to use the alternative template. However, the template was not required. For case study 6 the template was not needed, instead, more time to answer questions and verbal clarification of the received message from the author were required. For case studies 3 and 5 the template reminded the participants of a photograph book which they had put together while in speech therapy at the hospital. They then retrieved the photograph book which told their life story. The author let the participants lead their way through the book, and confirmed the pictures and stories they told with confirmation of her own statements to the participants. In both instances, the caregivers were present and were able to inform where the participant could not. For each of these case studies, clarification of the given information was provided by the survivor by verbal ques (case study 3), and non-verbal cues (case study 5). As stated in secion 5.1, the author let the participants control the way they told their story, regardless of the method in which they were able to tell it.

5.3.3.3 The Follow-up Interview

Revisiting the study participants and conducting a follow-up interview provided the opportunity to explore possible change over time. This took into account the dynamic nature of the outcomes of stroke. The follow-up interview also took the form of a BNIM interview. The templates for the follow-up interviews with the survivor and caregiver participants are appended in Appendices H and I. As Figure 8 shows, the follow-up interviews were informed by data collected during the first interview stage.

As with the first BNI template, the follow-up interviews began with a generative question (an example is shown in Appendices H and I). The follow-up interviews were conducted seven months after the preliminary interviews took place. Six of the nine study participants (case studies 2, 3, 4, 6, 8, and 9) continued with the study. Case study participants 1 and 5 were un-contactable, while one withdrew due to deterioration of the survivor's health.

The follow-up interview informed of the change in health and wellbeing of the study participants; both survivors and caregivers. This is discussed within the findings chapters, Chapters 6, 7, 8 and 9. Furthermore, the follow-up interviews highlighted key life events; a death of a caregiver, and a flooding of a home, which had occurred since the first interview stage, and changes in social participation.

5.3.3.4 Closing the Biographic Narrative Interpretive Method Interviews

Once the interviews had been completed the author ensured that the interview ended on a positive note. The author also took time to sit and talk to participants after the interview had been completed as the interview drew upon past experiences which may have been distressing to the participants (Beuthin 2014; Wengraf 2009). The author wrote up field notes immediately and noted down any non-verbal communications such as emotions and feelings which were apparent from facial expressions and body language, as well as reflections from the author's perspective. This helped the author reflect on the interview itself and both verbal and non-verbal aspects such as body language, which aided interpretation of the narrative.

5.3.4 Semi-Structured Interview with the Stroke Club Host: template development

Three of the Stroke Club hosts were interviewed in order to gain more insight into the service delivery and formation of the Stroke Clubs. However, all hosts shared information which contributed to the semi-structured interview templates (Appendix J). The semi-structured interview consisted of qualitative open-ended questions. This approach to interviewing allowed the author to deviate from the template and explore further avenues of interest which were drawn out of the participants' responses to the predefined interview template (McGivern 2013; Silverman 2011). Upon meeting the hosts of the Stroke Clubs at the first observational session, hosts provided the author with a brief background of each club including such aspects as the Stroke Clubs aims and objectives. They highlighted issues with service delivery for those survivors of stroke and how the clubs had formed and developed. This information contributed towards the interview templates, which guided the semi-structured interviews.

The interviews provided an opportunity to ask any further information which needed clarification. This further ensured clarification of the research findings and contributed to their reliability.

The semi-structured interview template was designed to identify themes around:

- The roles each representative plays in arranging, providing and coordinating support to people who have been affected by stroke and their caregivers;
- How they deliver their service;
- What they consider to be the challenges, strengths and weaknesses of the service; and,
- Any priority areas for development and improvement.

5.3.5 Conducting the Interviews

Eight of the nine case study interviews took place at the participants' own homes. The case study recruited through the caregiving organisation was interviewed away from their home. The survivor was interviewed at a day centre and the caregiver on university premises. This leads to a reflection as to whether the participants who had met the author prior to interview felt more comfortable with the author visiting their home than those who did not. Where possible, the interviews were conducted individually, however, some participants required their caregiver with them during the interview to assist with communication and memory recall. This included the caregiver participants responding to questions on the survivor's behalf in some instances.

5.3.6 Recording the Interviews

The author primarily used a dictaphone to digitally record the BNIM interviews with the survivors and caregivers. Brief notes made by hand during the interview also acted as a backup in case there were any issues with the digital recording.

Digitally recording the interviews also enabled the author to focus on the participant and engage in their conversation. Paying attentive attention to the participant contributes to the trust relationship between the interviewer and participant which can result in more detailed accounts been given (David and Sutton 2011; Wengraf 2009). By digitally recording the interviews, the author was able to record the way in which something was said; i.e. the tone in which a topic was discussed – whether it was humorous, serious, or whether the participant became upset. After conducting the BNIM interviews, the author collated the field notes which consisted of notes

from the interview, a list of possible themes, and notes about the encounter itself (Silverman 2011).

Many authors (McGivern 2013; Gray 2013; Silverman 2011) report of the time-consuming nature of data transcription; more so if there is background noise. Therefore, the author took this into account when conducting interviews by ensuring that there were minimal background noise and disruption in the interview setting. The semi-structured interviews with the Stroke Club hosts were conducted within the observational setting at their request, and so it was not appropriate to use a Dictaphone due to the level of background noise. Therefore, the author made notes regarding each answer.

On each occasion, participants signed the appended consent to interview form. Those participants who were participating in a digitally recorded interview also signed a consent to digitally record the interview form.

5.4   Data Management, Interpretation and Analysis

The way raw data is managed, interpreted and analysed can have an impact on its validity and reliability (McGivern 2013; Saunders 2015). Interpretation and analysis is the process of making sense of the raw data collected, and thus, this process should be thorough and planned for with an appropriate strategy.

5.4.1   Data Management

"Data have to be documented to become useful as a source and then as evidence for analysis."

(Bazeley and Jackson 2013, 63)

The way in which data is documented impacts on the data analysis in terms of its effectiveness and efficiency (Bazeley and Jackson 2013). The author used Computer Assisted Qualitative Data Analysis Software (CAQDAS) package Nvivo 9.2. This software assisted the author in project and data management, and provided a platform for the author to code, explore, and interrogate the data (Bazeley and Jackson 2013; Lewins and Silver 2006). Taking a systematic

approach to data management, once the raw data had been collected, it was transcribed and saved under an appropriate file name on the author's desktop in encrypted files and uploaded onto the Nvivo 9.2 software package. The file names identified which case study the interviews had come from, and the participant who had responded. Observational notes were stored under the letters A-F which had been allocated to the Stroke Clubs observed. The author then coded the transcripts into sections of data using nodes; categorising it into themes. The themes included pre-defined areas of interest which were identified through the literature review and areas of interest which were discovered from the participants and the observational data. The author then stored her jotted notes as memos and ran data queries which highlighted linkages in the data and contributed to thematic content analysis (Lewins and Silver 2006).

Self-transcription of the interview data provided the author with the opportunity to become immersed in the data and engage with the data on a deeper level and was the first stage of data analysis. This assisted with data recall during the coding and analysis stages as the transcriptions became familiar and the author became aware of common themes which were present within the data during the transcription phases (McGivern 2013; Saunders et al. 2015; Silvernman 2013).

All hard copies of data collected throughout this study were filed securely in adherence with the 1998 Data Protection Act. Signed consent forms and paper data were stored in a locked filing cabinet, in a locked room. Any documentation and recordings will be kept securely with adherence to the Data Protection Act 1998 for five years after the close of this study, then they will be securely destroyed in accordance with the Act.

5.4.2 Coding the Data

The author has produced the model presented in Figure 8 overleaf. This model demonstrates the coding and analysis framework used in order to manage, analyse and interpret the data.

Figure 8:   Qualitative Data Analysis Coding Framework
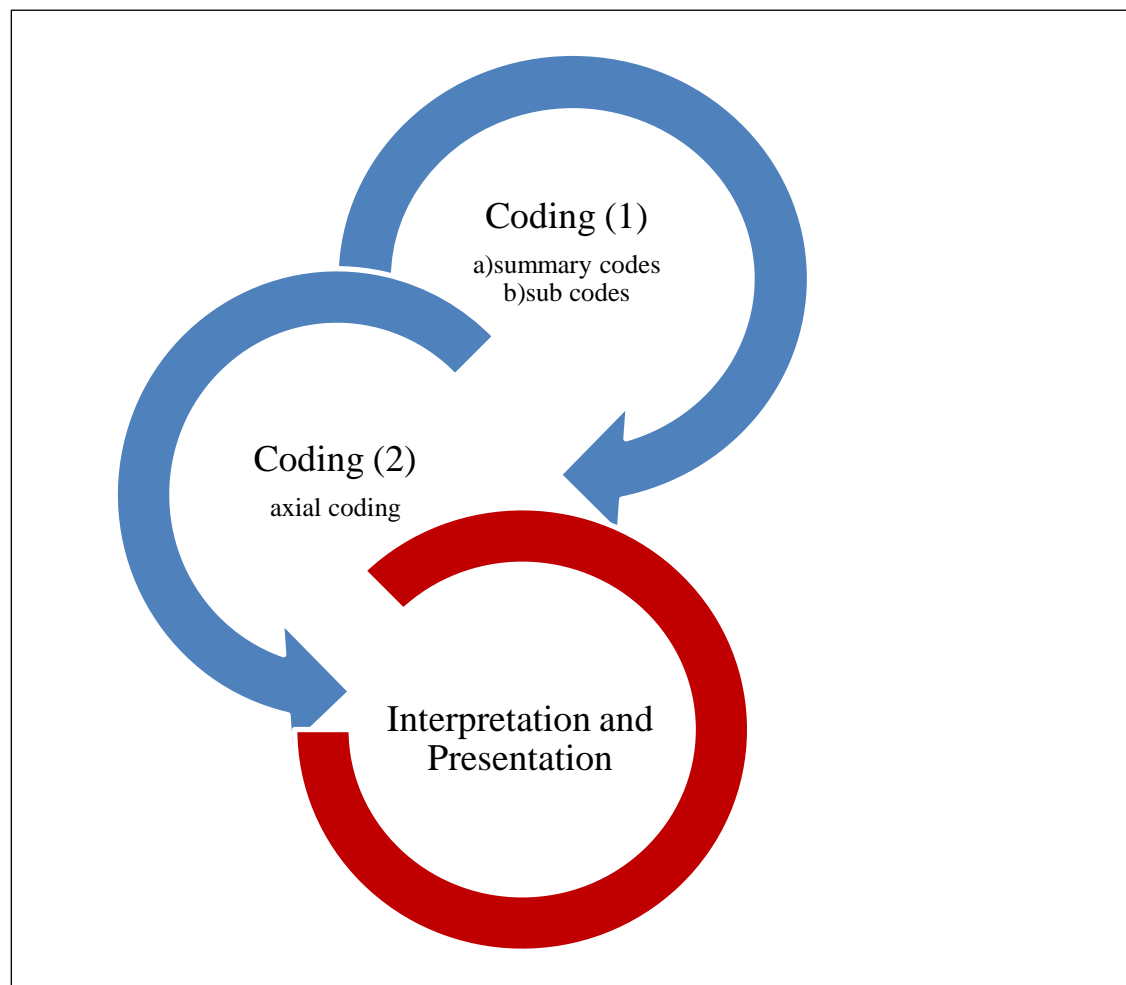
First, summary nodes coded down the data and informed of context in relation to questions: What? Why? Where? And When? The data was then further coded using sub-nodes to reduce the categories further, making them more defined. Axial codes then linked the coded data (the data within each node category) to one another, highlighting any patterns across data (Bazeley and Jackson 2013). This data reduction strategy (Figure 8) organised the data, categorising the raw data into manageable sections. This process was replicated across the multiple primary data sources and prepared the raw data for analysis. Furthermore, as themes emerged from the primary data, the author revisited the data source to ensure that all themes were considered in the coding process. This strategy ensured academic rigour, and enabled a priori themes as well as themes which emerged through primary research to be considered. Key themes are presented in tabular form in Appendix K. This table is designed to assist the reader in locating the area where key themes are discussed in the thesis.

5.4.3   Interpretation and Analysis

The role of the author here was to interpret the research for the reader, teasing around the themes to inform of the full picture of the participants' post-stroke lives, interpreting the narrative content and the narration itelf (Hurwitz et al. 2004). In particular, the narrative raw data, which was interpreted by the author with all aspects of the story told being explored in further depth through triangulation of data sources, ensuring that the narrated interpretation of the participants' lives to the audience, was thoroughly analysed to portray a real sense of post-stroke life, whilst considering the ideological perspective the participants may wish to adhere to (Riessman 1993). Here, depth can be added by the author (interpreter, the audience) as the audience can expand upon the narration told and is not bound by the narrator's evaluation of experience (Hurwitz et al. 2004).

Themes across the survivor interviews, caregiver interviews and Stroke Club observations were sythesised in order to discover end user perspectives of Stroke Club, and also the impact which Stroke Club had on the participants' everyday lives; contributing to the research aims and objectives. By coding the raw data as a node itself, the author was able to triangulate the data by running queries and exploring nodes or themes across individual and multiple data sources (Cronin 2014; McGivern 2013; Ritchie et al. 2013; Silverman 2011). This identified areas of convergence, inconsistency and contradiction by highlighting linkages between the data which confirmed common themes, and identified those themes which were independent (Bazley and Jackson 2013; McDermott 2011) and also highlighted areas which required further exploration; contributing to the template for the follow-up interviews. This further demonstrates the validity in multi-method strategies, as triangulation of the data increased the depth of which the data was cross-referenced, analysed and interpreted (Cronin 2014).

Effective data analysis relied on the author's ability to decipher the meanings of textual data. The author interpreted the textual data within its context, in relation to the research phenomena and identified literal themes such as disability and family circumstance, and underlying themes such as emotion and feelings which may, in part, underpin the participants' everyday lives. This ensured that the author did not take the told story too literally which reduced the risk of missing possible hidden meanings, thus focusing on the way an event is talked about in addition to the details of the event itself (Brannen 2013; Wengraf 2009). Therefore, it was critical that the

author personally managed, and transcribed the data herself to ensure full engagement with the data.

5.5 Ethical Considerations

In any given project it is essential to consider the ethical, political, and research implications (Saunders et al. 2015). Prior to the commencement of this study, the author sought approval from Bangor University College of Business, Law, and Social Science's Research Ethics Committee. Its rigorous ethics procedure ensured that the author had approved guidelines for interviewing vulnerable adults and research covering emotional and sensitive topics. This ensured that the author was aware of the necessity of consent forms (discussed further in Section 5.5.1) prior to study commencement (Flick 2009; Ritchie et al. 2013).

Here, the research ethics appropriate to this study are discussed. Throughout the research, the author considered Rowson's (2006) 'FAIR' framework of ethical principles which refers to professional ethics. This framework expresses: to treat all individuals justly and **F**airly, to respect the **A**utonomy of participants, to act with **I**ntegrity, and to seek the best **R**esults. The author also referred to the published Economic and Social Research Council (2010) Framework for Research Ethics. This ensured that the ethical considerations for this project were thorough, and met both academic and professional standards.

5.5.1 Informed consent

The author ensured that the study participants were provided with the appropriate information which they needed to make an informed decision as to whether to participate or not. There was also a strong emphasis on the participation of this study being voluntary, and the participants were made aware that they could leave the study at any time. Participants were also provided with a declaration of the use of data within the participant information sheet. This provided the participants with the knowledge that the data collected would only be used for the purpose of this study and correlating publication, and that the data would be anonymised. Consent for participation was provided by the participant completing and signing the consent form (Silverman 2011; Ritchie et al. 2013). The author was aware that there might be an option to consent by proxy. However, each of the participants were able to sign the consent forms.

The author provided potential participants with information about the purpose of the project and its intended outcomes, explaining clearly their rights, and the likely nature of their participation. It was affirmed in the research protocol that if any person(s) appeared to be confused, distressed or had difficulty understanding the information sheet that describes the research, then they would be excluded from the project. This was not necessary for this study.

The author ensured that the participants were made clear of the boundaries of confidentiality and anonymity throughout the data collection process, and in any outcome such as the written thesis itself, published journal articles, or conference proceedings. In addition, if the author was aware that if there was a concern about a participant which includes the following:

- Risk of harm to self;
- Risk of harm to others;
- Suspected abuse, bullying or harassment; and,
- Suspected severe misconduct.

Then the author is under obligation to report the concern to the local authorities. However, this did not need to be exercised during this research.

5.5.2   Managing the Interview

The author was aware that the context of this research was highly sensitive. Therefore, the author, as part of the requirements for ethical approval, formed a range of strategies for dealing with a variety of situations. For instance, if at any time a participant had become upset, the current activity would be stopped. The participant would be given the opportunity to reschedule the remainder of the activity at a later date, or given a momentary break from the activity. The respondent held the right to withdraw consent for this research at any time, and so they would have been asked if they would like to continue or not.

5.5.3   Exit Strategies

5.5.3.1   Where Permissions are Withdrawn

The Stroke Club information packs and case study participant information sheets (Appendices C and D) informed that if the participant or Stroke Club wished to withdraw from the study or opt

out of further involvement, they could do so at any time. If a withdraw option was taken, data collected previous to the request would also be withdrawn from the study. No participants opted to withdraw from this study, so this was not exercised.

The participants of this study who were non-contactable or did not wish to continue, did not officially withdraw from the study. Thus, data collected in the first interviews related to these individuals was not withdrawn and is included in the research study. None of the participants explicitly expressed they did not wish to continue. Two of the three case study participants that did not participate in the follow-up interview were contactable. The caregiver of the other informed that the survivor had been taken into hospital and was unlikely to recover from her deterioration in health. Due to the situation, the author decided it was not appropriate to request the caregiver partook in the follow-up interview as they became upset while talking to the author.

5.5.3.2   If a Participant Dies

On the death of a participant, the author holds the right to data which has been collected and for which consent was given prior to the participant's death. During the data collection stages of this research, the caregiver from case study 2 died. The survivor participant of the same case study wished to continue with the study.

5.5.3.3   If a Participant's Health Deteriorates

During the study the survivor participant from case study 7 experienced a deterioration in health, resulting in her daughter (the caregiver) opting out of the follow-up interview on behalf of herself and the survivor participant.

If appropriate, the author would have made adaptions to suit the participant's needs (such as the use of the alternative interview template presented in Appendix G). However, the deterioration in health was such that the survivor would not have been able to provide informed consent.

5.5.4   Exiting the Field

Due to the longitudinal aspect of the observational research and the personal stories told during the interviews with the study participant, the author formulated an exit strategy for leaving the research field.

The author spoke to the observation participants of each Stroke Club and communicated her thanks to them. They expressed a desire to keep in touch with the author and so the author stated that she would contact the Stroke Clubs observed once the course of study is complete. At the close of the follow-up interviews, the participants also expressed a desire to keep in touch. The author informed that she would contact the Stroke Clubs on the completion of her doctoral study.

5.6   Chapter Summary

Prior to this chapter, the thesis introduced the research aims and objectives and provided a context in which the study is set. This chapter now provides the bridging point of the thesis as it discusses the way in which the author sought to meet the research aims and objectives as stated in Chapter 1, and at the start of this chapter.

This chapter presented the research methodology and design. It discussed, in detail, the research approach, the design of the research and the methods chosen. In highlighting the strengths of the methods of data collection chosen, Chapter 5 provides detail of how they contribute to adding validity to the multi-method design.

The remainder of the thesis discusses the research findings through Chapters 6 to 9, and informs of how they contribute to the existing literature. This methodology also provides a framework which could be used for further research on a broader scale and research into other avenues of exploration. Some of which are discussed later in the final thesis chapter, Chapter 10.

6.0   Setting the Scene: An Introduction to the Study Participants

This chapter introduces the study participants and in doing so provides a context for the research findings, which are presented in Chapters 7, 8 and 9. The case study profiles are also presented in tabular form in Table 5 (overleaf). The survivor participants from each case study have been allocated a first name pseudonym, which is used throughout the remainder of this thesis. The caregiver participants are referred to by their relationship to the survivor. For example, the participants of case study 1 are Sarah and her 'daughter'. Please note that for the remainder of the thesis, where a caregiver is referred to as 'daughter', they are in fact adult daughters of the survivor participants. All of the participants of this study were over the age of 18. Where relevant, the author also uses ': interview 1' or ': interview 2' to indicate which interview any quotation or information referred to came from. For example, if there is a statement given by Sarah during her first interview the citation will read (Sarah: interview 1) and so forth.

6.1   The Case Study Profiles

Here, the case study profiles are introduced. Although aspects of the participants' everyday lives are presented here, they are discussed in more depth throughout Chapters 7, 8 and 9.

Table 5: Case Study Profiles: presented in tabular form

Case Study	Survivor Pseudonym	Caregiver Interviewed	When they experienced their stroke	Age at Stroke	Survivor Age at Interview 1	Number of ears since their stroke	Survivor Employment at time of stroke	Survivor Employment post stroke	Attends Stroke Club?	Who the survivor lived with	Caregiver employment	Supported by paid caregivers	Main mode of transport	Participated in second interview?	Additional Interview requirements	Moved house because of stroke?
1	Sarah	Adult daughter	2006	83	89	6	Full Time - Receptionist	Retired	No	On own	Part Time and also Family Farm	No	Taxi	No	Needed clarification from caregiver	Yes
2	Paul	Spouse	2009	62	65	3	Full Time - Carpenter	Voluntary	Yes	Spouse	Part Time	No	Own car (mobility adapted)	Yes	Needed more time to answer questions	No
3	John	Spouse	2009	56	59	3	Full Time – IT Technician	Retired	Yes	Spouse	Retired	No	Bus Caregiver	Yes	Needed some assistance in understanding and answering questions	No
4	Mark	-	2002	58	68	10	Self-Employed	Retired	Yes	Spouse	n/a	No	Own car (mobility adapted)	Yes	Needed more time to answer questions	No
5	Richard	Spouse	2001	70	81	11	Retired	Retired	Yes	Spouse	Retired	No	Own car (mobility adapted)	No	Spouse communicated on his behalf	No
6	Jane	-	2008	32	36	4	Part Time Factory Worker	Voluntary	Yes	On own	n/a	No	Own car	Yes	Needed more time to answer questions	No
7	Penny	Adult daughter	2009	89	92	3	Retired	Retired	Yes	On own	Part Time	Yes	British Red Cross transport	No	-	No
8	Ruth	Adult daughters (2)	2007	71	76	5	Retired	Voluntary	Yes	On own	Both Employed Part Time	No	Taxi	Yes	--	No
9	Thomas	Spouse	2007	68	73	5	Retired	Retired	Yes	Spouse	Retired	No	Bus	yes		Yes

6.1.1   Case Study 1

Sarah experienced her stroke in 2006 aged 83, while driving her car. Reflecting that she felt that *"there was something wrong with the gears"* (Sarah: interview 1) Sarah described how she had crashed her car into a brick wall. Having no further memory of the accident, Sarah expressed concern that she may have hurt someone, but could not remember. This aspect of the accident caused feelings of anxiety for Sarah who would regularly ask her daughter (the caregiver participant) if she had hurt anybody when she crashed. This was evidenced during Sarah's interview where she asked her daughter: *"I didn't hurt anybody did I?"* (Sarah: interview 1).

Sarah reported that her stroke had affected her physical ability, making her less mobile than she was before she experienced her stroke. Sarah was able to walk short distances around the home, however required the use of a wheelchair when outside of the home. Sarah also experienced post-stroke fatigue and coordination difficulties. This meant that Sarah was unable to walk long distances, and was now unable to drive her car which resulted in her no longer having use of her own independent transport.   The impact of Sarah's stroke on her physical ability and coordination difficulties meant that she found stairs difficult and there was an increased risk of her falling. This meant that she had to relocate from a privately owned two storey house to a warden-assisted bungalow. As Sarah's home was not suitable for her to reside in after discharge, there was a period of time where she resided with her daughter and her daughter's family while she waited for her new home to become available. This was in agreement with the hospital as they would not have discharged Sarah unless she had someone to live with on a temporary basis while arrangements were being made.

When Sarah moved into the warden-assisted bungalow, she developed a sense of routine. This helped Sarah to cope with her memory problems and provided reassurance in her everyday life. Such reassurance was provided by this routine, which was kept to a strict time schedule that enabled her to know when visitors would come to the house, when she would get a taxi to a day centre, and when her daughter would phone. Sarah also had specific meal times and a set time for when she would get up and also go to bed. As well as these weekly and daily routines, Sarah also had routines which she would follow when she awoke each day. Each morning Sarah would go to the bathroom for a wash and get dressed using the pile of clothes which her daughter had laid out for her the day before. Her daughter laid out the clothes in the order she would need to put them on. Regular appointments and social activities were set on the same day each week to help Sarah keep to a routine in her everyday life. Although such routine helped Sarah in her

everyday life post-stroke, it was often a cause of strain for Sarah's daughter as she had to follow the same routine in her caregiving role, making the time allocated to the caregiving role seem inflexible.

Sarah and her daughter had been offered support from local authority support services. However, this support was declined as they felt the support was not needed at the time (the support offered is discussed further in Chapter 9). Instead, support was provided by Sarah's daughter in money management, washing, ironing and laying out her clothes for each day, personal care, cleaning, and supplying cooked meals to be reheated in the microwave at mealtimes. This supported Sarah in maintaining her routine, something which Sarah's daughter reported has aided Sarah in *"living as independently as possible"* (Sarah's daughter: interview 1). Sarah's daughter would also take Sarah out for day trips and to a Sunday service at chapel. Both Sarah and her daughter report that their neighbours and family have been key people within their personal support networks.

Sarah's daughter was married with two adult children, was employed part-time in a mental health organisation and worked on the family farm. Sarah's daughter felt that the experience she had gained through her employment had helped her in knowing how to care for Sarah. Sarah's daughter felt that her employer had supported her by allowing her to be flexible in her working hours and by allowing Sarah to visit the day centre which was held weekly at her place of employment, therefore supporting Sarah, while also supporting Sarah's daughter in her caregiving role.

6.1.2 Case Study 2

Paul experienced his stroke at home in 2009, aged 62. Similarly to Sarah, Paul's stroke resulted in him experiencing post-stroke fatigue, memory deficits and reduced coordination ability. Paul also experienced paralysis in his left arm as well as sequencing problems, both neurologically and physically, which affected his physical ability and his written and verbal communication. Paul's wife, who was employed part-time as an administrator, supported Paul. Paul's wife reported that her mother had also experienced stroke which gave her an idea what to expect in their post-stroke lives.

When Paul retired from the public service sector prior to stroke, he took on employment as a carpenter and joiner. Paul and his wife had also renovated the house they lived in. The outcomes of Paul's stroke meant that he had *"given up joinery"* (Paul: interview 1), leaving his employment. Paul then volunteered for a social enterprise initiative that made adaptions to furniture and homewares for people living with physical disability. Paul had a mobility car which allowed him to have independent transport. Paul also reported that with his family not living nearby, their personal support network included their neighbours, friends and local Stroke Club. Paul's wife also reported that the hospital staff she met while Paul was in hospital and the occupational therapist who was assigned to Paul following his stroke were also valuable sources of advice in the early recovery stage. Considering support in the months and years after his stroke, Paul's wife reported that other caregivers who she had met at Stroke Club were *"a valuable source of advice and support"* (Paul's wife: interview 1). Similarly to Sarah's daughter, Paul's wife's employer was supportive and allowed flexible working hours. Paul was also welcome to visit his wife at her workplace.

During the first interview, Paul's wife stated that she managed any paperwork, household finances and bills, and oversaw Paul when he was cooking in the kitchen. Like Sarah, Paul also developed a routine which he incorporated into his everyday life.

Paul's wife died shortly after the first interview was conducted. During the follow-up interview, Paul informed the author that since his wife's death he had taken on the responsibility of the household bills and money management. This highlighted a change in everyday life for Paul. The death of his wife meant that Paul had to find a way of managing these tasks. With the use of an iPad and electronic banking, Paul was able to take on some of the tasks which his late wife had managed prior to her death (discussed later in Chapter 8). Paul did not receive support from local authority support services as the support was not needed. However, since the death of his wife, Paul had employed someone to iron his clothes for him on a weekly basis.

6.1.3   Case Study 3

John was supported by his partner and lived in a two storey house. John experienced his stroke at home in 2009, aged 56. The stroke impacted John's memory and the sequencing of his writing and speech which meant that John had to retire from full-time employment in information technology (IT). John was unable to remember how to use a computer after his

stroke despite being previously qualified in computing to a high level. John's partner was retired when John experienced his stroke. Both John and his partner identify their neighbours, friends and Stroke Club as key people within their personal support network. The couple reported that they were given little support when John experienced his stroke and felt particularly disappointed that they received no support from John's employer given that he was employed by a healthcare organisation. It was felt that John's connections with his employer should have meant that he was offered financial support in his retirement. John's partner also stated that they had met with local authority support services for an assessment *"and didn't hear from them again"* (interview 1) and so did not receive support from them.

Since his stroke, John has relearned basic computing skills through his local Stroke Club and a local college, which enabled him to communicate via email and engage in social media forums. John also felt that there had been an overall improvement in his speech. However, he also felt as though he would have benefitted from further speech therapy.

John's partner supports John with money management, household paperwork, and keeps a record of his appointments to attend. Summarising their caregiving relationship John's partner observed:

> *"I look after him, making sure he's got the right things on, on the right day."*
>
> (John's partner: interview 1)

However, being ten years older than John, John's partner reflected that she *"did not expect to be looking after him"* as they grew older (John's partner: interview 1), highlighting the unexpected nature of stroke itself and the subsequent caregiving role.

6.1.4   Case Study 4

Mark experienced his stroke in 2002 aged 58 and lived with his wife (not interviewed) in a bungalow. Mark experienced his stroke while he was driving his car to his mother's home. Mark found that he was suddenly unable to find her house and had experienced memory loss:

> *"I couldn't remember where she lived or how to get there; which I knew was strange."*
>
> (Mark: interview 1)

When Mark tried to get out of the car he experienced further difficulty:

> *"When I tried to get out of the car, I found I had difficulty standing, so I had to flip both legs out of the car door to stand up."*

<p style="text-align: right">(Mark: interview 1)</p>

Sensing that *"something was wrong"* (Mark: interview 1) Mark saw a doctor the next morning, who referred him to a hospital. He was then told that he had experienced a stroke.

Mark recalled being in denial and refusing to be admitted to the hospital overnight. However, when he attempted to convince the doctor that he was well enough to go home, he faced reality: *"I couldn't walk properly, and that was a shock"* (Mark: interview 1). Not wanting to accept this, Mark was determined: *"I'm going home"* (Mark: interview 1). After spending some time at home, Mark began to come to terms with his experience and later returned to the hospital, where he then learnt that this was, in fact, his second stroke. Mark was told by the hospital consultant that it was likely his first stroke was a transient ischemic attack, also known as a mini-stroke where the symptoms of the stroke last for 24 hours.

A business owner previously, Mark was unable to work because of the outcome of the stroke on his neurological and physical ability. Initially paralysed down the right side of his body, Mark felt there was an improvement in his physical ability over time. This meant he was able to walk with the support of a walking stick. Similarly to Paul, Mark also had use of a mobility-adapted car and so had independent transport. Reporting an emotional challenge he faced, Mark reflected that he had experienced depression in the early stages of coming to terms with stroke. During his follow-up interview Mark reported: *"I'm having more bouts of depression than I used to"* (Mark: interview 2) which suggests that depression was a fluctuating element of Mark's everyday life post-stroke. Demonstrating that the caregiver-caree relationship is not always one way (between the survivor and their caregiver) during his first interview, Mark reported that he was providing care for his wife, cooking her meals and helping her around the home, due to her temporary ill health. Not requiring support offered by local authority support services, Mark considered his wife and local Stroke Club key avenues of support in his personal support network, reporting that Stroke Club had been a *"main source of reality"* (Mark: interview 1) in helping him come to terms with experiencing his stroke.

6.1.5 Case Study 5

Richard experienced his stroke while on holiday in 2001, aged 70. Since his stroke, Richard had been unable to communicate, either verbally or through written word. Richard did not use services offered by the local authority as they were not required, and was supported by his wife who communicated on his behalf during his interview. Richard retained the ability to understand both written and verbal communication, and was able to verify information during the interview with a nod of the head for 'yes' and a shake of the head for 'no'. During his interview, Richard showed the author a photograph album which had been made up to tell his life story. Richard received additional support from his two adult daughters (not interviewed) and the host of his local Stroke Club who would visit on an ad-hoc basis. Richard used to attend Stroke Club regularly; however, with Richard and his wife residing an hour's drive away, they found it was too far to travel as Richard began to experience increased post-stroke fatigue. This highlights the changeable nature of the outcomes of stroke and how everyday life can change in the months and years thereafter.

Richard was previously employed in the public services sector and then became employed as a youth hostel worker in a joint appointment with his wife. Similarly to Paul, Richard also built his own house as a renovation project. Richard and his wife were both retired when Richard experienced his stroke. As Richard's stroke was experienced outside of the UK, Richard did not visit a UK hospital or doctor while he had acute symptoms. This meant that he was not registered with his doctor as having experienced a stroke. This resulted in a *"fight to get him treatment"* (Richard's wife: interview 1) when they returned to the UK. It was felt that this caused a delay in effective, timely treatment, which is essential for stroke recovery. Richard was also an active participant in his local community pre-stroke. However, Richard's lack of confidence post-stroke meant that he engaged less in local community activities. This lack of confidence stems from Richard's communication difficulties and highlights how an outcome of his stroke has impacted on Richard's everyday life.

6.1.6 Case Study 6

Jane lived alone in a three storey house. Jane experienced her stroke while on holiday in the UK in 2008, aged 32. Unlike Richard, Jane was registered in the UK statutory sector health service database and was able to receive treatment at the onset. Unable to communicate verbally

initially, Jane reported that over time she had regained some speech. Jane did not receive support from the lLocal aAuthority as it was not needed because she was supported by her local Stroke Club, her two sisters and her friends.

Jane reported that she found it hard to understand verbal communication on occasion, developed a stammer and experienced sentence-sequencing difficulties. Providing an example Jane informed:

> *"Sometimes if I'm tired I can't under er understand, or I can understand, but I can't tell you what I'm doing, you could ask me, I, would [stammer] make you a cup of tea but I couldn't explain it."*

<div align="right">(Jane: interview 1)</div>

This made the narrative element (phase 1) of the interview schedule short and the information given limited in subsequent discussion. However, the semi-structured and structured formats in phases 2 and 3 of the interviews with Jane allowed the author to ask more specific questions, to which Jane was able to provide answers.

Jane was previously employed at a local railway. Since her stroke, she had volunteered at a local charity shop and with her local Stroke Club (of which she was a former member in the early stages of her pre-stroke life). During her follow-up interview, Jane related that she had taken up more volunteer work and had begun volunteering at a local homeless shelter.

6.1.7   Case Study 7

Penny experienced her stroke while at home in 2009, aged 89. Penny's stroke resulted in her being paralysed from the waist down, having difficulty in moving both of her arms, and her being unable to straighten her back properly. This meant that Penny required caregivers to assist her in all aspects of her daily life. This care was delivered in her home, a warden-assisted bungalow, by professional paid caregivers who were employed by the local authority. Penny's daughter also assisted with all elements of personal care: shopping, eating, food preparation and household management. However, it is worth noting that when Penny was initially discharged from the hospital, her daughter was her sole care provider (discussed further in Chapter 9). As Penny's home was owned by the local statutory sector authorities, Penny was able to get

adaptions made to her home to make it more suitable for her specific care needs. Penny's house was already adapted to make it accessible for a wheelchair user. However, Penny was able to get her bathroom adapted and a hoist fitted into her bedroom and bathroom to assist her paid caregivers in manoeuvring her.

Penny's daughter was a single parent of dependent children and was employed part-time in the service sector. Penny's daughter reports that her friends provided emotional support when she became overwhelmed with her caregiving role. Similarly to Sarah's daughter and Paul's wife, Penny's daughter's employer had also been supportive in allowing flexible working when needed. However, whereas other caregivers report of family members being an avenue of support, Penny's daughter reported that her three elder siblings were *"less than useless"* (Penny's adult daughter: interview 1) which had left her to feel isolated in her caregiving role. This suggests that Penny's other children are perhaps unwilling to take on the caregiving role.

As discussed previously in Chapter 5 (Section 5.5.3.1), when the author contacted Penny's daughter by telephone to arrange a follow-up interview she learnt that Penny had been admitted to hospital. The author did not deem it appropriate to request Penny's daughter's participation in the follow-up interview as she sounded upset during the conversation and it was felt that it was not appropriate to make such request. The author later learned that Penny had died.

6.1.8   Case Study 8

Ruth experienced her stroke while at home in 2007, aged 71. Ruth reported feelings of fatigue, memory problems and reduced mobility post-stroke. Ruth also had osteoporosis and arthritis, which also contributed to her physical disability, highlighting that her reported difficulties were not all stroke related.

Widowed, Ruth lived alone in a warden-assisted ground floor flat. Receiving no support from the local authority, support was provided by two of her four adult children. Ruth's eldest daughter resided nearby whilst her youngest daughter resided with her husband over a two-hour drive away. Ruth left her paid employment before she experienced her stroke, to raise her four children. Similar to Richard and Jane, Ruth had taken on a voluntary committee member role for her local Stroke Club. Ruth's daughters reported that this role of responsibility encouraged Ruth

in her recovery as she was focused and motivated in running the Stroke Club, along with the other committee members.

Both of Ruth's daughters were employed part-time in the healthcare sector. They supported Ruth by doing her food shopping, assisting with paperwork and accompanying Ruth to her hospital appointments. Similarly to Sarah's daughter, Ruth's daughters had experience through their employment of providing care and considered it an advantage to them being able to support their mother.

During the time between the first and follow-up interviews, Ruth's home was flooded. This resulted in temporary living arrangements and a home refurbishment (discussed further in Chapter 9).

6.1.9   Case Study 9

Thomas experienced his stroke at aged 68, while living in Spain with his wife in 2007. During their first interview, Thomas and his wife reported that they felt that the UK had a better healthcare system than Spain and so chose to relocate back to the UK. Thomas and his wife purposefully chose a house that was near a GP surgery and public transport to have access to better healthcare provisions. Reporting that the Spanish healthcare system was not as effective for dealing with stroke compared to that of the UK, Thomas's wife suggested that the outcome of Thomas's stroke would have been better if physiotherapy treatment had been implemented from the onset, stating:

> *"We couldn't even get him out of bed before we came home."*
>
> (Thomas's wife: interview 1)

Thomas had a heart attack soon after he and his wife returned to the UK. He later reflected that the treatment for his stroke and its associated outcomes was only implemented following hospitalisation to treat his heart attack. This suggests that if Thomas had not experienced further health complications, he might not have been given treatment for his outcomes of stroke.

Stroke had resulted in Thomas experiencing post-stroke fatigue as well as neurological and physical problems, which affected both his memory and mobility. At the point of his first interview Thomas was receiving assistance from his wife in washing, showering, the application

of skin cream to treat a dry skin condition, and assistance in motivating Thomas to carry out his rehabilitative exercises. Thomas's wife reported that she found caregiving for Thomas and their own housework difficult as she experienced arthritis and back pain herself. During the follow-up interview Thomas's wife reported that a direct payment from the statutory sector had been set up, referred to by Thomas's wife as *"a cleaner's allowance"* which allowed them to employ a cleaner once a week, and that a paid nurse visited each day to assist Thomas with his personal care. The local authority provided this service after an assessment of the health of Thomas's wife and her caregiver needs (discussed further in Chapter 9). However, Thomas acknowledged that the difficulties they experienced were not all stroke related as he also had experienced other conditions such as osteoporosis.

Thomas and his wife received support from their two adult daughters who lived locally. Thomas and his wife provided an example of their daughters' support and explained that they had recently picked them up from the airport and cleaned the house before they came home. However, they also acknowledged that their daughters were both employed full-time in paid employment and support from them was, therefore *"not considered reliant"* (Thomas's wife: interview 1). The author also discovered that one of their adult daughters was a trained physiotherapist and had given Thomas exercises to do to help improve leg strength.

6.2   Chapter Summary

This chapter introduces the case study participants and highlights areas of similarity and difference between the cases. The case studies differ demographically regarding age, gender, and pre- and post-stroke lives. However, there are key areas of similarity and contrast not related to the demographic variations. For example, in terms of caregiving, the participant survivors from cases 1, 7, and 8 were cared for by their daughters which meant that they shared similarities between themselves, yet differed from the participant survivors from other cases (2, 3, 4, 5, and 9) who were cared for by their marital or cohabiting partners. Although there are similarities between all cases in that all the participants were living with stroke in their everyday lives, the cases have differences between them which make them unique and distinct.

Depth is added to the findings reported in Chapters 7, 8, and 9 through consideration of the participants' unique situations. This includes where they experienced their stroke (in the UK or abroad) and the impact that has had, as well as the employment status of the participant survivor

and caregiver, the relation of the caregiver to the survivor, and the implications which this may have had on the participants' everyday lives.

The background information provided by this chapter helps to provide context to the study findings. Such knowledge allowed the author to consider the unique circumstance of each case study when collecting the data and provided an opportunity to cross-reference the data with (and highlight) any contextual commonalities. For example, Sarah had a routine in place that supported her independence, as did Paul. By considering the case study demographic, the author can conclude that the sense of routine is individual to the survivors themselves and how they cope with post-stroke life, rather than a caregiving strategy trait of a survivor being cared for by their adult children. In other words, creating a routine is not unique to the caregiving situation where a survivor is being cared for by their adult son or daughter, and so there are other aspects to consider. This concept can again be cross-referenced with other aspects such as the outcomes of stroke, which enabled the author to identify that such routine behaviours are exhibited where the survivors have experienced sequencing or memory defects. There are other aspects to this, which are discussed in more depth later in Chapter 8.

7.0   Findings: Living with Stroke

This chapter primarily addresses research objective (1) to explore the everyday lives and experiences of survivors of stroke and their caregivers. It also contributes towards research objective (2) to identify key individuals and organisations that provide support to survivors and their caregivers in their everyday lives, whilst touching upon research objective (3) to explore how Stroke Clubs deliver support to survivors of stroke and their caregivers.

The findings discussed throughout the remainder of this thesis contribute to the existing literature by providing a deeper depth of knowledge and understanding through the report of the qualitative research findings. The existing literature as reported in Chapters 2 and 3 focuses on particular aspects of post-stroke life. Such themes included 'post-stroke depression', 'stigma and stroke', and, 'caring for stroke survivors'. Although these studies are valuable in their contribution to the existing knowledge base and provided a theoretical underpinning for this study, this thesis reports the findings of a study which considers all of these themes in relation to a consistent study sample through case study research. Therefore, the strength and contribution of the findings as reported in this chapter, along with Chapters 8 and 9, is that they report findings of multiple consideration; presenting the whole picture of life with stroke for the participants of this study, as reported by them. For example, as well as reporting 'life with post-stroke depression', the findings here also report the impact of such post-stroke depression upon other areas of the participants' lives. This is extremely valuable to academics and policy makers in understanding the complexity and uniqueness of the impact of stroke on a person's life, on a case-by-case basis. Furthermore, this insight into post-stroke life can provide a platform for further health and social care research and policy development.

Findings of the BNIM interviews are discussed throughout this chapter, with a focus on coming to terms with stroke and post-stroke life, mental and emotional wellbeing, feelings of stigma, and the positive perspective.

7.1   Coming to Terms with Post-Stroke Life

Post-stroke life in this context refers to the study participants' lives after stroke, in the months and years thereafter. The existing literature discussed in Chapter 2 informs of survivor and caregiver perceptions of post-stroke life. White et al. (2014) asserts that this is influenced in part, by if, and/or how well, they have come to terms with the stroke itself, and the impact that stroke has had on their physical and neurological state, and their everyday lives. The interviews with the survivor and caregiver participants allowed such reflection; of if and how well they had come to terms with their stroke and their post-stroke lives. Throughout Section 7.1 the feelings experienced, challenges faced, and the survivor and caregiver participants' perspectives of coming to terms with post-stroke life are discussed.

The sudden nature of stroke created several challenges for the survivor and caregiver participants at the outset. These challenges related to access to information, and support in taking on the caregiving role, both of which are discussed within this chapter.   However, the challenges faced were not isolated to the early stages of post-stroke life. They were also present in the longer term; in the months and years thereafter.

Both survivor and caregiver participants described how they had adapted to their post-stroke lives and caregiving roles during their interviews. The majority of the survivor participants described how they had changed the way they carried out everyday tasks in the home, while others had integrated a routine into their everyday lives (as discussed previously in Chapter 6). This suggests that an adaptive coping strategy (defined by Wallengren et al. (2008) earlier in Chapter 3 as finding ways to adapt to the new life) had been adopted, as they sought to plan such routines, or find ways to overcome any challenges they faced and complete tasks, whilst they aspired to partake in interests which they enjoyed prior to stroke. Meanwhile, the caregiver participants informed that they had planned their day, inclusive of the caregiver role, around the survivor's routine which had helped them to adjust to the caregiving role. However, this was not the case for all. One caregiver participant, Penny's daughter, reported that she had not adjusted to the caregiving role.   Penny's daughter stated that she found it difficult to take on the caregiving role alongside other family commitments of being a single parent to dependent children and sole breadwinner.

The survivor and caregiver perspectives are discussed in more detail throughout this section, with a focus upon how the survivor participants had come to terms with stroke, how caregiver participants had come to terms with the caregiving role and the different coping strategies which had been adopted. The coping strategies described throughout Section 7.1 are defined by the literature in Chapter 3 previous.

The survivor participants of this study stated that they had (at the time of the first interview) come to terms with their stroke. Seven of the participants from this study expressed content in their everyday lives, whilst Mark expressed that his contentment fluctuated as he experienced emotional highs and lows. Further to this, Penny informed that she was not content in her post-stroke life at all. Kuluski et al. (2014) state that those survivors who have not come to terms with their stroke, were more likely to be dissatisfied with their post-stroke lives.

Reflecting back upon Kuluski et al.'s (2014) study, their participants were under 55 years of age. This led the author to initially consider whether 'younger' survivors, as Kuluski et al. define as being aged 55 or less, are less likely than 'older' survivors to have come to terms with their stroke because their life goals are less likely to have been met. Although eight of the nine participants of this study were over 55 years of age making the sample differ from that of Kuluski et al.'s (2014) study, one participant Jane, was common with Kuluski et al.'s sample as she was 32 years of age. Jane expressed a good level of content in her everyday life, making her perception of post-stroke life also contrast with those reported by Kuluski et al.'s study. This highlights that coming to terms with stroke is not necessarily an age-related concept, but rather that whether or not a survivor has felt that have led a fulfilled life and met their life goals or expectations was actually the key factor. This statement is in sync with Krančiukaitė and Rastenytė (2006) and the WHOs (2014) assertion of perceived quality of life being related to a person's life goals and expectations and whether they have been met.

Further disproving age as a factor of whether or not someone is likely to come to terms with stroke, Mark (as previously stated) did not come to terms with his stroke initially, and he was over 55 years of age. The findings of this study actually highlight that living in a rural community where the survivor participants knew other people local to them was a key factor in adapting to post-stroke life as this reduced barriers to participation in the wider community as they felt confident in their local communities after stroke. This also contradicts rurality literature (discussed in Chapter 4 previous) which reports of rural living being isolating for vulnerable

people such as those living with a disability or the elderly. This notion is discussed further, in Section 7.8 and Chapter 8.

7.1.1   In Denial

Mark recounted that he was initially in denial when doctors had told him he had experienced a stroke. This reflects a trait of avoidance coping strategy as described by Gosman-Hedström and Dahlin-Ivanoff (2012) in Chapter 2 previous. This led to a refusal to accept treatment as well as feelings of confusion about what it was he was experiencing. Not wanting to accept that he had had a stroke, Mark would avoid socialising and seeing his friends. By avoiding seeing people who knew him before stroke, and not believing the doctors, Mark had opted to avoid the reality that he had experienced stroke, and in his words: *"that I have become disabled myself"* (Mark: interview 1).   During his interview 1, Mark attempted to rationalise his initial denial, and explained:

> *"Through my work, I had come into contact with some stroke people, and was familiar with the world of disabled people, and I think that the biggest shock to me, in my arrogance, is that I've become disabled myself. I'm that, so bloody arrogant, that I didn't think it could happen to me."*
>
> (Mark: interview1)

This statement from Mark truly emphasises the sudden unexpected nature of stroke and suggests that the acknowledgement of the stroke itself is a big step in coming to terms with stroke and adjusting to post-stroke life.

Mark explained how he later gained confidence through membership of a local Stroke Club, through socialising with other people who had also experienced stroke. This suggests that the coping strategies adopted may change over time. For example, an avoidance strategy may be adopted initially as the survivor struggles to accept that he had had a stroke, or a caregiver refuses to accept that there has been such a life-changing event. As time progresses, the survivor or caregiver may begin to accept the realisation that they are a survivor or a caregiver of a stroke survivor, and begin to adapt to post-stroke life; adopting the adaptive strategy in the months and/or years after stroke. This also highlights the value that Stroke Club provided Mark in reducing barriers to social participation by providing an opportunity for him to socialise with

other survivors of stroke. This helped him to come to terms with his stroke and his post-stroke ability.

7.1.2   A Period of Reflection

Reflection on the experience was considered to be an important factor in coming to terms with the uncertainties of post-stroke life. Paul, Mark, and Ruth felt that time had allowed for such reflection. The findings here contribute to the works of Bäckström and Sundin (2009), Boosman et al. (2011), Franze´n-Dahlin et al. (2007), Frankl (1963), Godwin et al. (2013), King and Hicks (2009), and Smith et al. (2009a) previously discussed in Chapter 3, by not only confirming that survivors of stroke typically adapt to life with stroke over time (as part of an adaptive coping strategy), but also highlighting that it is time which allowed for reflection. This enabled the survivor participants to come to terms with stroke. Mark demonstrated this as he recalled that time had allowed him to come to terms with the impact of his stroke, and adjust to post-stroke life. Paul and Ruth, on the other hand, reported that time had enabled them to reflect on the things that they could no longer do. This motivated Paul and Ruth to *"find other ways of doing things"* (Paul: interview 1), in order to be as independent as possible and discover ways of compensating for the things they could no longer do.

This presented the dynamic nature of time: time to take on board that stroke has occurred, helping towards psychological and emotional realisation; time to ascertain the extent of one's post-stroke neurological and physical ability; and time to establish what they may need to do differently, what they could no longer do, and what they were still able to do post-stroke.

To understand how a period of reflection can help to come to terms with stroke, reference must be made to the works of Frankl (1963), and King and Hicks (2009). In Chapter 2 previous, Frankl (1963), and King and Hicks (2009) assert that it is instinctive for survivors of stroke to attempt to rationalise their experience by applying meaning to the stroke itself, and reason to the uncertainties they may face. Both of which require reflection upon pre-stroke life and the event itself; stroke. The biographical nature of the interview process provided an opportunity for the survivor and caregiver participants to reflect on their experience, which they said, made the interview process a helpful and positive experience. The survivor participants each reported that they had led stressful pre-stroke lives and rationalised that such busy lives, they felt, had contributed to the onset of their stroke.

This study found that such reflection also enabled the survivor participants to consider their lives at present, and how they would aim to live their post-stroke lives:

> *"I won't give myself the pressure that I did, I won't have another one* [a stroke]*, I'm conscious that I could have. There are so many people in the* [Stroke] *Club that have had a second one; some people have several you see."*

<div align="right">(Ruth: interview 1)</div>

This realisation led to Ruth making a conscious decision to lead a less stressful post-stroke life in order to reduce her risk of further stroke or ill health.   This was also exampled by other survivor participants. Paul had started a diet programme to lose weight and eat a healthier diet, while John had joined a gym in order to become more active. These healthier lifestyle choices were a conscious effort to improve overall health and reduce the risk of further stroke. Mark felt that experiencing stroke meant that he had *"faced the concept of death"* (Mark: interview 2). Although he states that this did not scare him, Mark felt that his experience left him faced with the reality that there was a possibility of further strokes, which may result in further disability or even death itself. Similarly to Paul and Ruth, this realisation led Mark to *"re-evaluate* [his] *life"* (Mark: interview 2) and consider what was important to him. Mark reported that during the time of his life where he was coming to terms with experiencing stroke he had reflected upon his pre-stroke life and realised that he had spent too little time with his family and too many hours at work. Mark described such realisation as a positive aspect of stroke:

> *"One good thing about stroke is that it can be effective at looking at life and managing a different way in going forward."*

<div align="right">(Mark: interview 1)</div>

In acknowledging this self-reported realisation, Mark stated that stroke had taught him to value his life, and not take certain aspects of his life, such as time with his family, for granted. Feeling strongly about this, Mark reported that he had changed the way he considered his priorities in his everyday life post-stroke:

> *"I have found a new way in going forward."*

<div align="right">(Mark: interview 1)</div>

The other survivor participants where not so focused on the long-term. They tended to focus on one day at a time, talking no more than a couple of months ahead in their interviews. This further suggests the adoption of the adaptive strategy amongst the studies survivor participants.

7.1.3 Positive Thoughts

The survivor participants reported that positivity and focusing on the things they could do post-stroke was key to adapting to post-stroke life. This was also reflective of the participants describing themselves as survivors of stroke; they had survived a traumatic event and did not wish to describe themselves with negative descriptors such as 'sufferers' or 'victims' of the stroke itself:

> *"I am a survivor; I survived my stroke. I am not a victim of, or a sufferer. It just wasn't my time to die."*
>
> (Mark: interview 1)

Berges et al. (2012) describe 'being positive' as a coping strategy which minimises negative perception. Here, a context is provided. By referring to themselves as survivors, the survivor participants relinquished the negative terms 'victim' or 'sufferer' and therefore evoked a positive stance in their post-stroke identity.

Adopting a positive attitude encouraged Ruth to *"just get on with it"* (Ruth: interview 1); with her life post-stroke. While positivity helped the survivors come to terms with stroke and begin to rebuild their lives, they acknowledged that this was not always easy. This was due to the psychological and emotional impact which stroke had on their lives. The survivor participants made a conscious effort to focus on positivity in order to minimise any negative thoughts they felt in their everyday lives. Instead of focusing on what they were unable to do, they would focus on what they could do. Reflection on the stroke experience allowed the survivor participants to consider that their stroke had not affected them as much as other people who had experienced stroke. Penny reflected that *"at least I can talk OK, and think"* (Penny: interview 1), whilst others (Ruth, Mark, Jane, and John) commented that their post-stroke lives were not as bad as some survivors, as they had their families around them and they were able to 'get out and about'. However, Mark stated that despite aiming to focus on the positives, he often found himself dwelling on negative thoughts which resulted in him finding it hard to come to terms

with post-stroke life at times. When Mark was discharged from hospital, he had no desire to engage in the activities which he had participated in prior to stroke and withdrew from socialising in his local community and with his friends. The aforementioned period of reflection upon his experience and the realisation that he had experienced a stroke helped Mark to rebuild his life post-stroke:

> *"Today it's almost like I live in a world of the past, of old memories, some are happy memories, and some are not so happy memories, and most of the time I am able to disregard the unhappy ones and continue my life."*
>
> (Mark: interview 1)

Focusing on good memories and positive experiences helped Mark to come to terms with post-stroke life. This emphasises positivity as a strong influencer in recovery, and coming to terms with stroke and coping with post-stroke life. Despite being coined a coping strategy by Berges et al. (2012), the ethos of positivity was present in the participants' lives alongside other coping strategies. This suggests that in coping with post-stroke life, positivity can run parallel to other coping strategies in a survivor's post-stroke life. The notion of positivity is discussed further in Section 7.7.

7.1.4   An Inner Strength

The survivor participants reflected on their experience and informed that in coming to terms with stroke, they felt that they had discovered an inner strength that otherwise, they wouldn't have known existed. It was also felt that reflection on their experience had helped the survivors to gain a realistic perception of themselves post-stroke, which helped them to come to terms with the stroke itself. Part of this reality was formed by their awareness of the impact of their own stroke, compared to that of other stroke survivors whom they had met at Stroke Club. The feeling of an inner strength and overcoming something (stroke) which they thought they would never experience also contributed to the survivor participants' post-stroke perception of the self, and their realistic perceptions of stroke and their post-stroke lives.

Perhaps such inner strength was exerted because they also felt as though they had survived and experienced a life event which was like no other they had ever experienced.   By coming to terms with their stroke and gaining a realistic perception of the post-stroke self, the survivor

participants described how they had accepted that there were aspects of their lives, such as participating in activities they enjoyed and tasks around the home prior to stroke, which they could no longer do (discussed further in Chapter 8). Such activities included being able to go for walks and complete crosswords. Many of the survivor participants explained that the inner strength they felt had given them the motivation to compensate those activities which they had enjoyed pre-stroke and could no longer do, with other activities, and find alternate ways of completing tasks around the home. However, highlighting that this was not the case for all, Penny described how she was unable to find alternative ways of carrying out tasks and participating in activities due to the extent of her disabilities. This shows that post-stroke life is not as straightforward as adapting to post-stroke life by taking up new activities by way of compensation or doing things in a different way. For Penny, she had to accept that she could not partake in activities she used to, and that she was physically unable to find alternatives; to the extent that she had to accept (and come to terms with) that she needed support in all aspects of her everyday life, including those domestic tasks she once rendered thoughtless such as cleaning and hoovering, as well as personal care.

