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The early experience of Alzheimer's disease: a co-constructed grounded theory

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THE EARLY EXPERIENCE OF ALZHEIMER'S DISEASE

A CO-CONSTRUCTED GROUNDED THEORY

Thesis submitted in fulfilment of the requirements for the Degree of Master of Philosophy in the University of Wales, May 2008.

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ACKNOWLEDGEMENTS

DEDICATION

My heartfelt thanks to Grace, Mo and Pat, Linda and Gary, Jo and Gwen my co-authors in this study, who made this research possible and such a rewarding and satisfying experience.

ABSTRACT

This study examines the early experience of Alzheimer's disease and builds on the small number of studies that utilise grounded theory with people with dementia and their families. In particular, the study explores the complex area of early awareness and recognition of undiagnosed dementia, how people and their families come to terms with a diagnosis of Alzheimer's disease and how they cope and adapt over time to the condition and life experiences

It is in this context that the thesis reports on the development of a longitudinal research study that examines early awareness and adjustment to a diagnosis of Alzheimer's disease using constructivist approaches to understanding subjective experience (Guba and Lincoln, 1989) and utilising a constructivist grounded theory methodology (Charmaz, 2000), augmented by the supportive struts of a practitioner-research model and the use of life story narrative as part of the data collection. The aim of the research design sought not only to understand the experience of people with dementia, but also to enable them to theorise about these experiences by providing the framework for 'theory from data' (Glaser and Strauss, 1967) to be 'co-constructed' by people with Alzheimer's disease, supported by the author as a practitioner-researcher.

Key to this study has been the forging of genuine relationships and partnerships with the research participants and building a co-constructed grounded theory embedded

with in the person's individual narrative and biography in order to develop an individual theory of early awareness and adjustment termed 'My Theory'. To facilitate partnership working a co-constructed grounded theory approach adopts less complex and jargonistic terms (Charmaz, 2000) and uses diagrams and conceptual maps to represent the developing theory.

The co-constructed grounded theory was developed with 4 people with an early diagnosis of Alzheimer's disease. The co-constructed grounded theory took the form of the compilation of 4 separate 'My Theories' that were co-constructed with each participant, namely: Grace, Mo, Linda and Jo. The individual 'My Theories' were developed by the production of the participant's life story, which acted as a platform for the development of the 'My Theory'. The 4 participants co-constructed their experience of living with the onset of Alzheimer's disease as a process of 'Making Mistakes' and that their life stories had a powerful influence in determining their coping behaviours. Moreover, a sequence of balancing acts i.e. losing balance, finding balance and keeping balance both conceptualised and diagrammed their early adjustment experiences. A meta synthesis of the 4 'My Theories' led to the development of a 'Bridging' theory and metaphor as a conceptual description of the ongoing process of adjustment and adaptation to a diagnosis of Alzheimer's disease. The 'Bridging' theory provides a description that addressed the complex and biographically based responses to the onset, diagnosis and adjustment to Alzheimer's disease, in particular, the decision-making processes required at the time of transition between the stages of losing balance, finding balance and keeping balance.

It is suggested that the concept of 'Bridging' has the potential to inform research,

practice and policy in dementia care.

INTRODUCTION

This study constructs evidence from the subjective experience of people with an early diagnosis of Alzheimer's disease and uses their life stories to understand how their transitional experiences are grounded. As part of the 'story' of the research process in the thesis, the author will argue that the individual experiences of people living with an early diagnosis of Alzheimer's disease are central to this process of developing a grounded source of evidence. The voice of the service user is gathered through life story (Gubrium, 1993), a powerful tool for generating theory as part of social knowledge and service development. The methodology that guides the research work emphasises the value that the emic perspective of each person with a diagnosis of Alzheimer's disease contributes to understanding the experiences of people living with dementia. They have their own 'mental constructions' (Guba and Lincoln, 1989) of the condition, one that is influenced by factors such as: previous life experience, lay understanding of the experience, ways of handling difficult life events, social networks and coping patterns. The study of the emic perspective and the 'mental constructions' of people with Alzheimer's disease around early adjustment to a diagnosis underpins my research approach. In order to develop a better understanding about the complexities around how people with dementia cope and adjust to their life, the author adopted a longitudinal constructivist grounded theory approach (Charmaz, 2000). However, in consultation with my supervisory team (Professor John Keady and Dr Sion Williams), I decided to modify this approach so as to place people with Alzheimer's disease at the heart of the research act and make the research process a partnership driven by individual life experience.

The thesis will follow a chronological approach, so as the literature review, methods and methodology sections will cover the period up until September 2003 when I first engaged in the initial fieldwork. The discussion section will update the literature and place the presented theories within a contemporary (mid 2007) context.

The thesis comprises a series of chapters, as follows:

- Chapter 1: This explores the author's personal narrative and the rationale for conducting the research study. The reflective account will also address the decision to be a practitioner-researcher examining early adjustment to dementia and how this was rooted in an identity that included personal as well as professional issues. The narrative is centred on Gubrium's (1993) life story framework that was used to explore and share the life stories of the people with dementia that participated in the study. Engaging in life story work from the outset starts the process of uncovering identity and blurring the socially constructed roles between clinician and patient, researcher and research participant.

- Chapter 2: This reviews the literature in relation to dementia, including different models of dementia, such as biomedical and psychosocial approaches. In keeping with the general thrust of this thesis, the review will carefully consider the experience of early dementia and in doing so will set the context for the original study design. The chapter will place particular emphasis on early awareness and coping and adaptation models. The chapter

will conclude with an exploration of the historical context of dementia and outline definitions and key policy considerations.

- Chapter 3: This will review the literature on memory clinics and will describe the historical context and the development of the service. The role and function of memory clinics will also be discussed.

- Chapter 4: This outlines the three components to the methodology for the research study: namely, constructivist grounded theory, life story work and practitioner-research. The chapter will firstly describe the principles of grounded theory and the emergence of constructivist grounded theory. The processes underpinning the constructivist grounded theory approach will be described, together with the significance of the interview method. The elements of life story work and narrative will be described and the rationale for adopting practitioner research (Reed and Procter, 1995) will be outlined.

- Chapter 5: This will consider the details of study design based on the principles in the earlier chapter, including strategies of sampling, a discussion on participation, recruitment and research ethics and issues relating to consent. The chapter will describe the longitudinal nature of the research design, its phases and the use of life story approach. The chapter will be completed with an explanation of data collection and analysis methods.

- Chapter 6: This will detail the findings from the study. It will centre on the development of the personal accounts of early adjustment by people with

Alzheimer's disease. As will be explained, using a longitudinal constructivist grounded theory enabled a series of 'My Theories' to be 'co-constructed' with four people with dementia. The chapter describes how these 'My Theories' were built and the significance of co-constructing a theoretical model of dementia by people with the condition themselves, supported by the author as practitioner-researcher.

- Chapter 7: This chapter will discuss the development of a model of early adjustment to Alzheimer's disease. This model attempts to contribute to the debate surrounding adjustment and seeks to articulate how people with Alzheimer's disease understand and work within the experience of early dementia. The model is the result of the implementation of constructivist grounded theory and developed by the co-researchers from their life story and corresponding 'My Theories'. This chapter will describe the emergence of an early adjustment model in terms of maintaining a 'life in control' and introduces the concept of 'bridging'.

- Chapter 8: This final chapter will discuss the findings of the study. This chapter will consider the strengths and weaknesses of the study along with recommendations and future study. Reflections on working within a co-constructivist grounded theory approach are also included in this chapter.

Referencing and Language Used in Text

- The *Harvard* referencing system is used in text, and the author cites up to three authors consecutively. If a supporting reference has four or more authors, the lead author will be cited followed by *et al.*

- The term early dementia is used to refer to individuals in the early stage of dementia, regardless of age.

- The term 'people/person with dementia' is used to refer to those with an early diagnosis of dementia and an awareness of its impact upon their life. Terms such as 'sufferer' and 'mild dementia' will be used only when they are cited by other authors, or, in the case of the latter term, when the medical model is being discussed.

- The author will use whole numbers in text whilst referring to sample sizes, and so on, unless a number starts a sentence or the written format is more naturally assimilated within the context of a sentence.

Appendix items, Figures and Tables will be referred to throughout the text.

CHAPTER 1:

A REFLEXIVE ACCOUNT

1.1 Introduction

In this chapter, I (the author) describe the key features of my personal narrative as part of a reflexive account to identify my own sense of self and identity, in order to understand my role as practitioner and researcher. This account is based on the life story framework described by Gubrium (1993) that I used subsequently with people with dementia as the first part of the interview process. As part of this process people with dementia involved in this study also interviewed me about my life and this resulted in four key life chapters: childhood, working life, personal life and present day. These chapter headings will be used as a framework for my reflexive account and will provide insight into the research process and the individual work with the four participants in the study. The reflexive account as a whole provides readers with additional insights into my life and rationale for undertaking this study, including a final reflection on 'writing-up' the study.

1.2 My Childhood

I have spent the majority of my life either living with, or working with, people with mental health needs. I was born and brought up in psychiatric hospitals. My father was a psychiatrist and in the early days of his working career, he was required to live

within the confines of the hospital. I was fourteen years of age before I lived in a house that was not situated in a psychiatric hospital. There were both benefits and disadvantages to living in a psychiatric hospital. On the positive side, living in a large psychiatric asylum had its advantages; the environment was a pleasant one, living within acres of parkland, woodlands, lakes and rivers. It was an ideal world to grow up in. My two brothers and I had license to roam freely in the majority of the hospital, its grounds and numerous facilities.

The patients were our friends. We did not see them as 'different' or 'dangerous'; we mixed freely, played together, joined in therapy sessions such as art and woodwork, we went to the hospital cinema and saw the latest films and plays. We even helped the nursing staff by escorting patients to their wards at the end of the day for their evening meal. Many of the things we did, and the freedom we had would not be allowed today, but I can honestly say these were the safest and happiest years of my life.

The down side to living in a psychiatric hospital was the stigma. I was the boy who came from the 'Looney bin'. I found this particularly difficult to cope with. In school, there was the occasional name-calling and bullying. If I made friends, it was difficult to invite them home, as their parents would worry about how safe it was. I longed for the day we lived in a house that was not situated in the grounds of a psychiatric hospital.

We lived in several psychiatric hospitals, Graylingwell Hospital in Chichester (West Sussex Asylum), Ballamona Hospital in the Isle of Man and the North Wales Hospital in Denbigh. The older I became the less sensitive I was about my connection to

mental hospitals. However, it came as a shock to me when my father suggested to me that I should consider becoming a psychiatric nurse. He felt I had the right personality, temperament and sensitivity that would be ideal grounding for a nurse.

1.3 Working Life

I left school with little idea of what to. At first I adamantly refused to consider the idea of working in a mental hospital. I remembered my early experiences of living in the mental hospital, the stigma and embarrassment and those feelings came flooding back. However, my father persisted and he arranged a visit to the hospital where he was working. Reluctantly, I went. I was shown around the hospital, met patients and talked to staff. Immediately, the positive aspects and happy memories returned. I agreed to commence my training and I have never looked back.

As a nurse I saw a different side to hospital life. I was no longer the 'doctor's son' with the free run of the hospital. I was now the doctor's son who wanted to be a nurse. This caused some suspicion and raised questions as to why a doctor's son would want to be a nurse; was I a 'failed medic' or even a 'management spy'! This did not last long and I was soon accepted and quickly settled into the familiar life of the institution.

I started mental health nurse training in the late 1970s. At that time the most unpleasant place to work in the hospital was the older people's wards, or psychogeriatrics as they were then referred to. These were usually large 30-40 bedded wards and the patients were in the later stages of dementia. These wards were quite

challenging places to work in and had ascribed stigmatised nicknames such as 'the pit'. The patients were often mentally and physically ill, bed-ridden and doubly incontinent. The staff that worked on these wards, unfortunately, was not always the 'best staff' in the hospital. It was not uncommon to be sent to work on a psychogeriatric ward as a punishment, i.e. if you did not do your job well or you had upset management in some way.

After qualification my first staff nurse position was on a large female psychogeriatric ward; I don't think I had upset anyone during my training! I had expressed my intention to do my general nurse training and was consequently allocated to this ward to prepare for the physical demands of the acute hospital.

This was a time of change in psychiatric hospitals and attitudes towards older people were changing. People began to see that older people deserved a better service and this area of nursing could be satisfying and one in which a lot could be achieved. I enjoyed my time working with older people. I did not see it as a 'dead end job' and I saw a future in this area. When I had a spare minute, I used to sit and talk to those patients who were still able to communicate. Not all the patients were in the final stages of dementia and there were a number who had grown old in the hospital. They had been admitted as young adults for such misdemeanours as having children out of marriage. They had incredible stories to tell about their life and times in the institution.

I decided to undertake general nursing to enhance my knowledge and skills in the physical side of nursing. I completed the training and returned to work on an older

people's assessment ward. From there, I completed a project developing a domiciliary home support scheme, which involved supporting people with dementia who were living at home. This job required me, for the first time, to work closely with the families of people with dementia. More recently, I have been developing a memory clinic service, which involves working with individuals with early stage dementia and their families.

Since I started nursing there have been tremendous developments in the understanding and treatment of dementia. I have seen great changes in the attitude and quality of care for older people: from 'the pit' of the late 1970s to the present day state-of-the-art memory clinics. Older people's mental health services are now rightfully regarded as a specialist area, and one I am proud to be associated with and to work in.

Professionally, I have always been ambitious. I never felt I have had to 'prove myself' or live up to my father. I have never wanted to be a doctor. My father was right when he told me that my personality was better suited to nursing than medicine, I feel medicine is about finding the cause of a given illness and providing a diagnosis and implementing treatment. Nursing is about helping that individual and family cope and adapt to the diagnosis and the condition. There is a subtle difference between the two roles. Like many nurses, as I progressed up the nursing career structure, I became a manager and gradually had less patient contact. On a management course, I shadowed a senior nurse who had no patient contact at all. It became clear to me that this was not what I wanted to do. Fortunately, an opportunity came along to develop a memory clinic service in the area in which I lived and practice and create the post of nurse

specialist. This allowed me to stay more clinically focussed and maintain close contact with patients and their families. Three years on, my current role continues as a nurse specialist, working closely with the development and implementation of memory clinics in Conwy and Denbighshire, North Wales. Future plans will focus on the integration of early intervention in dementia into mainstream older people mental health services, and the expertise gained by working in partnership with people with early Alzheimer's disease will be shared with the whole service. The development of early intervention in dementia care has the potential to change traditional ways of thinking and working and my greatest expectation is to see a move away from a traditional 'reactive', crisis orientated service to a more 'proactive' user led endeavour.

1.4 Present day

This brings me to the present day and to the question as to why I have embarked on academic study in the form of an MPhil. The answer to this is, quite simply, the time was right. By this I mean a combination of factors fell into place to allow academic study and for this to be a successful and worthwhile endeavour. People involved in this study will benefit and have a stake in the outcome of the study, namely people with early stage Alzheimer's disease, their families, colleagues, research supervisors, the service in general and, as I see it, this is an important pre-requisite for beneficial research.

On a personal level, having made the decision to embark on a clinical career pathway, completing a research degree is a necessary requirement to enhance my nursing role

and become an advanced nurse practitioner. Working with people with early stage dementia is a relatively new area of practice, and the research act has enhanced my knowledge and understanding of the needs of these individuals and their families. In particular, how individuals cope and adapt to the early stages of dementia. I will be well placed to use the findings of the study to continue to develop evidence-based practice. As already mentioned, my current position is a developmental and clinical role. I will be in an ideal position to implement the findings of the research, within memory clinics in Conwy and Denbighshire. At a time when patient and public involvement in service delivery and development is high on the political agenda, the nature of this research and its chosen methodology supports the drive to involve service users in the development of services.

1.5   Chapter Summary

In describing my life story I have concentrated on my experiences of living and working in psychiatric hospitals. I feel this best provides the reader with an insight into my life and how this has shaped me and my beliefs and values. We are all products of our life story and experiences. My early life and early nursing experiences have had a powerful influence on my career and on my philosophy of nursing, and hopefully this is reflected in my work and approach to this study, a body of work that I will now outline.

CHAPTER 2:

DEMENTIA: A LITERATURE REVIEW

A search of the literature was undertaken to identify any significant sources of information in relation to dementia. Databases searched included MEDLINE, CINAHL, EMBASE, PsycINFO, Cochrane and assistance from the Dementia Services Development Centre in the University of Wales, Bangor. Search parameter included Alzheimer's disease, adjusting and coping, early awareness and subjective experience.

2.1   Introduction

Over the past twenty years, there has been an increased understanding of the aetiology, course and diagnostic categories of dementia, and models of understanding. This has seen the development of medical and social care perspectives in dementia care. The primary aim of these approaches has been to develop effective interventions for cognitive, behavioural and social challenges arising from the onset and progression of dementia (Kasl-Godley and Gatz, 2000). Medical approaches have largely centred on neurogenerative changes in the brain, in particular: the reduction of specific neurotransmitters; the development of amyloid plagues and neurofibrillary tangles; and the development of pharmacological treatments. The ambition being the discovery of a preventable or curable treatment for dementia. In contrast, the social

model of dementia seeks to understand the emotions and behaviours of the person with dementia by learning about each person with dementia as an individual, with their own unique history and background (Fares, 1997). Moreover, by viewing dementia through the lens of a social model of disability, the onus is transferred to society to develop systems and values of acceptance and inclusivity, rather than rejection and stigmatisation that previously summarised the experience of living with dementia. Against this backdrop, health policy in relation to dementia care has also changed considerably over the past twenty years, with the emphasis on the closure of the large psychiatric asylums and the development of community-based services (Nolan, 2003). More recently, health policy in dementia has focused upon health promotion/education and early intervention services (DoH, 2001; National Institute for Clinical Excellence, 2001) processes that emphasise proactive work and activity in dementia care.

This chapter will develop each of these points and review relevant literature on health policy, medical, psychosocial and social models of dementia. In keeping with the focus of this thesis, an emphasis on early stage/awareness of dementia, in particular Alzheimer's disease will be present during the review.

2.2   What is Dementia?

2.2.1   Biomedical model

Dementia is an umbrella title which covers a number of conditions including, Alzheimer's diseases, vascular dementia, mixed dementia (a combination of

Alzheimer's disease and vascular dementia) and Lewy body disease. Dementia is identified by changing patterns of behaviour such as confusion, disorientation in time and space, inapproprite responses and actions, as well as memory and language impairment and sometimes personality changes (Ronch, 1993). There is currently no diagnostic tests that can be used to confirm or rule out dementia and an accurate diagnosis of dementia can only be achieved at post-motem, where detailed examination of brain tissue reveals degeneration of nerve cells and the presence of plaques and tangles (World Health Organisation (WHO), 1992). However, there are a number of standardised diagnositic criteria that exist to help define dementia in order to aid diagnosis and clinical reserarch.

The diagnosis of dementia through multi-disciplinary examination is reported to be relatively accurate, partly by eliminating other possible causes of dementia, and partly by identifying the key signs of dementia (Stanton, 2002). The criteria most commonly used in the UK for diagnosing dementia are listed in the tenth revision of the International Classification of Diseases (10e) (ICD – 10) (WHO, 1992). These are broadly similar to those in the fourth edition of the American Psychiatric Association's Diagnositic and Statistical Manual of Mental Disorders (DSM-IV) (American Psychiatric Association, 1994, McKeith and Fairburn 2001). In the ICD – 10 definition (WHO,1992), dementia is defined as:

'A syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is a disturbance of multiple higher cortical function, including memory, thinking, orientation, comprehension, calculation, learning capability, language and judgement. Concsiousness is not impaired. Impairment of cognitive function are commonly accompnied and occiasionally

proceeded by deterioration in emotional control, social behaviour and motivation'. (p. 45)

ICD –10 classifies the progression of dementia into three stages: mild (or early), moderate and severe. In the author's experience, there can be confusion between the terms 'early dementia' and 'early onset dementia'. Early onset dementia starts before the age of 65 and late onset dementia begins after the age of 65 (WHO, 1992).

Dementia can be classified in a number of different ways. For example, dementia can broadly be classified into reversible and irreversible forms. The irreversible dementias include early and late onset Alzheimer's disease, vascular dementia, mixed dementia, Pick's disease, Creutzfeldt-Jokob disease and HIV (WHO, 1992). A smaller number of people have 'reversible dementia'. When dementias occur in association with treatable conditions they are referred to as reversible or secondary dementias. There are a number of conditions which may cause reversible dementia, the three most common causes are depression, medical conditions such as infections, thyroid deficientcy or Vitamin B I2 deficiency and, finally, the side effect of medication. (Fares, 1997). It is estimated that the percentage of people with a reversible cause of dementia has varied from 0-23% (partial reversal) and 0-10% (full reversal) (WHO, 1992). However, in recent studies the prevelence of reversable dementia is found to be low. Clarfied (2003 – cited in NICE-SCIE, 2006), reviewed 39 studies of over 7,000 cases and found potentially revesable causes in only 9%, though only 0.6% of cases actually reversed.

2.2.2   Diagnosing early/mild dementia

The ICD – 10 diagnostic criteria define mild dementia as the having the following properties:

> 'The decline in cognitive abilities causes impaired performance in daily living, but not to the degree that makes the individual dependent on others. Complicated daily tasks or recreational activities cannot be undertaken.'
> (WHO, 1992, p.29)

However, there remains uncertainty regarding the projected course and clinical criteria for accurately establishing mild dementia. This has led to the development of a proliferation of assessment scales to measure mild dementia (Burns, Lawlor and Craig, 1999).

There is much debate as to the usefulness in the staging the progression of dementia. On the one hand, it gives structure to the course of the disease and it allows people with dementia, their families and professionals to organise care and plan ahead. On the other hand, 'fitting' individuals into predetermined criteria can be seen as a rather insensitive and a medicalised process. There are also concerns regarding the accuracy of diagnosing early stage dementia due to variable clinical interpretation and the different diagnostic criteria available. Keady and Gilliard (1999) describe a number of studies that have attempted to address this. An interesting finding here is that there is a time-delay, or pre-clinical phase, between the onset of decline and diagnosis of Alzheimer's disease. This pre-clinical phase can last for between 5 to 7 years (Almkvist and Backman, 1993; Linn *et al.*, 1995). These studies suggest that the early

subtle signs of Alzheimer's disease include problems with episodic memory, psychomotor speed, semantic memory and visuospatial functions and, eventually, primary memory. Keady (1996), in a comprehensive review of literature on the experience of dementia, found that confirming an early diagnosis of dementia is a complex task which involve the exclusion of other symptomatology, including benign senile forgetfulness, age associated memory impairment, depressive psuedo-dementia and other underlying physical causes, such as normal pressure hydrocephalus, cerebral tumour and drug toxicity (Burns, 1994).

2.2.3   Incidence and prevalence of dementia

Accurate estimates of the numbers of people with dementia are important as they provide the information for health and social policy makers. Estimates of the numbers of people with dementia are made by applying a prevalence estimate (the proportion of people affected) to the numbers of people in any given population. Prevalence estimates are obtained from population based epidemiological surveys such as Hofman et al., (1991) that estimates dementia affects around 5% of the over 65s, rising to 20% for the over 80s. Using these estimates there are about 550,000 people in England and Wales with dementia. However, these estimates are open to criticism, as they tend to lack accuracy and often underestimate the true figure. Prevalence estimates tend to be based on only one single epidemiological study and fail to take account of all relevant evidence such as variation in prevalence by age, gender and region. The 2007 *Dementia UK Report* (Knapp *et al.*, 2007) was commissioned by the Alzheimer's society to determine a more accurate estimation of prevalence of dementia in England and Wales. To estimate the numbers of people with dementia in

the UK, Knapp *et al.* (2007) undertook a systematic review of all relevant studies and synthesised the evidence into a single consensus estimate of likely prevalence (known as the Expert Delphi Consensus). The systematically reviewed evidence showed that currently 741, 000 people in England and Wales have dementia. The review showed the prevalence of both young onset and late onset dementia increases with age, doubling with every 5-year increase across the age range. The prevalence of both young onset and late onset dementia was adjudged to be higher in men than women aged 50-65, while late onset dementia was considered to be marginally more prevalent in women than in men. Alzheimer's disease continues to be the main type of dementia, particularly among older people, and in women. The report also estimates that the total number of people with dementia in the UK is forecast to increase to 940,110 by 2021 and 1,735,087 by 2051, an increase of 38% over the next 15 years and 154% over the next 45 years.

In Wales, there are approximately half a million people aged over 65, which equates to 17.3% of the population. This prevalence rate is higher than in England, Scotland and Northern Ireland. The population aged 65 and over in Wales is projected to rise to 18.4% by 2011 (Welsh Assembly Government, 2001). These prevalence rates suggest that around 40,000 people living in Wales are likely to have some form of dementia (Audit Commission, 2002). Using these figures, the author has estimated that locally, in Conwy, there are 2,062 people with dementia whereas in Denbighshire the figure is 1,636.

One of the consequences of biomedical developments, alongside the growing number of people with dementia as the population ages has been the identification of more

people with early stage dementia. It is estimated that at any time 30% of people with

dementia have early dementia (Alzheimer's Scotland, 2000). Using current

prevalence estimates this suggests that there are around 230,000 people with mild

dementia in the UK, with the figure rising to over 250,000 by 2010. These estimates

may well underestimate the true numbers of people with early dementia as the rate in

which new cases of early dementia are detected in a population is heavily dependent

on the extent to which services are proactive about early recognition and diagnosis,

the general level of public awareness of dementia and attitudes towards early

diagnosis. Using these figures, the author has estimated that locally, in Conwy, there

are 618 people with early dementia whereas in Denbighshire the figure is 490. These

populations inform the area of the study.

2.2.4   Alzheimer's disease

Alzhiemer's disease is the most common cause of dementia in old age and also occurs

in those under 65. It was first described in 1907 by Alois Alzheimer (Alzheimer,

1907) who described the case of Auguste D who died aged 56 years with the

symptoms of dementia. This intially led to Alzheimer's disease being thought of as a

disease of younger people. However, it is now recognised that Alzheimer's disease

does occur in both older and younger people (Gao *et al.,* 1998), and Alzheimer's

disease accounts for approximatley 60% of all dementias (Henderson, 1994). In the

United Kingdom (UK), the Alzheimer's Society estimates that there are 750,000

people with dementia of whom 413,000 have Alzheimer's disase (Alzheimer's

Society, 2000). Alzheimer's disease is characterised by insidiuos onset and slow

deterioration and its presentation is one of loss of memory, especially for learning

new information. The disease progresses gradually and the clinical features are considered in three stages.

1. In the early stage the clinical features include: memory impairment, difficulties in performing everyday tasks, impaired concentration, spatial disorientation, disturbance in mood, fatigue, anxiety and lack of motivation.

2. The mid stage the clinical features are a further deterioration of the early features. Other features may include apraxia and agnosia, deterioration in reading and writing skills, speech problems, emotional liability, delusions and hallucinations.

3. The features of the late stage will include: incontinence, lack of communication, emaciation, limb contractions and grand mal seizures. The person with dementia often becomes bedridden and death frequently results from a subsequent infection e.g. a chest infection (Alzheimer's Society, 2000).

The rate of progression is variable. On average, in each of the stages the person with Alzheimer's disease performance on cognitive testing will deteriorate by about 10 % per year and life expectancy from onset of symtoms varies from two to twenty years, with an average of about ten years (McKeith and Fairburn, 2001).

In Alzheimer's disease there are three key features of pathology (Adams, 1997). First, a general loss of nerve cells, especially in the cortex of the brain. Secondly, there are large numbers of neuritic (senile) plaques. Plaques consist of altered axons and dentrites of neurones surrounding an extracelluar mass of thin fillaments. Thirdly, there is the development of neurofibrillary tangles these consist of dense bundles of a protein called Tau which prevent the cell from working by interfering with the

transport of materials between the nucleus of the cell and the dendrites by forming

twisted structures which build up in the cell, forming tangles. It is generally accepted

that the presence of plaques and tangles is indicative of Alzheimer's disease.

However, the presence of plaques and tangles are found to be present in post-mortem

specimens from older people who demonstrate no signs of Alzheimer's disease. The

explanation for this anomolie appears to be in the amount and placement of plaques

and tangles (Fares, 1997).

In Alzheimer's disease there is also a depletion of the neurotransmitter acetylcholine.

a neurotransmitter thought to be important in the chemical basis of a number of

cognitive processes including memory, thought and judgement and is responsible for

the conduction of messages across synapses (Adams, 1997). It is estimated that levels

of acetylcholine are reduced by 60% or more in Alzheimer's disease and these

reductions will correlate with the severity of cognitive impairment (McKeith and

Fairburn, 2001).

2.2.5   Pharmacological Treatments

Dementia is often regarded as an untreatable condition and the mainstay of treatment

has been to support the person with dementia and their carer by addressing their

personal, social, medical and behavioural problems.

New approaches to the pharmacological treatment of dementia, in particular

Alzheimer's disease, have seen the introduction of the acetylcholinesterase inhibitors,

which inhibit the breakdown of acetylcholine. Acetylcholinesterase inhibitors used in

clinical practice are called donepezil (aricept), rivastigmine (exelon) and galantamine

(reminyl). Another type of pharmacological treatment for Alzheimer's disease is the drug Memantine (Ebixa). The mode of action of Memantine differs to that of the acetylcholinesterase inhibitors and modulates the activity of neurotransmitter glutamate and in doing so appears to have benefit in terms of cognitive function and functional ability in moderate to severe dementia.

Guidelines issued by the National Institute of Clinical Excellence in 2001 (NICE, 2001) recommended that these drugs should be made available as a component of the management of people with mild to moderate dementia Alzheimer's disease whose score on the Mini Mental State Examination (MMSE) is 12 or above. The guidelines specified that treatment should be initiated by a specialist following an assessment of cognition, global and behavioural function and of activities of daily living. Treatment should only be continued on reaching the maintenance dose where there have been benefits to the person's cognitive condition with either and improvement or no deterioration seen on the MMSE score, evidence of global and behavioural improvement and no major drug side effects. Assessment of the ongoing benefits will take place every 6 months and the drugs should normally be continued with a MMSE of 12 and above. Below the boundary of moderate and severe dementia usually associated with an MMSE score of 10 or below the clinical effectiveness of these drugs has not been demonstrated. MMSE score of 12 (rather than 10) was indicated as the boundary of usage for these drugs for reasons of cost-effectiveness rather than clinical effectiveness (NICE, 2001).

The rationale of the effectiveness of donepezil, rivastigmine and galantamine was determined by a systematic review of the published literature of 5 randomised controlled trials (RCTs) and 3 systematic reviews (NICE, 2001). All 3 drugs showed

from RCT evidence to have some effect on improved cognitive function, global and behavioural improvement and proved cost effective in delaying admission into institutional care. However, RCT evidence showed that not all people treated appeared to benefit and there was limited analysis to indicate why this is the case. The RCT evidence for improvement in quality of life was also less positive. There was no universally accepted measure of quality of life in people with dementia used in the RCTs and claims that the quality of life had improved by these drugs was therefore suspect.

A recent review of the clinical and cost-effectiveness of donepezil, rivastigmine and galantamine for mild to moderately severe Alzheimer's disease and memantine for severe Alzheimer's disease has been undertaken by NICE (2006). Further RCT studies on the benefits of acetylcholinesterase inhibitors are now available. The meta-analysis shows quite consistently that these drugs continue to have some beneficial effects (Birks, 2006). However, the positive treatment effects are small and not always apparent in practice and there is also increasing concerns over the cost of the drugs (Birks and Harvey, 2006; Loveman et al., 2006). Revised guidelines by NICE (2006) have concluded that acetylcholinesterase inhibitors should no longer be available on the NHS to people in the early stages of Alzheimer's disease as they do not provide value for money. Donepezil, rivastigmine and galantamine should only be used for the management of people with Alzheimer's disease of moderate severity who have a MMSE score of between 10 and 20. This proposed decision has been met with anger and disappointment by clinicians, patients, carers and representative organisations. However, this is not the case in Scotland where an audit of the use of acetylcholinesterase inhibitors for Alzheimer's disease in the district of Falkirk

(McLean, 2006), reported that admissions to acute psychiatric beds for organic

diseases had almost halved since the introduction of acetylcholinesterase inhibitors

and there had also been a reduction in admissions to general hospitals. The study also

found there to be a saving in social care. 18% of people using cholinesterase

inhibitors required home care compared to 48% of untreated people. The audit took

the form of a retrospective case study of 300 patients who attended the 'cognitive

enhancement clinic'. However, This study does not detail any explicit financial

savings and makes no mention of the psychological and emotional support received

from the service, which may also have contributed towards the findings. Of

significance however, this audit has provided the evidence for the continued use of

acetlycholinesterase inhibitors for early stage Alzheimer's disease in Scotland.

So what does the future hold? First trials of a potential drug treatment for Alzheimer's

disease in the form of a vaccine targeting beta amyloid was unsuccessful and had to

be stopped when some recipients developed brain inflammation. However, there was

enough encouraging evidence to sustain strong interest in this approach and several

second-generation vaccines are under development or in the early stages of clinical

development (Gilman *et al.,* 2005; Fox *et al.,* 2005).

2.2.6   Risk Factors and Alzheimer's disease

As previously rehearsed, advancing age remains the single biggest risk factor for

developing Alzheimer's disease. Other risk factors can be considered as gender,

genetics and the environment (lifestyle)

Gender

Prevalence studies have shown higher rates of Alzheimer's disease in women than in men - 67% in women compared 55% in men (Knapp, *et al.*, 2007). The significant difference between women and men is generally thought to be the result of women living longer than men. Other factors are thought to be hormonal. Some studies have suggested that oestrogen replacement can prevent or delay the onset of Alzheimer's disease. A 16-year follow up study of nearly 500 subjects found that hormonal replacement therapy led to a 54% reduction in developing Alzheimer's disease (Kewas *et al.*, 1997). However a more recent study was not able to demonstrate improved cognition or delay in disease progression in women with Alzheimer's disease given therapeutic oestrogen (Mulnard et al., 2000)

Genetics

Developing dementia before the age of 65 is referred to as early onset dementia, this a rare condition and, in the case of Alzheimer's disease suggests genetic factors. At least 3 genes with multiple mutations can be identified for early onset Alzheimer's disease they are: beta amyloid precursor protein, presenilin 1 and presenilin 2 account for most cases (Hardy, 1996). For late onset Alzheimer's disease a combination of genetic and environmental factors are risk indicators. Having a common genetic variant, the apolipoprotein E (apoE) gene Q4 allele greatly increases risk of going on to develop Alzheimer's disease; it is estimated that up to 25% of the population has this genetic variant (Saunders et al., 1993).

Environment

Environmental (lifestyle) appears to ba risk factor. For instance, people who suffer severe or repeated head injury are at a 3 to 4 fold increased risk of developing Alzheimer's disease (Mortimer *et al.*, 1985) altough a more recent study did not support these findings (Launer *et al.*, 1999). People with limited education (Ott et al., 1995) are felt to be at risk, research which is only partly supported by longitudinal studies (Stern *et al.*, 1994). Conversley, higher educational attainment or high IQ has shown to have a protective effect against the development of dementia. It is possible that such people have developed more complex connections in their brains in earlier life, allowing for extra capacity to cope with the physical changes to the brain associated with dementia (Schmand et al., 1997).

Research suggests that vascular disease and vascular risk factors predispose to Alzheimer's disease (Hofman *et al.*, 1997). Large prospective epidemiological studies have shown that smoking is a particular risk factor for Alzheimer's disease (Ott et al., 1998), high blood pressure and high cholesterol levels especially in middle age (Kivipelto et al., 2001), diabeties (Desmond et al., 1993) and hyperlipidaemia (Moroney, 1999). A recent influential study has shown that mid life smoking, diabetes, high cholesterol and high blood pressure raises the risk of Alzheimer's disease by 20 – 40%. Having all four risk factors more than doubles the risk (Whitmer *et al.*, 2005). There fore the importance of preventative strategies and initiatives are growing in significance. For instance, a population –based study over 21 years by Rivio *et al.* (2005) found that middle-aged adults who exercise vigorously enough to

perspire and breathe hard for 20-30 minutes at least twice a week might reduce their risk of Alzheimer's disease by 60%.

There is some evidence to suggest that depression in earlier life may be a risk factor for developing dementia, however this could be because depression may be an early presenting symptom of dementia (Devanand *et al.*, 1996). There is also an increased risk of all dementias with a past history of severe psychiatric problems (Cooper and Holmes, 1998).

2.2.7 Future developments

Early detection is likely to be significantly improved by the European Alzheimer's disease neuroimaging initiative (EADNI). This is a landmark initiative to establish standards for acquiring, processing and interpreting brain images. The ultimate goal is to find better ways to diagnose Alzheimer's disease, tract disease progression and monitor responses to next generation drug treatments (Alzheimer's Association, 2005).

Currently it is estimated there are over one hundred biomedical studies recruiting patients with Alzheimer's disease. This unprecedented number of Alzheimer's studies offers compelling evidence of progress towards effective treatments and preventative strategies (AA, 2005)

2.2.8 Psychosocial models of dementia

Alongside the dominant medical model there has developed a psychosocial model of dementia. In common with other approaches, the psychological perspective on dementia has undergone a radical shift in emphasis and approach over the last 20 years. In particular, the work of the late Professor Tom Kitwood and his associates at the University of Bradford, UK heralded a radical shift towards recognising the person and not their dementia. The concept of personhood and the accompanying theory of dementia care as developed by Kitwood (1997a) has had a profound influence on the psychological perspective of dementia (Maciejewski, 2001).

Personhood is based on the recognition that the person with dementia is unique; it takes into account personal likes and dislikes, knowledge of the person's life history and the environment in which they exist (Fare, 1997). If we deny people with dementia their personhood, then their well-being will diminish and person-centred care will not become a reality (Kitwood, 1997b). The development of a psychosocial model of dementia has come to prominence for a number of reasons. Firstly, as an alternative to the 'biomedicalisation of dementia' (Kitwood, 1993). Secondly, there has been a political and societal move away from providing institutional, task-based care for people with dementia to the provision of community care. This has highlighted the plight of the informal carer, mainly family members, who provide the lions share of the caring role. As a result, health professionals have needed to develop new strategies and interventions to help support informal carers maintain the person with dementia at home (Adams, 1997).

2.2.9   Kitwood's approach to dementia

The late Professor Tom Kitwood was a major influence in bringing the person with dementia from the margins of care provision and professional attention to centre stage. Kitwood (1997a,b) argued that the extent of a person's dementia is not only dependent on physiological factors, such as neurological impairment and damaged brain, but can also be affected by the person's medical and social processes including the individual's personality, biography, physical health, social psychology. Fare (1997) provides a salient description of these social processes as rehearsed below:

- Personality – each person brings to the lived experience of dementia his or her own personality, which consists not only of that which the individual has been given constitutionally, but the results of social learning. Each individual personality consists of 'positive' resources and negative 'hang-ups'. Resources are positive attributes, developed from successful experiences, which the person can do without undue anxiety such as; make new friends; approach unfamiliar situations comfortably; and cope with loss and change. Hang-ups, on the other hand, can cause anxiety and are acquired through failure, real or imagined. As we grow older, more 'resources' and 'hang-ups' are added to our repertoire. Despite having memory and orientation problems, many people with dementia will remain their 'old selves', however some may display change in personality and behaviour as underlying 'hang ups' become more prominent.