Coming to terms with stroke and coping with post-stroke life, perhaps better than one would expect, was linked to positive perceptions of the self post-stroke. The findings here contribute to Berges et al. (2012) who identified a similar phenomenon in their research, by also identifying a link between (1) coping well, (2) positive attitude and (3) positive perception of the self. However, the findings here build on this by highlighting that in the context of post-stroke life, (4) discovery of an inner strength, and (5) reflection of the experience were linked with those three aspects. Considering the quality of life literature reported in Chapter 3 previously, this further suggests that these five elements, established initially by inner strength and coping, to be linked to a positive perception of post-stroke quality of life, especially when a realistic perception of post-stroke ability is rationalised (through reflection and awareness of other possible outcomes) as less severe than it could have been. This actually led to the survivor participants feeling lucky in their post-stroke lives. This is discussed further in Section 7.8.

The findings suggest that adaptive strategies are not always formed straight away. Paul described feeling a sudden surge of motivation, which gave him an inner strength to try and complete tasks at home himself months after his stroke. This arose as he had had to employ workmen to come to his home to fix a door, something which he would have been able to do himself prior to his stroke. This motivated Paul to find ways of carrying out such tasks himself, demonstrating how an adaptive coping strategy was implemented.

As previously asserted in Chapter 3, Krančiukaitė and Rastenytė (2006) and the WHO (2014) consider that individual perception of quality of life is made up of, in part, a person's own perception of their own life expectations, and whether or not their goals in life have been met. Here, such reflection had assisted the survivor participants in building a sense of post-stroke life which they felt was realistic. While it cannot be disputed that stroke is life-changing and can potentially lead to an impact on the life goals and expectations of its survivors, the author considers two probable scenarios: (i) in coming to terms with stroke and post-stroke life and re-evaluating their lives, perhaps more or different life expectations and goals were set post-stroke, or (ii) life goals set pre-stroke had been exceeded regardless of the impact of stroke on their everyday lives. Either of these scenarios suggests that although perceptions of quality of life may decrease when someone experiences stroke initially, a participant's perception of their quality of life may actually increase between the early stages of post-stroke life and periods of time where they are living with stroke in the months and years thereafter. Therefore, coming to terms with stroke and adapting to post-stroke life by exerting an inner strength that they did not know they had meant that the survivor participants considered themselves to have had exceeded their own expectations for themselves in their post-stroke lives.

The author does ponder whether such inner strength is something that we as human beings instinctively have and do not necessarily exercise until we find ourselves in a situation where we experience something in our lives which requires it. Such occasion may be the onset of stroke, or another life-changing condition such as cancer, or perhaps disability as a result of an accident. However, in this context such inner strength was exampled by the way the study participants had coped with their post-stroke lives – the full extent of which is not merely described in this section; it is evidenced throughout the findings chapters and drawn upon in the concluding chapter, Chapter 10.

7.2   Taking on the Caregiving Role

Stroke caused a variety of changes to the everyday lives of caregiver participants as well as those who had experienced the stroke itself. This confirmed the findings of Davies and Honeyman's (2013) and Gaugler's (2010) studies reported in Chapter 2 previously. These changes varied considerably depending on the support needs (albeit physical, psychological or emotional) of the survivor, the relationship between the survivor participants and their caregiver, and the personal circumstance of the caregiver.

There were some differences identified between those case studies where the caregiver was the partner of the survivor and those case studies where the caregivers were the adult children of the survivor. During their interview, spousal caregivers stated that they admired the way their partners had come to terms with their post-stroke lives. Paul's wife expressed that Paul had come to terms with stroke, and *"he never says 'why me?' or anything"* (Paul's wife: interview 1). This presents a contrast to the existing literature as survivor participants from Yu et al.'s (2013) study were reported to often question 'why has this happened to me?'.

However, the reality for both Sarah's and Penny's daughters was that they felt as though *"everything* [had] *changed"* (Sarah's daughter: interview 1). During their interviews, the caregiver participants reflected on the changes to their everyday lives. The participants of this study who were caregiving for a parent informed of a change in employment patterns and their ability to manage other commitments and family life, alongside the caregiving role, whereas the spousal caregivers reported changes to their role and tasks within the home. This demonstrates how caregivers often lead multi-role lives of spouse and caregiver, or daughter, caregiver, and mother. Some of the caregivers also reported a role reversal (discussed further in Chapter 8, Section 8.4.1.3). For Paul's wife, this meant her carrying out manual tasks at home, as she was sometimes asked to by her husband Paul, who before stroke would have been the person she went to if something needed to be fixed. For Penny's daughter, this meant her looking after her mother Penny; whereas before stroke Penny was the one who helped to look after her grandchildren.

Those caregivers who were providing care for their parents were supported at home by their families, who took on tasks around the home which the caregiver may have done prior to taking on the caregiving role. Such tasks included the preparation of family meals at home; however, it is worth highlighting that there is not always a second adult in the homes of the people who are providing care for a parent. As previously mentioned, Penny's daughter, for example, was a caregiver to her mother (who resided at her own home elsewhere) and was also the breadwinner for her family and a single parent of dependent children. Penny's daughter did not receive support at home from other family members and therefore did not receive informal support as Sarah's daughter (who lives with her husband and adult son) did.

Each of the caregiver participants reported that the caregiving role had also impacted on their level of social participation (discussed further in Chapter 8, Section 8.4). The survivor's stroke

had changed the everyday routines of the caregiver's lives and contributed to emotional strain and burden as the caregiver participants felt that they had little or no free time to themselves. A lack of physical space and thinking space was also reported.

The caregiver participants also experienced changes to their life goals and expectations – which Krančiukaitė and Rastenytė (2006) and the WHO (2014) claim influence a person's perception of their quality of life. An example of this was provided when the wives of John and Thomas both reported that the loss of their husbands' driving capability was a considerable challenge. Describing this as *"the greatest difficulty"* Thomas's wife asserted:

> *"That certainly meant us coming back from Spain."*
>
> (Thomas's wife: interview 1)

This indicates that other than there being a better healthcare system in the UK (as previously mentioned in Chapter 6), the poor public transport provisions and poor access to services which existed where they resided in Spain contributed to the need for Thomas and his wife to return to the UK.

John's partner expressed frustration about the change in John's abilities post-stroke. Driving herself as John was unable to drive post-stroke, John's partner experienced an added strain as she was not a confident driver. Furthermore, John was also unable to work post-stroke which John's partner considered to be a key factor in adjusting to post-stroke life. Describing the transition into post-stroke life as *"a stressful time"* (John's partner: interview 1), John's partner reflected that John's unemployment resulted in financial concerns due to a drop in household income. This confirms that changes to everyday life can also cause strain to the caregiver's aspects of their lives which are independent of the caregiving role, not just challenges which are a by-product of the caregiving role itself.

However, the caregiver participants shared the same ethos as the survivors and reported that they had a tendency to carry on with life:

> *"Things just become routine, you just accept it as that's the way it is now."*
>
> (Penny's daughter: interview 1)

Reflecting on the feelings of strain, burden and grief experienced as a result of the time constraint and changes experienced by taking on the caregiving role, Penny's daughter

commented: *"I hate it"* (Penny's daughter: interview 1). Particularly, in regards to seeing her mother become less independent as a result of her stroke.

In Chapter 2 previous Bäckström and Sundin (2009) highlighted the unexpected nature of the caregiving role. This was highlighted by John's partner:

> *"He's ten years younger than me so I wasn't expecting to have to end up looking after him, I thought he'd be looking after me in my old age."*
>
> (John's partner: interview 1)

For the caregiver participants, coming to terms with stroke and post-stroke life meant that they sought to understand what stroke was, how it occurred, how it would impact on the survivor participant's life, and what they would need to do in their caregiving role. This augments upon Frankl's (1963) and King and Hicks's (2009) theories discussed in Section 7.1 previously. The findings show that it was not solely the person who has experienced the life-changing event (in this context stroke), but also the family members transitioning into the caregiving role who sought to apply meaning to the life event, stroke - and rationalise the experience. The author acknowledges that this is a small research sample, however with this notion of seeking to apply meaning in order to come to terms with the caregiving role being dominant among it, she advises further research in this area. This also conflicts with Bäckström and Dundin (2009) who report that caregivers are reluctant to seek support in their caregiving role; the caregivers of this study expressed explicitly that they actively sought support.

The data revealed the challenging nature of the transition into the caregiving role:

> *"Nobody can predict at that [acute] stage, the level of potential disability and because of this, there was no preparation for whatever the outcome may be."*
>
> (Ruth's youngst daughter: interview 1)

This supports researchers Kuluski, et al. (2014), Girgis et al. (2013), McKevitt et al. (2011) Thompson and Ryan (2009), Vincent et al. (2009), and Yu et al. (2013) who affirmed that family members are often placed into a caregiving role with no prior support or knowledge.

Contributing to this knowledge, case study research allowed the author to discover the impact of this on the caregivers' lives. A lack of available information led to the caregiver participants

feeling as though they did not know how best to support survivors in their post-stroke lives. The wives of Paul and Thomas, Penny's daughter and John's partner felt there was a lack of information available to them: *"I knew nothing about stroke"* (Penny's daughter: interview 1).

As a result of this, John's partner reflected that not knowing what to expect contributed to feelings of fear and anxiety:

> *"The scary thing about it was I didn't know anything about it, what to do, what to expect."*
>
> (John's partner: interview 1)

John's partner also expressed feelings of loneliness:

> *"I really felt I was coping on my own."*
>
> (John's partner: interview 1)

This emphasised a key area of caregiver support need, produced by the research data. However, on the other end of the knowledge spectrum, Paul's wife also reported *"a sudden rush of fear"* (Paul's wife: interview 1) she felt when she learned of her husband's stroke. This fear was founded upon her previous experience as a caregiver to her late mother who had also experienced stroke. This notion of fear from the known entity of stroke is discussed further later in Section 7.3.3.

Summarising her experience of transitioning into the caregiver role Penny's daughter stated:

> *"You go into this totally blind and nobody tells you a bloody thing."*
>
> (Penny's daughter: interview 1)

Penny's daughter also felt that she would have benefitted from knowing more about what to expect when her mother was discharged from hospital:

> *"It would have been helpful for there to be more communication with people who know what to expect when she came out of hospital."*
>
> (Penny's daughter: interview 1)

Rationalising why this would have been beneficial, Penny's daughter explained that *"because Mam was in hospital for over three months"* (Penny's daughter: interview 1) it would have helped her to prepare for the caregiving role and given her an opportunity to have made necessary arrangements for her mother's return home. Penny's daughter felt unprepared for her mother's return home. This challenge was made greater by the delay in the local authority services making necessary adaptions to her home (discussed later in Chapter 9). The findings here show that there is a need for information in relation to the possible outcomes of stroke, arrangements to be made at home, and what to expect in the caregiving role prior to the survivor returning home. Such information could be provided by hospital staff and/or statutory sector services. However, Penny's daughter emphasised that she wanted to learn from people who had gained first-hand experience of stroke and the caregiving role. This suggests that the advice and information received from people with first-hand experience is considered more valuable than advice distributed by professional staff. This also confirms claims reported by Burholt and Dobbs (2014) and Wilson et al. (2007) (quoted earlier in this chapter), that caregivers often seek advice from social avenues of support such as community-run support groups or family and friends, rather than professional services.

However, the findings of this study contribute to the existing knowledge by highlighting Stroke Club as an effective avenue for such support. The perceived value of learning from people with lived experience supports the notion of caregiver support provided through support networks such as Stroke Clubs. The findings show that they provided an avenue of support and information sharing for both survivors and caregivers, giving caregivers the opportunity to meet other caregivers and share their experience, whilst also providing a social outlet. By providing a substantial amount of support for survivors and caregivers, Stroke Clubs created a valuable contribution to people living with stroke in their everyday lives; both survivors and caregivers. While the participant perspectives of Stroke Club are discussed throughout Chapters 7, 8, and 9, Stroke Club delivery is discussed further in Chapter 9.

Such support was considered extremely key by the caregiver participants in coping with their post-stroke lives. The existing literature informs that when caregivers gain knowledge of stroke and are able to learn about it, they often experience a reduction in angst (Franze'n-Dahlin et al. 2007; Kuluski et al. 2014), uncertainty, fear and distress (Vincent et al. 2009; Visser- Meily et al. 2005:2006:2008), and depression (Godwin et al. 2013; Visser-Meily et al. 2005:2006:2008). This highlights the value of such support for caregivers in their everyday lives. In turn, this is said to promote a more positive perception of caregiver quality of life (Larson et al. 2008;

Schlote et al. 2006; Yu et al. 2013), a decrease in anxiety levels (McCullagh et al. 2005), and more efficient caregiving (Yu et al. 2016). However, the findings of this study show that due to the complexity of stroke and the caregiving experience, these reductions and contributions to perceived quality of life cannot be assumed as fact for all cases. For instance, the existing literature reports that fear of the unknown entity of stroke can contribute to feelings of anxiety, strain and worry. This was disproved in the case of Paul's wife who, as previously mentioned, reported that the fact she knew about stroke and its potential impact actually contributed to feelings of fear and angst rather than reduced it. What the research findings tell us here is that fear of the unknown is exampled, but not necessarily in the way the existing knowledge base portrays. Here, fear was closely linked to feelings of anxiety, and related to not knowing how to care for the survivor in the future, and feelings of being alone in the caregiver role, rather than fear of the stroke itself. The caregivers of this study actively sought information about stroke as they wished to learn how to best support their survivor:

> *"It was a sudden change, and I had never come across stroke before but had to learn myself, how to toilet Mam, no, nobody tells you anything, what to expect, nothing, there's no actual information."*
>
> (Penny's daughter: interview 1)

Penny's daughter actively sought statutory sector advice because she did not have any informal avenues for support. However, she did not receive the information or help she needed:

> *"There wasn't no training or anything, in lifting her to the bathroom, nothing at all."*
>
> (Penny's daughter: interview 1)

Penny's daughter was frustrated during the interview and emphasised that she would have considered it beneficial to have been given more information and/or training about how to provide care for her dependent mother, as well as more support in preparing for the caregiving role alongside her other commitments; looking after her dependent children and continuing her employment. Penny's daughter was fearful for the future, in relation to how she would learn to cope and care for her mother in the most effective ways. This fear stemmed from being isolated in the caregiving role and feeling a lack of support from professional statutory sector services. This fear was not necessarily fear of the unknown entity of stroke as the literature suggests; more of a 'what do I do now' ethos. The notion of fear is discussed further in Section 7.3.3.

The findings here identify a weak area in health and social care policy in relation to supporting self-care in the home and supporting families in providing care at home. This is a cause for concern as this is a key aim of healthcare policy initiatives across the UK, as discussed in Chapter 4 previous. This lack of available information was a cause of stress and strain for the caregivers of this study (Penny's daughter, John's partner and Thomas's wife) as they transitioned into the caregiving role. This lack of information also inhibited the caregivers' awareness of what they were entitled to in terms of statutory sector care and financial support, confirming the findings of Johnson and DeSouza's (2009) study discussed earlier in Chapter 2. This meant that Penny's daughter did not have the help that she was entitled to from the onset, further highlighting a possible weakness in the access and delivery of support services to caregivers. This further supports the notion of caregivers being 'active seekers' of information, and feeling a lack of acknowledgement or assessment of their caregiving ability or preparation for the role, as reported by Thomson and Ryan (2009) earlier in Chapter 2.

Paul's wife proposed a recommendation for:

> *"An idiot-proof pack, written in layman's terms telling you about the possible outcomes of stroke, who to talk to, how to get help, what to do."*

(Paul's wife: interview 1)

Paul's wife suggested that this pack could be distributed to close family members of people who had experienced stroke so that they were aware of what stroke was and were able to prepare for post-stroke life. Further details of this pack can be seen overleaf.

Compiling data collected from the caregivers, it is proposed that such a pack could include:

- Facts about stroke
- The possible outcomes of stroke
- Challenges the survivor may face in the future
- What stroke means for family members – transition into the caregiving role
- Challenges that caregivers may face
- Practical advice in relation to forms and documents
- Driving assessments
- Benefits and financial entitlement
- Statutory sector support entitlement
- Employment rights
- Practical caregiving advice
- Helping to eat or drink
- Nutrition
- Physical lifting
- Personal care
- Sources for more information, guidance and support

The author acknowledges that a pack such as this would need to be broad and generic due to the unique nature of the outcomes of stroke. However, despite stroke resulting in unique and individual outcomes a generic pack would still act as a source of information which would inform about stroke itself (to help the reader rationalise the experience), possible outcomes (for caregivers to understand what the possible outcomes may be) and act as a signposting pack for more information and support services.

The author wishes to stress that this recommendation is based on the perspectives of the participants of this study. Therefore, if a pack such as this exists, it had not been received by the participants.

The issues raised by these findings have since been acknowledged by the Welsh Government and addressed in their 2012 Stroke Delivery Plan for Wales (Welsh Government 2017). This plan was implemented during the data collection stages of this study. The findings from this study suggest that the aims of the 2012 Stroke Delivery Plan: to support survivors in their local communities and to improve caregiver experience is an appropriate focus for the strategy.

However, this study further informs the statutory sector by providing recommendations for developing efficient and effective policy further, particularly in relation to support initiatives, implementation, and delivery of stroke policy.

Despite there being more focus on survivor and caregiver support in recent years, this research evidences that there is still scope for further improvement: at the time of data collection for this study, the existing needs were acknowledged but were still failing to be met. The findings discussed throughout this section also highlight a need for an integrated discharge strategy for those who have been in hospital for a long period of time. Such integrated strategy should assist the survivor in returning home by encouraging independent living, and participation in the home environment and wider community. However, there is also an opportunity here for a support package which helps prepare family members for the caregiving role. These recommendations are discussed further in Chapter 10.

7.3   Mental and Emotional Wellbeing

The impact of a sudden life event such as stroke not only has a profound effect on the individual who experienced it, but also their family and friends. The findings previously reported in Chapter 6 and Section 7.1 focused on the physical impact of stroke and the physical changes that had been experienced by the participants in their everyday life, such as a change in physical ability and/or paralysis. However, these changes, along with the experience of having a stroke itself, had impacted significantly on the mental and emotional wellbeing of the study participants.

7.3.1   Survivor Perspective

Ruth asserted that she felt content in her post-stroke life stating:

> *"I'm quite happy…….being on my own. I never get lonely."*

(Ruth: interview 2)

Part of Ruth's contentment came from her *"keeping busy"* (Ruth: interview 2). As previously stated, although survivors expressed that they were generally happy with in their everyday lives,

this perspective was not shared by all. Penny expressed discontentment in her everyday life, and described her daily routine:

> *"I'm put in the hoist out my bed, moved in here* [the living room] *in the* [living room] *chair for the day, then back again. It's no life really; all I've got is this, I'm fed up to the back teeth."*

<div align="right">(Penny: interview 1)</div>

Confirming findings of studies conducted by Godwin et al. (2013), Hackett et al. (2005), Hayhow et al. (2014), the National Institute of Neurological Disorders and Stroke (2008:2016) and Wilson et al. (2007) which define depression as a common outcome of stroke and a mental health issue which impacts on a person's emotional wellbeing, the survivor participants of this study expressed that they had felt depressed at some point in their post-stroke lives. They informed that these feelings were linked with fatigue, and asserted that being positive motivated them to 'keep busy' and occupy themselves mentally to overcome those feelings. Mark described feeling as though he was living in a *"deep* [state of] *depression"* in the early years of his post-stroke life. Describing a typical day at that time Mark described:

> *"I'd be sitting in a chair; my wife would be at work. She was now the breadwinner. I'd lost my business; I couldn't function my business. She'd come home, and I'd be crying. I'd be crying, and I'd be tired, and I'd go off to sleep, so basically I was fit for nothing."*

<div align="right">(Mark: interview 1)</div>

Mark expressed that he felt 'helpless', which the Department of Health (2007) and Tsang (2003) consider being a common feeling post-stroke. Mark also had a strong desire to be *"left alone"* (Mark: interview 1). This contributed to Mark's resistance to seeing his friends as mentioned earlier, as he would try and stay away from the wider community:

> *"People started coming around and knocking on the door…….. I wouldn't answer the door to anyone."*

<div align="right">(Mark: interview 1)</div>

Such feelings, of wanting to stay away from the wider community as reported by Mark, confirm the findings reported by Kitzmuller et al. (2012) and McKevitt et al. (2011) in the existing literature. However, the findings inform that survivor participants had become more social over

time (since their early post-stroke life). The participants stated that having a familiar local community and being a member of a Stroke Club supported them due to the participants feeling safe in a familiar environment, or an environment where other members had had the same experience. This supports the aims of the Stroke Association's (2015b) 'Together we can conquer Stroke 2015-2018 strategy' and highlights ways in which social enterprise can support survivors and caregivers in their everyday lives. In fact, the findings of this study show that Stroke Clubs go beyond the aims of the Stroke Association in supporting caregivers as well as survivors of stroke. Interestingly, Mark explained that despite becoming more sociable, the feelings of depression which he experienced did not completely disappear. This emphasises how depression can feel like a constant battle of the mind; trying to keep positive and active, in a sense fighting the negative self against the positive self. Therefore, survivor emotional and psychological wellbeing can be considered as changeable over time, rather than something which improved with time. This was evidenced in the follow-up interviews as Thomas and Mark reported feeling increased stroke fatigue than they did at the time of their first interviews, which Mark felt had led to *"more bouts of depression"* (Mark: interview 2).

This emphasises the importance of supporting survivors in achieving and maintain a good level of psychological and emotional wellbeing in their everyday life. This would also reduce the risk of depression and the outcomes that depression itself brings, such as self-exclusion, feelings of loneliness, isolation, and helplessness.

Mark felt that mixed emotions made it hard for him to gauge social situations. Giving an example Mark explained that sometimes he *"craved human contact"* (Mark: interview 1), and at other times he wanted to be alone. Mark also informed that due to the neurological impact of stroke, he found it difficult to gauge appropriate actions in some social situations:

> *"Sometimes just I want say* [a] *cuddle, but because the other person can get offended or the wrong impression you have to physically keep your distance."*
>
> (Mark: interview 1)

This was also observed during Stroke Club observations as some of the members of the Stroke Clubs seemed over-familiar, and would hug the observer and new members when they first met. The host explained that this was a common post-stroke trait. As stated previous, the Stroke Clubs created an environment where the survivor participants did not feel that they had to worry about such challenges as they were in an environment where they were surrounded by people who they felt understood them, and such behaviours.

The contradiction of Mark feeling as though he wanted to be left alone one minute and then seeking human contact the next, really emphasises the challenge in dealing with mixed emotions. This was emphasised through Mark's and Ruth's beliefs that people in the 'outside world', external to their home environment, did not understand stroke (discussed later in Section 7.6). This had become a barrier to social participation for Mark in the external environment. This demonstrates how psychological and emotional challenges can lead to survivors building their own barriers to social participation in a response to their perceptions of the world around them. The observation findings reported here further show how Stroke Club provided a social outlet for the survivor participants where they would be surrounded by people who are living with the shared experience; thus reducing barriers to social participation. As well as Stroke Club, support from the statutory and third sectors in reducing such barriers to social participation could contribute to a better perception of the outside world and improve mental and emotional wellbeing. This could potentially improve the survivors' own perceived quality of life. Dealing with such conflicting emotions can create further emotional strain for the survivor, but also impact on the caregivers and family members and their relationships. The notion of social participation is discussed further in Chapter 8 (Section 8.4).

7.3.2   Caregiver Perspective

As stated previously, Penny's daughter hated being a caregiver. However, the other caregivers did not share the same feeling. Penny's daughter did not express this as reluctance to care but more as a statement of the emotional strain of seeing her mother in her post-stroke life, and the challenge of leading a multi-role life. Penny's daughter commented:

> *"I work full time, I'm a single parent, and I have now become a carer for my mother as well, and I hate it. I struggle now I do; I hate it."*
>
> (Penny's daughter: interview 1)

However, despite the other caregiver participants not reporting that they hated the caregiving role, ultimately in the long term, the mental, physical and emotional strain expressed by the caregiver participants could potentially have a dramatic impact on their mental and physical health. This was demonstrated by the caregivers of Prescho's (2008) study discussed in Chapter 2.

As previously discussed in Chapter 6, Sarah was discharged from hospital on the proviso that she lived with her daughter on a temporary basis while she awaited a more suitable place to live. Sarah's daughter stated that this situation was a cause of strain for other family members as Sarah was sharing a twin room with her teenage grandson:

> *"It wasn't fair [on him] really because she was asking: 'Where are you going? How long will you be? I'm going to bed now it's only 8 o'clock, but I want to go, are you going to bed now?'."*
>
> (Sarah's daughter: interview 1)

This placed psychological strain on the grandson and infringed on his privacy. However, considering how the family as a whole coped with the situation, Sarah's daughter reflected:

> *"It wasn't really suitable, but you managed knowing that there was something at the end of it."*
>
> (Sarah's daughter: interview 1)

This suggests that the foreseen positive outcome and the temporary nature of the situation had helped Sarah's family to adapt to their new circumstances, demonstrating how positive attitude can help caregivers to cope with difficult situations. Furthermore, where the situation was deemed permanent, burden and strain felt by caregivers may be considered greater. This was the case for Penny's daughter who acknowledged that the permanence of her mother's physical disability meant that their situation would not improve, stating: *"this is it!"* (Penny's daughter: interview 1). The findings here highlight a relationship between there being no perceived future improvement of the survivor's outcomes and greater feelings of the caregiver's emotional burden and strain, regardless of the level of statutory sector support from care services they received in their everyday lives. The author considers that in the case of Penny's daughter an element of this is the emotional impact of her observing how stroke had impacted upon her mother's everyday life; she sees her mother as a different person since stroke:

> *"She has no dignity; she's lost her independence."*
>
> (Penny's daughter: interview 1)

7.3.3 Feelings of Worry, Fear Anxiety and Uncertainty

There was an overall feeling of concern and anxiety expressed by the caregiver participants in their everyday life, of which fear was an element. As Chapter 2 defines, fear can be an emotional response to confusion and uncertainty. Fear can also result in anxiety and may impact upon a person's perception of the self and a person's ability to come to terms with their stroke. The findings identified that there was a lack of information which confirmed the findings of McKevitt et al.'s (2010) study, and emphasised that this is an on-going issue. As previously stated, this contributes to the notion of fear of the unknown entity of stroke, which Girgis et al. (2013) found to lead to feelings of fear, uncertainty and anxiety among participants about what might happen in the near and distant future. However, as previously stated the findings in this study contribute to the existing literature by highlighting the effect of fear of the known entity of stroke on the anxiety levels of a caregivers' everyday life. Paul's wife's fears and concerns were grounded upon her past experience of being a caregiver for her mother who had experienced a severe stroke: however, she reflected that Paul's stroke was *"not as bad"* (Paul's wife: interview 1).

> *"I suppose when it happened it wasn't as big a shock to me as it would be to most because I had….., my mother started having strokes when I was 13, so of course I have experience of stroke, so it wasn't an unknown entity, but unfortunately also the bad side of that was the fact that I knew what the results of stroke could be, er, because she was just a vegetable in a chair."*

(Paul's wife: interview 1)

Paul's wife recalled feeling a sense of relief once Paul's stroke was diagnosed:

> *"Once that had been diagnosed as a clot rather than a bleed I knew it was different from Mum's."*

(Paul's wife: interview 1)

The known entity of stroke had initially created an element of fear and apprehension for Paul's wife who reflected and drew upon her past experience. This fear was reduced once she learnt that Paul's stroke was, in her words, "less severe" than her mother's.

The survivor participants tended to report feelings of worry, fear and uncertainty in their external environment (outside of the home, in their local community and wider society) whereas the caregiver participants reported feelings of worry, fear and uncertainty in their internal environment (inside of the home, inclusive of close family relationships). Richard's wife informed the author that Richard expressed anxiety outside his home environment, stating that Richard did not feel safe *"anywhere but home"* (Richard's wife: interview 1). This implies that Richard feared for his safety in the external environment which impacts his participation outside of the home in both his local and wider community. This supports earlier discussion about Mark who reported that he wanted to stay away from the outside world because he felt that the outside world did not understand. This is discussed later in Section 7.6.

In contrast, fears reported by caregivers related to the internal environment and included that of safety in the home. Sarah's daughter was concerned about her mother cooking as on one occasion Sarah forgot to turn off the cooker. Sarah's daughter explained that when Sarah first resided in the bungalow post-stroke, Sarah would cook her own food, however, Sarah's daughter became concerned when she:

> *"walked in and couldn't see with black smoke……Mam was sitting in the dining room eating a boiled egg, the ring was on, the grill was on she'd done toast under the grill and Mam hadn't put anything off."*
>
> (Sarah's daughter: interview 1)

This demonstrates how Sarah's memory problems impacted upon her post-stroke life. Similarly, Paul's wife stated that she worried about Paul when he was cooking due to his aforementioned sequencing difficulties. However, when she returned to work after having a break in employment when Paul had his stroke, Paul's wife (interview 1) reflected:

> *"Well I thought, everybody's keeping an eye on him, so I didn't need to worry, but that helps."*
>
> (Paul's wife: interview 1)

This emphasised the value of support within their local community, which is further discussed in Chapter 9.

Penny's daughter expressed concern for her mother's safety in relation to visitors to the home, as Penny would let people into the home via an electric door release without querying who they were. This is because Penny was so used to different professional carers coming to the home each day. Penny's daughter commented: *"she'll just let anyone in"* (Penny's daughter: interview 1) and reflected that if a stranger came into the home:

> *"Because she is as disabled as she is, she wouldn't be able to do anything about it."*
>
> (Penny's daughter: interview 1)

This was observed by the researcher as upon pressing the doorbell to Penny's home the door was released by the survivor without any question as to who was at the door.

Expressing further concern for Sarah being home alone Sarah's daughter reflected:

> *"She does get up in the night, she could fall during the night, and she will not use the assistance alarm."*
>
> (Sarah's daughter: interview 1)

Sarah's daughter reported feelings of frustration and concern which stemmed from Sarah keeping her assistance alarm on her bedside table; Sarah was at risk of potentially falling and not being able to reach the alarm to call for assistance. This contributed to feelings of anxiety. Sarah's daughter further expressed that:

> *"People have tried to talk to her, she won't even put it* [the alarm] *in her pocket in the day; she thinks that if she falls somebody will know; but we won't know."*
>
> (Sarah's daughter: interview 1)

Fear in this context contributes to caregiver anxiety and uncertainty. Although these concerns may be speculative, over time these fears can result in increased stress within a relationship and emotional distress as caregivers become protective of the survivor. This confirms the findings of Morris et al. (2014) reported earlier in Chapter 2.

The caregiver participants also expressed a fear of further decline in survivor health and the safety and physical and psychological wellbeing of the person they care for. This was demonstrated by John's partner being concerned about a future decline in John's health as he had

epilepsy which was brought on by his stroke: *"he might have another epileptic attack"* (John's partner: interview 1). Thomas's wife expressed concern about the possible further deterioration of Thomas's physical ability which included his arthritis, while all caregivers were concerned about the survivor experiencing a further stroke and the impact that a further stroke may have. This confirms the work of Haley et al. (2009), Morris et al. (2014), Lawrence (2010), and Laurence and Kinn (2013) who identified that it was common for caregivers of survivors of stroke to be concerned about a further decline in health.

Survivors Mark and Ruth also expressed concern about experiencing a further stroke, particularly Mark who suggested that he had come to terms with that possibility of a further stroke, and the possibility that that may result in death: *"I'm not afraid of death or dying"* (Mark: interview 2). As previously stated, Ruth addressed her concerns by opting for a less stressful lifestyle to reduce the risk of a reoccurring stroke. This confirms claims by Haley et al. (2009), Lawrence (2010) and White et al. (2014) who assert that fear of recurring stroke is common amongst stroke survivors.

Mark felt that his personality had changed since his stroke, and he feared experiencing a further change in personality (discussed further in Section 7.4). This fear stemmed from Mark being concerned that he may one day become aggressive as he had heard that some survivors did so over time. Mark stated strongly that he was against any act of any person which could potentially harm another person in any way, which provided a rationale for his fear. These feelings extended to Mark having deep concerns about what may happen to his body when he died. During his follow-up interview, Mark strongly expressed that he did not want any of his organs to be donated as he feared that they could be given to someone that he would consider to be a bad person. Mark expressed that these fears were founded on the overarching fear that he may one day lose control over his body, or the ability to communicate his wishes should his health decline in the future.

7.3.4   Caregiver Feelings of Frustration and Feeling Restricted

The caregiver interviews told of the strains and burden of caregiving. One could assume that the more severe the outcome of stroke is, or the less professional caregiving support received, the more strain and burden would be felt. However, this was not the case. The caregiver participants reported burden and strain in different areas of their everyday life, regardless of the

impact of stroke and the support provided by professionals. Furthermore, caregivers talked about the physical aspects of caregiving which contributed to feelings of burden and strain that in some cases were relieved by professional care services and respite care. Caregivers also reported the emotional strain they had experienced in their everyday lives.

Those caregivers who were either adult children or spouses of the survivor participants who were also employed expressed that when they were away from home and the survivor they were not able to detach themselves from the caregiver role, regardless of any service provision in place. This contradicts Bäckström and Sundin's (2009) theory that caregivers often considered being away from the survivor for a period of time, such as for employment, as a break from the caregiving role. The caregiver participants who were the adult children of the survivors and those caregivers who were employed spouses of the survivors of this study felt that the survivors were *"fully dependent"* (Sarah's daughter: interview 1) on them. Sarah and Penny's daughters reported feeling as though they always had to be 'there' for their mothers. This confirms Bäckström and Sundin's (2009) claims (reported earlier in Chapter 2) that survivors would unintentionally put up barriers to caregiver 'time-out':

> *"Because of the way she is, she doesn't think I have a life, and she thinks that I am there now, totally at her beck and call."*
>
> (Penny's daughter: interview 1)

Reflecting on life pre-stroke, Sarah's daughter reflected:

> *"I felt I used to have the freedom then* [prior to mother's stroke] *more than I have now."*
>
> (Sarah's daughter: interview 1)

Highlighting that these caregiving constraints were also experienced when the caregiver was not physically with their parent, Sarah's daughter commented:

> *"I'm constantly leaving my mobile on just in case they want something. Is my mobile on just in case? 'In case this' all the time. You're not so relaxed when you do go out."*
>
> (Sarah's daughter: interview 1)

This suggests that Sarah, despite having physical time away from her mother, believed the caregiving role continued to impact her psychologically. Sarah would often phone her daughter

and tell her she had not seen anybody, or tell her daughter not to go to see her for an evening visit. This added to the psychological and emotional burden. This further demonstrates that the burden of caregiving is not just in the physical sense but also the psychological, as the commitment to being contactable by mobile phone, and making regular telephone calls at agreed times impacted on Sarah's daughter's sense of *"freedom"* (Sarah's adult daughter: interview 1). However, being able to contact her mother through regular phone calls at specific times of day does relieve Sarah's daughter of some worry about her mother.

> *"I like to know well at least she's alright at seven o'clock, it's a peace of mind for me more than anything else."*

(Sarah's daughter: interview 1)

Sarah's need of routine in her everyday life also meant that Sarah's daughter had adopted a sense of routine in hers. Sarah's daughter stated that the routine could cause strain because she had to plan her day around her mother's routines. On the other hand, the routine also enabled Sarah's daughter to gain peace of mind as the routine had allowed Sarah's daughter to know where Sarah was and what she would be doing, and also gave specific times to call to make sure Sarah was okay. Reflecting further on Sarah's routine in their everyday life, Sarah's daughter said that her mother had taken to keeping multiple clocks around the house which she liked to keep at the exact same time:

> *"And if any two clocks are not exactly the same it's a hell on earth for me."*

(Sarah's daughter: interview 1)

Sarah maintained a rigid sense of routine in her everyday life, which also impacted on the daily life of her daughter. Sarah's daughter expressed further frustration as Sarah would not take up the service provisions offered to her by the local authority such as the Meals on Wheels Scheme and Sit-In Service (discussed later in Chapter 8). When Sarah rejected the Meals on Wheels scheme offered by the local authority, Sarah's daughter declared: *"I felt I had to provide her with meals"* (Sarah's daughter: interview 1). This further confirms Bäckström and Sundin's (2009) findings which report of unintentional barriers to caregiver 'time-out' being raised by survivors through reluctance to accept support from others. This also supports the notion of kinship obligation by Johnson and DeSouza (2009) and Kuluski et al. (2014) which was discussed earlier in Chapter 2.

Sarah's daughter commented that she would prefer Sarah to be on the Meals on Wheels scheme or take up the Sit-In Service as she was concerned about:

> *"What if?... what if I am taken poorly one day? How would Mam cope? There has been a lot of mention of it, but my cousin said she could help if anything happened."*
>
> (Sarah's daughter: interview 1)

If Sarah was to take up the support Sit-In Service offered, the strain and burden expressed by Sarah's daughter may reduce:

> *"Sometimes I feel, 'yes Mam, have them', coz they never goes out on a Tuesday, they've got nothing on a Tuesday."*
>
> (Sarah's daughter: interview 1)

Yet she felt reassured that:

> *"The offer has been there; it's something that I can think of if needed, they're not needed at the minute."*
>
> (Sarah's daughter: interview 1)

Although the support services were there and it was felt they were not needed, the services offered, if taken up, would relieve Sarah's daughter of some of her caregiving responsibilities.

7.4   A Change in Personality

Confirming the work of Anderson and Whitfield (2013), some of the survivor participants experienced a change in personality post-stroke. This was acknowledged by Mark personally, and was also observed by the caregiver participants of other survivors (Paul's wife and Sarah's daughter). Therefore, it was more common for the caregivers of this study to identify a change in survivor personality than the survivors themselves. Perhaps Mark identified a change in personality because he was more reflective on how stroke had affected him than the other participants.

The literature reports that caregivers often find it hard to cope with such changes in survivor personality, with some likening their feelings to bereavement, grieving for the person they once knew. This can be due to changes in the survivor's neurological or physical condition (Boosman et al. 2011; Gosman-Hedström and Dahlin-Ivanoff 2012). The caregiver participants of this study confirmed this by commenting that the survivor was not the same person they were prior to their stroke. The findings also contribute to the existing knowledge base by highlighting the ways in which a survivor's personality may have changed since their stroke and the impact that has on the caregivers.

As previously mentioned, Penny's daughter felt that her mother was not the same person post-stroke and that she had lost her dignity. She expressed that she felt a sense of *"constant grief"* (Penny's daughter: interview 1) as she observed the permanence of her mother's disabilities and the impact which stroke had had upon Penny's everyday life:

> *"She used to be so active, it is horrible, it really is."*
>
> (Penny's daughter: interview 1)

Penny had also *"become selfish"* (Penny's daughter: interview 1), however, Penny's daughter rationalised:

> *"Other than her she has got nothing else to think about has she? She would go the whole day in there* [in her living room].*"*
>
> (Penny's daughter: interview 1)

This was also expressed by Paul's wife:

> *"He can play the game without realising that he is playing it because there have been quite a few times where we've had visitors, and he's fine you know he'll tend to them. If it's only the two of us, he'll tend to look after himself."*
>
> (Paul's wife: interview 1)

Acknowledging the change in Paul's behaviour after stroke Paul's wife asserted: *"it wasn't like that before"* (Paul's wife: interview 1), and explained that *"Paul used to be really attentive."* Paul's wife rationalised this change by commenting that *"it is easier for him to ask, rather than do it himself"*.

> (Paul's wife: interview 1),

Paul's wife's explained:

> *"If he wants to open a bottle of sauce he can't, he has to give it to me, but if he wants to open a bottle of whisky he can do it."*

<div align="right">(Paul's wife: interview 1)</div>

This shows how Paul was more motivated to carry out some tasks himself than others, highlighting that motivation was what made Paul try harder.

Paul's wife (interview 1) also informed that Paul: *"will quite often plan my day"* (Paul's wife: interview 1) and explained: *"he doesn't like taking responsibility"*.

Stroke had affected Paul's memory and Paul's wife felt that by relinquishing responsibility by informing her of tasks which needed doing around the home on a particular day, he no longer needed to remember. This was also reported by Sarah's daughter and Penny's daughter, who considered their days to be typically scheduled around the needs of their mothers.

Relinquishing responsibility contributed to caregiver burden and the caregivers feeling confined in their everyday life. This confirms the work of Gosman-Hedström and Dahlin-Ivanhoff (2012) discussed earlier in Chapter 3. These behaviours were considered by the caregivers to be part of a post-stroke change in personality. However, the trait of relinquishing responsibility resembled descriptions of people who had adopted an adaptive coping strategy, whereby responsibility was relinquished.

Here, the caregiver perspectives support Boosman et al. (2011) who consider that caregivers of survivors of stroke often find the cognitive difficulties which lead to a change in personality harder to cope with than the more physical outcomes of stroke. However, the feelings of grief reported by Penny's daughter for her mother being less active than she was prior to stroke highlight that these feelings are not purely associated with the cognitive ability and neurological ability post-stroke, but also the emotional feelings about the person they care for.

This further emphasised that caregiving for a partner or parent who has experienced a stroke is an extraordinary caregiving experience. The author found that there was no direct relationship between these feelings and survivor support needs, the relationship between the survivor and caregiver, or the support provisions in place from professional caregivers. Exampling this, Penny had considerably more care needs in her everyday life compared to Paul and Sarah.

However, the caregivers of all three (Penny, Paul and Sarah) expressed that they felt confined in their everyday lives and that their days were planned around the survivor and their caregiving role. Despite Penny receiving an extensive care package from statutory sector professional caregivers, Penny's daughter still felt as though she was constrained, suggesting that where professional support provisions are in place they do not necessarily alleviate the caregiving strain and burden felt by caregivers; despite this being a key health and social care policy objective (discussed further in Chapter 9). This demonstrates that statutory sector service provisions are failing to address caregiver need.

The findings show that it is possible for an event such as stroke to impact on the element of the 'me' identity concept as this aspect considers the perceived perceptions of others, contributing to the work of Mead (1934) who stated that the self was presented in two forms: (1) 'me', a self-concept where the perceptions of others are considered, and (2) 'I' which is subjective and refers to the inner being. In doing so, the findings also challenge the work of Best (2005) and Goffman (1967), who state that the 'real me' concept remains the same throughout life, by considering that the perception of the 'real me' identity was challenged by the survivor participants as they reflect upon stroke and what it meant to them. The realisation of surviving stroke, something that is potentially fatal, led to the survivor participants of this study challenging their self-perception and revaluating their lives, and therefore the perception of the 'real me' may change. This was exampled by Mark who asserted that:

> *"A good thing about stroke, is that it makes you evaluate uour life, and makes uou realise what is actually important."*

(Mark: interview 1)

Mark felt that this self-evaluation of his life since stroke had made him *"a more positive person"* (Mark: interview 1). Through reflection of his own experience, Mark had found contentment in his everyday life. However, Mark considers that his spouse (not interviewed):

> *"Must find it hard to cope with, but I can't help it, it's who I am today."*

(Mark: interview 1)

7.5   Communication Difficulties

Richard, John, Jane and Ruth experienced speech difficulties. Richard was unable to communicate verbally, and John and Ruth explained that they would know what it was that they wanted to say, but found it difficult to communicate their thoughts:

"I knew what I wanted to say, but I couldn't."

(Ruth: interview 1)

Jane commented: *"If I am tired I cannot understand"* (Jane: interview 2), and on occasion:

"I can understand, but I cannot tell you what I'm doing, you could ask me, I would make you a paned [Welsh, for cup of tea] *and explain it, how I am going to sort it, it's terrible, no no its different."*

(Jane: interview 2)

During her interview, Jane explained how she knew how to make a cup of tea, but she would find it difficult to explain the process involved or explain how she was going to make it.

Furthermore, the survivor participants became frustrated with their caregivers when they tried to help unprompted, particularly where communication difficulties exist. This was evidenced by John who informed that he felt frustrated with trying to converse and ensure people understood what he was trying to say. During John's follow-up interview when John paused to think about the words he was going to say and his wife attempted to answer on his behalf. John got very frustrated as she was not stating the words he was trying to think of. This confirmed the findings of Schepers et al. (2006) and Thomson and Ryan (2009) who observed such feelings of frustration from participants of their research.

This was also experienced by Richard and his wife due to Richard losing all verbal communicative ability. Richard nodded his head in agreement to express that he felt frustrated when communicating with his wife as she could not always understand what it was he was trying to say. Sharing the frustration of her spouse, Richard's wife reflected:

"He can't always express what he needs; that can be frustrating sometimes."

(Richard's wife: interview 1)

This demonstrates how communication difficulties can be a source of frustration for both survivors and their caregivers. However, Richard's wife reflected:

"We have communication problems but we do manage."

<div align="right">(Richard's wife: interview 1)</div>

Richard and his wife considered communication to be the key challenge in their everyday lives. However, Richard's wife reflected:

"We've been together 40 odd years so consequently we know each other really really well, so I can kind of guess what he wants or needs, but sometimes it is very difficult."

<div align="right">(Richard's wife: interview 1)</div>

This contributes to the existing research by highlighting that caregivers who were partners of the caregivers and had been so for a while pre-stroke, could find it easier to understand and interpret what it was the survivor (their spouse) was intending to say. This further defines the caregiver as an interpreter for the survivor, in this context.

However, where a caregiver is not as familiar with the survivor, perhaps in the instance of a professional caregiver being employed, the challenge of communication may be heightened, and additional strain could occur for both the caregiver and the survivor. This could potentially impact on the overall quality of life for both parties and impact on the overall recovery and willingness to participate in rehabilitative activity, or wider society for the survivor. This also emphasises that specialised skills training for care staff in relating to providing professional care to people with communication difficulties is essential in providing an effective service provision. This could be by way of training care staff how to communicate with survivors with such difficulties.

7.6   Stigma

When first considering stigma, the first description which comes to mind is that stigma is something someone may experience due to a lack of understanding of the people around them. They may feel outcast, or stared at. We hear of extreme cases of bullying in the media, from

people in society who do not understand disability or hidden disability. The findings of this research present a much deeper level of stigma. There were no reports of bullying from the external world or statements of incidents where people had acted towards the participants inappropriately. However, this deeper level, the author feels, can have just as big an impact on a person's everyday life, and their willingness to socialise.

Mark and Ruth felt that people who have not experienced stroke did not understand how stroke can impact on a person's life. They felt as though they were different from the general population because they had this 'thing', this unique experience. This is reflective of public stigma, which Corrigan (2016) states can be simply defined as negative attributes a person assigns themselves. This can lead the person to make assumptions about what people may think of them. Reeder and Pryor (2009) and Weiss (2008) define this further, as anticipation, or a fear of what the general public might think. This can lead to paranoia and/or anxiety. The anticipation of public stigma resulted in Mark feeling reluctant to socialise outside of his home (in his external environment). He commented how people might think: *there he goes, the drunk stumbling fool"* (Mark: interview 1). This contributes to the work of Corrigan et al. (2009) and Fung et al. (2007:2008) who assert that such self-stigmatisation (stigma perceived by the self) creates a self-built barrier to social participation in the external environment. These barriers can only be removed by the survivors themselves, through feeling more confident, perhaps through a safe environment such as Stroke Club. This is a key consideration in accessibility to services and should be considered by service providers. As stated previously, Stroke Club had reduced barriers for social participation for Mark. However, Ruth also informed that she had observed that Stroke Club allowed members to build their confidence in engaging with the wider community. This further emphasised the value of Stroke Club in the participants' everyday lives, and their ability to adapt to post-stroke life.

Mark reported more feelings towards stigma than the other participants. However, his feelings were so strong that they produced a rich insight into this concept. Although these feelings should not be assumed as the same for all survivors due to the small sample of this study, and Mark being one of nine participants. The author feels that his views were so pertinent that they justified a strong consideration.

Through experiencing stroke first hand, Mark felt that he had gained a more rounded and realistic perspective of the world in which he lived than he had pre-stroke due to him experiencing life as an able-bodied person, becoming disabled himself:

"I believe that disabled people need able-bodied people with them, to conjoin with them in order for them to go on, and flourish and grow as people. Disabled people on their own don't seem able to do this themselves. As I said, erm, I believe that's a realistic statement. I'm not proud of saying that, but that's after 30 years. I think I've arrived at that having been non-disabled then becoming disabled. And now elderly disabled, you can't do it on your own ok. So that I still see the, er internet, as a powerful weapon, or could be a powerful weapon."

(Mark: interview 2)

This really emphasises how Mark felt that people who are living with a disability are not supported in society. The statement is disconcerting. However, this was the experience observed by Mark himself. Therefore it cannot be ignored. This also highlights the potential of the internet in providing an avenue of communication for people living with disabilities. Perhaps the internet could host potential for many reasons: (1) as a platform for a voice, (ii) to enable people to communicate with people with a shared experience, and (iii) formation of an identify, perhaps where the user feels as though they do not need to express the extent of their disability. This notion is discussed further in Chapter 8.

Mark was particularly conscious of how people in the wider community would perceive him. More so than the other participants. Mark felt as though people outside of his home criticised him:

"I don't always use a stick, and I've been criticised very often [for not doing so]*, and I have tumbled OK; so what?"*

(Mark: interview 2)

Mark also felt as though people stared at his mobility car:

"OK, people look at it, I don't care what people think OK, if I'm safe" and further asserts, *"I think not disabled, able-bodied people disapprove, and what am I supposed to do? Sit there and wait for some bugger to get me? Well, they do that anyway, don't get me wrong, but I don't want to be part of that."*

<div align="right">(Mark: interview 2)</div>

Emphasising the importance of his independence on his self-identity, Mark affirmed: *"this is me, I want my independence"* (Mark: interview 2). This demonstrates how Mark felt that he was stigmatised outside of the home (in his external environment) by people who did not understand stroke and disability. However, Mark did not let this stop him from doing whatever he could to be independent; he was motivated to remain as independent as possible.

However, Mark also felt as though people close to him, within his internal environment, did not understand stroke. An example of this was demonstrated by Mark when he spoke of his stroke:

"Now that's something I have not been able to share with my wife or get my wife to understand."

<div align="right">(Mark: interview 1)</div>

Therefore, Mark was at risk of feeling isolated and experiencing feelings of loneliness as he felt that people who he reported as being close to him did not understand. Mark felt as though he could not fully disclose his feelings with his wife, or that she may not fully understand his feelings. This could potentially cause distance between the couple in their relationship.

Similarly, Richard felt a fear of the wider community:

"He does not feel safe anywhere but home."

<div align="right">(Richard's wife: interview 1)</div>

Suggesting a fear of the outside world was felt by both Mark and Richard; a fear of the outside world, of a world that did not understand. Building on this, the follow-up interviews also informed that Mark felt that:

"Society is ignorant of what disabled people can do."

<div align="right">(Mark: interview 2)</div>

7.7 A Positive Perspective

While reflecting on their post-stroke lives, the survivor participants considered whether they felt they were content in their lives or not. Those participants who reported feeling content also reported positive feelings. Mark and Ruth were consciously positive in their everyday lives:

"I always look on the bright side of life, and that's now how I conduct myself outside in the world, and I'm not quite sure if it is real, fictional, but it is me, that is who I am today."

<div align="right">(Mark: interview 1)</div>

Chapter 2 introduced the notion of a positive attitude as defined by Berges et al. (2012) and Stiers et al. (2012) who informed that taking a positive approach to a situation and focusing on what they can do rather than what they cannot, can help people come to terms with challenging aspects of their everyday lives, in this context, life after experiencing stroke. Positive perspectives have been discussed throughout this chapter and inform how being positive has enabled the participants to come to terms with elements of their post-stroke lives. The positive 'can do' attitude asserted by some of the study participants contributed to them being able to remain as independent as possible and had allowed them to increase their self-esteem and confidence in their own ability. The positive perspective encouraged survivors to focus on the things they could do rather than the things they could not. This had also influenced their levels of social participation and contributed to their perception of their own quality of life.
Ruth reflected that:

"There is a life after stroke, it won't be the same, but there is, you know, there's other ways of doing."

<div align="right">(Ruth: interview 1)</div>

While Mark reflected:

> *"One of the advantages I find of having a stroke is that I have stopped worrying so much and enjoy what you have to enjoy in life whilst I can still enjoy it."*
>
> (Mark: interview 1)

Stroke resulted in Mark and Ruth gaining a new perspective on their lives, reflecting upon other people's perceptions. Mark commented:

> *"If having stroke means that you are bordering on lunacy or insanity, I put my hands up and say - yes but it can be good!"*
>
> (Mark: interview 1)

Mark preferred to disregard the negative and focus on the positive and live his life for the future (Berges et al. 2012). This ensured that he absorbed those things in life which he felt he had previously taken for granted before his stroke. A positive attitude has already been identified in Chapter 3 as being beneficial for rehabilitation and achieving mental and emotional wellbeing. Berges et al.'s (2012) literature of positive attitude is further supported by Ruth who states that:

> *"It is no good getting, 'my my, oh my', if doesn't do any good and it probably makes you worse anyway."*
>
> (Ruth: interview 1)

Ruth reports being initially naïve in regards to how stroke had affected her:

> *"I suppose in a way I was worse than I thought I was, but I never thought, I never worried, it just kind of washed over me."*
>
> (Ruth: interview 1)

7.8 Feeling Lucky

The survivor participants compared themselves and their lives to those of others when reflecting on their post-stroke abilities. Such comparison supported them in rationalising their experience and developing a sense of the post-stroke self. This confirms the work of Frankl (1963) and

King and Hicks (2009). When the survivor participants compared themselves against other survivors it gave them a grounded sense of their own reality:

> *"There are others a lot worse than me, at least I can talk."*
>
> <div align="right">(Penny: interview 1)</div>

This was also felt by Paul, John, Mark, and Penny. Such consideration helped the survivor participants accept the outcome of stroke. Similarly, Mark compared that although he felt his own experience of stroke was difficult to come to terms with, he observed other people who were living with stroke. Mark considered that there were others with more severe stroke outcomes than himself. These observations were made at his local Stroke Club which informed that Stroke Club provided the survivor participants with the opportunity to rationalise their experience, which ultimately helped survivors come to terms with the stroke. Mark asserted that this helped him to recognise his sense of self and be positive in his post-stroke everyday life.

Furthermore, Sarah, Paul and Ruth reflected on their own lives and expressed that they felt lucky compared to others. The sense of feeling lucky could either be an outcome of, a contributor to, or run parallel to, a positive perspective. Ruth asserted*: "I really really am lucky"* (Ruth: interview 1) and compared herself against a fellow member of the Stroke Club she attended:

> *"It's affected her eyesight; she can't trundle along on an electric trolley because she can't see properly. I mean there's all sorts of things, you know, it is such a varied illness."*
>
> <div align="right">(Ruth: interview 1)</div>

In summary, Ruth commented:

> *"I never felt 'oh it's happened to me' or anything like that because it happens. But fortunately, it wasn't a bad one."*
>
> <div align="right">(Ruth: interview 1)</div>

This rationalisation enabled Ruth to find contentment in her post-stroke life. Similarly, Mark considered:

"I am very happy with me today, which gives me a strength that most other people wouldn't understand."

<div align="right">(Mark: interview 1)</div>

Further emphasising that stroke is a unique experience that people who have not experienced stroke cannot comprehend.

Demonstrating that other things in life can contribute to their wellbeing, Richard's wife reflected:

"We're very lucky, we've got a nice house, we've got a nice family; things could be a great deal worse."

<div align="right">(Richard's wife: interview 1)</div>

This showed how Richard's wife looked at their life as a whole, not just focusing on stroke. Highlighting how support from others can contribute to wellbeing, Sarah and Ruth felt lucky that their daughters provided the care for them they needed:

"I am lucky compared to some coz some children don't bother, do they. I'm very very lucky."

<div align="right">(Sarah: interview 1)</div>

Reflecting on the support of his wife Paul reflected:

"I was lucky I had her, a lot of people, single people, are sent home, and they need people to keep an eye on them type. I don't think there is a lot of after-care."

<div align="right">(Paul: interview 1)</div>

This highlights that the survivors in coming to terms with their experience of stroke are aware of the support around them and are reflective of how their lives could be different if they did not have the people around them to care for them that they did have. This indicates a reliance on

family as caregivers over professional caregivers and emphasises the importance of supporting caregivers in their roles, further emphasising the desire for more community-based support.

Reflecting on the post-stroke experience as a whole, Paul's wife commented:

> *"I do think we are lucky, but then again we are lucky because of the background support we have."*
>
> (Paul's wife: interview 1)

While reporting the valuable contribution of support from the community and suggesting that the perspective of post-stroke life can be influenced by past experience and expectation Paul's wife stated further:

> *"We are lucky, I mean if someone had told us we'd get to this level after the stroke we'd have been made up, because I knew what the consequences of stroke could be."*
>
> (Paul's wife: interview 1)

These feelings were based upon her previously providing care for her mother, highlighting how feelings of 'being lucky' can be based on past experience and expectation.

Feeling lucky to reside where they do, Sarah's daughter and Ruth's eldest daughter considered the logistical aspects of the support they provide for their mother:

> *"We are fortunate she* [Ruth] *had her acute treatment fairly nearby when she had a stroke, the local hospital is on our doorstep."*
>
> (Ruth's eldest daughter: interview 1)

Also considering their being local to each other, Sarah's daughter reflected *"Mam is lucky as she lives by me"* (Sarah's daughter: interview 1) informing that she visits the survivor as often as she can, as she lives near her home and place of work. This highlights that location, being physically close to services and being physically close to the person they care for impacts on the perception of the caregiving experience. Also, Ruth considered herself to be lucky as she lived close to the services she needed to access. Furthermore, Mark reflected on where he resided, in a rural town in Wales, and commented that he found where he lived to be good for his mental

wellbeing. Comparing his locality to London, where he grew up and still visits his family from time to time, Mark described the area in which he lived as:

"Spiritually uplifting, especially compared to a cesspit like London; I love it."

(Mark: interview 1)

7.9   Chapter Summary

This chapter defines the caregiver participants of this study as daughters, partners, caregivers, and interpreters of the survivor participants, and informs that the caregiver experience varied greatly depending on the survivors' personal needs and the outcome of their stroke, building on the existing literature. This was not only for the physical tasks but also because caring for someone with physical and/or neurodisability can be both physically and psychologically draining. This combined with the emotional feelings and emotions experienced when a family member experiences a stroke, can have a profound effect on those who care for their parents. Furthermore, a lack of information was reported as a key unmet need for the caregivers of this study. It was felt as though this impacted negatively on the caregiver participants' ability to provide effective care for the survivor.

In coping with life after stroke, the findings inform that the dominant coping strategy exerted by the participants was an adaptive strategy, as they made adjustments to their everyday lives. This applied to both the survivors and caregivers, particularly where a sense of routine had been incorporated into their everyday lives. The participants' perceptions of their everyday lives are influenced by whether they have come to terms with stroke, how they have applied meaning to the experience, and their own self-perception, and the perception of themselves in society. As this chapter informs, part of the post-stroke self-evaluation process included a reflection of the participants' own lives compared to others who had also experienced stroke and their past experience and awareness of the possible outcomes of stroke. Such reflection required time and allowed the participants to come to terms with their stroke. This also allowed the participants to consider whether their life goals and expectations had been met. Those survivor participants who reported feeling content in their everyday lives also reported positive perspectives. This suggests that those participants who have come to terms with stroke, are content in areas of their lives and consider positive perspectives are more likely to report a better quality of life than those who are not content and feel as though their life goals and expectations have not or will not

be met. The findings in this chapter also highlight how Stroke Club contributes to the participants' everyday lives by reducing barriers to social participation and providing a source of information for caregivers.

Throughout this chapter, study participants demonstrate that they value positivity within their everyday lives and highlight positive attitude as a crucial aspect to their coping with post-stroke life. Furthermore, the findings suggest that a positive 'can do' attitude has contributed to the motivation to participate in the external environment and motivated them to make adaptions to everyday tasks within the internal environment to enable them to regain aspects of their pre-stroke life.

This also supports theory discussed in Chapter 3 which highlights that there is a general lack of provisions for supporting partners of people needing care, and highlights areas where such support would be beneficial, such as gaining more information; talking to other caregivers of survivors of stroke; and training in how to provide care. Such support should be provided to caregivers prior to discharge to ensure that they are ready for the caregiving role when the survivor returns home. Furthermore, the findings show that this needs to be a proactive effort from the statutory sector services, rather than reliant on caregivers seeking the information themselves. The author does not state here that the statutory sector services do not provide information or support, merely highlights that there is an area of weakness in the implementation as the caregivers of this study felt that they had to find the information they needed themselves.

8.0   Findings: Intellectual Fulfilment, Hobbies, Interests and Social Participation

The findings discussed throughout this chapter continue to address research objective (1) to explore the everyday lives and experiences of survivors of stroke and their caregivers and research aim (2) to identify key individuals and organisations that provide support to survivors and their caregivers in their everyday lives. The findings reported here are informed by the participants' BNIM interviews. Whereas Chapter 7 focused on coming to terms with post-stroke life, the emotional and psychological impact of stroke, and survivor and caregiver feelings in post-stroke life, this chapter discusses participants' everyday lives in relation to their intellectual fulfilment; hobbies and interests, activities they participate in and, social participation.

8.1   Intellectual Fulfilment, Hobbies and Interests

Survivor participants described that they sought intellectual fulfilment from activities such as reading books, watching television, browsing the internet, engaging in debates and current affairs, email communication and engagement with social networking sites such as Facebook. However, the impact of stroke upon some survivor participants meant that not all were able to continue with the activities and interests they engaged in prior to their stroke. This confirms a plethora of findings from existing literature and confirms that the outcomes of stroke, physical, psychological and neurological, can impact upon social participation and participation in activities (Arntzen and Elstad 2013; Eriksson et al. 2012; Fallapour et al. 2013; Kitzmuller et al. 2012; the National Institute of Neurological Disorders and Stroke 2008; the Stroke Association 2016; Thomson and Ryan 2009).

Throughout this chapter, those activities, hobbies and interests which are specifically affected by stroke, for example, those activities which the participants reported they had to give up or, or activities which participants explicitly stated that they had taken up since stroke, are noted by the author. Interestingly, in some cases (where the physical and neurological outcomes of stroke permitted) stroke had allowed the participants to take up new activities, hobbies and interests through their local Stroke Club.

8.1.1 The Impact of Stroke

As discussed in Chapter 7 previously, the physical outcomes of stroke meant that survivor participants were less able (or in some cases unable) to continue with some of the hobbies and interests they had enjoyed before they experienced their stroke. Corroborating the findings of the National Institute of Neurological Disorders and Stroke (2008) discussed earlier, that informed that survivors were often faced with having to give up activities, hobbies and interests after stroke, the findings here highlight these activities, and the impact which 'giving up' some of these activities had on the participants' everyday lives. Sarah explained:

> *"The one thing that I do miss is walking."*
>
> (Sarah: interview 1)

Sarah considered herself to have been very physically active before she experienced her stroke. However, post-stroke fatigue and difficulties she experienced with the reduced strength in her legs (resulting from muscular weakness after her stroke) meant that she had become less physically active. This impacted on Sarah's level of post-stroke social participation (discussed further in Section 8.4) in her everyday life. The other survivor participants noted similar changes to their everyday lives since stroke. Demonstrating that this is changeable over time, Thomas identified that he experienced more post-stroke fatigue at the time of his follow-up interview than he did at the time of his first. Richard also found that post-stroke fatigue meant that he was not able to attend Stroke Club as often as he had in the early months of his post-stroke life; therefore engagement in this avenue for interests and support had been reduced. Thomas, Paul and Mark reported that their stroke had affected their coordination and arm movement. This impacted on their ability to partake in some hobbies and interests they had enjoyed prior to stroke:

> *"I gave up model making; ships, planes, models. I used to make them for the kids, it* [Mark's arm coordination] *just don't work now."*
>
> (Mark: interview 1)

This further highlights how Mark was unable to participate in hobbies he shared with his children, such as building model planes, demonstrating how the effects of stroke can impact on elements of family life such as participating in activities with children. However, as discussed in Chapter 7, Section 7.1 previously, Paul and Ruth had found new ways of doing the things which

they had previously enjoyed, when they found their post-stroke disability may prevent them from doing so. The National Institute of Neurological Disorders and Stroke report (2008) previously asserts (in Chapter 3), that survivors of stroke are forced to 'give up' activities they were no longer able to do after stroke. The findings here show that yes, in Mark's case, he was unable to participate in model making with his children, however, where an adaptive coping strategy is adopted, the survivors, such as in Paul and Ruth's cases, they were able to find other ways of doing things or compensate for those things they were no longer able to do. Therefore, the findings here show that not all survivors have had to 'give up' all activities they enjoyed after stroke. However, there are other factors to consider in relation to this, such as the type of activity undertaken, and the motivation of the survivor to continue to carry out said activity.

Regarding the neurological impact of stroke, Paul, Mark, Penny, Ruth and Thomas experienced difficulties with their short-term memory, similar to the participants of studies conducted by Haley et al. (2009), Hilari (2011), and McKevitt et al. (2011). This meant that Penny and Ruth could not partake in the activities they used to enjoy prior to stroke due to their now reduced concentration. Such activities included doing crosswords and word searches. However, further suggesting traits of an adaptive strategy as identified by Wallengren et al. (2008) in Chapter 3 previously, Ruth stated:

> *"I compensate my mind with other things."*

(Ruth: interview 1)

Here, Ruth acknowledged she found crosswords and word search difficult due to her struggling to concentrate and so occupied her mind with activities which required less concentration and, which she could do in order to keep herself intellectually stimulated. This adds a further dimension to the adaptive strategy being about changing the way survivors carry out everyday tasks and changing the way they do things (discussed previously in Chapter 7). Ruth adapted the source of intellectual fulfilment by seeking out activities she was able to do. Stroke Club offered an opportunity for the survivor participants and their club members to try different activities, and identify activities that they could enjoy post-stroke. They did this by holding various types of activity sessions, which are discussed further in Section 8.1.2.6.

However, this was not always the case. The extent of Penny's physical disabilities meant that she was unable to take up any activity which required physical action. Therefore, Penny was unable to stimulate her mind by picking up a book to read, or a pen to do a crossword, despite

her memory not being affected and her being able to carry out those tasks on a neurological level. Furthermore, there was the outcome of post-stroke fatigue, which had been reported by all of the study participants, and which fundamentally impaired all daily tasks and varied day to day and, seemingly worsened over time for some survivor participants.

8.1.2 Activities and Intellectual Fulfilment

The survivor participants reported reading, watching television, knitting, computing, the internet, stamp and railway collections and photography as activities and hobbies in which they actively engaged. There were also activities they participated in which occurred outside of the home such as day trips (discussed later in Section 8.3) and going to clubs and socialising (discussed later in Section 8.4).

8.1.2.1 Reading

Jane reported that she enjoyed reading a newspaper. Demonstrating the impact of stroke on Ruth's reading ability, Ruth commented that she had reduced concentration post-stroke:

> *"I used to read a lot, that's one thing I find difficult now, concentrating on the pages you know, but I, I'm getting there, I think."*

> (Ruth: interview 2)

Highlighting that she was determined to keep trying to concentrate enough to read, Ruth stated:

> *"I can lose myself in a book, and that's one of my…. I can't concentrate so much, but I'm quite happy."*

> (Ruth: interview1)

The concept of losing oneself in a book is an interesting one. Here, the author considers whether it is merely a desire to immerse herself in a good storyline, or a way of escaping from reality. Further research into reading to escape reality in this context would be a recommendation for future research.

8.1.2.2   Watching Television

Penny would spend each day watching television and stated: *"this is all I've got"* (Penny: interview 1). Television was Penny's main source of stimulation. Thomas also reported that he would watch television throughout the day, as did Paul each evening and during the daytime if it was raining. Television provided an avenue of entertainment and potentially an avenue of intellectual fulfilment for the survivor participants, particularly in Penny's case. However, highlighting that this was not the case for all, Mark stated:

> *"I forced myself for the week to just watch the telly and nothing else, and I found it the most frustrating experience of my life."*

(Mark: interview 2)

8.1.2.3   Computing and the Internet

Mark expressed that he much preferred using his computer and the internet over watching the television as he found it more intellectually stimulating.

Using his computer to communicate with the external environment (discussed further in 8.4), Mark observed that since his stroke he had become interested in politics and worldwide current affairs as an avenue of intellectual fulfilment:

> *"Without these things, I'd be bored out of my bloody mind."*

(Mark: interview 1)

Paul (follow-up interview), John and Mark also highlighted that they enjoyed communicating with people via the internet. This provided an avenue of intellectual fulfilment for the survivor participants. John, who was proficient in using computers pre-stroke, had relearnt computing skills at his local Stroke Club and had gone on to do a computer course at a local college. The internet provided a platform for communication with people outside of the survivors' home environment. This highlights how Stroke Clubs have the potential to break down barriers to participation in the external environment for their members, by showing them how to use the internet, and engage in social networking sites, as John's local Stroke Club did.   This also

200

demonstrates the intellectual fulfilment and stimulation which technology and the internet has the opportunity to provide to a survivor of stroke, and potentially people living with similar outcomes from other chronic disease and lifelong disability.

8.1.2.4 Collecting as a Hobby

John reported that he had begun to keep a stamp collection and since stroke, had become a collector of model railways. However, John had *"always had an interest in railways"* (John's partner: interview 1) which suggests that John becoming retired due to the outcomes of his stroke meant that he had more time to pursue his interests. Therefore, it is worth noting that John may have begun a railway collection after retirement because of having more time rather than him having an interest in model railways as a way of discovering new interests after stroke.

8.1.2.5 Photography

After their strokes John and Mark developed a keen interest in photography. This complemented John's interest in viewing photographic images on social media as a way of communicating with people.

> *"I like photography, in the Stroke Club I like to photograph people and then over the years you realise that friends, that people, have passed away."*
>
> (Mark: interview 1)

This suggests that Mark may use photography to reflect upon his past, and to compensate, in part, for his decline in his memory by observing photographs to reflect on significant changes in his life; such as friends that have passed over time. This further demonstrates how Mark felt in his everyday life, as stated in Chapter 7 previously Mark felt as though he was *"living in a world of past memories"* (Mark: interview 1).

8.1.2.6   Activities at Stroke Club

The observation data informed that Stroke Club provided the opportunity for Stroke Club members to engage in activities such as scrabble, painting and computing (Stroke Club D), verbal quiz (Stroke Clubs C and D), games such as beetle drive (Stroke Club F) and word tasks to encourage thought, verbal communication and handwriting skills (Stroke Club B), bingo (Stroke Club D) and dominoes (Stroke Club C). The tasks and games such as beetle drive, painting and word tasks were observed as being thought-provoking and provided an opportunity for participants to practise their handwriting and drawing skills at an easy level, with no pressure; they could go at their own pace. Games of dominoes were also observed where people with mixed communication abilities were able to participate, which meant that those who could not verbally communicate were invited by other members to participate in the activity. This highlights the inclusive nature of Stroke Club activities and demonstrates how the activities reduced barriers to participation.

In addition, there was a volunteer who provided an art activity for the members of Stroke Club D as she was a qualified artist. The artist (volunteer) helped the members who participated in this activity to paint on pre-drawn pictures, saving all pictures into a folder for the participating members, sometimes making calendars for them to take home. The pictures encompassed themes such as boats, birds, landscapes and flowers which related to the members' own interests. The volunteer commented that over time there were some improvements noticed in the ability of the members who engaged in this activity. There was also a volunteer at Stroke Club D who practised computing skills (inclusive of email, setting up a social media presence and using search engines) with the members, making a record of their progression each week. There were laptop computers available for the members that had been purchased through funds donated through a grant scheme; they also had online computer courses which the members could enrol on and complete at the Stroke Club. It was through this that John relearned some of the computing skills which he had lost when he experienced his stroke. This also demonstrates how Stroke Clubs support survivors in developing an online presence, allowing them to participate in online communities, and learn vocational skills, providing them with intellectual fulfilment.

There were also individual activities observed including members reading the newspaper (Stroke Club D) and knitting (Stroke Club D). Furthermore, all of the Stroke Clubs observed held a Queen's Jubilee Party and Christmas Party to celebrate key events of the year.

8.1.2.7   Guest Speakers

The observations discovered that guest speakers were invited to Stroke Clubs, and they offered an avenue for intellectual fulfilment and in some cases advice on nutrition, health and wellbeing after stroke. This further highlights how Stroke Clubs are a source of information for their members. Guest speakers observed included representatives from a variety of special interest groups and speakers from third sector organisations (Stroke Club F); a nutritionist from the local hospital (Stroke Club E), a town councillor, a local naval reverend who came to talk about his career in the Navy, and a representative from a social enterprise which offered services of interest for people living with disabilities (Stroke Club A). In addition, performances from a local singer (Stroke Club C), a local band (Stroke Club E), and bell ringers (Stroke Club C) were also observed.

8.2   Caregiver reported Activities and Intellectual Fulfilment

Richard's wife reported that she enjoyed swimming once a week but had recently stopped going. However, she acknowledged that this was *"not specifically because of* [Richard's] *stroke"* (Richard's wife: interview 1). Richard's wife reflected that the caregiver role had not impacted on her enjoying the hobbies and interests she had. However, Thomas's wife had wanted to go swimming in the mornings, but she had felt that she was not able to because she needed to be at home when Thomas's paid carers came to their home. This was so she could explain what they needed to do, as she felt that this provision was not consistent (discussed further in Chapter 9). This highlights that statutory sector support by way of professional service provisions does not necessarily provide the caregivers of this study with more free time to themselves, despite this being an aim of the Stroke Delivery Plan (2017) and Welsh Government's (2014) Carers Strategy: Second National Action Plan 2014 – 2016, both of which were discussed earlier in Chapter 4 Section 4.3.4.

As previously mentioned in Chapter 7, Section 7.1.2, the impact of Penny's stroke meant she was unable to look after her daughter's children. This meant that Penny's daughter *"gave up learning piano"* (Penny's daughter: interview 1) as she no longer had anyone to look after her children while she went to her piano lessons. This demonstrates how stroke can indirectly impact on the everyday life of the caregiver. This further identifies a barrier to social participation for the caregiver where caregivers are taking on the multiple roles; in this case

being a mother of dependent children as well as being employed and being a caregiver of a dependent parent. This confirms McKevitt et al.'s (2010) theory that there are not enough provisions to help caregivers maintain their leisurely activities. This also supports the initiatives introduced by the Stroke Delivery Plan (2017) and Welsh Government (2014a) Carers Strategy: Second National Action Plan 2014 – 2016, which are to better support caregivers in their caregiving role, enabling them to live a fulfilled life.

8.3   Day Trips

Day trips were reported to provide a break from everyday routine. Sarah, Paul and Thomas regularly took day trips. Sarah's daughter had often taken her mother out for day trips to the local garden nursery or local town:

> *"She likes going out, I take her out for the day if say, I'm off* [work] *on a Monday."*
>
> (Sarah's daughter: interview 1)

However, Sarah's daughter reported that due to Sarah's disabilities post-stroke:

> *"I am limited to where I can take her now."*
>
> (Sarah's daughter: interview 1)

Such limitations are considered a barrier to access to services, activities and places of interest outside of the home as well as for carrying out tasks such as food shopping (discussed later in Section 8.4). Such limitations included access to the store, access around the store and amenities within the store.

Paul and his wife as well as Thomas and his wife would occasionally go on a bus trip to a coastal town: *"it's half a day's work you know getting there"* (Thomas's wife: interview 1) and continued:

> *"It does help. It kills a day, doesn't it? You see something more interesting than just sitting at home."*
>
> (Thomas's wife: interview 1)

This demonstrates how a day out provided a change to the everyday life routine for the survivor participants who engaged in day trips (Sarah, Paul and Thomas), which was viewed as a refreshing time for the participants, and a break from the routines of the caregiving role for the caregivers. Much of the existing literature, policy and practice, identifies that caregivers should be given a break from the caregiving role, advising respite as the solution. However, the findings here inform that such day trips are a break for both the survivors and the caregivers, from their everyday lives. Although the author acknowledges that this may not be the case for all, the benefits of having a day trip together in this case outweigh the benefits of a caregiver's day to themselves. Not only are the participants here having a break from the daily routine that is the survivor-caregiver relationship, they are spending quality time together, therefore, spending time as husband and wife, and mother and daughter, rather than survivor-caregiver. This has a psychological benefit, whilst also provides physical benefit. Demonstrating her efforts to encourage Thomas to be active, Thomas's wife asserted:

"It keeps his legs going because we do try and take him out every day."

(Thomas's wife: interview 1)

This provided an example of where a caregiver can support survivors in rehabilitative activity by providing encouragement.   This suggested that Thomas and his wife viewed day trips as a way of occupying themselves, as a way of experiencing a change to their everyday routine. Reflecting on changes to their everyday life since Thomas experienced his stroke, Thomas's wife commented:

"We don't go to the pictures or anything very often, you know, but try and get a walk into town and back, most days anyway – weather permitting."

(Thomas's wife: interview1)

Similarly, Paul's wife said that on occasion Paul would drive to the local bus station and they would get the bus to a coastal town:

"It's a nice change for Paul, he gets to see things that he wouldn't see if he was driving."

(Paul's wife: interview 1)

8.4   Social Participation

Social participation, defined in Chapter 3 previously, is considered by Stiers et al. (2012) and Van Brakel et al. (2012) to be individualistic and dependent on the level of survivor disability, the type of survivor disability, and the stage of rehabilitation. This was also evidenced by the participants of this study. Although this study's findings confirm that of Stiers et al. (2012) and Van Brakel et al. (2012), the findings of this study offer deeper insights by identifying how survivor ability impacted on social participation.

Throughout Section 8.4, engagement in social participation is considered in both internal and external environments. Stiers et al. (2012) consider social participation to differ from participation in activities (as discussed in Chapter 3 previously). Stiers et al. (2012) define social participation within the internal environment to be exhibited by engagement in domestic roles and family life; as a caregiver, a family member, or as a friend. Whereas, social participation in the external environment is inclusive of engagement in education, employment, engagement with community groups and clubs, and social engagement (Stiers et al. 2012).

As discussed in Chapter 2 previously, Fallapour et al. (2013) consider there to be three different stages of post-stroke social participation: (1) the survivor feels they cannot do activities as before, (2) the survivor feels as though they are a different person, and (3) the survivor feels as though they are not living their life. This study found that, whilst confirming these stages, the stages do not necessarily occur in an incremental process, meaning that the survivor does not move in order through the stages. Therefore, the survivor participants could not be bracketed into any one of the three dimensions. In fact, when comparing these 'levels' or 'stages' alongside the findings, the survivors moved between dimensions, depending on the context of the social participation itself. Table 6 overleaf summarises this in tabular form.

Table 6: Survivor Participants Categorised by Fallapour et al. (2013)

Fallapour et al's (2013) category/ Survivor Name	1 Survivor cannot do activities as before	2 Survivor feels as though they are a different person	3 Survivor feels as though they are not living a full life
Sarah	*		
Paul	*		
John	*		
Mark	*	*	
Jane			
Richard			
Penny	*		*
Ruth	*		
Thomas			

As Table 6 shows, Jane Richard and Thomas did not meet any of the three stages, whilst Penny and Mark met two and Sarah, Paul and Ruth met one.

Furthermore, Stroke Clubs were also considered an avenue for social participation for survivors and provided a safe place away where survivors felt they were with people who understood what it meant to have a stroke. At Stroke Club, caregivers were also provided with the opportunity to meet with people who understood the caregiving role. This proved an avenue of support in helping people come to terms with their post-stroke lives.

The Stroke Club observations and interview findings inform that Stroke Clubs contribute to increasing social participation within the internal and external environments. This was achieved by activities and excursions laid on by the Stroke Clubs, and the informal social setting which Jane considered as beneficial for people who were living with stroke in their everyday lives.

8.4.1   The Internal Environment

This section discusses social participation in the internal environment. This includes engagement in domestic roles and family life; as a caregiver, a family member, or as a friend. The majority of the survivor participants engaged in family roles, home maintenance, housework, household shopping and, food preparation. However, this was not the case for Penny due to her high level of physical disability. In terms of caregiver engagement in the internal environment, the caregiver participants exhibited informal helping behaviours in personal care, food preparation, housework, money management and, household administrative tasks. This demonstrates the instrumental support aspect noted by Burholt and Dobbs (2014) who identified that support networks consist of social, emotional and instrumental support. The level of engagement in the internal environment varied between the cases, as did the abilities and needs of the survivor participants.

In Section 8.4.1 the notion of independent living is first discussed, followed by discussion of the support provided by the caregivers within the internal environment, participation in the home environment, and the changing roles within the family unit.

8.4.1.1   Independent Living

A person's own perception of themselves and their post-stroke life is influenced in part by their perceived level of independence (Krančiukaitė and Rastenytė 2006).

> *"I try to do most things if I can, but I accept the things I cannot do and don't let them destroy me."*

(Mark: interview 1)

The study participants valued independent living in their everyday lives. Five of the nine survivors (Paul, Mark, Jane, Ruth, and Thomas) highlighted that it was important for them to be as independent as possible in their post-stroke lives. Meanwhile eight of the nine survivors of stroke (with exception of Penny) reported that they still did the tasks which they enjoyed doing prior to their stroke, either independently or with support within the internal environment from their caregivers. Emphasising the importance of *"doing it for yourself"* (Paul: interview 1), Paul (interview 1), Jane (interview 1); Ruth (interview 1), and Thomas (interview 2) reflected upon

adaptions they had made to the way they conduct everyday tasks in order to be as independent as possible:

"There are ways of adapting, so I haven't had to stop anything really."

(Paul: interview 1)

Thus, where it was stated in Chapter 7 previously, that Paul's wife felt that Paul would rather ask her to do things rather than do things himself, this was not representative of all aspects of his everyday life. Similarly to Paul, Ruth commented that she also compensated for her limitations by adapting the way she carried out everyday tasks, demonstrating how she would use the door hinges to open bottles and jars as she struggled to use a tin opener:

"It's little things like that that have affected me."

(Ruth: interview 1)

The extent of reported independence varied from case to case. The survivor participants, with exception of Penny, stated that they were able to get themselves:

"Up, washed and dressed each morning."

(Sarah's daughter: interview 1)

In Sarah's case, her daughter assisted by placing out her clothes out for the next day as she had difficulty with selecting clothes to wear:

"She would put something like a short sleeve cardigan over a long sleeve blouse."

(Sarah's daughter: interview 1)

By placing her clothes out, Sarah's daughter enabled Sarah to be independent in getting herself dressed. Furthermore, Sarah's daughter and Thomas's wife reported that they assisted with showering, with Thomas's wife helping Thomas to apply a medicated skin cream. However, during the first interview Thomas's wife described difficulties in helping Thomas shower and apply his cream daily as she herself experienced health problems. This evidence supports the findings of Thomson and Ryan (2009) who identified the need for caregivers to be assessed on their ability to care. During the follow-up interview Thomas and his wife reported that since the first interview, the local authority had set provisions for professional paid caregivers to visit the

house twice a week and help Thomas to shower and apply his medicated cream. This helped to relieve Thomas's wife of this responsibility and demonstrates how external factors such as statutory sector caregivers can contribute support to the survivors' internal environment.

The interviews also found that Paul, John, Mark, Richard, Jane and Thomas conducted their own food shop independently.   On further reflections of their independent daily routines, Paul, John and Thomas reported that they prepared breakfast and most of the evening meals (Paul) *"I've become obsessed with food"* (Paul: interview 2). Paul reported that he enjoyed doing things himself around the home. These activities also contributed to a sense of increased self-esteem. Sarah and Penny were unable to do these activities themselves due to physical and cognitive impairment and had their meals prepared for them each day. Sarah's daughter prepared meals for her mother to reheat in the microwave when required, whereas Penny had paid caregivers who would prepare and cook her meals for her, and help her to eat by cutting up her food and placing it into her mouth.

The findings also show that for the participants, both survivors and caregivers, everyday tasks which are typically considered 'routine and requiring little thought' required a greater depth of consideration post-stroke. This was evidenced by Sarah's daughter's earlier reflection about her being limited as to where she can take her mother. Contributing to this evidence, Sarah's daughter stated that she preferred one supermarket over the others in the area. This was because it was more accessible and meant that Sarah could be pushed around the aisles in her wheelchair, and that there was also a café and good access to facilities.

Sarah's daughter summarised:

> *"She can go to the loo independently, she can go to the café, she'll have something to eat, she'll sit in the cafe while I run round to do my shopping; brilliant."*
>
> (Sarah's daughter: inteview1)

This leads the author to note that making local provisions accessible and suitable for the needs of survivors and their caregivers helps support them in their everyday life. This is a consideration for service and amenity providers and can also be considered on behalf of people living with a range of conditions, not just those resulting from stroke. Issues getting around a store if the survivor is in a wheelchair may also cause embarrassment and contribute to feelings of perceived public stigma.

During his follow-up interview Paul informed that when his wife died he then employed a cleaner for two hours a week to help maintain the home, as well as someone to do his ironing. Paul also took over the management of household bills and finance using online banking. He now manages the household administration independently, taking on more responsibility in the home. This further confirms Oswalt et al.'s (2009) theory and earlier findings which suggested that caregivers may unintentionally underestimate a survivor's ability. However, taking Paul's wife's comments at interview and previous discussion into account, Paul may have preferred to delegate such tasks. The findings contribute here by informing that survivors may also underestimate their own ability too, as Paul did.

As previously discussed in Chapter 7, in the early months of Paul's post-stroke life, Paul felt a surge of motivation to do things for himself. Considering his independence post-stroke, Paul reported a pivoting point in his life where he recalled: *"feeling motivated"* (Paul: interview 1):

> *"I had to pay somebody to put a porch on the back door* [of his home].*"*
>
> (Paul: interview 1)

Being a retired carpenter and joiner Paul reported:

> *"It aggravated me so much that I felt I had to start doing things myself."*
>
> (Paul: interview 1)

This sense of aggravation encouraged Paul to make a change; to accept the impact that stroke had had upon his everyday life and progress forward, adding another dynamic to King and Hicks's (2008) theory of accepting the stroke being a big element of coming to terms with post-stroke life. Paul began using clamps to secure items to a workbench so he could drill holes, screw nails, and saw materials himself. This allowed Paul to make adaptions around the home. Paul also bought a buttering board which would hold a slice of bread in place to enable him to make a sandwich. During his follow-up interview Paul reported that he had recently bought a chopping board with a series of nails in which held meat and vegetables in place so he could chop food and, peel potatoes and carrots independently.

8.4.1.2   Supporting Independent Living

Jones and Morris (2013) assert that the biggest challenge for caregivers is supporting survivors in their everyday lives, whilst encouraging them to be independent. The findings from this study confirm this. The findings also confirm the findings of Thomson and Ryan (2009) who assert (in Chapter 2) that those survivors living with physical disability report a need for assistance in the home. The participant survivors in this study reported a requirement for variable levels of support at home such as, housework, meal preparation, dressing, eating meals, and food shopping.

Sarah's daughter, Paul's wife and Ruth's daughters highlighted their commitment to supporting the participant survivors in independent living. Reflecting back on an earlier discussion where Paul's wife highlights that Paul would ask her to open a bottle of sauce for him, but can open a bottle of whisky for himself, this suggests that when Paul was more motivated to complete a task, such as opening a bottle of whisky, then he had more motivation to try. This notion of asking for help rather than trying themselves was also highlighted by Sarah. However, the caregivers reflected that they would feel guilty if they did not help despite acknowledging that it is important to *"make her try, and be more independent"* (Sarah's daughter: interview 1) further supporting the findings of Jones and Morris (2013).

Aware of this, Paul's wife accounts:

> *"I suppose in a lot of ways I am guilty of answering him, but I've learned now that really I shouldn't, I should make him."*
>
> (Paul's wife: interview 1)

This correlates with earlier findings within this chapter, and confirms Oswalt et al. (2009) who suggested that caregivers can unintentionally demotivate the survivor in trying to do things for themselves, by helping too much; potentially unintentionally inhibiting long-term recovery. These feelings and conflicting emotions can contribute to feelings of frustration for the caregiver, and caregivers feeling as though survivors are more dependent on them than they need to be. This also emphasises the important role of caregivers in supporting survivor rehabilitation. If the caregivers encourage the survivors to be more independent and complete tasks themselves, then they may be more likely to have a higher level of independence than if the caregivers help the survivors too much. This would also relieve caregiver strain and feelings of

burden as the survivors would be more independent. This would also provide more time for caregivers to partake in activities they enjoy, allowing them to have a better perceived quality of life. Helping caregivers know how to support survivors in independent living should be a key focus of caregiver support.

However, it is worth noting that quality of life is subjective and based upon experience. Therefore, the survivor and caregiver participants may not have reported a better perception of their quality of life if the survivors were more independent, and the caregivers had more time to themselves, even if perceived feelings of strain and burden may be less. This confirms the literature reported in Chapter 2 by Gosman-Hedström and Dahlin-Ivanoff (2012) and White et al. (2014) who assert that caregivers often feel confined or restricted in their role, and also Bäckström and Sundin (2009) who noted that survivors may unintentionally present barriers to caregivers getting alone time, away from the caregiving role.

Highlighting that it is best for caregivers to actively encourage survivors to be as independent as possible, Ruth's youngest daughter reflected that:

> *"Trying to put yourself together in order to re-engage in motor activities is quite key and I think it is an important issue for people because otherwise the person who has had the stroke can become even more dependent on their family members."*
>
> (Ruth's youngest daughter: interview 1)

This was demonstrated by Sarah and her daughter. Sarah maintained the routine learned whilst she lived temporarily with Sarah's daughter post-stroke. This sense of routine assisted Sarah in maintaining a level of independence once she moved into her current home. Sarah's daughter reported that independent living was a priority in the way she provided support for her mother, as she considered supporting independent living to be a key aspect of the caregiving role. This supports suggestions made earlier in Chapter 4, for a more rigorous caregiver policy which provides greater detail as to how caregivers can encourage and motivate stroke survivors to undertake tasks whilst providing adequate care and support.

Where the suggestion previously put forward suggested a focus on practitioners integrating social participation into rehabilitative programmes, the focus on independent living routines in rehabilitative support practiced by Sarah's daughter indicates a key contribution to survivor

independence. This further supports the author's previous statement that caregiver policy and stroke support service should support caregivers in helping survivors in independent living.

Sarah was able to carry out aspects of her everyday life independently which reflected on her self-esteem and confidence, aiding overall recovery and perspective of post-stroke quality of life. This was expressed in Sarah's interview as she reflected that she was independent at home. Therefore, the author considers that it would be valuable for practitioners to inform ways of supporting survivors in independent living routines. The flip side of this of course is that the more independent the survivor is, the less strain there may be on the caregiver. For instance, if Sarah's daughter had not thought to leave clothes out for her each day, there would be a chance that she would be making additional visits to Sarah to assist her in dressing each morning. Sharing these thoughts around the value of independent living, Ruth's daughters also expressed a value in independent living.

Ruth's youngest daughter recounts that supporting independent living required a degree of commitment of time and patience alongside her other commitments. Therefore, a focus on participation in the internal environment and independent living would be beneficial to survivors of stroke and their caregivers prior to the survivor being discharged from hospital, and particularly for those survivors who do not have family at home or nearby to assist them.

8.4.1.2.1 Social Participation and Rehabilitation

Sarah's daughter, John's partner, Ruth's daughters and Thomas's wife reported that they felt a responsibility to improve survivor social participation and support the survivors in independent living. Sarah's daughter and Thomas's wife encouraged the survivors to do their exercises and move around the house in order to encourage increased mobility and help them to retain independence, contributing to their social participation and rehabilitation.

Also being aware that depression can be an outcome of stroke, Sarah's daughter reported that she actively encouraged her mother to be as independent as possible and 'not give up':

> *"I don't want her to give up on herself, I've got to push push push and I want to push because I don't want her to go to a corner."*

> (Sarah's daughter: interview 1)

The significance of carers wanting to support survivors in independent living and improving social participation confirm the findings of Morris et al. (2014) who assert that caregivers are often key to supporting survivors in rehabilitation and recovery.

Expressing a key challenge they faced, Ruth's daughters considered making the initial transition from:

> *"Being in hospital for quite a long time and encouraging her* (Ruth) *to get back to social and personal activity; to be as independent as possible."*
>
> (Ruth's elder daughter: interview 1)

> *"It was becoming a little bit more stressful and requiring a bit more intervention and tending to be a bit last minute."*
>
> (Ruth's elder daughter: interview 1)

Ruth's youngest daughter acknowledged that this transition stage impacted more so on her sister (Ruth's eldest daughter) as she lived more locally to Ruth's home. This contributes to the existing literature in that this presents a further challenge in the caregiving role, but this case also rejects Johnson and DeSouza (2009), Kuluski et al.'s (2014) and Twigg and Atkin (1994) theory of kinship obligation as here it was not the eldest sibling taking sole caregiving responsibility but the closest, and in Ruth's case, two of her four children are supporting Ruth in her everyday life. Similarly, Penny's daughter also contradicted this theory as she had a brother who lived a considerable distance away:

> *"And a sister who's less than useless, so there you go, it's all down to me."*
>
> (Penny's daughter: interview 1)

Therefore, the notion that caregiving responsibility (where there is no spouse) automatically falls on the eldest child has been found to be untrue in this study. In fact, the findings suggest that the caregiving responsibility where there is no spouse falls to the child who either resided closest, or was most willing to provide care. This further supports the notion of assessing caregiver willingness to care (Thompson and Ryan 2009) which has been addressed by the Carers Strategy: Second National Action Plan 2014 – 2016 (discussed in Chapter 4 previously, Section 4.3.4.

A contribution to the literature reported in Chapter 2 surrounds the notion that caregivers can unintentionally inhibit stroke recovery (Oswalt et al. 2009) as contrary to this opinion, in this study, the findings report that in some instances the caregivers were very much consciously encouraging the survivor participants:

> *"I was chivvying you* (John) *up, making you do the exercises, making you, doing the speech therapy."*

<div align="right">(John's partner: interview1)</div>

This suggests that John's partner assisted in John's rehabilitation as she kept encouraging him to do his exercises. This motivated John which supported his rehabilitation. However, this did not occur in every case in this study. Sarah's daughter, Ruth's daughters and Thomas's wife were aware that they may be offering too much caregiving support and indeed, Thomas's wife was aware that Thomas was *"not as agile as he was"* (Thomas's wife: interview 2) at the point of the follow-up interview.

This indicates that Oswalt et al.'s (2009) claims are not clear cut. In this study, there are some areas where the caregiver participants may unintentionally inhibit the survivor participants' recovery by helping too much, but there were also some instances where they were aware that they were helping too much, such as Paul's wife who asserted *"I suppose I am guilty of helping him too much"* (Paul's wife: interview 1), and others such as Sarah's daughter, John's partner and Thomas's wife where they were actively encouraging recovery. Although Oswalt et al. do not claim that all caregivers unintentionally inhibit recovery; these findings contribute further knowledge of this research area by providing further dimensions to their theory. Furthermore, it cannot be assumed that one individual caregiver exhibited solely one or another of the behaviours identified, but that they may fluctuate between encouraging the survivor and unintentionally doing too much, depending on the situation they are in. This could even reflect the caregiver's confidence and level of feeling they want to protect the survivor in certain environments. This finding is key in helping to understand how to support survivors and their caregivers as it informs the type of support caregivers need in their caregiving role.

Reflecting on the notion of caregivers inhibiting recovery by helping too much, Paul's wife acknowledged that she perhaps provided too much assistance in daily tasks, which discouraged Paul from trying to do things for himself. However, as this section highlights, caregivers of this

study also provide encouragement for their caree to carry out rehabilitative exercises, and encouragement to be independent.

The author also observed Stroke Club members participate in rehabilitative exercises at Stroke Clubs A, B, C, and D. The exercises varied from club to club, were based on physiotherapy movements and were interactive. The exercises consisted of movements which mimicked the range of movement used to get dressed and undressed, and household tasks in an attempt to support that range of movement. Stroke Club B consisted of voice exercises and Stroke Club C and Stroke Club D consisted of seated exercise to music from a professional. However, during observation 1 of Stroke Club D exercises were played on a projector screen whereas observations 2-4 were in person. This highlights that this provision is not consistent. The exercises were based on physiotherapy movements and were interactive with use of a ball to pass to each other and catch, and songs to sing along to. The exercises included movements such as putting on gloves, and also coordination exercises. These exercises were designed to help the members dress independently and carry out tasks at home. All of the members of Stroke Club B participated in the voice exercises which consisted of mouth movements, talking, and thought-provoking tasks such as 'name a name beginning with the letter A' games. Commenting on this this activity, Jane observed that the speech exercises at Stroke Club (Stroke Club B) had helped her with her speech. However, Jane did state that she felt more at ease when talking around family and friends as opposed to strangers.

John had sought such speech exercises, however they were not offered at his local Stroke Club. This highlights inconsistencies in delivery and suggests that if the clubs had a standardised activity role then the members would all have the opportunity to access the desired activities. This suggests that there is an opportunity to improve stroke support via the Stroke Club delivery by initiating speech and language sessions across them all. This of course would have resource implications. Notably the Stroke Club which Thomas attended did not have rehabilitative exercises. Reflecting on Thomas's wife's comments in Chapter 8, where she stated that she felt that she had a responsibility to motivate Thomas to do his exercises, if Thomas's Stroke Club had held rehabilitative sessions then this would have assisted in motivating Thomas; perhaps relieving Thomas's wife of the responsibility she had felt.

The majority of survivors in Stroke Club C and D participated in the exercises, and were all encouraged to do so. The Stroke Club hosts felt that the exercises (both verbal and physical) had helped the survivors. The hosts commented that they had seen an improvement in many of the

members who engaged with the exercises they offered. The exercises were participative and were facilitated in a very informal way which meant that the participants were laughing and joking throughout the sessions. Survivors from Stroke Clubs C and D also sang along to the songs they liked when they were played, carrying out actions to songs such as 'The Hokey Cokey' and 'The Twelve Days of Christmas' during their physical exercise sessions. It was a notable observation that the voice exercises (Stroke Club B) were facilitated in a way that encouraged participation, for instance taking it in turns going clockwise around the circle, each person in turn. The participants were also encouraged to try for themselves, with hints by volunteers if they were really struggling to say the words they wanted which allowed them to complete the rest of the word themselves.

8.4.1.2.2   Housework

Describing Sarah's independence at home, Sarah's daughter stated that Sarah:

> *"Will dust the house and clean the kitchen floor on a regular basis."*
>
> (Sarah's daughter: interview 1)

Sarah's daughter carried out a *"thorough clean* [of her mother's home] *every six or eight weeks"* (Sarah's daughter: interview 1), in addition to hoovering and carrying out a quick clean every Sunday. This demonstrates how Sarah's daughter provided assistance for Sarah in her home to support Sarah in managing the home herself.

8.4.1.2.3   Food preparation

Reflecting on the early stages of Sarah's post-stroke life, Sarah's daughter observed that she herself had considered ways to enable her mother to be more independent at home. Due to her concerns about Sarah cooking meals at home in case she left the cooker on (as she had done before) Sarah's daughter would prepare meals for Sarah to reheat in the microwave. Prior to this Sarah's daughter had left notices up around the home to remind Sarah to turn all of the kitchen appliances off. However, neither Sarah nor Sarah's daughter liked the note as they felt that it affected Sarah's dignity and pride, particularly if friends came over to the home and saw the notices. This led to alterations being made. Sarah's daughter bought a toaster for Sarah to use

instead of a grill, and a microwave instead of the oven. This demonstrates that Sarah and Sarah's daughter developed an adaptive strategy.

8.4.1.2.4   Money Management

Sarah's daughter assisted with money management, describing how she would pay the household bills on behalf of Sarah. Sarah's daughter would also separate Sarah's money into envelopes for each day of each week to allow Sarah to maintain a sense of financial independence:

> *"I do her money every week with her, she likes doing Sunday school savings but I still want her to have her independence, I'm a strong believer……I don't want to take everything away from her so I give her her purse, and I give her £100 – I've got it to do with her and she will do it like this: she gives me £40 for her electric, her gas, her phone and her lottery and papers…. so that's the £40 which leaves her with £60. I have to do it like that so she knows what I am doing. She gives me £20, puts it in little wallets because she saves £16 every week for Sunday school savings; it's a club she has to save money for each week through the year for her Christmas spending. Then she gives each grandson £2 into their Sunday school savings, so that's the other £20 which leaves Mam with £40 which is her pocket money."*

<div align="right">(Sarah's daughter: interview 1)</div>

This supported Sarah in independent living as money was distributed into money wallets to make sure she had enough for the week, and she can distribute the money to the relevant payees.

Activities held at the Stroke Clubs also provided the opportunity for survivors to improve their numerical and money management skills. John reported that he had gained more confidence with handling money through activities at his local Stroke Club.

8.4.1.2.5   Participation in the Home Environment

Demonstrating his involvement in maintaining the family home, during his first interview, Paul presented a wooden display unit which he had made for displaying ornaments inside the house, and showed the researcher a coal bunker which he had built, located outside in the garden. Contributing to discussion presented earlier in the chapter, this highlighted how Paul discovered ways of continuing his woodwork and joinery hobbies and interests through various adaptions. This allowed Paul to contribute to manual tasks within the home.

Similarly, Thomas also continued to engage in do it yourself (DIY) tasks around the home and garden post-stroke, reporting in his follow-up interview that he had recently fixed the fireplace in the living room. This supports earlier claims of feeling motivated to continue to contribute to the home environment in ways that they did prior to stroke. This may contribute to building upon survivor self-esteem, confidence, and identity forming post-stroke.   However, Thomas acknowledged:

> *"Obviously I can't do what I used to do; used to do a bit of DIY which is very limited now."*

> (Paul: interview 1)

 The author considers this to be another dimension which confirms King and Hicks (2008) theory of accepting the outcome of stroke and having a realistic perception of one's own abilities post-stroke in order to be able to come to terms with post-stroke life; as this could be considered a by-product of coming to terms with stroke and moving forward with a post-stroke way of life.

Paul, Mark, and Jane report that they enjoyed gardening, as did Richard's wife. However, Mark reported:

> *"I like my gardening, although I'm getting less able to do it; my wife now has a tendency to take over now."*

> (Mark: interview 1)

This highlights a variation to his wife's role within the home since Mark experienced his stroke. Similarly, Paul enjoyed tending to his own garden, however he also tended to a vegetable plot at a neighbour's home where he produced vegetables for local shows.

This challenges the definition of social participation as defined by Stiers et al. (2012) earlier in Chapter 3, as for those survivors who enjoyed gardening, this can be considered an individual activity, however under Stiers et al.'s definition, it is a domestic role within the internal environment. Furthermore, Paul's interest in showing his produce merges his gardening hobby into social participation in the external environment. Therefore, the activity itself must be clearly defined along with its intent in order to ascertain whether or not it is: (i) an activity or a hobby, a contribution to the internal environment, or (ii) a contribution to the external environment. Stiers et al.'s (2012) earlier definition of social participation in the internal and external environments may be to some extent, reflective of or guided by the individual activities a person participates in, inside and outside of the home. Paul also highlighted that he had always enjoyed gardening, and that as he was now retired he had more time to pursue his interests. This notion was earlier reported by John who asserted that he had more time to persue his hobbies when he retired. This again highlights that the changes in levels of engagement in hobbies and interests reported by the participants are not necessarily a post-stroke life change, but that they have more time to pursue their interests due to being retired because of the outcomes of their post-stroke.

Paul reported previously that he had *"become obsessed with food"*, adding to this, Paul's wife commented that he *"makes the most wonderful sandwiches"* (Paul's wife: interview 1) and that Paul is capable of cooking. However, Paul's wife described how when cooking a hot meal Paul would not necessarily prepare and cook the meal in the right order:

> *"He has problems sequencing, because he will do the jobs he can do first, so new potatoes he can do, he'll cut potatoes in half and put them in the pan so he'll do that because he can do that but won't think about the meat having to go into the oven because it'll take longer, he just focuses on 'he's going to make food', so he just gets the easy bits he can do over with first."*

> (Paul's wife: interview1)

This meant that often the ingredients for the finished meal would not be cooked and ready at the same time:

> *"He'll put gravy granules in the water, but then won't think of heating it in a microwave because it looks alright."*
>
> (Paul's wife: interview1)

However, Paul was motivated to participate in meal preparation despite these challenges.

Paul's wife also recalled two occasions where Paul had set fire to the microwave:

> *"Twice he's set fire to the microwave, two different microwaves, he put a jacket potato in, like a small potato, and put it on for 15 minutes, and has no sense of smell so even when it starts burning he doesn't realise and that's twice now, so would have been things like that I would have worried about".*
>
> (Paul's wife: interview 1)

Paul's wife began to assist in the kitchen with cooking meals due to these challenges. However, notably Paul's wife would assist rather than 'take over', thus supporting earlier claims that the caregiver participants of this study sought to support survivors in their everyday lives, rather than limit activity. Similarly, John's partner would often assist with cooking, whereas Thomas's wife recounted that typically Thomas would make a cereal breakfast and cups of tea in the morning and she would cook the hot meals.

As previously mentioned Paul's wife took on the management of household bills and administration. This also applied for Sarah's daughter, John's partner and Thomas's wife. However, John's partner highlighted: *"I'd rather help him with filling in forms"* (John's partner: interview 1) suggesting that her role here was more of an overseeing role rather than her doing things on his behalf. John's partner would also:

> *"Take him to appointments where I've got to sort of speak for him."*
>
> (John's partner: interview 1)

222

Here John's partner also presents another aspect of the caregiving role where she would act as a mediator in John's meetings due to his post-stroke communicative ability. This further demonstrates another way in which caregivers may provide support for survivors of stroke in their everyday lives.

8.4.1.3   A Change of Roles and Family Relationships

Throughout this chapter, findings are discussed which highlight that there are some role changes in the family unit post-stroke. Chapter 2 asserts that in some cases survivors of stroke transition from being care providers in the family unit; for example, a parent looking after their children, to being cared for by their children (Presho 2008). This role reversal was apparent in case studies where some of the caregivers were providing care for their parents. Furthermore, as a single parent of dependent children, Penny's daughter used to rely on Penny to look after her children on occasion, however the outcome which stroke had on Penny meant that Penny was no longer able to child mind for her grandchildren.

Highlighting a change in role within their cohabiting unit Paul's wife reported of a *"role reversal"* (Paul's wife: interview 1), where Paul had called for his wife to tell her that the fridge had stopped working, asking her to fix it:

> *"I was in here* (in the living room) *one night and Paul was in the kitchen, and he came through and said "the fridge isn't working" so I automatically went into the kitchen, pulled out the fridge, and hit it with a wooden spoon, and I mean I don't know why I hit it with a spoon but it started working again so I pushed it back and then said "you know what, in any other house it's the wife who asks to husband to fix things" and all he did was laugh."*

(Paul's wife: interview 1)

Mark also described a role reversal within the home from him being the major breadwinner to him not being able to run his business anymore. Therefore, Mark's wife (not interviewed) had also experienced a change in her role as she became the major breadwinner. This had a negative impact on Mark's self-esteem as he described that he felt he was *"fit for nothing"* (Mark: interview 1). These feelings contributed to Mark experiencing a *"downward spiral"* (Mark:

interview 1). Mark's explanation of his depression feeling like a downward spiral resonates with the NHS Choices (2014) description of feelings associated with depression

This provided an example of Boosman et al.'s (2011) notion of 'role switching', further demonstrating how caregivers often lead multi-role lives, presented earlier in Chapter 2. Further to this, John's partner reflected upon another role within the caregiving spectrum. When John became unwell, John's partner reflected:

> *"They wouldn't see you in hospital, so I was being a nurse then."*
>
> (John's partner: interview 1)

The hospital would not admit John onto a ward because he was contagious. Although this experience was not stroke-specific, it is still an important element of everyday life as it further demonstrates that the caregiving role is variable in nature.

Considering support within the internal environment and the survivor-caregiver relationship, Sarah reflected upon her life with stroke and summarised that both her and her daughter have *"been like clockwork"* (Sarah: interview 1) and asserted along with Ruth that she had not taken any of the support which she had had form her daughter for granted. Similarly, Thomas's wife and Richard's wife reflected that:

> *"It's been ok up to now, we're managing alright."*
>
> (Thomas's wife: interview 1)

This suggests that the study participants, although they manage post-stroke life differently and the caregiver participants provided care for survivors in different ways, all of the participants had adapted to post-stroke life in a way which suited the survivor's personal circumstance. This further emphasises the unique nature of the stroke experience and the caregiver role.

8.4.2   The External Environment

Social participation in the external environment includes engagement in education, employment, engagement with community groups and clubs, and social engagement (Stiers et al. 2012). This section informs of the barriers to social participation in the external environment as reported by caregivers.

The survivor participants asserted that adopting a positive attitude enabled them to increase their social activity over time. Mark, Jane, Ruth, Paul and Paul's wife expressed that it was important to meet people and socialise as this contributed to a positive lifestyle. This shows their awareness of the effects that a positive attitude can have on post-stroke life. This supports Berges et al's (2012) theory of positivity which was discussed previous in Chapter 7, Section 7.6.

Five of the survivor participants (Paul, John, Mark, Jane, and Ruth) reported that they felt they had a good social life whilst Penny considered her social life to be poor. At the point of the follow-up interview Thomas and his wife stated that they had started going to concerts, despite saying that they *"don't go out as often as we used to"* (Thomas's wife: interview 1). This suggests that social participation can improve with time. Furthermore, Richard's wife reflected upon Richard's aforementioned post-stroke fatigue and his not feeling safe away from home, and described that this had impacted on his level of engagement outside of the home. This supports Stiers et al.'s (2012) theory of emotions being able to impact on social participation and also the individual's own feelings. However, Richard reported being more socially active post-stroke than he had been in recent years which suggests that him not feeling safe away from home is due to concerns which surround his increased fatigue. Therefore, it may be that Richard felt less confident to leave home as he was not sure if he would become suddenly tired.

On the other hand, Jane reported feeling safe in her local community. This suggests that there are other factors to consider. Jane's local town was a place that she considered *"everybody knows each other"* (Jane: interview 2), a place where everyone and everything is familiar. Whereas Richard resided in a deep rural area, a considerable distance away from a local village or town. It may be that the local towns or villages host different levels of community integration and community life, however it could also be that pre-stroke levels of community engagement were different for Jane and Richard. However, both Jane and Richard were employed in their locality and Richard worked with community groups, thus highlighting that the place they live may be a

factor as well as the distance to the nearest village or town. It could also be confidence. As previously reported both Richard and Jane experienced verbal communication difficulties, however Jane had more verbal ability than Richard. This may be why she feels more confident outside of the home than Richard. However, the point here is that there are various aspects to consider when comparing the case studies.

The communication difficulties reported by John, Jane and Richard had also meant that they engaged less in social participation, however Jane reported that confidence in her speech had improved as she had joined Stroke Club, and this gave her the confidence to socialise more.

Highlighting an example where social participation had been positively influenced by feelings of contentment within the local environment, during her first interview Jane identified that people from her local town knew her and were able to understand what she was trying to say. This helped Jane feel confident shopping locally and practising her communication:

> *"It's good being* [in a] *local area, people know me and* [if I] *want apples* [I] *just point and* (holds four fingers up) *and they know* [what I] *want"*.
>
> (Jane: interview1)

During her follow-up interview Jane built on this information and reported that she had begun to enjoy going to the local pub with friends and felt confident to do so. She found it easy to socialise, Jane reiterates: *"everybody there ………knows me … you see"* (Jane: interview 2) which suggests that unlike Mark and Richard, Jane felt that there was an element of community support within the area where she lived. This helped her feel confident outside of the home which had a positive impact on her engagement in social participation, particularly as Jane reported that her speech was better when she felt confident in her surroundings. This suggests that the community support where the survivor lives can have an impact on recovery and adaption to post-stroke life.

8.4.2.1   Online Communities and the Internet

Paul reported during his follow-up interview that he had gained an interest in technology and had begun to use online banking; accessing banking services from his own home. This had allowed Paul to manage the household finances after his wife's death. Further to this, and as previously

discussed, Paul (interview 2), John (interview 1), and Mark (interview 1) reported that they actively engaged in online communities and on social networking sites. Although internet use can be included in the internal environment, in this context, the internet is considered as a connection into the 'outside world', and thus is categorised by the author as participation within the external environment.

Over the last decade the use of social media and the internet has dramatically increased the opportunities for people socialising globally (Simplican et al. 2015). More specifically, social networking sites such as Facebook and Twitter have enabled people to engage in online communities, allowing them to keep in touch with friends and family, and also participate in social and political engagement. This highlights an avenue for intellectual fulfilment and social stimulus, which in this context contributed to the everyday lives of people living with stroke. Gil de Zúñiga et al. (2012) consider social networking sites to be pro-social, commenting that social networking often supports people in constructing their personal identity, form social relationships and for entertainment (Gil de Zúñiga, et al. 2012). This research study also confirms this. For example, Mark explained that he enjoyed engaging in online debates:

> *"It's interesting to talk to people, to challenge people. They don't know who I am, I don't always know who they are; but it's the engagement in their opinion. Finding out what makes people tick."*

(Mark: interview 1)

John stated that he enjoyed using social networking sites to communicate with people and felt confident in doing so. John had learnt to use social networking sites at his local Stroke Club. Communicating online using a keyboard allowed John time to think about any comments he made and he was able to communicate them in the same way as everyone else; by text. This took away the need for him to communicate with people with his caregiver (his partner) alongside to help him converse what he was trying to say. This suggests an avenue for feeling independent. However, John's partner observed that John was *"struggling with emails"* (John's partner: interview 1) because he had difficulties in reading, writing and interpreting written communication. Johns wife went on to explain that with social networking sites John was able to view short written posts from other people and see pictures, *"something that isn't easily observable by email"* (Johns partner: interview 1).

At the point of follow-up interview Paul also informed that he had been using social networking sites to communicate:

"When I was in Australia, my daughter put me on Facebook, so she can keep in touch. She persuaded me to get an Apple iPad, so I can go through there. So, I mean, I'm getting more into technology than I was, and I'm enjoying it, it keeps me out of mischief (laughs). So that's a change, for the good".