- Biography – each individual has a unique life history consisting of joyful and painful events. Events during childhood, relationships within the family, type of occupation and quality of interests all contribute to individual biography. Some people enter dementia with their support structures intact, however others may have experienced destabilising life changes such as bereavement which may affect the experience of living with dementia.

- Physical health – each individual will have varying degrees of health problems, which may also affect the presentation of the dementia, such as infections, pain, depression and vitamin deficiency leading to increased confusion. There is a danger that these signs and symptoms may be attributed to the dementia, resulting in treatable conditions being untreated.

- Social psychology – This is what is happening constantly during interaction with other people on a minute-to-minute basis. How we respond to each other, and to people with dementia can diminish or enhance their sense of value and personal well-being. This is what Kitwood (1997b) refers to as 'personhood'. By respecting 'personhood' aspects such as abilities, preference, tastes, strengths and vulnerabilities are taken into account by those people close to the person with dementia. Failure to take personhood seriously allows an individual to 'fall apart' and become prey to cognitive impairment and emotional distress. Good person-centred care will support and maintain personhood and can provide compensation and reassurance as mental powers fail.

It is also important to consider the value of the social psychology of the environment with which the person with dementia interacts. This environment, such as a nursing home or hospital ward, can promote interactions between staff and the person with dementia, which either maintains, or destroys, personhood. Kitwood (1997a,b) refers to this as 'malignant social psychology'.

Kitwood (1997a,b) argues that if these social processes are not considered, then the person with dementia may appear more impaired, or have a more severe level of dementia in comparison with their current level of brain damage. Consequently, people with dementia may stop 'deteriorating' when their life-situation becomes stable and even undergo a degree of 'rementia', i.e. a reversal of the impact of dementia upon the person's life.

This relationship shows the importance of an holistic assessment of medical and social processes, and leads towards a more hopeful view of the potential for both medical and psychosocial interventions. Neurological impairment alone may not be readily treatable, but a number of the other processes, referred to by Kitwood (1997b), may be amenable to interventions so that reductions in disability become feasible (Woods, 2001). Brooker (2001) highlights a number of psychological therapies that promote personhood in people with dementia, they include: reality orientation, reminiscence, validation therapy (Feil, 1993) and resolution therapy (Goudie and Stokes, 1989).

The social and biomedical models view dementia in very different ways. A sociological model of dementia focuses on the way that people with dementia and

their informal carers interpret their own experiences of living with dementia, and the meaning that their situation has for them. Sociological theory draws on a variety of different perspectives. Bond (2001) describes a phenomenological perspective which maintains that an understanding of dementia be grounded in the 'lived experience' of those who have the condition. Therefore, the experience of dementia is only meaningful through the subjective definitions of individuals. This perspective is at odds with the biomedical and psychosocial models of dementia because of the expectation of profound loss of self. The social perspective challenges the biomedical model of disease progression, cognitive decline and associated behavioural problems. Additionally, social and environmental conditions are more likely to affect the illness, than the neuropathology of dementia.

The author will now discuss aspects and constructions of the self and selfhood to aid understanding

2.2.10 Selfhood

Sabat and Harré (1992) divide the self into two parts, 'self' and 'selves'. 'Self' is how an individual perceives and constructs his or own personal identity. 'Selves' is how others construct and perceive the person. Sabat and Harré (1992) suggest that in the 'self' we enable a person with dementia to be present, and this influences the way that they can be heard and understood. The problem here is that there is a tendency for others, like health care workers, to construct identities for people with dementia, and this constructed identity may fail to take into consideration the 'self' the person with dementia is trying to portray (Innes and Capstick, 2001). Building on the work of

Harré (1991), Sabat (2002) used a social constructionist approach to demonstrate that manifestations of selfhood exist in people living with moderate to severe stages of Alzheimer's disease. Using the constructionist paradigm, selfhood is explained in a variety of ways in public discourse (conversation as well as behaviour) and can be analysed into three different forms, which Sabat (2002) called Self 1, Self 2 and Self 3:

- Self 1 refers to the self of personal identity and is expressed via the use of personal pronouns such as 'me, myself, my, mine, our. Self 1 tells us that each individual has one single point of view in the world, one continuous experience of events that forms the narrative of our life.

- Self 2 is comprised of a person's physical and mental attributes and beliefs about those attributes. This can include one's height or weight, sense of humour, religious and political convictions and educational achievements.

- Self 3 is comprised of the various different social personae, which are constructed in a variety of situations in which we live our lives and each persona involves a specific pattern of behaviour, which is distinct from the others.

Each of these different social personae requires for its existence the cooperation of at least one other person in their 'social world'. Drawing on detailed case studies, Sabat (2002) demonstrated that the self of personal identity (Self 1), and to a lesser extent Self 2, persists into the later stages of dementia. However, Self 3 personae are

particularly vulnerable in ways that Self 1 and Self 2 are not. For example, if negative attitudes are displayed towards a person with dementia in their social world, and where people fail to respond to that individual's attempts to construct and maintain their social identity, this would lead to a loss Self 3 personae. Therefore, Sabat's argument is that losses in aspects of selfhood may be traced to dysfunctional social interactions rather than to the neuropathology of the disease.

2.2.11 Current perspectives on personhood and dementia

As previously rehearsed, the work of the late Dr Tom Kitwood heralded a major paradigm shift in how we approached working with people with dementia and their families. Kitwoods concept of person centred care (Kitwood, 1997) has had a major influence in the field of dementia care and this approach has become enshrined in national policy and performance targets such as the National Service Framework for Older People (DoH, 2001). However, there is growing scepticism as to the effectiveness of the person centred care (Nolan et al., 2004) along with gaps in the systematic evidence demonstrating the benefits of this approach (McCormack, 2004). The interpretation of person centred care is increasingly being seen as to narrow a concept and fails to capture the intricacy of the relationship between the person with dementia and those involved in their care (Nolan et al., 2004; Dewing, 2004).

To truly understand the subjective experience of the person with dementia, it is argued that people with dementia do not live their lives in isolation, but in the context of 'family-type' relationships (Harris and Keady, 2006). People with dementia have cautioned against taking a uni-dimensional view of their life, and to remember their

lives are lived within the context of a relationship (Nolan *et al.*, 2006), with all the concomitant layers of complexity, dependency and inter-dependency that result. Relationship centred care recognises not only the importance of the interaction between the person with dementia and their carer, but also the interaction between the person with dementia and the professional caregiver (Nolan *et al.*, 2006), and how these relationships can either help or hinder efforts to adjust to a diagnosis of dementia (Steeman *et al.*, 2006). Steeman *et al.* (2006) conclude that the importance of relationships is crucial to positive adjustment; however, this area has only been superficially touched on in the current literature.

2.2.12 Family models of dementia

In addition to the medical and social models of dementia, approaches have been developed that incorporate the experience of the family as well as that of the person with dementia. Family models differ from social models as they do not attempt to define dementia, rather, they attempt to address the effects of dementia on the informal carer (Adams, 1997).

2.2.13 Family burden model

Keady (1996) describes the importance of an early study by Grad and Sainsbury (1965) which distinguishes between the objective and subjective burden of caring. Objective burden refers to the practical impact, the physical health effects and the daily routine changes caused by the behavioural problems displayed by the person with dementia. Subjective burden is the emotional response to caring, including

perception of strain, morale, anxiety and depression (Woods, 1999). In terms of objective burden, a review by Donaldson *et al.* (1997) found that behaviour or non-cognitive features are closely related to caregiver burden, in particular, deficits of behaviours such as withdrawal and apathy, are more likely to cause carer burden than excesses of behaviour such as hoarding or sleep disturbance (LoGuidice *et al.*, 1995). No direct relationship was found between carer burden and deficits in cognitive function and activities in daily living (Burns, 2000). In terms of subjective burden, the emotional effect of providing informal care to a person with dementia is associated with higher incidences of mental health problems for the caregiver (Gilleard, 1984) and can lead to the person being admitted to institutional care (Brown, 1990). This is shown in longitudinal studies as well as cross-sectional studies (Donaldson et al., 1997). Compared with non-caregivers, carers are more likely to take prescribed medication and to visit their General Practitioner (Burns and Rabins, 2000). Subjective burden can cause the carer to experience loss, grief and bereavement before the actual death of the person with dementia (Woods, 1999). Family members, such as husbands or wives, do not always see themselves as carers. It is not until the emotional changes brought on by the burden of dementia do they accept a change of status and become a caregiver (Gilliard, 2001). Therefore, the emotional burden of caring is great, and may involve an inability to come to terms with the illness, change in status, as well as the loss of a friend or loved one, and made more difficult because the relative is still living. This process has been described as a 'living bereavement' (Taylor, 1987).

2.2.14 Transactional Model of Stress and Burden

When considering the relationship between the objective and subjective burden, it is not always a straightforward process, as it appears that some caregivers are better adjusted to caring than others (Adams, 1997). This phenomenon is explained by the transactional model of stress developed by Lazarus (1966). This model is based on the belief that potentially stressful events are 'appraised' by an individual and consequently what one person finds difficult may not be a problem for another (Nolan, 1996). The value of a transactional model and a subjective approach to understanding stress has led to a better understanding of the most difficult aspects of caring. These are related to factors such as the quality of relationships, gender, age of carer or person with dementia and coping strategies (Adams, 1997; Nolan and Keady, 2001). Closeness and affection of the past and present relationship and higher levels of marital intimacy correlate with lower levels of burden (Morris *et al.*, 1988). Negative changes in the relationship between the person with dementia and the caregiver may influence the degree of commitment relatives have towards caring. Disturbed behaviour, such as aggression, mood changes and withdrawal are closely related to negative changes in caregiver's feelings (Horowitz and Shindelman, 1983).

2.2.15 Gender and age

The literature suggests that caring is more stressful for women, although Gilhooly (1984) found that male carers have higher morale than female carers. The importance of maintaining a social life is considered a possible explanation for this finding, as men are more able to leave their relative unattended and thus maintain social contacts.

Men are also more successful in their requests for support from statutory services than woman in similar positions (Gilliard, 2001). Caregiver burden may also be related to the age of the caregiver and the younger a carer is, the greater the carer burden (Schneider *et al.*, 1999). Moreover, carer burden in carers of people in the earlier stages of dementia is significantly higher than in carers looking after people in the later stages of dementia (Freyne, 1999).

Therefore carers are not a homogeneous group. There are differences associated with the relationship to the person with dementia and between male and female carers. Other significant factors are whether the carer is co-resident, and in the caring roles and expectations within different ethnic groups (Briggs and Askham, 1999). Having a co-resident carer, for instance, reduces the risk of entering residential or nursing care by 20 times (Murray *et al.*, 2001). As previously rehearsed, caring for people with dementia is associated with higher levels of stress and depression than caring for other conditions, there is also a significant financial impact and high levels of unmet need (Philp *et al.*, 1995).

However, it is also important to consider the capabilities of carers, the satisfactions that they experience and how they cope in practice (Nolan and Keady, 2001). Reported areas of satisfaction include a feeling of job satisfaction, continued reciprocity and mutual affection, companionship, and the fulfilment of a sense of duty (Murray *et al.*, 1999).

2.2.16 Coping Strategies

Caregivers employ a variety of coping strategies when supporting a person with dementia. In order to explore the ways in which carers cope, Nolan, Grant and Keady (1996) developed the 'Carer's as Experts' model based on the transactional model of stress, that also lead to the development the Carers Assessment of Managing Index (Nolan *et al.*, 1995). This index was developed following a review of relevant literature and in-depth interviews of carers, many of whom were looking after people with dementia. The index identifies how carers manage the stresses of caring. As Nolan and Keady (2001) later reported, in dementia this is seen in three specific contexts: managing events or problem-solving, managing and reframing the meaning of the situation and managing and dealing with stress. In managing events, the most frequently used and successful coping strategies were:

- Finding out as much information as possible;
- Getting as much help as possible;
- Talking over problems with someone you trust;
- Relying on own experience, expertise;
- Planning in advance;
- Establishing regular routine.

In managing meaning, the most frequently used and successful coping strategies were:
- Realizing cared-for person not to blame;
- Taking life on day at a time;
- Realising someone is worse off;

- Seeing the funny side of things;

- Ignoring the problem, hoping it will go away.

In managing stress, the most frequently used and successful coping strategies were:

- Keeping a little free time to self;

- Taking mind off things;

- Maintaining interests outside caring.

(Nolan and Keady, 2001)

Helping carers to develop and improve their ability to cope is one of the most essential of all interventions. To do this effectively requires a comprehensive individualised assessment of individual coping styles and stressors.

The Carer's as Experts' model provides a holistic assessment of need and an individual approach to understanding carer stress and the use of coping strategies. Such a model provides a valuable foundation for developing interventions that can assist in enhancing the well-being and self esteem of carers.

A criticism of the current literature is that it tends to focus on the negative aspects of caring for a person with dementia. There are numerous studies on carer burden and stress but fewer publications on interventions for carers. Current guidelines recommend that carers should have their own assessments, and that information, education, training and support be provided for them (NICE, 2006).

There is a lack of studies concerning the impact of providing carers with information and it can prove difficult to make comparisons between studies and determine the

most effective range of interventions. However, a qualitative study by Graham *et al.*, (1997) involving 109 carers of people with dementia found that better informed carers were less depressed, The findings suggest the importance of information and knowledge in reducing stress and burden in carers and that the provision of information and educational interventions for carers at an early stage was potentially beneficial. The most recent meta-analysis (Brodaty *et al.*, 2003), which analysed 30 controlled studies, concluded that the quality of recent studies had improved. Outcomes of theses studies remained variable but overall there appeared to be a small intervention effect. Interventions involving training or stress management or involving the person with dementia alongside the carer appeared to have the largest effect on the carer's psychological health and well-being.

There is growing evidence to suggest that interventions and education for carers can be effective in improving burden and well-being and in doing so may reduce crisis and delay institutional care for people with dementia. However, the relatively small intervention effects and the large variability between studies suggest that there is much more to learn about which interventions will be most helpful to carers.

2.3   The Early Experience of Dementia

As previously rehearsed, there has been considerable research and literature aimed at understanding the experience of the caregiver. In comparison, the experience of the person with dementia has received less attention and they have been seen as incidental subjects and passive recipients in the process of their dementia (Keady and Gilliard, 1999). Coping with the onset and transition into Alzheimer's disease is anything but a

natural process and the transition is one of secrecy and fraught with anxiety (Keady and Gilliard, 1999).

The processes of seeking and establishing a diagnosis is one of the most crucial elements in the experience of dementia (Pratt and Wilkinson, 2001). Early assessment and diagnosis are complex issues and to be successful early intervention depends on the ability to detect early cognitive changes, a willingness and awareness of the individual and their carer to seek medical intervention and a general practitioner who is willing to consider that the early signs of memory impairment may indicate the need for further investigation and treatment (Clark *et al.*, 2003).

The importance of being able to accurately define mild dementia is vital if support, services and pharmacological treatments are to be offered at an early part of the condition. For an early diagnosis of dementia to be made, it is essential that the individual be assessed as soon as possible during the early stage. Unfortunately, for a number of reasons, this is not always achievable. For instance, there are concerns regarding the ability and willingness of general practitioners to diagnose early dementia. A study of 1,005 general practitioners carried out by the Audit Commission (2000) found that only half believed that it was important to actively look for the early signs of dementia and make an early diagnosis. A similar number felt they did not have sufficient training to be able to make a diagnosis and did not routinely use any diagnostic tools (Audit Commission, 2000). Many patients and carers expressed concern that their early symptoms were either missed or ignored when they first sought help and advice from primary care (Naidoo and Bullock, 2001).

Current studies suggest that General Practitioners continue to experience difficulty diagnosing and disclosing a diagnosis of dementia (Cahill *et al.*, 2006). There is also continues to be a widespread reluctance of General Practitioners to recognise dementia in the early stages (Vernooij-Dassen *et al.*, 2005). General Practitioners are reluctant to report an early diagnosis partly due to the distress that is evoked in patients and families (Greaves, 2004), their negative attitudes in regard to ageing and dementia, and the belief that there is little to offer until the later stages of the disease (Vernooij-Dassen *et al.*, 2005). However, with the advent of specialist memory clinics there is increasing evidence of earlier referral. A recent study looking at changes in referral patterns from General Practitioners to specialist services (O'Loughlin and Darley, 2006) concluded that more people with suspected dementia were being referred to specialist services and diagnosed earlier in their illness. Valdemar *et al.*, (2006), argue that a multidisciplinary approach based on close collaboration between the General Practitioner and specialist memory clinics to be an ideal model for early and accurate diagnosis of dementia and subsequent initiation of pharmacological and psychosocial interventions. However, to achieve this specialist training for General Practitioners in the recognition of early dementia and frequently updated practice guidelines are recommended (Waldemar, 2006).

The person with dementia and their carer may also play a part in delaying access to early advice and support. A study by Keady and Gilliard (1999) found that some people were able to sustain a prolonged period of subterfuge in an attempt to keep from others the reality of their difficulties. Family carers too have a responsibility in early identification and evidence suggest that they have a tendency to protect and compensate for their loved one and only seek help when a crisis is reached (Clark *et*

al., 2003). World Alzheimer's Day Bulletin (ADI, 2001) reinforced the importance of early diagnosis and emphasised the relief of knowing the signs had a name, and outlined the diagnosis as having three phases:

1.   Describing the symptoms

2.   Naming the disease;

3.   Conveying information about cause, outlook and treatment

Table 2.1 summarises the importance of early diagnosis for people with dementia, their family and relatives and professionals (ADI, 2001)

Table 2.1: The importance of an early diagnosis

For the person with dementia: • A diagnosis will convey information about cause and outlook; provide an opportunity to discuss the problem and the future and initiate access to resources and treatments. **For carer and family:** • A diagnosis should provide recognition of the carer's role; access to resources, information and support; and an opportunity to discuss outlook and practical arrangements. **For the clinician and providers of dementia services:** • A diagnosis creates a professional and therapeutic bond between the doctor and the patient; is essential for communication between professionals and can encourage funding of dementia services (ADI, 2001 p.4)

Once a diagnosis has been reached, the literature suggests that disclosing this information is a complex and sensitive issue that can be affected by the attitudes of the person with dementia, carers and clinicians. A survey by Maguire *et al.* (1996) examined the views of relatives of people with Alzheimer's disease and found that 83% of carers expressed a wish that their relative should not be told the diagnosis. Despite this, 71% of the same cohort indicated that they would like to be told if they were developing the illness. Often carers have concerns about their relative knowing their diagnosis. Those who withheld the diagnosis believed disclosure would cause too much distress, or their relative was too impaired to understand. Those carers who did share the diagnosis report that they did so either because their relative wanted to know, or to provide a meaningful explanation of what they were experiencing (Husband, 1999). A study by Johnson *et al.* (2000, cited in Pinner, 2000), examined the attitudes of geriatricians and psychiatrists of old age to giving a diagnosis of dementia. The results of the study showed that only 40% of doctors regularly inform patients the diagnosis, and 20% see no benefit in telling the patient. However, 72% would wish to know themselves if they were suffering from the illness. A finding very similar to that reported by Maguire *et al.* (1996) in a different population group.

A study of UK memory clinics by Gilliard and Gwilliam (1996) found 9 (56%) reported telling people of a specific diagnosis. Interestingly, the rationale for withholding diagnosis is to prevent harm and distress, depression and hopelessness, the difficulties of accurate diagnosis and the ability of the patient to understand and remember what they have been told. However, there is evidence to suggest that patients with a diagnosis of dementia want to know their diagnosis (Pinner, 2000).

Conversely, it must also be recognised that some people undergoing diagnostic assessment do not want to know the nature of their illness and for a minority a diagnosis can be harmful (Aluja and Williams, 2000). In clinical practice, individuals usually give 'clues' as to whether or not they wish to be told their diagnosis, and research suggests that those who do not wish to know are able to successfully articulate this in pre-diagnostic screening (Bahro *et al.*, 1995 cited in Husband, 1999). A study by Pratt and Wilkinson (2001) indicated that for most people being told the diagnosis outweighed the limitations; however, patients would require support and information to help them through the initial period after diagnosis.

Current studies suggest there remains strong opinion as to the advantages and disadvantages of the disclosure of a diagnosis of dementia and little remains known about how the person with dementia and their families understand and respond to this information (Vernooij-Dassen, 2006). A systematic review of the literature about sharing the diagnosis of dementia suggests that non-sharing of information or vague information about it is experienced as confusing, upsetting and difficult for some people with dementia and their families (Bamford *et al.*, 2004). People with dementia should receive a diagnosis and information about the prognosis and available treatments, however, disclosure is neither routine nor inevitable and their remains wide variation in practice (Monaghan and Begley, 2004). Current evidence suggests that the vast majority of people with dementia would wish to be told (Pinner and Bouman, 2003). In their study, a quarter of carers still do not wish their relatives to be informed, but a would wish to be told if they themselves were developing the illness. This is however, a significantly lower figure than previously reported suggesting a shift in attitude. The study also showed that the disclosure of a diagnosis of dementia does not cause depression or any irreversible harm to the individual (Pinner and

Bouman, 2003). People may experience distress on receipt of a diagnosis, but equally evidence suggest that with holding a diagnosis of dementia can also cause distress and hinder the ability of the individual to access positive coping strategies (Pratt and Wilkinson, 2003). In Vernooij-Dassen's (2006) study of the disclosure of the diagnosis of dementia, the findings suggest there is a gradual process of realisation of what the diagnosis means. This results in important subtle changes in the understanding of dementia and changes in personal relationships. Vernooij-Dassen (2006) stresses the importance of fully involving the person with dementia and their families in the disclosure and the importance of communicating the diagnosis clearly providing information about the condition and its prognosis. Harman and Clare (2006) stress the need for choice and to remain sensitive to individual preference, including the preference not to be told the diagnosis or not to be told certain details at a particular time.

2.4   The subjective experience of dementia

So far, this review has demonstrated that the experience of the caregiver is relatively well documented in the literature but, on the other hand, understanding the experience of people with early dementia is a relatively new area. The understanding of the subjective experience of dementia has been achieved through a number of ways as Kitwood (1997a) illustrated:

- Accounts have been written by people who have dementia during a period when their cognitive powers are relatively intact (for example, McGowin, 1993);

- Careful listening to what people say in some kind of interview or group work (for example, Cheston, 1996; Goldsmith, 1996);

- Attending carefully and imaginatively to what people say and do in the course of their ordinary life;

- Consulting people who have undergone an illness with dementia-like features and are later able to report;

- The use of our own poetic imagination (for example, Killick, 1994);

- The possibility of using role play, or acting the part of a person with dementia, and living it out in a simulated care environment.

To further increase knowledge of the subjective experience of dementia, there have been a number of research studies involving people with early dementia. A study by Keady and Nolan (1994b, 1995), informed by the experiences of ten people with an early diagnosis of dementia, described the experience as moving through 9 stages, which were identified as:

1. Slipping – the person gradually becomes aware of the lapses in his or her memory;

2. Suspecting – the lapses become more frequent, cannot be so easily discounted and the person suspects that something is not right;

3. Covering up – the person suspects that something is not right;

4. Revealing – the person shares his or her concerns with someone close;

5. Confirming – the diagnosis is made and understood;

6. Maximising – the person adapts by using coping strategies;

7. Disorganisation – there is a diminishing ability and awareness;

8. Decline – the demands of care become more prominent;

9. Death.

To aid practice in early intervention, Keady and Nolan (1995a) used these subjective experiences to create a practice assessment tool named the Index for Managing Memory Loss (IMMEL). Included in the 42 item IMMEL scale were such coping behaviours as: establishing routines; accepting memory loss and finding ways of overcoming it; writing in a personal diary; using lists and other memory aids; staying in familiar surroundings; exhibiting humour; information seeking; constant repetition to help self remember; and practising relaxation techniques. The data, from which the IMMEL was developed, was based on qualitative interviews with 10 individuals with dementia and their carers. It is recognised that the use of IMMEL could play an important part in helping to shape professional understanding of the world of the person with dementia, and enable the development of specific interventions for individuals with early dementia and their families, which is based on determining and augmenting individual coping strategies. Nolan *et al.* (1996) also suggested that the contextual issues of such transactional approaches would be enhanced if the following issues were addressed:

- Establishing the context of the caring relationship and the individuals and carer's understanding of the disease;

- Identifying and reinforce appropriate coping responses;

- Identifying and reduce inappropriate coping responses;

- Augmenting existing coping responses by building larger support networks;

- Helping to develop new coping resources/responses; and

- Recognising the need to act for the individual when they are unable to cope.

In a study by Keady and Gilliard (1999), living with early Alzheimer's disease is described as a transitional experience that involves developing a range of different coping behaviours. Table 2.2 draws together the physical, psychological and sensory sensations, which people with Alzheimer's disease describe as their first awareness of the onset of the disease.

Table 2.2   First signs and symptoms of Alzheimer's disease

- Problem-solving difficulties
- Being unable to concentrate for prolonged periods
- Thought Block
- Inability to quickly recall names
- Losing track of conversations
- Feeling disassociated from reality
- Becoming sad and depressed
- Feeling unduly angry
- Tearfulness
- Feeling and becoming lost in familiar surroundingsNot being able to fully co-ordinate and control speech and actions
- Writing block;
- Heightened sense of taste and smell

(Keady and Gilliard, 1999 p.240)

Keady and Gilliard (1999) make the point that this list is not intended to represent fully all reported first signs and some people, in their study, reported an initial experience of a combination of such signs.

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2.4.1   Awareness and adjustment in early dementia

Developing dementia will have a major impact on the person and their family and as the person attempts to make meaning of their situation and come to terms with the diagnosis, they will develop adaptive and coping strategies. A number of qualitative research studies have attempted to conceptualise the process of adaptation and coping. Cohen, Kennedy, and Eisdorfer (1984, cited in Woods, 2001) describe the following six phases of adaptation:

1. Recognition and concern;

2. Denial;

3. Anger/guilt/sadness;

4. Coping;

5. Maturation; and

6. Separation from self.

There will be individual differences in adaptation due to the interaction of the person's personality style with their biography and life experiences, influencing the range of coping strategies and adaptive mechanisms within the person's coping repertoire (Woods, 2001).

In the United States, a study by Harris and Sterin (1999) attempted to gain an in-depth understanding of the concept of self in a person diagnosed with early stage Alzheimer's disease. The qualitative study was based on semi-structured interviews with 17 participants with early stage Alzheimer's disease. One of the researchers,

Gloria Sterin, had a diagnosis of early Alzheimer's disease. Sterin interviewed the

people with early Alzheimer's disease and Harris interviewed the caregiver. The study

examined the social and psychological interactions that either affirmed or devalued

the sense of self. The study describes participant's feelings of being pushed to the side

and no longer feeling part of society after diagnosis and paints a negative picture of

early Alzheimer's disease.

Harris and Durkin (2002) build upon Harris and Sterin's (1999) earlier study and

considered the emerging area of research that examines the positive coping and

adaptation behaviours of people in early stage Alzheimer's disease. This qualitative

study was based on interviews with 22 people in early stage Alzheimer's disease and

their carers; these interviews were cross-sectional and conducted by one or other of

the authors of the paper. The analytic framework from which these narratives were

examined was organised around common themes of successful coping and adaptation

to early stage Alzheimer's disease that emerged from the data. Noteworthy from the

analysis of these narratives was that the people who adapted successfully used

multiple coping strategies from a range, and these were identified as: Acceptance and

Ownership; Disclosure; Positive Attitude and Self-Acceptance; Role Relinquishment

and Replacement; Innovative Techniques/Use of Technology; Fluidity; Utilising Pro-

Active Skills; Connection with Past Activities; Anticipatory adaptation; Altruism;

Holistic Practices; and Spirituality. As Harris and Durkin (2002) go on to explain,

this range of positive coping behaviours assist individuals with early stage

Alzheimer's disease to adapt to the challenges of living with dementia by increasing

their resilience to the stressors. Moreover, the range of coping behaviours also

provided people with Alzheimer's disease with some feelings of control over their condition and helped to instil a sense of hope in their situation.

Clare (2002) describes a model of psychological response to the early onset of Alzheimer's disease, in particular, the impact that cognitive change has on self-concept, social relationships and networks. This model aimed to offer an understanding of the way in which people experience and live with the onset of early dementia, and provides a starting point for offering appropriate support. Clare's study involved detailed interviews of twelve participants with early stage dementia and their partners, they were interviewed separately on two occasions, the interviews were transcribed then analysed using interpretive phenomenological analysis to identify common themes in their narrative. The participant's responses identified five interrelated processes (Clare, 2002 p.145):

1. Registering the changes;

2. Reacting to them;

3. Finding ways of explaining them;

4. Experiencing the emotional impact of them;

5. Attempts at adjusting.

The attempts at adjustment were shaped by the individual's reaction to the changes, the explanations they developed to account for them and their emotional responses. Responses tended to fall into two groups: self-protective and integrative responding. A self-protective stance related to attempts to normalise the situation and minimise the difficulties, thus maintaining continuity with a prior sense of self. An integrative

stance was an attempt to confront the difficulties and adapt accordingly. Most participants described strategies in the self-protective categories, whilst fewer tended to give accounts that fell into the integrative categories. Clare (2002) identified the main themes as being:

- Holding on – trying harder, sticking to routines, hoping, using medication;

- Compensating – relying on partners, use of memory aids, developing strategies;

- Fighting – fighting it as long as we can, finding out more, talking about it, being useful, focusing on the good things;

- Coming to terms – balancing hope with despair.

These four themes provide a model of adjustment and coping in early stage Alzheimer's disease and included both practical and emotional coping strategies. As we have seen, Clare (2002) defines coping strategies as falling along a continuum from self-protective to integrative responses and that there can be a tension between the two processes. In the face of this tension, there was a need to find equilibrium or balance. The need to achieve balance was reflected in a number of ways:

- Participants needed to have a realistic view of medical treatments such as medication and what their own efforts could achieve;

- Accepting help and becoming to dependent;

- Information they wanted to have and learning about the horrifying and upsetting details of their illness;

- The negative aspects of Alzheimer's disease and the ways they could learn from it and understand themselves better.

This need to achieve equilibrium could be summed up as needing to find a balance between hope and despair. Achieving and maintaining equilibrium, therefore, could be viewed as a key adaptive task that participants faced. This model of adjustment and coping provides a foundation for developing interventions that should aim to enhance well-being and self esteem in early stage Alzheimer's disease.

The limitations of these studies require discussion. Firstly, all the studies were cross-sectional and represented accounts elicited at one stage of the participant's experience. The experience of early Alzheimer's disease will change over time and understanding these changes will help to clarify the relevance of different explanatory models. To date, there have been few longitudinal studies of the early experience of Alzheimer's disease and further studies are indicated. Secondly, few of the studies have elicited the perspective of the person with dementia directly, and relied on carer interviews only or were based on observation. Such approaches tend to fall into the trap of conducting research *on* people with dementia rather than *with* people with dementia and their social networks. An exception to this rule was the study by Harris and Sterin (1999). This study commenced a new social research agenda through the integration of a person with dementia (Sterin) within the research design, conduct, approach, analysis and status (co-author) in the presented and published paper.

The current research literature is increasingly recognising the importance of the direct involvement of people with dementia as part of the research process, particularly those living with the early awareness and adjustment to dementia (Clare, 2004).

Awareness in early dementia has been the focus of a considerable amount of recent research (Steeman *et al.*, 2006). However, reviews suggest that so far this has produced little clear evidence and guidance for practitioners (Clare, 2004). There appears to be a link between awareness and the process of adjustment and the extent to which people are aware and accept the changes they are experiencing, influences the person's coping responses and benefits they get from treatments and interventions (Clare *et al.*, 2006).

In a comprehensive review of 33 qualitative studies on living with early stage dementia, Steeman *et al.* (2006) conclude that dementia, and in particular, early stage dementia is lived as a socially embedded phenomena and knowledge of this lived experience is vital to provide the most appropriate care and to maintain the quality of life of the individual. People with early stage dementia experience a transitional period that starts with the feeling that something is wrong and extends to the integration of the disorder into their lives. Common features in the experience of living with early stage dementia are feelings of uncertainty, the importance of autonomy, meaningfulness and security and the struggle between self-protection and self-adjustment (Steeman *et al.*, 2006). Clare (2003) observed that people with early stage Alzheimer's disease engage in a cyclical process of registering, reacting, explaining, experiencing, and adjusting as they live through the changes dementia brings. Positive adjustment can be seen as a balance between acknowledging the nature and prognosis of dementia and wanting to maintain a sense of identity (Harman and Clare, 2004).

Of significance, however, in Steeman *et al's*,. (2006) literature review is that there continues to be was a total absence of longitudinal studies of early awareness and

adjustment to dementia. Also it was striking that there was little evidence of partnership and collaboration between the person with dementia and their researchers. Harris and Keady (2006) argue that the experience of dementia is no longer a diagnostic label, but an evolving dynamic that embraces the whole person and covers areas of 'ethical social-psychological and neurological significance' (p. 6). Research into the experience of dementia has centred on the impact on the individual and how this affects the individual's personhood. The person with dementia does not face the illness alone and consideration of the relationships that individual has is essential in fully understanding how one adapts and copes with early dementia (Hellstrom *et al.*, 2005).

2.5   Health Policy and Dementia Care

2.5.1. Institutional Care

The provision of care to people with dementia has changed considerably over the last 30 years. The institutional approach to care that was the 'norm' prior to the 1970s (Nolan, 2003) lent itself to two fundamental criticisms. First, people with mental health problems were kept apart from other people and housed in large asylums, where they remained for long periods and often lived out their lives with little in the way of treatment. Many of the people who occupied the psychogeriatric wards were either older patients with a functional mental illness or elderly patients with dementia, or people who had entered hospital before modern methods of treatment were available and had simply grown old in them. Secondly, the care people received were often suspect and secondary to the needs of the staff and the institution. This

institutional atmosphere, with its rigid rules and timetables, and often-low standards of nursing and medical care, led to patients becoming 'institutionalised'. As Murphy (1991, cited in Tinker, 1997) describes it:

'Apathy, passivity, social withdrawal, difficult behaviour and helpless dependence on staff for daily care were regarded as an inevitable consequence of remaining for years under the control of an institutionalised, repressive regime where social conformity and acquiescence to the rules were rigidly imposed' (pp.10-11).

Murphy goes on to suggest that these symptoms were not 'miraculously prevented' by keeping people out of the institution. Since the early 1980s institutional care has fallen out of favour and has been replaced by community care and person-centred values.

2.5.2   Community Care

The growing criticisms of institutional care led to a policy emphasis on a shift from hospital to community care. This move towards community care was not without its problems. The Audit Commission (1986) report 'Making a Reality of Community Care' identified 'serious problems' with community care for older people, which included: slow build-up of community based services; uneven provision of local authority services across the country; and the rapidly growing number of people in private residential and nursing care supported by social security benefit payments and without a needs assessment. In response, the UK government commissioned the Griffiths Report (HMSO, 1988). This report heralded a new approach to community

care and introduced the concept of a free market. The recommendations of the Griffiths Report (HMSO, 1988) informed the White Paper *Caring for People* (Department of Health (DoH), 1989) and it was this document that introduced the 'mixed economy of care' that saw the role of the Local Authority move away from direct service provision to purchasing services from independent sector organisations (Cantley, 2001).

The philosophy behind this new approach was embedded in the National Health Service and Community Care Act (DoH, 1990). The objectives of this Act were to:

- Enable people to live as normal life as possible in their own homes or in a homely environment in the local community.
- To provide the right amount of care and support and to give people a greater individual say in how they live their lives and the services they need to help them do so (DoH, 1990).

At the turn of this century, the production of the National Service Framework (NSF) for Older People in England (DoH, 2001) has reiterated the governments on-going commitment to helping people stay in their own homes and advocating this as an important component of a modern health and social care service. Standard 7 of the NSF outlines a comprehensive strategy to provide mental health and social care for older people in England. Standard 7 also addresses the needs of younger people and promotes the positive virtues of younger people with dementia. At the time, it was anticipated that much of the content and targets of the NSF in England would be duplicated in Wales, a statement that turned out to be true. Standard 7 of the NSF

(DoH, 2001) sets out key requirements for a comprehensive mental health service for older people as:

- Promoting good mental health in older people;
- Early detection and diagnosis;
- Integrated approaches to assessment, care planning and treatments;
- Support for carers;
- Providing a specialist mental health service.

To make this a reality, health and social policy advocates that traditional ways of working need to change with the development of multidisciplinary teams and the greater involvement of users and carers (DoH, 2001).

Adams *et al.* (2001) describe two main approaches that have helped people with dementia stay at home. The first approach is the 'care for the carer approach', which focuses on the needs of carers, who provide care for people with dementia. This approach is advocated by a number of health and social care policies, such as Caring about Carers (DoH, 1999b). As a result, the focus of dementia care became the caregiver and this resulted in the development of new assessments and interventions concerned with the carer's ability to cope effectively. The second approach focused on the person with dementia rather than their family carers. In the early 1990s a greater understanding of the experience of the illness from the person with dementia perspective was achieved. At the same time the work of Professor Tom Kitwood and his colleagues at the Bradford Dementia Group was becoming influential in promoting the personhood of people with dementia and developing a 'new culture of

dementia care' (Kitwood, 1997). As previously discussed, this alternative approach has served to raise the profile of the person with dementia and their ability to make choices about the services they wished to receive, and has been instrumental in influencing health and social policy such as the NSF for Older People (Department of Health, 2001).

Early assessment of dementia is increasingly seen as an important requirement of a mental health service for older people and has been reflected in a number of key policies. The Carers (Recognition and Services) Act (DoH, 1995: p.4) states that services should recognise the value of early intervention and ongoing support in preventing deterioration in the carer's and user's welfare. The importance of early identification of symptoms and referral to specialist services are key themes running throughout the Audit Commission (2000) report *Forget Me Not*. In England, Standard 7 of the NSF for Older People (DoH, 2001) sets out clear guidelines recommending the early recognition of symptoms, access to specialist care and increased support for GPs and members of the primary care team. The significance of early intervention is that it represents a subtle shift in emphasis from a reactive to proactive response to the identification of early dementia. This raises some complex questions for service providers and policy makers were the traditional emphasis of service provision lies with the more advanced stages of dementia where services can be visible and support for the carer recognisable (Keady and Gilliard, 1999).

2.5.3 Contemporary Policy Themes

Current services for people with dementia have been shaped by the community care reforms of the 1990's and a plethora of more recent government initiatives. Cantley (2001) describes six main policy themes that shape dementia services:

1. The development of planning and commissioning services to ensure a consistent multi-agency approach to assessing needs and raising the profile of dementia services;

2. The development of primary care services to play an essential role in the delivery of effective dementia care;

3. Greater emphasis on joint working between agencies;

4. Improving standards and making them explicit is a central theme. An example of this is the introduction of a National Service Framework to improve the quality of services and reducing local variations in services;

5. The development of a sustainable system to fund long term care for older people in their own homes and in other settings;

6. Increased emphasis on independence and empowerment for older people to enable them to shape the services and care they receive.