(Paul: interview 2)

Paul is using social networking sites to keep in touch with his family who live abroad. This demonstrates the way in which social media sites reduce barriers to social participation in the external environment. Therefore, such advances in technology allow for increased social engagement as the participants are able to engage with other people, online, from their own home. This can potentially reduce feelings of isolation and loneliness which contribute to feelings of depression (Gilbert 2014), and provide an avenue for survivors to form an online identity which may present the self that the survivor wants to present, sharing only what they want to with the outside world. This may reduce feelings of vulnerability and perceived public stigma (defined and discussed earlier in Chapter 7, Section 7.5). Mark also identified that the internet can be an outlet for people with shared experiences to communicate and acknowledged the impact which technological advances have had on people's lives. Expressing that he felt that disabled people are not often heard in society, Mark reflects on the benefits of the internet for disabled people:

"I believe the internet is the way forward for disabled people, who can't connect physically, somehow, they can get a coming together."

(Mark: interview 1)

This is an area which the Welsh Government aims to address in the 2014 Social Services Wellbeing Act through its initiatives to provide a stronger voice for its service users. Mark reported that he gained intellectual fulfilment through use of the internet. Demonstrating that he felt that the internet had given him a voice, Mark described how he had also created a website to campaign for areas of interest he felt strongly about, bringing matters into public debate. One key area of current interest was described by Mark during his follow-up interview, as wanting to *"prove the cruelty of man to man"*, explaining that he felt that *"people in society can be cruel"* (Mark: interview 2).

"I hope I have another 20 years of this (his current life)*, because then, I'll get to really prove my point, insanity and the cruelty of man to man"*.

<div align="right">(Mark: interview 2)</div>

The findings here support the notion of telecare packages from the statutory sector (discussed earlier in Chapter 4) as they have the potential to provide more regular communication between service users and professionals. However, the findings also suggest that social networking sites may be another avenue of exploration for the initiative, or a community online forum, particularly for those service users who may have communication difficulties as they allow for easy access to imagery, verbal communication via podcast and video link, as well as written form.

8.4.2.2   Engagement in Educational Activity and Re-learning Skills

Prior to stroke John was highly computer literate however he *"lost all his keyboard skills"* (John's partner: interview 1) when he experienced his stroke. Since his stroke John had pursued his interest in computers and retrained, learning basic computer skills at a local library and at his local Stroke Club. John described how he was actively engaging in educational activities at a local college and in order to relearn some of the skills that he had *lost since stroke"* (John: interview 1). John was also relearning money management and numeracy skills at his local Stroke Club using *"pretend money and* [playing] *Sudoku"* (John: interview 2). When asked during his follow-up interview if the money practice had helped since the first interview, he replied *"I think so"* (John: interview 1) to which John's partner said:

"He tends to just give the cashier a note at the shop and come home with lots of change, I think he finds it easier than dealing with change".

<div align="right">(John's partner: interview 2)</div>

To which John nodded and laughed in agreement.

During his first interview, John stated that he had enrolled on a course on researching family history which he had completed at the time of the follow-up interview. John's enrolment onto the course at college resulted in the college asking John to talk about his life with disability to

<div align="right">229</div>

students on another course, which he enjoyed. John felt that this broadened his socialising opportunities. John's motivation to purse social opportunities to relearn the skills he had lost when he experienced stroke demonstrated how he was working towards rebuilding his life, working towards attaining the skills he had had prior to stroke. This suggests desire to return to a pre-stroke life to be at the route of his motivation, driving John to participate in educational and social activity. This highlights that rehabilitative support needs to be person-centred. Learning about a person's pre-stroke life and helping them to find ways to return to that pre-stroke life could provide them with the motivation they need to rebuild their lives post-stroke. This supports the notion of goal setting as reported by Reed et al. (2010), which Reed et al. suggest is usually provided through community support, through avenues such as the Stroke Club and local college as John exampled.

8.4.2.3 Survivor Engagement in Employment

Stiers et al. (2012) consider employment, either voluntary or paid, to be an avenue of social participation. As identified in Chapter 6, the outcomes of stroke resulted in five of the survivor participants (Sarah, Paul, John, Mark, and Jane) leaving paid employment post-stroke as they were unable to continue their current vocations. John, Paul, Ruth and Jane acknowledge the importance of social activity, whilst Jane commented that it was important to *"get out and about"* (Jane: interviews 1 and 2), and did so by taking on voluntary work. At the point of first interview, Jane was volunteering as an assistant at a charity shop and also the stroke support group of which she was a member. During the follow-up interview Jane informed the researcher that she had taken on more voluntary work; at a bird sanctuary and also helping housebound people, stating *"it helps me to help people"* (Jane: interview 2) as it gave her a sense of responsibility and purpose. This helped to form Jane's post-stroke identity.

Whereas Chapter 4 described and confirmed that policy makers, practitioners, and academics are in agreement that the third and social enterprise sectors provide a useful avenue for providing support to survivors and caregivers, the findings from this study also highlight that they do more than that; they also provided voluntary employment for the survivor participants. Paul also carried out voluntary work for a social enterprise which he was introduced to at his local stroke group. This enabled him to use his own skills to make items which assist people living with disabilities in their everyday lives. This *"hobby with a purpose"* (Paul: interview 1) assisted him in finding motivation to do things and provided an opportunity to socialise. This supports the

notion of survivors being motivated to rebuild their lives post-stroke through opportunities such as this, discussed in 8.4.2.2.

Both Paul and Jane report of their voluntary employment as a means of socialising and *"keeping busy"* (Jane: interview 2), highlighting how voluntary employment had reduced barriers to social participation and socialising. Jane felt that her voluntary employment also helped to retain a good level of self-esteem and maintain a sense of her pre-stroke identity; supporting Bäckström and Sundin's (2009) notion of survivors seeking to retain a sense of pre-stroke life, as discussed earlier in Chapter 3, and the previous section (Section 8.4.2.2). This highlights the third and social enterprise sectors as a source of support for survivors in their everyday lives, contributing to research aim 3: To explore how the social enterprise sector delivers support to survivors of stroke and their caregivers.

Furthermore, John and Ruth demonstrate how their local Stroke Club had become an avenue for voluntary employment in that they had become committee members of their local Stroke Club. Ruth reflected that she had initially felt that: *"no more was I going to be in charge of anything"* (Ruth: interview 1) as part of her initiative to have a less stressful post-stroke life. However, she was encouraged to take on the role as the committee was formed to run their local Stroke Club as a result of a threat of closure (discussed further in Chapter 9).

The findings suggest that where Jane volunteers at a local charity shop, she does so for her own incentives, such as to *"keep busy"* (Jane: interview 2) and to get her *"out and about"* (Jane: interview 2); highlighting that it is important to her psychological wellbeing, conforming to the non-idealist theoretical perspective. However, when Jane volunteered for the Stroke Club and the home help centre, she was conforming to the idealist perspective in that she volunteered to help people within those groups, suggesting that a person may not necessarily portray the behaviour of either one or the other perspectives. Similarly, where Paul volunteered with a voluntary organisation, he was conducting a combination of the two as his incentives are initially to help people in wider society, but also had the incentives of keeping busy and practising his skilled hobbies of carpentry and joinery. The findings suggest that those survivors who were not able to gain paid employment but were able to seek voluntary employment, reaped the benefits in that it helped them to build a sense of identity and maintain their physical and psychological wellbeing; conforming to the non-idealist perspective.

8.4.2.4   Caregiver Employment

As the Table 4, in Chapter 6 previous shows, Sarah's daughter, Paul's wife, Penny's daughter, and Ruth's daughters were employed part-time alongside their caregiving responsibilities. This demonstrates the multiple roles and responsibilities of the caregivers in their everyday lives with Sarah's daughter reporting light-heartedly: *"I divorce my husband on a Sunday"* (Sarah's daughter: interview 1). Ruth's youngest daughter who resided a considerable distance away sought employment in Wales in order to help her sister care for their mother mid-week. This meant that Ruth's youngest daughter commuted a long distance during the week, staying away from her own family unit. This not only demonstrates a change to Ruth's daughter's (b) life, but also her own immediate family back at home. Ruth's youngest daughter reflected that:

> *"It just happened to be at the right point in my working life and personal life where it was possible to give up work* (her previous place of employment) *and then come and actually spend part of the week up here and part of the week back home."*
>
> (Ruth's youngest daughter: interview1)

As mentioned earlier, this highlights an area of contradiction to Johnson and DeSouza (2009) and Kuluski et al.'s (2014) theory of kinship obligation as here, caregiving responsibility was shared – despite the distance between residences within the studies sample. Reflecting on her employment, Paul's wife stated that she sometimes felt her employment was a *"break away"* (Paul's wife: interview 1) from the caregiving role. This supports the theory reported by Bäckström and Sundin (2009) earlier in Chapter 2 which reported caregivers viewing their employment as an opportunity for time away from the caregiving role.

8.4.2.5   Engagement in Community Groups

As Table 4 in Chapter 6 previous shows, seven of the survivor participants stated that they attended Stroke Club on a regular basis, some of which attend with their caregivers.   Richard and his wife noted that they attended Stroke Club on an occasional basis and Sarah regularly attended a day centre run by the local authority services, thrice weekly. Survivors also reported that they attended the Women's Institute (Sarah), chapel or church (Sarah and Paul), an over 50s club (Paul and Mark), a gym (John), a luncheon club (Paul), a book club (Richard) an osteoporosis group (John), an employer-related retirement club (John and Thomas), and a GP-

referral rehabilitative exercise class (Sarah). Notably, during her interview Sarah used the phrase 'I belong to' which suggests a sense of attachment; a belonging to a group. Such phrase and attachment to a group, is thought by Goffman (1967) to contribute to a sense of individual identity.

In the wider community, participants from case studies 2, 3, and 9 reported going to clubs which they were invited to through friends they had made at Stroke Club. This demonstrates that Stroke Clubs were also an avenue for other social opportunities for participants to engage in. Notably those caregivers who were spouses of the survivor participants also attended Stroke Clubs with the survivors, informing of a social aspect to Stroke Club which the survivor and caregivers may participate in together. Paul's wife reflected *"we don't have a bad social life actually"* (Paul's wife: interview 1) noting that both herself and Paul got invited to attend the Over 50s club by a member of their local Stroke Club. Paul's wife further commented:

> *"We went there and we knew different people, and through that, a girl we met there* (at the local Stroke Club) *invited us to the luncheon club, so we go to the luncheon club, and then, from the luncheon club we got invited by a friend of ours, who invited us to go to the church carol service, which we did, and we enjoyed it so much we started going to the church on a Sunday."*
>
> (Paul's wife: interview1)

Emphasising that: *"all the time we were meeting new friends"* (Paul's wife: interview 1). Paul and his wife had been proactive in finding avenues of social participation in the external environment through social groups within their local community. As previously mentioned in Chapter 7, Paul would also attend his wife's place of work. Paul would see his wife and visit his wife's employers club house and socialise with the members, however, since his wife's death Paul no longer felt a need to go there.

Reflecting upon her and her husband's pre- and post-stroke lives, Thomas's wife compared:

> *"I find the social life a bit lacking to what it was in Spain."*
>
> (Thomas's wife: interview 1)

This emphasises the impact of the life change which Thomas and his wife encountered when they returned back to the UK after Thomas's stroke.

Penny reflected that she used to play bingo, and stated that:

> *"There was an afternoon club there on a Monday, I used to go there."*
>
> (Penny: interview1)

However, the impact of Penny's stroke had prevented her from attending such social groups with exception of her local Stroke Club. Furthermore, Penny stated that the only time she would leave her house was once a month to attend her local Stroke Club. John also revealed that he had stopped attending several general interest clubs due to the impact that stroke had had on his life. However, John still attended the real ale club meetings post-stroke although his role there had changed. Before his stroke John would manage the website design, after stroke he attended as the club's photographer instead. Richard reported that he had recently become a less regular attendee of his Stroke Club due to increased post-stroke fatigue and the distance it was to travel from his home:

> *"It's too much in a day; he's tired before we get there."*
>
> (Richard's wife: interview 1)

Mark felt he gained intellectual fulfilment through his membership of a political organisation and also the *"the old peoples club"* (Mark: interview 1) which was an over 50s social club. Mark described:

> *"They're not all stroke victims, or they're not all disabled; some of them are quite bright, and I like that, I like intellectual stimulus".*
>
> (Mark: interview 1)

Throughout his interviews Mark expressed a desire for intellectual fulfilment, however again there were contradictions against earlier statements presented by Mark. As previously stated, Mark sometimes felt the desire to be left alone. Perhaps some days Mark felt better than others, or perhaps it was that Mark felt secure in certain groups of people he knew and certain community groups which he associated himself with, further highlighting the importance of such groups to Mark's everyday life. Expressing the importance of positivity in his everyday life

Mark commented that he consciously surrounded himself with positive people and would avoid negative people *"because* [negativity] *it's contagious"* (Mark: interview 2). This highlights that such membership of a social club or community group is an avenue of intellectual fulfilment. However, during his follow-up interview Mark informed that he had stopped going to the over 50s club as:

> *"It was looking as though it was going to lose funding"*.

<div align="right">(Mark: interview 2)</div>

This emphasises how vulnerable such community groups are (discussed further in Chapter 9). Notably, the Stroke Clubs observed had also faced closure whilst they were an initiative financially supported by the statutory sector and run by the third sector. However, they were taken over by the members and became social enterprises, sustaining their own future (discussed further in Chapter 9).

8.2.2.4   Transport

Paul and Mark reported upon how having a mobility car assisted in independent living:

> *"It's independent, I go on my own I come on my own."*

<div align="right">(Mark: interview 2)</div>

This highlights that support from the statutory sector support and DVLA (Driver and Vehicle Licensing Agency) in regaining a driving licence post-stroke and adapted mobility cars supported Paul and Mark in independent living. However, Paul reported that it was very difficult to obtain the information needed to apply for his driving assessment, indicating further information which could be inserted into the information pack suggested by Paul's wife in Chapter 7 previously. This is discussed further in Chapter 9. Paul described:

> *"I have a special adaption to the steering knob with the controller about the size of a cigarette packet next to the steering wheel – you control it with your thumb."*

<div align="right">(Paul: interview1).</div>

John informed that he lost his driving licence due to him experiencing epileptic secures as an outcome of his stroke. At the time of his follow-up interview John was reapplying for his driving license as he had not experienced an epileptic seizure for two years. This presented an opportunity for John to potentially drive again; increasing his level of social participation in the external environment. This would also reduce strain on his partner in her everyday life as despite holding a driving licence herself, John's partner identified John being unable to drive post-stroke as a barrier to her own (caregiver) social participation:

> *"In the beginning it was a bit difficult; I used to have to take him."*
>
> (John's partner: interview 1).

Reflective of her social life since John experienced his stroke, his partner commented: *"we don't go out and about as much as we used to"* (John's partner: interview 1), and rationalised, *"because of the driving really, I don't like driving in the dark"* (John's partner: interview 1). This suggests that it cannot be assumed that because a caregiver is able to drive, they are confident in driving in all driving conditions. This has already been identified as a factor which impacts on the activities John and his partner engage in, but could also potentially present further challenges when considering hospital appointments.

8.2.2.4.1   A Reliance on Public Transport Services

Paul's wife had never held a driving licence. While Paul was awaiting his driving assessment and modifications to his car, their neighbour would drive them on occasion, but otherwise they would use the bus. Paul's wife described how on occasion, they would still get the bus from the bus stop outside of their house and go to the coast for a day out, however the bus service did not need to be relied upon as a main mode of transport. Paul's wife reflected:

> *"I suppose, if we had been off the main roads it would be more difficult but the fact that we are so handy for local transport anyway."*
>
> (Paul's wife: interview 1)

Both John and Thomas reported that having a bus pass which they obtained on grounds of their disabilities made their travel free of charge and allowed them to access local amenities:

"He wasn't affected at all, he can walk to the bus stop and to the local facilities. The only thing was when there were lots of appointments to attend."

<div align="right">(John's partner: Interview 1)</div>

Thomas and his wife asserted that: *"there's one* [bus] *every 12 minutes or something like that"* (Thomas: interview 1). This bus service passed close to their home while sometimes a change of bus was needed if going further afield for a day trip. Thomas's wife reflected:

"It's been very good since we have been here."

<div align="right">(Thomas's wife: interview 2)</div>

"We chose this house so that we could get easily to the shop."

<div align="right">(Thomas's wife: interview 2)</div>

8.2.2.4.2 A Local Taxi Firm

Thomas' wife further commented that there is a taxi service if they need one, but added:

"If you want a taxi even if for the shortest journey it is £2.50 and when you are on pension you try not to."

<div align="right">(Thomas's wife: interview 1)</div>

Whereas Thomas's wife initially reported that they walked to the bus stop or into town and that they avoided using the taxi as it was considered expensive, during the follow-up interview she reported that she had started to use the taxi service:

"I do get the taxi to my friends because it's a bit far really."

<div align="right">(Thomas's wife: interview 2)</div>

Sarah's daughter provided transport for Sarah on occasion, however Sarah would tend to get a taxi to day centre and to her GP-referred exercise class. Sarah's daughter considered taxis to be expensive and would maybe be cheaper if there were service provisions closer to Sarah's home.

> *"I feel sorry that she has got to pay £12 to get a taxi to go from one village to another, to have the keep fit class just for an hour."*
>
> (Sarah's daughter: intreview1)

However, Sarah's daughter reflected on the value of the service provided and considered that the travel cost to get there was worth paying:

> *"They've got to pay £12 to go to my place of work on a Saturday but that's from choice, isn't it? It's somewhere to go, isn't it? She doesn't have to sit down in a little room on her own on a day that she don't see me."*
>
> (Sarah's daughter: interview 1)

Ruth considered that there would be potential difficulties if the outcome of her stroke was worse, however reflected that she lived local to the services she needed. Ruth used a local taxi service for her main mode of transport. Whilst comparing the taxi to obtaining a lift from a friend:

> *"It's less hassle; I'm not beholden to anybody. I'll use taxis as long as I can."*
>
> (Ruth: interview 1)

This further expressed her desire to remain as independent as possible and informed how using a local taxi firm allowed her to do so.

8.5 Planning Ahead, Holidays and Respite

As affirmed in Chapter 2 previously, stroke can result in uncertainty which can lead to survivors and caregivers often avoiding making plans for the future. Eight of the nine survivor participants (Sarah, John, Mark, Richard, Jane, Penny, Ruth, and Thomas) stated that they were not considering any holidays in the near future. However, Paul and his wife vacationed abroad shortly after their first interview. Paul had also just returned from Australia prior to the follow-up interview.

Highlighting that stroke can also impact on the caregivers in this context, those caregivers who were providing care for their parents reflect that their caregiving responsibility had impacted on them being able to plan ahead for holidays:

"Because I know that today's been planned, tomorrow is planned it's alright, but it has affected me like things like holidays."

(Sarah's daughter: interview 1)

Emphasising her need to consider the care for her mother; *"all my world revolves around Mam"* (Sarah's daughter: interview 1). Sarah's daughter further commented:

"We don't go on holidays as holidays; wherever we go we, go for three or four days."

(Sarah's daughter: interview 1)

Sarah's daughter explained that Sarah would say:

"As long as I've enough stews in the freezer and your cousin it wouldn't bother me....as long as you get my clothes out for two weeks."

(Sarah's daughter (mimicking Sarah): interview 1)

Other caregivers make other arrangements. John's partner and Richard's wife would take holidays separately from their spouses, whilst other caregivers reported that they did not plan for holidays due to care commitments, and increased insurance premiums for the survivor.

Sarah's daughter and John's wife stated that their neighbours had offered to provide meals for Sarah and John, and expressed that both Sarah and John would cope if they had some meals at home they could reheat at mealtimes. However, Sarah's daughter expressed concern about 'what if', suggesting that even if Sarah's daughter did take a vacation, she may worry about her mother and would not have time off mentally away from the caregiving role. Sarah's daughter also reflected that if Sarah would accept the aforementioned meals on wheels service or sit in service it would take some of the worry away from her and they could go away for a short break.

This suggests that it was not Sarah who was intentionally preventing her daughter from vacating, but it was Sarah's daughter and her own concern about the wellbeing of her mother. The reluctance to take up services offered supports Bäckström and Sundin (2009) theory that

239

survivors often unintentionally 'put up' barriers to social participation for their caregivers. In this instance Sarah is not intentionally preventing her daughter from taking a holiday but due to her refusal of the meals on wheel scheme, and her daughter's own anxiety about leaving her alone,, Sarah's daughter is reluctant.

On a similar note, John and his partner looked into having meals delivered to John whilst John's partner was away and were unsure who to contact. This suggests another area where there is a lack of information for people living with stroke and their caregivers, further supporting the need for an information pack which provides such information. This further emphasises that caregivers are active seekers of information as Johnson and DeSouza (2009) describe in Chapter 2 (Section 2.2). However, highlighting that professional care provisions do not necessarily provide opportunity for caregivers to vacation, Penny's daughter commented that despite having around-the-clock care, due to her mother's care needs she:

> *"Can't plan ahead, you can have thoughts but you can't be specific because you don't*
> *know what the next thing will be."*
>
> <div align="right">(Penny's daughter: interview 1)</div>

This highlights that the support offered by professional services was not relieving Penny's daughter of the caregiver role to the extent that she could take a break away.

John's partner and Richard's wife also reported of changes when it came to planning holidays, reporting that they were unable to travel with their partners as they did prior to stroke and now vacationed alone or with friends. This indicates a change in travel patterns for John's partner and Richard's wife. However, in contrast Thomas and his wife informed that they may be vacationing in the UK on a canal boat:

> "We *talked about having a holiday on the* (canal) *boat which we'd love to do, and my*
> *daughter said she'd come with us to help because we couldn't manage the locks on our*
> *own."*
>
> <div align="right">(Thomas' wife: interview 2)</div>

John and his partner informed the author that they struggle find a hotel suitable for a holiday or a respite *"unless you're ancient; nothing for their age group"* (John's partner: interview 1). John's partner highlighted that he approached a stroke-specific third sector organisation to gather

information, however they were unable to make any recommendations for respite or services which would deliver meals to the house. Both John and John's partner were uncertain as to who they would approach about this, expressing an unmet need regarding information for respite provisions. Reflecting on a previous occasion where John's partner went away with friends, John and his partner described how they had relied on informal support provisions, supporting the work of Burholt and Dobbs (2014) which defined support networks as consisting of social, emotional and instrumental elements:

> *"A good friend across the road came over and checked they was fed and Ok, I left plenty of food and instructions to check on you if they hadn't seen you."*
>
> (John's partner: interview 2)

It was then revealed that on one occasion John had stayed at a hotel in a local town while John's partner went away.

John's partner stated that because the cost of travel insurance for John had become *"phenomenal"* (John's partner: interview 1) because he had experienced stroke, they were reluctant to fly abroad:

> *"Of course, we can't go abroad any more, well because we I suppose we could but the insurance; hence we went on the cruise because there was no flying involved, we went from Liverpool, and all other holidays are taken in this country, aren't they?"*
>
> (John's partner: interview 1)

Therefore, John and his partner had changed their holidaying behaviours, valuing holidays away, rather than ceasing to vacation despite reporting that they *"are not getting out and about as much as we used to"* on a daily basis (John's partner: interview 1).

However, Paul and his wife still vacationed abroad post-stroke and reported during the first interview that they were flying to Portugal to visit friends for a week, one week after the first interview. At the follow-up interview Paul informed that he had spent Christmas and New Year with his daughter in Australia. This emphasised that not all participants had changed their holidaying behaviour.

Feeling as though he could no longer vacation because he found walking difficult Mark explained:

> *"My wife always says…She talks about going on holiday, but I can't, I've had to give up going away because I can't walk and I'd be useless."*

<div align="right">(Mark: interview 1)</div>

This also indicated a change in Mark's wife's life, as similarly to Richard's and John's wives', if she wished to vacation she would do so alone or with friends. Furthermore, Richard had on occasion gone camping post-stroke, however due to his reduction in confidence over time he had recently stopped going away. This also highlights a change in life since stroke as before stroke Richard was a keen mountaineer and travelled the world on various expeditions. The findings here suggest that reduced confidence in going outside of the home can impact negatively in holidaying activity. Therefore, building confidence and self-esteem outside of the home should be a key focus in supporting survivors of stroke in their post-stroke lives.

8.6   Chapter Summary

This chapter discussed the survivors' and caregivers' everyday lives in terms of intellectual fulfilment, hobbies, interests and social participation. The survivor participants engaged in a wide range of activities in order to reap intellectual fulfilment, some of which exampled an adaptive strategy. Exploring this in more depth, this chapter examined how the survivor participants have made adaptions to their everyday lives, not only in the way they carry out tasks but also the type of hobbies which they engage with. One reason for this is that they actively sought to find activities which they were able to do post-stroke, however this chapter also highlighted that some of the activities taken up were not new interests for the survivor participants, but highlighted that for some survivor participants, becoming retired from employment, their stroke had provided them with more time to pursue the interests that they did not have time to pursue prior to stroke.

The survivor participants valued their independence and the caregiver participants played a part in supporting them with this. However, despite expressing that they sought the survivors to live independently, their actions did not always reflect that. There was also reluctance for caregivers to take on support which they were entitled to as they felt that they were coping. Therefore,

there were opportunities for caregivers to be relieved of some of the burden which were not being taken up. This demonstrates how caregivers may construct their own barriers to relieving caregiver burden.

In terms of the level of social participation and engagement in activities, survivor ability was a factor as to how engaged or how independent a survivor could be. The caregiver participants supported the survivors in many aspects of their everyday lives, again the level of which was dependent on the needs of the survivor. The common areas of support included an overseeing role of cooking tasks, and household administration. Over time the caregiver participants reflected upon many roles they have undertaken: overseer, nurse, representative, mediator, and caregiver as well as being a wife, a daughter, or a cohabiting partner. This emphasises the dynamic nature of the caregiving role, not to mention the added complexity for those caregivers who were mothers of dependent children or employed.

One key consideration was that the more independent the survivor was perceived to be by the caregiver, the fewer burdens was felt by the caregiver. Therefore, supporting caregivers in supporting survivors with independent living is a key element for reducing caregiver strain and burden. The caregiver experiences varied case by case. Some of the caregiver participants reported that they had to give up activities due to lack of time since their caree experienced stroke, whereas others did not report giving anything up. However, it is worth noting that where there were service provisions in place, they did not relieve the caregiver participants of their caregiving responsibilities. The service provisions and their delivery are discussed further in the next chapter, Chapter 9.

The survivor participants, who were able, were focused on keeping busy. Some of them were able to take on committee roles at the Stroke Club in voluntary employment. This provided them with a sense of post-stroke identity and responsibility which contributed to their overall wellbeing. The findings also show that social media and online technologies are reducing barriers to social participation for the survivor participants, allowing them to socialise easily in both text and image form. The internet allowed the survivor participants to form an online identity and supported a sense of self and they were able to communicate with other people from inside of their home.

This chapter further informs of the value of Stroke Clubs in reducing barriers to social participation in the external environment by being a 'safe zone'; a place where the world of

stroke is familiar and where people understand stroke and its impact. Through Stroke Clubs, barriers to the outside world may be reduced or even removed by working with other organisations to provide them with opportunities to regain the confidence in the external world for some survivors and, relearn the skills they had before stroke while being around people who they feel understand them, and seek safety away from their perceived public stigma. This resonates with the findings of Van Brakel et al. (2012) who observed that stigma reduction activities and socio-economic rehabilitation are urgently needed in addition to strategies to reduce the development of further physical impairment after release from treatment.

The findings here confirm the literature on the caregivers' influence on the everyday lives of survivors. However, this study builds on the existing knowledge by explaining why and how, and highlights the challenges experienced by the caregivers. This highlights the value of using a narrative approach and qualitative research as the findings here build on the quantified measures reported by researchers in this field.

The next chapter builds on the findings reported so far by discussing survivor and caregiver support.

9.0   Findings: Supporting Survivors and their Caregivers

Building upon discussion within the earlier findings chapters (Chapters 6, 7, and 8), this chapter further contributes towards research aim (2) to identify the avenues of support of the study participants, and also addresses research aim (3) to explore how Stroke Support Clubs deliver support to survivors of stroke and their caregivers.

The findings thus far assert that survivor support should revolve around social participation, independent living, aspiring to return to a pre-stroke sense of life, forming post-stroke identity, and reducing barriers to social participation.

This highlights that supporting the survivor participants in being independent in their everyday lives can reduce caregiver burden. This also provides survivor participants with renewed confidence and increased self-esteem. The caregiving role presented a variety of challenges for the families of the survivor participants of this study. Caregiver support was important in reducing caregiver burden and strain; however, burden and strain did not disappear completely. It was identified that survivor-focused support also helped ease the burden for the caregiver participants. In particular Penny's daughter who stated that the paid caregivers by supporting Penny also supported her: *"they help me to help Mam"* (Penny's daughter: interview 1).

Support was provided to the participants in their everyday lives via various avenues: family, friends, neighbours, people within the local community, the caregivers' employers, the statutory sector, the third sector and the social enterprise sector. The participants' perspectives of such support are discussed throughout this chapter. This chapter also discusses the ways in which social enterprise, in this context Stroke Clubs, have supported the survivor and caregiver participants as they live with stroke in their everyday lives.

With this in mind, the author reflects upon Wenger's (1989) support network typologies, discussed in Chapter 4 previously. Table 7 shows the typology which best describes the circumstance of each of the survivor participants. By considering Wenger's research here, the table provides a summary of support, as defined in the existing knowledge base. Throughout this chapter, the findings build on these descriptors by describing in more depth, the support received by the study participants in their everyday lives.

Table 7 overleaf shows where the survivor participants and caregiver participants meet the network typology descriptions. Notably those caregivers who were daughters of the survivor participants had a wider support network than their mothers. However, the spousal caregiver participants met the same characteristics as their husbands or partners, with exception of Richard's wife who had a wider support network also. This was due to the daughter's own lifestyles, and Richard's wife being more involved in the external environment as Richard's care needs were such that allowed it. However, this cannot be generalised for all caregivers and is solely reflective of the participants of this study.

The author notes that Jane meets two descriptions. This is because she had established a local support network through long-term residency, however, she also participated in the wider community. It is worth recalling earlier discussion from Chapter 3 which accounted that over time, a person may transition between descriptions. This can be due to increased dependency (Wenger 1989). However, in this context it could be due to increased confidence in the post-stroke self or that the survivor has come to terms with stroke, and the caregiver has come to terms with the caregiving role.

To provide an example, the author refers to Richard. Earlier in Chapters 6, 7, and 8 it was established that during the early days and months of his post-stroke life Richard had been more active and was more involved in the external environment than he was at the time of his first interview. Richard's decrease in confidence as his post-stroke fatigue increased meant that his support network had changed. Perhaps in the early months of his post-stroke life Richard would have met the descriptors of the local integrated support network or wider-community focused. However, at the time of interview Richard met the private-restricted typology.

Furthermore, it is worth noting that not all of the participants meet (fully) the typology they have been assigned. For example, Richard and Penny have local kin. However, they are a closer fit to the private-restricted typology than the others due to their lifestyle and limited contact with the local community. Thus, these typologies must be considered loosely.

Table 7: Support Network Typologies

Support Network Typology	Description of Traits	Participants who Portrayed these Traits
Local Integrated	Typically incudes close relationships with family, friends and neighbours; usually based upon long-established residence and active community involvement in the past or present.	Jane , John and John's partner
Local Self-contained	Typically arm's length relationships or infrequent contact, if any, with local kin. Relies mainly on neighbours. Have a retiring nature and largely privatised house-centred life style. Community involvement if any is low key.	Mark
Wider-community Focused	Typically includes distant kin, with high salience of friends and some neighbours; characterised by high levels of community activities and involvement, usually associated with absence of local kin.	Jane, Paul and Paul's wife, Sarah's daughter, Penny's daughter Richard's wife and Ruth's daughters
Family-dependent	Primary focus on close family with few peripheral friends or neighbours. Often based on shared housing with, or living close to, an adult child.	Sarah, Ruth, Thomas and Thomas's wife
Private-restricted	Absence of local kin, other than perhaps a spouse. Limited contact with local community. No local friends and superficial contact with neighbours.	Penny and Richard

(Informed by Wenger 1989, *in* Jefferies M. 1989, 171-172, presented in Figure 3 of this thesis: Wenger's Network Typologies, page 52).

9.1   Support from Employers

Those caregiver participants who were also employed full-time highlighted that their employers had been supportive alongside their caregiving roles. As previously mentioned, Sarah's daughter and Paul's wife found their employers to have been supportive in allowing Sarah and John to attend their place of work during the day; each day for Paul, once weekly for Sarah (when there was a day centre clinic on). Paul's wife and Penny's daughter were employed within the service sector, whilst Sarah's daughter and Ruth's daughters were employed in the healthcare sector. Paul's wife considered:

> *"I was lucky really; I had a job where it was alright."*
>
> (Paul's wife: interview 1)

Sarah's daughter, Paul's wife, Penny's daughter and Ruth's daughters also reported that their employers had been supportive in allowing flexible working hours with Ruth's daughters reporting that they were able to take unpaid leave from their employment if required:

> *"I think we are probably both fortunate in that where we work, there is a degree of understanding if we need to take leave to organise things."*
>
> (Ruth's daughter (a): interview 1)

This suggests that as their employer was aware of the potential challenges they faced as they were employed within the statutory health sector, there was a degree of support which existed.

9.2   Support from the Local Community, Family and Friends

The study participants valued the support they received from people residing within their local community, their families and their friends. The WRO (2009) identified that 94 percent of Welsh respondents to their studies reported a very good or fairly good perception of quality of life, owing it to a positive feeling of community life. Their participants reported that they valued the community in which they lived and the support which they received.   This was also evidenced by the participants of this study.   Furthermore, the participants of this study reflected that they found the areas in which they lived spiritually uplifting; contributing to a feeling of wellbeing in their everyday lives. More specifically, Paul's wife found that the community in

which she lived hosted a: *"relaxed way of life"* (Paul's wife: interview 1) which she felt was beneficial to her wellbeing. Paul's wife also commented on the friendliness of people within her local community:

> *"There is always somebody you can talk to, even strangers, they will all stop in the lay-by and have a chat."*

<div align="right">(Paul's wife: interview 1)</div>

These views were also expressed by Sarah and her daughter, Jane, and John and his partner who commented that they felt a sense of security where they resided, as they knew everybody within their community, and had family and friends who lived nearby. These views build upon community structure theory reported earlier in Chapter 3 by Williams (2008).

As previously mentioned in Chapter 8, community cohesion allowed Jane to feel confident within her community as people were aware of her communication difficulties and were supportive in understanding other ways which Jane may communicate, such as using hand gestures for example. However, this was not the case for all of the participant survivors. Mark and Richard expressed that they lacked confidence within the external environment (in their local community) due to perceived public stigma (discussed in Chapter 6 previously). This supports earlier statements from Reeder and Pryor (2009) and Weiss (2008) in Chapter 2 who claim that anticipation of public stigma is a barrier to social participation to the external environment. In addition, Ruth described that she felt there was a lack of awareness about stroke within her local community as well as a general lack of awareness of physical and neurological disability.

Describing this as *"an on-going battle"* (Ruth: interview 1) Ruth considered that with an increase in stroke awareness campaigns coming from the statutory sector people were:

> *"Finally beginning to become more aware of stroke."*

<div align="right">(Ruth: interview 1)</div>

Reflecting back to the literature discussed in Chapter 4, this highlights an area of contrast. Williams (2008) suggested that traditional community structures in Wales were eroding due to increased migration. This suggests that the increase of migration into Welsh communities could result in the close-knit community networks not being as strong as they once were due to cultural divergence, which was said to impact upon community values. Although the study findings

cannot be generalised across the whole of Wales, the participants of this study had not experienced this. For instance, Jane had lived in her local community all of her life and felt that there was strong community cohesion, as did Paul and his wife who had migrated into the area from England. Paul's wife reflected on their experience of the community in which they lived, and reflected that they had migrated from England into Wales not long before Paul experienced his stroke:

"With us only been here 18 months so you don't know how people are going to react."

(Paul's wife: interview 1)

Emphasising community cohesion, she continued:

"The thing that made a big difference is that everybody asks and talks to us, 'how you doing?'"

(Paul's wife: interview 1)

Identifying the extent of support and cohesion within the community, Paul's wife (interview 1) asserted: *"even the bus driver."* However, despite this contrast with the literature reported by Williams (2008), it is worth considering that in this case, the participants and their neighbours were able to communicate in fluent English. The literature here may refer to migration patterns reported by Williams (2008) as inclusive of Polish, Lithuanian, Estonian and other migrant groups, where the cultural divergence and communication gap may be greater.

Reflecting further upon family support, Sarah's daughter found that support and understanding from other family members alongside the caregiving role was beneficial to her coping with her caregiving responsibility, as her caregiving role meant that she spent a lot of time away from her family and the family farm. This contributes to the findings reported in Chapter 7 which highlight the impact on the lives of those family members of caregivers. Suggesting that such support was not the case for all, such support was not felt by Penny's daughter who expressed frustration at her siblings:

"I've got an older brother and a sister actually; one lives away and the other is less than useless so, it's all down to me."

(Penny's daughter: interview 1)

This also suggests that where others receive support from their family in their caregiving role, this is not always the case. This highlights a potential conflict as Penny's daughter had taken on sole caregiving responsibility as one of three siblings, as did Ruth's daughters, being two of four. In fact, Penny's brother had followed the migration trend informed by Williams (2008) in Chapter 4 as he migrated into England in search of further work. This further highlights the change in community structures as people are moving out of rural Wales into more urban areas, seeking employment. This supports Williams's (2008) theory that migration is corroding typical community structures (discussed in Chapter 4 previously) which leads to there being increased reliance on statutory sector healthcare and support (the Institute of Rural Health 2009).

A key change in everyday life reported by Paul during this research was the aforementioned death of Paul's wife. The support Paul received from his community; friends, neighbours, and Stroke Club had helped him to come to terms with this event:

> *"My neighbours have been an absolute godsend; they can't do enough for me."*
>
> (Paul: interview 2)

Another key event experienced during the duration of this study was reported by Ruth, whose home had been flooded prior to her follow-up interview. Praising her family for their support, Ruth explained how she temporarily resided with her youngest daughter until the local authorities had repaired the flood damage to her home. This emphasised a key value in support from family as the local authorities could not arrange temporary accommodation for Ruth at this time. However, Ruth's daughters reflected that they were disappointed that the Stroke Club did not do more by way of community support:

> *"She didn't hear from them and she had lost everything."*
>
> (Ruth's daughter (a): interview 2)

The findings here emphasise how community support can impact on a survivor's everyday life, and how those people within their community; their friends, family members, neighbours, and employers contributed to supporting the caregivers in their caregiving role. This further supports the aims of the Welsh Governments Stroke Delivery Plan (Welsh Government 2017) and its aim to support people in their local communities.

9.3   Statutory Sector Support

With older populations and vulnerable people in Wales being more reliant on informal social support structures, The Institute of Rural Health (2009) suggest that the aforementioned erosion of traditional communities will result in greater reliance on the statutory sector. Here the participants' reflections on their statutory sector support experiences are discussed.

Statutory sector support was provided via local authority services provisions which included in-home adaptions, accommodation, and professional caregivers. Support from the statutory sector also included financial support by way of state benefits.

Throughout Section 9.3 the participants perspectives on the support they received from the statutory sector whilst at hospital during the early stages of their post-stroke lives, and the support received in the months and years thereafter are discussed.

9.3.1   Whilst at Hospital

During the early stages of their post-stroke lives, the participants' experiences were mixed. Ruth's eldest daughter recalled feeling *"grateful"* (Ruth's daughter (a): interview 1) that they happened to be employed at the hospital where their mother was receiving treatment. This was because they felt that:

> *"Some of the things that were happening were quite upsetting"*.
>
> (Ruth's daughter (a): interview 1)

 Ruth's daughters explained that they were able to visit their mother outside of normal visiting hours. This meant that they saw Ruth was not being helped to eat at mealtimes.   Ruth's eldest daughter reflected that she would feed her mother by helping her cut up her food and put it on a fork for her:

> *"If I hadn't been there she wouldn't have had proper food to eat."*
>
> (Ruth's daughter (a): interview 1)

Feeling dissatisfied with the support Ruth was receiving at meal times from nursing staff, Ruth's eldest daughter affirmed that the hospital:

"Hadn't done the thorough assessment. That should have been done!"

(Ruth's daughter (a): interview 1)

The reflections of the early stages of stroke highlighted that Ruth's daughters felt that the outcome of Ruth's stroke in relation to her communication difficulties had been misdiagnosed, which Ruth believed to have impacted upon her communication effectiveness in the months and years thereafter:

"I went to a speech place, but all they did was show me objects, and I couldn't say what they were, they didn't seem to realise that it wasn't that I couldn't talk, it was.... all of a sudden…………... I couldn't remember what they were."

(Ruth: interview 1)

In this instance, Ruth felt that her diagnosis was incorrect, and her recovery affected. Ruth's eldest daughter also felt that Ruth was at risk of a decline in nutritional health because she was not given the assistance she needed to consume food.

Expressing further frustration, Ruth's youngest daughter reported that she felt that there was also a lack of focus on prevention. Providing an example, she explained that Ruth had experienced reoccurring urine infections as a result of her stroke. As a result of this Ruth's daughters felt that Ruth had increased vulnerability:

"When in the middle of one (a urine infection) *you have a limited capacity to move around, which obviously make the person a bit more vulnerable if they fall."*

(Ruth's daughter (b): interview 1)

Explaining that the hospital was aware, Ruth's youngest daughter explained that:

"It was sort of assessed (by the hospital) *with a view to whether she might be eligible for provision of prescription pads."*

(Ruth's daughter (b): interview 1)

Emphasising that this was a limited solution and failed to solve the long-term issue, Ruth's youngest daughter continued: *"but that is only one element of it"* (Ruth's daughter (b): interview 1).

Informing of her frustration that the hospital had not provided an effective solution to the ongoing problem, and had not provided a solution to prevent the initial infection, Ruth's youngest daughter emphasised:

> *"It is actually recognition that these were becoming an occurrence and what that could be doing was never addressed."*
>
> (Ruth's daughter (b): interview1)

Taking matters into her own hands, Ruth's youngest daughter, through her employment, carried out a referral to an incontinence specialist and reflected:

> *"They'll assess you and decide whether or not you can have something."*
>
> (Ruth's daughter (b): interview 1)

However, Ruth's daughter b) further asserted:

> *"It looks like you were asking for that kind of provision when in fact you are not, you are asking for general help in management and controlling it and preventing something which if it wasn't controlled, had an impact on that person's capacity to manage."*
>
> (Ruth's daughter (b): interview 1)

Summarising, Ruth's daughter reflected:

> *"There was a certain level and depth of support, but it would be nice if it went to a deeper level occasionally."*
>
> (Ruth's daughter (b): interview 1)

This suggests that there could be more of a focus on prevention and management of conditions in general incorporated into the hospital's patient strategy. It is a concern that Ruth's daughters had to refer for appropriate treatment themselves. This leads the author to consider other scenarios: what if the caregivers were not employed in the statutory sector and were not able to refer Ruth

themselves? Or what if Ruth didn't have any caregivers? The impact of experiencing reoccurring infections was likely to take a toll on Ruth's wellbeing. Furthermore, treating problems as they occur is not the most cost-effective strategy for the statutory sector; prevention being far more cost-effective as well as being better for the wellbeing of the patient.

Recognising that their own employment could be considered advantageous to the situation, Ruth's daughters reflected:

> *"I feel really strongly around those people who don't know the system or are not local so they don't know who they are trying to contact – that I should imagine has quite a big impact on time and just dealing with it must be quite hard."*

<div align="right">(Ruth's daughter (a): interview 1)</div>

This notion and gaining information is discussed further in Section 9.3.3.

9.3.2   Rehabilitation

At point of discharge from hospital a stroke patient, once assessed, is typically given a rehabilitative plan. This plan is unique to the individual and aims to help them return to an independent life.

Sarah and Paul both had an occupational therapist who would visit their homes as part of their rehabilitative plan. Paul's wife reflected that Paul's occupational therapist, who visited the house twice weekly, was considered *"a mentor"* (Paul's wife: interview 1) as they were able to answer any queries Paul and his wife had, acting as:

> *"A safety net really, someone there if I had a problem."*

<div align="right">(Paul's wife: interview 1)</div>

Thomas also received speech and language therapy at his local hospital. Furthermore, a physiotherapist had given Thomas a list of exercises to carry out, however there were no follow-up appointments to assess his progress.

Thomas's wife highlighted that this lack of follow-up meant that Thomas was not very motivated to try:

> "He's got all the help but he doesn't do it."
>
> (Thomas's wife: interview 1)

This highlights that the support was there, however as there was no follow-up procedure in this case, there was a lack of motivation to participate in the recommended exercises and activity. This further supports goal-setting as a way of motivating survivors to carry out rehabilitative exercise, and further examples how caregivers take on the role of encouraging participation.

Ruth's youngest daughter reflected that:

> "If you felt that you needed certain support around exercise opportunities to continue your rehabilitation as much as is possible it would be extremely difficult."
>
> (Ruth's daughter (b): interview 1)

Ruth's daughters informed that Ruth was offered access to additional rehabilitation locally however the provision was unreliable as it was cancelled on three out of four occasions. Furthermore, Ruth's daughters felt that the period of service delivery on this occasion was not sufficient:

> "They tend to concentrate on the very basics of personal care and although there was some suggestion that they might look at that next stage which is getting people back to moving around in the wider environment, which is very key; that didn't really happen."
>
> (Ruth's daughter (b): interview 1)

Ruth's eldest daughter affirmed that there was a lack of stroke-specific rehabilitation and opportunities to gain on-going support after hospital discharge and commented:

> "The services stopped a little soon in that they do tend to concentrate on the very basics of personal care."
>
> (Ruth's daughter (a): interview 1)

This suggests that it is key to provide support for survivors outside of the home in their local community, not just enabling them to return home. Further highlighting the insufficiency of the support provided, Ruth's eldest daughter affirmed:

"That is where there is a lack of support – in rehab, definitely."

(Ruth's daughter (a): interview 1)

This further emphasised the need for support in the months and years after stroke. When Paul and John were discharged from hospital they returned as day patients for physiotherapy once weekly, which was limited to a specified number of weeks. The survivors reflected that they would have liked such provisions to be a part of their everyday life for the longer term; for the months and years after stroke. More specifically Paul reflected upon a joinery workshop which he had attended as part of his rehabilitation and wished that he was still able to attend. This emphasises that the participation aspect of this was a valuable part of Paul's rehabilitation programme and that Paul wished to incorporate such clubs into his everyday life. This highlights a demand for a long-term strategy focused upon supporting people living with stroke. However, this may not necessarily be through the statutory sector rehabilitative strategy; but through supporting people through activities in everyday life which could be best delivered through social outlets, and community groups such as Stroke Club, or other social enterprise or third sector organisations. In fact, Paul's keenness to have such activity in his everyday life was further evidenced by his participation in voluntary employment. Therefore, encouraging survivors into voluntary employment (where they are able) may help to address some of their own needs whilst supporting their local community.

9.3.3 Gaining Information

Lack of information was reported by McKevitt et al. (2011:2012) to be an unmet need of survivors. McKevitt et al.'s studies dated in 2011 and 2014 suggest this to be an on-going issue. This study shows that lack of information was still an issue, despite the changes in statutory sector policy which sought to address it.

This lack of information was experienced whilst in hospital, and in the months and years after discharge. Supporting Johnson and DeSouza's (2009) notion of the caregiver being 'active seekers of information', the study participants describing that information sharing was *"pretty*

much one way" (Ruth's daughter (a): interview 1). The caregiver participants felt that they were given information if they asked for it, and that they were:

> *"Relying on others to fill in those blank bits."*
>
> <div align="right">(Ruth's daughter (a): interview 1)</div>

Supporting this, Penny's daughter affirmed: *"they don't tell you anything"* (Penny's daughter: interview 1).

As previously stated, the caregivers felt that this lack of information caused a great deal of unnecessary uncertainty, strain and worry. They felt that if they were told more about the possible outcomes of stroke they would have been better prepared for the caregiving role. Furthermore, those caregivers shared a desire to learn more about stroke such as how and why it occurred, and the cause, regardless of their prior experience or potential knowledge base. This highlights a weakness in Welsh health and social care strategy and is something which the Welsh Government (2015) aims to address in its 2014 Social Services Wellbeing Act, through its efforts to make information available to all. Ruth's daughters explained that despite them working in the sector, there were still things that they were not aware of:

> *"We are not aware of the carers groups, or aware of what support there is out there."*
>
> <div align="right">(Ruth's daughter (a): interview 1)</div>

Ruth's eldest daughter reflected:

> *"We know the system and what to ask, but it makes you wonder how much support new carers who have never had that role at all; never having experienced anything like that before, how much information you get imparted to you to help make their journey into the caring role."*
> (Ruth's daughter (a): interview 1)

However, Ruth's youngest daughter added:

> *"We didn't seek it and it wasn't offered, but it makes you wonder whether it is offered on a regular basis."*
>
> <div align="right">(Ruth's daughter (b): interview 1)</div>

Ruth's daughters felt that the hospital staff had made assumptions about their prior knowledge and perhaps the staff didn't share information with them because they thought they knew all there was to know. Ruth's daughters considered that their experiences may be non-comparable to those who were not employed in the healthcare profession. They reflected that hospital staff may have assumed that their knowledge base was adequate for their situation because they had some knowledge through their employment. However, they did not feel that this was the case. Considering the reflections from other caregivers, it can be stated that the lack of information provided wasn't because the staff assumed they knew the information; it was a general issue with information sharing. However, this issue has been acknowledged by policy makers in their plans to improve caregiver information, and support services they are entitled to through the Welsh Government's (2014) Carers Strategy for Wales.

Furthermore, Ruth's youngest daughter pondered:

> *"Perhaps because you are seen to deal, they* (the hospital staff) *don't feel the need for that kind of pushing (to give you information), regardless of what your potential knowledge base is."*
>
> (Ruth's daughter (b): interview 1)

Despite a lack of information whilst at hospital being a key issue for the participants, Ruth's daughters and Paul's wife stated that there were some staff at the hospital who were a good source of reference:

> *"If you did ask the questions you got reasonable answers, and you got a reasonable understanding of what the difficulties might be."*
>
> (Ruth's daughter (b): interview 1)

Paul's wife also had this experience and expressed concern that people would be asking the right questions:

> *"You don't know the questions, so you can't ask, and it's up to us to ask."*
>
> (Paul's wife: interview 1)

This supports the notion of caregivers being 'active information seekers' further supporting Johnson and DeSouza's (2009) description of caregivers being active seekers of information.

Ruth's daughters reflected that their employment within the statutory sector was beneficial when accessing support as they had:

> *"Some knowledge of the system, of the way the system works, and the way that* (LA) *Services work."*
>
> (Ruth's daughter (a): interview 1)

However, Ruth's eldest daughter commented that despite them having this knowledge they found that:

> *"It was quite frustrating sometimes to get everything in place."*
>
> (Ruth's daughter (a): interview 1)

Furthermore Richard, Thomas and their wives reflected that they had received support and information from their district nurse and their local GP practice:

> *"If I needed support the* (GP) *surgery is very good, so if I needed support that would be the place to go."*
>
> (Richard's wife: interview 1)

The GP practice had informed Thomas and his wife of where to find information about financial support and home adaptions Thomas's wife reflected:

> *"The doctor told me to get onto the county council, so we did."*
>
> (Thomas's wife: interview 1)

However, John's partner recalled an incident when she was approaching the GP practice asking for referrals to an exercise scheme:

> *"I think a lot of it was me sort of instigating these things."*
>
> (John's partner: interview 1)

John's partner here demonstrated the proactive information seeking behaviours described by Johnson and DeSouza (2009) discussed earlier in Chapter 2. This highlights the importance of the caregiver role in ensuring that the survivors' needs are taken care of, and that the survivors also receive the information they need. The lack of information reported by caregivers is not just

in relation to the caregiving role, but also information for the survivor participants and how they can address their needs, and ensure that they get the treatment and support they need and are entitled too. However, as Paul's wife questioned (interview 1): *"How do the caregivers know what to ask if they do not know what is available to them?"* This highlights an area of great concern for survivors and their caregivers in their everyday lives.

Highlighting inconsistencies with the delivery of information, the caregiver participants reported that:

> *"It was just down to individual staff, because when you went in the unit sometimes they imparted information and sometimes you had to go and ask and seek."*
>
> (Ruth's daughter (b): interview 1)

This resulted in the caregiver participants feeling responsible for finding out information, when in reality they wanted to be offered the information unprompted:

> *"You would quite like them to be answering the questions for you."*
>
> (Ruth's daughter (b): interview 1)

The caregiver participants reported that this contributed to feelings of burden and strain during what they considered to already be *"a challenging time"* (Paul's wife: interview 1). This suggests that there is a need for healthcare professionals to focus on the timeliness and consistency of information delivery to service users.

Ruth's daughters described a challenge they faced with Ruth's GP practice. Despite them being aware of Ruth's difficulties with her writing and memory, the receptionists would telephone Ruth with the results of her warfarin tests. However, Ruth found: *"writing down numbers"* (Ruth's daughter (a): interview 1) hard, furthermore Ruth could not memorise the numbers either:

> *"This lack of recognition at a GP practice meant that they are sending information verbally over the phone to somebody who potentially couldn't record it."*
>
> (Ruth's daughter (a): interview 1)

This highlights an area where improvements could be made by training receptionists of the GP practices in being more aware of the communication needs of their service users. This would assist them in providing a more effective and efficient service. With the Welsh Government investing into GP surgery staff training, the author hopes that this issue will be addressed in the future.

Policy makers have acknowledged that there is an issue with information sharing to survivors and caregivers, and although the strategy may be implemented from 2012, the delivery of the strategies in place to address this issue need to consider not just those survivors and caregivers as they leave the hospital from 2012, but also those who are living with stroke in their everyday lives from strokes which occurred prior to 2012.

However, there are further challenges in delivery. There is the issue of caregivers and how to identify them, but also how to deliver the initiatives to survivors who may have had a stroke outside of the UK, as was the case for Richard and Thomas who had already faced difficulties in trying to access the support they needed from the UK's statutory sector.

Identifying that there is a need for continuous support post-stroke, Paul's wife also affirmed that:

> *"Some issues don't manifest themselves until they have got over the initial trauma and they are trying to regain their life."*

> (Paul's wife: interview 1)

This was emphasised by caregivers in this study who valued their local Stroke Clubs as avenues of support which allowed them to ask other members for advice and guidance about issues which occurred in their everyday lives. Providing an example of this, Paul and his wife reflected that they were not aware that Paul could apply for a mobility car initially. However, with the help and advice from the host of their local Stroke Club and other members at their local Stroke Club, Paul discovered who to contact about a driving assessment, which allowed him to get an adapted mobility car which allowed him to drive again, supporting his independence. Paul's wife also described how Paul had developed a rash under his immobile arm which caused them concern: *"nothing was shifting it"* (Paul's wife: interview 1). After asking a caregiver at Stroke Club if they had ever come across something similar she discovered that the rash was a common occurrence for survivors with immobile limbs due to the skin irritation caused by the lack of movement. They were advised which cream worked and therefore gained a remedy. This

further demonstrates how Stroke Club provided an avenue for gaining information for the study participants.

In addition, Paul and Thomas's wives, John's partner and Penny's daughter expressed irritation, confusion, and frustration in regards to claim forms they were required to complete for DVLA and financial support.

Paul's wife explained:

> *"We kept getting these forms, but nobody tells you, you don't know! But even if we'd known that with the modifications he could drive again, we wouldn't have known what modifications Paul would need because until he had been assessed he wouldn't know what he was capable of anyway."*
>
> (Paul's wife: interview 1)

Paul's wife recalled that she was also unaware that they could claim Disability Living Allowance (DLA) until she had a chance conversation with a nurse at the hospital:

> *"If it wasn't for the lady at the hospital mentioning that we could apply for disability living allowance, we wouldn't have known it even existed."*
>
> (Paul's wife: interview 1)

Reiterating the issue with delivery of information Paul's wife also explained that the civil servants who she had dealt with regarding benefits and financial support were not helpful in telling her what Paul and herself were entitled to:

> *"Civil servants think you know more than you do, or you should know more than you do. I wish they would realise that, they ought to be more well-informed."*
>
> (Paul's wife: interview 1)

This added further stress to what was already a stressful time. In addition, this highlights that the effectiveness of statutory sector support offered, and any policies and initiatives in place rely on the people employed in the customer-facing roles. This suggests that there is an issue with implementation and delivery of information. Such issues can lead to barriers to access to information and thus access to support structures put in place. Furthermore, there is also

potential for survivors who are not coping well with their stroke, or caregivers who are not coping with their caregiving role, to feel reluctant to ask for support if the information is not easily available.

There is also potential for opportunities to support such individuals being missed as the system was not proactive in offering support to survivors and caregivers:

> *"They don't know the consequences for the people at the other end, and also, you don't necessarily know what questions to ask, you know, as to what you are entitled to."*
>
> (Paul's wife: interview 1)

Reflecting upon early post-stroke life the caregiver participants reported that they felt they were alone and were unaware of what was going on. However, Ruth's daughters reported that they were more informed once Ruth had been referred to a rehabilitation unit:

> *"They give a lot more information to you themselves when you are visiting in the rehab unit."*
>
> (Ruth's daughter (a): interview 1)

Furthermore, a contradiction of information provided and actions between different professionals was reported, highlighting that there was an inconsistency of communication between hospital staff, support services and the service users themselves. This impacted negatively on the overall efficiency and coordination of treatments and services. However, reflecting back to the outcomes of stroke and their unpredictability, it is possible that the hospital staff were better informed at rehabilitation stage. This suggests that once medical staff establish the outcome of the stroke and the patient is undergoing rehabilitation, the appropriate information may be more available.

The findings discussed here support Paul's wife in her recommendation for a standardised pack, as discussed in Chapter 7 previously.

> *"Written in layman's terms that everyone can understand."*
>
> (Paul's wife: interview 1)

9.3.4   Local Authority Support

Representatives from the local authority services visited the homes of the survivor participants and offered support to Sarah and Penny. As previously stated, carers in the morning and evening, the meals on wheels and the sit in service schemes were rejected by Sarah:

> *"I don't know who they are going to be. No, I don't want strangers coming to my house"*.

<div align="right">(Sarah: interview 1)</div>

Other than concerns that the visitors may be people she did not know, Sarah felt that she may be restricted by the times they would want to come over:

> *"If I want to go to bed and they have not been, I can't go*."

<div align="right">(Sarah: interview 1)</div>

Furthermore, Sarah's daughter considered: *"why pay when we are managing?"* (Sarah's daughter: interview 1). This suggests a preference for support from people known to the survivor, and contributes towards the findings discussed in Chapter 8 previously in supporting Bäckström and Sundin's (2009) theory of survivors putting up barriers to caregivers by not accepting support from others. However, Sarah's daughter felt reassured in knowing that there was support available if it was needed at any point in the future. However, in-home adaption provisions had been put in place for Sarah and Penny. John also reported that he had received a home assessment by local authority services, however he did not require any of the provisions that they suggested.

Penny was fully dependent on professional carers for all aspects of daily living. Describing the support put in place by the local authority services, Penny described:

> *"They do my shopping, they wash me, and dress me, they take me to the toilet and bring me back to this chair, and then they come back at dinner time, give me something to eat."*

<div align="right">(Penny: interview 1)</div>

Penny's paid caregivers would also ensure that Penny had eaten a sufficient amount of food at meal times. The professional care provided by local authority services relieved Penny's daughter of some of the caregiving responsibilities:

> *"They're a godsend as far as I'm concerned, they really are."*
>
> (Penny's daughter: interview 1)

Although the provisions of professional caregivers were initially centred around caring for their client, such provisions also provided a level of support for their caregivers. This supports initiatives that have been put in place by Welsh Government with the aim of supporting caregivers in living a fulfilled life.

Thomas's wife reflected that the local authority employed a caregiving organisation which had sent nurses to their home to help Thomas with his personal care, helping him to shower and apply body cream. Dissatisfied with the service provided, Thomas's wife reported that they were unorganised and irregular:

"Sometimes they're an hour and a half late, and Thomas would be sitting in their pyjamas waiting when we could be out walking."
(Thomas' wife: interview 2)

This highlights where this provision had placed time constraints on Thomas. Furthermore Thomas's wife reflected that because the caregiving organisation would send different people each day, she was also constrained to stay in the house to wait for them so that they could be informed what needed to be done, reflecting that Thomas would often:

> *"Say that he is OK today, and then they don't do anything."*
>
> (Thomas's wife: interview 2)

This supports claims within the literature reporting the support provided to be inadequate (McKevitt et al. 2011). Thomas's wife also reported that she had asked the nurses to let themselves into the house as Thomas had hearing difficulties and could not always hear the doorbell. However, the nurses would not walk in and so often they had been and gone, and Thomas would still be sat there waiting. This resulted in Thomas's wife staying at home to wait for the nurses to come. Thomas's wife considered the local authority paid caregivers to have

been helpful as she was struggling before due to her own health, however she felt that she was still constrained to being in the house until they had been.

Similarly, Penny's daughter reported feeling frustrated at the rotation of paid caregivers, rationalising that:

> *"Once they have been here a while and they had become familiar* [to the person they cared for]*, and they had gotten to know the routine, they'd turn them out."*
>
> (Penny's daughter: interview 1)

Penny's daughter had expressed that it was useful when the paid caregivers became aware of the type of things Penny liked for her shopping and how Penny liked things done around the home:

> *"She won't always say what she wants or if she needs anything."*
>
> (Penny's daughter: interview 1)

The nurses who knew Penny would prompt her with suggestions of food she had liked in the past. Penny's daughter concludes her frustration: *"it's a joke"* (Penny's daughter: interview 1). However, acknowledging how beneficial the paid caregivers could be, Penny's daughter reflected that: *"having good carers makes a lot of difference"* (Penny's daughter: interview 1). They relieved her of some of her caring responsibility and supported her in her own life by giving her time for her own commitments; her work and children.

However, highlighting other areas where support had been good, Jane, Penny and Thomas (interview 2) informed that they received an allowance for them to have a cleaning service visit their homes:

> *"This is all through the local authority and the hospital board Our Care, very good – and people get a little allowance which pays for the cleaning."*
>
> (Thomas's wife: interview 2)

This took some of the household responsibility from the participant caregivers:

"I've given up worrying about the house now."

(Penny: interview 1)

This highlights the broad depth of support which the local authority services provide in supporting the participants in their everyday lives. Here, the caregivers also highlighted that although the support provisions were client focused; they also provided a support to the caregivers as it relieved them of some element of the caregiving role.

However, implementing the provisions required for Penny hosted further challenges for Penny and her daughter. Despite Penny and Ruth reporting that they felt lucky as their homes had already been adapted for wheelchair users, Penny's daughter informed that it took a long time to get the necessary additional adaptions made to meet the needs of Penny. Frustrated, Penny's daughter's stressed: *"it took them* (LA services) *ages"* (Penny's daughter: interview 1). Penny's daughter reported that the bathroom should have had the necessary adaptions before Penny was discharged from hospital as although it was adapted for a wheelchair user, it was unsuitable for Penny's post-stroke needs. Penny's daughter reported that the adaptions were made three years after Penny's discharge. This is an area of great concern and highlights where there is a lack of communication between the hospital and social service departments. This is something that the Welsh Government aims to address in its 2014 Social Services Wellbeing Act. The fixtures for the bathroom were a necessity as they assisted Penny's daughter in getting Penny showered and washed properly. Not only did this situation cause upset, strain, stress and frustration, it contributed further to the burden of caregiving and could potentially have implications for the privacy and dignity of the survivor:

"She had no dignity. It was awful."

(Penny's daughter: interview 1)

9.3.5 Financial Support and Advice

Those survivor participants who were not eligible for a pension at the time of their stroke were able to draw on their pensions early because they were unable to work, or claim pension credits. The survivor participants informed that they also claimed Disability Living Allowance, with Penny also being eligible for income support. With Sarah, Penny and Ruth residing in warden-assisted accommodation, they also stated that their rent was paid in part by the statutory sector. When reflecting upon gaining awareness as to what they could apply for, Paul's wife reflected (in Section 9.3.3) that a *"chance conversation"* (Paul's wife: interview 1) with a nurse at the hospital enabled her to find out which financial support both Paul and herself may be able to apply for. Furthermore, they reflect that the advisors at the Job Centre were also helpful at this stage.

9.4 Third Sector Support

During the transition home, five of the nine (Sarah, Paul, John, Ruth, and Penny) case studies declared that a representative from a stroke charity had visited them whilst at the rehabilitation unit or recently after discharge at home, informing them of their support services and Stroke Clubs in the area. Furthermore, John's partner recalled that the stroke charity representative also telephoned to assess if John needed any home adaptions, exampling how the third sector organisation aimed to meet their aim of making at least 90 percent of survivors aware of their services when they experience stroke by 2015 (Stroke Association, 2013). However, John's partner felt: *"they didn't really tell us much, did they?"* (John's partner: interview 1), this suggests that this opportunity for communication with the survivor and caregiver participants here was not utilised effectively. This was a missed opportunity for information to be distributed. Penny had also received support from an older person's charity who sent a representative to her home to help complete finance-related forms. The older person's charity had also provided Sarah with:

> *"A green pot, I call it the emergency pot, and they've got a piece of paper inside the pot which you fill in details of your next of kin, all the medication and everything, and then put a sticker on the door outside to say that you've got a pot in the house so that in the event of an emergency, the paramedics or whoever comes out, they know they have the details they need."*

This demonstrated how the older persons' charity focused on helping with practical advice in everyday life.

Thomas and his wife had also been offered support from a caregiving organisation as they responded to a leaflet which was distributed through the letter box. Thomas's wife further stated:

> *"We've had a lot of good people, they're good down at the carers service, they keep ringing up to make sure everything is alright."*
>
> (Thomas's wife: interview 1)

Thomas's wife reflected:

> *"I think we're very well looked after really you know, the 12 months that we've been here, I think Wales is excellent for elderly care you know."*
>
> (Thomas's wife: interview 1)

However, reflecting on carer support, Thomas's wife observed:

> *"I can go to the carers' meeting, and can go to lunches and things, but the trouble is sometimes you can't take your partner but I mean what is he going to do for lunch while I go somewhere else for it? You see?"*
>
> (Thomas's wife: interview 1)

Thomas's wife reflected that *"I don't think that I've been to a meeting properly"* (Thomas's wife: interview 1), highlighting that she would like to go, however her caregiving role was preventing her from being able to take up the support offered. However, Thomas's wife reflected that if the carer's service was delivered in a way that:

> *"We could go together and have a coffee there, you can sit and have a chat even while I nip around and do some shopping."*
>
> (Thomas's wife: interview 1)

Thomas's partner expressed that she would be more able to attend if Thomas was able to come too. This highlights that access to caregiver support becomes a barrier when the survivor is not considered by the support provider; rendering the provision inefficient. However, as they would get the bus there, they would more likely only go when the weather was nice. This highlights that the support is there if it is needed, however accessibility prevented Thomas's wife from utilising the carers support service on a regular basis.

9.5   Support from Social Enterprise: The Stroke Clubs

Each of the eight participants who were recruited via the Stroke Clubs considered the Stroke Club to be a valuable contribution to their personal support network and their everyday lives. This supports Burholt and Dobbs (2014) research which describes support networks to include social, emotional and instrumental support. In this section the Stroke Clubs are introduced and discussed, followed by the case study participants' perspectives which were gathered during interviews.

9.5.1   Defining Social Enterprise in this Context

Using Leadbeater's (1997) Cross Sectional Model of Entrepreneurship (Figure 4, Chapter 4 previous) in this context, the Stroke Clubs demonstrate ways in which social enterprise incorporates elements of each sector. Within the statutory sector, the Stroke Clubs share the same social aims as statutory policy; to support people living with stroke in their everyday lives. From the private sector, the Stroke Clubs use private sector business structures and practice, giving people roles such as treasurer and member coordinator. Finally, from the third sector, Stroke Clubs were offered some promotional support. However, more specifically, they fundraise in a similar way, and again, share a common social aim; to support people living with stroke in their everyday lives.

With that in mind, reflecting upon Martin and Thompson's (2010) Triple Bottom Lines, discussed earlier in Chapter 4 (Section 4.6). In this context the social aim of the Stroke Clubs is to support survivors and their caregivers in their everyday lives, the economy element relates to the Stroke Club supporting society as a whole through their support of people in their everyday lives. Whilst the finance element of the model refers to the Stroke Clubs raising money in order to be a sustainable initiative. Becoming self-sufficient protects the social enterprise from fluctuations in the third and statutory sector which may impact on their resource and thus the

ability for them to meet their social aim. Therefore, the Stroke Clubs are a good example of social enterprise as they show how businesses in this sector are focused on social aims and output, and profit to reinvest into the initiative. This is discussed further throughout the remainder of the chapter.

However, instead of being set up by people to meet a social aim, or support others in society. The Stroke Clubs are run by individuals who run the clubs to meet a need which they themselves wish to be met, as such the social entrepreneurs in this context are described as social entrepreneurs by necessity.

9.5.1.1 Background Context: Stroke Club

Each of the Stroke Club hosts have experienced stroke in their lives; either personally, in their professional capacity, or as caregivers. A semi-structured interview with the host of Stroke Club A informed of her motive to form the club which came from her own unmet need when she was recovering from stroke. The host (Stroke Club A) had sought to attend a stroke support club and discovered that there was nothing available in the area. Considering that there must be more people in a similar situation, the host started the Stroke Club in order to meet her own needs. Twelve years later her Stroke Club had recruited over 50 members, highlighting that there was a need for such a club in that area. Presenting a similar demand trend, Stroke Club C began as a club of eight members and rapidly expanded to have 60 members registered over the four years it had been running. The host was concerned that the venue was becoming too small and was concerned that they might have to turn people away. They had considered a larger venue, but the costs were too great. Similarly, Stroke Club D began as five members and has expanded to have 21 members registered. The mere expansion of the Stroke Clubs over time highlights that there was a demand for the initiative and such support in the community. Especially when you consider that, due to the geography of the study site which was in a rural region; some of the Stroke Club members were travelling 45 minutes or over to attend. Furthermore, in terms of establishment and longevity, these clubs varied from four years to 25 years. Despite Stroke Club B being a referral club there was no restriction on the length of time people stay members, and they do not turn anybody away. This emphasises the lifelong support they are able to provide, which was not offered by statutory sector provision.

Interestingly, Stroke Clubs were offered support from the third sector, but realising their potential to raise funds on their own initiative, the larger clubs (A-E) were sustainably sufficient being managed by entrepreneurial individuals who exhibited both a social and economic focus. This highlights how the Stroke Clubs have transitioned into becoming a social enterprise, and their founders into social entrepreneurs. When asked about support they receive from external organisations, they informed the author that a related third sector organisation had given them affiliated status which enables them to receive communications from them and posters if they were having a fundraising event, in return for half of the money they would raise. However, all the clubs in the study stated that they preferred to fundraise without the support of the third sector organisation as they were then able to keep all of the funds they raised.

9.5.1.2 Social Aim

The common mission of the Stroke Clubs was to provide support to people living with stroke, and a place where people could socialise with others who have the shared experience. They also focused on making the service accessible, by organising car share and some providing a minibus which was driven by a volunteer. Transport to and from the Stroke Clubs was primarily by car or taxi with a small number of members from Stroke Clubs D and E walking to the venue. One club owned a mini bus (Stroke Club E) which the members who use pay a small fee, and another club had a charity mini bus (Stroke Club A) which charges a small fee for people who use it. However, accessibility was also achieved by providing a support service which had reduced barriers to access such as it being run by people in the community (caregivers and survivors), and it being a social setting where there were people with the lived, shared experience.

The stroke-specific element of the Stroke Clubs contributed towards the survivors' sense of 'belonging' and the reassurance of the shared experience which reduces the perceived and anticipated stigma and misunderstanding of the external environment. However, showing that they were not turning people away who were living with other lifelong conditions, one Stroke Club observed had a member with dementia and another member living with physical disability.

9.5.1.3 Financing and Income Generation

Initially supported financially by funding from the local authority and a related charity, with clubs B-F being run by the related third sector organisation, the financial recession recurred and there was a change in monetary focus. The third sector organisation was unable to support the clubs financially and local authority funding was also withdrawn. Participants of the study and the club hosts described the impact withdrawal of funding had on its members. They were tearful, distressed, and upset, when they thought their local Stroke Clubs were going to close, commenting that *"it makes such a difference to their lives"* (Ruth's daughter (a): interview 1). For several of the members:

> *"It is the only social interaction they get, and not just for people with stroke."*
>
> (Stroke Club B Host)

As publicly funded clubs, these enterprises were once considered a service of the third sector. When the funding was withdrawn, certain individuals who were members of the clubs sought to keep the club open and investigated ways for the support clubs to become self-sufficient and sustainable. Some of the clubs formed committees to run the club and adopted an organisational structure not dissimilar to a private sector organisation (although they were not paid); the Stroke Club committees consisted of their host and founder, a treasurer, a member's secretary and club volunteers. Sales of raffle tickets, fundraisers, table top stalls and sales of the service is what make the clubs a social enterprise. As illustrated in Table 4: Stroke Club Profiles, members of Stroke Clubs C, D and E paid a small sum[1] in addition to a raffle which contributed towards tea, coffee, snacks and the hire of the venue. In addition, Stroke Club C members paid for their own lunch which was ordered on the day (if they wanted it) and delivered by a local sandwich shop. The Stroke Club A members paid no fee but paid for their own food which was ordered in advance, and drinks from the bar. Money for the running of Stroke Clubs A, B, and F was raised through fundraising efforts and a raffle they held each time.

The money they raised from raffle and fundraising events outside of the regular session went towards the venue and outings and entertainment. Venue hire costs varied between clubs as Stroke Club A was hosted in a hotel, Stroke Club C was hosted in a social club, and clubs B, D, E and F were hosted in community centres. Clubs A and C had relocated their venue due to a growing number of members, and with Stroke Club F having few members and a charge of £20

---

[1] Stroke Club C: £1.50, Stroke Club D: £5.99, and Stroke Club E: 50p.

for use of the hall, their future was under threat as the raffle did not cover the cost. Although some members donated money into the club each week, the host was topping up the amount to cover costs herself which she stated was not going to be sustainable. In addition, as previously mentioned, the host from Stroke Club A expressed a desire to run the club each week, but it was too much for her to organise due to her own post-stroke health.

The smaller club (F) is faced with low membership and high hire charges for the hall, and so the host makes up the shortfall with her own financial input. This club could potentially recruit more members by raising awareness of the club. However, as it is in a very rural area, perhaps one option could be that the club could make itself less stroke-specific in its image, and thus open its services to people living with disability in the community. However, this may take away the ethos of the Stroke Club as the survivor participants who were Stroke Club members reported that it was beneficial having a stroke-specific club to go to.

9.5.1.4   Economic Impact

Stroke Clubs are valuable to the communities. Their contribution in providing support to survivors and caregivers, in areas where policy and support from other sectors lacks is particularly crucial. The economic output of Stroke Clubs is their contribution to supporting survivors and caregivers in their everyday lives. Findings discussed earlier in Chapters 6, 7, and 8 emphasised the value of Stroke Clubs in this context by discussing the participants' perspectives and observation data. Further discussion is also provided below.

9.5.2   Supporting Social Participation through Stroke Support Clubs: Observations

Earlier in this chapter, as well as Chapters 7 and 8 previously, Stroke Clubs have been identified as a valuable source of advice, rehabilitative exercise and intellectual fulfilment. It has been identified that Stroke Clubs create a 'safe zone' for their members and are a valuable contribution in reducing barriers to social participation both in the external and internal environments. Each of the Stroke Clubs was set in an informal setting. Stroke Club A was hosted in a hotel, Stroke Club C in a social club, and clubs B, D, E and F in community centres. However, as the members of Stroke Club B were generally recruited by GP referral, and the host of Stroke Club B referred to their service users as clients, whereas the other hosts referred to

their service users as members, this suggests that Stroke Club B may take a more service-provider than a support-club approach. This informal setting enabled the Stroke Club members to communicate with each other. This allowed the formation of a few friendship groups within the clubs, some of whom were planning holidays together.

Refreshment provisions were provided in various forms, dependent on the provisions of the venue and time of day the club was held. Being held over the lunch hour, members from Stroke Club A were offered a sit-down pre-ordered meal served by hotel staff, and drinks were bought from the bar. Members from Stroke Club C consumed tea, coffee and biscuits throughout the session laid on by the host and committee, and ordered food from a local sandwich shop which would later be delivered. Members from Stroke Club D would have tea, coffee and biscuits throughout (served by the volunteers) and sit down to a buffet laid on by volunteers, members of Stroke Club E would have tea and coffee, as well as sandwiches and cake laid on and distributed by the volunteers. Being afternoon sessions, Stroke Clubs B and F volunteers would lay on tea, coffee, and snacks for their members.

9.5.3 Supporting Each Other

The observed participants were supported by Stroke Club volunteers, and also each other. On some occasions one member was helped to stand up, move around the venue, and to and from the lavatories and to and from the taxi (Stroke Club D), and members from Stroke Clubs with communication difficulties (Stroke Clubs A, B, C, D, and E) were observed talking to people, despite communication difficulties, demonstrating a sense of support from members:

> *"We've had people that haven't spoken and because we understand and we continue to talk to them, I think what's needed is, their confidence has gone and we need to get that back."*

> (Ruth: interview 1)

Notably, assistance was given by both volunteers and able-bodied survivors (Stroke Clubs B, C, D, E). Volunteers helped to cut up food and put it on the fork for the survivors to eat. Volunteers also encouraged Penny to eat as much as she could as they were aware that Penny was not eating as much as she usually would (Stroke Club A). Other ways in which survivors were observed

helping each other eat was exampled at Stroke Club D, members were observed helping another take a cake out of the wrapper, so they could eat it, and holding a cup of tea to their mouth.

Stroke Club D observation 4 observed an incident were a member was dropped off at the Stroke Club by his daughter without his wheelchair because she did not want him to use it. However the member required assistance from a volunteer as he was unable to walk. Another member insisted they used their wheelchair to help get the member into their taxi when the needed to go home. In addition, Stroke Club C observation 4 observed a new member who became overwhelmed and thus became too hot, and felt music too loud and so was moved closer to the door. The Stroke Club host and other volunteers looked after them and phoned the key worker on their behalf as they felt it was too soon for them to be coming to the club. This highlights a level of understanding of adapting to life with stroke from the Stroke Club organisers; something which may not have been understood by a more generic non-stroke-specific support club.

This level of empathy with support was observed at all of the Stroke Clubs who participated in this study. The host from Stroke Club A observed that when someone is ill, they telephone around to other members to let them know, send letters and flowers, telephone the person, and go and see them at home or in hospital. They give each other support and a morale boost. If a member does not attend for a few weeks, the host phones to check they are OK as she commented that it can be lonely, and that some members live on their own too. However, Ruth's daughter mentioned previously that they had expected that the Stroke Club would have been in touch when Ruth's home was flooded, unfortunately this was not the case.

9.5.4   Stroke Club Support: The Participants' Perspectives

> *"Stroke Club is all she's got; it's the only time she leaves the house, otherwise, she just sits here; it's no life really."*
>
> (Penny's daughter: interview 1)

Emphasising that the Stroke Clubs provide a valuable avenue for social participation in the external environment, Penny's daughter identified this as the only time Penny will leave the house and see other people.

Ruth's eldest daughter felt that *"Stroke Club was really important"* (Ruth's eldest daughter: interview 1) as going there gave Ruth something to focus on:

> *"To get out of the house twice a week, which they might not have otherwise done."*
>
> (Ruth's daughter (a): interview 1)

The survivor participants informed that they enjoyed the activities (discussed in 8.1.2.6 previous) which are laid on for them at their local Stroke Clubs. The participants who attended Stroke Clubs B, C and D noted that the rehabilitation exercises had helped them, in some cases, improve their physical and communicative ability, which made them more confident in performing their everyday tasks. For example, Jane and John were more confident in their communication at the follow-up interview. The survivor participants also described how Stroke Club gives them a 'safe zone'; a safe place where they are surrounded by people who have a shared experienced, and they felt understood them which Schales and Schneider (2012) state as key for making support services accessible. These perspectives are discussed in more detail throughout the remainder of this section.

> *"It's my only real sense of reality because I see people who are far worse than me physically or mentally. Yet somehow I'm connected or sharing. They understand me better than people who have not had a stroke."*
>
> (Mark: interview 1)

Furthermore, Mark comments on how Stroke Club had helped him come to terms with his stroke emotionally:

> *"The comfort I get from Stroke Club; in accepting the things I can't do and being grateful for what I can do."*
>
> (Mark: interview 1)

Being reflective, Mark considered how stroke had affected him compared to other Stroke Club members. This helped him to come to terms with stroke and its reality. Mark also reported that he takes comfort in having the opportunity to socialise with other people living with the shared experience and be around people he can connect with, who understand what they have been through. This shows how Stroke Club provided an opportunity to help Mark to come to terms with post-stroke life. By attending Stroke Club, Mark was able to evaluate his life and consider

his own ability and post-stroke self compared to others who he met at the Stroke Club. This contributed to him asserting a realistic self-perception of his post-stroke life. This supports the viewpoints of Frankl (1963) and King and Hicks (2009) (reported previously in Chapter 7), that gaining a realistic perception of the self after a life-changing event such as stroke was key in coming to terms with the event itself and moving forward in your post-event life.

Ruth identified:

> *"You cannot always see what the outcome of stroke is as not all outcomes are physical, and so, from the outside looking in, you can't see what that individual is coping with."*
>
> (Ruth: interview 1)

This was supported by the participants considering Stroke Club as a place to go where other people have had a shared experience, and they are aware of *"what you're going through"* (Mark: interview 1) and so became a familiar social setting where there was shared understanding of stroke and where survivors who may lack confidence and can feel safe. Supporting this point, Mark reported that Stroke Club was a place that he felt he could confidently socialise without fear of being exposed to public stigma.

This was supported by the interviews with the Stroke Club hosts, who identified that the members really valued having a place to socialise that they considered to be a friendly, unthreatening place where *"they don't have to worry, they can just be themselves. On bad days where they are struggling, we all understand"* (Stroke Club A Host).

John's partner reflected upon how Stroke Club had assisted John in regaining his confidence and rebuilding his life after his stroke:

> *"Didn't think he was going to live to get here."*
>
> (John's partner: interview 1)

John's partner did not expect John to reach the stage of recovery which he had at the time of his first interview.

Highlighting the contribution which Stroke Club had made to John's recovery, John's partner asserted:

> *"He was a different person before the Stroke Club, I didn't think he would live to get here."*

<div align="right">(John's partner: interview 1)</div>

Also supporting this view, Ruth also highlighted how Stroke Club helped people to regain their confidence and self-esteem.

Paul also confirmed the additional support received from the Stroke Club when his wife died. However, this depth of support was not experienced by all. From another Stroke Club, Ruth's daughters previously claimed that they were disappointed that there was no contact from the Stroke Club when Ruth was having a difficult time after their home was flooded. However, upon reflection Ruth's daughters consider that:

> *"There wasn't a lot they could have done."*

<div align="right">(Ruth's eldest daughter: interview 2)</div>

Richard and his wife highlighted that now Richard experienced more post-stroke fatigue than he used to, they were unable to attend Stroke Club regularly. However, the host of the Stroke Club which Richard is associated with often visits them and keeps in touch; highlighting a further depth of support.

Emphasising the value of Stroke Club, Paul's wife asserted:

> *"We couldn't cope without the Stroke Club."*

<div align="right">(Paul's wife: interview 1)</div>

Stroke Club allowed Paul's wife to receive support in her caregiving role as she was able to gain information from other members, and the host of Stroke Club. It was felt by Paul's wife that this information would otherwise not have been gleaned, therefore highlighting that Stroke Clubs were providing information to their members which was not being distributed by the statutory sector provisions. This suggests that Stroke Clubs are 'filling several gaps' in such service

provision. Information and advice from people who had first-hand experience of stroke was valued by the caregiver participants over more professional avenues for information.

Further confirming Burholt and Dobbs (2014) research who assert that support networks consist of social, instrumental and emotional support elements; it was noted by the caregiver participants who were spouses of the survivor participants that they valued the Stroke Clubs too, for their social aspect as well as support. Reflecting back upon Table 4: Stroke Club Profiles, it was noted that different clubs have different frequency of delivery. Perhaps if the Stroke Club which Penny had attended was more frequent, then she would have felt that she had more social participation in the external environment as she would have had more opportunities to leave her home. However, this is speculative, and the interview with the host from Stroke Club A had declared that she *"wished we could do it more than once a month"* (Stroke Club A Host). On reflection, this could not happen because the host's own post-stroke health prevented her from doing so. This highlights a need to support social entrepreneurs running such support clubs. Particularly as this study found that the hosts of the Stroke Clubs observed were either survivors of stroke themselves and had their own needs and challenges such as stroke-fatigue and disability, or they were already acting as caregivers who were caring for people who had experienced a stroke and they were running the clubs alongside a caregiving role.

Reflecting on those members who formed a committee, Ruth's eldest daughter felt that Stroke Club gave them an opportunity to contribute to helping others:

> *"It gave people that were involved in the setting it up, and actually, did what it was set out to do which was to empower people who have had strokes and to understand that they could continue to contribute and that they didn't have to be passive participant, but it is a really really difficult thing to do."*

(Ruth's daughter (a): interview 1)

This demonstrates how Stroke Clubs can contribute to the lives of survivors and caregivers in many ways. For committee members and organisers, they provided a sense of responsibility, while for survivor participants they provided a place to meet other people who have experienced stroke; helping them to come to terms with their post-stroke lives (King and Hicks 2009) as well as make friends and widen opportunities for social participation. Furthermore, they provided the survivor participants with a social output, while providing activities which provide intellectual stimulation and rehabilitative support which was reported as lacking from the statutory sector

provisions in the longer term. Although managing the Stroke Clubs has some benefits, it also holds concerns. The larger clubs, clubs A, C, D and E, had a key host, but also a committee who take on different roles, which relieved some of the responsibility. However, the host from Stroke Club A reports that she experienced post-stroke fatigue which meant that she often finds it challenging to organise the Stroke Club.

9.5.5   The Stroke Club Hosts' Perspective

These research findings define social enterprise in this context, and demonstrate how social enterprise can complement the statutory sector in meeting their aims and objectives; of supporting survivors and caregivers in their everyday lives. The transition from being supported by the statutory sector and third sector, to becoming a 'self-sufficient' social enterprise demonstrates the ways in which the Stroke Club hosts have become social entrepreneurs out of necessity. Defining the social entrepreneurs in this context; they are survivors, or caregivers. Social entrepreneurs exhibit unique social entrepreneurial traits as they are driven by benefitting a community group rather than a financial return (Edwin 2014). Although this had its benefits as they are familiar with stroke, it also held concerns as the outcome of stroke on their everyday life in addition to this, added responsibility can cause great strain. Survivor participants reported a desire to lead a less stressful post-stroke life.   However, the larger clubs (A, C, D and E) had a host, but also a committee who take on different roles which relieve some of the responsibility.

The Stroke Club Hosts from Stroke Clubs A, E and F were interviewed. A survivor of stroke herself, the host of Stroke Club A explained that when she was in hospital, she was daunted by the prospect of being discharged and having *"nowhere to go"*:

> *"I couldn't keep working, but I couldn't just sit there and do nothing. I'd have been bored and felt useless. So I asked the nurse if there was a club or something for others in my position, she said there was nothing. So I just decided to start one myself and see if it would take off."*

> (Stroke Club Host A)

This describes how the host of Stroke Club A had started Stroke Club to meet her own need, the need to be doing something. This story really is remarkable as the host explained that there were

12 people the first week, and the club grew to over 50 people over the next six years. Reflecting of its popularity, the host commented that some people travel about 40 minutes to get there and:

> *"For some, it's the only interaction with an actual person they get. We all keep an eye on each other too. If someone is not here and we expected them to be, we rally around to check they are ok, as some people are so lonely."*
>
> (Stroke Club Host A)

The host from Stroke Club E was also found that their Stroke Club was popular. Both hosts commented about possibly needing bigger venues, with Stroke Club E having already changed venue in order to accommodate its growing membership. The host of Stroke Club E was a caregiver. She commented that her motivation for running the club was that:

> *"We all want to support one another, the stroke people and us as family and caregivers. It can be hard, especially when your husband cannot talk to you because of stroke. There are a few here that cannot talk, and us caregivers would go potty in a week if we didn't have people to talk to!"*
>
> (Stroke Club E Host)

Stroke Club F, however, reports of low membership rates and was concerned that it might have to stop running the club. More rural than the other Stroke Clubs, the host of Stroke Club F stated that she paid for the venue out of her own money because the membership didn't cover it and the members would not be able to afford to pay more money. Stroke Club F struggled with recruitment, despite feeling that there must be people who did not know about the Stroke Club.

Stroke Clubs E and F differ from that of Stroke Club A as they were originally set up by the Stroke Association, as was Stroke Club B, of which Ruth was a committee member. As Ruth stated, the clubs were going to face closure due to funding cuts. Similar to Stroke Club B, Hosts E and F took over the clubs as there was a need for them. They were so important to people's lives. When asked about third sector support, the hosts informed:

> *"Pfft, it's not worth it! All they do is turn up every once in a while and see what you are doing, give you ideas in a booklet, which you cannot use because they do not help you set them up, and there isn't always enough money to make it work long term..... And then they just then go off....And if you want to raise money, they give you things to help*

advertise, but then they want half of everything you raise! So, it's not worth the effort in the end. So we just try and raise the money ourselves and keep the lot."

(Stroke Club E Host)

The hosts felt that it was disheartening that the third sector organisation which offered them help took such a large percentage. Therefore, third sector support it is not always appropriate or effective. This suggests that there must be a more effective way of supporting Stroke Clubs. Supporting survivors, caregivers and widows or widowers (of survivor), the Stroke Clubs deliver value to all their members. However, this is not without its challenges. Other than the lack of support from the third sector, the Stroke Clubs felt that they primarily needed support in marketing and fundraising. Recommendations for Stroke Clubs are provided in Chapter 10.

9.6 Chapter Summary

This chapter discusses the ways in which the participants were supported in their everyday lives. The findings here report of the observational research, which is strengthened by the participants' perspectives obtained by their interviews. During the early stages of their post-stroke lives, in the first days and months living with stroke, the participants were supported by hospital staff, with exception of those participants where the survivors had experienced stroke abroad. The study participants were supported in their everyday lives, in the months and years after stroke, by their family, friends, people in their local community and Stroke Clubs (for those eight participants who attended).

The study participants highlighted a key issue for survivors and caregivers as the scarcity and lack of clarity of information. This had been acknowledged by policy makers, practitioners, and academics alike. However, the findings here contribute to the existing literature by affirming that it is not that the information is not available; it is that the participants had to actively seek the information. This suggests that the issue is with the accessibility and delivery of information. The findings here also highlight that there are issues with the service user interface. More specifically, the people at the forefront of customer service in hospitals, GP practices and financial support teams.

The findings here emphasise the significance of Stroke Clubs in the participants' everyday lives. They provide an opportunity to share their experiences and act as an informal route to obtaining

information. However, this rather understates the value of the Stroke Clubs observed. Stroke Clubs offer a stable pattern of interaction, a branch of community, and provide a valuable social and participative outlet for survivors of stroke and their caregivers.

Policy makers have reported the value of social enterprise and community groups in complementing policy initiative and supporting people with complex conditions in their everyday lives. The findings contribute to the existing literature on policy and social enterprise by showing how Stroke Clubs, an example of how social enterprise, fill a gap in statutory sector service provisions by providing a focus on lifelong support for survivors of stroke. Therefore, social enterprise in this context creates a world for survivors of stroke where they feel they can express themselves in a 'safe' environment and have an opportunity to contribute to and engage with society as a whole.

The final chapter of this thesis, Chapter 10, concludes the research findings of this study, their contribution to the existing knowledge base and recommendations for future policy, practice, and research.

10.0   Conclusions, Recommendations, Implications and Reflections

This chapter synthesises the key research findings and exposes the authors concluding thoughts. In doing so, it lays out the authors recommendations, and informs policy makers, practitioners, social entrepreneurs and the academic community.   The limitations of this study are also addressed, along with the author's reflection of the study itself and the methodology adopted.

This thesis reports a study which set out to better understand the everyday lives of survivors of stroke and their caregivers in Wales.   To do this, the research sought to meet the following research aims: (1) to explore the everyday lives and experiences of survivors of stroke and their caregivers, (2) to identify the key avenues of support for survivors of stroke and their caregivers, and (3) to explore how Stroke Clubs deliver support to survivors of stroke and their caregivers. These aims were met through a multiple case study approach and observational work in Stroke Clubs.   In-depth elicitation of the perspectives and experiences of nine survivors and eight caregivers provided a rich and detailed dataset.

The opportunity to include dyads (of survivor and caregiver participants) in primary research is a particular strength of this piece of work. This allowed an insight into the context of the lives of the survivor participants inclusive of their support network and the relationships with their caregivers.   The case study approach also meant that the context of the caregiver could also be explored, in relation to their support network, and their relationship with the survivor participant. This also included identifying the impact that particular stroke outcomes, such as communication difficulties, had on the caregivers. Often research focuses on just one half of the dyad (the survivor or caregiver), with researchers struggling to recruit dyadic case studies.   The dyadic nature of this study helped to better understand the unique perspectives of the participants' experiences, as shaped by their individual contexts on a case-by-case basis.   These contexts provide a background to the findings and inform policy makers and practitioners about the full impact of post-stroke life as reported by the participants.   This knowledge can be used to inform future policy development and support initiatives.   Recommendations on how this can be achieved are discussed later, in Section 10.3.

10.1 The Empirical Findings: meeting the aims of the study

In answering the aims and objectives of this study, the empirical research findings were presented in previous chapters, Chapters 6, 7, 8 and 9. The author offers here both a synthesis of the research findings in the context of each research aim but also starts to elaborate on the policy and practice implications of the findings. Addressing the impact of the research is an important intermediary to completing a piece of work and also to informing the direction of future research. The empirical findings will be synthesised below by research aim. The key findings from this study are aligned centrally, introducing further discussion below each theme. Furthermore, key findings relating to the overarching themes are also highlighted in bold within their subsequent paragraphs.

10.1.1 Addressing Research Aim 1: To Explore the Everyday Lives and Experiences of Survivors of Stroke and their Caregivers

The Outcome of Stroke

Stroke is no doubt a complex and dynamic phenomenon. The impact of stroke on the participants' lives varied greatly case by case. **It was also established that the impact of stroke on the neurological and physical self could show improvement or deterioration over time.** Similarly, the mental and emotional wellbeing of the survivor and caregiver participants varied over time. This was as a result of many different changes and adaptations such as coming to terms with the stroke itself.

Identifying the Caregiver

Survivor participants in this study were cared for by their spouse or daughter. **For the most part, the caregiving role was taken on by those family members who lived the closest to the survivor, rather than consideration of any gender or age.** There was variance in the caregivers' satisfaction and ability to cope with the caregiving role. These findings challenge the notion of caregiver and kinship obligation discussed in the literature (by authors: Burholt and Dobbs 2014; Johnson and DeSouza 2009; Qureshi and Walker 1989; Twigg and Atkin 1994; Schales and Schneider 2012) by identifying that it cannot be assumed that the eldest child is the one who takes on the caregiving role. Penny's adult daughter was not the eldest child and rather than caregiving being the responsibility of one sibling, Ruth's adult daughters shared the

caregiving responsibility. Although this can be due to physical distance, there is also evidence presented in this thesis which suggests that there may be an unwillingness to care in some instances. This was expressed by Penny's daughter who described her sister as *"less than useless"* (Penny's daughter: interview 1) when it came to supporting Penny, despite her living close by.

The research findings here are not dissimilar to earlier work. For example, Bäckström and Sundin's (2009) study identified that caregivers were typically (and primarily) members of the survivor's immediate family; their adult children, second to their cohabiting partners (where applicable). However, there were variances in the caregiving relationships; between those who cared for their cohabiting partners and those who cared for their parents. **The adult children caregiving for their parents appeared to express more feeling of being burdened or their personal life was being encroached upon compared to those caregivers who resided with the survivor.** This could be a result of the adult children caregivers living away from the survivor's home and not being physically close to the survivor on a day-by-day basis, as well as them having commitments of their own family. Reflecting back upon Berges et al.'s (2012) theory that the more confident a caregiver is in their caregiving role the better their perception of their own quality of life is, **the lack of information, support and advice available to the caregivers of this study can only contribute to negative feelings towards of caregiver quality of life, adding further strain and reduced confidence for the caregiver.**

The caregivers reported similar feelings and emotions as the survivor participants which highlights that although caregivers are being identified by policy makers as patients with their own needs, caregivers and survivors do need to be considered as a dyad, as well as two separate people. A recommendation of this is presented in Figure 9 later in this chapter. Such feelings and emotions included fear, frustration and uncertainty. However, these feelings changed over time. The key challenge for caregivers was expressed as the transition into the caregiving role. As the survivor participants and caregivers formed a sense of routine the caregivers began to ease into their roles. This reduced feelings of strain in the caregiving role, although the challenge of being a caregiver did not disappear completely. The survivor and caregiver participants were reflective at times, and considered themselves on occasion to be more fortunate than others. This contributed to positive feelings about their everyday lives which were shown to help the participants overcome negative thoughts.

Spousal caregivers adapted to the caregiving role more easily than those who were adult children of the survivors. One reason for this is that the adult children faced the challenge of maintaining their own primary family life while supporting their mothers, who in this study resided elsewhere. Another was that they felt saddened that they saw their parent become less independent than they were before they experienced stroke. **The caregiving role was found to impact on the level of social participation for all of the caregivers; however, those caregivers who were adult children experienced a greater impact as there were disruptions to their personal and family life and employment due to the caregiving role**. The greatest impact on social participation was when caregivers considered holidays. Time constraints in the caregiving role meant that those who were caregivers for their parents had to be mindful of leaving their mother for too long, whereas spousal caregivers changed their holiday habits, with the majority of spousal caregivers choosing to go on holiday without their husbands. The husbands would then either stay at home and be reliant on support from their neighbours, or they would stay in a local hotel if they had appropriate facilities. However, the latter was not always desirable to the participants. This in itself highlights how spousal caregivers were opting to vacation separately from the cared for person over changing their holiday habits to accommodate the survivor's post-stroke needs. This suggests how taking holidays may be considered as a break away from the caregiving role.

Weaknesses in Supporting Survivors and Caregivers

Adopting a multiple case study approach to research enabled the author to consider the similarities of each case, which included areas of unmet need such as the lack of available information (discussed previously), but also areas of difference such as the impact of stroke, and the caregiver's personal situation. This was core to understanding that **a one-size-fits-all approach to providing support for survivors and caregivers is not appropriate**. The similarities between the cases were that they reported poor access to information, lack of time for caregivers to pursue interests, and caregiver burden and strain being felt when not physically with the care recipient. Furthermore, **where support provisions were put in place, they were not always fully effective**. The differences between the cases related to who the caregivers were, the circumstances of the caregivers, and survivor's ability. Despite these differences, the stroke survivor's goal was the same: to be positive and live as independently as possible.

The Negative Impact of Unmet Need

Lack of information for both the survivor and caregiver participants was a consistent feature in the interviews. This was related to the coordination of information about healthcare, caregiving advice, driving assessments, support services and financial support. The caregivers felt that **this increased levels of burden and strain**. This research evidence supports existing literature reported by McKevitt et al. (2011:2012) which shows that this unmet need is on-going and has not adequately been addressed by support provisions. This is a key weakness of statutory sector support, with many of the caregiver participants reporting that they were not sure where to find the advice or support they need. Thus, caregivers were seeking advice from other caregivers at Stroke Club in relation to their caregiving role and how to support the survivor. Furthermore, **caregivers and survivors were relying on advice from each other** about the support they may be entitled to from the statutory sector, and in Paul's case, how to go about driving his own car again. However, a really interesting finding from this research was the notion of *knowing too much about stroke causing anxiety and worry* as experienced by Paul's wife when she first learned of her husband's stroke. Therefore, it is important that a person-centred approach to providing information is employed.

Fluctuations in Coping Strategies Employed

The participant caregivers and survivors exhibited behavioural traits of an adaptive coping strategy; changing the way they carried out tasks, or finding activities they could do to replace the activities they found challenging post-stroke. Although interestingly, the narrative of the participants informed that the participants had transitioned through the three coping strategies; adaptive, positive, and avoidance (discussed in Chapter 3, Section 3.4.1). Therefore, the findings of this study contribute to the existing literature by providing depth to the coping process; showing that it is not a case of one person adopting a specific strategy, and that **there are fluctuations in the coping strategy employed** over time, and for other factors such as personal circumstance and in fact, positive thinking as a coping strategy ran parallel to the adoption and adaption strategies employed. This is perhaps as positive thinking is a state of mind.

Furthermore, positive thinking was thought to enable the participants to come to terms with their post-stroke lives and help them to cope in the months and years after stroke. The findings strongly support Berges et al.'s (2012) theory of positive attitude in reducing barriers to social participation. **This study builds upon Berges et al.'s work as it uncovered reports of how**

positive attitude influenced the survivor participants' motivation, rehabilitation, social participation, participation in activities, increased self-confidence, increased self-esteem and promoted positive relationships by reducing negative thoughts psychologically.

Furthermore, **positive perceptions helped to reduce barriers to participation** and helped the survivor participants to feel motivated to live as independent a life as possible. This informs that initiatives and practices which promote and support positive attitude are beneficial in encouraging social participation, building relationships and encouraging independent living. All of which contribute further to the perception of post-stroke quality of life. However, it is worth noting that because a survivor may seem positive at one point in time, does not mean that they always are. For instance, during his first interview, Mark stated that he felt an inner strength, and focused on being positive, whereas during his second interview Mark stated that he experienced *"more bouts of depression."* This further highlights the variable nature of post-stroke life, and that there are so many factors to consider when considering a person's post-stroke self-perceived wellbeing and quality of life.

A Positive for Rural Living

Wales itself is considered to host a rural landscape. Much of rural life literature discusses themes of a lack of services, further distance to services, poor transport routes, weak infrastructure, isolation, depression, and loneliness. However, **this thesis presents a positive perspective contrary to the somewhat negative perspectives currently reported in the existing literature**. The study participants perceived rural living to have positive benefits. The participants reported a relaxed way of life and a sense of community. The findings further present themes of confidence within small local communities where everybody knew one another. Participants also reflected that the area in which they lived was spiritually uplifting and contributed to a positive wellbeing. This further highlights **a relationship between positivity and perceived quality of life.**

10.1.2 Addressing Research Aim 2: To Identify the Key Avenues of Support for Survivors of Stroke and their Caregivers

Statutory Sector Support

The study participants received support from the statutory sector in the form of local authority services, local GP practices, and third sector organisations. This support was more concentrated at the acute stage of post-stroke life, up until the end of rehabilitation from hospital staff and the return home. Some local authority support provisions such as paid carers coming into the home were provided in the months and years after stroke. However, **the support offered by the statutory sector had its weaknesses in delivery and implementation**, as identified by the study participants. For example, there were concerns regarding the amount of time Penny had to wait for adaptions to her home, this had severe consequences for her wellbeing and dignity. This also **made the caregiving role unnecessarily challenging** for her daughter while she awaited the adaptions to be made. Furthermore, the participants felt that there was inconsistency with the information being shared between hospital departments and GP practices which lead to the need for a caregiver intervention to ensure that the survivor was cared for properly by statutory sector provisions. Observations were also reported by the participants regarding GP receptionists telephoning through results to people who were not able to make a note of them, and instances in hospital where nurses had not helped people to eat their food when assistance was needed. In addition, the participants highlighted that the people at the forefront of the telephone systems for benefits advice were not helpful in informing what the participants were entitled to claim. Despite these areas of concern however, the participants did acknowledge that the customer service and support received was **dependent on the individual who happened to be at the forefront at the time**. Furthermore, the inconsistent timings of professional carers coming to the home meant that the **spousal caregivers were not relieved of caregiving burden** or necessarily given the time away from the caregiving role as part-intended by the provision.

Support from the Social Enterprise Sector: Stroke Clubs

Those participants who were recruited to this study via Stroke Clubs considered **Stroke Clubs to be key to their personal support networks**. Stroke Clubs were found to be a social outlet which gave the participant survivors a sense of reality and familiarity where experiences could be shared. **Stroke Clubs provided the survivor participants with a sense of unity and solidarity**. They were described by the participants as 'safe zones' and were an area where the

survivors felt they could be themselves. This helped to reduce anxiety about perceived stigma and increase social participation for the survivor participants.

Reflecting upon Burholt and Dobbs (2014) theory that support networks consist of emotional, social and instrumental support, it can be seen that the Stroke Clubs do just that. Such support was also provided by caregivers, friends or families; however, this avenue of support encompassed all three areas in one for the survivor and caregiver participants. Furthermore, they bridged the gap in support implemented by the statutory and third sectors. The Welsh Government's (2017) recent Stroke Delivery Plan had identified the value of such support clubs and had suggested integration of support for social enterprise and community-based services. However, the plan did not say how they intended to do this. Recommendations for this are discussed later in Section 10.3.1.

Support from Informal Avenues

The findings of this study emphasise the valuable contribution which family members and friends make to the lives of survivors of Stroke. The support from these avenues were deemed more reliable and consistent, and in those cases where statutory support was implemented, the **support from the family caregivers complemented the support offered by the statutory sector**. Caregivers reported being supported by other family members and their employers. This emphasises that **valuable support in the caregiving role also tends to come from more informal networks**.

10.1.3   Addressing Research Aim 3: To explore how the Social Enterprise Sector delivers Support to Survivors of Stroke and their Caregivers.

Addressing a Gap in Statutory Sector Provision

The findings show that **Stroke Clubs meet a gap in support provisions from the statutory sector**. However, the ways in which support was provided through the Stroke Clubs differed between those Stroke Clubs observed. Statutory sector support was provided at the acute stages of stroke, and during rehabilitation. Although important and key to recovery, that support was limited by time and therefore was not provided in the long-term. The Stroke Clubs, being run by survivors and caregivers, provides support in the long term; in the months and years after stroke.

Therefore, they meet the needs of survivors and caregivers in their post-stroke lives. The survivor and caregiver participants also received support from the third sector. However, this support was also more predominant in the early stages of post-stroke life.

Stroke Club Identity

Some of the Stroke Clubs were created as social enterprises from the start; **although, they did not identify themselves as social enterprises.** This is an interesting finding, and also poses further questions such as: 'If they do not know they are social enterprises, how can they access the support they need? How can policy makers identify them?' However, for many of the others observed, the clubs were initially set up with statutory sector and third sector support. When the funding was withdrawn, and the Stroke Clubs faced closure, those people who recognised the need for continued support made the transition from being service users into becoming social entrepreneurs. This not only helped them to meet people in a similar situation; contributing to their own wellbeing, but also supported other people living with stroke in their post-stroke lives.

Entreprenurship out of Social Necessity

As Stroke Clubs provide a service which was not provided by the statutory, private or third sectors, the **Stroke Clubs represented support clubs which grew out of necessity**, to meet a social need. Such needs being the needs of its members - the survivor and caregiver participants. This challenges the existing literature on business growth which suggests that enterprise growth is a conscious decision that business owners need to work at and aim for.

As Stroke Clubs were run by people who had experienced stroke in their everyday lives, either as a survivor themselves, or a caregiver, the Stroke Club hosts (the social entrepreneurs) were able to relate to the club members and post-stroke life. They understood first-hand what the survivor needs and wants may be, and they also understood the needs of caregivers. This also gave them ownership of the group which helped to provide a sense of life purpose post-stroke as well as build confidence and self-esteem.

Furthermore, as the Stroke Clubs were aimed at supporting survivors and caregivers they catered for the access and needs of the dyad and so did not create added burden of organising respite care as services aimed at carers sometimes create. This is in contrast to the caregiver organisation which Thomas's wife had attended, which focused on the caregiver and so caused

294

the challenge of finding someone to visit Thomas when she attended. In addition, the social aspect of Stroke Club also meant that it was enjoyable for the spousal participant survivors and caregivers to go together.

Differences in Delivery

Each of the Stroke Clubs observed were different. They consisted of a range of activities, formats and events. However, despite being different they shared many similarities as their ethos was the same. For some members, Stroke Club was the only time they left home; for some, this was their only engagement in their external environment and thus their only avenue for social participation external to the home. The Stroke Clubs provided a social setting for survivors and their caregivers where they could share their experiences, seek advice and engage in hobbies or rehabilitative activity. The findings of this study conclude that social enterprise is valuable for society. Stroke Clubs have supported the survivor participants in adapting to a post-stroke way of life by providing support in the months and years after stroke. Stroke Clubs also provided support to the caregiver participants, again being an avenue of lifelong support. In some cases such support extended to where a caregiver's spouse (the care recipient) had once been a Stroke Club member then died. This demonstrates how the Stroke Club provides support for caregivers of survivors of stroke, in the long-term; in all aspects of their post-stroke life. Social enterprise in this context is able to provide such support without limitation as the clubs are run by their members and there are no specific criteria or an agenda which is sought to be met - other than to provide proactive support for survivors and caregivers.

10.2   Thesis Contribution

This thesis provides dyadic insight, and contributes to existing life-after-stroke research. It does this by providing in-depth exploration into the everyday lives of the survivor and caregiver participants whilst informing of their unique contexts, case by case. Existing knowledge reports specific outcomes of stroke and the impact of these outcomes on survivors' lives, and the caregiver. This means that it tends to go no further than to describe that specific outcome. For example, studies which discuss post-stroke depression explain the impact of depression on the survivor. They do not tend to go as far as to describe the impact of depression on the survivors' social participation, motivation to participants in rehabilitative activity, and perspective of their quality of life. Indeed, research does address this; however, it typically does so with different participants. Therefore, there is a lack of individual context to support the study findings. This does not provide a full picture, regarding the impact of depression (by this example) on a survivor's everyday life. This study contributes to the existing knowledge base through case study research, by considering the context and circumstance behind the findings. This challenges the existing literature by considering wider peripheral influencers on key elements of survivor and caregiver everyday life post-stroke.

Likewise, **this study also contributes to the literature which reports of caregiving and stroke by providing the everyday life context**. This means that the findings discuss caregiver experience with consideration of the context of the everyday life of the survivor and the impact of their stroke, and the circumstances of the caregiver; whether they are employed and so forth. This, therefore, provides a rich contextual background to the caregiver context by providing insight into the feelings and experiences associated with particular everyday life contexts. This not only builds upon knowledge by adding more depth and understanding, rather it provides policy makers and service providers from all sectors with important information which is essential in understanding survivors of stroke and their caregivers.

Figure 9 'Living with Chronic Disease' provides a framework for better understanding the complexity of the everyday lives for people living with chronic conditions. This model has been informed by the findings of this study and will be tested in future research against other conditions. By gaining knowledge on survivor and caregiver experiences with such rich contextual information, policy makers will be better informed at understanding how to support survivors in leading the lives that they aspire to live, whilst supporting caregivers in providing effective care and supporting them to meet their aspirations. As a result of this, survivor and

caregiver perceptions of everyday life will improve, and they will feel as though they have a better quality of life. As Figure 9 below shows, this does need to be done via a person-centred approach, taking into account each survivor and caregiver's unique case. This further highlights that survivor and caregiver support needs to be combined to provide holistic and complimentary advice.

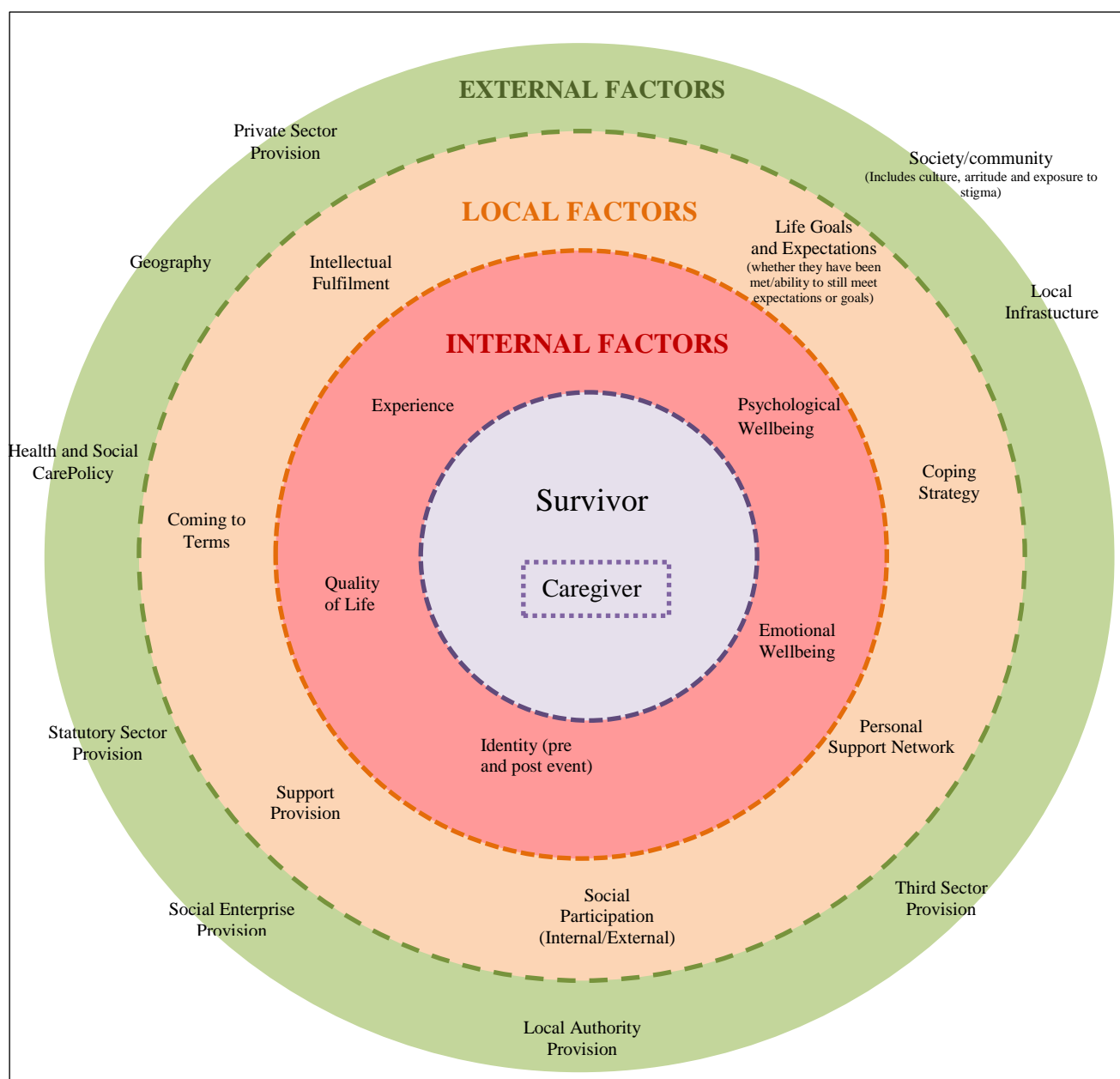**Figure 9:** **Living with a Chronic Condition: factors influencing on personal perception**

Figure 9 is informed by the findings of this study and shows the key considerations that policy makers, academic and practitioners should consider when considering everyday life for survivors and/or caregivers. This model is designed to complement existing professional diagnostic measures. Emphasising the need for a person-centred approach, the survivor and/or caregiver is located at the centre of the sphere. The caregiver is contained within a broken line as this model can be applied to the survivor or caregiver singular, but also shows that the everyday life of the survivor impacts on the everyday life of the caregiver and vice-versa. This is inclusive of the individual's self-perception of everyday life. The red ring represents the internal aspects. Internal aspects include those factors which are personal to the individual. The beige ring informs of those factors which are 'local', or close to the individual. These factors may be influenced by the internal factors and the external factors. The broken lines around the rings symbolise the influential nature of the factors across boundaries. The green outer sphere represents the external factors which influence local factors, and in turn the internal factors. All of which therefore impact on the individual's perception of their everyday life. It is also worthwhile considering control factors as the individual has no control over the external factors and relies on actors and organisations within that sphere to be accessible, best address their need, and be effective in service delivery.