As the location of this study takes place in the counties of Conwy and Denbighshire in Wales, the Welsh Assembly Government (WAG) governs health policy and strategic direction as it impacts on all aspects of such care provision and funding, the next section will review specific Welsh policy in relation to dementia care.

2.5.4 Review of Welsh Policy

Since the establishment of the WAG in 1998, a number of policy documents have set out a distinct vision for older people in Wales. The Welsh Assembly's Strategic Plan for Wales (WAG, 2001) provides an overall framework for policymaking. It includes a requirement for the NHS and its partners to work together to improve health and social well-being for the people of Wales and reduce inequalities in health. Another key policy document, Improving Health in Wales - A plan for the NHS with its Partners (WAG, 2001), provides further direction for health and social services in Wales, in particular, the formation of Local Health Boards (LHB) and enhancing primary care services.

The requirements of carers in Wales are represented by its own specific strategy Caring about Carers (WAG, 2001), which ensures that carer's issues, are represented in key strategies and policies. The WAG regards the development of effective mental health services as a priority for health and social care agencies in Wales. In September 2001 it released separate strategies for children and for adults of working age. The WAG intention is to develop mental health services for older people that link closely with those for younger people, and has committed itself to develop a specific strategy for older people with mental health problems. The intention of these policies is to improve and modernise the health service in Wales and give a clear direction for local services.

In January 2000, the Audit Commission published Forget Me Not (Audit Commission, 2000) a report on mental health services for older people. As detailed

earlier in section 2.3 of this thesis, this report sets out the Commission's analysis of the state of these services, based on visits to twelve areas, including two in Wales. Since this publication, there have been further reviews of mental health services for older people, specific to Wales. *Losing Time* (Audit Commission, 2001) is a review of mental health services in Wales and used the same methodology as *Forget Me Not* adapted to take account of Welsh Policy. The Audit Commission's focussed on the following key requirements for a comprehensive older people mental health service, and there is some duplication with NSF requirements. :

- Early diagnosis and help;
- Helping people to stay at home;
- Services for people stay at home;
- Services for people who can no longer stay at home.

The Audit Commissions *Forget Me Not* and *Losing Time* reviews (Audit Commission, 2000 and 2002b) have identified shortcomings in mental health services in Wales. There are local variations, but if mental health services in Wales are to improve then the following actions are identified as being required:

- Improving access to service for people in the early stage of their condition, in particular general practitioners should diagnose dementia early and refer to specialist services such as memory clinics;

- Develop specialist multi agency older people mental health teams and have clear access criteria;

- Actions to improve joint working between agencies;

- Specialist older people mental health teams to provide dementia training for residential, nursing home staff along with hospital staff.

The Audit Commission will subject older people mental health services in Wales to on-going reviews, and it is clear that health services will need to act on the review recommendations and develop services accordingly.

2.5.5 National Institute for Health and Clinical Excellence (NICE)

For people with early dementia, the National Institute for Clinical Excellence (NICE) guidelines on the use of anti-dementia drugs has been instrumental in the development of new services in Wales, such as memory clinics (NICE, 2001). NICE is an independent organisation responsible for providing national guidance on treatment and care for those using the NHS in England and Wales. The guidance is for health care professionals, patients and their carers to help them make decisions about effective treatment and health care. NICE (2005) produces guidance in three key areas:

- The use of new and existing medicines and treatments;
- The appropriate treatment and care of patients with specific diseases;
- Whether current procedures used for diagnosis and treatment are safe enough and work.

In January 2001, NICE recommended that the drugs Donepezil, Rivastigmine and Galantamine should be made available in the NHS as one component of the management of those people with mild to moderate Alzheimer's disease

The guidelines also recommend the establishment of specialist clinics to diagnose Alzheimer's disease and prescribe and monitor the drugs. These guidelines were taken forward by the Audit Commission who recommended the establishment and funding of memory clinics.

The NICE guidelines and recommendations are a clear example of 'evidence' of good practice in dementia care (Cochrane Reviews). With the publication of these key policies, reviews and guidance a framework has emerged, that outlines a comprehensive mental health service for older people in Wales.

The National Institute for Health and Clinical Excellence (NICE) and the Social Care Institute for Excellence (SCIE) (2006) have recently produced a major evidence based good practice guideline on health and social care for people with dementia and their families (NICE/SCIE, 2006). The guideline makes a large number of detailed recommendations for the identification, treatment and care of dementia across the whole health and social care systems. Besides incorporating the NICE appraisal guidance on the use of drugs for people with Alzheimer's disease, the guideline also sets wider standards for the care of people with all types of dementia which clinicians and commissioners are expected to implement. The guideline recommends therapies and treatments in addition to the use of acetylcholinesterase inhibitors for moderate Alzheimer's disease, including:

- Structured group cognitive stimulation programmes in all types of mild and moderate dementia;

- Alternative therapies for people with dementia and agitation such as aromatherapy, multi-sensory stimulation, therapeutic use of music and/or dancing, animal-assisted therapy, or massage;

- Cognitive behaviour therapy for people with dementia who have depression and/or anxiety; the therapy may include their carers; and

- Various sensory stimulation therapies for anxiety e.g. reminiscence therapy, multi-sensory stimulation, animal assisted therapy and exercise for people with dementia with depression and/or anxiety.

These new guidelines have been open to some criticism particularly in relation to the prescription of acetylcholinesterase inhibitors; however the success of the NICE/SCIE (2006) guidelines for dementia care is that it has provided an exemplar for the future development of practice guidelines for integrated health and social care services (Gould and Kendall, 2007).

2.6 Chapter Summary

There have been significant advances in the understanding and treatment of dementia over the past twenty years. In the past dementia services were without doubt 'Cinderella services' typified by low professional and organisational status. This period has witnessed a number of key changes in philosophy, practice and policy in relation to dementia care. The biomedical model has made a number of important scientific advances in the understanding of dementia. However, this approach has its

limitations in some aspects of dementia care since 'cure' is not an option. As a result, there has been a substantial shift towards the psychosocial aspects of dementia care. Kitwoods view of dementia has brought about a radical shift in thinking about the nature of dementia. This change in philosophy has also brought about a shift towards recognising the person despite their dementia and a growing interest in the subjective experience of dementia. There has been a growth in professional enthusiasm for practice development in dementia care, this can be seen in the introduction of psychosocial interventions to compliment existing biomedical approaches. The main health and social policy thrust has been towards the provision of care in the community. The challenge has been to develop comprehensive community dementia services to meet the growing numbers of older people vulnerable to developing dementia. Policy has also reflected the changing role of the caregiver from the unseen supporter to the primary focus of intervention. Finally, there has been a more recent change of emphasis in philosophy, practice and policy towards early intervention and diagnosis bringing with it a fundamental shift from a reactive to a proactive response to dementia care.

CHAPTER 3:

MEMORY CLINICS

3.1   Introduction

There have been significant advancements in the treatment and understanding of dementia in recent years and as a result, older people's mental health services have needed to move towards the diagnosis of early and mild dementia rather than intervene at the moderate to severe stages (Bullock, 2002).

Indeed, the importance of the early identification of dementia and referral to specialist services, such as a memory clinic, are now seen as a service and policy imperative (Audit Commission, 2000; DoH, 2001). For example, early intervention has been shaped by national policy and standards such as NICE guidance on the use of anti-dementia medication (NICE, 2001) and the NSF for Older People (DoH, 2001). Memory clinics have also been supported by the Audit Commission (2000) report '*Forget Me Not*' as being valuable for their role in co-ordinating assessment and treatment for people with early memory problems.

In 2000, WAG made available funding to develop a comprehensive memory clinic service in Wales. It was at this time that I was appointed to the position of nurse specialist with responsibility to develop and implement a memory clinic service in the counties of Conwy and Denbighshire in North Wales. The most established of these

memory clinics is situated in the town of Rhyl, and this clinic has been used to recruit

people with early Alzheimer's disease reported in this study.

Whilst advocating the importance of developing early intervention in dementia care

and the development of memory clinics, the NICE guidelines and NSF standards stop

short in providing a definitive guidance as to what exactly constitutes a memory clinic

(Phipps and O'Brien, 2002). This creates a national conundrum as to what exactly

constitutes such a service. Critically addressing this point forms the remainder of this

chapter and will start with a review of the history of the memory clinic service.

3.2   History of Memory Clinics

Memory clinics originated in the USA in the early 1970s and subsequently in the UK

in the early 1980's. In the UK, the first clinic was established in 1983 at St Pancras

Hospital, London subsequently moving to the Whittington Hospital in North London

(Wright and Lindesay, 1995). This initiative coincided with the development of the

psychogeriatric movement in the UK that recognised the speciality of old age

psychiatry, and established a nationwide system of specialist services for older people

with mental health problems, including specific services for younger people with

memory problems (Fraser, 1992). A survey of British memory clinics carried out in

1993 found there were 20 memory clinics in the UK, and these first clinics were

established in academic centres and were used primarily for research purposes

(Wright and Lindesay, 1995), and as a means of identifying early causes of dementia

and instigating early research on anti-dementia medication (Pitt, 2001). The survey

was repeated in 2002 and saw an increase in the number of clinics to approximately

58 (Lindsay *et al.*, 2002). These newer clinics were providing a broad range of services, moving away from the traditional academic research clinics to NHS funded clinics, concentrating more on service provision than research (Phipps and O'Brien, 2002). The introduction of drugs for Alzheimer's disease to clinical practice in 1997 saw the development of many new memory clinics to facilitate the treatment of patients with early and moderate Alzheimer's disease, many of whom previously would not have been known to services (Ellis *et al.*, 2000). The reluctance of physicians to give a diagnosis of dementia to someone who is either young or whose dementia is in the early stages is also cited as a reason for the growth in the number of memory clinics (Luscombe *et al.*, 1998).

3.3   What is a Memory Clinic?

From a review of the literature, it appears that the aim of a memory clinic is to provide a service for people with early memory problems and to provide assessment and diagnosis before their problems become too advanced (Philpot and Levy, 1987). This represents a shift from traditional older people mental health services whose focus is mainly on people in the moderate to later stages of dementia (Luce *et al.*, 2001). To be successful, early intervention depends on the ability to accurately detect early cognitive changes, a willingness and awareness of the individual to seek medical intervention and a GP willing to consider that the early signs of memory impairment are worth further investigation and treatment (Clarke *et al.*, 2003). There is no single definition of the role or function of a memory clinic and a number of models exist (Phipps and O'Brien, 2002). However, an effective memory clinic should provide a full range of services which involve: accurate cognitive assessment, counselling,

education and involve the carer in this process (Logiudice *et al.*, 1999). Those clinics that restrict their interest to the diagnosis and treatment of dementia, will fail to meet the psychological and emotional needs of the person with dementia and their family (Moniz-Cook, 1998). Therefore, a comprehensive memory clinic service should provide a number of core functions such as the provision of specialist multi-disciplinary assessment, information and advice to patients and carers, initiation and monitoring of treatment and education and training (Lindesay *et al.*, 2002).

For those clinics that provide a full range of services, there appear a number of benefits:

- The earlier availability of information and support will offer the patient and their families the opportunity to adapt and cope with later decline (Luscombe, 1998);

- By focusing on memory problems as an early indication of dementia, it may result in people being referred earlier in the condition allowing for comprehensive assessment to have been completed before a crisis has developed, with specialist services being called in too late to provide sufficient help (Moniz-Cook, 1998);

- Early diagnosis will allow access to pharmacological and psychological interventions, which are more likely to be effective if commenced early in the disorder (Lindesay, 2003).

In a comparison of memory clinics and traditional old age psychiatric services by Luce *et al.* (2001), it is apparent that memory clinics are attracting a different

population, where patients are younger, they have lower levels of cognitive impairment, are being seen two years earlier in the course of the disorder and are more independent and living at home. The conclusion is that memory clinics identify dementia earlier and have the potential to make a valuable contribution to patient care.

As a means of providing an early diagnosis of dementia, and co-ordinating medication and psychosocial support for people with dementia and their families, memory clinics appear central to any modern, reflexive, mental health service (Wilcox *et al.*, 1999).

3.4   The Memory Clinic Team

A successful memory clinic will require a core team of clinicians which will include, medical staff, clinical psychologists, nursing staff, occupational therapy, and administrative staff. The core team will have links to other expertise including social worker, speech and language therapist, dieticians, welfare rights officer, and the Alzheimer's Society (Walker and Butler, 2001). A multi-disciplinary assessment is seen as preferable (Ferran *et al.*, 1996) and where memory clinics exist, people find this is a more acceptable means of having their memory problems investigated than being referred to a psychiatrist or neurologist alone (McLennan, 1999).

3.5   The Work of the Memory clinic

There appear to be three essential components to a comprehensive memory clinic service: assessment, review and post diagnostic interventions (Lindesay, 2003), and each of these components will be reviewed in turn.

3.6   Assessment

The first component of assessment is the measurement of cognitive performance. The aim of the assessment process is to determine the cause of memory impairment, provide a diagnosis and initiate psychosocial interventions and pharmacological treatments, such as anti-dementia medication. However, in its broadest sense, assessment refers to the assessment of the individual's health, cognitive profile and their psychosocial context. Assessment will need to cover all these areas if it is to make a meaningful contribution to the care of the individual (Bucks *et al.*, 1998).

To ensure an early and accurate diagnosis people should be referred to a memory clinic as soon as they start to experience, or have concerns, regarding their memory. The individual's general practitioner will typically initiate a referral. General practitioners and primary care staff are often the first port of call and should be alert to the early signs of dementia (Naidoo and Bullock, 2001). Specific referral criteria should be developed, which includes a simplified cognitive test to facilitate appropriate and early referral (Naidoo and Bullock, 2001). Studies have shown that in health districts where memory clinics exist, referral patterns and the identification of dementia is increased (Thompson *et al.*, 1997; Audit Commission, 2000).

Before attendance at the memory clinic, the patient and their carer will require information about their assessment and what to expect. A preliminary assessment should be provided (Bucks *et al.*, 1998) as this can filter out inappropriate referrals, those people who are found not to have dementia, but may be experiencing conditions such as depression, can be referred to more appropriate services (Lindesay, 2003).

Preliminary assessments carried out at home generally provide better information about the patient and their carer and will ensure the establishment of a therapeutic relationship in the person's 'own territory' where they are more relaxed and less threatened (Naidoo and Bullock, 2001).

3.6.1   Medical Assessment

A medical assessment will include a detailed history, mental state examination, physical examination and information obtained from carers (Harvey *et al.*, 1999). The history is the most important part of the medical assessment, determining early symptoms are helpful in making an early diagnosis, in particular the consequences, duration and progress of memory impairment (Walker and Butler, 2001). The patient's medical history is important as it may indicate a specific cause such as cerebrovascular disease, head disease injury and Vitamin B12 deficiency (McLennan, 1999). This information will help to establish a specific cause of the dementia; it will also identify any potential reversible cause for the memory impairment such as delirium or depression or conditions such as infection, side effects of medication, polypharmacy or endocrine disorders such as hypothyroidism (Naidoo and Bullock, 2001). It is also important to diagnose depression as it can be misdiagnosed as early dementia, or it may coexist with dementia in the early stages (Woods, 2001).

A detailed physical examination is also an important part of the diagnostic process in dementia. Initial blood tests and physical examination should be completed by the GP and be included as part of the referral care pathway (Lindsey, 2003). Currently, there is no diagnostic blood test for dementia (Walker and Butler, 2001). The focus of these

investigations is to identify conditions that might themselves account for, or compound, memory problems (Freter *et al.*, 1998). Routine blood tests will include a full blood count, urea and electrolytes, liver function tests, thyroid function test and serum B12 and folate. The results of these tests will be useful in determining the presence of reversible causes of dementia (Naidoo and Bullock, 2001). More detailed physical tests will involve a neurological examination. The presence of focal signs can suggest a diagnosis of cerebrovascular disease or space-occupying lesion (Lindsey, 2003). Physical examination of the limbs, in particular increased tone, can be an indicator of dementia with Lewy bodies (Walker and Butler, 2001).

Most memory clinics will have access to the structural neuroimaging methods of computerised tomographic (CT) and magnetic resonance imaging (MRI) scans. The main purpose of these scans is to exclude intracranial causes for the patient's symptoms such as tumours, abscesses, normal pressure hydrocephalus and subdural haematomas (Bullock and Qizilbash, 2002).

3.6.2 Psychological Assessment

A comprehensive assessment of memory problems requires three key elements: medical assessment, neuroimaging and psychological assessment (Walker and Butler, 2001). A clinical psychologist may conduct psychological assessment. In many clinics, however, basic assessments are undertaken by other staff (Lindesay, 2003). The assessments will make use of validated instruments and rating scales designed to measure aspects of cognition and non-cognitive function (Berrios and Hodges, 2000). The purpose of psychological testing is to determine the presence of cognitive

deficits, to measure the nature and scope of such deficits, to act as a diagnostic tool

and treatment aid, and act as a baseline for future assessments (Walker and Butler,

2001). There is no 'hard and fast rule' as to the choice of which psychological tests

should be used in the assessment process and there are a number in existence (Bucks

and Lowenstein, 1999). The information provided by these tests will assist in

obtaining an accurate diagnosis, inform the patient and their carer about current

performance, the changes they may expect in the future and the implications of these

for every day functioning (Bucks *et al.*, 1998).

3.6.3   Non-cognitive Assessment

There are a number of other scales used by memory clinics in the assessment process

to measure non-cognitive symptoms such as behavioural and psychological

symptoms, activities of daily living, depression, and quality of life and caregiver

burden. As with cognitive assessments, there are no standardised tests for measuring

non-cognitive symptoms and there are a number in existence (Burns *et al.*, 1998).

3.6.4   Assessment Scales

Lindesay *et al* (2003) describe the most commonly used assessment scales in UK

memory clinics. They are the Mini Mental State Examination (MMSE) (Folstein *et

al.*, 1975), the Geriatric Depression Scale (GDS) (Yesavage *et al.*, 1983), the

Neuropsychiatric Inventory (NPI) (behaviour and carer burden) (Cummings *et al.*,

1994) and the Bristol Activities of Daily Living Scale (Bucks *et al.*, 1996). Potential

limitations of the MMSE include associations with low education levels and

sensitivity to depression. There will also be difficulties in its use with people with language impairment and sensory impairment or people who are been tested in a second language. Where English is not the person first language, the use of an interpreter should be considered (NICE-SCIE, 2006).

Cognitive and non-cognitive assessments are also a key requirement of NICE guidelines on the specialist assessment of early dementia and the prescription of acetylcholinesterase inhibitors.

3.6.5 Other Assessments

Other assessments will include a social assessment comprising the carer's perspective a functional and financial assessment (Walker and Butler, 2001). Memory clinics are ideally placed to provide practical advice and written information on Enduring Power of Attorney, Living Wills and driving with dementia (Lindesay, 2003).

3.6.6 Diagnosis

After the assessment process is complete, the multidisciplinary team will meet to determine whether a diagnosis can be made. If not possible, then a re-assessment may be offered at a later date, which may provide additional evidence to support the presence or otherwise of a dementia. When diagnosis is possible, careful consideration is required as to how this information is given to the patient and carer (McLennan, 1999). Disclosure of the diagnosis has become of greater significance in recent years due to success of memory clinics in identifying people in the early stages

of the condition and the necessity for individuals to be able to consent to drug

treatments, make decisions regarding their care and plan for the future (Pinner, 2000).

There is increasing evidence to suggest that memory clinics are providing pre and

post diagnostic counselling, based on models developed in cancer and HIV services

(Royan, 2000). The preparation of the patient and their family is an essential part of

the process of sharing a diagnosis. It will give clues as to how best to break this news,

and assess the best approach and timing that will be individually required (Bucks *et

al.*, 1998).

When the diagnosis is shared, sensitivity, flexibility and discretion are required.

Disclosure should not be a 'one-off event' and but an ongoing, dynamic process and a

fundamental part of the care of the patient with dementia (Pinner, 2000). Alzheimer's

Disease International have described the shock of a dementia diagnosis, emphasising

the value of good, accurate information in assisting to resolve some of the anxiety to

the person and their families. The delivery of the diagnosis should include an

explanation of the assessment and a summary of the test results (Bucks *et al.*, 1998).

This information should be given in clear terminology so that the patient can

understand it (McClelland, 1999). However, McClelland (1999) makes the point that

very few people retain up to 50 per cent of the content of a consultation. Therefore,

the use of written information and ongoing explanation of the interventions and

treatments is vital (review process). Carers will require an explanation of the

diagnosis, its prognosis and treatments along with an explanation of support services

and voluntary organisations (Lindesay, 2003).

3.6.7   Medical Treatments

Memory clinics play a significant part in the prescription and review of anti-cholinesterase treatments such as donepezil, rivastigmine and galantamine (Bullock, 2002). The National Institute of Excellence (NICE, 2001), regard ChEI as an important part of a comprehensive pathway of care and acknowledges the further development of memory clinics to support these medications (Phipps and O'Brien, 2002). The licensing of these medications has increased the importance of an accurate diagnosis of Alzheimer's disease in particular (McKeith and Fairburn, 2001). Memory clinics can play a significant role in ensuring that these treatments are targeted effectively and that their benefit is established for individuals (Evans *et al.*, 2000).

Research suggests that the use of these drugs have a positive impact in improving cognition and behavioural symptoms especially in the early stage of dementia (Ellis *et al.*, 2000). Bullock (2000) makes the point that these drugs are only the first generation of treatments, and it is important that the person and their carer receive a full explanation as to their effectiveness, in order not to raise expectation. On a positive note, these medications have increased awareness of Alzheimer's disease, and are seen as a stepping-stone to more effective disease modifying medications (Bullock, 2000).

3.7   The Review Process

The second main function of a memory clinic is review. The post diagnosis period has traditionally been a time when little is offered in the way of regular support and

contact by health and social services, whose main attention shifts to crisis management or taking responsibility for people in the later stages of the condition (Page, 2003). However, evidence suggests that after diagnosis of early dementia regular review is important (Naidoo and Bullock, 2001).

The review process will be concerned with how the person with dementia and their family have adjusted to the diagnosis and treatment options (Page, 2003). The provision of timely and accurate information, communicated in an acceptable way, has been found to have a beneficial effect on how carers and the person with dementia understand and work with the disease over the remainder of the course of the illness (Clark *et al.*, 2003). An important part of the review process will be to determine the persons and carers coping strategies, whether there has been a positive adjustment to diagnosis, is there evidence of depression or other psychiatric morbidity (Lindesay, 2003).

The review process is also governed by guidelines issued by NICE (2001), which calls for memory clinics to repeat testing of cognitive and non-cognitive function and to determine effectiveness of anti-dementia medication. This guidance also stresses the importance of monitoring medication compliance and a physical review to determine the presence of any adverse effects. In order to provide prompt advice and support to the patient and their family, NICE (2001) recommend that the frequency of review is typically every four to six months.

3.8   Post-Diagnostic Interventions

The third component of a memory clinic service is the provision of post-diagnostic interventions. These interventions cover three main areas, psychosocial interventions, crisis prevention and future planning (Bucks *et al.*, 1998).

There is great potential for developing psychosocial intervention strategies through memory clinics and for those with early memory impairment (Moniz-Cook and Woods, 1997). Psychosocial interventions include a range of therapies such as: counselling, cognitive training and rehabilitation, reminiscence and life review, cognitive behavioural therapy and relaxation (Kasl-Godley and Gatz, 2000; Woods, 2001). Those memory clinics that provide interventions such as cognitive behavioural therapy and relaxation have found this to make an important contribution to meeting the psychological needs of people with early dementia and of particular benefit to their carers (Ashton, 2003). However, programmes of memory training and other psychosocial interventions are often only patchily available (Royan, 2000).

For carers of people with dementia attending a memory clinic in itself has been shown to improve their quality of life (Longiudice *et al.*, 1999) and carer education and support groups of benefit, even delaying time to institutionalisation (Brodaty *et al.*, 1997). Helping the person newly diagnosed with dementia and their family to understand the disease and to plan for the future may restore their feeling of control, contain anxiety and reduce the risk of crisis (Moniz-Cook and Woods, 1997).

3.9 Research and Education

In their survey of memory clinics in the U K in 2002, Lindesay *et al.* (2002) found that the majority of memory clinics were providing a focus for clinical dementia research and professional training. In particular, memory clinics were establishing links with academic centres for the purpose of training, subject recruitment for research, protocol development, service evaluation and the dissemination of good and innovative practice.

3.10 The Role of the Nurse in Memory Clinics

To date, there is limited research on the specific role of the nurse in the memory clinic. However, it is suggested that the nurse can make a significant and positive contribution to the function of a memory clinic (Page, 2003). Page describes the work of the Manchester Memory Clinic, which was the first to be awarded a Charter Mark for excellence in public service and is cited by the NSF for Older People (DoH, 2001), as a positive model of clinical practice. This clinic provides a unique nurse triage model where the nurse takes the lead in a number of the memory clinic functions, such as the preliminary assessment where the nurse will begin to develop the all important therapeutic relationship with both patient and family. The nurse also leads the review process that will include the monitoring of anti-dementia medication. In the post-diagnostic phase, the nurse plays a crucial role in the psychosocial support of the person with dementia and their family, and in reducing crisis by working in a preventative and therapeutic way. This approach helps to fill the service void after

diagnosis by working with the person with dementia and their family to help them adjust to living with its early impact (Page, 2003).

3.11   Memory Clinics and the Early Experience of Dementia

As previously rehearsed, early intervention in dementia is a relatively new and evolving area of service provision and the evidence base for practice is in many respects limited (Keady and Gilliard, 1999). There is no single agreed model as to what constitutes a comprehensive memory clinic service and different models and approaches exist. The unique needs of the person with early dementia and their families are significantly different to that of people and their families with moderate to later stage dementia. Understanding the early experience of dementia will be essential if appropriate, comprehensive services for this group of people are to be developed. The key aim of this study is to gain a greater understanding of the early experience and, in doing so, make a significant contribution to service and practice development.

3.12   Current literature and perspectives on Memory Clinics

In most areas memory clinics continue to be the focus of early intervention in dementia care, and continue to enjoy a prominent position in Government policy and initiatives. For example, Everybody's business, a service development guide produced by the Department of Health, sets out the key components of a modern older peoples mental health service (DoH, 2005). This key document advocates the importance of early assessment and intervention and the development of a memory assessment

service to provide this. The document stresses the importance that such a service should provide activities such as pre and post diagnostic counselling, diagnosis sharing and psychosocial interventions. In Wales, a National Service Framework for older people has been published (WAG, 2006). This Welsh Assembly Government document, aims to provide a strategic framework and standards for mental health services for older people in Wales. The framework stresses the importance of early diagnosis and assessment and memory clinics should be made available for the specialist diagnosis and management of dementia (page 138). Another key Welsh Assembly document, Designed for Life (WAG, 2005), is a strategy aimed at modernising the NHS in Wales and advocates that each local health service should ensure there is access to memory clinics for individuals who require an early assessment of memory difficulties. The strategy recommends that each area in Wales should have a memory clinic service by April 2007 (WAG, 2005 p 68). A recent review by the National Institute of Health and Clinical Excellence (NICE, 2005) while questioning the cost effectiveness of the licensed, and previously approved, acetylcholinesterase inhibitors, made it clear that they were pleased that their earlier guidance had initiated the development of memory clinics.

However, despite the predominance and importance given to memory clinics, there still remains no clear definition of an exemplar clinics or evidence regarding the effectiveness of memory clinics within a comprehensive older people mental health service (Jolley et al., 2006a). The National Audit Office (NAO, 2007) have recently produced a critical review of dementia services, in particular the lack of priority given to early intervention. The report claims that vast amounts of money are being wasted on inadequate dementia care and resources need to be re-directed to early

interventions services such as memory clinics. The report was also critical of the time it took to receive a diagnosis and it can take twice as long to be diagnosed with dementia in the UK than in Europe (NAO, 2007). Early intervention may be cost effective by enabling more to be done to delay the progression of the disease, reduce the number and length of acute hospital episodes and delay admission to more expensive long-term care (NAO, 2007). As previously rehearsed, the demand for dementia services are expected to reach 'crisis levels' as the aging population means the numbers of people developing dementia will soar with a projected increase of nearly 40% over the next 15 years (Knapp *et al.*, 2007) and the NAO (2007) review argues that prioritising early intervention will be a cost-effective way to meet predicted demand.

A recent review of memory clinics (Pelosi *et al.*, 2006) has been critical of the development of early intervention services. Pelosi *et al.* (2006) argue the development of memory clinics has caused tensions within traditional older people mental health services. Pelosi *et al.* (2006) argues the development of specialist memory clinic services has distorted clinical priorities. In particular, specialist memory clinic teams have recruited full multi-disciplinary teams while there is a shortage of staff in mainstream services. Specialist memory clinics have an over reliance on detailed neuropsychiatric assessment and nurses waste valuable time monitoring the decline of patients on cholinesterase inhibitors rather than ensuring the delivery of multidisciplinary care plans. Pelosi *et al.* (2006) argue that this model of memory clinic targets individuals at the early stage of the illness and fails to offer a service as the patients mental state declines, this means that the clinics are confining themselves to the easy parts of the management of the disorder and patients are discharged to the

old age psychiatric services when their cognitive and behavioural disturbances become problematic. Pelosi *et al.* (2006) calls for a more integrated model and advocate that modern dementia health care involves working with patients and their families from referral to death. They argue that old age psychiatric services and their multi-disciplinary teams are best placed to provide a memory service, including the monitoring of acetylcholinesterase inhibitors, and these teams should aspire to early intervention work, as well as working with patients and their families in the moderate and later stages of the condition. However, not all agree, as Jolley and Benbow (2006b) are strong advocates of the specialist memory clinic model citing the ongoing success of memory clinics in encouraging early identification of memory problems, the provision of high quality investigation and diagnosis, counselling and education for patients and their families along with a valuable contribution to research and audit. However, as Jolley and Benbow (2006b) point out, as early intervention services evolve there is evidence to suggest that these two services are beginning to integrate.

A modern dementia service is now seen to have two 'streams' of service: an 'early intervention stream' provided by the memory clinic and a 'serious mental health stream' provided by the community mental health team (Knapp *et al.*, 2007) The key to the future development of dementia care services is whether these two streams of service remain separate or integrate into a one all embracing memory assessment service.

The NICE SCIE (2006) revised guidelines continue to stress the importance of specialist assessment of suspected dementia and recommend that memory assessment services can be provided by either a memory clinic or the community mental health

team. NICE-SCIE (2006) recommend that memory assessment services should be the single point of referral for suspected dementia but does not detail how this should be provided. NICE-SCIE (2006) recommends that memory assessment services should provide early intervention to maximise quality of life and manage risk, offer home based assessment, give pre- and post diagnostic counselling, make use of specialist psychometric assessments and timely brain imaging for diagnosis, explain the diagnosis, give information about prognosis and options for care, provide advice and support and pharmacological treatment, follow-up and review.

3.13   Chapter Summary

Memory clinics are constantly changing. From the few academic and drug research clinics of the 1980s have developed the comprehensive assessment and treatment clinics we see today. The increasing demand for assessment and treatment of early dementia is likely to continue as the general population ages and public knowledge of treatments and interventions increases. As memory clinics develop further they are moving out of their central bases and increasingly taking the assessment to their clients in their own home. Memory clinics are integrating more closely with general practitioner services and existing community mental health teams. Memory clinics have often been used to pilot and test research in dementia care this study is a further example of this. Memory clinics are ideally placed to lead the development of services for people with early dementia. Before the availability of treatments, clinicians had largely ignored this group of people, but, as we have seen, they have considerable needs for help in adjusting to their diagnosis and making plans for their uncertain future (Moniz-Cook and Woods, 1997).

CHAPTER 4:

METHODOLOGY, METHODS AND VALUES

4.1 Introduction

As noted in previous chapters, there has been considerable interest in the field of care giving in dementia with limited research into the subjective experience of the person with dementia (Keady and Gilliard, 1999). In order to further understand the complexities of the subjective experience, the author argues that not only is a qualitative approach required but also an approach that enables understanding to be transformed into theory. In other words, it is important to map *how* people with dementia and their family come to terms with a diagnosis of dementia and *how* they cope and adapt over time to the presentation and progression of the condition. The author seeks to explore and document the transitions through the early diagnosis of dementia and develop a constructivist grounded theory to account for the ways of coping and adapting described by people with dementia and their families.

The study uses a grounded theory approach (Glaser and Strauss, 1967; Glaser, 1978), embedded in a constructivist grounded theory design (Charmaz, 2000; Walker and Dewer, 2002). It is longitudinal and as part of utilising constructivist principles, it adopts some elements of life-story to inform the data collection process using the framework developed by Gubrium (1993). Importantly, at the time of data collection,

the author is both a practitioner and a researcher and this dimension of the research

act is supported by the principles of 'practitioner-research' (Reed and Procter, 1995).

In this way, the fieldwork will be integrated into routine home visits by the author

with the person with early dementia and their close family member(s). The adoption

of a practitioner-research principles (Reed and Procter, 1995) takes forward the

constructivist principle of 'intimate familiarity' (Blumer, 1969) that places a demand

on the researcher to maintain a close relationship with the research participant(s)

throughout the duration of the study so that the person's stories and experiences can

be 'cast in their terms' and their meanings tested over time (Charmaz, 2000).

The following sections of this chapter will seek to describe the constructivist

perspective of understanding subjective experience describing the work of Guba and

Lincoln (1989). There will be a description of the basic tenets of grounded theory

methodology, drawing on the work of Glaser and Strauss's (1967) seminal text *The

Discovery of Grounded Theory: Strategies for Qualitive Research.* The significance

and principles of constructivist grounded theory will be described predominantly

through the work of Charmaz (2000). The supporting struts of narrative-based life

story work and practitioner-research and will also be sketched in outline prior to a

consideration of the research design for the study. However, it is firstly important to

identify the author's role as the researcher, as Glaser (1978) argues grounded theory is

a 'human endeavour' and the researcher or analyst is fundamental to the research

process. Being the 'human instrument' within the conduct of grounded theory requires

the development of theoretical sensitivity. Hence, the first section is about the

researcher as expressed in the first person, the "I" and sense of self that has informed

the study design. The second will address the principles of constructivism that

underpin the study's approach to generating and producing co-constructed grounded theory.

4.2   Building Understanding: A Constructivist Perspective

Each researcher works from a particular way of 'viewing the world' (Guba and Lincoln, 1989 p. 160), this is often referred to as a 'paradigm'. Denzin and Lincoln (2000) define a paradigm as a set of beliefs that is used as a guide to interact with our world. The particular paradigm that best describes my research orientation is that of 'constructivism'. Constructivist thinking aims to 'understand and interpret the complex worlds of lived experience from the point of view of those who live it' (Schwant, 1994). It is about employing research strategies where 'meaning' rather than 'truth' as the legitimate end product of inquiry is explored (Bailey and Tilley, 2002).

Constructivism, as it is understood through the works of Egon Guba and Yvonne Lincoln, seeks to undertake research in natural settings and aims to examine human experience as people live and interact within their own social worlds (Guba and Lincoln, 1989). The approach aims to understand the variety of constructions that people posses, trying to achieve some consensus of meaning, but always being alert to new explanations with the benefit of experience and increased information (Appleton and King, 2002).

Guba and Lincoln (1998) describe constructivism from the perspective of ontology, epistemology and methodology. Constructivism takes a relativist approach to reality

as it is believed that people through complex processes of interaction construct reality, and, as time passes, these constructions become more informed and sophisticated (Guba and Lincoln, 1998). Epistemologically, constructivism is transactional and subjectivist, where the researcher and participant interact with each other to create theory (Guba and Lincoln, 1998). Constructivist methodology is said to be hermeneutical and dialectical (Guba and Lincoln, 1998) since knowledge is created through interaction between the researcher and participant. The final aim is to arrive at a construction that is 'more informed and sophisticated than any of the predecessor constructions' (Guba and Lincoln, 1998). Appleton and King (2002 p.642) describe five fundamental principles that underpin the constructivist paradigm, these being:

1. Reality and its elements;

2. Causality;

3. Unique contexts resulting in absence of generalisation;

4. The relationship between the researcher and the phenomena under study;

5. The impact of values on the inquiry process.

The constructivist paradigm develops the methodology of naturalistic inquiry (Lincoln and Guba, 1985) based on the precepts of multiple realities, which are 'ungoverned by natural laws, causal or otherwise, a relativist ontology' (p.86). In essence, such a relative perspective starts from an emic view with individuals attempting to 'make sense' of their own experiences. Therefore, social reality is constructed through interaction between individuals in an iterative process, with previous knowledge being recast in light of new experiences as they emerge over time.

Appleton and King (2002) suggest a constructivist approach does not make generalisations between cases. From my readings and understanding, this would appear to be informed by the following two reasons. Firstly, human activity cannot be determined by one universal set of relationships (Guba and Lincoln 1998). Secondly, no two social settings are sufficiently similar to allow sweeping generalisations between the two (Erlandson *et al.,* 1993) and it is the uniqueness of the settings being studied that is of particular value. Constructivists believe that the values and preconceived ideas of the researcher will always influence the inquiry design and processes (Guba and Lincoln, 1989). Guba and Lincoln (1982, cited by Appleton and King, 2002), describe four different ways in which values influence constructivist inquiry:

1. Researcher's own beliefs and values;

2. The particular theoretical paradigm and chosen methodology;

3. The research will be influenced by the presence of values ingrained in the study settings;

4. The belief that all groups represented in a study should be recognised as influential and 'deserve equal consideration in shaping constructions'.

For me, the constructivist perspective has been quite revolutionary in 'opening up' my views on 'doing research' and the importance of aligning a philosophical view of the world with a methodological approach that may (or may not) be appropriate for exploring my research question. To enable the 'constructions' around adjustment and early awareness of Alzheimer's disease required not only a constructivist lens that

valued subjective experience, but also a systematic methodology. In November 2003 following discussions with my supervision team, Dr. Sion Williams and Dr. (later Professor) John Keady, I was attracted to the principles of grounded theory and the opportunity for creativity combined with rigour building on negotiating 'realities' within a framework that could provide not only a descriptive but also an explanatory account. Furthermore, as a practitioner, I had read with interest the grounded theory work on coping and care-giving in dementia produced by Dr. John Keady and Professor Mike Nolan.

4.3 Grounded Theory

Arguably, grounded theory is currently one of the most comprehensive qualitative research methods available and derived its theoretical underpinnings from the related movements of American pragmatism and symbolic interactionism (Haig, 1995). Symbolic interactionism is a term coined by Herbert Blumer, which defines the source from which knowledge is derived. Symbolic interactionists contend that interactions with others play a role in developing constructions, and it is through interactions between people that individuals ascribe meaning to the world (Blumer, 1969). Grounded theory is an approach to performing qualitative research in that its procedures are neither statistical or quantitative in some other way. Grounded theory is a general method of comparative analysis designed to discover theory with four central criteria i.e. work (generality), relevance (understanding), fit (validity), and modifiability (control) (Glaser and Strauss, 1967). Grounded theory is a straight forward methodology and guides the researcher from the moment they enter the field to a finished written theory (Glaser, 1997).

Grounded theory was developed and established forty years ago by Barney Glaser and the late Anselm Strauss. Their book, *The Discovery of Grounded Theory*, laid out a set of procedures to describe the process of building theory from empirical data (Glaser and Strauss, 1967). The two authors came from different but influential backgrounds. Strauss had worked in the Chicago School of Social Research, particularly noted for its expertise in qualitative research methods, exemplified by the work of Park, Dewey and Mead. Glaser had worked at Columbia University with Lazarsfeld who emphasised the importance of empirical research and developed innovative ways in using qualitative methods (Strauss and Corbin, 1994). Whilst studying dying patients, Glaser and Strauss discovered the core categories of awareness contexts as well as a dying trajectory (Glaser and Strauss, 1965). The research method was coined 'Grounded Theory Methodology' in the Discovery Book (Glaser and Strauss, 1967). In this book, Glaser and Strauss questioned the hegemony of quantitative research in the social sciences that had marginalized the rich ethnographic tradition of their field, sociology. As Charmaz (1995) contends, Glaser and Strauss's (1967) work was revolutionary because it challenged the:

- Arbitrary divisions between theory and research;
- Views of qualitative research as primarily a precursor to more 'rigorous' quantitative methods;
- Claims that the quest for rigor made qualitative research legitimate;
- Beliefs that qualitative methods are impressionistic and unsystematic;
- Separation of data collection and analysis;

- Assumptions qualitative research could produce only descriptive case studies rather than theory development.

Glaser and Strauss (1967) were concerned that the gap between theory generating and empirical studies is too wide. They hoped to help bridge this gap and advocated for qualitative research to move more towards theory development. By providing a rationale and guidelines for conducting qualitative research, it permitted and encouraged novices to pursue it (Charmaz, 2000). Grounded theory has been described as 'middle-range theory' and the aim of a grounded theory study is to produce theory that explains the data, rather than a grand formal theory (Charmaz, 2000)

4.3.1   When should a Grounded Theory Methodology be used?

Grounded theory is used in a wide-range of research settings, and is especially highly regarded as a method of social analysis in psychology, education and nursing (Cutcliffe, 2000). Grounded theory should be used when other methodologies do not work well, especially in the sensitive dependent variable fields within health care (Glaser, 1997), or for the investigation of relatively uncharted waters, or to gain a fresh perspective in a familiar situation (Stern, 1994a). According to Strauss and Corbin (1990):

'If someone wanted to know whether one drug is more effective than another, then a double blind clinical trial would be more appropriate than a grounded theory study. However, if someone wanted to know what it was like to be a

participant in a drug study, then he or she might sensibly engage in a grounded theory study or some other type of qualitative study'. (p.37)

Grounded theory is concerned with understanding social phenomena and addressing *how* and *why* people engage in particular social processes. Yet there is much diversity in the field of grounded theory.

4.3.2 Different Approaches to Grounded Theory

The understanding and interpretation of grounded theory is contested and the method has moved in conflicting directions (Glaser and Strauss, 1967; Glaser 1978, 1992; Strauss 1987; Strauss and Corbin 1994; Charmaz 1995, 2000). After publication of the *Discovery* text, Glaser and Strauss worked separately from one another. Glaser (1978) developed the theoretical side of grounded theory in his book *Theoretical Sensitivity* whilst Strauss (1987) developed a more 'hands on' approach in his 1987 book *Qualitive Analysis for Social Sciences*. As a result, two different methodologies emerged, often referred to as Glasarian Grounded Theory and Straussarian Grounded Theory. However, both approaches remain imbued with positivism with objectivist underpinnings (Guba and Lincoln, 1989).

Charmaz (2000) describes Glaser's position as one of a more traditional positivism, with emphasis on supposition of an objective and external reality as well as being a neutral observer. Strauss and Corbin's (1994) work is based on the assumption of having an unbiased position in collecting data and allowing the research participants to have their own voice. This viewpoint as Charmaz explains moves towards

postpositivism because it gives a voice to the respondents, representing them as accurately as possible, discovering and acknowledging how respondents' views of reality conflict with their own (Charmaz, 2000).

It is important at this point in the thesis to clearly specify which method of grounded theory is to be used to guide this study. The author will use Glaser and Strauss (1967) and Glaser's (1978) traditional grounded theory as the methodological framework. In my opinion, Glaser and Strauss (1967) and Glaser's (1978) approach to grounded theory provides a flexible, yet systematic, methodology and framework for qualitative data analysis with a key emphasis on theoretical sensitivity, the emergence of data and generation of theory. Strauss and Corbin's (1990) method of grounded theory, on the other hand, details a more systematic and structured approach with the main emphasis being on the verification and validation of theory. As Charmaz (2000 p. 513) suggests, grounded theory should offer a set of flexible strategies and not rigid prescriptions and notes that Glaser argues that the purpose of grounded theory methods should be to generate theory, not to verify it. Stern (1994a) agrees, and suggests recent developments in grounded theory methods are an erosion of the subsequent analysis.

In the next section, the author describes grounded theory based on the core principles established by Glaser and Strauss (1967), providing an overview of the methodology, the positioning of the methodology in the field of social research and techniques for collecting and analysing data.

4.3.3. Grounded Theory Procedures

Grounded theory is a research methodology that provides a systematic (but flexible) template for collecting and analysing data, and advocates an integrated link between data collection and data analysis (Glaser and Strauss, 1967). Grounded theory research begins by focusing on an area of study and gathers data from a variety of sources, including interviews and field observations. Once gathered, the data are analysed using coding and theoretical sampling procedures. When this is done, theories are generated, with the help of interpretive procedures, before being finally written up and presented (Haig, 1995). Glaser and Strauss (1967) assert that this is an integral part of the research process. Moreover, a grounded theory study will work through the following, mostly over-lapping, procedures:

- Data collecting and analysis;
- Constant comparative method;
- Coding;
- Memo Writing;
- Theoretical sampling;
- Sorting and writing up;
- Use of literature.

In short, data collection, coding, sampling, comparative analysis and memoing occur simultaneous from the onset of the fieldwork. The author will now further explore each of these points.

Data Collection and Analysis

The first stage in the process of doing grounded theory is to collect data. Theory will be developed from interviews, autobiographies, conversations, formal interviews, diaries, journals and our own taped recorded reflections (Charmaz, 2000) and researchers should gather extensive amounts of rich data with thick description (Charmaz, 1995). A fundamental feature of grounded theory is its method of constant comparative analysis (Glaser and Strauss, 1967), where data collection and analysis occur simultaneously and each item of data is compared with every other item of data. The theory produced is said to be conceptually dense (Strauss and Corbin, 1994), that is theory with many conceptual relationships, and these relationships are embedded in a context of descriptive and conceptual writing (Cutcliffe, 2000).

Constant Comparative Method

The constant comparative method can be seen as the 'core category' of grounded theory and makes sure that every part of the data i.e. emerging codes, categories, properties and dimensions are constantly compared with all other parts of the data to explore variations, similarities and differences (Glaser and Strauss, 1967).

Coding

The aim of coding is to define and categorize the data. Coding is defined as the analytical process through which data are fractured, conceptualized and integrated to form theory (Strauss and Corbin, 1998 p.3). Coding data can be seen as the first stage

of theory development. Its aim, therefore, is to recognize, develop and relate the concepts that are the building blocks of theory. Analysis will begin early in the research process and codes will be created as the data emerges. Unlike quantitative research that requires data to fit into preconceived standardized codes (Denzin and Lincoln, 1994), the researcher's interpretations of data shape his or her emerging codes in grounded theory (Charmaz, 2000). The initial coding of data is called open coding. The analyst codes the incident into categories and properties of categories. A category is a group of codes, a conceptual element of theory whilst a property is a conceptual aspect or element of a category.

Whilst looking at the data the analyst has three types of questions in mind (Glaser, 1978):

- What is this data a study of?

- What category does the incident indicate? What category or property of a category, of what part of the emerging theory does this incident indicate;

- What is actually happening in the data? Or what is the chief concern or problem of the people.

Coding will examine each line of data and define actions or events within them. This method is referred to as line-by-line coding (Glaser 1978), a point developed by Charmaz (2000) as follows:

'Line by line coding leads to our frequent refining and specifying of developing concepts. Line-by-line coding keeps us thinking about what meanings we make of our data, asking ourselves questions about it, and

pinpointing gaps and leads in it to focus on during subsequent data collection'. (p.515)

It is important that the researcher does their own coding. A simple coding example as described by Glaser (1978): 'When I have arthritis pain, I take aspirin. After a while, I feel better.' This is understood as representing the following items:

- Condition: have;

- Phenomenon: arthritic pain;

- Strategy: aspirin;

- Consequence: feel better (Glaser, 1978 pp. 55-58).

As the data collection continues, categories and properties are further refined using the constant comparison method. After a time one category (occasionally more) will be found to emerge frequently, which may also be connected to other categories that are emerging. This is referred to as the core category. A core category may be a particular type that deals with process in some way, and if it has two or more clear emergent stages it is referred to as a Basic Social Process (Glaser, 1978). Theoretical coding often occurs simultaneously with selective coding. Theoretical coding tends to happen more when the researcher is theoretically sorting and integrating memos. According to Glaser (1978), theoretical coding conceptualise how the selective codes may relate to each other as a hypothesis to be integrated into theory, they 'weave the fractured story back together' (p72). Glaser (1998) suggests that the grounded theorist should 'talk selective codes and think theoretical codes' when writing.

Memo Writing

Memo writing is the intermediate step between coding and the first draft of the completed analysis (Charmaz, 2000). Glaser (1998) describes memoing as the core stage of grounded theory methodology. Memos are the theorizing write up of ideas about substantive codes and their theoretically coded relationships as they emerge during coding, collecting and analyzing data, and during memoing (Glaser, 1998). Memos are important tools to both refine and keep track of ideas that develop when comparing individuals to individuals and then concepts to concepts in evolving theory. Without memoing the theory is superficial and the concepts generated can be considered as unoriginal.

Theoretical Sampling

As categories are developed into evolving theory, gaps in data and holes in the theory are found. Theoretical sampling is used to fill these conceptual gaps (Charmaz, 2000) through a process of data collection for generating theory whereby the analyst jointly collects codes, analyses the data, and decides what data to collect next and where to find them, in order to develop theory as it emerges. The emerging theory, whether substantive or formal, controls the process of data collection. Substantive theory is developed for a specific area of inquiry, such as patient care or professional education, whilst formal theory is for a conceptual area of inquiry, such as stigma or socialisation. It is often better to begin with generating substantive theory from data and then let the formal theory emerge from the substantive theory (Glaser and Strauss,

1967 p. 45). By the time theoretical sampling is planned, a researcher would have some hunches or even hypothesis, which he or she may wish to check (Glaser, 1978).

Sorting and Writing up

In the next step, memos are sorted, which is the key to formulating the theory. Sorting memo's generate a theoretical outline, or conceptual framework for the development of grounded theory for presentation or writing (Glaser, 1998). Sorting is essential as it puts the fractured data back together (Glaser, 1998). During sorting, many new ideas emerge which in turn are recorded in new memos, giving the 'memo on memo' phenomena. If the analyst omits sorting, the theory will be linear, thin and less than fully integrated (Glaser, 1998).

Use of Literature

According to Glaser (1978, 1994), grounded theory gives the researcher freedom to generate new concepts explaining human behaviour. This freedom is optimal when the researcher refrains from doing a pre-research literature review. This advice makes grounded theory different from most other methods using qualitative data, as Glaser (1994) explains:

'To undertake an extensive review of literature before the emergence of a core category violates the basic premise of Grounded Theory, that being, the theory emerges from the data, not from extant theory' (Glaser 1994, p.14)

Glaser goes onto make the point that a pre- research review of the literature will cloud the researchers ability to remain open to the emergence of new categories and thus 'thwart theoretical sensitivity' (Glaser 1994 p.14).

The place of the literature review in grounded theory can be open to dispute and misunderstanding (Charmaz, 2000). Charmaz (2000) suggests that there may be a role to play for using some literature prior to data collection and analysis. For instance, Glaser (1978) speaks of possessing prior knowledge of the research area in the development of theoretical codes. A small literature review will be required for the research and grant proposal and in doing so there has already been a review of some of the leading studies and theories in the area of research (Charmaz, 2006).

This study will take the stance that a pre-literature review will force the emerging data into pre-existing categories. The intended purpose of delaying the literature review is to avoid importing these preconceived ideas into the emerging data. Therefore, delaying the review encourages the researcher to articulate *their* ideas. This stance reiterates Glaser's (1978) position that theoretical sensitivity is central to the research process and the emerging grounded theory should not be embedded in a pre-research literature review

4.3.4   Judging the Quality of Grounded Theory

The goal of grounded theory is to explain the underlying social processes occurring in a given area. Glaser and Strauss (1967) established the criteria of 'fit', 'work' and 'relevance' for evaluating grounded theory and assessing its integrity. Later, Glaser

(1978) added modifiability to the list of available criteria. Glaser and Strauss (1967) describe the need for emerging grounded theory to 'fit and work' i.e. to have the ability to predict and explain the data under study. By 'fit', Glaser and Strauss (1967) described the need for conceptual categories to be readily (not forcibly) applicable to, and indicated by, the data under study. Similarly, theory was seen to 'work' if it was meaningful, relevant and able to explain the behavior under study. Glaser (1978) describes the need for 'modifiability' as new data emerges means that the theory continues to fit, work and be relevant as time passes and conditions change.

4.4 Constructivist Grounded Theory

The original or traditional form of grounded theory was devised by Glaser and Strauss in the mid to late 1960s (Glaser and Strauss, 1965; 1967) and since then, researchers have adapted grounded theory methodology to fit with a variety of ontological and epistemological positions. As student of Glaser and Strauss, Kathy Charmaz has emerged as a leading proponent of what she describes as constructivist grounded theory. Charmaz's (2000) constructivist grounded theory provides guidance in making meaning from data and 'rendering' participants experiences into readable theoretical interpretations.

Ontologically relativist and epistemologically subjectivist, constructivist grounded theory reshapes the interaction between researcher and participant in the research process (Charmaz, 2000). Undertaking a constructivist enquiry requires the adoption of a position of mutuality between researcher and participant in the research process, which necessitates a rethinking of the grounded theorist traditional role of objective

observer (Charmaz, 2000). Historically, grounded theory has been judged as silently authored, that is, researchers have maintained a positioned of 'distant expert' (Charmaz, 2000, p.513). The researcher as the author of a co-construction of the experience and meaning is an important next step in grounded theory research. The constructivist grounded theory design of Charmaz (1990; 2000) attempts to address this.

Charmaz (2000) critiques grounded theory through a constructivist lens and advocates developing grounded theory through the integration of constructivism. She draws on the conflicts in grounded theory and identifies the shift from the positivism of Glaser and Strauss as seen in the *Discovery* book (Glaser and Strauss, 1967) to the post-positivist stance of Strauss and Corbin (1994), drawing in the 'realities of subjects' into the equation and exploring conflicting realities and those of the researcher. For Charmaz (2000), the synthesis between constructivism and grounded theory provides another vision for the future of qualitative research which in her view takes a middle ground between postmodernism and positivism, and by doing so, offers accessible methods for taking qualitative research into the twenty-first century (Charmaz, 2000).

It is argued by Charmaz (2000) that constructivist grounded theory can help the researcher further their knowledge of subjective experience. Constructivist grounded theory assumes that people create and maintain meaningful worlds. These worlds are created and maintained through a dialectical process of 'sense making' and constructing meanings out of their realities (Charmaz, 2000). By adopting a constructivist approach, the researcher can move grounded theory methods more into interpretive social science consistent with Blumer's (1969) emphasis on meaning.

Constructivist grounded theory recognizes the interaction between data collection and analysis and studies the experience from the standpoint of those who live it (Charmaz, 2000, p.522).

In this way constructivist grounded theory enables the researcher to gain an in-depth understanding and familiarity of the participant and their worlds and seeks the creation of a sense of reciprocity between participants and researcher in the co-construction of meaning, and, ultimately, a theory that is grounded in the participants' and researchers' experiences (Charmaz, 2000). To seek participant's meanings, Charmaz (2000) suggests the researcher should explore all forms of meaning, in particular, tacit meaning, which enables the person to clarify fully their views about reality.

Undertaking constructivist research commits the researcher to a relationship of reciprocity with the participants. In contrast, more traditional researcher/participant relationship is one of the participants being subordinate to the researcher. The establishment of relationships will need to explicate power imbalances between researcher and participant (Charmaz, 2000). A constructivist approach necessitates a relationship with participants, which allows them to 'cast their stories in their terms' and the researcher should listen to their stories with 'openness to feeling and experience' (Charmaz, 2000, p.525), and allow the participants to disclose all 'raw experience and feelings'. The key to this process will be the researchers' sustained involvement with the research participant as Charmaz (2000) states 'one-shot interviewing leads to a partial, sanitized view of experience, cleaned up for public discourse' (p525).

The conceptual level of coding, writing memos and developing categories differ in objectivist and constructivist grounded theory (Charmaz, 2000). The constructivist design of Charmaz (2000) moves away from the use of diagrams or conceptual maps as well as advocating the use of less 'complex terminology and jargonistic terms' (p. 525), using 'simple language and straightforward ideas that make the theory readable (p.527). The style of the written narrative attempts to move from simple reporting experiences of the participants to encouraging the reader to share these experiences:

'This means taking the reader into a story and imparting its mood through linguistic style and narrative expositions. This strategy removes the writing from typical scientific format without transforming the final product into fiction, drama, or poetry' (Charmaz, 2000 p.527)

To summarise, what constructivist grounded theory advocates, is the positioning of the researcher as the participants' partner in the research process. This is in marked contrast to the traditional grounded theory stance of the objective analyses of the subject's experience. Such an approach will facilitate the mutual creation of knowledge by the researcher and participants and the interpretive understanding of subjective meanings (Charmaz, 2000).

However, Charmaz (2000) did not give an empirical example of what a constructivist grounded theory should look like, or how to build theory with participants over time. Such omissions created a vacuum of understanding, one the author attempted to address through the integration of narrative and life story work into the study design.

This use of biographical sensitivity, it was anticipated, would help provide a bridge between the ideals and values of grounded theory (Glaser and Strauss, 1967), constructivist grounded theory (Charmaz, 2000) and naturalistic inquiry (Guba and Lincoln, 1989) that looks to locate the meaning of experience within everyday lives and context. To provide a further example of this methodological bridge, the author will now review narrative and life story work.

4.5   Narrative and life-story work

Cheston (1996) describes the way in which people with Alzheimer's disease use stories of past events to describe their present experiences. Cheston (1996) states that stories have two functions. Firstly, they enable individuals to explore their experiences; as a result stories act as a metaphor for the personal experience of having dementia. Secondly, they act as a means of creating a sense of social identity. The most common form of data collection is the qualitative interview. Cowdell (2006) describes a number of issues that need to be taken into consideration when interviewing people with dementia. These include whether the person with dementia should be interviewed alone or whether another person should be present to offer support and the way in which the questions are asked and the number of interviews required are also important considerations. Developing this further, Adams (1998) argues the way in which people with dementia are spoken to affects their ability to participate in interviews. The ability of the person with dementia to recall events and their meaning is grounded in and constructed through interaction and the interviewer may help to 'create' a person's presentation of their dementia.

The 'semiotic or meaning-driven subject' identified by Sabat (2001) is significant in understanding the role of the author's use of life story work as part of constructivist grounded theory in order to construct emic theory from data. Sabat's (2001) emphasis upon examining the lives of people with Alzheimer's disease and 'the situations from which they derive meaning, and how the meaning is expressed' (p.171) directs attention towards people with Alzheimer's disease as semiotic subjects. In such a discussion exploring the meaning of 'meaning' is important in order to establish key propositions. Sabat (2001) identifies three different ways:

1. Acting out of intention – based upon reflection and intention resulting from a system of meaning;
2. The interpretation of events and situations;
3. The evaluation of events, situations or actions.

(Sabat and Harre, 1994 cited in Sabat, 2001, p.171)

The case for viewing people with Alzheimer's disease as semiotic subjects pivots on these three roots of meaning, with people acting intentionally based on their interpretations of the 'circumstances in which they find themselves'. Of particular significance is Sabat's (2001) description of the interpretive-conceptual scheme that grounds meaning:

'The meaning of a situation takes into account all of the possible interpretations or inferences which a person can make in light of what Shweder and Sullivan (1989) call a 'conceptual scheme', in which specific situations, or texts, are

understood in light of some overarching interpretative way of thinking (pp 171-172).

For the author, the 'conceptual scheme' and 'overarching way of thinking' have to be understood as a prelude to interpret emic meaning. The author argues that the focus of the research enterprise should be solely upon the narrative 'storyline' of the person with Alzheimer's diseases and the individual 'storyline' will then provide a platform to develop theory from data. A focal point on meaning underpins constructivist grounded theory (Charmaz, 2000) and reflects the attention of constructivist grounded theory on the importance of seeking the subjective meaning of people living with Alzheimer's disease. However, as outlined earlier, constructivist grounded theory attempts to draw the person's exploration of meaning from the periphery as 'participant' to the centre of the research enterprise as co-researcher. Furthermore, constructivist grounded theory seeks to enable the fluctuation and modification of meaning to be addressed as part of the research process, rather than only seek temporally bound-up 'slices' of meaning that are removed from the procedural and contextual backcloth of the life lived by people with Alzheimer's disease.

In essence, the underlying premise of narrative-based approaches is the belief that individuals make sense of their world most effectively by telling stories (Ricoeur 1981; Bruner 1991). Narratives have the power to enable people to explore the full impact and meaning of human experience (Vezeau 1994, cited in Carlick and Biley, 2004)). In the formation of a story, Vezeau (1994) states that the unique aspects of an experience are highlighted and meaning and understanding are formed against a backdrop of previous life experience. However, as part of approaching narrative and

story, it is clear there are varying definitions of what narrative is or what constitutes narrative research (Reissman, 1993). Similarly, there are some common elements, and Denzin (1989) provides a definition that captures the main features:

> 'A narrative is a story that tells a sequence of events that are significant for the narrator and his or hers audience. A narrative as a story has a plot, a beginning, a middle and an end. It has an internal logic that makes sense to the narrator. A narrative relates events in a temporal, causal sequence. Every narrative describes a sequence of events that have happened'. (p.37)

Bruner (2004) argues that through story making as human beings, we portray ourselves. At its most basic, narrative research is about asking for people's stories, listening and making sense of them and establishing how individual stories are part of a wider 'storied' narrative of people's lives (Bruner, 2004; Roberts, 2002). The narrative and story components pivot on a consideration of the 'self' and the issue of identity located within 'selfhood'. Arising from 'selfhood' are issues centered on the construction of memories, self-conception and identity and portrayal of what Roberts (2002) termed 'personal myths'.

These features of narrative have emerged from the range of disciplines that underscore narrative type work, such as anthropology, linguistics, cultural studies and ethnography (Berger, 1997; Polkinghorne, 1988). The nature of analysis has also evolved and reflects the influence of these different disciplines on the form and function of narrative work, resulting in either highly structured analysis or interpretive strategies (Wiles *et al.*, 2005). Yet a central value of narrative work is that it provides

a means to explore and map out the relationships between selfhood, identity and the social world (Bruner, 2004; Roberts, 2002; Lieblich *et al.*, 1998; Somers, 1994; Somers and Gibson, 1994). A narrative account explores the interplay between past and present, relies on a construction of self and is concerned with uncovering an emic perspective on the life-course. Osatuke *et al.* (2004) assert that narratives preserve the 'rich complexities of lived experience' and draws listeners to the person's 'complexly textured world' through characterization, plot and theme (p.193).

Identity is central to any narrative inquiry (Bruner, 2004; Roberts, 2002). Somers (1994) provides a framework for understanding narrative and its role in uncovering identity. Somers (1994) positions narrative as 'ontological' rather than 'representational', the latter a traditional view of narrative studies. Traditional modes of narrative were representational forms with the narrative providing order to the chaos of lived experience by the external voice of researchers and academics (Somers, 1994). The 'ontological' form of narrative described by Somers (1994) significantly presents a different approach with a recognition that life is itself storied and that "narrative is an ontological condition of social life". Stories guide action and that people construct identities, these are multiple and changing, also people locate themselves or are located 'within a repertoire of emplotted stories' (Somers, 1994). To analyse narrative, Somers (1994) distinguishes four dimensions of narrative. These are:

- The person's own 'inner world' (Ontological narrative);
- The social context and its expectations (Public narrative);
- The broad cultural and historical context (Master narrative);

- The researchers frame of reference (Conceptual narrative).

The ontological narrative contains the stories that define the identity of people as social beings and are stories that people use to make sense of, an act in their lives. Public narratives refer to cultural and institutional formations that are larger than the individual. Master or Metanarrativity refer to the narrative which people are embedded as a part in society. Conceptual narratives contain the concepts and explanations constructed by the researcher (Somers, 1994). Importantly, these are connected and a relationship exists between ontological and public narrative, informing the formulation of selfhood.

The central aim of any narrative interview is to facilitate the story to be told and see how people make sense of their lives (Riessman, 1993) and describe their experience and actions (Polkinghorne, 1995). Not only do interviews provide the opportunity for people to tell their stories but also enables the researcher to understand such accounts and as a result be in a better position to conceptualise and generate theory (Price, 2002).

Within the broad field of narrative research the use of life-story work was first described by Johnson (1978). Corbin and Strauss (1987) recognised the value of examining biography as a method to gain understanding of chronic illness. Gearing and Dant (1991) develop the use of biographical work as a research tool in social gerontology and the recent work of Clarke, Hanson and Ross (2003) indicate its contribution in advanced health care practice as part of a research agenda. Plummer (2001) and Cole and Knowles (2001) provide a detailed account of using life story work and how it may uncover the complexities of experience, in particular transitions

during the life course. The area of 'life story' has been defined as the story a person chooses to tell about the life he or she has lived (Atkinson 2002).

There are also contrasting approaches to the analysis of narrative with no standard set of procedures available compared with other forms of qualitative analysis (Riessman, 1993). McCance *et al,* (2001) reviewed the literature and confirmed the diversity of frameworks for narrative analysis yet provided no clear guidance on the processes involved in their use. However, there have been attempts to differentiate the various approaches used for analysis. Lieblich *et al.* (1998) provides a useful framework for the analysis and interpretation of data, emphasising the connection between how to approach the narrative and function what is the focus of analysis:

1. *Holistic-content* – involves two approaches to analysis, firstly as an overarching 'case' study drawing on the general themes and emerging foci from the narrative; or secondly, utilizing a specific segment of the text to demonstrate the story as a whole. Both involve reading/listening to the material several times until a pattern emerges focused on the whole story and its context.

2. *Holistic form-* this involves consideration of the narrative as a whole with careful consideration being given to the formal aspects of structure in the narrative as an expression of the perspective of the storyteller.

3. *Categorical-content-* this approach breaks the text into smaller units of content prior to analysis and follows the principles and techniques of content analysis

4. *Categorical-form*- this involves a focus on the oral narrative with the aim
   of analysing the speaker and the narration in order to understand what the
   dialogue can disclose about the speaker.

In essence, the analytical process reflects the purpose of the researcher (Lieblich *et al.*, 1988).

4.6   The Practitioner- Research Approach

Practitioner researchers, quite simply, are practitioners who are involved in doing research into areas of their practice (Reed and Procter, 1995). Practitioner research is distinguished by a number of factors. Firstly, the need to meet a professional agenda, that is, by involving nurses as the instigators of research then research based nursing practice is more likely to be a reality. Secondly, the aim of practitioner research is to improve knowledge and practice. Rolfe (1998) suggests that traditional large-scale generalizable studies tell us little about the unique nurse patient encounter, and the only way to explore these encounters and generate knowledge and theory from them is if the nurse and the patient are themselves the focus of the research process. Rolfe (1998) goes on to argue that the most effective and perhaps the only way to achieve this is through practitioner based research carried out by nurses themselves. The final factor in practitioner research is the relationship between researcher and research participant, a cooperative partnership between researcher and research subject and is typified by 'mutual exchanges of information and insight and shared control over the progress of the research' (Procter and Reed, 1995, p.9).

Nonetheless, there are tensions between the practitioner researcher and the traditional academic researcher. Academic researchers value the objective stance, that is, unfamiliarity with the participants and area under study, and this is valued as the most appropriate way to conduct research. The criticism of the practitioner research stance is that the same level of objectivity or distance cannot be achieved and thus the data and its analysis will be contaminated by ' their subjective impressions and opinions (Reed and Procter 1995). As Reed and Procter (1995) point out, practitioner researchers are people who are part of the world that they are researching in a way the academic researcher cannot be. Their commitment to developing knowledge and understanding will be motivated by their position as practitioner researchers. There are two central themes in relation to the development of practitioner research, namely roles and relationships in practitioner research and practitioner knowledge and data collection. I will now further develop each of these themes.

4.6.1 Roles and Relationship

As previously discussed, the traditional researcher is an 'outsider' or 'visitor' to the research setting; the practitioner researcher who undertakes research into their own practice adopts an 'insider' position, i.e. they will undertake the research role along side their role as a full-time clinician. As a result, the research practitioner will occupy a number of roles within the research environment such as work colleague, nurse or person in charge. This can cause difficulties for both the research practitioner and research subject, in deciding whether one is a researcher or a practitioner. Whilst this may be seen as a potential weakness, it can also be construed as a strength. For example, the researcher is most likely to adopt the role of practitioner doing research

rather than a researcher who is a practitioner, this is because the practitioner role is better understood and more familiar and so asking practitioner orientated questions is easier (Reed, 1995). Procter and Reed (1995) suggest that insider knowledge about the area of research is an advantage as 'the starting point for insider research is extremely well informed' (p. 17). The insider practitioner researcher will have a continuing relationship with the research subjects that predate the research and, most likely, continue after the research has ended. This will make it difficult for the researcher to step in and out of role and may well interfere with other roles held by the researcher such as nurse or manager. It is advisable for the insider researcher to isolate their research activities from their practitioner role for the duration of the research (Reed and Procter, 1995). From the authors own experience this can be difficult and the practitioner researcher, who is the research subjects nurse specialist, may have to switch roles if clinical needs dictate. However, the sharing of life story has proved useful in helping to break down potential 'power' relationships allowing the nurse specialist to be seen as a researcher as well as the research subject's clinician.

4.6.2 Practitioner Knowledge and Data Collection

The success of a research project depends on the ability of the researcher to select and identify relevant and appropriate samples and consider any variables that will be important to the study. Practitioner knowledge will play an important role in achieving this. Insider researcher knowledge of the work area can inform the study from its onset, shaping the research question and sample selection (Reed, 1995). The lack of insider knowledge, Reed argues, can be viewed as problematic for research

studies if they are to produce results that are meaningful for practitioners. She goes on to make the point that using practitioner knowledge in research design fits in many ways with Glaser and Strauss' (1967) notion of theoretical sampling in which samples are chosen not because of concerns with generalisations, but because they afford an opportunity to develop theory. In order to do this the researcher must not only have a clear idea of how they wish to develop theory, but also of the people or settings likely to help them do this (Reed, 1995).

The impact of practitioner knowledge is also apparent during data collection and analysis. Methods of data collection, whether it is asking questions, recording and analysing data is going to be affected by prior experience of the researcher. The research practitioner will ask questions differently and will be derived from their understanding of the area under investigation. Observational studies will also be governed by practitioner knowledge, as the practitioner researcher will observe actions in a more global context rather than a microanalysis of activity undertaken by an outsider researcher. Again, the practitioner research approach can be open to criticism as it lacks necessary detail and perpetuate their existing views of practice. However, the advantage of this approach is that the practitioner researcher can group activities into 'professionally meaningful units', thus the practitioner research approach can record and analyse data more quickly and effectively (Reed, 1995)

4.7   Chapter Summary

In recent years, there has been a shift from traditional dementia research driven by 'caregiver burden' to the involvement of the person with dementia in understanding

their own 'illness and course' (Cotrell and Shultz, 1993 p. 205). The aim of this study

is to involve the person with dementia in the research process and to help them

understand their illness and its impact, and to utilise the most appropriate

methodology to achieve this. This chapter has outlined a qualitative research approach

consisting of three key components that of constructivist grounded theory, narrative

and life story work and the practitioner research model. Constructivist grounded

theory can be seen as a modification of grounded theory, its primary aim being to

bring a co-researcher model to the practice of grounded theory to develop over time a

shared understanding of subjective meaning and interpretation. Narrative and life

story provide a methodological bridge for engaging and enabling people with

dementia and their families to participate in this process. A practitioner research

model is important as a constructivist approach places demands on the researcher to

maintain a close relationship with the research participant's in the research process

study so that the person's stories and experiences can be cast in their terms and their

meanings tested over time.

CHAPTER 5:

RESEARCH DESIGN: EXAMINING EARLY ADJUSTMENT IN ALZHEIMER DISEASE

5.1   Introduction

The earlier chapters have established the small, but growing, body of research into the experience of early dementia and the active engagement of people with dementia in this process. However, Dewing (2002) argued that researchers in this area should ensure that the design of their studies are ethical, meaningful and, above all, maintain the personhood of the person with dementia. It is in this context that the author set about establishing a research study that examined early adjustment to a diagnosis of dementia building upon the reading of constructivist approaches to understanding subjective experience (Guba and Lincoln, 1989) and utilising a constructivist grounded theory methodology (Charmaz, 2000). As outlined in the previous chapter, the research study was embedded in a constructivist grounded theory approach, augmented by the supportive struts of a practitioner-research model and the use of life story narrative as part of the data collection. At the heart of the endeavour was using a life story approach to make the constructivist principles of Charmaz's (2000) work in

the 'practice' of research. The author argues that through the research design described in this chapter the principles espoused by Charmaz (2000) were transferred into a research design that sought not only to understand the experience of people with dementia, but also to enable them to theorise about these experiences. Hence, the research design provided the framework for 'theory from data' (Glaser and Strauss, 1967) to be 'co-constructed' by people with Alzheimer's disease, supported by the author as a practitioner-researcher.

The following sections detail the transforming of the research methodology and approach into the shape and form of the study. The author will firstly outline the development of the broad research question into a series of research aims and objectives before describing the basic components of the research process and the longitudinal design.

5.2 Research Aims and Objectives of the Study

Informed by the gaps in the literature in the previous chapter the aims of the study were to:

- Explore the person with dementia's early awareness and recognition of the signs of undiagnosed dementia;
- Examine, through reflection, ways that people with (undiagnosed) dementia and, where appropriate, a close family member, decide to seek help from members of the primary care team, including the memory clinic;

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- Explore transitions through the early diagnosis of dementia and further understand the person's ways of coping and adapting to their condition and life experiences;

- Document such change over time in the context of a research-practitioner-patient-family relationship.

- Better inform the bases for professional intervention, the nurses role and patient information during the early adjustment to dementia.

5.3   Research Design: Examining Early Adjustment to Alzheimer's disease

The study was a longitudinal design involving a two-year period of fieldwork with people with Alzheimer's disease drawn from a memory clinic in North Wales. A cardinal feature of the study is the intimate involvement and close working of the author as a practitioner-researcher with four people with an early diagnosis of dementia (and a close family member, as appropriate). As part of the research governance procedures, the author applied and received ethical approval to conduct the study during early 2003. This involved seeking and gaining approval from the Head of the author's community mental health services (Appendix 1) and, together with Dr Sion Williams, Professor John Keady and Consultant Psychogeriatrian Dr Terry Crowther obtaining North Wales Central Research Ethics Committee approval to conduct the study through the Conwy and Denbighshire Trust Research and Development Committee (Appendix 2 and 3). Following the completion of these procedures, active recruitment to the study commenced through the Glan Traeth Memory Clinic, Rhyl, North Wales on the 1st September 2003.

5.3.1   Research Design: A Modified Constructivist Grounded Theory Approach

With the support of the supervision team, the author established a phased approach to data collection that enabled the author to address his role as both a practitioner and researcher with the people with Alzheimer's disease recruited into the study. As will be outlined later, this generated a number of criteria for conducting the study as a constructivist grounded theory study. At the heart of the process and the emergent criteria was ensuring that the basis for developing theoretical sensitivity was established in such a way as to enable the author to listen to the stories of people with Alzheimer's disease with 'openness to feeling and experience' (Charmaz, 2000 p.525). As part of the author's approach to the stories of people with Alzheimer's disease, the author adopted the perspective of Roberts (2002) that 'credibility' is not solely about factual accuracy but also the 'sincerity of the reported view of feelings' (p.66). At its core 'credibility' is the facilitation of an account of 'personal feelings' embracing all the 'inconsistencies and contradictions' that are an integral part of such stories (Yow, 1994; Roberts, 2002).

Importantly, in a constructivist design, Charmaz (2000) argues that grounded theorists should move away from the use of diagrams or conceptual maps as well as adopting less 'complex terminology and jargonistic terms' (Charmaz, 2000 p. 527). However, the author found that diagrams were central to achieving the goals of constructivist grounded theory as they communicated 'simple language and straightforward ideas' in order to 'make the theory readable' (Charmaz, 2000, p.527). In this important difference with Charmaz (2000) the author's study used diagramming and conceptual

maps in order to accomplish 'straightforward ideas' to be developed with people with dementia, and their families as appropriate. As part of the 'modified' constructivist grounded theory approach, the author used life story work, to develop the foundations for diagramming. Accordingly, describing experiences becomes 'straightforward' and allowing 'simple language' to emerge was facilitated by focusing on starting the research work with life history. This focused on the exploration of the author's and 'participants' life story. The subsequent sections in this chapter will describe the process of generating a life story, its 'chaptering', writing a 'Life Story' in order to develop 'My Theory' and, finally, producing a synthesized version of early adjustment in people with Alzheimer's disease.

5.3.2   Research Design: Phases of the Study

The author's modified constructivist grounded theory involves two key phases. The first phase is the production of a Life Story. Here, individual life stories were generated with the research participants using Gubrium's (1993) life story interview format (Appendix 4), paying particular attention to question 8-'chaptering your life'-to provide the methodological framework for the production of a life story. The second phase saw the production of an individual 'My Theory' of the persons experience and condition, a process that was co-constructed. When this was complete, the four 'My Theories' were synthesised into one whole theory of early adjustment to Alzheimer's disease. As part of the design the author did not specify the length of time required for the completion of each phase as the journey of each person with Alzheimer's disease would inevitably vary and the locus of control was

to be retained by him or her throughout the 18-24 months fieldwork. The author will

now elaborate further on the two phases of the research design.