Recommendations are made in Section 10.3 which inform how this can be used to inform a framework for future policy development and collaborative approaches. These recommendations focus on supporting survivors and caregivers in their everyday lives, and in doing so, provides recommendations to strengthen Welsh stroke policy. Recommendations are also provided regarding support accessibility and how this can be improved by reducing psychological barriers.

Moreover, this thesis highlights the value of social enterprise in this context. **The Stroke Clubs provided support for survivors, caregivers, and widows and widowers in their everyday lives, in ways which other sectors were unable to do.** The current Stroke Delivery Plan (Welsh Government 2017) states social enterprise should be supported in delivering their social aims in this context, however, it fails to explain how such enterprises can effectively be brought into stroke support strategy. Similarly, the Social Services and Wellbeing (Wales) Act (Welsh Government 2014b) also highlights the potential that social enterprise has in complimenting existing policy. The act states that local authorities must promote social enterprise development, and involve those who would benefit (i.e. the survivors and caregivers, in this context). There is concern however, that **the definitions used within the Social Services and Wellbeing (Wales)**

Act are not accurate when describing social enterprise as they are narrow and exclude social enterprise under the definition proposed in this thesis which describes social enterprise in this context.

Definitions of social enterprise used within policy typically make the assumption that the social entrepreneur would be willing and able to take on a more formal business model. As such, support provisions set out by the Welsh Government (2014b) make the assumption that social entrepreneurs will accept support, and in return will be bound to perform to a specific target. As some of the Stroke Club hosts are survivors themselves, it is unlikely they would welcome extra accountability as they are already dealing with life changes such as post-stroke fatigue. Therefore, **policy makers using such definitions in this context risk being ineffective in supporting of social enterprises which are set up in the same way as those in this study**. Furthermore, social ownership in this context would refer to it being owned by survivors, who in this study, did not identify themselves as social entrepreneurs. Therefore, they would (potentially) not actively seek to implement leadership and organisational structures to the same strength that other organisations, and even other social enterprises set up in a more private sector way, may do. This ultimately means they risk not meeting the definitions presented by the Social Services and Wellbeing Act (2014).

The contribution here is that this research highlights a growing area of social enterprise, that is social entrepreneurship out of necessity, which in some instances were set up to meet the needs of survivors and caregivers which were not been met whilst in others, social enterprises were established from third sector support groups when they faced closure. The latter statement truly emphasising the value that the Stroke Club members feel are provided by such initiatives. More research is needed to establish the ways in which the Government aims to support social enterprise, and the support appropriate for social enterprise as defined in this context. **The findings of this study also introduce a new kind of entrepreneur to the literature, a new kind of entrepreneur by necessity; an entrepreneur by personal need.** This also challenges the literature which reports reasons for volunteering and forming social enterprise as the participants of this study were volunteering, or running these social enterprises, to meet their own personal need. Not just to help others. This adds another dimension to the ideological perspectives of voluntary work which suggests people only volunteer to help others.

This research also contributes to the academic field of research methodology. The Research Process Model presented in Chapter 5 (Figure 6) presents a proven methodological strategy for

researching people in the everyday lives contexts. This framework contributes to research methods literature and can be applied to many disciplines. In the field of applied social science research, this framework can be used to explore other sociological trends in the everyday lives contexts. In the health and social care arena it can be used to explore the impact of disease and support and/or rehabilitation initiatives. In the field of social policy research, the framework can allow the evaluation of policy initiatives. In the business studies discipline the framework helps academics to understand the perspectives of the consumer.

These findings have been presented at international academic conferences. The papers presented have been double blind peer reviewed and presented at international conferences:

Heyworth Elizabeth M., Jones Rosalind., Roach David (2013), Providing support in Rural Wales: motives, observations and end user perspectives. *Institute of Small Business and Enterprise (ISBE) Conference*, Cardiff, November 12th-13th.

(Abstract appended in Appendix L)

Heyworth Elizabeth M., Jones Rosalind (2014), Social Enterprise: bridging the gap between the statutory sector and the third sector. *International Council for Small Business (ICSB) Conference*, Dublin, June 11th – 14th.

(Abstract appended in Appendix M)

The author is also currently writing papers for submission which have been informed by this research. A research proposal is also in progress which will be submitted for consideration of a funding bid by the Economic and Social Research Council. This proposal outlines a support initiative for Stroke Clubs in order to help them continue to support survivors and caregivers in their everyday lives.

10.3   Recommendations for Future Policy, Practice, and Research

The research findings reported throughout this thesis provide implications for policy makers, practitioners and social entrepreneurs.   Furthermore, the findings lead the author to consider avenues of future research. The recommendations for each are discussed throughout Section 10.3.

10.3.1   Recommendations for Policy Formation and Delivery

This study has highlighted the value in the notion of joined-up delivery of support services for disadvantaged groups, and facilitation of social enterprise. Cross-sector collaboration has the potential to allow organisations across the sectors to work together towards shared aims. By supporting socially motivated entrepreneurs, they can effectively rise to meet current economic challenges in times of austerity and retraction of statutory sector funded services, while supporting person-centred care. Not only is this potentially cost effective for the statutory sector and beneficial to the Stroke Clubs, but it provides a continuum of coherent lifelong support for survivors and caregivers.

Despite policy promoting person-centred care, there is a strong perception from research participants that the clinicians, nursing staff and professionals at the forefront of key customer service points have failed to offer adequate guidance and support. This is concerning, as no matter how thoroughly thought through policy is, if the people at the forefront of its delivery are ill-informed or lacking the essential skills to deliver a policy initiative, there will be huge consequences in its effectiveness.   It is recommended that staffs at the forefront of customer-facing roles are made aware of the possible outcomes which can result from stroke and how to best support the people they are communicating with. The model presented in Figure 9 (Figure 9: Living with a Chronic Condition: factors influencing on personal perception) provides a template to assist practitioners in understanding the key elements which impact on a person's everyday life. There is also considerable scope for improvements in providing information and scope for collaboration between departments and the statutory, third, and social enterprise sectors. The overall study findings support Paul's wife and Penny's daughter's recommendation for a standardised information pack for survivors and caregivers.   However, such a pack should include core information and there needs to be a focus on practitioners providing survivors and

caregivers with relevant information when their needs are being assessed prior to discharge. Notably, information also needs to be in a format that the survivors can understand.

As outlined in Chapter 7 (Section 7.2) previous, the caregivers informed that such an information pack should include:

- Facts about stroke

    The possible outcomes of stroke

    Challenges the survivor may face in the future

    What stroke means for family members – transition into the caregiving role

    Challenges that caregivers may face

- Practical advice about forms and documents

    Driving assessments

    Benefits and financial entitlement

    Statutory sector support entitlement

    Employment rights

- Practical caregiving advice

    Helping to eat or drink

    Nutrition

    Physical lifting

    Personal care

- Sources for more information, guidance and support

This addresses the unmet need of a lack of information. However, the variety of stroke outcomes means that such a pack would need to cover a multitude of different situations, and be in formats which could be understood by survivors who experience difficulties reading written text. It would also be advantageous for caregivers to receive training on how to provide physical care, as Penny's adult daughter reports this as the key challenge in the caregiving role. Caregiver policies state that they want to support this. The author does acknowledge that the complexity of stroke means that there are challenges when it comes to implementing such information and or training. However, these initiatives are not being delivered. Furthermore, as previously discussed, the caregivers who had prior knowledge of stroke were not privy to feeling well informed. This emphasises the need for a personable approach to information giving, alongside such an information pack. More research needs to be done in this area in order to

establish where the specific gaps are in implementation, and how they can effectively be addressed.

It is also recommended that policy makers consider a more accurate definition of social enterprise, taking into account definitions presented by academics such as Ridley Duff and Bull (2011:2016). For example, the definition provided by the Social Services and Wellbeing (Wales) Act (Welsh Government 2014b) does not distinguish social enterprise from the third sector model. It is also very narrow in that it assumes that social enterprise has an affirmed structure. However, the Stroke Club hosts identified themselves as social clubs, rather than a social enterprise. Although there were delegated roles in place (such as treasurer), the Stroke Clubs did not have a strong leadership framework to support substantial profit-making practices. Instead, Stroke Clubs were run (in some cases) by survivors of stroke, who experienced their own set of post-stroke life challenges such as post-stroke fatigue. Although some were run by caregivers, there is still a need to support such enterprises in gaining such structures in order for them to be strong enough to cope with the strategic focus that policy makers are hoping to implement. If they were like other social enterprises which are typically set up by individuals as a business to meet a social aim, this model would work. However, at present, policy makers need to understand that in this context, the social entrepreneurs are not necessarily looking at the business as a social enterprise, more as a social group of like-minded people coming together to help each other, because they feel there is no other provision what can give them that long-term community support. More research needs to be done in this area to either (i) identify ways in which Stroke Clubs can be supported by other sectors in order to make them established enough for policy makers to be able to support them, or (ii) inform policy makers how to address such challenges when supporting social enterprise in this sector.

The best way to support social enterprise in this unique context; that is, social enterprises set up by necessity, is to allow the social entrepreneurs to maintain control and learn from them how best to support them. This addresses the policy aim of person-centred support, and allows the members to feel as though their voices are being heard and for them to maintain that feeling of responsibility and control in their everyday lives which is so crucial for their post-stroke identity. This helps maintain the ethos of a Stroke Club run for the members, by the members which helps create the social club image and the feel of a non-threatening environment where there are other people with shared experience. Collaboration efforts to meet policy objectives could be implemented between local authorities and social enterprise. It is recommended that policy makers consider such social enterprises as a referral service for survivors when they are

discharged from hospital care, perhaps alongside (or after) an outpatient rehabilitation programme. Again, more research will need to be done in this area to identify the most appropriate time as for some, the setting of Stroke Club can be overwhelming at first. Additional recommendations which support this include collaboration of support from the statutory sector by way of rehabilitative support. This would help improve consistency of rehabilitative activities across Stroke Clubs. There is also justification from the findings that online support provisions would help survivors and caregivers through access to support forums via online platforms. Such forums and tele-care packages exist, however, these could be linked to more professional platforms and support rehabilitation through the provision of activities for engagement and intellectual stimulus. This could be done in a way which makes the provision accessible for all, through consideration of alternative ways to communicate. Further research into the most effective way to provide electronic support is advised.

Despite these recommendations the author cannot discount discussion in Chapter 4 where Baldock et al. (2012) assert policy implementation can fail through delivery due to disagreements between those departments required to collaborate in order to meet the policy aims. Unfortunately, the population which the policy aims to support are the ones which suffer. Therefore, it is strongly recommended that policy makers consider possible areas of conflict between departments when setting out frameworks for policy delivery, and focus on supporting collaborative approaches.

Social enterprise strategies could be put in place by policy makers which support them in supporting people in the months and years after stroke in the most effective way possible. This research indicates that supporting people in social participation and integration into wider society can build confidence, reduce perceived public stigma, and promote mental and emotional wellbeing. This then impacts on the perception of the self and perceived quality of life, which further encourages them to participate in rehabilitative activity; reducing barriers to participation in the internal and external environments. Support for caregivers in coping with the transition into the caregiving role and providing caregiver support can assist them in being better informed as to how to best support the cared for person, and increase confidence in the caregiving role. This integration strategy would potentially improve the caregiver's self-esteem and perception of their quality of life. This, in turn, further supports the survivor.

It is possible to provide a holistic support structure which supports people in their everyday lives in all communities across Wales. This can be achieved by social enterprise with collaboration

and guidance from practitioners from the statutory sector and guidance from the third sector, as well as adopting a business approach similar to the private sector.

There is no doubt that the statutory sector's focus upon stroke prevention policy is worthwhile. If effective, this will reduce the number of people experiencing stroke and therefore reduce the number of people living with stroke in their everyday lives.   However, a life-long focus on supporting people in their everyday lives is needed and will benefit people living with stroke at present. This will also set a framework for lifelong stroke services in the future. This has been acknowledged by the Welsh Government's Stroke Delivery Plan (Welsh Government 2017).

Furthermore, it cannot be assumed that the survivors and caregivers are aware of support groups or the types of support they are entitled too. In addition, caregiver participants were frustrated and concerned that they were asking the right questions. They felt that if they asked questions, they got answers.   This demonstrates that the information was there, it just was not easily accessible for them. This is an area of concern as the situation was already stressful and overwhelming. The practitioners at the forefront of service delivery should be able to comfort and reassure their patients, and be proactive in providing the information they may need. Furthermore, practitioners at GP surgeries should consider their patients' needs when giving out information and it should be delivered in a way they best understand, and in a manner which they can have a record of it.

10.3.2   Recommendations for Social Enterprise: the Stroke Clubs

For the Stroke Clubs themselves, a collaborative network between the Stroke Clubs which run throughout Wales would be beneficial in providing a consistent level of support across the region. A collaborative approach would provide support for the Stroke Club hosts and provide a knowledge sharing platform. This would also help the hosts to recognise themselves as social entrepreneurs and encourage them to take a business approach. With a committee structure not dissimilar from a private organisation, more focus on business practice through collaboration could help them toward sustainability.   This may help find solutions in addressing the inconsistencies in the rehabilitative activities and social activities between the Stroke Clubs, and allow them to work towards a standardised delivery structure which allows Stroke Clubs across Wales to come together and collaborate, and have standardised delivery and offers through collaboration with statutory sector provisions to ensure consistency among the service users. As previously mentioned, a research bid has been submitted to develop such a network.

In Section 10.3.1, recommendations were made for policy makers to provide support to social enterprises which would enable them to deliver consistent support across the country. However, there is scope for social enterprise to take this on board themselves. There is also scope for the stroke-specific third sector organisation to instigate this; however, they do not provide sufficient support. It would be beneficial for a standardised package for the groups to enable rehabilitation activities to be provided at all of the groups, which goes beyond the leaflets distributed by the third sector organisation. This could be achieved by coordination of the social enterprises through affiliated activities. This recommendation would assist in social enterprise development, particularly where the social entrepreneurs have lived the experience and are driven by their own needs to support statutory sector policy delivery for the social good. Such a pack or information could be provided by online provisions, supported by a discussion forum. This will be addressed by the proposal the author is working on (discussed previously in Section 10.2) which has been informed by this study. The aim of this is to provide support from an academic team to create a support network for Stroke Clubs. In order to further develop this, research will need to be conducted into social enterprise in this context from the entrepreneurs' perspective and local authority government in the first instance.

10.3.3   Recommendations for Future Research

This study has identified various suitable avenues of research for further exploration, some of which have been mentioned previously. Further research into the everyday lives of those who are not currently accessing the support provisions such as Stroke Club would highlight how non-members are supported in their everyday lives, and whether they are aware of support provisions such as Stroke Club. If they are aware, exploration into why they are not accessing the support provision may highlight barriers to access in relation to social enterprise, and perhaps ways in which they can be reduced.

This thesis also provides a robust, tried and tested research protocol to further explore everyday life, living with chronic conditions and/or lifelong disability to ascertain best practice for providing support in their everyday lives. The author will use this methodology to explore the everyday lives of people living with, and caring for people living with, other chronic conditions such as (but not limited to) Parkinson's disease, terminal cancer, multiple sclerosis and dementia, testing the 'Living with a Chronic Condition: factors influencing on personal perception' model presented in Figure 9. This would help further develop the existing knowledge of how to support

vulnerable adults in their everyday lives. Moreover, the author will further explore the link between positivity, coping and social participation. Further exploration into this thematic relationship, combined with the Living with Chronic Disease model would further inform practitioners how to best support survivors in adapting to post-stroke life.

Exploring social enterprise in the context of supporting vulnerable groups, the managerial perspective will help identify ways in which to support social enterprise initiatives which are set up by necessity. It would also help to establish whether a statutory sector commissioning framework would be suitable for social enterprise of this context and the kind of support appropriate. Further research in this area could also help charitable organisations adopt a social enterprise model and become less reliant on donations. However, it is appreciated that this wouldn't be appropriate for all charitable organisations. This would then relieve more donated funds to focus on prevention agendas, as in the instance of the stroke-related charity referred to in this thesis. Further data collection from Stroke Clubs across Wales would also establish whether support from the Wales Co-operative Centre or Welsh Government (2017) as discussed in Chapter 4 (Section 4.5) would be of benefit to Stroke Clubs. On the onset from this research, however, further exploration would allow for consideration of any potential barriers to this.

10.4   Limitations to the Research

First considered a potential weakness, recruiting survivor and caregiver participants through Stroke Clubs resulted in a growing area of social enterprise being unexpectedly discovered. Although recruiting participants via a stroke register would have provided more generalisable data, this insight into Stroke Clubs provides a valuable contribution to the literature and highlights the value in social enterprise, and how it can potentially contribute to the everyday lives of vulnerable groups. This could have otherwise been overlooked.

Moreover, the original protocol for this study aimed to interview policy makers and the heads of the local authority services across Welsh counties. Unfortunately, they were not willing to be interviewed on this occasion. This highlights the challenge in recruiting participants in some instances. However, this limitation, although it would have generated useful insight, did not detract from the aims and objectives of this study. In fact, this limitation was superseded by a higher than anticipated participation response rate of Stroke Clubs to be observed as discussed in Chapter 5 (Section 5.2).

10.5   Reflections on the Research

At the beginning of the study public awareness campaigns were highlighting stroke and the impact it has on people's lives.   The study itself can be applied to alternative conditions, however by focusing on stroke; it highlighted the complexity of not only living with the outcomes of stroke, but also living with physical disability, and living with neuro-disability. Furthermore, being based on a Welsh context allowed for the investigation into policy development as the infrastructure of Wales and the devolution of Welsh powers make Welsh policy development an interesting topic.

The methodology informed of valuable insights from a range of perspectives. This adds strength to the thesis and conclusions and recommendations drawn. A rigorous methodology produced robust research findings from a variety of perspectives. The findings contribute to social science literature, and business disciplines. As already noted from feedback from peer reviewed conference papers presented, the methodology and approach to research have produced rich data which provides a valuable insight into living with stroke in everyday life. The methodology chosen also allowed for reflection of the participants' perceptions, their reflections on aspects of their everyday life and reports of their emotional and psychological wellbeing. Furthermore, the BNIM provided the best opportunity for the researcher to gain trust with the participant by listening to their story, *"Now that's something I've not been able to tell my wife"* (Mark: interview 1).   Participants divulged information which they stated they had not shared with anyone else, proving that this method can work well and that interviewees presented the reality. The respondents were asked to tell their story as completely and honestly as possible.

The narrative element of the BNIM was appropriate for researching people perspectives of stroke, as the author had no experience of stroke herself. This allowed her to learn about the experience, without the risk of reducing the depth of the interview questions by attempting to predefine questions to ask. The participants also perceived the interview technique as a positive experience, reporting that *"it has strengthened me to talk to you"* (Mark: interview 1), and *"I'm glad of the opportunity to talk to you"* (Sarah's daughter: interview 1). Furthermore, it was also evident that the narrative helped the participants who had memory problems to recall events and reflect on their experience; something that may have been lost by using other methods. Furthermore, when caregivers were interviewed, it was found they tended to answer with a focus on the survivor. Participants who were caregivers were not self-focused with their responses and needed to be prompted to focus on themselves during stages 2 and 3 of the BNI.   Furthermore,

phases 2 and 3 of the BNI template allowed the research to ask more direct questions, to those survivors who had communication difficulties and struggled to answer the narrative element.

The observational findings also provided insights into the participant's lives, and how Stroke Club plays a part. The observations provided the opportunity for the author to place the interviewed participants' reflections of Stroke Club into context, which reinforced statements made. The author feels that she gained a deep insight into the Stroke Clubs and participant perspectives through her observer role. By entering each observation site as a non-participant, she was non-intrusive. Engaging within the observation site when requested was courteous, respectful and helped to gain trust. This was in line with Rowson's (2006) 'FAIR' framework of ethical principles, discussed earlier in Section 5.5, which were to treat all individuals justly and Fairly, to respect the Autonomy of participants, to act with Integrity, and to seek the best Results.

10.6   Close

This chapter draws the thesis to a close. Chapter 10 concludes the thesis and synthesised how the research findings support and contribute to the existing body of knowledge by drawing on the participants' BNIM interviews, Stroke Club host interviews, observational work, and review of existing literature and policy documents.

The analysis and interpretation of this data has produced outcomes of this thesis which will be published and disseminated to appropriate audiences and to further support current and developing knowledge in the area, and has the potential to provide further evidence for policy makers; particularly in relation to how to support stroke survivors and their caregivers; and how to increase effective support for social enterprise within this context. The research approach, method, and design used for this study presents a template for application in further research studies to investigate the everyday lives of people living with other chronic conditions. Finally, this thesis emphasises the value of support groups for people living with lifelong conditions, and how they can complement policy aims in their delivery.

Stroke was unexpected for all of the study participants. There is no doubt that it is a life-changing event. However, no matter how great the challenges were that the participants faced, all of the participants felt happy about one thing; they survived.

11.0   List of References

Age UK (2017), About Us. *Http://www.ageuk.org.uk/about-us/* (Last Accessed 8th February 2017).

Alajbegovic, Azra., Djelilovic-Vranic, Jasminka., Alajbegovic, Salem., Nakicevic, Amina., Todorovic, Ljubica., and Tiric-Campara, Merita (2014), Post stroke depression. *Medical archives* 68, No. 1:47.

Alaszwqaki, Andy., Alaszewski, Helen., and Potter, Jonathan (2004), The Bereavement Model, Stroke and Rehabilitation: a critical analysis of the use of a psychological model in professional practice. *Disability and Rehabilitation* 26, No. 18: 1067 - 78.

Alcock, Pete., Haux, Tina., May, Margaret., and Wright, Sharron (ed, 2016), *A Students Companion to Social Policy*. 5th edition. Oxford, UK: Wiley-Blackwell.

Alexander, Tatjana. and Wilz, Gabriele (2010), Family Caregivers: Gender Differences in Adjustment to Stroke Survivors' Mental Changes. *Rehabilitation Psychology* 55, No. 2: 159-159-169.

All Wales Stroke Improvement Collaborative (2009), *NHS Wales End of Year Report.* Welsh Government: Wales.

Alleyne, Brian (2014), *Narrative networks: storied approaches in a digital age*. London: Sage.

Anderson, Sharron. and Whitfield, Kyle (2013), Social identity and stroke: 'they don't make me feel like, there's something wrong with me'. *Scandinavian Journal of Caring Sciences* 27, No.4: 820-830.

Arnzen, Catherine., and Elstad, Ingunn (2013), The bodily experience of apraxia in everyday activities: a phenomenological study. *Disability and rehabilitation* 35, No. 1: 63-72.

Ashby, Michael., Hoog, Corinne op'T., Keller, Allan., Kerr, Peter G., Brooks, Denise., Nicholes, Kathy., and Forrest, Marian (2005), Renal dialysis abatement: Lessons from a social study. *Palliative Medicine* 19: 389-396.

Ashton, Charlotte., Bajelal, Madhavi., and Raine, Rosalind (2010), Quantifying the contribution of leading causes of death to mortality decline among older people in England, 1991–2005. *Health Statistics Quaterly* 45, No. 1: 100-127.

Auton, Malcom F., Patel, Kulsum., Carter, Bernie., Hackett, M., Thornton, Tim., Lightbody, Catherine E., Leathley, Michael J., and Watkins, Caroline L (2016), Motivational interviewing post-stroke: An analysis of stroke survivors' concerns and adjustment. *Qualitative health research* 26, No. 2:264-272.

Ayerbe, Luis., Ayis, Salma., Wolfe, Charles D A., and Rudd, Anthony G (2013), Natural history, predictors and outcomes of depression after stroke: systematic review and meta-analysis. *The British Journal of Psychiatry* 202, No. 1:14-21.

Bäckström, Britt., and Sundin, Karin (2009), The experience of being a middle-aged close relative of a person who has suffered a stroke, 1 year after discharge from a rehabilitation clinic: A qualitative study. *International journal of nursing studies* 46, No.11: 1475-1484.

Baldock, John., Mitton, Lavinia., Manning, Nick., Vickerstaff, Sarah (2012), Social Policy 4th Edn. Oxfors University Press, Oxford.

Barman, Apurba., Chatterjee, Ahana., and Bhide, Rohit (2016), Cognitive impairment and rehabilitation strategies after traumatic brain injury. *Indian Journal of Psychological Medicine* 38, No. 3:172.

Barskova, Tatjana., and Wiltz, Gabriele (2007), Interdependence of stroke survivors' recovery and their relatives' attitudes and health: A contribution to investigating the causal effects. *Disability and Rehabilitation* 29: 1481-1491.

Bastawrous, Marina., Gignac, Monique A., Kapral, Moira K., and Cameron, Jill I (2014), Adult daughters providing post-stroke care to a parent: a qualitative study of the impact that role overload has on lifestyle, participation and family relationships . *Clinical Rehabilitation* 29: 524.

Baumann, Michele., Lurbe, Katia., Leandro, M-E., and Chau, Nearkasen (2012), Life Satisfaction of Two-Year Post-Stroke Survivors: Effects of Socio-Economic Factors, Motor IImpairment, Newcastle Stroke-Specific Quality of Life Measure and World Health Organisation Quality of Life - bref of Informal Caregivers in Luxembourg and a Rural Area in Portugal. *Cerebrovascular Disease* 33: 219-230.

Bazeley, Patricia., and Jackson, Kristi (ed, 2013). *Qualitative data analysis with NVivo*. London: Sage Publications Limited.

Becker, Gay (1998), *Disrupted Lives: how people create meaning in a chaotic world.* California: California University Press.

Berges, Ivonne M., Seatle, Gary S., and Ostit, Gary V (2012), The Role of Positive Affect on Social Participation following Stroke. *Disability and Rehabilitation* 34, No. 25: 2119-2123.

Bochel, Catherine (2016), *State Welfare*. In: Alcock, Pete ., Haux, Tina., May, Margaret., and Wright, Sharron, (Eds.) *A Students Companion to Social Policy*. 5th edition. Oxford, UK: Wiley-Blackwell.

Best, Joel (Eds) (2005), *Interaction Ritual - Essays in Face to Face Behaviour.* 2nd edition. New Jersey: Transaction Publishers.

Beuthin, Rosanne E (2014), Breathing in the mud: Tensions in narrative interviewing. *International Journal of Qualitative Methods* 13:122-134.

Bjerke, Björn (2013), *About Entrepreneurship.* Cheltenham, Edward Elgar.

Boosman, Hileen., Schepers, Vera., Post, Marcel., and Visser-Meily, Joanna (2011), Social activity contributes independently to life satisfaction three years post stroke. *Clinical rehabilitation* 25, No. 5: 460-460-467.

Brandon, Inez L (2013), Easing the burden on family caregivers. *Nursing2016* 43, No. 8: 36-42.
Brannen, Julia (2013), Life Story Talk: Some Reflections on Narrative in Qualitative Interviews. *Sociology Research Online* 18, No. 2:15.

Brewin, Chris (2003), *Post-Traumatic Stress Disorder: Malady Or Myth?* London: Yale University Press.

Briggs, Rick (2014), *Caregiving daughters: Accepting the role of caregiver for elderly parents.* Routledge: Oxford.

British Red Cross (2017), Health and Social Care. *Http://www.redcross.org.uk/en/What-we-do/Health-and-social-care* (Last Accessed 15th February 2017).

Brogan, Emily., Langdon, Claire., Brookes, Kim., Budgeon, Charley. and Blacker, David (2015), Can't swallow, can't transfer, can't toilet: Factors predicting infections in the first week post stroke. *Journal of Clinical Neuroscience* 22, No. 1:92-97.

Bulley, Cathy., Shield, Jane., Wilkie, Katie., and Salisbury, Lisa (2010), Carer experiences of life after stroke - a qualitative analysis. *Disability and rehabilitation* 32, No. 17: 1406-1413.

Buschenfeld, Karin., Morris, Reg., and Lockwood, Sally (2009), The experience of partners of young stroke survivors. *Disability and rehabilitation* 31, No.20:1643-1643-1651.

Burholt, Vanessa., and Dobbs, Christine (2014), A support network typology for application in older populations with a preponderance of multigenerational households. *Aging and Society* 34, No. 7: 1142-1169.

Cai, Wenzhi., Wang, Juan.,Wang, Li., Wang, Jungxin., and Guo, Li (2015), Prevalence and risk factors of urinary incontinence for post-stroke inpatients in Southern China. *Neurourology and urodynamics* 34, no. 3: 231-235.

Cameron, Jill I., Naglie, Gary., Silver, Frank I., and Gignac, Monique A M (2013), Stroke family caregivers' support needs change across the care continuum: a qualitative study using the timing it right framework. *Disability and rehabilitation* 35, No. 4:315-324.

Care Forum Wales (2017), Taking Care of Wales. *Http://www.careforumwales.co.uk/* (Last Accessed 15th February 2017).

Carers Outreach (2017, About Us. *Http://carersoutreach.org.uk/about_us.html* (Last Accessed 15th February 2017).

Carlsson, Eva., Ehnfors, Aargareta., Eldh, Ann C., and Ehrenberg, Anna (2012), Accuracy and Continuity in discharge information for patients with eating difficulties after stroke. *Journal of Clinical Nurcing* 21, No. 1-2:21-31.

Cecil, Rosanne, Parahoo, Kader., Thompson, Kate ., McCaughan, Eilis ., Power, Michael., and Campbell, Yvonne (2011), The hard work starts now': a glimpse into the lives of carers of community‐dwelling stroke survivors.*Journal of clinical nursing* 20, no. 11‐12: 1723-1730.

Chamberlin, Kerry (2012), Do you really need a methodology? *QMiP Bulletin* 13:59-63.

Chamberlyne, Prue., and King, Annette (2000), *Cultures of Care. Bibliographies of carers in Britain and the two Germanies.* Bristol: Policy Press.

Chandler, Jim (2008), *Explaining Local Government: Local Government in Britain since 1800.* Manchester: Manchester University Press.

Chang, Chen-Shu, Chun-Hui Liao, Che-Chen Lin, Hsien-Yuan Lane, Fung-Chang Sung, and Chia-Huang Kao. "Patients with epilepsy are at an increased risk of subsequent stroke: a population-based cohort study." *Seizure* 23, no. 5 (2014): 377-381.

Chaney, Paul. (2016), Women and policy-making: devolution, civil society and political representation. In: Mnnay, Dawn (Ed), *Revisiting Gender, Class and Idenity in Contemporay Wales*. Cardiff: University of Wales Press.

Cheng, Ho Y., Chair, Sek Y., and Chau, J P (2014), The effectiveness of psychosocial interventions for stroke family caregivers and stroke survivors: A systematic review and meta-analysis. *Patient education and counseling* 95, no. 1: 30-44.

Clark, Patricia., Dunbar, Sandra., Aycock, Dawn M., Blanton, Sarah., and Wolf, Steven L (2009), Pros and Woes of Interdisciplinary Collaboration With a National Clinical Trial. *Journal of Professional Nursing* 25, No.2: 93-93-100.

Cooley, Charles H (1902), *Human nature and the social order*. New York: Scribner's.
Corrigan, Patrick W., Larson, Jonathan E., and Rusch, Nicolas (2009), Self-stigma and the 'why try' effect: impact on life goals and evidence-based practices. *World Psychiatry* 8:75-81.

Creswell, John W (2009), *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches.* 3rd edition. London: Sage.

Cronin, Camille (2014), Using case study research as a rigorous form of inquiry. *Nurse Researcher* 21. No.5:19-27.

Crotty, Michael (1998), *The Foundations of Social Research.* London: Sage.

Cumming, Toby B., Marshall, Randolf S., and Lazar, Ronald M (2013), Stroke, cognitive deficits, and rehabilitation: still an incomplete picture. *International Journal of Stroke* 8, no. 1: 38-45.

Cura, Pep (2011), From traditional communities to virtual communities. H*ttp://en.blog.zyncro.com/2011/06/17/from-traditional-communities-to-virtual-communities/* (Accessed 17th July 2015).

Dahlberg, Lena., Demack, Sean., and Bambra, Clare (2007), Age and gender of informal carers: a population based study in the UK. *Health and Social Care in the Community* 15, No.5: 439-445.

David, Matthew., and Sutton, Carole D (2011), *Social Research: An Introduction.* 2nd edition. London: Sage.

Davies, Kerri., and Honeyman, Gemma (2013), Living with a child whose behaviour is described as challenging. *Advances in Mental Health and Intellectual Disabilities* 7, No. 2: 117-123.

Deacon, Merek., Fitzpatrick, Maurice., and Presho, Margaret (2008), *Informal carers: valuing our assets*. In: Presho, Margaret (ed.), *Managing Long Term Conditions.* 1st edn. West Sussex: Wiley-Blackwell, pp. 66-82.

Denno, Melissa S., Gillard, Patrick J., Graham, Glenn D., DiBonaventura, Msrco D., Goren, Amir., Varon, Srpi F., and Zorowitz, Richard (2013), Anxiety and Depression Associated with Caregiver Burden in Caregivers of Stroke Survivors with Spasticity. *Archives of Physical Medicine and Rehabilitation* 94:1731-1736.

Denzin, Norman., and Lincoln, Yvonna (2000), *Handbook of Quality Research.* 2nd edition. Thousand Oaks, CA: Sage.

Denzl, Megan M., Hunter, Elizabeth G., Campbell, Sarah., Stlvia, Violet., Kuperstein, Janice., Maddy, Katherine., and Harrison, Anne (2013), "Living with a Ball and Chain":The Experience of Stroke for Individuals and Their Caregivers in Rural Appalachian Kentucky. *The Journal of Rural Health* 29: 368-382.

Department of Health (2001), Older People's National Service Framework. *Https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/198033/National_Service_Framework_for_Older_People.pdf* (Last Accessed 15th February 2017).

Department of Health (2007), National Stroke Strategy, *Http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_081 059.pdf* (Last Accessed 16th November 2011).

Department of Health (2008), *Building on Excellence, Maintaining Progress. . .Coronary Heart Disease National Service Framework Progress Report for 2008.*

Department of Health (2013), The NHS Outcomes Framework 2014/15. *Https://www.gov.uk/government/publications/nhs-outcomes-framework-2014-to-2015* (Last Accessed 19th January 2016).

Department of Health (2014), Carers Strategy: Second National Action Plan 2014 – 2016, *Http://www.mpsv.cz/files/clanky/22729/Strategie_pecovatele_britanie_2014.pdf* (Last Accessed 17th November 2016).

Dewar, Richard (Dr.) (2010), Welsh Stroke Bulletin. *Http://www.strokeupdate.co.uk/wp-content/uploads/2010/04/MWSB-March-2010.pdf* (Last Accessed 15th February 2017).

Donnellan, Claire., Martins, Ana P., Conlon, Amy., Coughlan, Tony., O'Neill, Daniela K. and Collins, D Louis (2013), Mapping patients' experiences after stroke onto a patient-focused intervention framework. *Disability and rehabilitation* 35, No**.** 6: 483-491.

Dowswell, George., Lawler, John., Dowswell, Theresa., and Young, J (2000), Investigating recovery from Stroke: a qualitative study. *Journal of Clinical Nursing* 9, No. 4: 507 - 15.

Drakeford, Mark (2006), Health policy in Wales: Making a difference in conditions of difficulty. *Critical Social Policy* 26, No.3: 549-561.

Draper, Peter., Brock;ehurst, Hilary (2007), The impact of stroke on the well-being of the patients spouse: an exploratory study. *Journal of Clinical Nursing* 16, No. 2: 264-271.

Drinkwater, Michael (2011), Independence without isolation. *Community Care* 1: 26-27.

Drummond, Avril E., Whitehead, Phillip J., Fellows, Karen., Sprigg, Nikola., Sampson, Christopher J., Edwards, Claire., Lincoln, Nadina B (2013), Occupational therapy

predicischarge home visits for patients with stroke (HOVIS): results of a feasability randomised conreolled trial. *Clinical Rehabilitation* 27: 387-397.

Duthie, Andrew., Roy, Dianne., and Niven, Elizabeth (2015), Duty of care following stroke: family experiences in the first six months. *Http://unitec.researchbank.ac.nz/handle/10652 /3460*(Last Accessed 15th February 2017).

Duxbury, Shari., DePaul, Vincent., Alderson, Monica., Moreland, Julie. and Wilkins, Seanne (2012), Individuals with Stroke Reporting Unmet Need for Occupational Therapy Following Discharge from Hospital. *Occupational Therapy in Health Care* 26, No. 1: 16-32.

Dyspraxia Foundation (2017), Dyspraxia at a glance. *Http://dyspraxiafoundation.org.uk/about-dyspraxia/dyspraxia-glance/* (Last Accesssed 145th February 2017).

Econimoc Social Research Council (2010), Framework for Research Ethics. *Http://www.esrc.ac.uk/funding/guidance-for-applicants/research-ethics/* (Last Accessed 14th December 2016).

Ekstam, Lisa., and Borell, Lena (2008), *Challenges, dilemmas and patterns of occupations among couples after stroke*. Stockholm: Karolinska Institute.

Ekstam, Lisa., Tham, Kerstin., and Borell, Lena (2011), Couples' approaches to changes in everyday life during the first year after stroke. *Scandinavian Journal of Occupational Therapy* 18, No.1: 49-49-58.

Ellis-Hill, Caroline., Payne, Sheila., and Ward, Christopher (2000), Self-body Split: issues of identity in physical recovery following a stroke. *Disability and Rehabilitation* 22, No. 16: 725 - 33.

Emery, Catherine E (2015), Relieving Post-stroke Fatigue Using a Group-based Educational Training Approach. Doctor of Philosophy. Virginia Commonwealth University.

Eriksson, Gunilla., Aasnes, Malin., Tistad, Malin., Guidetti, Susanne., and von Koch, Lena (2012), Occupational gaps in everyday life one year after stroke and the association with life satisfaction and impact of stroke. *Topics in stroke rehabilitation* 19, No. 3: 244-255.

Faircloth, Christopher., Boystein, Craig., Rittman, Maude., and Young, Mary E (2004), Sudden Illness and Biographical Flow in Narratives of Stroke Recovery. *Sociology of Health and Illness* 26, No. 2: 242 - 61.

Fallapour, Mandana., Jonsson, Hans., Joghataei, Mohammad T., Nasrabadi, Alireza N., and Tham, Kerstin (2013), "I Am Not Living My Life": Lived Experience Of Participation In Everyday Occupations After Stroke In Tehran. *Journal of Rehabilitation Medicine* 45, No. 6: 528--534.

Fatoye, Femi O., Komolafe, M.A., Adewuya, Abiodun O., and Fatoye, Grace K (2006), Emotional distress and self-reported quality of life among primary caregivers of stroke survivors in Nigeria. *East African medical journal* 83, No. 5.

Fayers, Peter., and Machin, David (2013), *Quality of life: the assessment, analysis and interpretation of patient-reported outcomes*. UK: John Wiley & Sons.

Fitzpatrick, Maralyn (2008), Frameworks for Supporting Patients with Long Term Conditions. In: Presho, Margaret (Ed), *Managing Long Term Conditions.* West Sussex: Wiley-Blackwell.

Flick, Uwe (2009), *An introduction to qualitative research.* London:Sage.

Flyckt, Lena., Hassler, Ejda., Lotfi, Louise., Krajau, Ingvar (2014), Clinical cues for detection of people with undiscovered depression in primary health care: a case–control study. *Primary Health Care Research and Development*15, No. 3: 324-330.

Folkman, Susan (2013), *Stress: appraisal and coping.* Springer New York.

Forsberg-Warleby,Gunilla., Moller,Anders., Blomatrand,Christian (2007), Life satisfaction in spouses of patients with stroke during the first year after stroke. *Journal of Rehabilitation Medicine* 36, No. 1: 4-11.

Frankl, Viktor E (1963), *Man's search for meaning: An introduction to logotherapy.* New York: Washington Square Press.

Franze´n-Dahlin, Asa., Laska, Ann-Charlotte., Larson, Jenny., Wredling, Regina., Billing, Ewa., and Murray,Veronica (2007), Predictors of life situation among significant others of depressed or aphasic stroke patients. *Journal of Clinical Nursing* 18: 430-1580.

French, Beverley., Thomas, Lois., Leathley, Michael., Sutton, Christopher., McAdam, Joanna., Forster, Anne., Langhome, Peter., Price, Christopher., Walker, Andrew., and Watkins, Caroline (2010), Does Repetitive Task Training Improve Functional Activity After Stroke? A Cochrane Systematic Review And Meta-Analysis. *Journal of Rehabilitation Medicine* 42, No. 1: 9-9-15.

Fung, Kelvin M., Tsang, Hector W., Corrigan, Patrick W., Lam, Chow S., and Cheung, Wai-ming (2007), Measuring self-stigma of mental illness in China and its implications for recovery. *Internatiuonal Journal of Social Psychiatry* 53, No. 5: 408-418.

Fung, Kelvin M., Tsang, Hector W., Corrigan, Patrick W (2008), Self-stigma of people with schizophrenia as predictor of their adherence to psychosocial treatment. *Psychiatr Rehabil Journal* 32, No. 2: 95-104).

Gallacher, Katie., Morrison, Deborah ., Jani, Bhautesh., Macdonald, Sara., May, Carl R., Montori, Victor M., Erwin, Patricia J., Batty, David., Eton, David T., Langhorne, Peter., and Mair, Frances S. (2013), Uncovering treatment burden as a key concept for stroke care: a systematic review of qualitative research. *PLoS Med* 10, No. 6: e1001473, *Http://journals. plos.org/plosmedicine/article?id=10.1371/journal.pmed.1001473* (Last Accessed 14th Febuary 2017).

Garcia-Calvente, Maria., Hidalgo-Ruzzante, Natalia., Marcos-Marcos, Jorge., Martinez-Morante, Emilia., Maroto-Nacarro, Gracia., Mateo-Rodriguez, Inmaculada., and Gil-Garcia, Eugeina (2012), Exhausted Women, Tough Men: a qualitative study on gender differences in health, vulnerability and coping with illness in Spain. *Sociology of Health and Illness* 34, No. 6: 911-926.

Gaugler, Joseph (2010), The Longitudinal Ramifications of Stroke Caregiving: A Systematic Review. *Rehabilitation Psychology* 55, No.2:108-125.

George, Linda K., Gwyther, Lisa P (1986), Caregiver well-being: a multidimensional examination of family caregivers of demented adults. *The Gerontologist* 26: 253–259.

Gil de Zúñiga, Homero., Jung. Nakwon., and Valenzuela, Sebastián (2012), Social Media Use for News and Individuals' Social Capital, Civic Engagement and Political Participation. *Journal of Computer-Mediated Communication* 17, No. 3: 319-336.

Gilbert, Paul (2014), *Depression: the evolution of powerlessness.* 2nd edition. London: Psychology Press.

Girgis, Afaf., Lambert, Sylvie D., McElduff, Patrick., Bonevski, Billie., Lecathelinais, Chroistophe., Boyes, Allison., and Stacey, Fiona (2013), Some things change, some things stay the same: a longitudinal analysis of cancer caregivers' unmet supportive care needs. *Psycho-oncology* 22, No. 7: 1557-1564.

Glasby, Jon (2017), *Understanding health and social care.* London: Policy Press.

Glendinning, Caroline., and Moran, Nicola (2009), Reforming long-term care: recent lessons from other countries. *Social Policy Research Unit*, University of New York.

Green, Anne (2016), Challenging Dynamics of Rural Labour Markets. In: Shucksmith, Mark., and Brown , David L (Eds.), Routledge International Handbook of Rural Studies. Oxon: Routledge.

Godwin, Kyler M., Ostwald, Sharon K., Cron, Stanley G., and Wasserman, Joan (2013), Long-term health related quality of life of survivors of stroke and their spousal caregivers. *The Journal of neuroscience nursing: journal of the American Association of Neuroscience Nurses* 45, No. 3: 147-154.

Golafshani, Nahid (2003), Understanding Reliability and Validity in Qualitative Research. *The Qualitative Report* 6, No. 4: 597-606.

Goffman, Erving (1967), In: Best, Joel (Eds) (2005), *Interaction Ritual - Essays in Face to Face Behaviour.* 2nd edition. New Jersey: Transaction Publishers.

Gosman‐Hedström, Gunilla., and Dahlin‐Ivanoff, Synneve (2012), 'Mastering an unpredictable everyday life after stroke'-older women's experiences of caring and living with their partners. *Scandinavian Journal of Caring Sciences* 26, No. 3: 587-597.

Grav, Siv., Hellzĕn, Ove., Romild, Ulla, Stordal, Eystein (2012), Association between social support and depression in the general population: the HUNT study, a cross-sectional survey. *Journal of Clinical Nursing* 21, No. 1-2: 111-120.

Gray, David E (2013). *Doing research in the real world.* London: Sage.

Gray, Ann M., and Birrell, Derek (2013), *Transfering Adult Social Care: contemporary policy and practice*, Bristol: The Policy Press.

Green, Judith., and Thorogood, Nicki (2013), *Qualitative methods for health research.* 3rd edition. London: Sage.

Greenwood, Nan., MacKenzie, Ann., Cloud, Geoffery., and Wilson, Nikki (2009a), Informal primary carers of stroke survivors living at home-challenges, satisfactions and coping: A systematic review of qualitative studies. *Disability and rehabilitation* 31, No. 5: 337-337-351.

Greenwood, Nan., MacKenzie, Ann., Wilson, Nikki., and Cloud, Geoffery (2009b), Managing uncertainty in life after stroke: A qualitative study of the experiences of established and new informal carers in the first 3 months after discharge. *International journal of nursing studies* 46, No. 8: 1122-1122-1133.

Griffiths, Roy (1988), An Adgenda for Action on Community Care.

Grigorovich, Alisa., Forde, Samantha., Levinson, Dahlia., Bastawrous, Marina., Cheung, Angela M., and Cameron, Jill I (2015), Restricted Participation in Stroke Caregivers: Who is at Risk? *Archives of Physical Medicine and Rehabilitation* 96, No. 7: 1284-1290.

Guarneros-Meza, Valeria., Down, James., and Entwistle, Tom (2014), Putting the Citizen at the Centre? Assembling Local Government Policy in Wales. *Local Government Studies* 40, No. 1: 65-82.

Gubrium, Jaber F., and Holstein, James A 2002. *Handbook of Interview Research: Contect and Method.* America: Sage.

Haley, William E., Allen, Jessica Y., Grant, Joan S., Clay, Olivio J.., Perkins, Martinique., Roth, David L (2009). Problems and Benefits Reported by Stroke Family Caregivers
Results From a Prospective Epidemiological Study. *Stroke* 40, No. 2:2129-2133.

Hackett, Maree L., Yapa, Chaturangi., Parag, Varsha., and Anderson, Craig S (2005), Frequency of depression after stroke: a systematic review of observational studies. *Stroke* 36, No. 6: 1330-1340.

Hagen, Bryan (2013), *Assessing need for geriatric psychiatric services in rural settings.*
Oregon Health and Science University: Digital Commons.

Hassan, Syed T S., Khaw, Wan F., Rosna, Abd R., and Husna, Jamilah (2011), Traumatic brain injury: caregivers' problems and needs. *JNMA; journal of the Nepal Medical Association* 51, No. 181: 53-55.

Hayhow, Bradleigh D., Brockman, Simone., and Starkstein, Sergio E (2014), Post-stroke
Depression. In: Schweizer, Tom A., MacDonals, Loch R (Eds.). *The Behavioral Consequences of Stroke*. New York: Springer

Harmandayan, Maria., Romanowicz, Magdalena., and Sola, Christopher (2012), Successful use of ECT in post-stroke depression. *General hospital psychiatry: Psychiatry, Medicine and Primary Care* 34, No. 1: 105-105.

Health Wellbeing and Local Government Committee (2010), *Report of Inquiry into Stroke Serices in Wales.* Cardiff Bay, UK: National Assembly for Wales.
Heller, Agnes (2016), *Everyday Life*, Routledge: Oxen.
Hemmersley, Martyn (2008) *Questionning Qualitative Inquiry: Critial Essays.* London: Sage.

Hilari, Katerina (2011), The Impact of Stroke: are people with aphasia different to those without? *Disability and rehabilitation* 33. No. 3: 211-218.

Holloway, Wendy., and Jefferson, Tony (2000). *Doing Qualitative Research Differently.* 3rd edition. London: Sage.

Hurwitz, Brian., Greenhalgh, Trisha., Skultans, Vieda (2004), *Narrative Reseatch in Health and Illness*, Oxford, Blackwell Publishing Org. k

Hywel Dda University Health Board (2017), Your Health and Wellbeing. *Http://www.wales.nhs.uk/sitesplus/862/page/68860* (Last Accessed 15th February 2017).

Ikemoto, Satoshi., Yang, Chen., Tan, Aaron (2015), Basal ganglia circuit loops, dopamine and motivation: a review and enquiry. *Behavioural Brain Research* 209: 17–31.

Independent Commission on Social Services in Wales (2010), *From Vision to Action: the report of the independent commission on social services in* Wales, Cardiff: Independent Commission.

Intercollegiate Stroke Working Party (2004), *Royal College of Physicians National Clinical Guidelines for Stroke.* 2nd edition. London: RCP.

Jaracz, Krystyna., Grabowska - Fudala, Barbara., Górna, Krystyna., Jaracz, Jan., MOCZKO, J., and Kozubski, Wojciech (2015), Burden in Caregivers of Long-Term Stroke Survivors: prevalence and determinants at 6 months and 5 years after stroke. *Patient education and counseling* 98, No. 8: 1011-1016.

Jefferys, Margot (1989), *Growing old in the twentieth century*. London: Routledge.

Jeong, Yeon-Gyu, Jeong, Yeon-Jae., Kim, Won-Cheol., and Kim, Jeong-Soo (2015), The mediating effect of caregiver burden on the caregivers' quality of life. *Journal of physical therapy science* 27, no. 5: 1543-1547.

Johnson, Julia., and DeSouza, Corinne., 2008. *Understanding Health and Social Care: an introductory reader.* 2nd edition. London: Sage.

Jones, Lisa., and Morris, Reg (2013), Experiences of adult stroke survivors and their parent carers: a qualitative study. *Clinical rehabilitation* 27, No. 3: 272-280.

Jones, Isla., Marshall, Julie., Lawthom, Rebecca., and Read, Jennifer (2013), Involving people with communication difficulty in research in Uganda: A response to the World Report on Disability. *International Journal of Speech-Language Pathology* 15, No. 1: 75-78.

Jordan, Timothy., Khubchandani, Jagdish., Wiblishauser, Michael., Glassman, Tavis., and Thompson, Amy (2011), Do respiratory therapists receive training and education in smoking cessation? A national study of post-secondary training programs. *Patient education and counseling* 85, No. 1: 99-105.

Joubert, Jacques., Christie, Anita., Laing, Jason., Wilks, Barbara., Barnes, I., de Bustos Medeiros, E., and Moulin, T (2013), Telestroke: Long-term risk factor management–part II. *European Research in Telemedicine/La Recherche Européenne en Télémédecine* 2, no. 2: 57-67.
Jungehulsing, Gerhard J., Heuschmann, Peter U., Holtkamp, Martin., Schwab, Stefan., and Kolominsky‑Rabas, Peter L (2013) Incidence and predictors of post‑stroke epilepsy. *Acta Neurologica Scandinavica* 127, no. 6: 427-430.

Kaizik, Cassandra., Caga, Jashelle., Camino, Julieta., O'Connor, Claire M., McKinnon, Colleen., Oyebode, Jan R., Piguet, Olivier., Hodges, John R., and Mioshi, Eneida (2017), Factors underpinning caregiver burden in frontotemporal dementia differ in spouses and their children. *Journal of Alzheimer's Disease* Preprint: 1-9.

Kalaria, Raj N., Akinyemi, Rufus., and Ihara, Masafumi (2016), Stroke injury, cognitive impairment and vascular dementia. *Biochimica et Biophysica Acta (BBA)-Molecular Basis of Disease* 1862, no. 5: 915-925.

Karp, David., Yoels, William., Vann, Barbara., and Borer, Michael (2016), *Sociology in Everyday Life*, 4th Edn. Waveland Press, Illinois.

Katbamna, Savita., Ahmed, Waqar., Bhakta, Padma., Baker, Richard., and Parker, Gillian (2004), Do they look after their own? Informal support for South Asian carers. *Health and Social Care in the Community* 12, No. 5: 398-406.

Kaufman, Sharron R (1988), Toward a phenomenology of boundaries in medicine: chronic illness experience in the case of stroke. *Medical Anthropology Quaterly* 2, No. 4: 338 - 54.

Kim, Kyung., Kim, Young M., and Kim, Eun K (2015), Correlation between the Activities of Daily Living of Stroke Patients in a Community Setting and Their Quality of Life. *Journal of Physical Therapy Science* 26, No. 3: 417-419.

King, Laura A., Hicks, Joshua, A (2009), Detecting and constructing meaning in life events. *Journal of Positive Psychology* 4, No. 5: 317–330.

Kitzmüller, Gabriele., Häggström, Terttu., and Asplund, Kenneth (2012), Living an unfamiliar body: the significance of the long-term influence of bodily changes on the perception of self after stroke. *Medicine, health care, and philosophy* 16, No. 1: 19-29.

Korner, James (2007), Brits Most Reluctant to Change Their Lifestye in Comparson to the Rest of Europe. *Http://www.stroke.org.uk/media_centre/press_releases/brits_most.html* (Last Accessed 2nd Febuary 2011).

Krančiukaitė, Daina., and Rastenytė, Daiva (2006), Measurement of quality of life in stroke patients. *Medicina (Kaunas)* 42, No. 9: 709-716.

Kruithof, Willeke J., Visser-Meily, Joanna M A., and Post, Marcel W M (2012), Positive caregiving experiences are associated with life satisfaction in spouses of stroke survivors. *Journal of stroke and cerebrovascular diseases: the official journal of National Stroke Association* 21, No. 8: 801-807.

Kuluski, Kerry., Dow, Clare., Locock, Louise., Lyons, Renée., and Lasseron, Daniel (2014), Life interrupted and life regained? Coping with stroke at a young age *International Journal of Qualitative Studies on Health and Well-Being* 9 :1-12.

Kumar, Rajesh, Kaur, Sukhpal., and Reddemma, Konduru (2015), Needs, Burden, Coping and Quality of Life in Stroke Caregivers A Pilot Survey." *Nursing and midwifery research journal* 11, no. 2: 57-67.

Lamb, Norman (2014), How the government is supporting carers (Speech authorised by the Department of Health). *Https://www.gov.uk/government/speeches/how-the-government-is-supporting-carers* (Last Accessed 17th December 2016).

Larson, Jenny., Franzén-Dahlin, Asa., Billling, Ewa., von Arbin, Magnus., Murray, Veronica., and Wredling, Regina (2008), The impact of gender regarding psychological well-being and general life situation among spouces of stroke patients during the first year after the patients' stroke event: a longitudional study. *International journal of nursing studies* 45, No. 2: 257-265.

Larsson, Julia., and Mattsson, Sofia (2016), Post Stroke Fatigue, Malmo University:Electronic Publishing. *Https://dspace.mah.se/handle/2043/20160* (Last Accessed 15th February 2017).

Lawrence, Maggie (2010), Young adults' experience of stroke: a qualitative review of the literature. *Young adults' experience of stroke: a qualitative review of the literature* 19, No. 4: 241-248.

Lawrence, Maggie., and Kinn, Sue (2013), Needs, priorities, and desired rehabilitation outcomes of family members of young adults who have had a stroke: findings from a phenomenological study. *Disability and rehabilitation* 35, No. 7: 586-595.