Phase 1: Developing a Life Story

The first phase involved the production of a life story. This consisted of a number of

activities based on developing what the author and supervision team described as

'biographical sensitivity'. The author considers that 'biographical sensitivity' is best

understood as involving two reciprocal parts, 'synchronic' and 'diachronic

narratives'. For the author, understanding autobiography as constituted of both

synchronic and diachronic narratives results in a dynamic perspective on how

narrative is storied and life story presented. Biographical sensitivity represents the

'tuning in' of both the researcher and person with Alzheimer's disease to their life

history and providing an account of their present. As will be detailed later, the life

story produced during the first phase are likely to be subject to ongoing revision and

modification as the person with Alzheimer's disease articulates different

interpretations between the synchronic and diachronic narratives over time. The first

series of interviews involved building up a life story focused on an initial series of

questions based on Gubrium's Life Story Interview (1993) (Appendix 4). The

question regarding 'life chapters' developed by Gubrium (1993) provided the

platform for starting the autobiographical process.

Phase 2: Development of 'My Theory'

The initiation of phase two draws upon the intra-case work of the life story and seeks to elaborate upon the autobiography of the person with Alzheimer's disease. An important part of this process is the exchange of life story between the person with Alzheimer's disease and the practitioner-researcher. This process is supplemented by providing a copy of the practitioner-researchers 'chaptered' life story to the person with Alzheimer's disease. An ideas book (memo book) was also provided to the person with Alzheimer's disease where the next phase involves moving from 'biographical' to 'theoretical sensitivity'. The focal point of the second phase is the engagement of the person with Alzheimer's disease in representing the illness experience as co-researcher with the practitioner-researcher. The guided autobiography of the first phase becomes the bulwark for advancing the second phase work of empowering the person with Alzheimer's disease to 'inspect' the data and generate situational theory from data. The final chapter of the life story represents the 'diachronic narrative' that initiates the development of 'theoretical sensitivity' by the person with Alzheimer's disease. The final chapter brings the person with Alzheimer's disease to a focus upon the contemporary, a context that is delineated by a substantial biographical account of their sense of self and identity. The practitioner-researcher can only support the person with Alzheimer's disease to analyse the narrative if there has been an engagement in building *relationship, trust, equity* and *self-awareness*. Equally, the practitioner-researcher has to have developed 'biographical sensitivity' towards themselves and the person with Alzheimer's disease. As part of the second phase involving 'My Theories' both the person with Alzheimer's disease and the practitioner-researcher jointly describe in words, phrases

and diagrams the experience under study, as outlined in the research aims. However, the primary focus of the practitioner-researcher's role during phase two is to support the person with Alzheimer's disease to generate an individual model of illness representation without bringing into the encounter any additional theoretical understanding, concepts or inter-case analects from outside the relationship.

The development of 'My Theory' involves a number of processes. First, the co-researchers read the life story, negotiate and agree the content of the life story as a prelude to drawing out current life experiences. Secondly, the co-researchers seek out key words and phrases to act as a platform for co-construction, and to help in this process they will use a 'shared ideas book' and tape recorder. In doing so, the co-researchers will seek out and represent what is centre stage in the person's story.

5.4   Sample

Participants were to be recruited from the Glan Traeth Memory Clinic in North Wales for the study. The Glan Traeth Memory Clinic was established in April 2000 to provide a service to people with early dementia. The clinic forms part of the North Denbighshire Older Peoples Mental Health Team and is situated in Rhyl, Denbighshire which is located on the North Wales coast. The Rhyl area is a favoured retirement area and has a high proportion of older residents. The Memory Clinic has a phased approach to its role in the diagnosis of dementia and follow-up support, which includes:

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Phase 1: Screening

This is conducted through a multi-disciplinary assessment of needs. Screening is used to determine pathology, assess mental capacity, and ascertain patient consent to assessment, diagnosis giving and prescription of anti-dementia medication.

Phase 2: Review

Here, the effect medication and other interventions have on the health and well being of the patient and their family are monitored through regular contact with memory clinic and its staff.

Phase 3: Education and Support

Through information, counselling, memory groups for patients, and education to carers, amongst other approaches.

Planned recruitment of the study was at phase two, the review phase of the memory clinic. During this phase, patients have their first appointment four to six weeks after diagnosis and starting acetylcholinesterase inhibitor medication, then every three months and then every six months.

5.4.1 <u>Inclusion criteria</u>

The participant must have a medical diagnosis of probable Alzheimer's disease, having been assessed and diagnosed at the Glan Traeth Memory Clinic by the Registered Medical Officer (RMO) based on ICD – 10 (WHO, 1992) criteria.

Alzheimer's disease has been chosen for this study because it is the most common of the dementias and it is a particular area of interest for the researcher.

The participants must be classified by the RMO as being in the mild/early range of severity with a Mini-Mental State Examination Score (MMSE) (Folstein *et al.*, 1975) of 25 or above. The MMSE was used in this study as the majority of studies involving people with early stage dementia utilise this cognitive assessment to indicate early or mild stage dementia. It was also the main cognitive assessment tool employed at the Glan Traeth Memory Clinic. The MMSE (Folstein *et al.*, 1975) comprises a series of questions each scoring one point if answered correctly. The questions measure the person's levels of orientation, memory, attention and calculation, language skills and writing and drawing abilities. A maximum score of 30 points is possible. Whilst the screening and diagnostic properties of the MMSE (Folstein *et al.*, 1975), are open to question (White *et al.*, 2002), people with early Alzheimer's disease generally score 26 points or more (Alzheimer's Society, 2002);

The participants must be classified by the RMO as having no major psychiatric illness or presenting with clinical depression as determined by the Geriatric Depression Scale (GDS) (Yesavage *et al.*, 1983) indicated by a score ranging between 0 and 5. Research suggests that low mood may affect self –report, appraisal about illness and coping strategies (Mathews and Wells, 1996) cited in (Pearce *et al.*, 2002). In this study the '15 item' version was deployed (Shiekh and Yesavage, 1986). Each of the 15 questions has a 'yes/no' response, with the scoring dependant upon the answer given. The 15-item version has cut-off score of 5, above this score suggests the

presence of a depressive illness. At the commencement of the study none of the participants were experiencing moderate or severe depression.

Participants must be classified by the RMO as making a positive adjustment to the diagnosis of Alzheimer's disease. As determined by the participants and their families awareness of their diagnosis, adjustment and levels of acceptance of their memory loss and a willingness to engage in monitoring and support services provided by the Glan Traeth Memory Clinic.

Participants were living alone or with their husband or wife/partner in the community, proficient in English and able to give informed consent.

5.4.2   Exclusion criteria

A past history of head injury or currently experience psychosis. These presenting conditions could affect levels of awareness and therefore would fail provide a clear picture of adjustment in early stage Alzheimer's disease.

5.5   Ethics

Conducting a co-constructivist inquiry involving the participation of potentially vulnerable people as co-researchers, places an obligation on the researcher to articulate and justify sound ethical procedures (Tee and Lathleen, 2004).

Central to any study that involves the active participation of people with an early diagnosis of dementia are the ascertainment of the person's informed consent to participate, and their understanding of the research aims and objectives. The process of gaining informed consent has been noted to involve three aspects: (1) the person is fully involved; (2) consent is given freely and willingly; and (3) the person is competent (Crossan and McColgan, 1999). Prior to the commencement of the study it was the RMO responsibility to assess those patients that had made a positive adjustment to the diagnosis and were able to give informed consent. The veracity of informed consent was further assessed through clinical judgement of the person's:

1. Awareness of their diagnosis of Alzheimer's disease;

2. Adjustment and level of acceptance of their memory loss;

3. Level of competence and ability to give informed consent to a procedure; and

4. Retained verbal fluency and level of concentration.

It was considered essential that each of these four criteria was met before a person could be approached for recruitment to the study. Once these conditions were satisfied, the RMO introduced the main aims of the study to those attending clinic via a verbal explanation supported by a Patient Information Sheet and Expression of Interest Form (Appendix 5). The Patient Information Sheet provides detailed information on the proposed study, its aims and objectives. Information on how to take part, how to withdraw once the study has commenced and the potential harm the participant may be exposed to as a result of the study (Appendix 5). These forms will be colour coded to minimise uncertainty over their selection. The person with Alzheimer's disease (and their close family member, as appropriate) was then asked

to discuss and reflect upon the request to be part of the study. If they then wished to participate in the study, the Expression of Interest form (Appendix 5) was completed and returned to Dr Terry Crowther at Glan Traeth Memory Clinic. Upon receipt, and to further augment the consent procedure, the researcher then visited the person with dementia (and their close family member, as appropriate) at their home to once again talk through the research design and consent procedures. At this meeting the researcher discussed the interview process, the collaborative design of the study, the exchange of life stories, issues relating to confidentiality and the use of personal information. The following points were discussed:

5.5.1   The interview process

The aim of the interview was to develop and analyse the participant's life story. It was anticipated that the participants would be able to talk freely about their life, however it was made clear that they did not have to discuss any life experiences that they considered upsetting or private. If during the interview participants showed any signs of emotional distress as a result of the nature of the conversation, the researcher would check whether they wished to continue. On completion of each interview the researcher will engage the participant in a debriefing conversation with the aim of ensuring that he or she was not left contemplating distressing or highly emotive issues without access to adequate support. If a clinical intervention were required as a result of the interview the participants were informed they would have immediate access to the researcher who is also the participants CPN and the RMO at Glan Traeth Memory Clinic.

5.5.2 The practitioner researcher role and the exchange of life stories

The collaborative nature of the research design was explained to the participants and their family. As the researcher was also the participants CPN, and to enable effective collaboration, the research would need to be free from the constraints of the clinical relationship. To facilitate this process the research participants and the researcher would exchange their life stories. This was explained to the research participant as a way of creating a more meaningful and closer relationship by developing points of common interest and experience that will help to 'connect' the researcher and participant. In doing so it was anticipated that the research participants would feel more able to talk freely with the researcher about their life experiences. As one or the researcher participants succinctly put it:

'It was the difference between telling them (the researcher) what you think they want to here as opposed to telling them what you (the research participant) really wants to say'. (Theoretical memo dated September 7th 2005)

It was made clear to the participants that if they were not happy with this process then there was no obligation to join the study or if the study had started they could withdraw at any time.

5.5.3 Confidentiality and the use of personal information

As the content of the life story had the potential to contain personal details and locations the procedures for confidentiality and anonymity of the research participants was discussed in detail. Due to the collaborative and co-authored innovative design of

the study, participants were given the choice of being able to use their own names and some personal details, or maintain total anonymity. All the research participants decided they wished to use their first names and some location details. As one of the research participants put it:

> I wanted my name and details to be shown in the research, I'm not ashamed of my illness, we need to reduce the stigma associated with dementia'. (Theoretical memo dated August 6th 2006).

There were some external and contextual issues in relation to family members and life circumstances that remained confidential. Each participant and family members were encouraged to read through their life story and its content agreed and signed before proceeding to the next stage of the research. During the course of the study, all personal information that could link individuals to the transcripts was kept securely and the transcripts were accessible only to the researcher, in line with research governance. Following the completion of the study, the original recordings were erased, and information linking participants to the transcripts destroyed.

If agreement was given to continue then the person with dementia was recruited into the study and the consent forms signed (Appendix 6) including the consent to tape-record the areas of discussion (Appendix 7). If the carer was to be involved in the study they signed a separate consent form (Appendix 6) and consent to tape record (Appendix 7). For those that gave consent to participate, the researcher was the main research contact and Community Psychiatric Nurse during the time of the study.

The nature of this research also meant that the process of consent is not a single event but a continual, on-going process between the researcher and participant (Kayser-Jones and Koenig, 1994). This may be particularly evident with people who have dementia and because of their memory changes may forget that he/she has consented to participate and may require continual reminders. Therefore, it is important to ensure that the person with dementia continues to give consent throughout the duration of the research study, i.e. at each point of contact with the researcher. In dementia literature this is referred to as 'process consent' (Dewing, 2002). Maintaining process consent will primarily be achieved through the skills and sensitivity of the main research worker on the study who has considerable practice experience in working with people with early dementia and their families. Therefore, during each home visit the aims and objectives of the research was repeated and capacity to give consent determined before continuing with the research. If the mental condition of the participant deteriorates during the course of the study, and it is no longer felt that retain the capacity to make informed decisions regarding their continued involvement in the study then the Mental Capacity Act (2005) will be followed with the family care-giver as consultee.

5.6   Data Collection: The Interview Process

The use of interviews provides the most appropriate strategy for data collection and the potential for rich and in-depth data rests on the interview as an interpersonal process. Patton (1990) notes:

- 'Interviews are interventions. They affect people. A good interview

   lays open thoughts, feelings, knowledge and experience not only for

   the interviewer but also the interviewee.' (p.352)

Completing interviews is a difficult and skilful task (Denzin, 1988). Lincoln and Guba (1985) provide a guide to the best way of undertaking an interview:

- Deciding who to interview;

- Preparing for the interview – including the role of the researcher, the level of familiarity and so on;

- Initial 'muses' – begin with a 'warm up' or general questions of a 'grand tour' variety to establish a relaxed atmosphere and for the informant to clarify any queries they may have;

- 'Pace' the interview and use a variety of strategies such as reflection, use of encouragement such as 'mmm' or hand waving to signal a desire for elaboration;

- Terminating the interview and gaining closure – they suggest that this is best achieved by summarising the information obtained and seeking clarification, a process they call 'playback'. This allows for preliminary 'member checking'. At the end of the interview it is important to be courteous and to thank the informant for taking part.

The role of the researcher in the interview process is appropriately highlighted by Patton (1990) who notes that:

'Effective interviews should cause both the interviewer and the interviewee to feel that a two way flow of communication is going on' (p327).

Hence the researcher is responsible for the interpersonal process of 'pacing the interview' (Lincoln and Guba, 1985) and the use of techniques such as probes to ensure the 'richness of the data' (Patton, 1990) by increasing the depth of the participants' response. Patton (1990) discusses at length the need for the researcher to be attentive to the interpersonal context of the interview. This involves attention to rapport as part of 'pacing' and neutrality in questioning both rapport and neutrality enable the researcher to keep the interview 'productive' (Lincoln and Guba, 1985). Rapport emphasises the researcher's engagement with the person being interviewed, conveying empathy and understanding without being judgemental (Patton, 1990).

A constructivist approach to interviewing requires a transformation of the participant researcher relationship and for the researcher to analyse and prioritise the interaction between the two. This approach is in marked contrast to traditional approaches that pay little attention to such relationships (traditional grounded theory). As a result the interview becomes vital to the construction of knowledge and the participant and researcher will produce this knowledge together. Crucial to the success of the constructivist interview is the need to counteract potential imbalances of power. Traditional approaches see the researcher/participant relationship represented hierarchically with the participant subordinate to the researcher (Fontana and Frey, 1994). Constructivist approaches advocate a more equal position of power within the research relationship. O'Connor (2001) outlines several strategies that move the researcher and participant to a more equal sharing of power in the interview process:

- Scheduling the interview time and location to participants choice

- Flexible and unstructured approach to questioning

- Sharing the researchers understanding of the key issues arising

- Sharing of personal details and answering questions asked during the interview and afterwards.

The interpersonal information gathering process can be best recorded by the use of tape recording and the transcribing of interviews. Tape recording interviews ensures that the researcher does not 'tune out' (Patton, 1990) what the participant has said in the conversation in an attempt to manually record their responses. It allows the researcher to focus on the person being interviewed and complete field notes which can contribute to the analytic process (Patton, 1990). The full transcription of interviews provides the 'gold standard' approach in analysis, enabling independent scrutiny of the data. However, as Patton (1990) notes, this can be prohibitively expensive and a compromise position can be obtained by working 'back and forth' between the sections of the tape recording on tape and the field notes, with only the most important sections of the taped interview being transcribed.

Field notes (memos in grounded theory methodology) provide an additional and important tool for both data collection and analysis for the researcher. Field notes are not only significant as part of the 'face to face' interpersonal interview process but also for documenting the post interview analysis. The period following the interview presents the researcher with a number of key tasks, which Patton (1990) describes as follows:

- Check the tape recording, if a faulty recording has occurred the researcher should make extensive notes immediately;

- If recording is satisfactory the researcher should review the field notes made during the interview and uncover areas of ambiguity or uncertainty. This enables checking up of details for clarity with the participant as soon as possible, since 'guessing the meaning of a response is unacceptable';

- Recording of any observations made during the interview process, indicating when the interview occurred, who were present, the participants' response and the interviewer's own role and responses so as to 'establish context for interpreting and making sense of the interview' (p353).

5.7   Data Collection Methods

The planned contact with the 3 families and 1 person with dementia were through a minimum contact of one visit per month by the author. Initial vists would establish a life story that would be gathered through a life-story interview using Gubrium's (1993) schedule (Appendix 4). This schedule provides a degree of organisation, allowing for flexibility to the narrative structure and covers the key stages or chapters of life experience. Subsequently the identified chapters represented prompts to develop what became known as the life story.

Each interview was to be tape-recorded and transcribed (with consent) and returned to the person with dementia for verification and clarification of any discussed points. Interviews to develop the life-story ranged from between 1-2 hours, with an average

visit of 1hour 30 minutes. For the data set as a whole, there have been 80 practitioner-research contacts, 71 of those facilitating documented research contact. The method of process consent was adopted at each clinical/research contact to ensure willingness to participate and understanding of the aims of the project (Dewing, 2002). The author also kept detailed theoretical memos during each encounter and received regular supervision on both his clinical contact and on-going data analysis by both Professor John Keady and Dr Sion Williams.

5.8   Data Analysis Methods

Underpinning the development of a life story and 'My Theory' is the use of constant comparative analysis at each stage, and using the processes of theoretical sampling and theoretical sensitivity (Glaser, 1978). Data analysis methods involve two main stages: narrative analysis and grounded theory analysis

5.8.1   Narrative analysis

The narrative component of the first phase of the data collection centred on the development of the life story and the author developed a set of criteria as benchmarks for data analysis. These criteria were adapted from those suggested for narrative studies by Lieblich, Tuval-Mashiach and Zilber (1998). The terms have been retained but with an emphasis on constructing narrative categories:

- *Width:* the comprehensiveness of evidence – this relates to the comprehensiveness of the narrative provided in the life story, built through

prolonged engagement between the practitioner-researcher and the person with Alzheimer's disease and their development of 'relationship' and 'trust'. *Width* is ensured by 'fleshing out' the chaptered life story and adding to it (dated entries) whenever necessary.

- *Coherence*: the way different parts of the interpretation create a complete and meaningful picture – as part of the interview process it is centred on 'internal coherence' (Lieblich *et al.,* 1998) focused on how the parts fit together to describe the person's 'mental constructions' of their life and subjective meanings.

- *Insightfulness*: the sense of innovation or originality in the presentation of the story and its analysis – this criteria is closely related to 'self awareness' and is focused on exploring a 'meaning making' process with the person with Alzheimer's disease, allowing the meaning-making to shift as the life story is completed and the contemporary narrative is inspected and co-construction occurs.

- *Parsimony*: the ability to provide an analysis based on a small number of concepts and elegance or aesthetic appeal – this involves the person with Alzheimer's disease being able to represent their illness experience in words, phrases or diagrams. Of central importance is that the 'representation' is driven by the person's account and involves the reduction of their experience to a small number of concepts/descriptions. The role of the practitioner-researcher is to ensure *parsimony* and hence 'reduction' of the representation.

At the heart of the process is the 'relationship' and 'equity' dimensions. The aim of the 'guiding' process of the practitioner-researcher is to enable *width* and *coherence* through the completeness of the life story and the exploration of the narrative to build *insightfulness* and the *parsimony* of the constructed situational theory of the person with Alzheimer's disease.

The process of narrative analysis involves the following steps:

- The development of a life story by asking the participant to review and reflect on their past life using Gubrium's (1993) life story interview format. The use of the chaptered approach to developing a life story provides structure and is developed further during each visit

- The structure provides a chronological and biographical account of the participant's life and is then subject to analysis using the techniques described by Lieblich *et al.* (1998) called Holistic Content. (Refer to page 108).

- Holistic Content involves a focus on the individual narrative and developing biographical sensitivity leading to theoretical sensitivity between the practitioner researcher and research participant. This joint analysis of the narrative is undertaken during the research visits.

- Holistic Content is produced by transcription of each interview and subsequent development of the life story text by dialogue between the research practitioner and research participant.

- A constant approach of comparing the different life stories by each research participant was then undertaken to develop narrative categories.

- The units of analysis as part of the Holistic Content (Lieblich *et al.,* 1998) were the storylines produced as part of the process of life review using the transcribed material i.e. life story.

- This led to the production of a storyboard, this was an innovative technique produced to pull together the analysis of the life story based on the chapters of Gubrium's (1993) life story interview to guide the conversation. The storyboard was produced on an A4 piece of paper where the practitioner researcher and research participant jointly wrote down keywords and phrases from the life story that describes their life experiences.

5.8.2 Grounded Theory Analysis

- The grounded theory analysis builds on the development of the storyboard through the use of diagramming (Glaser, 1978; Charmaz, 2000)

- The process of diagramming involved further analysis of the storyboard and asking the research participant to identify critical points in their present life with Alzheimer's disease. In particular, the identification of any key phases, any experiences that have changed overtime and any critical junctures. The research participant was encouraged to use their 'ideas book' to develop the diagram supported by the practitioner researcher and refer back to their life story and storyboard as required.

- The process of diagramming follows 4 processes. 1) creating phases. 2) mapping experiences 3) confirming critical junctures between phases 4) seeing how these experiences can be represented diagrammatically using the research participants own words, using their storyboard as a resource.

- The second part of the grounded theory analysis uses diagramming again. With the facilitation of the practitioner researcher the research participants are asked to develop a 'My Theory' diagram as a representation of their early experience and process of adjustment to a life with Alzheimer's disease. Again they are encouraged to use the storyboard and first set of diagrams for reference.

- Participants are asked to work on the diagram between research visits. During each visit the practitioner researcher worked with the research

participant to clarify and 'flesh-out' (Glaser, 1978) the developing diagram.

- As this is a longitudinal study and it is important to detail the length of time it took to perform the data analysis. As previously documented there were over 80 research contacts, 71 of those resulting in documented research contacts. On average there were 17 documented research contacts for the 4 research participants. The narrative analysis took an average of 10 visits over a 12-month period and the grounded theory analysis 7 visits over an 8 to 10 month time span.

5.9 Dissemination of the research findings

Dissemination of the research findings will be undertaken in the following ways:

- Publish findings in scientific journals and present at scientific conferences
- Present information to local groups such as the Alzheimer's society branches and Alzheimer's cafes and carer's groups.
- Present information to health and social care professionals at relevant meetings
- Develop training material and courses for health and social care staff.
- Bring the findings to the attention of policy-makers and professional bodies.

5.10　Chapter Summary

Constructivist grounded theory is about generating evidence from a biographical perspective and asserting that the 'real expert' in the study is not the researcher and his or her theoretical sensitivity and constant comparative skills, but the person living with the condition using their understanding and language. Constructivist grounded theory will provide the structure and framework for the mutual creation of knowledge as outlined by Charmaz (2000). To be successful constructivist grounded theory requires the utilisation of narrative and biography to help unlock and document the subjective experience in a facilitative and partnership orientated way.

CHAPTER 6:

FINDINGS

6.1 Introduction

This chapter will discuss the findings of the study based on a detailed account of the grounded theory developed from 'co-constructing' the experience of Alzheimer's disease with four people living with the condition. The chapter will start by describing the four 'case-exemplars' and in particular, describe their biography and map the development of their individual life story. The chapter will then go on to detail the development of the individual 'My Theory' for each participant using the modified approach to constructivist grounded theory (Charmaz, 2000), described in the previous chapter. Each case exemplar is presented in a similar fashion to aid continuity and presentation and to magnify the development of the one, synthesised theory that will follow.

Ten people were invited to participate in the study of which four declined to participate. Six people, five women and one man, were therefore interviewed. Of the sample, four women were married, one lady had a close friend and the one man was married. Two of the initial sample, two ladies, left the study within the first six months due to health and personal reasons. These consisted of one man and three women between the ages of 57 and 78 who met the diagnostic criteria of possible Alzheimer's disease as defined by ICD-10 (WHO, 1992). All were of white European

origin and half had worked in professional jobs, while the remainder had worked in clerical or caring occupations. Of the sample all had moved to the area from the North West of England and all spoke English. All 4 were taking acetylcholinesterase inhibitors.

Active research data collection lasted for 18-24 months from the time of first contact following the signing of the consent form and gained through community visits in each instance. On average, contact with the four research participants was one visit per month. At the end of the active phase of data collection clinical contact with the person with dementia was maintained through attendance at the memory clinic.

In the account that follows it is important to note that actual names of the participants are used. This was with full permission of the 4 participants and their carers and is with in keeping with the co-constructed design and intention of the study.

6.2   Case Exemplar 1: Grace

About Grace

Grace is a 68-year-old woman who lives alone, supported by her friend Chris until November 2004 and, after that time, with no immediate carer. She was diagnosed with Alzheimer's disease in September 2002. My first co-research visit occurred in March 2004 with a final visit in December 2005. In all there were seventeen research contacts. The location of the encounters was in Grace's bungalow. The first seven visits were with Grace and Chris and then all subsequent research visits were with

Grace alone and a more complete account of the co-research process is referred to in Appendix 8.

At the commencement of the study, Grace's MMSE (Folstein *et al.*, 1975) score was 27 out of 30 and the end of the study she continued to score 27 (average score for the duration of the study was 27). On testing of mood, at the beginning of the study Grace's GDS (Shiekh and Yesavage 1986) score was 6 out of 15 and the end of the study she scored 2 (average score for the duration of the study was 2). This indicated that Grace was not significantly depressed at the end of our co-research encounter.

6.2.1   Developing Grace's Life Story

The production of Grace's complete life story using the chaptered approach outlined in the research design section of the thesis (Gubrium, 1993 and Appendix 4) took approximately 12 contacts from the 18th March 2004 to 12th May 2005. On average there was one research contact per month. All interviews were taped and transcribed in time for the next visit. Grace was provided with an 'ideas book' which she was encouraged to use between visits. The author kept a memo book that was used to write key thoughts and experiences after each visit, this will be referred to during the compilation and development of this chapter as it was co-researched and co-constructed.

The first 2 visits produced a rough 'draft' of Grace's Life Story using Gubrium's (1993) chaptered life story interview schedule, this took 4 weeks to produce from taped interviews. Grace immediately identified with and took to the task of chaptering her life and at the end of the 4 weeks had compiled the following descriptive list:

- An Introduction to My Life:

- Chapter 1: Childhood

- Chapter 2: Teenage Years

- Chapter 3: Working Life

- Chapter 4: Married Life

- Chapter 5: Life After the Death of My Husband

- Chapter 6: Joan and the Fellowship

- Chapter 7: My Life Now

As will shortly be discussed, these chapters constituted Grace's life story and provided the platform for the generation of Grace's 'My Theory'.

On the 3rd visit in May 2004 we exchanged life stories, with Grace and Chris interviewing the author. This was a new and strange experience for me as I was the one used to asking the questions and being 'in control'. I was nervous at first and didn't know what to expect. Grace and Chris (her partner) used Gubriums (1993) chaptered life story interview to guide them and they both enjoyed the opportunity to find out more about me. They were particularly interested in my childhood, in particular my experience of living in psychiatric hospitals and how I coped with the embarrassment and stigma. I chaptered my life around 4 headings: childhood, working life, personal life and present day. My chaptered life story is illustrated in chapter 1 of this thesis. To illustrate this experience and how I felt, I wrote a reflective memo after the interview:

'The initial fear of losing control soon passes and as the interview develops the experience can become quite enjoyable, therapeutic even … nurses are used to asking the questions and listening to people. To have someone who is interested in you and prepared to listen to your story can be a rewarding experience'.

(Theoretical memo date 25th May 2004)

At the 4th visit in June 2004, there was a more detailed discussion regarding Grace's Life Story and the content of each chapter. Grace's son Peter was present during this co-research visit. Visit 5 in August 2004 became a practitioner visit due to physical illness and subsequent deterioration in Grace's cognitive condition, from which she made a full recovery. On subsequent visits Grace and I decided to look more closely at each life chapter and agree the content and 'sign off' before moving on to the next chapter. Visit 6 saw a closer examination of Grace's early life and her first two life chapters were called 'Childhood' and 'Teenage Years' respectively. Visit 7 in November 2004 was a closer examination of chapter 3, which describes Grace's experience of being a nurse and this chapter was called 'Working Life'. Visit 8 in January 2005 reviewed chapters 4 and 5 and considered Grace's marriage and subsequent death of her husband and was called 'Married life' and 'Life after Death of My Husband'. Visit 9 in March 2005 considered chapter 6 of Grace's life 'Joan and the Fellowship'. Visit 10 in late March 2005 became our second practitioner visit due to Grace's ill health; again she made a good recovery. Visit 11 was a closer examination of Grace's final life chapter, termed 'My Life Now'. Grace's finalised life story was put together and on visit twelve in May 2005, at this meeting, the life story with its 7 chapter headings was agreed and 'signed – off' by Grace.

Whilst it is not possible to share the full contents of each of these chapters, I have selected sections of each of the chapter headings that contain the salient points of her life story. This process was seen and approved by Grace. The spaces in between the text indicate a break in the storyline and all other words, grammar and phrases in the next section are those used by Grace. This process is repeated for the other 3 case exemplars that constitute the cornerstone of the Findings chapter.

Grace

An Introduction to My Life

The most important turning points in my life, there's quite a few! When I left nursing, and joined the blood bank. I said 'if this job incurs any responsibility I can't do it! Anyway they took me on, and they called me the 'leader of the bleeders' I had a great time in that job

Getting married was a turning point for me; I had to leave that job to get married – a lot of resentment there. This is when I became self-destructive because I couldn't stand up to him. He used to shout 'Don't you dare cry'. So I just went into a shell. He didn't let me go anywhere and he would be standing at the door waiting for me. After he died I started going to the Church and other activities and I thought I was starting to come to terms with my past. - 'Come on now why are you working yourself up'. 'Resentment is bad for the soul'. There's no point being resentful – see what good it's doing you. I became very defensive.

The happiest points in my life were working in the blood bank. And I also worked for a time as a Nursery Nurse I loved working with children. The birth of my children was also an important time for me.

The saddest point in my life was that I couldn't understand what was wrong with my Dad. He didn't have a diagnosis as we do today. He was a lovely man and then he started doing weird things. He had a mini stroke, and I thought it must be that, and then it was getting worse and worse, until I used to have to write things on the calendar for him. He went out buying clocks every day; they were all over the house. In the end we had go to the shop to tell them to stop selling clocks to him. The tests in those days were a bit dated; the doctor asked him 'who's the Prime Minister'? He was doing pretty well, and the doctor asked him again 'who's the Prime Minister'? After a few minutes he answered 'That bloody bitch'! The doctor said could I assume its Margaret Thatcher? Is that your answer? And then they decided he had to go into a Nursing Home. They weren't very good at looking after him. They used to say 'do you know what your father's been doing?' He's been getting into bed with other old ladies' Well I said 'Is there anyone on duty at night?' I said he may be lonely and he's looking for his wife and wanted a cuddle!' So I had learnt to laugh at this point. However this was the saddest point in my life.

The most important people in my life have been my sons and my aunts who I used to go and stay with in my school holidays. And I would have to say my husband; he had had a bad background as a child. I have no resentments against him any more, I just feel sorry for him. We had this rose in the garden, and what was happening was, we had a dog, and every morning after my husband went to work the dog went into the

garden and pulled up the rose! My neighbour would then replant the rose and water it.

When my husband returned my neighbour would warn me 'The master is coming'.

And my husband used to say 'I don't know why this rose isn't growing'. So you see I

was a very conniving women!

My friend Chris and my dog are closest to me now.

If I could live my life again I don't think I would change anything. I would of stood

up to my husband more.

How would you explain what's happened to me in my life? I think I missed

companionship of younger people (when I was young) and this affected my

confidence. I was always in the company of older people.

Chapter 1 – Childhood

I was an only child; they brought me up in the old fashioned way, when children were

seen at not heard! If you wanted to leave the table you had to get permission, so that is

the way I was brought up. I spent a large part of my childhood in Liverpool. I was

born in my Aunt's nursing home, where I helped out taking meals up to the patients. It

was a maternity home. I would watch the babies being born and helping as I thought, I

was probably a flipping nuisance! I had a lot of friends there, people who had been

born in the nursing home and were about my age.

For a short time I went to a convent. I was frightened to death of the nuns. My mother

was moving house so I was there for quite a while and then she wasn't well. I was

quite happy in the nursing home but terrified of school. I was very unhappy there, I

shouldn't say unhappy I was uncomfortable. I didn't fit in because I was a different religion. They were Catholic and I was, if anything, Church of England. I just didn't fit in.

I was over weight in those days. I got a lot of teasing. That put a lot of determination into me and I made the netball team in junior school and the rounders team. But PE no, I couldn't do that. Then I moved on to a Grammar school. I liked it there; I got on okay there.

Chapter 2 – Teenage Years

In my teenage years, I found it extremely difficult to mix with other children because I was an only child. I could mix with adults. I was the favourite of the head teacher, and he used to ring the bell if he wanted me, I thought this is wonderful; it was a miracle to me that, he always wanted me in the middle of a math's lesson! I could never do those damn tables!

I spent most of my time at home, apart from the guides, I wasn't allowed out very far. And it wasn't until my teens that I was allowed to go out any distance with friends. I spent an awful lot of time behind the settee, listening. They would say go and be quiet over there while we're talking, so I would go behind the settee and sit there! I would sit and read a book with a torch.

My mum was a person that went out if anyone was ill in the area. She went out and looked after them. I always wanted my mum to have a baby. 'Why won't you have a baby' I would say. 'I've got enough with you' she would say. I had a good childhood, but quite lonely, but that was down to me. I liked it that way.

I passed a scholarship for a Grammar School, which had just been changed from a private school, which was quite difficult as there were people still paying for their education – they didn't talk to us, as they were very upper class! So it was quite difficult, but I did have some friends, so there was someone to talk too. And then I got my O Levels. I did very well.

Chapter 3 – Working Life

My first job was a nurse. I started as a Nursery Nurse. I was too young to go into nursing, so I was advised to become a nursery nurse to gain experience and get a qualification. I started my nursery nurse training, part of which was residential; I was fortunate to get on that course because they could only take so many in a year. And I enjoyed it; I enjoyed looking after the babies/children, I was looking after 4 or 5 babies at a time. I then went on to the Manchester Royal Infirmary, I passed the entrance exam and started at the MRI and I enjoyed it. But I found it increasingly difficult towards the end, I was on the ward where they were doing brain operations, it was neurosurgery, and that dragged me down. I did 6 months on nights in charge, which brought me near to breakdown. When I finished there I went to work on a ward where they had Leukaemia patients, it was a children's ward and I couldn't cope with that and I finished just a few weeks before my exams. And from there I went to what

they called the nurse's graveyard. I went to the Blood Bank! It was called the nurse's

graveyard because there were so many nurses working there who had not finished

their training. You had to have gone so far in your training or they wouldn't have

taken you. I had a wonderful time there I loved it! We were out every day meeting

different people. Lots of pals, brilliant! I enjoyed this job.

Chapter 4 – Married Life

I married when I was about 29; I had had several boy friends before. We went out for

12 months, there were no signs of any problems between us; it went very well. He did

his National Service and then we got married, and it didn't last, the marriage lasted

but nothing else! I had 2 children eventually. It wasn't a very good marriage 'How

dare you do this, how dare you do that'. He had a violent explosive temper. Great

long sulks, this was the way he was. I didn't expect him to be like that, there had been

no signs of that before we married.

Chapter 5 – Life after the Death of My Husband

After his death they called me the merry widow! Because I was going out all the time,

I was only going to church but they didn't know that! That was a good outlet for me.

There were two things I did after my husband died. I gained confidence by going to

the Fellowship, which I certainly didn't have before. I started to change; I had been

the heart and soul of the party who cried inside constantly. Now I am beginning to

believe in myself and learn to love myself.

I also went to the no smoking clinic. I was supposed to go for 4 – 6 weeks but I was still there 12 months later! But during that time the doctor said to me I've got this boy coming in, he's 14 and badly hooked on the tobacco and he said 'would you do the group tonight'? I was shocked, he said' There's nothing to it' He said all you do is sit there and prompt them. So I did and stayed for the 12 months and it took me that time to stop smoking.

Chapter 6 – Joan and the Fellowship

I then came to live in Wales and I started in the Fellowship (a group for women who were 'survivors of bad marriages'). I met my friend Joan and we developed the Fellowship together. I was enjoying life again. I stopped smoking because I was a heavy smoker, hence the cough. That was the biggest thing I did along with joining the Fellowship. The Fellowship was called Recoverers Anonymous and we met once a week. I worked for the Fellowship for a long time – arranging workshops. It was to help people who were basically 'destructive'. I was self-destructive – alcohol, I don't drink now. I drank during my marriage due to the pressures. I don't drink now.

I carried on with the workshops; I wrote and became interested in Spiritualism I started to write some beautiful spiritual messages. And then Joan died, that was a bad year; she had a brain tumour. I remember saying 'what am I going to do now'. Then I had a lifesaver. Joan couldn't have dogs, because she was asthmatic and I got this little creature who had been ill treated and she was terrified when she first came, terrified of men, she still is to a degree. And she's been my saviour.

It was quite hard when Joan died but I met Chris, she took me out and we went all over the place. We tried to keep the Fellowship going but there wasn't the interest so it finished.

Chapter 7 – My Life Now

I first noticed it when I was adding up my money and I thought 'this isn't right, this isn't normal', I was never a mathematician but I could add up. I have got a sense of humour and I know that rather than sit and cry over it you might as well laugh at it and look to the funny side of it and that's what I try to do. It was a difficult time for me with a sense of losing control as it was beginning to affect my day to day living. I was slowing down, losing my train of thought. I couldn't do things as well as I used to. I was increasingly becoming overwhelmed by things. I couldn't understand what was happening to me and why I was unable to do things I'd always been able to do.

I was diagnosed with Alzheimer's disease in September 2002. It was important to me that I was told the diagnosis; I had an idea anyway, because my father had dementia. I've had tremendous support from Chris and my sons so I'm not alone. My only concern was how I was told I had Alzheimer's disease. I'm glad that you people did give the diagnosis, because I'm coping, I'm not worrying about it, because I know I've got all you people to ask questions if I need to, and fall back on if I needed to. My only criticism, if you like, was the number of people in the room when they told me. It would have been better if just one or two people I knew well told me what I had. Although I live alone I'm not alone. And I just love my life at the moment. I go to the day centre and I love it there. They call me Disgrace! And I get on well with the older people there. Because I like older people, I always have done they fascinate me.

I know the illness will progress so I do everything now; I live life to the full. I try not to look too far ahead. I tell people I have Alzheimer's disease, if appropriate. It's nothing to be ashamed of and we all know where we stand. I tend to make a joke of it or it would get to me. I understand that if I make mistakes it's normal. Other people will need to accept me for what I am. I can still do things, even new things. I've recently got a bus pass and I go to Llandudno every week. Getting on the bus is like a club; it's a social event for me. It keeps my independence. I meet other people and have a chat. I was never a person to talk; now I can! I'm not afraid anymore I used to think people would laugh at me. I'm really enjoying life at the moment and having Alzheimer's disease hasn't stopped this. As for the future I recently met with my Social Worker to discuss nursing homes so I know I will get help when I reach the stage when I need more help.

6.2.2 Working Together to Produce Grace's 'My Theory'

The focus of the next phase of the study was to engage in a co-constructed theory building process that used the (adapted) principles of constructivist grounded theory (Charmaz, 2000). With the chaptered life story as an empirical and shared enterprise we embarked on a process that used the life story contents to understand what was at the 'heart' of Grace's life experiences. By working together in this way, the aim was to search and consolidate the main life 'storylines', and then to develop the co-constructed theory on Grace's early adjustment to Alzheimer's disease using previous life experience as a theoretical guide.

To begin this theory building process, Grace and I met for the first time on this new phase of the study on the 6th June 2005. During this visit we re-visited the aims of the research and discussed the requirements and direction of the next stage, as it was important to clarify that Grace had a complete understanding about what was being asked and to allay any fears over the collaborative conceptual work. It was also important to ensure that Grace continued to be fully involved of the research consent process and was free to disengage in the process at any time. In the event, Grace, like the others in the study, fully engaged with the theory building process and took enormous pride in completing and undertaking the task.

On the meeting of the 6th June 2005 we each had a copy of Grace's life story and together we read through the document paying particular attention to the chapter headings. Over the next 3 meetings between June and September 2005 we worked together to develop the key themes of Grace's life expressed as categories of experience. We both understood from the onset of this process that these categories of life experience needed to be present throughout her life and not just a feature of her current life. We both agreed that that her life experiences were going to have a significant bearing on her how Grace has adapted to her diagnosis of early Alzheimer's disease and, in doing so, pave the way to develop Grace's 'My Theory'. Of significance, was an entry in Grace's 'ideas book':

> 'To understand the way I am now, you must understand the ups and downs of my life' (1st July 2005)

The development of the categories of experience were guided by Grace's reference to the 'chapter headings' in order to produce a storyboard of life experience. The

storyboard we constructed is displayed in Table 6:1, and highlights four categories of experience that emerged as part of this co-construction and dialogic process. The four categories of experience were: lonely journey, journey of survival, making mistakes and walking a pathway.

Table 6.1:   Grace's Storyboard

Lonely journey	**Making mistakes**
▪ Only and Lonely child ▪ Dad and his illness ▪ Marriage and addiction ▪ My illness	▪ It isn't normal ▪ It doesn't add up ▪ Embarrassment ▪ 'Where do I go?'
Journey of Survival	**Walking a pathway**
▪ Respite: leader of the bleeders ▪ Recovery Anonymous and The Fellowship ▪ 'Worm that turned ▪ Merry widow	▪ Journeying ▪ Contentment and life ▪ 'The happiest time of my life' ▪ People that matter

To illustrate the process of developing these categories I wrote this reflective memo after the work with Grace early in June 2005:

> The first category is one of a lonely journey. We see this illustrated in her
>
> childhood experiences of being an only child. Coping with a poor marriage
>
> and addiction to alcohol and nicotine. Her father's experience of dementia and
>
> Grace's attempts to support him with little support and understanding. Her
>
> recent experience of coping with Alzheimer's disease especially since her

friend and carer is no longer available to provide support. Throughout her life she has had to cope with adversity on her own.

This links to Grace's second category a 'journey of survival'. Even though she has had to survive on her own, we both agree, that she has always coped well. For instance, she was an only child, however she was able to adapt well to this situation, 'it was down to me, I liked it that way'. When she was unable to complete her nurse training she went to work for the blood transfusion service, she enjoyed the challenge, did well and became the manager of the service 'Leader of the bleeders' as she referred to it. After the death of her husband, she had a new lease of life the 'merry widow' as she called it. She rediscovered herself and joined recovery anonymous and the fellowship. Grace refers to this period in her life as the 'worm that turned'

Her early experience of developing Alzheimer's disease will be her third category. We both agreed that her collection of symptoms which, included among other things, difficulty in calculating money and adding up, forgetting names, the embarrassment and frustration of this, and the uncertainty of what was happening to her. We have come up with term 'making mistakes' to categorise this experience.

The final category is one of 'walking a pathway'. We both agree that Grace describes her philosophy of life as 'walking a pathway' and this begins to give us an indication as to how she has coped and adapted to the challenges of her life and has remained positive in her current life living with Alzheimer's disease.

(Theoretical memo date: 6th June 2005)

After Grace and I had agreed and finalised her four categories of experience, we were now in a position to start developing Grace's 'My Theory'. The focus of the research involved further analysis of Grace's storyboard and this took from June 2005 to August 2005. To help in this process we started to develop our concepts and ideas in diagrammatical form. In particular, we began to concentrate on Grace's early adjustment to Alzheimer's disease and how she has adapted and coped with her diagnosis.

As previously rehearsed, Grace's storyboard describes a lonely journey; she has faced large parts of her life, and more recently, her illness, on her own and having to cope independently. Her life is a story of survival, coping with adversity and pulling through. Her early awareness of Alzheimer's disease was one of making mistakes and the fear and uncertainty it caused.

After reflecting on this account Grace and I came up with the idea of 'Balance and Control' to explain the over arching experiences of her life. To further illustrate the meaning of these concepts I wrote this memo:

> Grace describes her life in terms of 'balance and control'. In particular, losing, gaining and keeping balance. Not just now but through out her life. As she has developed Alzheimer's disease, losing, finding and keeping control has become evident in the way she has coped.

> (Theoretical Memo: 10th August 2005)

Looking at her storyboard, we identified that losing, gaining and then keeping control had been 'centre stage' in her life, she had been involved in a 'lonely' journey and one that required her to survive despite her difficulties:

'My philosophy of life is that I believe we are walking a pathway, and we can only learn and develop by taking this journey. And we should try not to harm any one thing'

(Grace, An Introduction to My Life).

The issue of 'control' was contextualised within this 'journeyed' storyline and lay at the heart of her response to the present chapter, of life with Alzheimer's disease. With the onset of Alzheimer's disease this notion of losing and finding control has been apparent in the way Grace has come to terms with and coped with her illness. Her early awareness of Alzheimer's disease was one of 'making mistakes', unable to count her money and adding up incorrectly. This caused great frustration and anxiety and for Grace this was a frightening experience:

'I first noticed (Alzheimer's disease) when I was adding up my money and I thought this isn't right, this isn't normal. I was never a mathematician but I could add up. I have got a sense of humour and I know that rather than sit and cry over it you might as well laugh at it and look to the funny side of it and that's what I try to do'. (Grace, Chapter Seven, My Life Now).

Grace describes this as feeling she was 'changing as a person', a feeling of losing control:

> 'It was beginning to affect my day-to-day living. I was slowing down, losing my train of thought. I couldn't do things as well as I used to. Things overwhelmed me. I couldn't understand what was happening to me and why I was unable to do things I'd always been able to do'

> (Grace, Chapter Seven, My Life Now).

The diagnosis of Alzheimer's disease was a crucial turning point (critical juncture) for Grace as it provided her with a reason *why* her control was being eroded. Her father had suffered from dementia and Grace was able to associate his early symptoms with some of the problems she was experiencing. This was the reason *why* she decided to discuss her concerns with her GP and ask for a formal assessment of her memory. The diagnosis was also important as it enabled access to support services such as the memory clinic and the local day centre. Grace described *how* both have proved crucial in helping her adapt and cope with her memory problems. Since her diagnosis Grace has coped in a positive manner:

> 'I take one day at a time and I'm quite happy and content, I wouldn't say it's the happiest time of my life but it compares well'.

> (Grace, Chapter Seven, My Life Now)

We worked together to produce the diagram that is illustrated in Figure 6.1. The diagram explores the development of Grace's 'My Theory' based on what was 'centre stage' in her storyboard. The diagram connects the key centre stage categories of experience and considers the impact of the diagnosis as a critical juncture in Graces' experience of living with Alzheimer's disease.

Figure 6.1:   Grace: Developing 'My Theory'
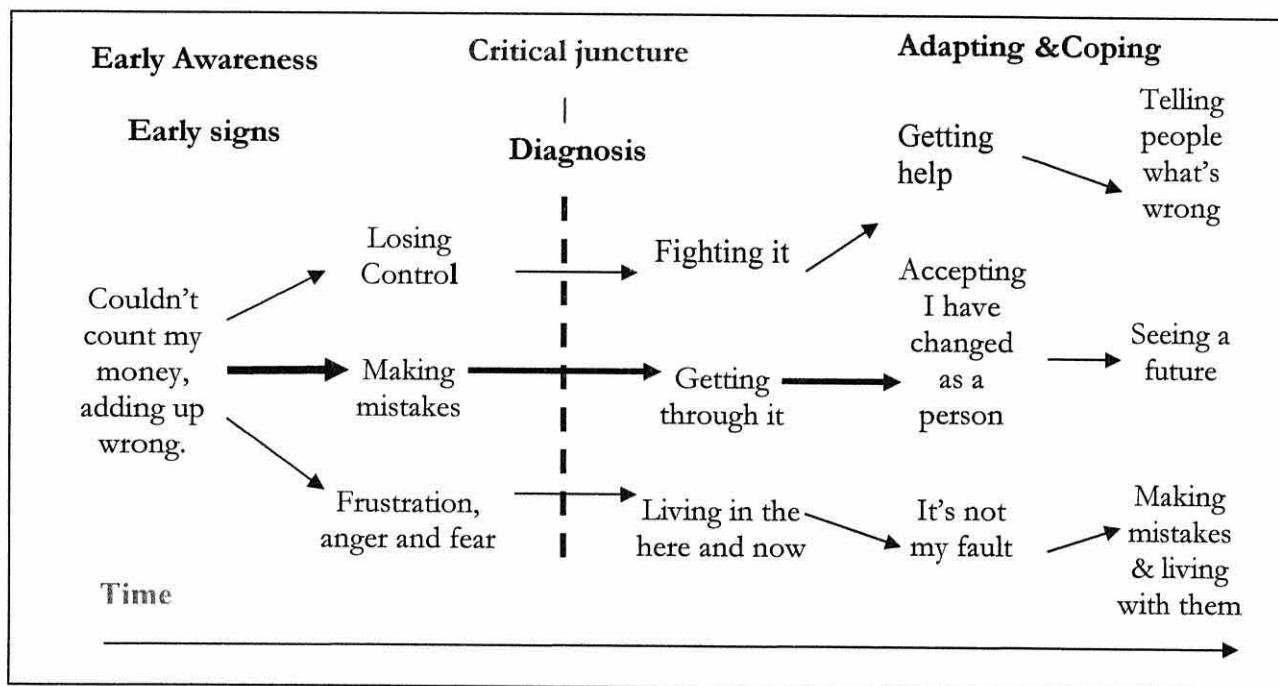
Once we were happy with the content of the diagram as a true representation of Grace's early awareness and adaptation to her diagnosis of Alzheimer's disease, we met to consider some of the key concepts we had developed. In particular, we considered Grace's desire to achieve a sense of balance in her life and at our research meeting on the 10th October 2005 Grace came up with the idea of her life being represented as a see -saw. Over this next two months we developed a number of diagrams to symbolise this idea

The first see-saw diagram, as figure 6.2 represents, shows Grace's life as being 'out of balance' and is identified by the term 'making mistakes'. Here, the see-saw is pushed up by the uncertainty and fear of the onset of Grace's symptoms:

Figure 6.2:   Grace's 'My Theory': Life out of balance
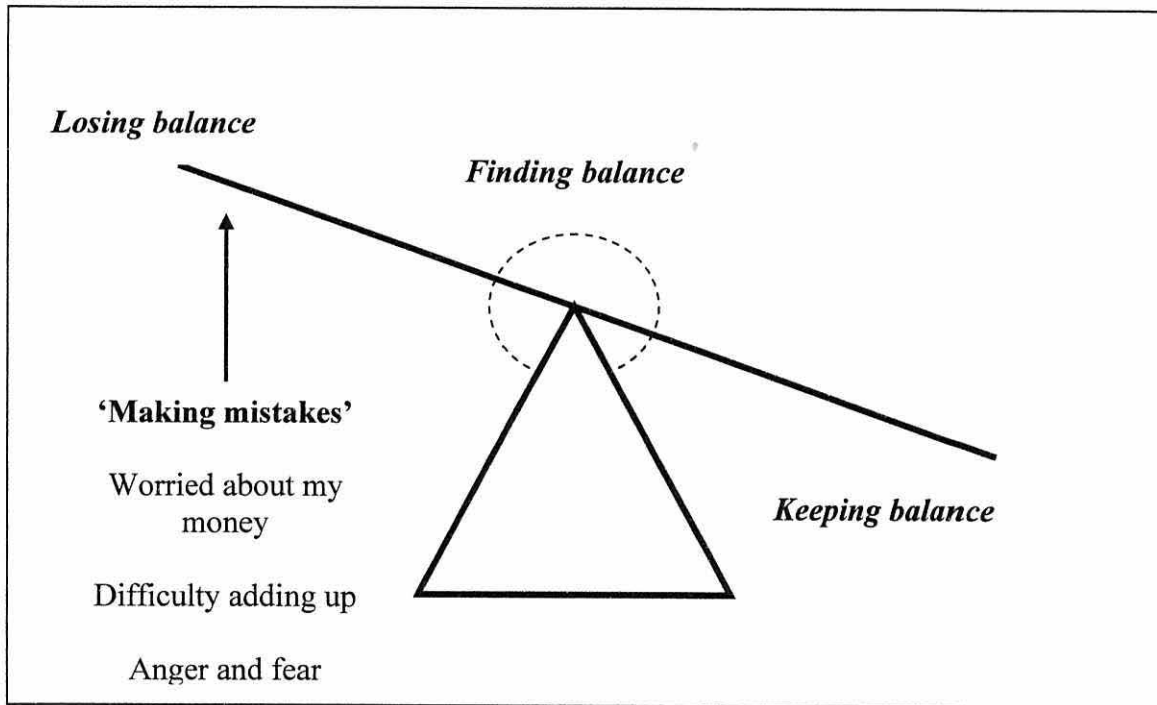
However, clearly Grace moved on from a life out of balance illustrated in Figure 6.2 and into a state of adjustment and acceptance. Having used a see-saw as a visualisation and conceptualisation of the movement seen in experiencing the early adjustment to (Grace's) Alzheimer's disease, we worked together to capture the transition and momentum that explained this process. As a result, Figure 6.3 illustrates the importance of the diagnosis in enabling Grace to understand the changes she was experiencing and begin to regain a sense of balance and control in her life. In this diagram the see-saw begins to tilt upwards helped by her previous life experiences, coping with adversity and being a survivor.

Figure 6.3: Grace's 'My Theory': Finding balance in my life
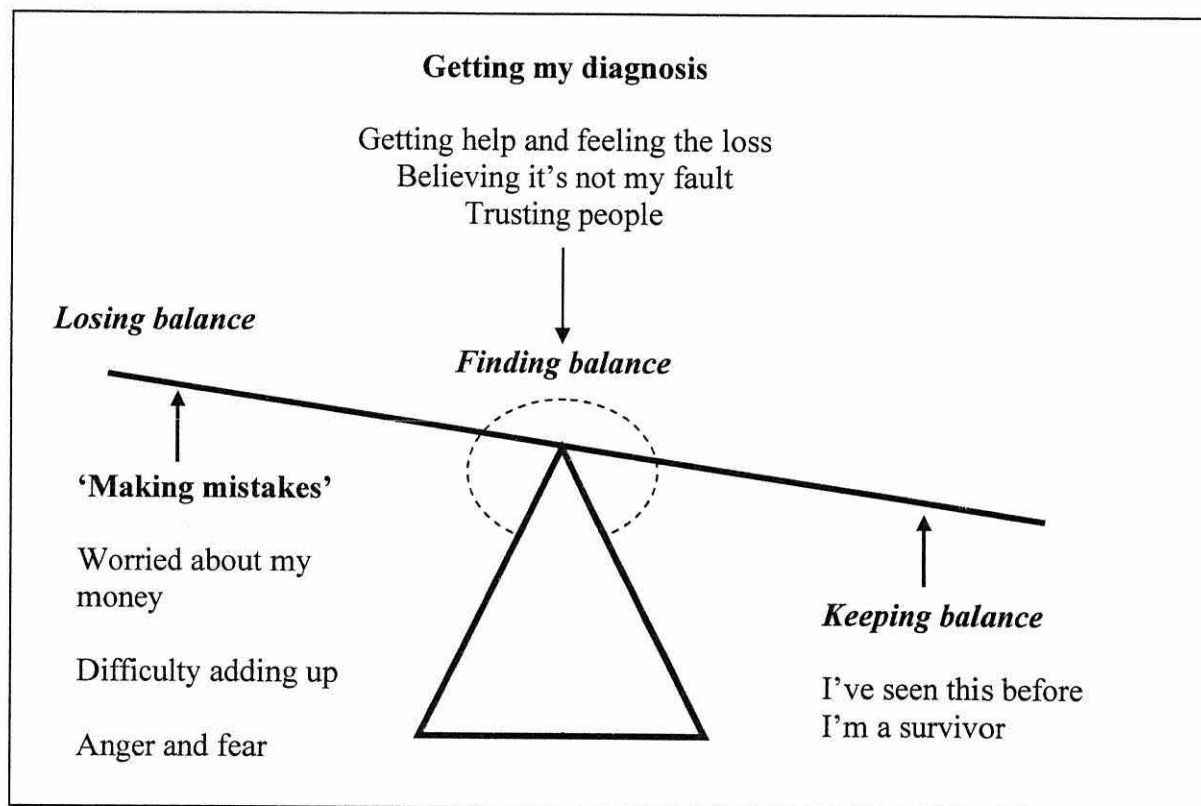
Figure 6.3 reveals more movement towards the centre line and illustrates, to Grace, the vital part played in obtaining, and more importantly hearing and accepting, a diagnosis of Alzheimer's disease. It was a critical moment her life and helped to locate issues of balance and control into more supportive and enabling processes so they started to work for her, and not against her.

The next diagram, Figure 6.4, represents Grace's current life, a life of balance and control. Grace identified that based on her previous journey in her life, involving 'surviving', she was determined to 'live each day as it comes', to 'fight her illness' and to 'get through it'. However, getting help has been important; especially her local day centre has provided major support, as Grace now lives alone:

'Although I live alone, I'm not alone. I've got the day centre, I love it there'

(Grace, Chapter Seven, My Life Now)

Confirmation of the diagnosis has helped Grace associate the changes she is experiencing with her condition. She is now able to understand and accept the changes she has been experiencing. She continues to *make mistakes*, however, she accepts it's the way she is now and knows it is *'not my fault'*. As a result she has learnt to live and cope with her memory problems

Figure 6.4:   Grace's 'My Theory': Keeping balance
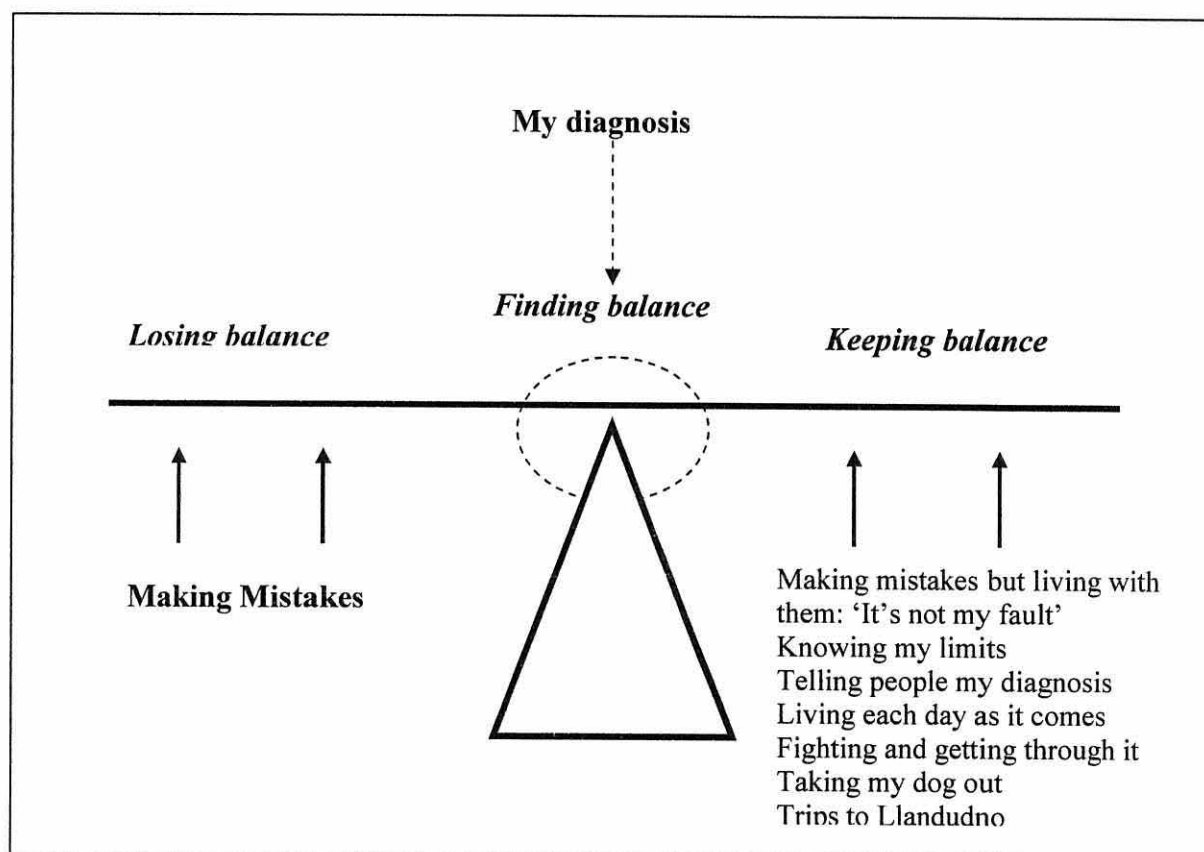
Within such a schema, Grace's early experience of developing dementia is described as a period of 'losing balance'. The critical juncture was seeking help and receiving the confirmation of a diagnosis and accepting the changes to her person and life and in this way 'finding balance'. Her current life, two years after the diagnosis, is one of further acceptance, understanding and living with her memory problems in a positive manner. She is facing her illness, largely on her own, but does receive important support from services such as her day centre and memory clinic, involving a constant process of trying to engage in 'keeping balance'.

6.3   Case Exemplar 2: Mo

About Mo

Mo is a 66-year-old woman who lives with her husband Pat. She was diagnosed with Alzheimer's disease in January 2003. The first co-research visit commenced in October 2003 with the final visit in November 2005, in all there were nineteen co-research contacts. A more complete account of the co-research contact is displayed in Appendix 9. At the commencement of the study Mo's MMSE (Folstein, *et al.*, 1975) score was 24 out of 30 and the end of the study she continued to score 23 (average score for the duration of the study was 25). This highlighted Mo's high level of performance and retained abilities over the time of her participation. On testing of mood, at the commencement of the study Mo's GDS (Shiekh and Yesavage, 1986) score was 7 out of fifteen and the end of the study she scored 3. (Average score for the duration of the study was 3). This indicated that Mo was not clinically depressed at the end of our co-research encounter.

6.3.1 Developing Mo's Life Story

The production of Mo's life story using Gubrium's (1993) chaptered life story interview schedule took approximately 13 contacts from 10th October 2003 to 6th May 2005. All interviews were taped and transcribed in time for the next meeting. To aid in the development of Mo's life story, Mo and husband Pat were provided with an 'ideas book' and the author kept a detailed memo book.

The location of the research interviews was at Mo and Pat's house situated in a pleasant area in Rhyl, north Wales. For each interview, Pat would meet me at the door and show me into the front living room, which had been chosen by Mo and Pat as the best location for us to meet. The room was arranged accordingly with Mo and Pat sitting on the main settee and a chair provided for me, positioned opposite. Mo would be waiting for me sat on the settee. We would have a brief chat, see how things were, and Pat would make us a cup of coffee and provide a plate of biscuits. When coffee had been supplied Pat sat closely with Mo on the settee and the interview would begin. At the end of the interview there would be a period of general chat before making arrangements for the next interview. The duration of the interviews would generally last around 1 hour.

The production of Mo's life story was a collaborative endeavour between Mo and husband Pat. They have a very strong and close relationship and have been together for almost 50 years. At the onset of co-research encounters they made it clear that they were a 'partnership' and did everything together, and as Pat was an integral part of Mo's life they wished to be interviewed together. Of significance was an early entry in Mo and Pats 'ideas book':

'Our marriage is a partnership, we do everything together, we cope together'

1st November 2003

The first 2 visits produced a rough draft of Mo's Life Story using Gubrium's (1993) chaptered life story interview schedule, this took around 3 months to produce from taped interviews (Mo and Pat spend each Christmas and New Year period in Spain). Both Mo and Pat immediately identified with and took to the task of chaptering her life and at the end of 3 months had compiled the following descriptive list:

- An Introduction to My Life
- Chapter 1: Childhood
- Chapter 2: Working life
- Chapter 3: Raising My Family
- Chapter 4: Retirement
- Chapter 5: My Illness
- Chapter 6: Moving On

As will shortly be discussed, these chapters constituted Mo's life story and provided the platform for the further generation of Mo's 'My Theory'.

The next 2 visits saw a further discussion and detail on the chapter headings. During visit 5 in June 2004, Mo asked if I could do Pat's life story. Both Mo and Pat felt this was important, as there were personal experiences Pat wished to talk about which they both felt pertinent to Mo's life story. I was pleased that Pat felt able to talk to me

about a difficult time in his life. Both Mo and Pat were upset during the interview, but what stood out during this encounter was the closeness and respect they had for each other and how they have supported each other through difficult times in their lives. After this encounter I felt there was a closer more meaningful relationship between us which paved the way for future co-research visits. During visit 6 in July 2005 we exchanged life stories. This was the 2nd time I had been interviewed and was a very different experience to my previous encounter with Grace and Chris. This time I felt less anxious and I was looking forward to the visit. Mo and Pat felt awkward, both had been frank and honest about their lives but found it difficult to ask questions about my life. However, Mo and Pat used Gubriums (1993) interview schedule and asked questions about my early life experiences in psychiatric hospitals, why I choose psychiatric nursing as a career, and my current life, in particular, my wife and children. On subsequent visits Mo, Pat and I looked more closely at each life chapter. Visit 7 in September 2004 considered chapter 1 of Mo's life her 'Childhood'. Visit 8 in November 2004 saw a closer examination of chapter 2 called 'Working Life'. In December 2004, visit 9 looked more closely at the chapter heading 'Raising My Family'. The chapter heading 'Retirement' was reviewed in January 2005. The 'My Illness' chapter detailing Mo's experience of developing Alzheimer's disease was analysed further in February 2005. Mo's final life chapter, 'Moving On', was reviewed in April 2005. Mo's finalised life story was presented and discussed at visit 13 in May 2005. At this meeting Mo's life story its 7 chapter headings and content was discussed and 'signed-off' as an accurate representation of Mo's life.

Mo

An Introduction to My Life

I was born in Liverpool the youngest of 7 children, 2 boys and 5 girls. I was born with paralysis in my arm so I always kept my arm held up. When I was 5 years old I started school at St Alexander School. I had a happy childhood. When I was 15 I went to work in a tobacco factory, my sisters worked there as well. I got married in 1958 and I've got five children and seven grandchildren.

The most important turning point in my life was having an operation on my arm when I was 10 years old. After the operation I was able to go dancing, which I loved.

The most important people in my life have been my husband, Pat, my family and my Mother and Father. My oldest sister was also very important. I was the youngest of seven children and my oldest sister was like a Mother to me, I went everywhere with her.

Pat and my family are closest to me now. I go to see my sister in Liverpool as often as I can because she's not well. My niece comes to visit and if I had a problem I could just pick up the phone and she would be here, she understands me.

Now, my life is happy. I've had a good life, a good husband and a good family. I just take one day at a time and I look forward to things. There isn't anything that I would have done differently in my life, except that I would have liked to work in an office.

I've had a good life really. I've been very lucky. I started courting Pat when I was 15, although we first met when I was 5 and we've always been together. We moved about a lot with Pat's job but that never bothered me. We've had our odd moments, everyone does, but you sort yourselves out, because if you think a lot of each other you can get over hurdles. I've always taken each day as it comes really.

Chapter 1 – Childhood

I was born and raised in Liverpool; I was the youngest of seven children, two boys and five girls. It was a very close-knit family and I had a happy childhood. When I was born I had paralysis of my arm and I spent a lot of time in hospital. There were a lot of things I couldn't do such as playing out and playing ball games. When I was ten I went to Myrtle Street Hospital and had a big operation on my arm. I was in hospital for quite a long time, lying on my back with my arm strapped up. I had a happy upbringing, my dad was lovely and my mother was the ruler of the house. My dad was a Docker and a Carter before that. He was a nice man, a gentleman. At five years of age I went to school at St Alexander, a Catholic school, I met Pat there. I stayed there until I left school at the age of fifteen years.

I don't remember my brother because he was killed in the war and is buried in Crete but I got on well with my sisters. My eldest sister took me everywhere; she didn't get married till late on in life so everyone used to think I was hers. She used to take me

into Liverpool and we'd go to those Fullers Cafes and have tea and cakes and different things, and to the pictures, she taught me a lot really.

Chapter 2 - Working life

When I was 15 I went to work in a tobacco factory, my sisters worked there so it was just a follow on. I could have gone to work in an office but my Mum said 'no'. I went to Catholic School and the Sister who was in charge, Sister Theresa, used to pick certain girls out and we used to learn typing, a bit of office work and that, and I had a job in an office but Mum wouldn't let me go, she said 'oh no, you're no better than your other sisters'. She was a lovely Mum but very strict about certain things.

I worked there for years and years, until we had our first son, I worked until I was about six months pregnant.

I worked in Jacob's, the biscuit factory for a while, just part time, and then I worked in the kitchens in the Masonic for quite a few years.

When then moved to North Wales and I worked on the school meals for Clwyd County Council. I worked in Christchurch School in Rhyl.

Chapter 3 – Raising My Family

I got married to Pat in 1958 and we have 5 children, the biggest surprise was when we had the twins. I've got seven grandchildren.

Dave is our oldest child, is an electrical engineer for Manweb. After Dave we had the twins, Debbie and Mike. Mike joined the army Debbie is a nurse. 2½ years later after the twins we had another daughter, Gill. She trained to be a printer and then started working in the retail trade where she has enjoyed considerable success. Steve's the youngest; he got his degree in chemistry. He goes all over the world advising companies on different techniques and things but then they wanted him to take over responsibility for a laboratory in Germany, which was supposed to be for three years, but he's just started his fourth year now.

I enjoyed bringing up my children, some people say its hard work but I enjoyed them, I've always liked children.

Chapter 4 – Retirement

We love our holidays; laziness is holidays, getting waited on, that's a nice part of it. We enjoy ourselves; enjoy the different company and things.

We go to the Day Club, in a sense that's like a little one-day holiday, particularly when we go out on trips. The group have just hit it off and there's a lot of banter and a bit of ribbing of each other! We're due to go to Germany, Austria, Switzerland and Luxembourg. We're staying the first night in Germany and then we're off to Austria for two or three nights and then Switzerland for five nights and then we stop overnight in Luxembourg on the way back. We will spend a month over Christmas and the New Year and our favourite hotel is in Benidorm, Spain.

Chapter 5 – My Illness

I was diagnosed with Alzheimer's disease in January 2003; I was 65 years of age. I first became aware something was wrong when my husband made arrangements to do things, he would tell me, but I would deny any knowledge of the arrangements, even though it was written on the calendar. I would say 'why didn't you tell me sooner?' We had no idea this was the start of the illness, not at this time – we had a series of disagreements – things were said that should not of been said. This lasted about 2 to 3 years. It then became more frequent. We had known each other since we were children. We were never like this. At first I thought it was my age. Then my husband decided to speak to my GP. He began to think it was Alzheimer's disease. We were beginning to associate the symptoms with my sisters who have Alzheimer's disease.

Initially I went to the surgery by myself. I forgot to tell my GP about my problems. In the end my husband insisted on coming with me. My GP said 'why would you want to know?' From then on things moved forward quickly. We saw the CPN, who arranged an appointment with the specialist. The diagnosis was important to Pat and me. It took a long time see the right people and to find out what was wrong.

My earliest awareness of the condition started with me feeling terrible, I didn't like my husband going out without me. I blew up. I was ashamed of my behaviour. I could of hurt him. I was never like that. I loved my children and grand children – they used to ask me to baby sit – I just couldn't do it any more. I was really nasty with them. I felt trapped in the house. You feel it building up in your stomach. Your mouth goes dry. It's an awful feeling, you feel like exploding.

I was frightened of being alone and something happening to me. I was also afraid of something happening to my husband. 'Who would look after me if he became ill?'

I'm still very interested in clothes, things like that, shopping, and Pat encourages me to go round the shops. And I still like to do my housework, Pat helps me a lot but I still like to do the dishes and tidy round.

If I knew someone who had just been diagnosed I'd tell them to be open about it and don't hide away. You're still your normal self, you're still a person and you can still do things. I think some people delve too much into the future but I just take it one day at a time. I'm not trying to avoid the issue but I think just live today and be happy, it's no good worrying about the future.

Chapter 6 - Moving On

I enjoy my life. I don't sit and think of the future much. Pat's marvellous with me and I very much appreciate all the help we get from the ACE Club. I don't worry about the future at all I just take each day as it comes and I enjoy my life. I sleep a lot!

I'm still very interested in clothes, things like that, shopping, and Pat encourages me to go round the shops. And I still like to do my housework, Pat helps me a lot but I still like to do the dishes and tidy round.

If I knew someone who had just been diagnosed I'd tell them to be open about it and don't hide away. You're still your normal self, you're still a person and you can still do things. I think some people delve too much into the future but I just take it one day at a time. I'm not trying to avoid the issue but I think just live today and be happy, its no good worrying about the future.

6.3.2 Working Together to Produce Mo's 'My Theory'

To begin this theory building process, Mo, Pat and I met for the first time on this new phase of the study on 10th June 2005. During this co-research visit (visit 14) we re-visited the aims of the research and discussed the requirements and direction of the next stage. I ensured that both Mo and Pat continued to be fully informed of the research consent process and were free to disengage if they so wished. They were happy to continue. Over the next 3 visits between July 2005 and November 2005 we worked together to develop the key themes in Mo's life expressed as categories of experience. During this period there were 2 visits that became practitioner visits due to adverse effects of the medication Mo was taking.

The development of Mo's categories of experience were determined by Mo's chapter headings and used to produce her 'storyboard'. The storyboard we constructed is displayed in Table 6.2 and highlights 4 categories of experience that emerged as part the co-constructing and dialogic process. The 4 categories of experience were: family life, changing life, never phased and independence and freedom.

Table 6.2:   Mo's Storyboard

Family Life
- Happy life
- Life with Pat
- My children

Changing life
- Losing control
- Making mistakes
- Nasty towards my husband
- Felling like I was going to explode inside

Never phased
- Easy going and laid back, Take things as they come
- I coped with everything
- Five children, never phased
- I never worried

Independence and freedom
- Getting on with life
- Holidays
- ACE club

To illustrate the process of developing these categories I wrote a series of reflective memos in June 2005:

'The first category is about Mo's 'happy life' and the importance she attaches to a strong family life. This can be seen in her childhood, growing up in Liverpool the youngest of 7 children to her current life with Pat and a mother of 5. There has been a strong commitment to family life and the love and security it brings and this appears to have been an important stabilising factor in her life and has helped her cope and adapt to the onset of Alzheimer's disease. Mo's second category we have referred to as 'never phased'. Mo has an easygoing, yet 'strong' personality. She is the 'rock' of the family, the one who has always held the family together and coped with everything'.

(Theoretical memo date: June 10th 2005)

'The 3rd category describes Mo's experience of developing Alzheimer's disease. Her illness has significantly changed her life. In particular, the feeling of losing control and making mistakes and the effect these changes have had on her relationship with her husband and family. Mo's 4th category describes her current life, in particular the importance of maintaining her independence and getting on with her life. Mo and Pat choose to go on holiday as often as they can and enjoy attending social events and the ACE Club'.

(Theoretical memo date: June 12th 2005)

After Mo and Pat and I had agreed and finalised her 4 categories of experience, we now started to develop Mo's 'My Theory'. The focus of this next phase of the co-research enterprise involved further analysis of Mo's storyboard and this took from June 2005 to October 2005. To help in this process we began to concentrate on Mo's early adjustment to Alzheimer's disease and how she has coped and adapted to the diagnosis. Again diagrams were used to help develop our key concepts and ideas.

As previously described, Mo's storyboard describes a person with strong family values, a person who has coped in the face of adversity. The onset of Alzheimer's disease was a devastating event and significantly changed her life. She was no longer the loving wife and mother, quietly in charge of her family and life. For Mo and Pat this was a time of great uncertainty worry and fear. It was not until Mo and Pat received the diagnosis that they could make sense of what was going on and re-gain some sense of stability and control in their lives.

After reflecting on this account and mindful of Grace's similar expression, Mo, Pat and I came up with the concept of 'control' and 'balance' to capture the experiences of Mo's life. To illustrate the meaning of these concepts I wrote this memo:

> ''Control' and 'balance' describe the experiences for Mo and Pat as they try to adjust and cope with the onset of Alzheimer's disease. For Mo especially, a loss of control and the subsequent impact this had on the balance of her life were most noticeable. A loss of balance was the result of the early signs of Mo's illness (undiagnosed Alzheimer's disease) and the disruption it caused to Mo's life and her relationship with her husband and family. The diagnosis was crucial event for Mo and Pat as it enabled them to regain 'control and 'balance' in their lives'.
>
> (Theoretical memo date: 20th August 2005)

As can be seen from Mo's storyboard (Table 6.2) her experience of living with early (undiagnosed) Alzheimer's disease is represented by the term a 'Changing Life'

Mo's early awareness of her dementia was one dominated by emotional changes and uncertainty as to the cause. She became increasingly hostile towards her husband, for no apparent reason, and this put a tremendous strain on their marriage. She was afraid of being left alone in the house and did not like her husband going out without her. She describes her early awareness as:

'Feeling terrible; you feel it building up in your stomach. Your mouth goes dry. It's an awful feeling, you feel like exploding'.

<div align="right">(Mo's Life Story, Chapter 5, My Illness)</div>

The trigger for seeking a diagnosis was the realisation that these changes and loss of control may be the onset of a dementia. Mo's mother and three sisters had Alzheimer's disease and Mo, and especially her husband Pat, became increasingly concerned that she was also developing Alzheimer's disease. Initially, there was some delay in convincing Mo's GP to refer her to the memory clinic. Her GP was not convinced that an early diagnosis was necessary or desirable and could even be harmful. The comment: 'Why would you want to know if you have early dementia' was made on several occasions. These comments had been made in a sympathetic and protective way, however they proved unhelpful and delayed referral to the memory clinic. The diagnosis was important to Mo and Pat as it confirmed what they had suspected and gave them access to support services. Mo describes this as 'seeing the right people and finding out what was wrong'.