Lawrence, Maggie., Pringle, Jan., Kerr, Susan., and Booth, Joanne (2016), Stroke survivors' and family members' perspectives of multimodal lifestyle interventions for secondary prevention of stroke and transient ischemic attack: a qualitative review and meta-aggregation. *Disability and Rehabilitation* 38, No. 1:11-21.

Lazarus, Richard S., and Folkman. Susan (2000), *Stress Appraisal and Coping*, New York: Springer.

Lee, Regina L T., and Mok, Ester S (2011), Seeking harmony in the provision of care to the stroke-impaired: Views of Chinese family caregivers. *Journal of Clinical Nursing* 20: 1436-1444.

Lee, Sally., Shafe, Anna C E., and Cowie, Martin R (2011), UK stroke incidence, mortality and cardiovascular risk management 1999-2008: time-trend analysis from the General Practice Research Database. *BMJ Open: Most-Read Full-Text Articles* 1, No. 2: 269-269.

Lewins, Ann., and Silver, Christina (2009), *Choosing a CAQDAS Package.* NCRM Working Paper (unpublished). Guildford, UK: University of Surrey.

Lewin-Richter, Andrés., Volz, Monica., Jöbges, Michael., Werheid, Katja (2015), Predictivity of early depressive symptoms for post-stroke depression. *Nutrition, Health and Aging* 19, No. 7: 754-758.

Linsey, Linda., Davis, Catherine., Gilliss, Lynch., and Harper, Mary S (2011), Family Caregiving: Implications for Rural Practice, Policy, Education, and Research. In: Talley, Ronda., Chwalisz, Kathleen., Buckwalter, Kathleen C (Eds.), *Rural Caregiving in the United States: Research, Practice, Policy,* New York: Springer.

Long, Andrew., Hesketh, Anne., and Bowen, Audrey (2009). Communication outcome after stroke: a new measure of the carer's perspective. *Clinical rehabilitation* 23, No. 9: 846-856.

Lord Bourne (2015), Welsh Go*vernment: Address to The Academy of Social Sciences. Https://www.gov.uk/government/speeches/lord-bourne-addresses-academy-of-social-sciences* (Last Accessed 16th July 2015.

Lorenz, Laura S (2016), Living with Brain Injury: Participatory Visual Methods and Narrative Analysis." *Disability and Qualitative Inquiry: Methods for Rethinking an Ableist World*: 189.

Lutz, Barbara J., Young, Mary E., Cox, Kim J., Martz, Crystal .,and Creasy, Kerry R (2011) The crisis of stroke: experiences of patients and their family caregivers. *Topics in stroke rehabilitation* 18, no. 6: 786-797.

Mani, Ashutosh., Dunning, Kari., Alwell, Kathleen., Moomaw, Charles J., Kleindorfer, Dawn O., Woo, Daniel., Flaherty.,and Matthew (2014), Falls with Injury After Stroke are Associated With Incontinence and Depression. *Stroke* 45, No. 1: Abstract.

Martin, Frank., and Thompson, Marcus (2010), *Social Enterprise: Developing Sustainable Businesses*. Basingstoke:Palgrave Macmillan.

Mazanderani, Fadhila., Locock, Louise., and Powell, John (2013), Biographical value: towards a conceptualisation of the commodification of illness narratives in contemporary healthcare. *Sociology of Health and Illness* 36, No. 6: 891-905.

McColl, Mary A., Adair, William., Davey, Sue., and Kates, Nick (2013), The Learning Collaborative: An approach to emancipatory research in disability studies. *Canadian Journal of Disability Studies* 2, No. 1: 71-93.

McCullagh, Emily., Brigstocke, Gavin., Donaldson, Nora., and Kalra, Lalit (2005), Determinants of caregiving burden and quality of life in caregivers of stroke patients. *Stroke* 36, No. 10: 2181-2186.

McDermott, Rose (2011), Internal and External Validity. In: Druckman, James., Green,Donald J., Kuklinski, James H., and Lupia, Arthur (Eds.)*, Cambridge Handbook of Experimental Political Science*. Cambridge: Cambridge University Press.

McGivern, Yvonne (2013), *The Practice of Market and Social Research: an introduction.* 4th edition. London: Pearson.

McGrail, Matthew, Stirling, Richard., Humphreys, John., and Ward, Bernadette (2015), Accessing doctors at times of need–measuring the distance tolerance of rural residents for health-related travel. *BMC health services research* 15, no. 1: 212.

McKevitt, Christopher., Fudge, Nina., Redfern, Judith., Sheldenkar, Anita., Crichton, Siobhan., and Wolfe, Charles D A (2010), *The Stroke Association: UK Stroke Survivor Needs Survey.* London: The Stroke Association.

McKevitt, Christopher., Fudge, Nina., Redfern, Judith., Sheldenkar, Anita., Crichton, Siobhan., Rudd, Anthony., Forster, Ann., Young, John., Nazareth. Irwin., Silver, Louise E., and Wolf, Charles D A (2011), Self Reportd Long Term Needs After Stroke. *Stroke* 42, No. 5: 1398--403.

McPherson, Christine J., Wilson, Keith G., Chyurlia, Livia., and Leclerc, Charles (2011), The caregiving relationship and quality of life among partners of stroke survivors: A cross-sectional study. *Health and Quality of Life Outcomes* 9, No. 1: 29.

Mead George, H., 1932. Mind Self and Society from the Standpoint of a Social Behaviorist. *University of Chicago, Chicago*.

Menlove, Leanne., Crayton, Elsie., Kneebone, Ian., Allen-Crooks, Rhani., Otto, Elizabeth., and Harder, Helena (2015), Predictors of anxiety after stroke: a systematic review of observational studies. *Journal of Stroke and Cerebrovascular Diseases* 24, No. 6:1107-1117.

Meihering, Louise., Nanninga, Christa S., Lettinga, Ant T (2016), Home-making after stroke. A qualitative study among Dutch stroke survivors. *Health and Place* 37: 35-42.

Mertens, Donna M (2009), Transformaive research and evaluation. *Qualitative Inquiry.* New York: Guilford.

Morgan, Rhodri (2002), *Speech at the National Centre for Public Policy Third Anniversary Lecture,* Swansea: University of Wales.

Morris, Reg (2011), The psychology of stroke in young adults: the roles of service provision and return to work. *Stroke Research and Treatment* : 534--812.

Morris, Jacqui H., Oliver, Tracey., Kroll, Thilo., Joice, Sara., and Williams, Brian (2014), From physical and functional to continuity with pre-stroke self and participation in valued activities: A qualitative exploration of stroke survivors', carers' and physiotherapists' perceptions of physical activity after stroke. *Disability & Rehabilitation* 37, No. 1: 64-77.

National Assembly for Wales (2016), About the Assembly. *Http://www.assembly.wales/ en/abthome/role-of-assembly-how-it-works/Pages/governance-of-wales.aspx* (Last Accessed 22nd December 2016).

National Assembly for Wales (2011) Health and Social Care Committee. *Http://www.senedd. assemblywales.org/ieListMeetings.aspx?CommitteeId=227* (Last Accessed 4th March 2012).

National Audit Office (2010), Department of Health: Progress in Impoving Stroke Care. *Https://www.nao.org.uk/wp-content/uploads/2010/02/0910291.pdf* (Last Accessed 5th March 2016).

National Institute of Neurological Disorders and Stroke (2008), Post-Stroke Rehabilitation Fact Sheet.   *Http://www.ninds.nih.gov/disorders/stroke/poststrokerehab.htm#disabilities*   (Last Accessed 24th November 2011).

National Leadership and Innovation Agency for Healthcare (2009), All Wales Stroke Services Improvement Collaborative: end of year report 2008-2009. *Http://www.wales.nhs.uk/sitesplus /documents/829/Stroke%20Services%20Improvement%20Collaborative.pdf* (Last Accessed 15th February 2017).

National Stroke Association (2010), What is Stroke? *Http://info.stroke.org/site/PageServer?pa gename=STROKE.*(Last Accessed 8th November 2010).

National Stroke Association (2017), We Can Help. *Http://www.stroke.org/we-can-help/survivors /stroke-recovery/post-stroke-conditions/emotional* (Last Accessed 22nd January 2017).
Nazarko, Linda (2004), *Managing a quality service.* Abingdon, Oxon: Harcourt Education Limited.

Nelson, Michelle L A., Hanna, Elizabeth., Hall, Stephen., and Calvert, Michael (2016), What makes stroke rehabilitation patients complex? Clinician perspectives and the role of discharge pressure. *Journal of Comorbidity* 6, no. 2: 35-41.

NHS Wales (2016), National Service Framework for Older People in Wales. *Http://www.wales.nhs.uk/documents/NSF%20for%20Older%20People.pdf. Last Accessed 15th February 2017.*

NHS Wales (2014), Health in Wales: Stroke *Https://www.wales.nhs.uk/healthtopics/condition s/stroke* (Last Accessed 18th June 2014).

Norris, Meriel., Allotey, Pascale., and Barrett, Geraldine (2012), 'It burdens me': the impact of stroke in central Aceh, Indonesia. *Sociology of Health and Illness* 34, No. 6: 826 - 840.

Office for National Statistics (2013), Language in England and Wales: 2011. *Https://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/language/articles/lang uageinenglandandwales/2013-03-04* (Last Accessed 22nd December 2016).

Office for National Statistics (2016), Small area population estimates in England and Wales: mid-2015 *Https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/pop ulationestimates/bulletins/smallareapopulationestimates/mid2015* (Last Accessed 22nd December 2016).

Olsson, Frida., and Berterö, Carina (2015), Living with faecal incontinence: trying to control the daily life that is out of control. *Journal of clinical nursing* 24, no. 1-2: 141-150.

Ostwald, Sharron K., Bernal, Maria P., Cron, Stanley G., Godwin, Kyler M (2015), Stress Experienced by Stroke Survivors and Spousal Caregivers During the First Year After Discharge from Inpatient Rehabilitation. *Stroke Rehabilitation* 16, No. 2: 93-104.

Pasi, M., Poggesi, A., Salvadori, E. and Pantoni, L., 2012. Post-stroke dementia and cognitive impairment. In: Paciaroni M., Agnelli, G.,Caso V.,Bogousslavsky J.*Manifestations of Stroke* (Vol. 30). Basel: Karger Publishers.

Palmer, Sara., and Glass, Thomas A (2003), Family function and stroke recovery: a review. *Rehabilitation Psychology* 48: 255 -265.

Parag, Varsha., Hackett, Maree L., Yapa Chaturangi M., Kerse, Ngaire., McNaughton, Harry., Feigin, Valery L., and Anderson, Craig S (2008), The impact of stroke on upaid caregivers: results from The Auckland Regional Community Stroke study, 2002-2003. *Cerebrovascular Diseases* 25, No. 6: 548-554.

Patterson, Sarah A., Ross-Edwards, Benjamin M., and Gill, Hannah L (2010), Stroke maintenance exercise group: pilot study on daily functioning in long-term stroke survivors. *Australian Journal of Primary Health - Interchange* 16, No. 1:93-97.

Persson, Josefine., Holmegaard, Lukas., Karlberg, Ingvar., Redfors, Petra., Jood, Katarina., Jern, Christina., Blomstrand, Christian., and Forsberg-Wärleby, Gunilla (2015), Spouses of Stroke Survivors Report Reduced Health-Related Quality of Life Even in Long-Term Follow-Up. *Stroke* 46, No. 9:2584-2590.

Pizzi, Assunta., Carrai, Riccardo., Falsini, Carrai., Martini, Monica., Verdesca, Sonia., and Grippo, Antonello (2009), Prognostic value of motor evoked potentials in motor function recovery of upper limb after stroke. *Journal of Rehabilitation Medicine* 41, No. 8: 654-654-660.

Pompili, Maurizio., Venturini, Paola., Lamis, Dorian A., Giordano, G., Serafini, Gianluca., Balvenderi, Murri., Amor, Mario., and Girardi, Paolo (2015), Suicide in stroke survivors: epidemiology and prevention. *Drugs and Aging* 32, No. 1: 21-29.

Presho, Margaret (2008), *Managing Long Term Conditions.* West Sussex: Wiley-Blackwell.

Pugh, Richard (2011), Reaching Rural Areas: Social Services in the Welsh Countryside. In: Williams, Charlotte (Ed) *Social Policy for Social Welfare Practice in a Devolved Wales.*2nd Edition. UK: British Association of Social Workers.

Punch, Keith F., and Oancea, Alis (2014), *Introduction to research methods in education.* London: Sage.

Qureshi, Hazel., and Walker, Alan (1989), The Careing Relationshi: Elderly people and their families, London: Macmillan.

Radcliffe, John (2011), *Email Communication.* World Health Organisation.

Reed, Mary., Harrington, Rachael., Duggan, Aine., and Wood, Victorine A (2010), Meeting stroke survivors' perceived needs: a qualitative study of a community-based exercise and education scheme. *Clinical Rehabilitation* 24, No. 1: 16-25.

Reeder, Glenn D., and Pryor, John B (2009), Dual psychological processes underlying public stigma and the implications for reducing stigma. *Mens Sana Monographs* 6, No. 1: 175-86.

Ribeiro, Marina V M R., Júnior, Hasten-Reiter., Nogueira, Hermann., Ribeiro, Eurica A N., Jucá, Mario J., Barbosa, Fabiano T., and Sousa-Rodrigues, Célio F (2015), Association between visual impairment and depression in the elderly: a systematic review. *Arquivos brasileiros de oftalmologia* 78, no. 3: 197-201.

Ridley-Duff, Rory., and Bull, Mike (2011), *Understanding Social Enterprise: theory and practice.* London: Sage.

Ridley-Duff, Rory., and Bull, Mike (2016), *Understanding Social Enterprise: theory and practice.*2ND edition. London: Sage.

Riessman, Catherine K (1993), *Narrative Analysis*, London: Sage Pubblications Ltd.

Ritchie, Jane., Lewis, Jane., Nicholls, Carol M., and Ormston, Rachel (2013), *Qualitative research practice: A guide for social science students and researchers*. London: Sage.

Rochette, Annie., Bravo, Gina., Desrosiers, Johanne., St-Cyr, Denise., and Bourgetm Annick (2007), Adaption process, participation and depression over six months in first-stroke individuals and spouses. *Clinical rehabilitation* 21, No. 6: 554-562.

Roberts, Adam., and Charlesworth, Anita (2014), *A Decade of Auterity in Wales? The Funding Pressures facing the NHS in Wales to 2025.* Nuffield Trust.

Romans, Sarah., Cohen, Marsha., and Forte, Tonia (2011), Rates of Depresion in Urban and Rural Canada. *Social Psychiatry and Psychiatric Epidemiology* 46, No. 7: 567-575.

Ronksley, Paul E., Sanmartin, Claudia., Quan, Hude., Ravani, Pietro., Tonelli, Marcello., Manns, Braden., and Hemmelgarn, Brenda R (2012), Association between chronic conditions and perceived unmet health care needs. *Open medicine: a peer-reviewed, independent, open-access journal* 6, No. 2:48-58.

Rosenwald, George C and Ochberg, Richard L (1992), *Storied Lives: The Cultural Polotics of Self-Understanding*, London: Yale University Press.

Rowe, Fiona (2013), Care Provision, Unmet Need and Good Practice in Post-Stroke Vision Services in the UK, Research statue: active. The Stroke Association. *Https://www.stroke.org. uk/research/care-provision-unmet-need-and-good-practice-post-stroke-vision-services-uk* (Last Accessed 14th February 2017).

Rowson, Richard (2006), *Working Ethics: How to be Fair in a Culturally Complex World.* London: Jessica Kingsley Publishers.

Russell, Bernard (2013), Social research methods: qualitative and quantitative approaches. 2nd Edition. Los Angeles: Sage.

Russell, Phillippa (2007), Care matters: a guide to the carers (equal opportunities) act 2004. *The Elizabeth Nuffield Educational Fund, The Nuffield Foundation, London*.

Saban, Karen L., and Hogan, Nancy S (2012), Female caregivers of stroke survivors: Coping and adapting to a life that once was. *Journal of Neuroscience Nursing* 44, No. 1: 12-14.

Sanuade, Olutobi. and Agyemang, Charles (2014), Stroke in Ghana: a systematic literature review. *Chronic Non-communicable Diseases in Ghana.: Multidisciplinary* Perspectives 1: 29.

Sarre, Sophie., Redlich, Cara., Tinker, Anthea., Sadler, Euan ., Bhalla, Ajay., and McKevitt, Christopher (2014), A systematic review of qualitative studies on adjusting after stroke: lessons for the study of resilience. *Disability and rehabilitation* 36, no. 9: 716-726.

Satink, Tom., Josephsson, Staffan., Zajec, Jana., Cup, Edith H C., de Swart, Bert J M., and Nijhuis-van der Sanden, Maria WG (2016), Self-management develops through doing of everyday activities—a longitudinal qualitative study of stroke survivors during two years post-stroke. *BMC neurology* 16, no. 1: 221.

Saunders, Mark., Lewis, Philip., Thornhill, Adrian (2015), *Research Methods for Business Students*, 5TH edition. Essex: Pearson Education Limited.
Schepers, Vera P., Visser-Meily, Anne M., Ketelaar, Marjolijn., and Lindeman, Eline (2006), Post Stroke Fatigue: course and its relation to personal and stroke related factors. *Archives of Physical Medicine and Rehabilitation* 87, No. 2: 184-188.

Schlote, Arieh., Richter, M., Wunderlicht, M., Poppendick, U., Moller, C., Schwelm, K. and Wallesch, C (2009), WHODAS II with people after stroke and their relatives. *Disability and rehabilitation* 31, No. 11: 855-855-864.
Schmid, Arlene A., van Puymbroeck, Marieke., Knies, Kasie., Spangler-Morris, Carrie., Watts, Kathryn., Damush, Teresa., and Williams, Linda S (2011), Fear of falling among people who

have sustained a stroke: a 6-month longitudinal pilot study. *American journal of occupational therapy* 65, no. 2: 125-132.

Schure, Lidwien L., van den Heuvelm Elisabeth T., Strwart, Robbert., Sanderman, Luc P., and Jogn, Betty (2006), Beyond Stroke: description and evaluation of an effective intervention to support family caregivers of stroke patients. *Patient Education and Counselling* 62, No. 1:46-55.

Schuurman, Nadine, Crooks, Valorie A., and Amram, Ofer (2010), A Protocol for determining differences in consistency and depth of palliative care service provision accross community sites. *Health and Social Care in the Community* 18, No.5: 537-548.
Scott, John (2014), *Oxford Dictionary of Sociology.* 4th edition. New York: Oxford University Press.

Seddon, Diane., and Robinson, Catherine A (2015), Carer assessment: continuing tensions and dilemmas for social care practice. *Health & social care in the community* 23, No. 1:14-22.

Seidman, Irving (2013) *Interviewing as qualitative research: A guide for researchers in education and the social sciences*. 3rd edition, New York: Teachers college press.

Simonic, Anja., Furlan, Maja., Ravnjak, Tanja., and Dirkse, Dale (2012), Caring for caregivers: a right way to do it? *Current opinion in supportive and palliative care* 6, No.3: 379-385.

Silverman, David (2013), *Doing Qualitative Research.* 4th edition. London: Sage.

Simplican, Stacy C., Leader, Geraldine., Kosciulek, John., and Leahy, Michael (2015), Defining social inclusion of people with intellectual and developmental disabilities: An ecological model of social networks and community participation. *Research in developmental disabilities* 38: 18-29.

Ski, Chantal., and O'Connell, Bev (2007), Stroke: the increasing complexity of carer needs. *Journal of Neuroscience Nursing* 39, No. 3: 172-179.

Skinner, Johnathan (2014), *The Interview: An Ethnographic Approach.* London: A&C Black.

Sklenarova, Halina., Krűmpelmann, Arne., Haun, Markus W., Friederich, Hans-Christioh., Huber, Johannes., Thomas, Michael., Winker, Eva C., Herzog, Wolfgang., and Hartmenn, Mechthild (2015), When do we need to care about the caregiver? Supportive care needs, anxiety, and depression among informal caregivers of patients with cancer and cancer survivors. *Cancer* 121, No. 9: 1513-1519.

Smith, Elliot R., Mackie, Diane M., and Claypool, Heather M (2014), *Social psychology.* Psychology Press.

Smith, Jane., Forster, Anne., and Young, John (2009a), Cochrane review: information provision for stroke patients and their caregivers. *Clinical rehabilitation* 23, No. 3: 195-206.

Smith, Katherine E., Hunter, David J., Blackman, Tim., Elliot, Eva., Greene, Alexandra., Harrington, Barbara E., Marks, Linda., McKee, Lorna., and Williams, Gareth H (2009b), Divergence or convergence? Health inequalities and policy in a devolved Britain. *Critical Social Policy* 29, No. 2:216-242.
Snyder, Barbara., and Keefe, Kathy (1985), The Unmet Needs of Family Caregivers for Frail and Disabled Adults, *Social Work in Health Care* 10, No. 3: 1-14.

Sommerfeld, Disa K., Eek, Elsy U., Svensson, Anna-Karin., Holmqvist, Lotta W. von Arbin, Magnus H (2004), Sparciticity after Stroke: its occurrence and association with motor impairments and activity limitations. *Stroke* 35, No. 1: 135-139.

Starosciak, Amy K., Payret, Kareys., Ramirez, Maygret., Viera, Yolexis., Alegria, Chris., Bedgio, Rodney., and Ruiz, Felix (2016), Effects of Ethnicity and Prior Depression on Hospital Course and Outcomes in First-Time Stroke Patients. *Cardiovascular Quality and Outcomes* 9, No. 2: Abstract 149

Statistics Wales (2012), Welsh speakers by local authority, gender and detailed age groups 2011. *Https://statswales.wales.gov.uk/Catalogue/Welsh-Language/WelshSpeakers-by-LocalAuthority-Gender-DetailedAgeGroups-2011Censu*s (Last Accessed15th July 2015).

Statistics Wales (2013), Population projections by local authority and year. *Https://statswales.wales.gov.uk/Catalogue/Population-and-Migration/Population/Projections/Local-Authority/2011-Based/PopulationProjections-By-LocalAuthority-Year* (Last Accessed 17th July 2015).

Statistics Wales (2014), Average earnings data by UK country/English region. *Https://statswales.wales.gov.uk/Catalogue/Business-Economy-and-Labour-Market/People-and-Work/Earnings/averageweeklyearnings-by-ukcountryenglishregion-year* (Last Accessed 17th July 2015).

Statistics Wales (2015), Population Density. *Https://statswales.wales.gov.uk/Catalogue/Population-and-Migration/Population/Density/populationdensity-by-localauthority-year* (Last Accessed 15th July 2015).

Stajduhar, Kelli I (2013), Burdens of family caregiving at the end of life. *Clinical and investigative medicine.Médecine clinique et experimentale* 36, No. 3:121.

Stevelink, Sharron A., van Brackel, Wim H. and Augustine, Valsa (2011), Stigma and social participation in Southern India: differences and commonalities among persons affected by leprosy and persons living with HIV/AIDS. *Psychol Health Med* 16, No. 6: 695-707.

Steultjens, Esther M J., Cup, E Edith H.C., Zajec, J., Van Hees, S. (2013). Ergotherapierichtlijn CVA. [Guidelines for occupational therapy after a Cerebrovascular Accident].

Stiers, William., Carolzzi, Noelle., Cernich, Alison., Velozo, Craig., Pape, Theresa., Hart, Tessa., Gulliver, Suzy., Rogers, Margaret.,Villarreal, Edgar., Gordon, Shalanda., Gordon, Wayne. and Whiteneck, Gale., 2012. Measurement of social participation outcomes in rehabilitation of vetrans with traumatic brain injury. *Journal of Rehabilitation Research and Development,* 49(1), pp 139-154.

Suárez-Ortega, Magdalena (2013), Performance, Reflexivity, and Learning through Biographical-Narrative Research. *Journal of Qualitative Inquiry* 9, No. 3: 189-200.

Svasek, Maruska., and Domecka, Markieta (2014), The Autobiographical Narratvive Interview: A Potential Arena of Emotional Remembring, Performanceand Reflection. In: Skinner, Johnathan (Ed.) *The Interview: An Ethnographic Approach.* London: Berg.

Svašek, Maruška., and Domecka, Markieta (2012), The autobiographical narrative interview. A potential arena of emotional remembering, performance and reflection. In: Skinner, Johnathan (2014), *The Interview: An Ethnographic Approach.* London: A&C Black.

Tang, Siew T (2003), When death is imminent:Where terminally ill patients with cancer prefer to die and why. *Cancer Nurcing* 26, No. 3: 245-251.

Tanaka, Tomotaka., and Ihara, Masafumi (2017), Post-stroke Epilepsy, *Neurochemistry International* 107: 219-228.

The National Institute for Health Research CLAHRC for Greater Manchester (2014), GM-SAT Greater Manchester Stroke Assessment Tool. *Http://clahrc-gm.nihr.ac.uk/resources/gm-sat/4/#sthash.lyKKM4KA.dpuf* (Last Accessed 2nd May 2014).

The Stroke Association (2012a), Factsheet: Communication problems after stroke. *Http://www.stroke.org.uk/sites/default/files/Communication%20problems%20after%20stroke.pdf* (Last Accessed 16th December 2016).

The Stroke Association (2012b), Epilepsy after stroke. *Https://www.stroke.org.uk/sites/default/files/epilepsy_after_stroke.pdf* (Last Accessed 15th February 2017).

The Stroke Association (2012c), Stroke Policy in Wales. *Http://www.stroke.org.uk/campaigns/stroke_policy/stroke_policy_wales.html* (Last Accessed 4th April 2012).

The Stroke Association (2015a), Life After Stroke Campaign. *Https://www.stroke.org.uk/sites/default/files/our_life_after_stroke_campaign_web.pdf* (Last Accessed 15th February 2017).

The Stroke Association (2015b), Together we can conquer stroke. *Https://www.stroke.org.uk/sites/default/files/together_we_can_conquer_stroke.pdf* (accessed 15th February 2017).

The Stroke Association (2016) The State of the Nation 2016 - Stroke Statistivs Report. *Https://www.stroke.org.uk/sites/default/files/state_of_the_nation_2016_110116_0.pdf* (Last Accessed 24th December 2016).

The Stroke Association (2017a), FAST. *Https://www.stroke.org.uk/take-action/recognise-signs-stroke*(Last Accessed 15th February 2017).

The Stroke Association (2017b) Keep in Touch. *Https://www.stroke.org.uk/finding-support/cwm-taf-keep-touch-service*(Last Accessed 15th February 2017).

The Stroke Association (2017c), Stroke Clubs and Groups. *Https://www.stroke.org.uk/take-action/stroke-clubs-and-groups/independent-affiliated-stroke-clubs*(Accessed 15th February 2017).

Thomas, Gary (2011), *How to do your Case Study: a guide for students and researchers.* London: Sage.

Thompson, Hilary S., and Ryan, Assumpta (2009), The Impact of stroke consequences on spousal relationships from the perspective of the person with stroke. *Journal of Clinical Nursing* 18, No. 12: 1803-1811.

Tseng, Chien-Ning., Huang, Guey-Shiun., Yu, Po-Jui., and Lou, Meei-Fang (2015), A Qualitative Study of Family Caregiver Experiences of Managing Incontinence in Stroke Survivors. *PloS one* 10, No. 6: e0129540.

Tummers, Johanneke F M M., Schrijvers, Augustinus J P., and Visser-Meily, Johanna (2013), *A qualitative study of stakeholder views of the effects of provider payment on cooperation, quality of care and cost-containment in integrated stroke care* 13, No. 1:127.

Twigg, Julia., and Atkin, Karl (1994), *Carers Percieved: Policy and practice in informal care.* UK: McGraw-Hill Education.

Van Brakel, Wim H., Sihombing, Benyamin., Djarir, Hernani., Beise, Kerstin., , H., Beise, K., Kusumawardhani, Laksmi., Yulihane, Rita., Kurniasari Indra., Kasim, Muhammad., Kesumaningsih, Kadeck I., and Wilder-Smith, Annelies (2012), Disability in people affected by leprosy: the role of impairment, activity, social participation, stigma and discrimination. *Global Health Action* 5: 3402.

Vincent, Claude., Desrosiers, Johanne., Landreville, Philippe., Demers, Louise (2009), Burden of caregivers of people with stroke: Evaluation and predictors. *Cardiovascular Diseases* 27, No. 5: 456-464.

Visser-Meily, Anne., Post, Marcel., Schepers, Vera., andLindeman, Eline (2005), Spouces quality of life 1 year after stroke: prediction at the start of clinical rehabilitation. *Cerebrovascular Diseases* 20, No. 6: 443-448.

Visser-Meily, Anne., Post, Marcel., van de Port, Ingrid., van Heugten, Caroline., and van de Bos, Trudi (2008), Psychological functioning of spouses in the chronic phase after stroke: improvement or deterioration between 1 and 3 years after stroke? *Patient Education and Counseling* 73, No. 1:153-158.

Wales Co-operative Centre (2017), Social Business Wales. *Http://wales.coop/social-business-wales/*(Last Accessed 18th February 2017).

Wales Rural Observatory (2004), *An Overview of Policy and Resources Impacting on Rural Wales.* Wales: Wales Rural Observatory.

Wales Rural Observatory (2009), *Deep Rural Localities.* Wales: Wales Rural Observatory.

Wallengren, Catarina., Friberg, Febe., and Sefesten, Kerstin (2008), Like a shadow – On becoming a stroke victim's relative. *Scandinavian Journal of Caring Sciences* 22, No. 1: 48-55.

Wolter, Michele., and Preda, Shannon (2015), Visual Deficts Following Stroke: maximising participation in rehabilitation, *Topics in Stroke Rehabilitation* 13, No. 3: 12-21.

Wei, Changjuan., Zhang, Fang., Chen, Li., Ma, Xiaofeng., Zhang, Nan., Hao, Junwei. (2016) Factors associated with post-stroke depression and fatigue: lesion location and coping styles. *Journal of Neurology* 263, No. 2: 269-276.

Weiss, Mitchell G (2008), Stigma and the social burden of neglected tropical diseases. *PLoS Negl Tropical Disease* 2, No. 5: 237.

Welsh Council or Voluntry Action (2013), About. *Http://www.wcva.org.uk/* (Last Accessed 2nd March 2014).

Welsh Government (2003), The Strategy for Older People in Wales. *Http://www.pembs-networking.org.uk/documents/TheStrategyForOlderPeopleinWales2003.pdf- Last accessed 15th February 2017.*

Welsh Government (2007), Fulfilled lives, Supportive Communities: A Strategy for Social Services in Wales Over the Next Decade. *Http://gov.wales/topics/health/publications/social care/strategies/lives/?lang=en* (Last Accessed 15th February 2017).

Welsh Government (2011a), Sustainable Social Services for Wales: a framework for action. *Http://gov.wales/docs/dhss/publications/110216frameworken.pdf* (LAST Accessed 15th February 2017).

Welsh Government (2011), Welsh Government Public bodies. *Http://wales.gov.uk/about/recruitment/publicapps/pubb/?lang=en* (Last Accessed 4th March 2012).

Welsh Government (2012), Stroke Delivery Plan 2012-2016. *Http://gov.wales /docs/dhss/publications/121206nhsplanen.pdf* (Last Accessed 15th February 2017).

Welsh Government (2013), Carers Strategy for Wales: Delivery Plan 2013-2016. *Http://gov .wales/docs/dhss/publications/130613strategyen.pdf* (Last Accessed 15th February 2017).

Welsh Government (2014a), Devolution, Democacy and Delivery: improving public services for people in Wales. *Http://gov.wales/docs/dpsp/publications/140708-response-to-commission-en.pdf* (Last Accessed 15th February 2017).

Welsh Government (2014b), Social Services Wellbeing Act. *Http://www.legislation.gov. uk/anaw/2014/4/pdfs/anaw_20140004_en.pdf* (Last Accessed 15th February 2017).

Welsh Government (2016a), Together for health: Stroke Annual Report 2016. *http://gov.wales/docs/dhss/publications/161128stroke-reporten.pdf* (Last Accessed 15th February 2017).

Welsh Government (2016b), Mid year estimates of the population. *Http://gov.wales/statistics-and-research/mid-year-estimates-population/?lang=en* (Last Accessed 22nd December 2016).

Welsh Government (2017), Stroke Delivery Plan 2017-2020. *Http://gov.wales/docs/dhss/ publications/170209stroke-dplan1720en.pdf* (Last Accessed 15th February 2017).

Welsh Local Government Association (2017), Social Services. *Http://www.wlga.gov.uk/social-services-3* (Last Accessed 20th January 2017).

Wenger, Clare G (1989), Network Typologies. In: Jefferys, Margot (1989), *Growing old in the twentieth century*. London: Routledge.

Wengraf, Tom (2009), *Qualitative Research Interviewing: Biographic Narrative and Semi-structured Methods*, New Delhi: Sage.

White, Carole L., Lauzon, Sylvie., Yaffe, Mark J., and Wood-Dauphinee, Sharon (2004), Toward a model of quality of life for family caregivers of stroke survivors. *Quality of Life Research* 13, No. 3: 625-638.

White, Carole L., Barrientos, Rosalinda., and Dunn, Kelly (2014), Dimensions of uncertainty after stroke: perspectives of the stroke survivor and family caregiver. *The Journal of neuroscience nursing : journal of the American Association of Neuroscience Nurses* 46, No.4: 233-240.

White, S., Wakjkey, C., Radcliffe, J. and Edwards, B (2007), Coping with Access to Services. *Http://www.walesruralobservatory.org.uk/sites/default/files/12_CopingAccessServices.pdf* (Last Accessed 15th February 2017).

Wiles, Rose., Ashburn, Ann., Payne, Sheola., and Murphy, Caroline (2004), Discharge from Physiotherapy following Stroke: the management of disappointment. *Social Science and Medicine* 59, No.6: 1263 - 73.

Williams, Charlotte (2008), *Social Policy for Social Welfare Practice in a Devolved Wales.* UK: British Association of Social Workers.

Williams, Charlotte (Ed, 2011) *Social Policy for Social Welfare Practice in a Devolved Wales.* 2nd Edition. UK: British Association of Social Workers.

Wilson, Erin (2006), Roundtable on Intellectual Disability Policy. *Deakin research online, Scope* : 24.

Wilson, Keith G., Chochinov, Harvey M., McPherson, Christine J., Graham, Merika., Allard, Pierre., Chary, Srini., Gagnon, Pierre R.,Macmillan, Karen., De Luca, Marina., O'Shea, Fiona., Kuhl, David., Fainsinger, Robin L., Karam, Andrea M., and, Clinch, Jennifer J (2007), Desire for euthanasia or physician assisted suicide in palliative cancer care. *Health Psychology* 26, No. 3: 314-323.

Wisker, Gina (2001), *The Postgraduate Research Handbook.* New York: Palgrave.

World Health Organisation (2014), Quality of Life. *Http://www.who.int/mental_health/public ations/whoqol/en/* (Last Accessed 20th December 2016).

World Health Organisation (2016), Disabilities. *Http://www.who.int/topics/disabilities/en/* (Last Accessed 15th February 2017).

Wren, Maev-Ann (2013), Fear and Institutions. *Journal of Economic Issues* 47, No. 2: 383-390.

Yeon-Gyu, Jeon., Jun-Po, Myong., and Koo, Jung-Wan (2015), The Modifying Role of Caregiver Burden on Predictors of Quality of Life of Caregivers of Hospitalized Chronic Stroke Patients. *Disability and Health Journal* 8, No. 4: 619-625.

Yin, Robert (2013), *Case Study Research: Design and Methods (Applied Social Research Methods).* London: Sage.

Yoong, Amanda., and Koritsas, Stella (2012), The impact of caring for adults with intellectual disability on the quality of life of parents. *Journal of Intellectual Disability Research* 56, No. 6: 609-619.

Yu, Xiaomin (2011), Social enterprise in China: driving forces, development patterns and legal framework. *Social Enterprise Journal* **7**, No. 1: 9-32.

Yu, Yunhong., Hu, Jie., Efird, Jimy T., ad McCoy, Thomas P (2013), Social Support, coping strategies and health-related quality of Life among primary carregivers of stroke survivors in China. *Journal of Clinical Nursing* 22, No. 15-16: 2106-2171.

Appendix A: Survivor Quality of Life Scales

Measure	Assesses	Measures
The Health Related Quality of Life Measure	Survivor	Self-perceptions of physical, mental, emotional, family, and social functioning, inclusive of therapeutic effectiveness (Krančiukaitė and Rastenytė 2006)
The Communication Effectiveness Index	Survivor	Post stroke communication effectiveness
The Stroke Survivors Quality of life Scale	Survivor	Communication and others
Stroke and Aphasia Quality of life Scale	Survivor	Same elements as above Communication effectiveness(understanding speech), decision making difficulties, impact of communication difficulties in everyday life interactions
American Speech Language hearing association quality of Communication Life Scale	Survivor	Quality of life for people with mild to moderate communication difficulties
SF-36 (8 domains)	Survivor	Emotional Health Bodily Performance Role-physical, emotional interaction, social functioning Pain General Condition Vigour/vitality
SIP (12 domains)	Survivor	Gregarious interaction, emotional conduct Mobility, ambulation Housekeeping ability - Alertness behaviour Rest/sleep Communication Self-care and mobility, eating
Euroqol (6 domains)	Survivor	Mood (distress/dependency) Mobility Daily practice Pain and discomfort Family and leisure activities Self-maintenance
NHP (6 domains)	Survivor	Emotional, Social Physical Pain - Energy Sleep

Appendix B: Caregiver Quality of Life Scales

Measure	Assesses	Measures
Caregiver reaction Assessment	Caregiver	Caregiver burden Self esteem
Carer communication outcome after stroke test	Caregiver	Carer perspective of post stroke communication in everyday life
13 item caregiver strain index	Caregiver	Strain
22 item challenges of caring for someone who has experienced stroke scale	Caregiver	General strain, isolation, disappointment
15 item oberst caregiving burden scale	Caregiver	Impact of communication difficulties in caring for people with aphasia.
Bakes caregiving outcomes scale	Caregiver	Burden and strain Impact on perceived life satisfaction, psychological social and physical functioning

Appendix C: Stroke Club Information Pack

This pack consists of:

- a letter of invitation;
- an information sheet; and,
- a consent to observe form.

Presented in both Welsh and English.

Ysgol Gwyddorau Cymdeithas
Prifysgol Bangor

Gwynedd LL57 2DG

Ffôn: 07837 689 644
elizabeth.heyworth@bangor.ac.uk
Elusen   Gofrestredig   Rhif:
1141565

School of Social Sciences
Bangor University

Gwynedd LL57 2DG

Phone: 07837 689 644
elizabeth.heyworth@bangor.ac.uk
Registered Charity No: 1141565

Dear [Stroke Club Host]

Life After Stroke in a Rural Area: a case study approach

I am a PhD student at Bangor University. My research project aims to explore the every-day lives and experiences of people who have been affected by Stroke, and their carer(s) including the challenges faced and the types of help and support that are provided. I am writing to invite you to take part in this project by allowing me to observe your Stroke Club. An information sheet about the project is enclosed with this letter.

If you decide that you would like to take part, please complete the **consent form** and return to the University using the freepost envelope enclosed - you do not need to use a stamp.

If you have any questions or would like to know more about the study please do not hesitate to contact Elizabeth Heyworth by telephone on 07837689644 or by email using the following address elizabeth.heyworth@bangor.ac.uk

Thank you for taking the time to read this letter.

I look forward to hearing from you.

Yours faithfully

Miss E M Heyworth

PhD Researcher

Ysgol Gwyddorau Cymdeithas
Prifysgol Bangor

Gwynedd LL57 2DG

Ffôn: 07837 689 644
elizabeth.heyworth@bangor.ac.uk
Elusen   Gofrestredig   Rhif:
1141565

School of Social Sciences
Bangor University

Gwynedd LL57 2DG

Phone: 07837 689 644
elizabeth.heyworth@bangor.ac.uk
Registered Charity No: 1141565

Information Sheet

Life After Stroke in a Rural Area: a case study approach

Information Sheet for Observation of Stroke Club

Introduction

Your Stroke Club is being invited to take part in a research observation. Before you decide whether or not to participate, it is important for you to understand what this will involve. Please take the time to read the following information.

What is the purpose of the study?

This three-year study looks at the everyday lives and experiences of people who have been affected by Stroke living in rural areas. It looks at the challenges people face, as well as the types of help and support offered to people who have been affected by Stroke and their carer(s) (if applicable).

Why has my Stroke Club been chosen for observation?

Your Stroke Club has been invited for observation to provide the researcher with an insight into what happens at your Stroke Club and its members.

Do I have to take part?

It is up to you to decide whether or not to take part in the observation – it is entirely voluntary. Your decision **will not** affect and services or support that you provide. If you decide to take part you should keep this information sheet.

What will happen if I decide to take part?

I will arrange to meet with you at a Stroke Club meeting were I will carry out the observation.

Will my taking part in this study be kept confidential?

All the information you provide about yourself and the people within your Stroke Club will be treated in the **strictest confidence.**

What will happen if I don't want to carry on with the study?

You are free to withdraw from the study at any time and you do not have to give a reason for this. If you decide to withdraw, your decision **will not** affect any services or support that you provide.

What will happen to the results of the study?

The findings from this study will provide useful insights into the experiences and support needs of people who have been affected by Stroke in Wales.

You will receive feedback sheets that describe some of the key findings.

Who is organising and funding the research?

The research is being funded by Bangor University, and organised by Elizabeth Heyworth (PhD Researcher) with supervisory support from Dr Catherine Robinson and Dr Diane Seddon.

Contact for further information

If you have any questions or would like to know more about the study please do not hesitate to contact Elizabeth Heyworth by telephone on 07837689644 or by email using the following address e.heyworth@bangor.ac.uk

You may also contact the Project Supervisor, Dr Catherine Robinson by telephone: 07808 362 613 or email: Catherine.robinson@bangor.ac.uk

Next steps

If you decide that you would like to take part, please complete and return the **consent form** in the freepost envelope provided. Once we have received this, the researcher will be in touch to arrange a convenient time for the observation to take place.

Thank you for taking the time to read this information.

Life After Stroke in a Rural Area: a case study approach

Consent for Conduct Observation

Please tick the boxes that apply to you.

o   I confirm that I have read and understand the information sheet for this study

o   I understand that my participation is voluntary and that I am free to withdraw without giving any reason.

Name:

Address:

Post code:

Telephone number:

Email:

Signature:

Date:

Please return this form in the freepost envelope. Thank you.

Ysgol Gwyddorau Cymdeithas
Prifysgol Bangor

Gwynedd LL57 2DG

Ffôn: 07837 689 644
elizabeth.heyworth@bangor.ac.uk
Elusen   Gofrestredig   Rhif:
1141565

School of Social Sciences
Bangor University

Gwynedd LL57 2DG

Phone: 07837 689 644
elizabeth.heyworth@bangor.ac.uk
Registered Charity No: 1141565

Bywyd ar ôl Strôc mewn Ardal Wledig: Astudiaeth achos

Annwyl

Rwy'n fyfyriwr PhD ym Mhrifysgol Bangor. Amcan fy mhroject ymchwil yw edrych ar fywydau a phrofiadau bob dydd pobl y mae Strôc wedi effeithio arnynt, a'u gofalwr/gofalwyr (os yw hynny'n berthnasol), yn cynnwys y sialensiau y maent yn eu hwynebu a'r mathau o gymorth a chefnogaeth sydd ar gael iddynt. Rwy'n ysgrifennu atoch i'ch gwahodd i gymryd rhan yn y project yma drwy ganiatáu i mi ddod i'ch Clwb Strôc i'w weld ar waith. Amgaeir taflen wybodaeth am y project gyda'r llythyr hwn.

Os penderfynwch yr hoffech gymryd rhan, a fyddech cystal â llenwi'r **ffurflen gydsynio** a'i dychwelyd i'r Brifysgol gan ddefnyddio'r amlen radbost amgaeedig - nid oes angen i chi ddefnyddio stamp.

Os oes gennych unrhyw gwestiynau, neu os hoffech wybod mwy am yr astudiaeth, mae pob croeso i chi gysylltu ag Elizabeth Heyworth drwy ffonio 07837689644 neu anfon e-bost at elizabeth.heyworth@bangor.ac.uk

Diolch yn fawr am roi eich amser i ddarllen y llythyr hwn.

Edrychaf ymlaen at glywed oddi wrthych.

Yn gywir

Miss E M Heyworth

Ymchwilydd PhD

Taflen Wybodaeth

Bywyd ar ôl Strôc mewn Ardal Wledig: Astudiaeth achos

Taflen Wybodaeth ar Arsylwi Clwb Strôc

Rhagarweiniad

Gwahoddir eich Clwb Strôc i gymryd rhan mewn astudiaeth ymchwil. Cyn penderfynu a ydych am gymryd rhan neu beidio, mae'n bwysig eich bod yn deall beth fydd hyn yn ei olygu. A fyddech cystal â rhoi ychydig amser i ddarllen y wybodaeth ganlynol.

Beth yw pwrpas yr astudiaeth?

Mae'r astudiaeth dair blynedd hon yn edrych ar fywydau a phrofiadau bob dydd pobl sydd wedi cael Strôc ac sy'n byw mewn ardaloedd gwledig.   Mae'n edrych ar y sialensiau y mae pobl yn eu hwynebu, yn ogystal â'r mathau o help a chefnogaeth a gynigir i bobl sydd wedi cael Strôc a'u gofalwr/gofalwyr (os yw hynny'n berthnasol).

Pam mae fy Nghlwb Strôc i wedi cael ei ddewis?

Dewiswyd eich Clwb Strôc chi oherwydd hoffai'r ymchwilydd ddod i'ch Clwb Strôc i weld beth sy'n digwydd yn eich Clwb ac i'r aelodau.

Oes rhaid i mi gymryd rhan?

Chi sydd i benderfynu a ydych am gymryd rhan neu beidio – mae'n hollol wirfoddol. **Ni fydd** eich penderfyniad yn effeithio ar y gwasanaethau neu'r gefnogaeth rydych yn eu darparu.   Os penderfynwch gymryd ran, dylech gadw'r daflen wybodaeth hon.

Beth fydd yn digwydd os cymeraf ran?

Byddaf yn trefnu i gyfarfod â chi mewn cyfarfod o'r Clwb Strôc lle byddaf yn edrych ar yr hyn sy'n digwydd yno.

Fydd y ffaith fy mod i'n cymryd rhan yn yr astudiaeth hon yn cael ei chadw'n gyfrinachol?

Bydd yr holl wybodaeth a roddwch amdanoch eich hun a'r bobl yn eich Clwb Strôc yn cael ei thrin yn **hollol gyfrinachol.**

Beth fydd yn digwydd os nad ydw i am barhau â'r astudiaeth?

Gellwch dynnu'n ôl o'r astudiaeth ar unrhyw adeg ac nid oes rhaid i chi roi rheswm am hynny. Os penderfynwch dynnu'n ôl, **ni fydd** eich penderfyniad yn effeithio ar y gwasanaethau neu'r gefnogaeth rydych yn eu darparu.

Beth fydd yn digwydd i ganlyniadau'r astudiaeth?

Bydd darganfyddiadau o'r astudiaeth hon yn rhoi golwg ddefnyddiol ar brofiadau ac anghenion cefnogaeth pobl yn ardaloedd gwledig Gogledd Cymru y mae Strôc wedi effeithio arnynt.

Byddwch yn derbyn taflenni'n disgrifio rhai o'r darganfyddiadau allweddol.

Pwy sy'n trefnu ac yn ariannu'r ymchwil?

Cyllidir yr ymchwil gan Brifysgol Bangor a chaiff ei threfnu gan Elizabeth Heyworth (Ymchwilydd PhD) gyda chefnogaeth oruchwyliol gan Dr Catherine Robinson a Dr Diane Seddon.

Cyswllt ar gyfer gwybodaeth bellach

Os oes gennych unrhyw gwestiynau, neu os hoffech wybod mwy am yr astudiaeth, mae pob croeso i chi gysylltu ag Elizabeth Heyworth drwy ffonio 07837 689 644 neu anfon e-bost at elizabeth.heyworth@bangor.ac.uk

Gellwch gysylltu hefyd â Goruchwyliwr y Project, Dr Catherine Robinson, drwy ffonio: 07808 362 613 neu e-bostiwch: catherine.robinson@bangor.ac.uk

Camau nesaf

Os penderfynwch yr hoffech gymryd rhan, a fyddech cystal â llenwi'r **ffurflen gydsynio** a'i dychwelyd gan ddefnyddio'r amlen radbost. Unwaith y byddwn wedi derbyn hon, bydd yr ymchwilydd yn cysylltu â chi i drefnu amser cyfleus i gynnal y arsylwi.

Diolch i chi am gymryd amser i ddarllen y wybodaeth hon.

Bywyd ar ôl Strôc mewn Ardal Wledig: Astudiaeth achos

Caniatâd i Arsylwi Ymddygiad

Ticiwch y bocsys sy'n berthnasol i chi

o Rwy'n cadarnhau fy mod wedi darllen a deall y daflen wybodaeth ar gyfer yr astudiaeth hon.

o Rwy'n deall mai fy newis i yw cymryd rhan ai peidio, a bod gennyf hawl i dynnu'n ôl unrhyw bryd heb roi rheswm.

Enw:

Cyfeiriad:

Cod post:

Rhif ffôn:

E-bost:

Llofnod:

Dyddiad:

Dychwelwch y ffurflen hon yn yr amlen radbost a ddarperir. Diolch yn fawr.

Appendix D: Case Study Participant Information Pack

Each pack consisted of:

- a letter of invitation;

- an information sheet;

- a consent for Interview form; and,

- a postage paid envelope for return of signed forms to the author.

Presented in both Welsh and English.

Ysgol Gwyddorau Cymdeithas
Prifysgol Bangor

Gwynedd LL57 2DG

Ffôn: 07837 689 644
elizabeth.heyworth@bangor.ac.uk
Elusen   Gofrestredig   Rhif:
1141565

School of Social Sciences
Bangor University

Gwynedd LL57 2DG

Phone: 07837 689 644
elizabeth.heyworth@bangor.ac.uk
Registered Charity No: 1141565

Dear Potential Participant

Life After Stroke in a Rural Area: a case study approach

I am a PhD student at Bangor University. My research project aims to explore the every-day lives and experiences of people who have been affected by Stroke, and their carer(s) (if applicable including the challenges faced and the types of help and support that are provided). I am writing to invite you to take part in this project and share your experiences. An information sheet about the project is enclosed with this letter.

If you decide that you would like to take part, please complete the **consent form** and return to the University using the freepost envelope enclosed - you do not need to use a stamp.

If you have any questions or would like to know more about the study please do not hesitate to contact Elizabeth Heyworth by telephone on 07837689644 or by email using the following address elizabeth.heyworth@bangor.ac.uk

Thank you for taking the time to read this letter.

I look forward to hearing from you.

Yours faithfully

Miss E M Heyworth

PhD Researcher

Ysgol Gwyddorau Cymdeithas
Prifysgol Bangor

Gwynedd LL57 2DG

Ffôn: 07837 689 644
elizabeth.heyworth@bangor.ac.uk
Elusen Gofrestredig Rhif: 1141565

School of Social Sciences
Bangor University

Gwynedd LL57 2DG

Phone: 07837 689 644
elizabeth.heyworth@bangor.ac.uk
Registered Charity No: 1141565

Life After Stroke in a Rural Area: a case study approach

Information Sheet Face to Face Interviews – Individual who has been affected by Stroke

Introduction

You are being invited to take part in a research project. Before you decide whether or not to participate, it is important for you to understand what this will involve. Please take the time to read the following information and discuss it with your relatives and friends if you wish.

What is the purpose of the study?

This three-year study looks at the everyday lives and experiences of people who have been affected by Stroke living in rural areas. It looks at the challenges people face, as well as the types of help and support offered to people who have been affected by Stroke and their carer(s).

Why have I been chosen for interview?

You have been invited for interview because (name of organisation) has distributed study packs to support and assist the researcher in participant recruitment.

Do I have to take part?

It is up to you to decide whether or not to take part in the interview – it is entirely voluntary. Your decision **will not** affect the standard of care and services you or the person who helps to look after you receive. If you decide to take part you should keep this information sheet.

What will happen if I decide to take part?

The researcher will arrange to meet with you to complete an interview, which will take about one hour. This interview can take place in your own home or at a mutually agreeable venue, during the day-time or in the evening. It will be conducted in the English language. During the interview you will be asked to share your experiences and describe any support you may receive. A second interview will also take place in approximately six months time.

Will my taking part in this study be kept confidential?

All the information you provide about yourself and the person who helps to look after you will be treated in the **strictest confidence.** Neither you nor the person who helps to look after you will be identified in any reports or publications.

In the (perhaps unlikely) event of a loss of capacity, the researcher would retain personal data collected and continue to use it confidentially in connection with the purposes for which consent is given.

What will happen if I don't want to carry on with the study?

You are free to withdraw from the study at any time and you do not have to give a reason for this. If you decide to withdraw, your decision **will not** affect the standard of care and services you or the person who helps to look after you receive.

What will happen to the results of the study?

The findings from this study will provide useful insights into the experiences and support needs of people who have been affected by Stroke in Wales.

You will receive feedback sheets that describe some of the key findings.

Who is organising and funding the research?

The research is being funded by Bangor University, and organised by Elizabeth Heyworth (PhD Researcher) with supervisory support from Dr Catherine Robinson and Dr Diane Seddon.

Contact for further information

If you have any questions or would like to know more about the study please do not hesitate to contact Elizabeth Heyworth by telephone on 07837689644 or by email using the following address elizabeth.heyworth@bangor.ac.uk

You may also contact the Project Supervisor, Dr Catherine Robinson by telephone: 07808 362 613 or email: catherine.robinson@bangor.ac.uk

Next steps

If you decide that you would like to take part, please complete and return the **consent form** in the freepost envelope provided. Once we have received this, Elizabeth Heyworth will be in touch to arrange a convenient time for the interview to take place.

Thank you for taking the time to read this information.

Ysgol Gwyddorau Cymdeithas
Prifysgol Bangor

Gwynedd LL57 2DG

Ffôn: 07837 689 644
elizabeth.heyworth@bangor.ac.uk
Elusen   Gofrestredig   Rhif:
1141565

School of Social Sciences
Bangor University

Gwynedd LL57 2DG

Phone: 07837 689 644
elizabeth.heyworth@bangor.ac.uk
Registered Charity No: 1141565

Life After Stroke in a Rural Area: a case study approach

Consent to Interview Form

Please tick the boxes that apply to you.

o   I confirm that I have read and understand the information sheet for this study

o   I understand that my participation is voluntary and that I am free to withdraw without giving any

     reason

o   I understand that the interviews will be conducted in English.

Name:

Address:

Post code:

Telephone number:

Email:

Signature:

Date:

Please return this form in the freepost envelope. Thank you.

Ysgol Gwyddorau Cymdeithas
Prifysgol Bangor

Gwynedd LL57 2DG

Ffôn: 07837 689 644
elizabeth.heyworth@bangor.ac.uk
Elusen   Gofrestredig   Rhif:
1141565

School of Social Sciences
Bangor University

Gwynedd LL57 2DG

Phone: 07837 689 644
elizabeth.heyworth@bangor.ac.uk
Registered Charity No: 1141565

Annwyl Cyfranogwr Potensial

Bywyd mewn ardal wledig ar ôl strôc: astudiaeth achos

Rwy'n fyfyrwraig PhD ym Mhrifysgol Bangor. Nod fy astudiaeth ymchwil yw edrych ar brofiadau a bywydau pob dydd pobl sydd wedi cael strôc a'u gofalwyr (os yn berthnasol, yn cynnwys yr heriau y maent yn eu hwynebu a'r math o gymorth a chefnogaeth a ddarperir iddynt). Ysgrifennaf atoch i'ch gwahodd i gymryd rhan yn yr astudiaeth hon a rhannu'ch profiadau. Amgaeaf daflen wybodaeth am yr astudiaeth gyda'r llythyr hwn.

Os penderfynwch yr hoffech gymryd rhan, a fyddech cystal â llenwi'r **ffurflen gydsynio** a'i hanfon yn ôl i'r Brifysgol gan ddefnyddio'r amlen radbost amgaeedig – nid oes angen stamp.
Os oes gennych unrhyw gwestiynau, neu os hoffech wybod mwy am yr astudiaeth, mae croeso i chi gysylltu ag Elizabeth Heyworth ar 07837689644 neu drwy'r cyfeiriad e-bost canlynol: elizabeth.heyworth@bangor.ac.uk

Diolch yn fawr am roi o'ch amser i ddarllen hwn.
Edrychaf ymlaen at glywed gennych.

Yn gywir

Miss E M Heyworth
Ymchwilydd PhD

Ysgol Gwyddorau Cymdeithas
Prifysgol Bangor

Gwynedd LL57 2DG

Ffôn: 07837 689 644
elizabeth.heyworth@bangor.ac.uk
Elusen   Gofrestredig   Rhif:
1141565

School of Social Sciences
Bangor University

Gwynedd LL57 2DG

Phone: 07837 689 644
elizabeth.heyworth@bangor.ac.uk
Registered Charity No: 1141565

Bywyd mewn ardal wledig ar ôl strôc: astudiaeth achos

Taflen wybodaeth i gyfweliadau wyneb yn wyneb – unigolion sydd wedi cael strôc
Cyflwyniad

Gwahoddir chi i gymryd rhan mewn astudiaeth ymchwil. Cyn penderfynu a ydych am gymryd rhan neu beidio, mae'n bwysig eich bod yn deall yr hyn y bydd yn ei olygu. A fyddech cystal â darllen y wybodaeth ganlynol a'i thrafod gyda'ch perthnasau a'ch ffrindiau os ydych yn dymuno.

Beth yw diben yr astudiaeth?
Nod yr astudiaeth dair blynedd hon yw edrych ar fywydau a phrofiadau pobl sy'n byw mewn ardal wledig ac sydd wedi cael strôc. Mae'n edrych ar yr heriau y mae pobl yn eu hwynebu, yn ogystal â'r math o gymorth a chefnogaeth a gynigir i bobl sydd wedi cael strôc a'u gofalwyr.

Pam ydw i wedi cael fy newis am gyfweliad?
Gwahoddwyd chi i gael cyfweliad oherwydd bod (name of organisation) wedi dosbarthu pecynnau am yr astudiaeth i gynorthwyo'r ymchwilydd i recriwtio pobl i gymryd rhan yn yr astudiaeth.

A oes rhaid i mi gymryd rhan?
Chi sydd i benderfynu a ydych eisiau cymryd rhan yn y cyfweliad – mae'n hollol wirfoddol. **Ni fydd** eich penderfyniad yn cael unrhyw effaith ar safon y gofal a'r gwasanaethau rydych chi, neu'r sawl sy'n gofalu amdanoch, yn eu derbyn. Os penderfynwch gymryd ran, dylech gadw'r daflen wybodaeth hon.

Beth fydd yn digwydd os penderfynaf gymryd rhan?

Bydd yr ymchwilydd yn trefnu i gyfarfod gyda chi i gynnal cyfweliad, a fydd yn cymryd oddeutu awr. Gellir cynnal y cyfweliad hwn yn eich cartref eich hun neu mewn lleoliad sy'n gyfleus i bawb, yn ystod y dydd neu gyda'r nos. Cynhelir y cyfweliad yn Saesneg. Yn ystod y cyfweliad, gofynnir i chi rannu'ch profiadau a disgrifio unrhyw gefnogaeth rydych yn ei chael. Cynhelir ail gyfweliad ymhen tua chwe mis.

A fydd y ffaith fy mod yn cymryd rhan yn yr astudiaeth hon yn cael ei chadw'n gyfrinachol?

Bydd yr holl wybodaeth a roddwch amdanoch eich hun a'r sawl sy'n gofalu amdanoch yn cael ei thrin yn **hollol gyfrinachol**. Ni fyddwch chi, na'r sawl sy'n gofalu amdanoch, yn cael ei enwi mewn unrhyw adroddiadau na chyhoeddiadau.

Pe baech yn methu â pharhau oherwydd eich iechyd (sydd efallai'n annhebygol), byddai'r tîm ymchwil yn cadw'r data personol a gasglwyd gennych ac yn parhau i'w ddefnyddio yn gyfrinachol i'r dibenion a ganiatawyd.

Beth fydd yn digwydd os nad wyf eisiau parhau â'r astudiaeth?

Gallwch dynnu'n ôl o'r astudiaeth ar unrhyw adeg heb roi rheswm am hynny. Os byddwch yn penderfynu tynnu'n ôl, **ni fydd** eich penderfyniad yn cael unrhyw effaith ar safon y gofal a'r gwasanaethau rydych chi, neu'r sawl sy'n gofalu amdanoch, yn eu derbyn.

Beth fydd yn digwydd i ganlyniadau'r astudiaeth?

Bydd canfyddiadau'r astudiaeth yn rhoi gwybodaeth ddefnyddiol i ni am brofiadau ac anghenion pobl yng nghefn gwlad gogledd Cymru sydd wedi cael strôc.

Cewch daflenni adborth fydd yn disgrifio rhai o'r prif ganfyddiadau.

Pwy sy'n trefnu ac yn ariannu'r ymchwil?

Ariannir yr astudiaeth gan Brifysgol Bangor ac fe'i trefnir gan Elizabeth Heyworth (ymchwilydd PhD) dan oruchwyliaeth Dr Catherine Robinson a Dr Diane Seddon.

Manylion cysylltu i gael rhagor o wybodaeth

Os oes gennych unrhyw gwestiynau, neu os hoffech wybod mwy am yr astudiaeth, mae croeso i chi gysylltu ag Elizabeth Heyworth ar 07837689644 neu drwy'r cyfeiriad e-bost canlynol: elizabeth.heyworth@bangor.ac.uk

Gallwch hefyd gysylltu â goruchwyliwr y project, Dr Catherine Robinson, ffôn: 07808362613 neu e-bost: catherine.robinson@bangor.ac.uk

Camau nesaf

Os penderfynwch yr hoffech gymryd rhan, dylech lenwi'r **ffurflen gydsynio** a'i dychwelyd gan ddefnyddio'r amlen radbost. Ar ôl i ni dderbyn hon, bydd Elizabeth Heyworth yn cysylltu â chi i drefnu amser cyfleus i gynnal y cyfweliad.

Diolch i chi am roi o'ch amser i ddarllen y daflen hon.

Ysgol Gwyddorau Cymdeithas
Prifysgol Bangor

Gwynedd LL57 2DG

Ffôn: 07837 689 644
elizabeth.heyworth@bangor.ac.uk
Elusen   Gofrestredig   Rhif:
1141565

School of Social Sciences
Bangor University

Gwynedd LL57 2DG

Phone: 07837 689 644
elizabeth.heyworth@bangor.ac.uk
Registered Charity No: 1141565

Bywyd mewn ardal wledig ar ôl strôc: astudiaeth achos

Ffurflen gydsynio i gyfweliad

Ticiwch y bocsys sy'n berthnasol i chi.

o Rwy'n cadarnhau fy mod wedi darllen a deall y daflen wybodaeth ar gyfer yr astudiaeth hon.

o Rwy'n deall fy mod yn cymryd rhan o'm gwirfodd, ac y gallaf dynnu'n ôl heb roi rheswm.

o Rwy'n deall y bydd y cyfweliad yn cael ei gynnal yn Saesneg.

Enw:

Cyfeiriad:

Cod post:

Rhif ffôn:

E-bost:

Llofnod:

Dyddiad:

Anfonwch y ffurflen hon yn ôl yn yr amlen radbost. Diolch yn fawr.

Ysgol Gwyddorau Cymdeithas
Prifysgol Bangor

Gwynedd LL57 2DG

Ffôn: 07837 689 644
elizabeth.heyworth@bangor.ac.uk
Elusen   Gofrestredig   Rhif:
1141565

School of Social Sciences
Bangor University

Gwynedd LL57 2DG

Phone: 07837 689 644
elizabeth.heyworth@bangor.ac.uk
Registered Charity No: 1141565

Dear Potential Participant

Life After Stroke in a Rural Area: a case study approach

I am a PhD student at Bangor University. My research project aims to explore the every-day lives and experiences of people who have been affected by Stroke, and their carer(s) (if applicable including the challenges faced and the types of help and support that are provided). I am writing to invite you to take part in this project and share your experiences. An information sheet about the project is enclosed with this letter.

If you decide that you would like to take part, please complete the **consent form** and return to the University using the freepost envelope enclosed - you do not need to use a stamp.

If you have any questions or would like to know more about the study please do not hesitate to contact Elizabeth Heyworth by telephone on 07837689644 or by email using the following address elizabeth.heyworth@bangor.ac.uk

Thank you for taking the time to read this letter.

I look forward to hearing from you.

Yours faithfully

Miss E M Heyworth
PhD Researcher

Ysgol Gwyddorau Cymdeithas
Prifysgol Bangor

Gwynedd LL57 2DG

Ffôn: 07837 689 644
elizabeth.heyworth@bangor.ac.uk
Elusen   Gofrestredig   Rhif:
1141565

School of Social Sciences
Bangor University

Gwynedd LL57 2DG

Phone: 07837 689 644
elizabeth.heyworth@bangor.ac.uk
Registered Charity No: 1141565

Life After Stroke in a Rural Area: a case study approach
Information Sheet for Face to Face Interviews – Carers

Introduction

You are being invited to take part in a research interview. Before you decide whether or not to participate, it is important for you to understand what this will involve. Please take the time to read the following information and discuss it with your relatives and friends if you wish.

What is the purpose of the study?

This three-year study looks at the everyday lives and experiences of people who have been affected by Stroke living in rural areas. It looks at the challenges people face, as well as the types of help and support offered to people who have been affected by Stroke and their carer(s).

Why have I been chosen for interview?

You have been invited to interview because a person in your care kindly responded to the researchers call for participants, and gave permission for you to be contacted. We will be interviewing a number of individuals to ask them about their experiences.

Do I have to take part?

It is up to you to decide whether or not to take part in the interview – it is entirely voluntary. Your decision **will not** affect and services or support that you receive. If you decide to take part you should keep this information sheet.

What will happen if I decide to take part?

The researcher will arrange to meet with you to complete an interview, which will take about one hour. This interview can take place in your own home or at a mutually agreeable venue, during the day-time or in the evening. It will be conducted in the English language. During the interview you will be asked to share your experiences and describe any support you might receive. A second interview will also take place in approximately six months time.

Will my taking part in this study be kept confidential?

All the information you provide about yourself and the person in your care will be treated in the **strictest confidence.** Neither you nor the person in your care will be identified in any reports or publications.

In the (perhaps unlikely) event of a loss of capacity, the research team would retain personal data collected and continue to use it confidentially in connection with the purposes for which consent is given.

What will happen if I don't want to carry on with the study?

You are free to withdraw from the study at any time and you do not have to give a reason for this. If you decide to withdraw, your decision **will not** affect any services or support that you receive.

What will happen to the results of the study?

The findings from this study will provide useful insights into the experiences and support needs of people who have been affected by Stroke in Wales and their carers.
You will receive feedback sheets that describe some of the key findings.

Who is organising and funding the research?

The research is being funded by Bangor University, and organised by Elizabeth Heyworth (PhD Researcher) with supervisory support from Dr Catherine Robinson and Dr Diane Seddon.

Contact for further information

If you have any questions or would like to know more about the study please do not hesitate to contact Elizabeth Heyworth by telephone on 07837689644 or by email using the following address elizabeth.heyworth@bangor.ac.uk
You may also contact the Project Supervisor, Dr Catherine Robinson by telephone: 07808 362 613 or email: catherine.robinson@bangor.ac.uk

Next steps

If you decide that you would like to take part, please complete and return the **consent form** in the freepost envelope provided. Once we have received this, Elizabeth Heyworth will be in touch to arrange a convenient time for the interview to take place.

<div align="center">**Thank you for taking the time to read this information.**</div>

Ysgol Gwyddorau Cymdeithas
Prifysgol Bangor

Gwynedd LL57 2DG

Ffôn: 07837 689 644
elizabeth.heyworth@bangor.ac.uk
Elusen   Gofrestredig   Rhif:
1141565

School of Social Sciences
Bangor University

Gwynedd LL57 2DG

Phone: 07837 689 644
elizabeth.heyworth@bangor.ac.uk
Registered Charity No: 1141565

Life After Stroke in a Rural Area: a case study approach

Consent to Interview Form

Please tick the boxes that apply to you.

o I confirm that I have read and understand the information sheet for this study

o I understand that my participation is voluntary and that I am free to withdraw without giving any reason

o I understand that the interviews will be conducted in English.

Name:

Address:

Post code:

Telephone number:

Email:

Signature:

Date:

Please return this form in the freepost envelope. Thank you.

Ysgol Gwyddorau Cymdeithas
Prifysgol Bangor

Gwynedd LL57 2DG

Ffôn: 07837 689 644
elizabeth.heyworth@bangor.ac.uk
Elusen   Gofrestredig   Rhif:
1141565

School of Social Sciences
Bangor University

Gwynedd LL57 2DG

Phone: 07837 689 644
elizabeth.heyworth@bangor.ac.uk
Registered Charity No: 1141565

Annwyl Cyfranogwr Potensial

Bywyd mewn ardal wledig ar ôl strôc: astudiaeth achos

Rwy'n fyfyrwraig PhD ym Mhrifysgol Bangor. Nod fy astudiaeth ymchwil yw edrych ar brofiadau a bywydau pob dydd pobl sydd wedi cael strôc a'u gofalwyr (os yn berthnasol, yn cynnwys yr heriau y maent yn eu hwynebu a'r math o gymorth a chefnogaeth a ddarperir iddynt). Ysgrifennaf atoch i'ch gwahodd i gymryd rhan yn yr astudiaeth hon a rhannu'ch profiadau. Amgaeaf daflen wybodaeth am yr astudiaeth gyda'r llythyr hwn.

Os penderfynwch yr hoffech gymryd rhan, a fyddech cystal â llenwi'r **ffurflen gydsynio** a'i hanfon yn ôl i'r Brifysgol gan ddefnyddio'r amlen radbost amgaeedig – nid oes angen stamp.

Os oes gennych unrhyw gwestiynau, neu os hoffech wybod mwy am yr astudiaeth, mae croeso i chi gysylltu ag Elizabeth Heyworth ar 07837689644 neu drwy'r cyfeiriad e-bost canlynol: elizabeth.heyworth@bangor.ac.uk

Diolch yn fawr am roi o'ch amser i ddarllen hwn.

Edrychaf ymlaen at glywed gennych.

Yn gywir

Miss E M Heyworth
Ymchwilydd PhD

Ysgol Gwyddorau Cymdeithas
Prifysgol Bangor

Gwynedd LL57 2DG

Ffôn: 07837 689 644
elizabeth.heyworth@bangor.ac.uk
Elusen   Gofrestredig   Rhif:
1141565

School of Social Sciences
Bangor University

Gwynedd LL57 2DG

Phone: 07837 689 644
elizabeth.heyworth@bangor.ac.uk
Registered Charity No: 1141565

Bywyd mewn ardal wledig ar ôl strôc: astudiaeth achos

Taflen wybodaeth i gyfweliadau wyneb yn wyneb - gofalwyr
Cyflwyniad
Gwahoddir chi i gymryd rhan mewn cyfweliad ymchwil. Cyn penderfynu a ydych am gymryd rhan neu beidio, mae'n bwysig eich bod yn deall yr hyn y bydd yn ei olygu. A fyddech cystal â darllen y wybodaeth ganlynol a'i thrafod gyda'ch perthnasau a'ch ffrindiau os ydych yn dymuno.

Beth yw diben yr astudiaeth?
Nod yr astudiaeth dair blynedd hon yw edrych ar fywydau a phrofiadau pobl sy'n byw mewn ardal wledig ac sydd wedi cael strôc. Mae'n edrych ar yr heriau y mae pobl yn eu hwynebu, yn ogystal â'r math o gymorth a chefnogaeth a gynigir i bobl sydd wedi cael strôc a'u gofalwyr.

Pam ydw i wedi cael fy newis am gyfweliad?
Gwahoddwyd chi i gael cyfweliad oherwydd bod rhywun sydd yn eich gofal wedi ymateb i alwad ein hymchwilwyr am gyfranogwyr gan roi caniatâd i ni gysylltu â chi. Byddwn yn cyfweld nifer o unigolion er mwyn eu holi am eu profiadau.

A oes rhaid i mi gymryd rhan?
Chi sydd i benderfynu a ydych eisiau cymryd rhan yn y cyfweliad – mae'n hollol wirfoddol. **Ni fydd** eich penderfyniad yn effeithio ar y gwasanaethau na'r gefnogaeth rydych yn eu derbyn. Os penderfynwch gymryd ran, dylech gadw'r daflen wybodaeth hon.

Beth fydd yn digwydd os penderfynaf gymryd rhan?
Bydd yr ymchwilydd yn trefnu i gyfarfod gyda chi i gynnal cyfweliad, a fydd yn cymryd oddeutu awr. Gellir cynnal y cyfweliad hwn yn eich cartref eich hun neu mewn lleoliad sy'n gyfleus i bawb, yn ystod y dydd neu gyda'r nos. Cynhelir y cyfweliad yn Saesneg. Yn ystod y

cyfweliad, gofynnir i chi rannu'ch profiadau a disgrifio unrhyw gefnogaeth rydych yn ei chael. Cynhelir ail gyfweliad ymhen tua chwe mis.

A fydd y ffaith fy mod yn cymryd rhan yn yr astudiaeth hon yn cael ei chadw'n gyfrinachol?

Bydd yr holl wybodaeth a roddwch amdanoch eich hun a'r sawl sydd yn eich gofal yn cael ei thrin yn **hollol gyfrinachol**. Ni fyddwch chi, na'r sawl sydd yn eich gofal, yn cael ei enwi mewn unrhyw adroddiadau na chyhoeddiadau.

Pe baech yn methu â pharhau oherwydd eich iechyd (sydd efallai'n annhebygol), byddai'r tîm ymchwil yn cadw'r data personol a gasglwyd gennych ac yn parhau i'w ddefnyddio yn gyfrinachol i'r dibenion a ganiatawyd.

Beth fydd yn digwydd os nad wyf eisiau parhau â'r astudiaeth?

Gallwch dynnu'n ôl o'r astudiaeth ar unrhyw adeg heb roi rheswm am hynny. Os byddwch yn penderfynu tynnu'n ôl, **ni fydd** eich penderfyniad yn effeithio ar y gwasanaethau na'r gefnogaeth rydych yn eu derbyn.

Beth fydd yn digwydd i ganlyniadau'r astudiaeth?

Bydd canfyddiadau'r astudiaeth yn rhoi gwybodaeth ddefnyddiol i ni am brofiadau ac anghenion pobl yng nghefn gwlad gogledd Cymru sydd wedi cael strôc a'u gofalwyr.

Cewch daflenni adborth fydd yn disgrifio rhai o'r prif ganfyddiadau.

Pwy sy'n trefnu ac yn ariannu'r ymchwil?

Ariannir yr astudiaeth gan Brifysgol Bangor ac fe'i trefnir gan Elizabeth Heyworth (ymchwilydd PhD) dan oruchwyliaeth Dr Catherine Robinson a Dr Diane Seddon.

Manylion cysylltu i gael rhagor o wybodaeth

Os oes gennych unrhyw gwestiynau, neu os hoffech wybod mwy am yr astudiaeth, mae croeso i chi gysylltu ag Elizabeth Heyworth ar 07837689644 neu drwy'r cyfeiriad e-bost canlynol: elizabeth.heyworth@bangor.ac.uk

Gallwch hefyd gysylltu â goruchwyliwr y project, Dr Catherine Robinson, ffôn: 07808362613 neu e-bost: catherine.robinson@bangor.ac.uk

Camau nesaf

Os penderfynwch yr hoffech gymryd rhan, dylech lenwi'r **ffurflen gydsynio** a'i dychwelyd gan ddefnyddio'r amlen radbost. Ar ôl i ni dderbyn hon, bydd Elizabeth Heyworth yn cysylltu â chi i drefnu amser cyfleus i gynnal y cyfweliad.

Diolch i chi am roi o'ch amser i ddarllen y wybodaeth hon.

Ysgol Gwyddorau Cymdeithas
Prifysgol Bangor

Gwynedd LL57 2DG

Ffôn: 07837 689 644
elizabeth.heyworth@bangor.ac.uk
Elusen   Gofrestredig   Rhif:
1141565

School of Social Sciences
Bangor University

Gwynedd LL57 2DG

Phone: 07837 689 644
elizabeth.heyworth@bangor.ac.uk
Registered Charity No: 1141565

Bywyd mewn ardal wledig ar ôl strôc: astudiaeth achos

Ffurflen gydsynio i gyfweliad

Ticiwch y bocsys sy'n berthnasol i chi.

o   Rwy'n cadarnhau fy mod wedi darllen a deall y daflen wybodaeth ar gyfer yr astudiaeth hon.

o   Rwy'n deall fy mod yn cymryd rhan o'm gwirfodd, ac y gallaf dynnu'n ôl heb roi rheswm.

o   Rwy'n deall y bydd y cyfweliad yn cael ei gynnal yn Saesneg.

Enw:

Cyfeiriad:

Cod post:

Rhif ffôn:

E-bost:

Llofnod:

Dyddiad:

Anfonwch y ffurflen hon yn ôl yn yr amlen radbost. Diolch yn fawr.

Appendix E: Survivor BNIM Template

Survivor Interview Schedule 1

The interview approach is based on the biographic narrative interpretive method (BNIM) of interview by Wengraf (2009) and will be conducted in three phases: phase 1 elicits individuals personal experiences in their own words; the aim of phase 2 is to clarify any issues and collect more detail about specific incidences or areas of interest in the narrative, and phase 3 allows asking more structured questions.

Before the start of the interview

Familiarise yourself with the protocol
Go through issues around consent (such as recording the interview, awareness of issues around confidentiality, and ability to terminate interview at any time) and assure that the interviewee has signed the consent form.

PHASE 1

Framing

As you know we are interested in the everyday lives and experiences of individuals who have been affected by stroke in rural Wales and their families. In a moment I am going to ask you about any changes which might have happened since my first visit.

Generative question

Can you please tell me about your everyday life since you experienced your stroke: all the events and experiences that are important to you personally".

Additional prompts once interviewee has finished

Is there anything more you would like to add?
Does anything else come to mind?
Thinking back about what you've said so far, is there anything else you'd like to say to make sure I understand fully what you've told me?

CHECK if the interviewee would like a break. Turn off the recorder during breaks.

PHASE 2

Interviewer to select a number of cue phrases from the list made during phase1. The decision of how many cue phrases to use depends partly on the length of phase 1. It is useful to rank the cue phrases. Cue selection should be based on the following: strong emotion words, particular incidence, research aim relevance, or apparently irrelevant remark.
I noted down some key points as you were telling me your story and I would like us to go back and talk about these some more:
You said [cue-phrase 2-6 words]. Can you remember a particular [magic word]... how it all happened

Magic words

Situation, happening, event, incident, occasion, time, day, memory of a moment, unmet need, dissatisfied, example
If the interviewee cannot remember/ give no specific example keep asking; if nothing is forthcoming, ask the negative – *"Can you remember a particular [magic word] when X did not happen?*
CHECK if the interviewee would like a break

PHASE 3 Semi-structured questions

Select the topics very carefully (or adapt as appropriate) from the following list
If the interviewee has already touched on some of the points summarise these and ask if there is anything else to add.
If the interviewee has discussed a topic in detail, do not go over the same ground again
Use phrases such as the following to introduce specific topics:

·   You have already mentioned a number of changes such as………, can you please tell me a bit more about X

·   You have talked about your experiences with…., can you tell me a bit more about X

·   Please tell me a bit more about X

You have kindly told me your story, about your life after you experienced stroke and talked about your experiences. I now have some specific questions that I would like to ask you. There are no right or wrong answers. Please take as long as you like to think about and answer them.

Topics to explore if not mentioned or to explore further

·   Specific challenges faced with changes which may have occurred; employment; housing; undertaking education and training; making friends/socialising, physical challenges;
·   Strategies to cope with change, including support, and the potential value of meeting with other people who have been affected by stroke.

- · Information to help with identified changes and social participation– accessing; assimilating; timeliness; relevance; gaps.
- · Establishing relationships with professionals, discussing their experiences and needs with them.
- · Experiences of assessment – process; focus; involvement in decision-making; perceived sensitivity; aspects of the process that worked well; aspects of the process that were problematic.
- · Services – accessibility; sensitivity; timeliness; effectiveness; integration and coordination; gaps; priorities for development/future services.
- · Support from professional and voluntary organisations.
- · Support from family/friends/peers.
- · Any new unmet needs and how these might be addressed.

More generic questions that might be useful

- · *Based on your experience, how do you feel about service provision and support for the changes you have experienced? Please tell me about any barriers that you have encountered.*
- · *Based on your experience, can you suggest anything that you think would improve service provision to prepare you for **x** change for you, or someone else, in the future?*
- · *Based on your experience, what has been helpful/not helpful for you in terms of services OR what would you have liked but did not get?*
- · *Based on your experience, do you feel that living in a rural area has had any affect on the support you receive, or your recovery? If so, how?*

Closing question

Is there anything else that you would like to tell me or ask me, perhaps something that you were expecting us to talk about that we have not covered?

Debriefing

The recorder should be turned off for the debriefing session. The interviewer might ask if the interview has brought-up any difficult thoughts or feelings.
The interviewer should leave the interviewee on a 'positive note'. If the interviewee is troubled, the interviewer can offer to contact someone on their behalf or stay with them while they contact a friend or other sources of support.

Appendix F: Caregiver BNIM Template

Caregiver Interview Schedule 1

The interview approach is based on the biographical narrative interview method (BNIM) by Wengraf (2009) and will be conducted in three phases: phase 1 elicits individuals personal experiences in their own words; the aim of phase 2 is to clarify any issues and collect more detail about specific incidences or areas of interest in the narrative, and phase 3 allows asking more structured questions.

Before the start of the interview

Familiarise yourself with the protocol
Go through issues around consent (such as recording the interview, awareness of issues around confidentiality, and ability to terminate interview at any time) and assure that the interviewee has signed the consent form

PHASE 1

Framing

As you know we are interested in the everyday lives and experiences of individuals who have been affected by stroke in rural Wales and their families. In a moment I am going to ask you about any changes which might have happened since my first visit.

Generative question

"Could you please tell me in your own words your experience of caring for (survivors name) since they experienced their stroke?"

Additional prompts once interviewee has finished

Is there anything more you would like to add?
Does anything else come to mind?
Thinking back about what you've said so far, is there anything else you'd like to say to make sure I understand fully what you've told me?

CHECK if the interviewee would like a break. Turn off the recorder during breaks.

PHASE 2

Interviewer to select a number of cue phrases from the list made during phase1. The decision of how many cue phrases to use depends partly on the length of phase 1. It is useful to rank the cue phrases. Cue selection should be based on the following: strong emotion words, particular incidence, research aim relevance, or apparently irrelevant remark.

I noted down some key points as you were telling me your story and I would like us to go back and talk about these some more:

You said [cue-phrase 2-6 words]. Can you remember a particular [magic word]… how it all happened

Magic words

Situation, happening, event, incident, occasion, time, day, memory of a moment, unmet need, dissatisfied, example

If the interviewee cannot remember/ give no specific example keep asking; if nothing is forthcoming, ask the negative – *"Can you remember a particular [magic word] when X did not happen?*

CHECK if the interviewee would like a break

PHASE 3 Semi-structured questions

Select the topics very carefully (or adapt as appropriate) from the following list

If the interviewee has already touched on some of the points summarise these and ask if there is anything else to add.

If the interviewee has discussed a topic in detail, do not go over the same ground again

Use phrases such as the following to introduce specific topics:

·   You have already mentioned a number of changes such as………, can you please tell me a bit more about X

·   You have talked about your experiences with…., can you tell me a bit more about X

·   Please tell me a bit more about X

You have kindly told me your story, about your life after you experienced stroke and talked about your experiences. I now have some specific questions that I would like to ask you. There are no right or wrong answers. Please take as long as you like to think about and answer them.

Topics to explore if not mentioned or to explore further

·   Specific challenges faced with changes which may have occurred; employment; housing; undertaking education and training; making friends/socialising, physical challenges;

·   Strategies to cope with change, including support, and the potential value of meeting with other people who have been affected by stroke.

·   Information to help with identified changes and social participation– accessing; assimilating; timeliness; relevance; gaps.

·	Establishing relationships with professionals, discussing their experiences and needs with them.
·	Experiences of assessment – process; focus; involvement in decision-making; perceived sensitivity; aspects of the process that worked well; aspects of the process that were problematic.
·	Services – accessibility; sensitivity; timeliness; effectiveness; integration and coordination; gaps; priorities for development/future services.
·	Support from professional and voluntary organisations.
·	Support from family/friends/peers.
·	Any new unmet needs and how these might be addressed.

More generic questions that might be useful

·	*Based on your experience, how do you feel about service provision and support for the changes you have experienced? Please tell me about any barriers that you have encountered.*
·	*Based on your experience, can you suggest anything that you think would improve service provision to prepare you for **x** change for you, or someone else, in the future?*
·	*Based on your experience, what has been helpful/not helpful for you in terms of services OR what would you have liked but did not get?*
·	*Based on your experience, do you feel that living in a rural area has had any affect on the support you receive, or your recovery? If so, how?*

Closing question

Is there anything else that you would like to tell me or ask me, perhaps something that you were expecting us to talk about that we have not covered?

Debriefing

The recorder should be turned off for the debriefing session. The interviewer might ask if the interview has brought-up any difficult thoughts or feelings.
The interviewer should leave the interviewee on a 'positive note'. If the interviewee is troubled, the interviewer can offer to contact someone on their behalf or stay with them while they contact a friend or other sources of support.

Who **helps** you in your **everyday life**?

What do they **help** you with?

Do you go to any groups?

How do you get there?

I want **extra help** with……………..

Do you think that living here affects the **groups** you go to?

How?

Do you think that living here affects the **help** you receive?

Have you had to **move house** because of your stroke?

Have you had to **retire** because of your stroke?

How has your **life changed**?

Did you have to **give up a hobby or interest?** – can you tell me what it was?

Have you **taken up a new hobby or interest** since your stroke? – can you tell me about it?

Examples of some of the images which were cut out for use when responding is shown below. These were printed to a parger scale.

Hobby / interest group
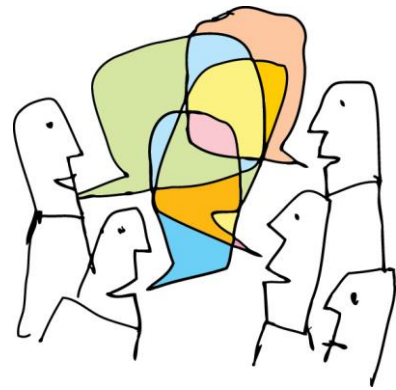
Social

Carer

Friend

Husband / Wife

family

Taxi

Car

Bicyle

Walk

Bus

Mini bus

Appendix H: Survivor Follow-up BNIM Interview Template

Example from case study 9.

Interview Schedule

The interview approach is based on the biographic narrative interpretive method (BNIM) of interview by Wengraf (2009) and will be conducted in three phases: phase 1 elicits individuals personal experiences in their own words; the aim of phase 2 is to clarify any issues and collect more detail about specific incidences or areas of interest in the narrative, and phase 3 allows asking more structured questions.

Before the start of the interview

Familiarise yourself with the protocol
Go through issues around consent (such as recording the interview, awareness of issues around confidentiality, and ability to terminate interview at any time) and assure that the interviewee has signed the consent form

PHASE 1

Framing

As you know we are interested in the everyday lives and experiences of individuals who have been affected by stroke in rural Wales and their families. In a moment I am going to ask you about any changes which might have happened since my first visit.

Generative question

When I was here several months ago you both told me about your life since you had experienced your stroke. Can you please tell me about any changes in your life since I visited you last?

Additional prompts once interviewee has finished

Is there anything more you would like to add?
Does anything else come to mind?
Thinking back about what you've said so far, is there anything else you'd like to say to make sure I understand fully what you've told me?

CHECK if the interviewee would like a break. Turn off the recorder during breaks.

PHASE 2

Interviewer to select a number of cue phrases from the list made during phase1. The decision of how many cue phrases to use depends partly on the length of phase 1. It is useful to rank the cue phrases. Cue selection should be based on the following: strong emotion words, particular incidence, research aim relevance, or apparently irrelevant remark.

I noted down some key points as you were telling me your story and I would like us to go back and talk about these some more:

You said [cue-phrase 2-6 words]. Can you remember a particular [magic word]… how it all happened

Referring back to the previous interview

In a moment, I will ask you to tell me about any changes which might have occurred since we the first interview.

At the first interview you mentioned that you had not received any physiotherapy and where having difficulties with your right arm. Have you since had any physiotherapy? (Has this helped? How did you go about this support?)

You also mentioned that you were having speech therapy. Can you please tell me more about this? (Has it helped?)

You mentioned that your DIY was limited. Can you please tell me more about this? (Do you still do some DIY?does someone else?)

You also told me about your social activities; that you went to stroke club, church and the early retirement club? Can you please tell me more about these? (do you go as often? if not-why not?)

You also told me that the bus was your main mode of transport. Is this still the case?(if not, can you tell me more?)

You also mentioned that you prepared the cereal in mornings and washed up the days dishes is the evenings. Can you please tell me more about what you do around the home? (Do you still do this? need more assistance?)

Magic words

Situation, happening, event, incident, occasion, time, day, memory of a moment, unmet need, dissatisfied, example

If the interviewee cannot remember/ give no specific example keep asking; if nothing is forthcoming, ask the negative – *"Can you remember a particular [magic word] when X did not happen?*

CHECK if the interviewee would like a break

PHASE 3 Semi-structured questions

Select the topics very carefully (or adapt as appropriate) from the following list
If the interviewee has already touched on some of the points summarise these and ask if there is anything else to add.
If the interviewee has discussed a topic in detail, do not go over the same ground again
Use phrases such as the following to introduce specific topics:

·   You have already mentioned a number of changes such as………, can you please tell me a bit more about X

·   You have talked about your experiences with…., can you tell me a bit more about X

·   Please tell me a bit more about X

You have kindly told me your story, about your life after you experienced stroke and talked about your experiences. I now have some specific questions that I would like to ask you. There are no right or wrong answers. Please take as long as you like to think about and answer them.

Topics to explore if not mentioned or to explore further

·   Specific challenges faced with changes which may have occurred; employment; housing; undertaking education and training; making friends/socialising, physical challenges;
·   Strategies to cope with change, including support, and the potential value of meeting with other people who have been affected by stroke.
·   Information to help with identified changes and social participation– accessing; assimilating; timeliness; relevance; gaps.
·   Establishing relationships with professionals, discussing their experiences and needs with them.
·   Experiences of assessment – process; focus; involvement in decision-making; perceived sensitivity; aspects of the process that worked well; aspects of the process that were problematic.
·   Services – accessibility; sensitivity; timeliness; effectiveness; integration and coordination; gaps; priorities for development/future services.
·   Support from professional and voluntary organisations.
·   Support from family/friends/peers.
·   Any new unmet needs and how these might be addressed.

More generic questions that might be useful

·   *Based on your experience, how do you feel about service provision and support for the changes you have experienced? Please tell me about any barriers that you have encountered.*
·   *Based on your experience, can you suggest anything that you think would improve service provision to prepare you for **x** change for you, or someone else, in the future?*

- · *Based on your experience, what has been helpful/not helpful for you in terms of services OR what would you have liked but did not get?*
- · *Based on your experience, do you feel that living in a rural area has had any affect on the support you receive, or your recovery? If so, how?*

Closing question

Is there anything else that you would like to tell me or ask me, perhaps something that you were expecting us to talk about that we have not covered?

Debriefing

The recorder should be turned off for the debriefing session. The interviewer might ask if the interview has brought-up any difficult thoughts or feelings.
The interviewer should leave the interviewee on a 'positive note'. If the interviewee is troubled, the interviewer can offer to contact someone on their behalf or stay with them while they contact a friend or other sources of support.

Appendix I: Caregiver Follow-up BNIM Interview Template

Example from Case Study 9.

Interview Schedule

The interview approach is based on the biographic narrative interpretive method (BNIM) of interview by Wengraf (2009) and will be conducted in three phases: phase 1 elicits individuals personal experiences in their own words; the aim of phase 2 is to clarify any issues and collect more detail about specific incidences or areas of interest in the narrative, and phase 3 allows asking more structured questions.

Before the start of the interview

Familiarise yourself with the protocol
Go through issues around consent (such as recording the interview, awareness of issues around confidentiality, and ability to terminate interview at any time) and assure that the interviewee has signed the consent form

PHASE 1

Framing
As you know we are interested in the everyday lives and experiences of individuals who have been affected by stroke in rural Wales and their families. In a moment I am going to ask you about any changes which might have happened since my first visit.

Generative question

When I was here several months ago you both told me about your life since your husband had experienced his stroke. Can you please tell me about any changes in your life since I visited you last?

Additional prompts once interviewee has finished

Is there anything more you would like to add?
Does anything else come to mind?
Thinking back about what you've said so far, is there anything else you'd like to say to make sure I understand fully what you've told me?

CHECK if the interviewee would like a break. Turn off the recorder during breaks.

PHASE 2

Interviewer to select a number of cue phrases from the list made during phase1. The decision of how many cue phrases to use depends partly on the length of phase 1. It is useful to rank the cue phrases. Cue selection should be based on the following: strong emotion words, particular incidence, research aim relevance, or apparently irrelevant remark.
I noted down some key points as you were telling me your story and I would like us to go back and talk about these some more:
You said [cue-phrase 2-6 words]. Can you remember a particular [magic word]... how it all happened?

Referring back to the previous interview

In a moment, I will ask you to tell me about any changes which might have occurred since we the first interview.

You also told me about your social activities; that you went to stroke club, church and the early retirement club? Can you please tell me more about these? (do you go as often? if not-why not?)
You also told me that the bus was your main mode of transport. Is this still the case?(if not, can you tell me more?)

Have you had any more involvement with the Carers Association at the metropole?

To caregiver: you mentioned when we last met that you would like a nurse to come and provide assistance to (name of IAS) with showering and cream application. Have any provisions been put in place?

You also mentioned that there is an allowance available from the Local Authority and the health board. Can you tell me more about this? (do you use this service now?)

Magic words
Situation, happening, event, incident, occasion, time, day, memory of a moment, unmet need, dissatisfied, example

If the interviewee cannot remember/ give no specific example keep asking; if nothing is forthcoming, ask the negative – *"Can you remember a particular [magic word] when X did not happen?*

CHECK if the interviewee would like a break

PHASE 3 Semi-structured questions

Select the topics very carefully (or adapt as appropriate) from the following list
If the interviewee has already touched on some of the points summarise these and ask if there is anything else to add.
If the interviewee has discussed a topic in detail, do not go over the same ground again
Use phrases such as the following to introduce specific topics:

· You have already mentioned a number of changes such as………, can you please tell me a bit more about X

· You have talked about your experiences with…., can you tell me a bit more about X

· Please tell me a bit more about X

You have kindly told me your story, about your life after you experienced stroke and talked about your experiences. I now have some specific questions that I would like to ask you. There are no right or wrong answers. Please take as long as you like to think about and answer them.

Topics to explore if not mentioned or to explore further

· Specific challenges faced with changes which may have occurred; employment; housing; undertaking education and training; making friends/socialising, physical challenges;
· Strategies to cope with change, including support, and the potential value of meeting with other people who have been affected by stroke.
· Information to help with identified changes and social participation– accessing; assimilating; timeliness; relevance; gaps.
· Establishing relationships with professionals, discussing their experiences and needs with them.
· Experiences of assessment – process; focus; involvement in decision-making; perceived sensitivity; aspects of the process that worked well; aspects of the process that were problematic.
· Services – accessibility; sensitivity; timeliness; effectiveness; integration and coordination; gaps; priorities for development/future services.
· Support from professional and voluntary organisations.
· Support from family/friends/peers.
· Any new unmet needs and how these might be addressed.

More generic questions that might be useful

· *Based on your experience, how do you feel about service provision and support for the changes you have experienced? Please tell me about any barriers that you have encountered.*
· *Based on your experience, can you suggest anything that you think would improve service provision to prepare you for **x** change for you, or someone else, in the future?*

· *Based on your experience, what has been helpful/not helpful for you in terms of services OR what would you have liked but did not get?*
· *Based on your experience, do you feel that living in a rural area has had any affect on the support you receive, or your recovery? If so, how?*

Closing question

Is there anything else that you would like to tell me or ask me, perhaps something that you were expecting us to talk about that we have not covered?

Debriefing

The recorder should be turned off for the debriefing session. The interviewer might ask if the interview has brought-up any difficult thoughts or feelings.
The interviewer should leave the interviewee on a 'positive note'. If the interviewee is troubled, the interviewer can offer to contact someone on their behalf or stay with them while they contact a friend or other sources of support.

Appendix J: Stroke Club Host Interview

Semi- structured Interview Template

1. How long has the Stroke Club been running?

2. How is the stroke club structured?

3. What are you organisational aims and objectives?

4. How they're delivered?

5. What are the challenges you face?

6. How are potential members informed about/referred to your services?

7. How are you funded?

8. Do you receive any support from other organisations? If so, what?

9. What support do you provide for people who have experienced stroke and their caregivers?

10. Are there any plans for future development?

Promps for self:
a. Is [X] support life long?
b. How does this support assist life after stroke
c. Consider strategies (such as life after stroke) and a discussion of them.

Appendix K: Thematic Index

Theme	Definition	A Priori Theme	Emerging Theme	Signpost to Literature Chapter(s)	Signpost to Findings Chapter(s)
Activities (given up since stroke)	Those activities survivors or caregivers have given up since stroke, or the caregiving role.	Yes		18	139, 194, **197-201**, 204-5.
Activities (Social)	Social activities engaged in by survivor or caregiver, or on occasion both together.	Yes		18, 20, 29-30, 32, 43, 48-49, 51-4.	136-46, 155-6, 194, **197-201**, 202, 204-5, 208, 211, 215, 217, 219, 227, 234, 240-42, 244, 255, 276, 287, 298-300.
Anger or frustration	Experienced by survivors and caregivers.			18-19, 36-37, 40-41, 47.	163,181,265-6,301.
Anxiety	Experienced by survivors and caregivers.	Yes		16, 18, **21-22**, 21-23, 33, 41-42, 47, 56, 87.	136, 160, 162,**172-176**, 182, 236, 290.
Caregiver burden and strain	Burden and strain felt by caregivers. Includes sources of and impact of.	Yes		18, **24-5**, 27, 33, 36, 38, 40-1, 43, 46-8, 53, 58-60.	137, 158-59, 162-3, 168-70, 174-3, 176-7, 179, 182, 210-12, 234, 241, 243, 256, 259, 266, 280, 286-8, 331.
Caregiver Obligation	The perceived obligation to care. Includes kinship obligation (Twigg and Atkin 1994), cultural obligation (Burtholt and Dobbs 2015) and moral obligation 2015)	Yes		**24-26**, 80.	178, 211, 228, 285.
Challenges (Survivors and/or Caregiver)	Challenges faced by survivors and/or caregivers in everyday life. Includes physical, psychological and practical.	Yes		14, 15, 18, 20, 23, 26-8, 36, 40-1, 47-49,54, 58, 74, 81.	140, 163, 170-1, 182-3, 209, 212, 218-9, 224, 233, 241-2, 245, 259, 266, 280, 285-7, 299, 304, 306.
Challenges (Policy Markers)	Challenges faced by policy makers in policy formation, delivery and implementation. Includes notion of hard to reach communities.	Yes		26, **18-24**.	261, 297, 299.
Emotional and psychological wellbeing	The emotional and psychological wellbeing of survivors and caregivers. *Includes depression and positive perspectives.	Yes		12-3, 15, 17-8, **18-24**, 29, 30, 40, 45.	168-9, 175, 188, 190-91, 229, 237, 239, 247, 253, 289-92, 298.
Coping Strategies	Coping strategies employed by survivors and caregivers. Includes adaptive, positivity and avoidance.	Yes		35, **46-50**, 60.	150-51, 155-7, 181, 192, 194, 288.
Employment (Survivor)	Pre and post-stroke employment for survivors. Includes changes and challenges and support from employer.	Yes		15, 31, 43, 52, 54.	136, 138, 144, 223, **228-229**, 240,-41, 256, 298.
Employment (Caregiver)	Pre and post-stroke employment for caregivers. Includes changes, challenges and support from employer.	Yes		22, 52, 56, 78, 93, 99.	136-7, 157, 172, 174, 221, **228**, 244, 251, 257-8, 287.
Everyday Life	The behaviours of, and situations experienced by the study participants p1 informed by Heller (2016).	Yes		1,15,23,27,32-34,37,41,43-44,46,48-51,53-59,68,98.	135-7,139-40, 150, 151, 156, 159, 167, 169, 171-2, 175, 177, 179-81, 183, 186, 199, 201, 203, 205, 212-3, 222, 232, 234, 249, 256, 269, 281, 292, 300.

Fear	Fear for the known and unknown. Experienced by survivors and caregivers.	Yes		**21-22**, 37, 40-41, 47, 49-50, 63, 63.	162, 164-165, **172-176**, 184, 187, 278, 286.
Holidays	Holidays taken, planned, or challenges around holiday planning for survivors and caregivers.	Yes		21, 30, 53.	140-1, **234-238**, 272, 287.
Independence (Survivor)	Support with and perspectives of independence and independent living.	Yes		14, 16, 23, 25, 39, 42, 55, 77, 85, 87-92, 98.	135-7, 139, 145, 150, 157-8, 171, 185-6, **206-17**, 225, 231, 236, 242-4, 254, 261, 287-8.
New hobbies and interest since stroke	New hobbies or interested engaged in since stroke, for survivors or caregivers or both together.		Yes		**197-201**, 225, 240.
Positive considerations	Positivity as a coping strategy, but also as an influence of perceived quality of life and wellbeing.		Yes	**28-29**, 32, 34, 38, 42-3, 45-6, **50-51**, 87, 89.	153, **155-7**, 164, 168-9, 172, 182, **188-93**, 223-4, 286-9.
Rehabilitation (Survivor)	Includes statutory sector provisions, support from caregiver, motivation and engagement in rehabilitative activity.	Yes	Yes *types of rehabilitative support from third sector and social enterprise	14-15, 17, 27, 37, 43-45, 49, 52, 54, 70, 77-78, 81, 100.	188, 210-214, **254-256**, 263, 268, 277, 296, 300, 302.
Social Participation	Survivor/caregiver involvement or participation in their home (internal) environment, and/or wider society (external environment) (Stiers et al. 2012).	Yes		14-17, 19,43,47, 49, **52-4**, 57, 86.	152, 160, 160-71,184-5, 187, 193, 195-6, 201, **204-37**, 239, 242, 248, 275, 278, 287, 290, 292, 299.
Self-perspectives on post-stroke life	Self-perceptions or survivors and caregivers. This themes crosses across other themes in the thesis.		Yes	15, 18, 28, 33-34, 40-41, 56-60, 80.	180, 190, 278, 289.
Stigma and Discrimination	Perceived stigma, and discussion of stigma on perception of quality of life. Includes the impact of perceived stigma on social participation and recovery.		Yes	23, **42-44**, 57, 60.	**184-187**, 208, 226, 242, 247, 272, 278.
Support (Survivor)	Support available for, or provided to survivor.	Yes		17, 20, 25-6, 30, 39, 48, 50-2, 87.	139-40, 141-3, 145, 157,170, 190-91, 205, 212, **243- 284** 288-91, 298.
Support (caregiver)	Support available for, or provided to caregiver.	Yes		20, 22, 24-5, 27, 29,50-2, 59,80-1,87, 92.	137,150, 161-2, 170, 178, 191, 205, **243-284**,288 -91, 300.
Transport	Help with transport, modification to transport , access to services	Yes	Yes *information about the type of adaptions made to own cars.	13, 54, 67, 76, 82, 84-7, 91, 98.	134, 135, 137, 141, 143, 159, **233-6**, 272, 288.
Quality of Life	a person's own perception of their own life, in relation to their goals, their expectations, their own standards, and their concerns (WHO 2014) p56	Yes		14-8, 21-8, 32-4, 37, 42, 46, 49, 51, **55-59**, 72, 77, 92, 98-99.	150, 156-7, 159, 169, 183, 186, 190, 247, 286, 292, 298.
Unmet Need (Survivor and/or Caregiver)	Survivor and caregiver needs which have not been met.	Yes		**29-4.**	161, 164-5, 171, 236, 254-7, 298.

Appendix L: Conference Paper Abstract

Providing Support in Rural Wales: motives, observations and end user perspectives

Elizabeth Heyworth
PhD Researcher
School of Social Science
Ogwen Building
Bangor University
Bangor Gwynedd
LL57 2DG
07837 689 644
elizabeth.heyworth@bangor.ac.uk

Dr Rosalind Jones
Lecturer in Marketing
Birmingham Business School
Birmingham University

Dr David. C. Roach
Assistant Professor
Dalhousie University

Track Title: Social, Environmental and Ethical Enterprise

Paper Title: Providing Support in Rural Wales: motives, observations and end user perspectives

Key Words: Rurality, social care, non-profit organisations, third sector organisations, social enterprise, support services, disability, stroke, community support, social participation.

Objectives: This research investigates social enterprise in the context of delivering support to people with neurological and physical disabilities as a result of stroke, in rural Wales, UK.

Prior Work: This research builds on community support research from the entrepreneurial and social enterprise perspective. It examines stroke rehabilitation from a cross-disciplinary perspective through a lens of social participation, community engagement, community cohesion and policy. The rural context and social enterprise perspective are both under researched area, specifically within the context of community support.

Approach: The research methodology uses ethnographic observation, combined with interviews (using the Biographic Narrative Interpretive Method) with end users to study social enterprises namely 'stroke support clubs' from a longitudinal perspective. Data was analysed using Nvivo and key themes extrapolated.

Results: Social entrepreneurs have created 'stroke support clubs' in rural regions, supporting stroke survivors and their care givers. These social enterprises have been created due to needs identified by social entrepreneurs who are the driving force behind development and funding of these clubs. Clubs fill a gap in public service provision in rural areas and create a 'safe zone' where people can be themselves and share experiences. For caregivers, the clubs provide somewhere to share problems, experiences and advice. For survivors, stroke clubs provide a place where survivors can partake in activities with people who have similar conditions, understand them, and seek safety away from 'societal stigma'. This research highlights the need for these social enterprises and how social entrepreneurs manage the challenges faced by funding crises. Implications: The research findings have implications for social enterprise development in rural regions reporting on social entrepreneurship where entrepreneurs have 'lived the experience' and are driven by their own needs to support public sector policy delivery for the social good. These findings are of interest to government policy makers, practitioners and other stakeholders who wish to offer holistic, long term and cost effective support to vulnerable groups, particularly in rural and disparate regions, where effective delivery of social support is challenging.

Value: The findings have implications for policy makers, practitioners and other stakeholders involved in providing support for people living with disability; with stroke as an example. This research highlights the importance of long term support for people who are living with physical and neurodisability, their families, and their care providers. This research also informs best practice recommendations for the service providers; and as social entrepreneurs who have created the enterprises in order to adhere to unmet needs. The recommendations inform how third sector and public sector organisations can collaborate into a Triple Helix working environment; providing support for the self-managed support groups.

Appendix M: Conference Paper Abstract

Social Enterprise: Bridging the gap between the Statutory Sector and the Third Sector

Elizabeth Heyworth
Lecturer in Marketing
University of Cumbria Business School
University of Cumbria
Bowerham Road,
Lancaster
LA1 3JD
07837 689 644
elizabeth.heyworth@cumbria.ac.uk

Dr Rosalind Jones
Lecturer in Marketing
Birmingham Business School
University of Birmingham

Track Title: Other Contexts

Paper Title: Social Enterprise: bridging the gap between the statutory sector and the third sector

Key Words: Social Entrepreneurship, Social Enterprise, Rural Enterprise, Personal Support Network, Rurality

Aim of the Paper:

There is much to study in the area of entrepreneurial activity and the role of the social entrepreneur. Globally and across regions, there are ever increasing demands for social policy to meet the health and wellbeing needs of populations. Entrepreneurship has long been acknowledged by researchers as being a driver for economic and social change. Here, this paper presents the role of the social entrepreneur in bridging the gap between the statutory sector (hospitals and healthcare institutions) and third sector (voluntary and charitable organisations). Entrepreneurial activity and behaviour cannot always be explained by assuming inherent pre-existing entrepreneurial characteristics. Seemingly social entrepreneurial activity can be driven by an essential need to help and improve the lives of others. For this perspective, the research reported in the paper identifies the role of the social entrepreneur and explores how entrepreneurial social enterprise is meeting the needs of vulnerable adults living in rural Wales within the context of stroke. Firstly, this paper explores how both entrepreneurs and the stroke clubs which the entrepreneurs have started, contribute to the personal support networks of people who have experienced stroke in rural North Wales. The organisational structure of the social enterprise in this context is also explored. Furthermore, this paper seeks to identify how social enterprise in this contexts supports vulnerable clubs in rural regions by meeting needs that are currently unmet by the statutory and third sectors. In so doing, this paper addresses the paucity of research social enterprise and entrepreneurship in social sectors and, the lack of research concerning the service demand required for disadvantaged clubs from the social enterprise perspective.

Background Literature

This research builds on community support research from the entrepreneurial and social enterprise perspective. It examines stroke rehabilitation from a cross-disciplinary perspective through a lens of social participation, community engagement, community cohesion and policy. The rural context and social enterprise perspective are both under researched areas, specifically within the context of community support. This paper refers to social enterprise as the 'bridging sector' which has an opportunity to utilise skills, abilities and knowledge by way of a triple helix. Ridley-Duff and Bull (2011) consider that social enterprise shares a combination of attributes from the statutory and third sectors. Where antipathy to the state is considered the driver for these businesses to meet the needs of disadvantaged clubs, seeing them as being realistic about the states capacity to oppress minorities, and the centre crossover is the overlap of all sectors, being 'idealist' it replaces private, public and voluntary competition with a democratic multi stakeholder model where all interests in a supply chain are acknowledge to break down barriers to social change.

Furthermore, the background literature states that the Welsh Government (2012) recognise the importance of stroke support clubs in meeting the needs of people who have experienced stroke, which informs of how such social enterprises can contribute to service delivery across the statutory sector, contributing to the wellbeing of people living with disability and neurodisability as a result of stroke.

Public awareness of stroke has increased over recent years with the increase of social media in the UK. Being the third largest cause of adult mortality and the largest cause of adult disability in the UK it has attracted some focus from researchers in the medical field for several years.

Stroke has a life changing impact on everyday life; for those who have experienced it themselves and their caregivers; families and friends as one third of people who experience stroke survive with varying degrees of long term disability (Ekstam et al. 2011; Jagger et al. 2007), resulting in everyday activities becoming daunting and tasks requiring more effort and possibly assistance. Mortality from stroke is decreasing, but with stagnant incidence rates this suggests that there is an increase in the number of people living with the effects of stroke in their everyday lives.

The Wales Rural Observatory (2004) identified that the rural infrastructure in Wales can make accessing services in rural communities a challenge, and with support being sparse in rural areas this paper reports of the value of social enterprise in this context and how it contributes to the everyday lives of the study participants. The challenges faced by entrepreneurial individuals who start social enterprises are explored and recommendations for governments and policy makers, so as to facilitate and support such social enterprises as key elements of PSNs are made. This also supports the aims and objectives of the Welsh Governments Stroke Delivery Plan (2012). Such research offers insights into service provisions for disadvantaged clubs and has the aim of highlighting the importance of social entrepreneurs and PSNs in respect of stroke and, identifies ways in which social enterprises may be supported to help maintain them sustainably within the community to improve support rehabilitation for stroke survivors within rural communities.

Methodology

This research was carried out in social enterprises and with social entrepreneurs in North Wales, UK. Key factors under study are the role of the social entrepreneur, the relationship and linkages between third sector, the statutory sector and the social enterprise and the impact and outcomes for the everyday lives of people living with stroke in rural counties of North Wales, in the United Kingdom (UK). This aspect of the research is set in the context of a larger research project which examines the Welsh context of support for people who are living with stroke. The research reported here explores the role of social entrepreneurs and how social enterprise in this context contributes to the personal support networks (PSNs) of survivors of stroke in rural areas and their caregivers In this context in which entrepreneurship takes place, "entrepreneurship is recognised as an interactive process that, to be effective, must involve a wider range of individuals, clubs, and organisations" (Shaw, 2013:147). While DeClequ and Voronov (2009) describe entrepreneurship as a "profound socially embedded process" and the environment in which they are embedded are critical to success of enterprises (Shaw 2013:395).

Adopting an inductive qualitative research approach with use of longitudinal multi case studies, this research uses ethnographic observation, combined with biographic narrative interpretive method interviews with entrepreneurs who developed the stroke clubs and also end users to study social enterprises namely 'stroke support clubs'. In total, nine case studies were researched which consisted of people who are living with stroke, and their caregivers (where applicable) and six stroke support clubs were also observed. Data was analysed using Nvivo and key themes extrapolated.

Results and Implications

Social entrepreneurs have created 'stroke support clubs' in rural regions, supporting stroke survivors and their care givers. These social enterprises have been created due to needs identified by social entrepreneurs who are the driving force behind development and funding of these clubs. The clubs fill a gap in public service provision in rural areas and create a 'safe zone' where people can be themselves and share experiences. For caregivers, the clubs provide somewhere to share problems, experiences and advice. For survivors, stroke clubs provide a place where survivors can partake in activities with people who have similar conditions, understand them, and seek safety away from 'societal stigma'. This research highlights the need for these social enterprises and how social entrepreneurs manage the challenges faced by funding crises. Considering the broader context, this research informs how social enterprise can

contribute to wider society in a variety of sectors, bridging the gaps between the sectors; supporting policy delivery and meeting unmet needs of survivors of stroke and their caregivers.

The research findings have implications for social enterprise development in rural regions reporting on social entrepreneurship where entrepreneurs have 'lived the experience' and are driven by their own needs to support public sector policy delivery for the social good. These findings are of interest to government policy makers, practitioners and other stakeholders who wish to offer holistic, long term and cost effective support to vulnerable clubs, particularly in rural and disparate regions, where effective delivery of social support is challenging.