After the diagnosis Mo and Pat made the decision to be open about her Alzheimer's disease, both at a personal level and sharing the diagnosis with other people. Mo and Pat were now able to associate the emotional changes and forgetfulness with the Alzheimer's disease. From the onset Mo and Pat wanted to share the diagnosis and being open about what was wrong:

'Be open about it, I'm still my normal self, I can still do things, I'm still a person'.

(Mo's Life Story, Chapter 5, My Illness)

Mo and Pat take each day as it comes, they try not to delve too much into the future but just take one day at a time. As Mo puts it:

'I'm not trying to avoid the issue, but I just live for the today and be happy, there's no point worrying about the future'.

(Mo Life Story, Chapter 5, My Illness)

Opening up is about finding control and accepting the changes that have occurred and making the decision to live as normal life as possible.

'I'm not going to hide away'

(Mo's Life Story, Chapter 5, My Illness)

The final and current chapter in Mo and Pat's life story is one of moving on and living positively with the illness. To ability to remain independent has proved significant in maintaining control over the illness. Being together and the strength of their marriage has also been highly significant. The freedom to be able to go on holiday when they choose and the support they receive from services such as the ACE club, memory clinic and CPN has also proved helpful.

We worked together to produce the diagram that is illustrated in Figure 6.5. The diagram explores the development of Mo's 'My Theory' based on what was 'centre stage' in her storyboard. The diagram connects the key centre stage categories of experience and considers the impact of the diagnosis as a critical juncture in Mo's experience of living with early Alzheimer's disease.

Figure 6.5:   Mo: Developing 'My Theory'
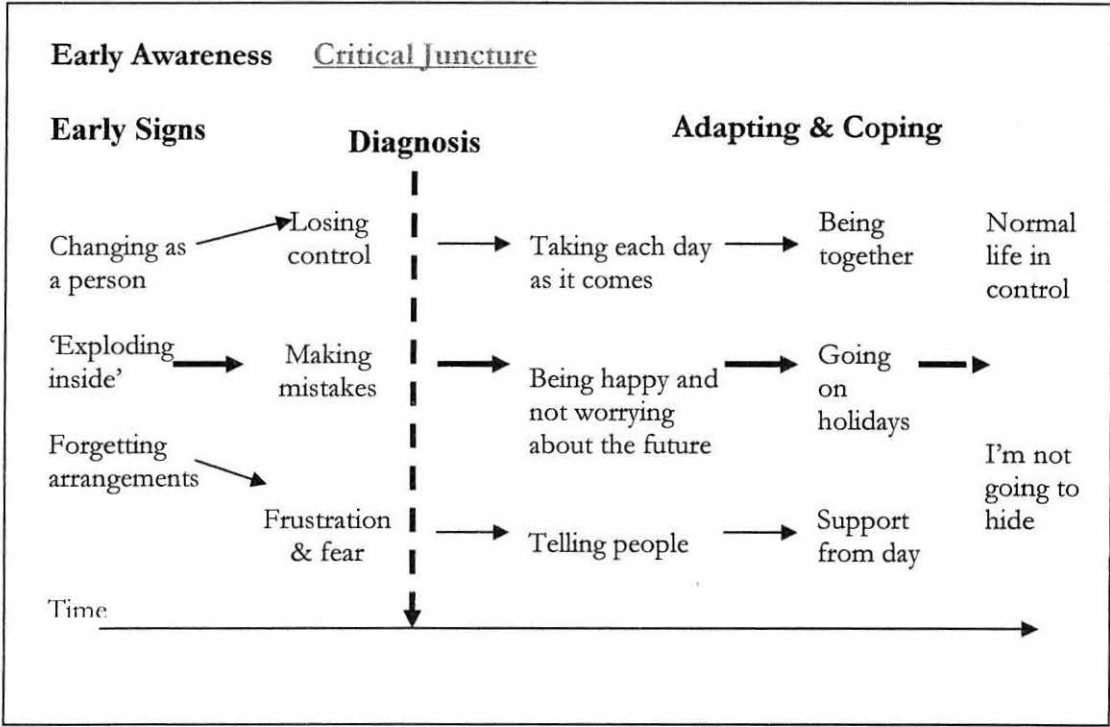
Early Awareness	Critical Juncture		
Early Signs	**Diagnosis**	**Adapting & Coping**	
Changing as a person → Losing control	Taking each day as it comes →	Being together	Normal life in control
'Exploding inside' → Making mistakes	Being happy and not worrying about the future →	Going on holidays →	
Forgetting arrangements			I'm not going to hide
Frustration & fear	Telling people →	Support from day	
Time →			

Once we were happy with the content of the development diagram as a true representation of Mo's early awareness and adaptation to her diagnosis of Alzheimer's disease, we met to consider some of the key concepts we had developed. In particular, we considered Mo's desire to re-gain control in her life and at our co-research meeting on the 3rd October 2005 Mo came up with the idea of her life being represented as a motor vehicle as it symbolised her desire to re-gain control and continual push to 'move on' (as reflected in the title of her final-and current- chapter

in her life story). Figure 6.6 represents a motor vehicle; the first wheel on the diagram starts to propel the model forward. This movement 'back in control' was drawn from Mo's own family history and knowledge that her mother and sisters had been diagnosed with Alzheimer's disease. Whilst undoubtedly traumatic, familial exposure to Alzheimer's disease and Mo's awareness of this, supported by her diagnosis helped her move on.

The headings of the other boxes in Figure 6.6 are self-explanatory, but it is important to highlight the meaning of the ACE club in the box headed 'My Independence and Freedom'. The ACE club are a day club for younger people with dementia that meet regularly for social outings and are based in Rhyl, North Wales – the emphasis in the club is on promoting and maximising the abilities of people with dementia, promoting positive life choices and continuing to live life to the full (for a review of the philosophy of the ACE club see, Davies-Quarrell, 2005).

As can be seen by Mo's 'My Theory' (Figure 6.6), the 'engine' for this advance is provided through her (on-going) life story and the importance of confirmation (of the diagnosis), getting help (to live with the condition) and acceptance (of the mistakes that reflect life with Alzheimer's disease and the need to confront and overcome them). This movement is diagrammed by the three circular 'wheels' at the foot of 'My Theory' which provide the on-going propulsion to Mo and Pat to live their life 'day by day'. The final agreement for this model of Mo's early adjustment to her diagnosis of Alzheimer's disease was agreed at visit 19 on 28th November 2005.

Figure 6.6:   Mo's 'My Theory' Diagram

A Life in Control

↓

Balancing

A Changing Life
Becoming nasty towards my husband

Afraid of being alone

Felling like I want to 'explode inside'

Forgetting arrangements & appointments

Opening Up
Sharing the diagnosis. Being open about what's wrong.

Knowing I'm still my normal self, I'm still a person.

Taking each day as it comes. Living for today.

Being happy and not worrying about the future

My Independence & Freedom
Being together. The strength of our partnership

Still able to go on holidays

Having support through:
ACE Club, Memory Clinic. My CPN

My Life Story →

Confirmation
Getting a diagnosis: 'We already knew my sisters had dementia'.

Getting help
Seeing the right people. Finding out what's wrong

Acceptance
'The mistakes are part of the illness 'I'm not going to hide away'

6.4   Case Exemplar 3: Linda

About Linda

Linda is a 57 old woman who lives with her husband Gary; they have no children. She was diagnosed with Alzheimer's disease in May 2002. The first co-research visit commenced in November 2003 with the final visit in November 2005, in all there were twenty co-research contacts, of which two became a clinical visit. For a more complete account of the co-research contacts is displayed in Appendix 10. At the commencement of the study, Linda's MMSE score was 27 out of 30 and at the end of the study she scored 26 (average score for the duration of the study was 28). This highlighted Linda's high level of performance and retained abilities over the time of her participation. On testing of mood, at the commencement of the study Linda's GDS score was 5 out of fifteen and the end of the study she scored 6. (average score for the duration of the study was 4). This indicated that Linda was not clinically depressed at the end of our co-research encounter. Linda's life story chapter headings will shortly be described and these will provide the platform for her 'My Theory'.

6.4.1   Developing Linda's Life Story

The production of Linda's complete life story (Gubrium, 1993) took approximately 11 contacts from 10th November 2003 to 25th April 2005. Linda and Gray were another couple who tended to take long holiday breaks. So, where possible, there was approximately 1 contact per month. Again, all interviews were taped and transcribed in time for the next meeting. In keeping with the co-researched and co-constructed

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approach of the study, Linda and Gary were provided with an 'ideas book' and the author kept a memo book.

The location of the co-research contacts was at the Glan Traeth memory clinic in Rhyl north Wales. This was at the request of Linda and Gary as they have two properties one in Holywell in North Wales and a cottage in the Lake District and the research contacts were timed to coincide with travelling between the two. Linda also felt more comfortable talking about her experiences at the memory clinic. Of significance was an early entry in Linda's 'ideas book':

'The memory clinic is the place that provides me with support; it is my safety net, my life line.' (12th January 2004)

As with Mo and Pat, the production of Linda's life story was a collaborative endeavour between Linda and her husband Gary. They have a very strong marriage and have always done everything together. At the onset of the co-research contacts Linda wanted her husband to be actively involved.

The first two visits produced a 'rough draft' of Linda's Life Story using Gubrium's (1993) chaptered life story interview schedule, this took 3 months to produce from taped interviews. Linda and Gary immediately identified with and took to the task of chaptering her life and at the end of the 3 months had complied the following list:

- An Introduction to My Life

- Chapter 1: Growing Up

- Chapter 2: Working Life

- Chapter 3: Getting Married

- Chapter 4: The Illness

As will shortly be discussed, these chapters constitute Linda's life story and will provide the platform for the generation of Linda's 'My Theory'.

On the third visit in February 2004 we started to consider in more depth Linda's life story. Visit 4 in March 2004 became a practitioner visit. Visits 5 and 6 in July and August of 2004, saw a closer examination of both Linda's and Gary's life story. At visit 7 on the 20th September 2004 we exchange life stories and this proved a challenging encounter for Linda and Gary. They were more than happy to be asked questions about their own lives, but 'didn't think it was right' to ask questions about my life. After gentle persuasion and reassurance that this was part of the research process and that I did not mind they asked questions about my family and working life.

At subsequent visits Linda, Gary and I decided to look more closely at each life chapter and agree content before moving on to the next chapter. Visit 9 in December 2004 saw a closer examination of chapter 1 which we called 'Growing Up'. Visit 10 in January 2005 saw a discussion of chapter 2 which we called 'Working Life'. At visit 11 in February 2005 we considered chapter 3 'Getting Married', and at visit 12 in March 2005 we considered chapter 4 'The Illness'. Visit 13 in April 2005 became a

practitioner visit. We agreed Linda's finalised life story with its 4 chapter headings at visit 14 on 25th April 2005.

<u>Linda:</u>

<u>An Introduction to My Life</u>

One of the happiest moments in my life was when I got married; I can remember walking down the aisle and Gary turned round and he was grinning at me and saying 'Oh, you look lovely!' Other than that, just odd things really; sitting halfway up a hill, out on a walk somewhere and just sitting down and looking at the view, it being a sunny day and eating sandwiches, just things like that. Most of our days have been happy, it's just the odd ones here and there that stand out.

The saddest point in my life was when my Dad died. He was too young and he was ill. We were supposed to go up and see him the weekend that he died but Gary couldn't get the time off work. We rang and spoke to him at the hospital, he was quite cheerful, and then on the Sunday my Mum and sister rang to say that he died. I'm so sorry that I didn't see him before he died.

Gary has been the most important person in my life and it's him that I am closest to now. I'm also close to my sister and then my brother and I've got good friends as well.

Looking back from where I am now I would describe my life as even; there have been no great dramas and its just kind of rolled along. I would describe myself as cheerful and easy going, never phased or bothered. Its funny really, you take happiness and everything for granted and it's only when you come across somebody who's really unhappy or having a really hard time that it makes you stop and think.

If I had the opportunity to write a story of my life the main chapters would be Growing Up, Working Life, My Marriage and then the present day which I call The Illness.

My philosophy on life is change what you can, be as happy as you can and if you can't change things don't worry about them.

Chapter 1 – Growing Up

I was born in Clatterbridge Hospital in Bebbington by Ellesmere Port. I had a happy childhood and my Mum and Dad and my family were always there; I've always been surrounded by people who care for me. My Dad worked for a Dutch firm called Van Lere, he was a sheet metal worker, and he made steel drums and that sort of thing. It was a big foundry and they used to treat the workers very well. They would all have meals out and go on trips and there was a big Christmas party for the children and we used to get wonderful presents; I think that's probably why they got taken over by another firm, but my Dad was happy there. My Mum didn't work at the time.

I was the eldest of three; there's two and a half years between me and my sister and then another three years between my sister and brother. My Dad's family were very close, we used to see a lot of them. Dad worked through the week but had weekends off. We didn't have a car or anything and so we walked everywhere. My parents would always take us out at the weekend and we used to go to Butlins for our holidays.

I was especially close to my Aunty Jane and Uncle Bill; well, I was the only niece for a little while. Because they didn't have any children of their own I did quite of lot of things with them. I can remember having a sort of roundabout in their back garden, it had two little chairs on it and it used to go round. Then my other aunty had her eldest daughter, Rosemary, so I used to have to share it with her. Sweet rationing was on then but everybody used to save their sweet rations for me and I used to get 2oz of Dolly Mixtures every Thursday.

I got on well at school, it was only around the corner from where we lived and I used to go to dancing classes as well. I left school when I was sixteen, I'd had enough, I think if they'd had things like sixth form colleges then I probably would have stayed on but I hated exams, I used to get very nervous and I'd be shaking so much that I couldn't write.

Chapter 2– Working Life

When I left school I went to work. I'd written away for different jobs and I got a job in an advertising agency, but it wasn't as much fun as I thought it was going to be so I

applied to the bank and got a job there and I stayed there for the next 33 years. I started off as a junior, working with ledgers on to the accounting machines and then I went on to the counter and I ended up doing enquiries and foreign currency. It was quite a responsible position and I enjoyed the work and the responsibility that went with it. I liked the direct contact with people. It was quite a senior position in the bank. It wasn't the same back then, it was very sexist in the bank, and when I got married I had to resign my job and reapply as a married woman! Women didn't work their way up then, women were just there to do the menial bits but when you've been there a long time you get to know quite a lot so they have to put you up a bit.

Chapter 3 – Getting Married

I met Gary when I was seventeen, We met on a night out and it went from there, we were from opposite ends of the scale, Gary worked for British Steel and I worked for a bank. I'd had other boyfriends before but we just suited. We just carried on going out and then got married. We never bothered about having children; the two of us seemed to be enough. And, at that time, if you had children your job automatically stopped and I was enjoying it, I didn't really want to give it up. We just weren't very maternal really. We didn't have a lot of time together because of Gary's shift patterns and we enjoyed the time we had together. Your job was never really safe, it was the same for everyone then wasn't it really, so the idea was that we'd get the mortgage paid off. So when the mortgage was paid off we bought the cottage in the Lake District, we spent a lot of time down there.

Chapter 4 – The Illness

When the illness first started I didn't realise anything was wrong; it was the people around me who noticed. I knew I wasn't working as well as I should be. I started making mistakes, I wasn't remembering up-to-date stuff, I remember we had a bank charge for invoicing which was always £6 and it went up to £7 and I just couldn't remember the change to £7 and that was the kind of thing that was jumped upon. Everything I did was wrong, I felt stupid and I retreated into my shell. I felt everybody was talking about me; people were out to get me. It made me feel terrible, I felt my life was being pulled apart. My husband and I thought it might be because of 'the change' at first. There were other signs as well, it wasn't just my memory, it was more than my memory, and it affected my senses. I remember one day sitting in my front room and smelling fish and chips! The worst of all it was affecting my relationship with my husband; I was increasingly taking my worries out on him.

It took four years from those first signs for me to get diagnosed. For 2 years I was treated for depression but there was nothing happening. I didn't tell my husband right away because I felt embarrassed really. I had always been good at my job and I felt embarrassed to tell him the things that I had done, or had forgotten to do. It was silly things really, I couldn't remember where things were and if we went out to meet friends I would forget their names; I had no recognition of their names at all. I began to feel very disassociated from everything. I became increasingly more withdrawn and shut myself off.

I used to bring work home with me, I just couldn't cope with it at work, and I would

hide it and get up in the middle of the night because I didn't want my husband to

know what was going on. I didn't seem to have the concentration anymore to get the

work sorted out. In the end my Manager phoned my husband and asked to meet him.

He wanted to know if there was a problem at home, he was concerned. After this they

moved me about to see if I could cope better with different responsibilities but it

didn't work and I finished work about 12 months later.

When I finished work I didn't do a lot. I would go out shopping but I would get lost

in the high street of all places! I had to give up carrying a bag in case I put something

in my bag that I hadn't paid for. It was a frightening experience because I felt I

couldn't trust myself. And I used to buy daft things, things that I was never going to

use.

In the end my husband went to see the GP and told him that the anti-depressants

weren't working and I was sent to see a Psychologist for memory testing. Initially,

my GP was reluctant to refer me to the memory clinic he told us 'you know when you

have Alzheimer's disease, it's when you can't cook the evening meal'. We had two

visits there and then we were referred to the memory clinic. The doctor there did a

few more tests and then we got the diagnosis. We knew where we were then; it's a

pity it didn't happen earlier.

There are things I find hard to talk about with my husband. It's hard to explain. I

want to be a person not an 'illness' and separate the two. I don't want to be put in a

box. I still want my husband to respect me, so there are certain things I can talk about

to my nurse that I could talk about to my husband but prefer not to. The nurse provides me with the emotional support I need along with the reassurance.

My life is back together again. After the diagnosis our relationship improved and it's okay again because we now know what was causing the changes that were happening to me. We have developed a number ways to help me cope with my poor memory; we use a blackboard and yellow stickers, which you need to move every couple of weeks because I stop seeing them! Keeping active is important we go on plenty of holidays if we can. We have started telling people as well I think that helps. We take each day as it comes. There are good and bad days, we call them 'blips'. We've noticed a few more little changes just recently, nothing really to worry about, a pointer for the future. The day club has been a great help. We are able to share things with other people who are going through the same problems. As regards the medication, we were told it would keep me on an even keel for a period of time but I do feel better since I've started taking them; my memory is sharper, my concentration is better.

6.4.2 Working Together to Produce Linda's 'My Theory'

The focus of the next phase of the study was to engage Linda and Gary in co-constructed theory building using the principles of constructivist grounded theory (Charmaz, 2000). The contents of Linda's life story was used to find out what was the 'heart' to her life experiences and then develop the co-constructed theory of her early adjustment to Alzheimer's disease using previous life experience as a theoretical guide.

To begin this theory building process, Linda, Gary and I met for the first time on this new phase of the study on the 30th May 2005. During this visit we re-visited the aims of the study and discussed the requirements and direction of the next phase as it was important to clarify Linda and Gary's continued understanding of the study and to ensure Linda's continued to be fully informed of the research consent process.

On the meeting of 30th May 2005 we each had a copy of Linda's life story and together we read through the document paying particular attention to the chapter headings. Over the next 3 visits between June 2005 and July 2005 we worked together to develop the key themes in Linda's life expressed as categories of experience. The development of these categories were guided by Linda's reference to the 'chapter headings' in order to produce a storyboard. The storyboard we constructed is displayed in Table 6.3, and highlights 4 categories of experience that emerged as part of this co-constructing and dialogic process. The 4 categories of experience were: normal life, supportive caring relationships and pulling apart coming together and normal life in control.

Table 6.3:   Linda's Storyboard

Normal Life	**Pulling apart and coming together**
■ Life rolling along ■ No great dramas ■ Just 'got' married ■ Never bothered to have children ■ Never phased and bothered	■ Making mistakes ■ Forgetting ■ Frustration, anger panic. ■ Strain on my marriage
Supportive caring relationships	**Normal life in control**
■ I've always been surrounded by people who have cared for me ■ My Dad ■ My husband Gary	■ The recognition that I had dementia ■ I'm not going to hide away ■ Independence, social outlets.

To illustrate the process of developing these categories I wrote this reflective memo in July 2005:

'The first category describes Linda's life before she developed Alzheimer's disease. A very 'normal life' as Linda refers to it, a life of no 'great dramas' a 'life rolling along'. The 2nd category describes the importance of the relationships she has had with her family and husband (particularly the men in her life such as her father and Gary) and we have called this supportive caring relationships

The 3rd category describes Linda's experience of developing Alzheimer's disease, and the massive impact it had on her life, in particular, the uncertainty, fear and anxiety it brought and the strain in put on her marriage.

Linda was still young enough to be in full time occupation and had a responsible position as a senior bank clerk. The onset of her illness caused her major problems in work and she uses the term 'making mistakes' to describe this experience – a common term expressed by other participants in the study.

The 4th and final category describes Linda's her current experiences and desire to live a normal life. Again, the importance of receiving an early diagnosis was a crucial turning point for Linda and Gary as they were able to associate the changes in their lives with 'the illness'. The importance of being able to be independent and to have access to social outlets and networks has also been significant. - Linda and Gary also attend the ACE Club.'

<div align="right">(Theoretical memo date: 20th June 2005)</div>

After Linda, Gary and I had agreed and finalised her 4 categories of experience, we were now in a position to start developing Linda's 'My Theory'. The focus of the research involved further analysis of Linda's storyboard and this took from May 2005 to June 2005. To help in this process we developed our concepts and ideas in diagrammatical form. In particular, we began to concentrate on Linda's early adjustment and how she has adapted and coped with her diagnosis.

As previously rehearsed Linda's storyboard describes her desire to live a 'normal life' and how this was torn apart by the onset of her illness and the length of time in took to receive a diagnosis. The eventual diagnosis brought with it a return to a degree of normality and control in Linda's life.

After reflecting on this account Linda, Gary and I came up with the concept 'Life in Control' to explain her overarching experiences of her life. To further illustrate the meanings of these concepts I wrote this memo:

'Linda describes in her life as 'normal'. No major traumas, crisis or risks. This has been the way she has lived her life. The onset of her illness, in particular, the period between developing the early symptoms and diagnosis shattered her orderly existence. We have referred to this as 'pulling her life apart'. The importance of the diagnosis was crucial in providing an understanding of the changes Linda was experiencing and gaining access to support services. The diagnosis allowed Linda to re-gain control in her life and return to living a relatively normal life again. We have referred to this as a 'coming together''

(Theoretical memo: 24th June 2005)

By looking at her storyboard, we identified that a 'Life in Control' had been 'centre stage' in her life. Linda describes an easy going and relaxed philosophy on life. She describes her life as just rolling along with no great dramas:

'Looking back from where I am now I would describe my life as even; there have been no great dramas and it's just kind of rolled along. I would describe myself as cheerful and easy going, never phased or bothered. Its funny really, you take happiness and everything for granted and it's only when you come across somebody who's really unhappy or having a really hard time that it makes you stop and think'. (Linda, An Introduction to My Life)

Linda has had a strong loving and supportive relationship with her family and this has continued into her married life with husband Gary. She describes her husband as the most important person in her life and it's him that she is closest to now.

The issue of 'life in control' has been significant throughout Linda's life and lay at the heart of her response to the present chapter, of life with Alzheimer's disease. With the onset of Alzheimer's disease the concept of 'pulling apart and coming together' has been apparent in the way both Linda and Gary have coped with the illness.

Her early awareness of the illness was one of making mistakes and falling out with her husband. Linda had a responsible job working in a bank; she had worked hard and gained promotion in what was a male dominated working environment. Then, out of the blue, she started experiencing difficulties, making mistakes and forgetting things, everything she did was wrong. This was particularly noticeable as she worked in a bank:

> 'I knew I wasn't working as well as I should be. I started making mistakes, I wasn't remembering up to date stuff, I remember we had a bank charge for invoicing which was always £6 and it went up to £7 and I just couldn't remember the change to £7 and that was the kind of thing that was jumped upon'.
>
> (Linda, Chapter 4, The Illness)

Linda was taking work home to cover for her mistakes; she hid her problems from her employers and her husband. Her employees eventually noticed Linda's difficulties;

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and initially, she got into trouble and was disciplined. Eventually the bank manager asked to see her husband Gary to find out whether there were any problems at home. It was at this time they realised that there might be something seriously wrong. Linda and Gary sort medical advice. This proved a frustrating and difficult period as Linda was misdiagnosed with depression and was prescribed a range of different medications. She was referred to the adult community mental health team who tried to provide ongoing support with little success. At this time, Linda was increasingly becoming 'withdrawn and disassociated' she describes these feelings as 'pulling her life apart':

> 'Everything I did was wrong, I felt stupid and I retreated into my shell. I felt everybody was talking about me; people were out to get me. It made me feel terrible. I felt my life was being pulled apart.'

> (Linda, Chapter 4, The Illness)

Linda's relationship with her husband has been an important factor in her life, which was also being pulled apart by her illness.

> 'The worst of all it was affecting my relationship with my husband; I was increasingly taking my worries out on him.'

> (Linda, Chapter 4, The Illness)

Further medical advice was sort by Gary with the suggestion that Linda was experiencing memory problems. At this point Linda's GP made the comment that it was unlikely that Linda had dementia:

'You now when you have Alzheimer's disease when you can't cook the evening meal.'

<div align="right">(Linda, Chapter 4, The Illness)</div>

This all served to delay referral to her local memory clinic and as a result it took four years from the onset of Linda's symptoms to receiving a formal diagnosis. The diagnosis proved a crucial turning part for Linda and Gary and it heralded a period of 'coming back together':

> 'We knew where we were then; it's a pity it didn't happen earlier'. My life is back together again. After the diagnosis our relationship improved and it's okay again because we know what was causing the changes'.

<div align="right">(Linda, Chapter 4, The Illness.)</div>

After the diagnosis, Linda has regained a degree of control of her life and has returned to 'normal living'. Linda and Gary describe good and bad days or 'blips' as they refer to them and are now are able to understand the cause of the changes and have been able to adjust accordingly. They have developed positive coping strategies; they tell people of the diagnosis and maintain an active and varied social life. Linda employs and has developed her own memory techniques and routines. To summarise, Linda describes her current life as one of regaining control and being able to 'separate me from the illness'.

We worked together to produce the diagram that is illustrated in Figure 6.7. The diagram explores the development of Linda's 'My Theory' based on what was 'centre stage' in her storyboard. The diagram connects the key centre stage categories of

experience and considers the impact of the diagnosis as a critical juncture in Linda's experience of living with early Alzheimer's disease.

Figure 6.7:   Linda developing 'My Theory'
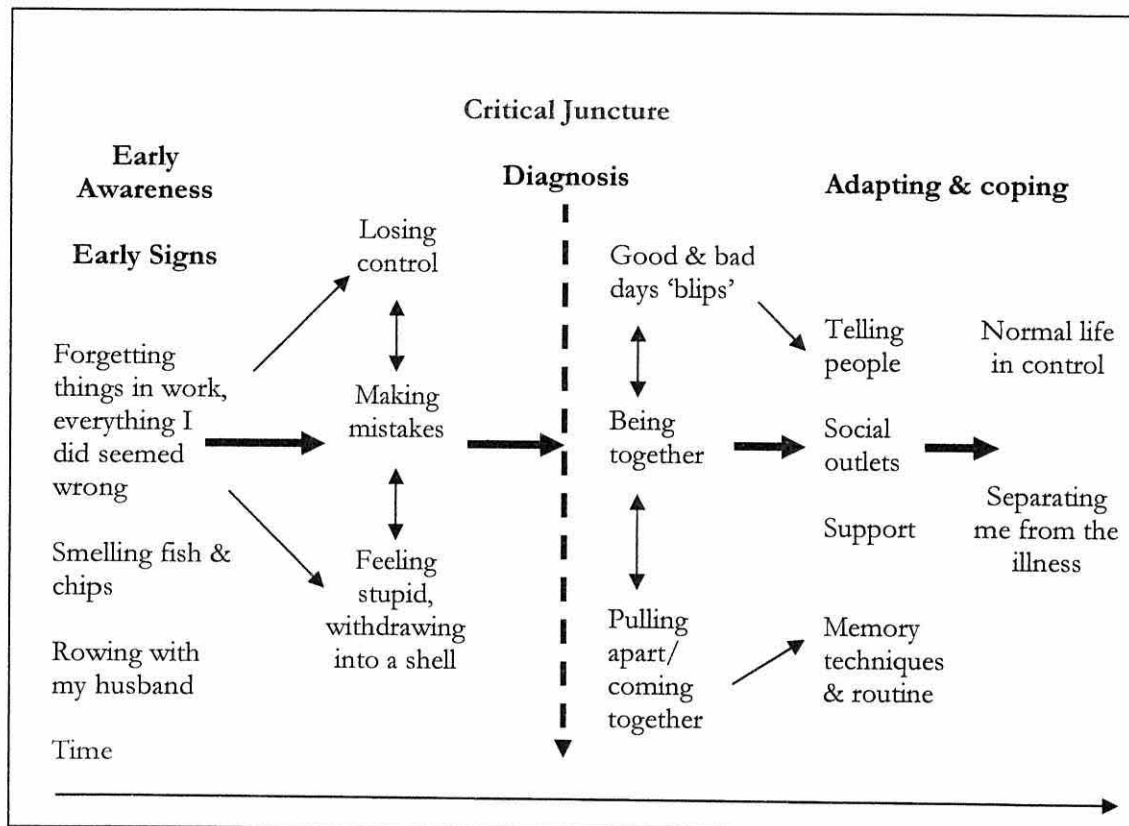
Once we were happy with the content of the development diagram as a true representation of Linda's early awareness and adaptation to her diagnosis of Alzheimer's disease, we met to consider some of the key concepts we had developed. In particular, we considered Linda's desire to have control over her life and for her life to be as normal as possible. We also considered the impact of the (undiagnosed) onset of Alzheimer's disease had on her life and the importance of the diagnosis. At our research meeting on 24th July 2005 Linda came up with a diagrammatical representation of her experiences.

Figure 6.8 illustrates Linda's need to live a life in control. The diagram primarily

consists of 2 rectangular boxes; the first is a representation of a life 'pulled apart' by

the onset of Alzheimer's disease identified by the term 'making mistakes', the mental

changes associated with the condition and the effects this had on her relationship with

her husband. The second box is a representation of a life 'coming together' after the

diagnosis of Alzheimer's disease and is identified with improving relationships,

regaining a normal life and being able to associate the changes she was experiencing

with her diagnosis of Alzheimer's disease. The 2 boxes are separated by a Z shaped

double-edged arrow, and situated under this is a cross shaped box titled 'My

Diagnosis'. To the left of the diagram is a further box titled 'My Life Story'.

Figure 6.8:   Linda's 'My Theory' Diagram
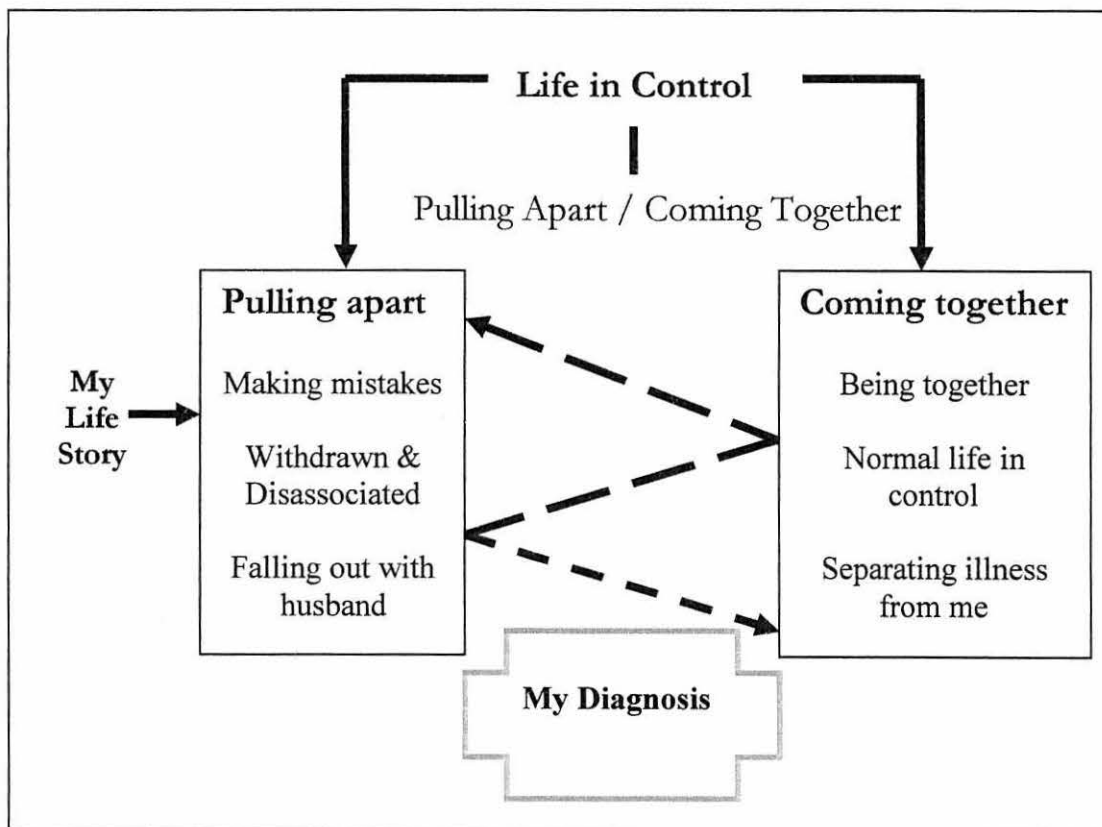
To illustrate the process of developing this diagram I wrote this reflective memo in July 2005:

> 'Linda's 'My Theory' diagram titled 'Life in Control' represents her experiences of developing Alzheimer's disease and the effect this had on her and Gary's life. The diagram consists of 2 boxes, the first box representing a life 'pulled apart', the second a life 'coming together' Crucially, these 2 boxes are separated by a jagged Z shaped line which symbolises a life 'ripped apart'. Strategically placed underneath the Z shaped *tear* is a cross, which denotes a healing process, or a 'healing of the rift' made possible by the diagnosis. The Z shape tear has arrowheads on both ends and this is done to signify movement back and forth suggesting the constant need and desire to live a life in control and the potential, as her condition progresses, for the tear to re-open'.

> (Theoretical memo date 25th July 2005)

The final agreement for this model of Linda's early adjustment to her diagnosis of Alzheimer's disease was agreed at visit 19 on the 28th November 2005.

6.5   Case Exemplar 4: Jo

About Jo

Jo is a 78-year-old man who lives with his wife Gwen; they have two children. He was diagnosed with Alzheimer's disease in April 2003. The first co- research visit

commenced in April 2004 with the final visit in July 2006, in all there were 19 co-research contacts, of which two became practitioner visits and a more complete account of the co-research contacts is displayed in Appendix 11. The location of the encounters was at Jo's house. At the commencement of the study Jo's MMSE score was 27 out of 30 and at the end of the study he scored 25 (average score for the duration of the study was 27). This highlighted Jo's high level of performance and retained abilities over the time of his participation. On testing of mood, at the commencement of the study Jo's GDS score was 2 out of fifteen and the end of the study he scored 3. (Average score for the duration of the study was 2). This indicated that Jo was not clinically depressed at the end of our co-research encounter.

Jo lives with his wife in a large detached house in Rhyl, North Wales. They have 2 grown up children and 2 grand children. Jo's daughter lives next door and their son, a journalist, lives in London. The location of the research encounters was the main living room. I was usually met by Jo at the front door and shown through to the living room, which had been prepared for the visit. Jo and Gwen had rearranged the chairs so they were sitting together and a chair and table was positioned opposite for me to sit at. Prior to the interview Gwen would make a pot of tea, whilst I had a brief talk with Jo and see how he was.

As with the other case exemplars there was a strong bond and a sense of partnership between Jo and Gwen and both wished to be interviewed together to jointly co-construct Jo's life story.

6.5.1 Developing Jo's Life Story

The production of Jo's complete life story using the Gubrium's (1993) chaptered approach took approximately 13 contacts from 14th April 2004 to 27th July 2005. On average there was 1 research contact per month. All interviews were taped and transcribed in time for the next visit. Jo and Gwen were encouraged to use an 'ideas book', and the author kept a memo book.

The first two visits produced a rough 'draft of Jo's Life Story using Gubrium's (1993) chaptered life story interview schedule and this took approximately 4 weeks to produce from taped interviews. Jo took a little more time to identify with the task of chaptering his life than the other case exemplars, however after 4 weeks we had compiled the following descriptive list:

- An Introduction to My Life
- Chapter 1 – Childhood
- Chapter 2 – My Wartime Experiences
- Chapter 3 – The Royal Air Force
- Chapter 4 - Work after the RAF
- Chapter 5 – Marriage and Children
- Chapter 6 — Retirement
- Chapter 7 – My Illness

As we will shortly be discussed, these chapters constituted Jos' life story and provided the platform for the generation of Jo's 'My Theory'.

On the 3rd visit in June 2004 we exchanged life stories. Gwen took the lead during this interview and asked questions regarding my childhood experiences, why I became a psychiatric nurse and my present life. Jo was particularly interest in my time working at the North Wales Hospital in Denbigh, North Wales as he had worked for a short time at the hospital as a Disablement Resettlement Officer.

On the 4th visit in July 2004, there was a more detailed discussion regarding Jo's Life Story and the content of each chapter. Visit 5 became a practitioner visit due to a physical illness and deterioration in mental state, from which Jo made a full recovery. On subsequent visits Jo, Gwen and I decided to look more closely at each life chapter and agree the content before moving on to the next chapter. Visit 7 in December 2004 saw a closer examination of chapter 1, Jo's childhood. Visit 8 in January 2005 looked at chapter 2 and considered Jo's wartime experiences. Visit 9 in February 2005 discussed chapter 3 and was about Jo's time in the Royal Airforce. At visit 10 in April 2005 we considered chapter 4, Jo's working life after the RAF. Visit 11 in May 2005 looked at chapter 5, Jo's marriage and children. The final visit, visit 12 was in June 2005 and considered Jo's retirement (chapter 6) and chapter 7 Jo's illness. Jo's final life story was put together and on visit 13 in July 2005 was agreed by Jo and Gwen as a accurate representation of Jo's life.

Jo: An Introduction to My Life

I was born on the 15th January 1926 in Oxford Street Maternity Hospital in Liverpool. My mother's name was Sarah and my father's Joseph. We lived with my Father's

parents in Sandbank Street in the South end of Liverpool. My mother had four children.

The biggest turning points in my life were meeting my wife, joining the RAF and my love of flying, and also injuring my right hand, which made flying difficult and caused my discharge from the RAF.

The happiest point of my life was meeting my wife, we've had a happy life of comradeship and we've stuck together, good mates, good comrades.
The most important parts of my life have been having children and having a career, I regard that as a successful career. Good job, good life, good family.

Now, a good rating for my life would be 'satisfactory', even better! There are a few regrets but you can't go back so why worry. The happiest time has been with my family life, some wonderful times with my children.

I don't think I would do anything differently; I could have had a better career, I was the Trade Union representative everywhere I went and really I think it wasn't a good idea, I was a bit outspoken!

Chapter 1 – Childhood

I was born on the 15th January 1926 in Oxford Street Maternity Hospital, Liverpool. My mother's name was Sarah and my father's Joseph. We lived with my father's

parents in Sandbank Street in the South end of Liverpool, towards Speke. They were lovely small houses, red brick with an alleyway at the back.

My grandfather was a man of great standing in the community; he had a gold watch chain! He was a gaffer in the docks and he wore a trilby hat. His main grumble was that he missed the war, World War One, because he was too old. He was a 'hirer and firer', not a man to be trifled with. My grandmother's name was Mary, a very nice lady, devout, the house was always immaculate. It was always a pleasure to go there, always good food like rice pudding!

I scarcely remember living there because my parents moved to their own rooms. They had a house on the corner of Violet Street; it had a big basement. They had lodgers, 3 gentlemen who worked in quite 'clean' employment.

I was a big reader long before I went to school. When my mother pushed me in my pram I would read bits of paper on the floor or posters on the wall, I would decipher them and ask questions, my mother thought it was a nuisance. One lady said to her 'You should be thankful, my lot can't read and they're five!' So I had a flair for reading from an early age. I went to school at the age of five and then two years later I went to the big school. I enjoyed school and my childhood, and then, in 1939, war broke out.

Chapter 2 – My Wartime Experiences

My Mother had four children; I was the eldest then Maria, Harry and Silvia, the youngest. And, would you believe, they went to four different schools. My Mother refused to allow us to be evacuated separately so she volunteered to go with the children and help the teachers, so that we could all stay together. We were evacuated to Holywell, with all of the school. Nobody wanted to take in a mother and four children so my Mother found us our own place to live. My Father reluctantly came back to Liverpool, he didn't like it at all, and this eventually broke the marriage up. As a result I took over from my father. I was often left in charge and I developed a stubborn streak.

I got a job working in a butcher's shop. I got 12 Shillings a week, which was about two bob more than the average. I had several little jobs, one was at Rhydmwyn; building that secret factory, a lot of money was spent on that factory. Then I was lucky enough to get a job in Shotton Steel Works, or John Summers as it was then. I started as a boy as an apprentice steelworker. I worked days. On my sixteenth birthday the shift manager, Jack Nokes, approached me to go on his shift; you got more money on shifts! We worked three shifts, 6am till 2pm, 2pm till 10pm and 10pm till 6am; it really disrupted your sleep pattern, and especially where there were children in the house! I think it has affected me all my life.

I joined the Air Training Core; I'd always had an interest in planes so I joined the Holywell Squadron. We used to meet at Holywell Grammar School in the evenings and we went to camp. The nearest camps were RAF Hawarden and RAF Valley and we went to camp there. We had great times, weekend exercises, and navigation exercises at night; one group would be prisoners and the other the Gestapo chasing them. I became a Corporal in the Air Cadets.

Chapter 3 – The Royal Air Force

I volunteered for the Royal Air Force at the Chester recruiting office. We were interviewed and went for a medical examination and the best of the group were sent to RAF Padgate for 3 days for a proper drilling. I got through that and I was accepted but the war had slowed down so I had to wait for 7 to 8 months for them to send for me. In June 1944 I reported to Regents Park. We did an introductory course at Walthamstow Technical College and then went to Torquay for some more assessment tests. Next I went to Burton-on-Trent for 12 hour Tiger Moth training and then to a camp at Bridgenorth – and then the European war ended!

We had been streamed to go for training in the USA and went up to Heaton Park, Manchester, which was used as a gathering point for RAF people going overseas on the ships. We were quite hopeful and then the Japanese war ended and it was all finished – all gone!

Then I volunteered for the regular RAF and I was accepted for 5 and 4, five years service and 4 years on reserve.

During my training I had injured my wrist and had spent some time at a hospital in Walton having Deep X-ray Therapy and eventually I was discharged, as I was unable to meet the medical requirements. I was awarded a small pension, which I still receive today.

Chapter 4 – Work after the RAF

After the war I worked in Swansea as a Clerk. I met my wife in a dance in Holywell and moved to Altringham to be near her. My wife was in her first teaching job at that time. I sat the Civil Service exam at the Town Hall in Manchester and passed. I was offered a job as a clerical officer in the Ministry of Labour. During the Cotton Crisis I was sent to Stockport. We were married by then. We got back to Chester eventually and that was my permanent office, we lived in Chester and had a happy time there. By this time we had decided to start a family. The cost of accommodation in Chester was too much so we moved to my wife's home village of Pentre Halkyn and I came to work for the Ministry of Labour and National Service in a wooden hut in Holywell! I worked for the Civil Service for 37 years and rose to Higher Executive Officer. I retired when I was 60.

I couldn't have had a better wife and we were married in 1952. Chris was born in 1959. Gill was born in 1963, Gillian Elizabeth, after the Queen Mother, and they've both been very successful, both university graduates

Chapter 5 – Marriage and Children

Chris, my son, obtained a scholarship to go to Rydal School. He didn't want to go to the senior school, he didn't want to be away from home so he came out of there and went to the local high school. Chris went to Jesus College, Cambridge; he won a scholarship and read English. He works as a writer now, a freelance writer, and lives in London. My daughter, Jill, went to Bristol University and works with computers. Her job was a consultant in computer hardware. She's married now and manages her husband's affairs; they've moved back to Rhyl and live next door.

My hobby was flying and I qualified as a civilian pilot. It was an expensive business so I hoped to get passengers on each flight, which was illegal, but they would pay. I didn't have a licence for hire so I would accept back handers! I would go to air shows all over the country. The last air show I went to was the International Air Show at Fairford, near Swindon, last year.

Chapter 6 – Retirement

In general terms my life now is happy. Retirement has been a happy experience for me and I'm lucky my wife has been with me, my life long companion. I thought I

would be bored to tears when I retired but I settled into it and when my wife retired as well it was even better. I'm still cutting the grass and doing things but you slow down the older you get; you do less but it takes longer! I walk around the block and we go out for lunch three times a week

Chapter 7 - My Illness

About seven years ago I started to have problems with my memory. I struggled to remember names of places and people. It was affecting my speaking and writing, words were getting 'blocked' in my head. I became irritable and bad tempered. It was a very worrying time. At first I thought it was my age but then we realised it was more than that. We decided to go and see my GP; the sooner I could find out what was going on the better. He referred me to the memory clinic and I received a diagnosis of Alzheimer's disease in February 2003. I have found it very difficult coming to terms with the diagnosis; I didn't want to believe it at first. At first we decided to tell only close family members and the diagnosis was not general knowledge. Gradually, we decided to tell more people. Over the past three years my memory has become worse. I've got insight into my situation and it's not much fun. However, I am still relieved I can do most things. I know I have to make allowances for my limitations. If we were to go to a lot of new places now it would be confusing, but I would still go on holiday with my daughter and son in law if they asked. We try and keep active; we think that's important, exercise and routine in particular.

I still enjoy my life, I'm quite happy. We are well supported, we have a good marriage, and we are a partnership! The way we handle ourselves now is helped by

our past experiences. I have a background that has helped to prepare me for now, in particular my childhood and the way we were brought up so we just 'get on with it'. We have friends that we go to see and we go out as often as we can so at the moment life's busy and hectic.

6.5.2   Working Together to Produce Jo's 'My Theory'

The focus of the next phase of the study was to engage in a co-constructed theory building process using the adapted principles of constructivist grounded theory (Charmaz, 2000). As previously rehearsed, this was achieved by analysing Jo's life story and determining the key themes of his life experience to develop a co-constructed theory of Jo's early adjustment to Alzheimer's disease.

To begin this theory building process, Jo, Gwen and I met for the first time on this new phase of the study on 22nd November 2005. During this visit we re-visited the aims of the study and discussed the requirements and direction of the next stage and made sure that Jo continued to be fully informed of the research consent process and was free to disengage in the process at any time.

On the meeting of the 22nd November 2005 we each had a copy of Jo's life story and together we read through the document paying particular attention to the chapter headings. Over the next 2 meetings between November 2005 and December 2005 we worked together to develop the key themes of Jo's life expressed as categories of experience. The development of the categories of experience were guided by Jo's reference to the chapter headings in order to produce his 'storyboard'. The storyboard we constructed is displayed in Table 6.5, and highlights 4 categories of experience

that emerged as part of this co-constructing and dialogic process. The 4 categories of experience identified by Jo were: being in control, just get on with it, coming to terms and making allowances.

Table 6.4: **Jo's Storyboard:**

Being in Control	Coming to Terms
▪ In charge ▪ Self belief ▪ Stubborn streak ▪ Civil Service	▪ I thought it was my age ▪ I didn't want to believe it (diagnosis) ▪ What holds us back is our age ▪ Telling close family only (diagnosis)
Just Get on With It	**Making Allowances**
▪ War time experiences ▪ A background that has prepared me ▪ The way we were brought up ▪ My wife, my life long companion	▪ I know my limitations ▪ Relieved I can still do things ▪ Not housebound we can get out

To illustrate this process of developing categories I wrote this reflective memo after the work with Jo and Gwen in January 2006:

'Jo's storyboard tells of a proud man, one who has been used to having a certain degree of authority, a man used to being 'in- charge', and as a result, having a degree of '*control*' over his life. This is evident from his childhood experiences when he became head of the family after they were evacuated

during the war, through to his working life and senior position in the Civil Service. Jo will say he is from a generation 'shaped by their wartime experiences', a generation who learnt to be self sufficient with a '*just get on with it*' attitude. This mentality has stayed with Jo through out his life and has been evident in the way he has '*come to terms*' with his illness. His diagnosis of Alzheimer's disease was a major shock that he has worked hard to come to terms with, helped by his wife and family. His current life is one of regaining control. He does this by recognising his limitations and '*making allowances*' for his memory problems'.

<div align="right">(Theoretical memo date: January 6th 2006).</div>

After Jo, Gwen and I had agreed and finalised the 4 categories of experience, we were now in a position to start developing Jo's 'My Theory'. The focus of the research involved further analysis of Jo's storyboard and this took from February 2006 to April 2006. To help in this process we started to develop our concepts and ideas in diagrammatical form. In particular, we began to concentrate on Jo's early adjustment to Alzheimer's disease and how he has adjusted to his diagnosis.

After further reflection on Jo's storyboard Jo, Gwen and I came up with the concept of a 'Life in Control' to express Jo's over-arching experiences of his life. In particular, how the traumatic impact of developing Alzheimer's disease caused him to lose control of his life and it was not until he was able to accept his diagnosis that he was able to regain a degree of control. To illustrate the meaning of these concepts I wrote this memo:

'The issue of a life in control was contextualised within Jo's storyline and lay at the heart of his response to the present chapter, of life with Alzheimer's disease. With the onset of Alzheimer's disease this notion of a desire to live a life in control has been apparent in how Jo has come to terms with and adjusted to his illness'.

(Theoretical memo date: February 10th 2006)

Jo finds it difficult to describe his early awareness and experience of developing dementia. He was experiencing problems with his memory, and becoming more irritable, which he initially accepted as an inevitable part of growing old. It wasn't until he began to experience problems with his speech and writing that he became aware that there was a significant problem. This was a difficult time for Jo and his wife. He was increasingly forgetting people's names and losing his chain of thought in conversation.

For a number of years Jo had denied he was having any problems with his memory. This period possibly lasted for up to seven years. This continued for a period after his diagnosis. This was a man who was used to being in-charge and in control of his life. For Jo and his wife this was a difficult time, a period of losing control. The trigger for seeking medical attention was his word finding difficulties. Jo is an intelligent, articulate man and his difficulty communicating was becoming increasingly noticeable and frustrating. They visited the GP who acted quickly with a referral to the memory clinic and a diagnosis of Alzheimer's disease was made. The diagnosis was a major shock to Jo and his wife and there was an initial period of denial on Jo's behalf,

'I have found it very difficult coming to terms with the diagnosis; I didn't want to believe it at first'.

<div align="right">(Jo, Chapter 7 – My Illness.)</div>

Figure 6.9   Jo: Developing 'My Theory'
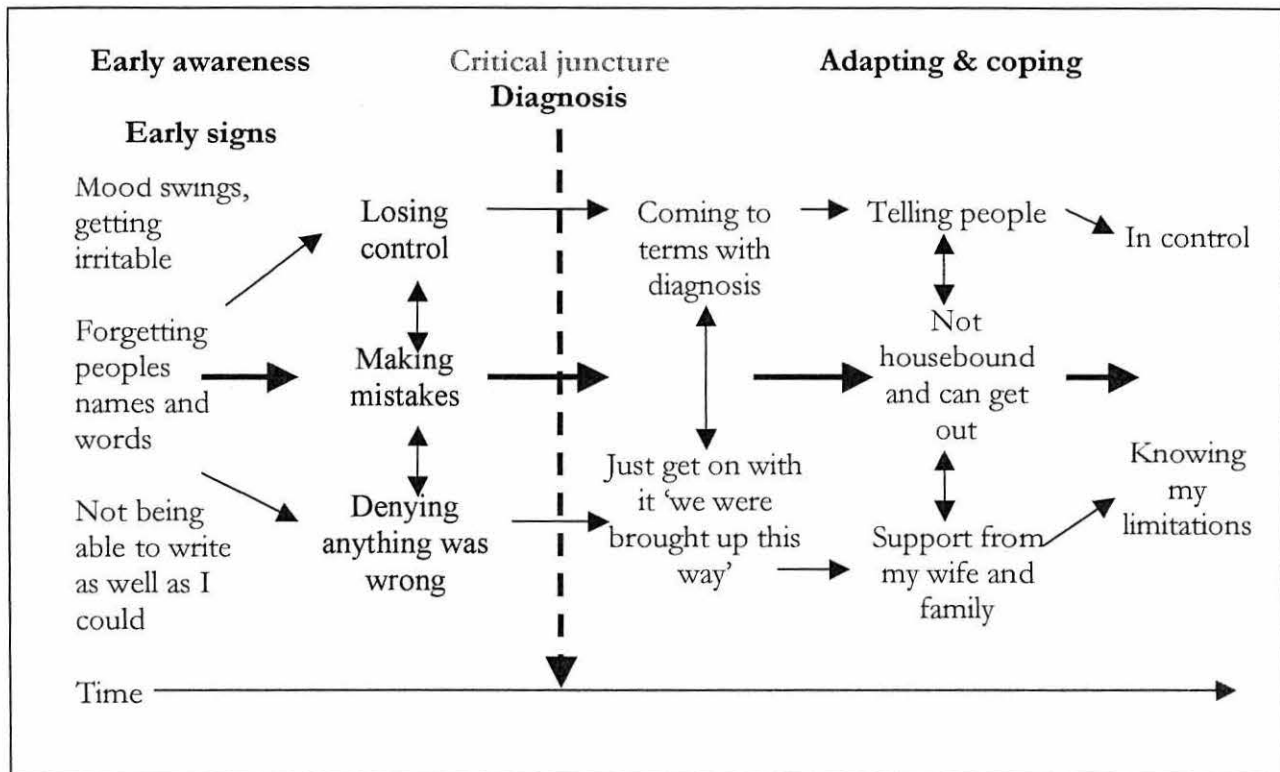
This was followed by a period of coming to terms and accepting the diagnosis:

'I've got insight into my situation and it's not much fun. However I am still relieved I can do most things. I know I have to make allowances for my limitations'.

<div align="right">(Jo, Chapter 7 – My Illness.)</div>

Jo's current life is about living positively with dementia. He has regained a degree of control in his life by accepting his diagnosis and making allowances for his limitations. He feels his past life experience have been important in helping him cope in a positive manner. The support of his wife and family has also been significant in helping Jo come to terms with his illness:

> 'I still enjoy my life, I'm quite happy. We are well supported, we have a good marriage, and we are a partnership! The way we handle ourselves now is helped by our past experiences. I have a past background that has helped to prepare me for now. It was also the way we were brought up so we just 'get on with it'
>
> (Jo, Chapter 7 – My Illness.)

Jo and his wife remain active and have found it important to tell people of the diagnosis.

We worked together to produce the diagram that is illustrates in Figure 6.9. The diagram explores the development of Jo's 'My Theory' based on what was 'centre stage ' in his storyboard. The diagram connects the key centre stage categories of experience and considers the impact of the diagnosis as a critical juncture in Jos' experience of living with Alzheimer's disease.

Once we were happy with the content of the development diagram as a true representation of Jo's early awareness and adaptation to his diagnosis of Alzheimer's disease, we met to consider some of the key concepts we had developed. At our co-

research meeting on the 17th February 2006, we considered Jo's desire to live a life in

control

Figure 6.10 is Jo's diagrammatical representation of his experience of living with

early stage Alzheimer's disease. The diagram explores Jo's overarching desire to

maintain a degree of control over his life. The diagnosis was unexpected and

traumatic and presented Jo with a dilemma. He could either, deny the existence of his

dementia and put it down to his age, or he could accept the diagnosis and in doing so

come to terms with his limitations and live as normal life as possible.

Figure 6.10: Jo's 'My Theory' Diagram
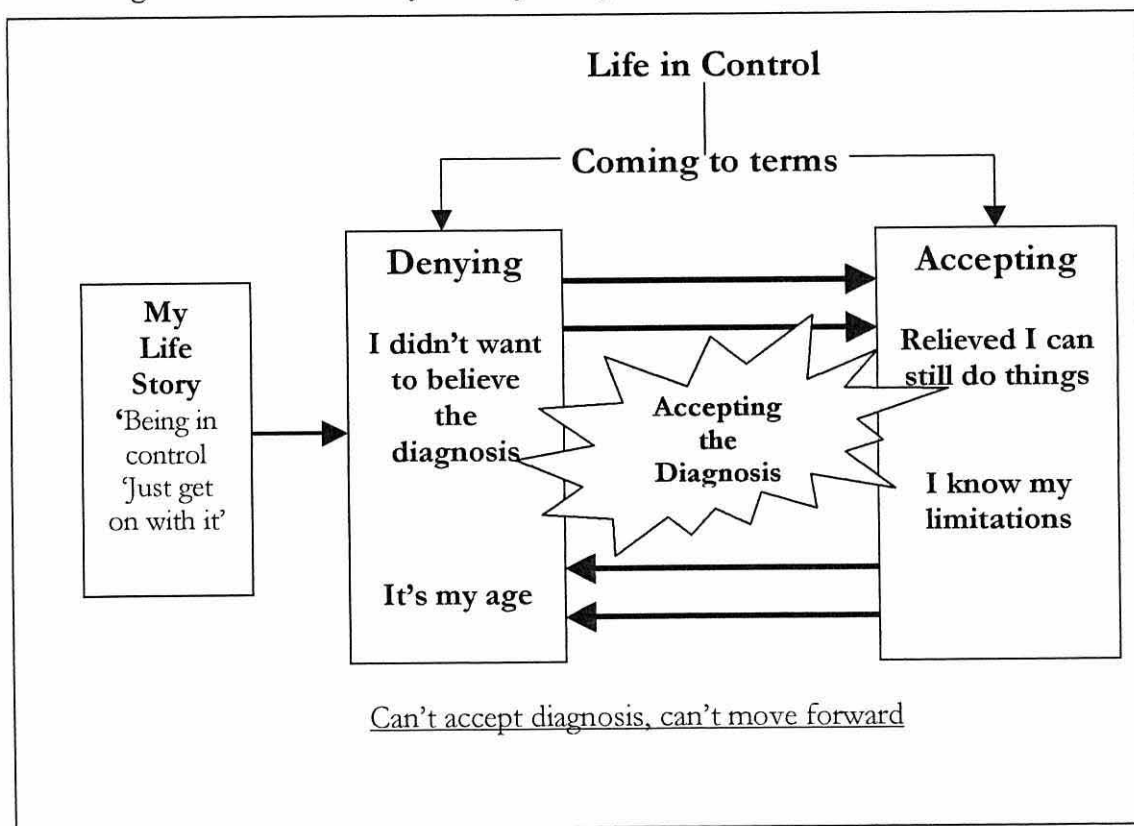
The diagram we came up with to describe Jo's overarching desire to live a life in

control is a symbolic representation of the struggle between denial and acceptance of

the diagnosis. The diagram consists of a number of boxes. On the far left is a box

representing Jo's life story and is positioned to indicate how his life experiences have shaped his current life. The 2 main boxes represent denial and acceptance. The first box represents 'denial' described by the terms 'not wanting to believe the diagnosis' 'It's my age'. The second box represents 'acceptance' described by the terms 'relieved I can still do things' and 'I know my limitations'. In the centre of the 2 main boxes is a further symbolic representation of the massive impact of developing Alzheimer's disease and the struggle to accept the diagnosis. Jo wanted this experience to be represented as an 'explosion' (using a wartime analogy). The positioning of the black arrows between the 2 main boxes explains the challenge it has been for Jo to come to terms with his diagnosis. The arrows show movement back and forth denoting the ongoing struggle between denial and acceptance. The red arrow at the foot of the diagram gives the diagram movement and shows the importance of acceptance in enabling Jo to move on and continue his life in control.

Within such a schema, Jo's early experience of developing Alzheimer's disease is described as a desire to life a life in control. The critical juncture was accepting the diagnosis coming to terms with his limitations and regaining control. Jo, Gwen and I agreed the final 'My Theory' diagram during visit 19 on the 24th April 2006.

Jo is a proud man who has had a good and successful life. He currently leads a happy life, living within the accepted limitations of his condition. Jo also makes the point that this has also been made possible by the loving support of wife and family.

6.6 Chapter Summary

Chapter 6 details the development of Grace's, Mo's, Linda's and Jo's co-constructed 'My Theory' using a longitudinal modified constructivist grounded theory approach. The chapter describes the utilisation of life story and biography and the development of the storyboard and categories of experience as a method of articulating the emerging grounded theory. Finally, the 4 'My Theories' are represented in conceptual and diagrammatical form with an emerging theme of life in control.

CHAPTER 7:

A SYNTHESIS OF THE MODELS

7.1 Introduction to 'Life in Control' and 'Bridging' in Alzheimer's disease

As will shortly be discussed, the conceptualisation and naming of 'bridging' emerged from the author's constant comparative analysis (CCA) of the respective 'My Theories' of Grace, Mo, Linda and Jo. Each of the individual 'My Theories' mapped out how participants constructed and viewed their early transition into a life with Alzheimer's disease and the different, but overlapping, ways of starting this journey. In many respects Grace's 'My Theory' was the platform for reflecting common adjustment processes, particularly the 'balancing' metaphor focused my attention on the dynamic nature of the process of adjustment and the factors which were attributed to losing, finding and keeping her life in balance (see Figures 6.3, 6.4 and 6.5). This simple sequential description chimed with my own personal experience of working with people with dementia and their families over many years, and was also seen in each of the presented 'My Theories' described in the previous chapter. However, there was something missing from this analysis, something that held all the models together and yet provided a theoretical explanation of movement between and within the process of living with the early experience of Alzheimer's disease.

After reflecting and comparing each 'My Theory', I hit upon the idea of 'Bridging' as a description that addressed the complex and biographically based responses to the onset, diagnosis and adjustment to Alzheimer's disease. To illustrate the meaning of this concept I wrote this memo:

'By analysis of the 4 'My Theories', there are a number of common themes that explain the early experience of Alzheimer's disease, in particular, how the adjustment to the onset of Alzheimer's disease is constructed in terms of control and balance. However, I feel these descriptions do not fully capture the subtle and complex processes of early adjustment. On further reflection the critical junctures between the key phases are significant, in particular, how these junctures are crossed or 'bridged'. The concept of 'bridging' therefore is crucial in understanding the journey individuals and their families need to embark upon to successfully navigate their way through the early experience of Alzheimer's disease'.

(Theoretical memo date: July 17th 2006).

The roots of 'bridging' lies in the My Theories i.e. the narratives developed by people through their life story work centred on what was important in their own experience of the living with Alzheimer's disease. To illustrate this further I wrote this memo:

'What became apparent on further analysis of the My Theories were a number of common themes of experience or categories of experience that needed to be overcome or 'bridged' in order for the individual and their families to move forward. Such themes included the association of the early signs such as

'making mistakes' with the onset of the illness. The desire to find out 'what was wrong' and seek a diagnosis and the importance of the relationship between husband/wife, family and supporting agencies in helping the individual come to terms with the diagnosis and move on'.

(Theoretical memo date: July 20th 2006).

The concept of 'bridging' had a sense of capturing people's responses far better than the concepts of coping and adaptation that had informed the formulation of the research question. The diagrammatic representation of their experiences by Grace, Mo, Linda and Jo was embedded in the life story work. The development of 'bridging' required a review of the narrative accounts combined with the diagrams that had developed the co-constructed ideas culminating in the 'My Theories'. To illustrate these developing concepts I wrote the following memo:

'The 'developing My Theory' diagrams in chapter 6 begin to capture the concept of 'bridging'. The diagrams reflect the key phases of onset, diagnosis and acceptance and the movement between them. The 'developing My Theory diagrams' show how the person moves and 'bridges' each of the key phases. The length and speed of this journey is dependent on factors unique to the individual and the response of carers, family and supporting agencies. Moving from early awareness to diagnosis, as already rehearsed, is dependent on realising something is wrong, discussing concerns with carer and family and deciding to seek help. This phase can only be successfully bridged if the carer and family agree there is a problem, a GP who is sympathetic and knowledgeable in the early signs of Alzheimer's disease, who takes the person

concerns seriously and initiates referral to an appropriate service. To obtain an accurate diagnosis there will need to be local services that specialise in early assessment and diagnosis such as a Memory Clinic. Finally, after the diagnosis the individual and their families will need to accept the diagnosis, make the necessary adjustment to their lives and seek help to do this'.

(Theoretical memo date: July 20th 2006).

Based on the co-constructed theories of Grace, Mo, Linda and Jo the process of 'bridging' represents *how* people with Alzheimer's disease experience and shape the complex and dynamic process of adjustment. The basic components of bridging are described in Figure 7.1.

Control

1 ——————— 2 ——————— 3 ——————— 4

Losing   Finding   Keeping

Start
With   Coming to   Confirming   Partnering   Continuing
journey   terms   with
                                                                                     journey

Making   Diagnosis   Accepting
mistakes

| Pre Diagnosis Life and biography | → | • Time of crisis
• Secrecy
• Self/mutual blame
• Finding out what's wrong | → | • Coming to terms
• Reconstructing events and futures
• Being together
• Start of partnership
• Negotiating early 'bridging' | → | • Living life with new horizons
• Maintaining quality of life
• Developing interests
• Continuing with interests |

Person's Journey

Biographical time
Chronological time

Figure 7.1   Life in control: 'Bridging' Alzheimer's disease

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This process hinges on the overarching attempt by people to engage in the psycho-social work of 'bridging' the difficulties caused by the experiences of Alzheimer's disease in their lives, initially signalled by the onset of 'making mistakes'. The description of journeying and being 'on a journey' had great resonance with Grace, Mo, Linda and Jo. The onset of Alzheimer's disease resulted in descriptions of particular life experiences that defined the broad phases between losing, finding and keeping control. The processes of bridging is built on these 'embedded experiences' at each particular phases of life with Alzheimer's disease, as illustrated in figure 7.1. These 'embedded experiences' are described further below in Table 7.1:

Table 7.1: The embedded experience of early Alzheimer's disease

Embedded experiences	Description
Pre Diagnosis Life and biography	• People's journey (self and partners) prior to diagnosis, understood and narrated as life journey with the present informed and critiqued in relation to past life (diachronic-synchronic). • Symptoms of Alzheimer's disease have emerged but are integrated (with increasing difficulty) into the life journey.
• Time of crisis • Secrecy • Self/mutual blame • Finding out what's wrong	• Characterised by the threshold of 'making mistakes' this involves the increasing difficulty/disjuncture between past and present life journey. Identity of self and self-other relationships challenged. • Losses associated with Alzheimer's disease are kept to self or others hide the symptom and do not acknowledge change or give a false meaning to events. • Meaning of events that constitute losses/making mistakes result in blaming within relationships and within self. • The sense of needing to know 'what's wrong' without necessarily acknowledging 'what it could be', requires decision by self and/or others (partners/close family) to 'push' the issue into the open based on recognition of difficulties and life in crisis.
• Coming to terms	• The naming of 'what's wrong' leads to a new and intense experience of trying to understand what's happening and relationship between past and present with implications for future.

• Reconstructing events and future • Being together • Start of partnership • Negotiating early 'bridging'	• Reconstruction of biography and life –meaning based on diagnosis that builds on biographical review. • Alzheimer's disease is seen as part of life journey and to be 'lived with/fought against' and valuing/re-valuing key relationships and sense of togetherness affirmed/regained. • Being together (with Alzheimer's disease) defines experience and start of partnership work in trying to deal with symptoms and losses. Re-organisation of self and others. Acknowledgement of 'what's wrong, why it's wrong and what do we/I do' in response. • Early bridging builds on the experience of trying to make sense of events, situate them in past and present and is concerned with making sense together and seeking not only individual but also a shared sense of meaning.
• Living life with new horizons • Maintaining quality of life • Developing interests • Continuing with interests	• The experiences of early bridging develop through shared meanings to trying to identify 'futures' and what it might look like. It is focused on trying to see new/old but re-shaped or alternative horizons. Biographical reviewing is part of this experience, both individual (self/others) and shared. • The experience of losing control and regaining a sense of control forms the backbone of a shift in re-defining quality of life, underpinned by biographical work focused on existing, new and possible horizons for life (within self, self and others). • Identifying losses is also accompanied by the experiences of seeing gains, through the development of new interests, instigates new relationships (for person with Alzheimer's disease and partner/family).

These 'embedded experience's are subject to change and modification over time, with such time being sensitive to both biographical and chronological time. In many respects the journey is defined, constructed and re-constructed constantly using both biographical (past- present/diachronic-synchronic) and chronological time by people with Alzheimer's disease. The narrative accounts that underpinned the diagramming of 'My Theories' highlighted the significance of people's biography and the 'measurement' or 'marking' of what occurred in their lives against biographical time,

such as 'making mistakes' involving a dissonance and separation between past and present life, combined with it increasing in its effect with the passing of 'clock' time (chronological).

Over chronological time bridging involves the person with Alzheimer's disease, their partner (if applicable) and those who are seen as close relationships into drawing upon a number of others to support the process of bridging, however as discussed later there are inherent weaknesses and strengths in such activity as the bridging continues and requires others, such as professionals from the Memory Clinic to be involved.

7.2   Critical junctures: losing, finding and keeping

The basic social process of adjustment in early Alzheimer's disease is hence best understood as a temporal model and process. It involves chronological and biographical time, but as a grounded theory model the identification of critical junctures are crucial and these create and involve particular phases: losing, finding and keeping. The 'My Theories' identified the distinct but linked phases of losing, finding and keeping. For Grace, Mo, Linda and Jo the losing phase is characterised by a period of great uncertainty, frustration and fear, and emotional change. The finding phase which begins after the diagnosis and is a period of coming to terms with their situation, developing a fighting spirit: 'taking each day as it comes, and 'getting through it'. The keeping phase is about adjustment and acceptance and during this phase the person will begin to accept the changes they are experiencing, they will learn to recognise their limitations and not to blame themselves.

- *Losing* – The critical juncture of losing identified people's awareness of the sense of losing control due to the onset of Alzheimer's disease. This critical juncture is preceded by a period (at times prolonged) of starting to lose control (gradual erosion or rapid change in different areas of life). Making mistakes is a cardinal feature of this process and the sense of 'making' the mistakes denotes the sense of control being lost because of the efforts not to make mistakes in different parts of the persons life. The sense of loss in control is seen as significant by the person with Alzheimer's disease and others (partners/family) and highlights a threshold of acceptance being breached and an acknowledgement of a dissonance with how the person was viewed in the past and the loss in the sense of agency. Making mistakes is about a loss in agency and the critical juncture is about recognizing this by the person with Alzheimer's disease and others. This leads to efforts to 'come to terms' not only with the losses (mistakes) but also to the loss of agency.

- *Finding* – The critical juncture of finding identifies the way in which the person with Alzheimer's disease (self) and others (partners/family) seek to come to terms and find out why are the losses occurring and what is taking away the person with Alzheimer's disease and their partner/family agency over events and life. Answering these questions requires addressing the fundamental question 'what's wrong'. Seeking answers underpins 'finding' and involves finding sources/people to gain understanding of 'what's wrong'. The diagnosis presents a symbolic as well as a practical juncture by providing a 'name' to the loss of agency and opens up access to a wider range of understanding and information in order to make sense of what's happening.

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- *Keeping* – The critical juncture of keeping involves the psychological and social acceptance by the person with Alzheimer's disease (within self) and their partner/family of what's wrong, why it happened and what can be done about it and by who. Acceptance is a starting point not an end point, a mental construction that locates understanding of what's wrong. By naming and understanding Alzheimer's disease the sense of agency is regained and 'making mistakes' becomes part of 'making meaning' out of events/life by acknowledging the presence of Alzheimer's disease as part of a new biography.

7.3 Bridging as a process of adjustment

It is necessary now to examine more closely the key parts of bridging and how these relate to the embedded experiences, as part of seeking control from the stage of losing control, finding control and keeping control:

- *Coming to terms* –'Coming to terms' in Figure 7.2 describes the process of recognizing that something is 'wrong' and does not 'fit' with one's past life. The process of 'seeking' aims to understand what is happening and why. It is about seeking information, understanding of what's wrong through finding reliable and trustworthy sources. These processes of 'coming to terms', 'seeking' and 'checking' are complex and involve people with Alzheimer's disease 'seeking sense' by engaging in a discourse (indicated by arrows) that goes 'round and round' and includes an increasing number of people from

oneself (self), partners, close family members, professionals and others. At some point a judgement is made that the information is sufficient to confirm (confirming) that something is wrong and an explanation presented as to why.

Figure 7.2   Coming to terms
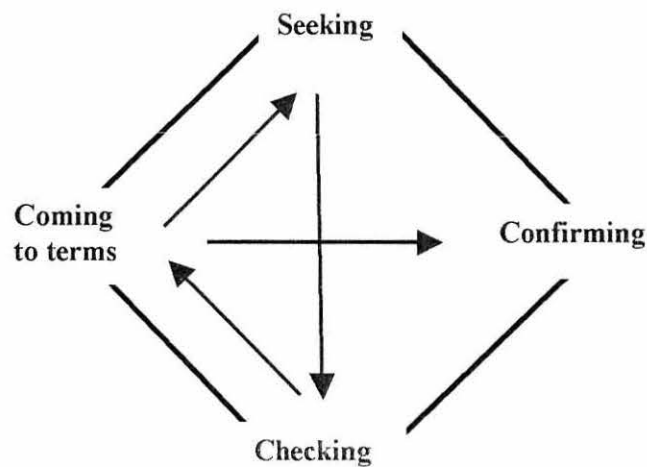
- *Confirming* – The process of 'coming to terms' develops a process of 'confirming' in Figure 7.3 and builds on the existing network of going 'round and round' oneself (self), partners, close family members, professionals and others to 'make sense' of what has happened and why. It is concerned about 'negotiating' the meaning of what's happened within close relationships (self, partners and close family) and seeking further information, critically appraising and rejecting or accepting such information. Such a process is dynamic and in many respects involves individuals and their close relationships in a range of processes that rotate around their biographies and life-meanings. 'Accepting' requires people with Alzheimer's disease to act

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upon what comes out of these negotiations is also underpinned by dynamic

process grounded in biography and particular life-meanings prior to starting to

tackle the self/relationship based-process of 'adjusting'.

Figure 7.3   Confirming

Negotiating

Confirming   Adjusting

Accepting
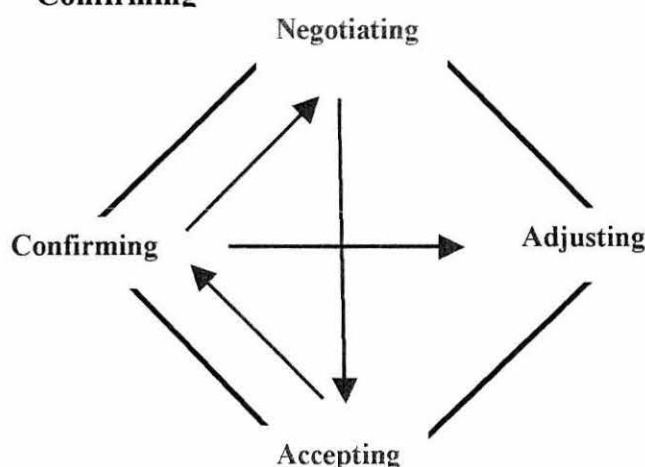
- *Partnering and Continuing* – As Figure 7.4 reveals, in 'partnering and

  continuing' the process of 'adjusting' is extended and involves both seeking

  meanings and making meanings from the situation. In the first instance it is

  concerned with 'balancing' what has been found out, accepted and rejected

  from 'coming to terms and 'confirming' processes. It involves 'balancing off'

  the situation as narrated/from the perspective of oneself (self), partners, close

  family members, professionals and others, identifying gains and losses. This is

  intimately biographical in its orientation and leads to a process of 're-

  affirming' a sense of identity (who am I/who are we) and sense of purpose

  (linked to biographical markers). This process of 'adjusting', 'balancing' and

  're-affirming' goes 'round and round' until a judgement (by self or pushed by

  others) is made that the Alzheimer's disease makes sense and has to be

  accepted as part of the person's life (and partner's) and adjusted-to as part of

the life-meaning. Adjustment involves 'partnering and continuing' under the

umbrella of meaning provided by the 'balancing-re-affirming' process and

focuses on seeking people to 'partner up with' as part of a life with

Alzheimer's disease. This may involve building upon the existing network or

developing a wider network in order to continue.

Figure 7.4   Partnering and Continuing

Balancing

Adjusting

Partnering
and
Continuing

Re-affirming
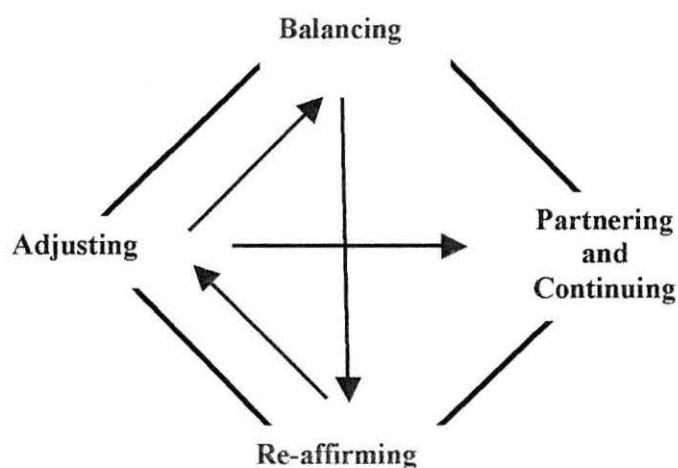
7.4   Bridging as a dynamic process

As noted in the description of coming to terms, confirming and partnering (Figures 7.2, 7.3 and 7.4) the processes involve 'going round and round' as a dynamic not linear process. The diagrams arrows (Figure 7.5) point to the dynamic process of how people may move back and forth (over time) as they either seek or make meaning of life events:

Figure 7.5   Bridging as a dynamic process
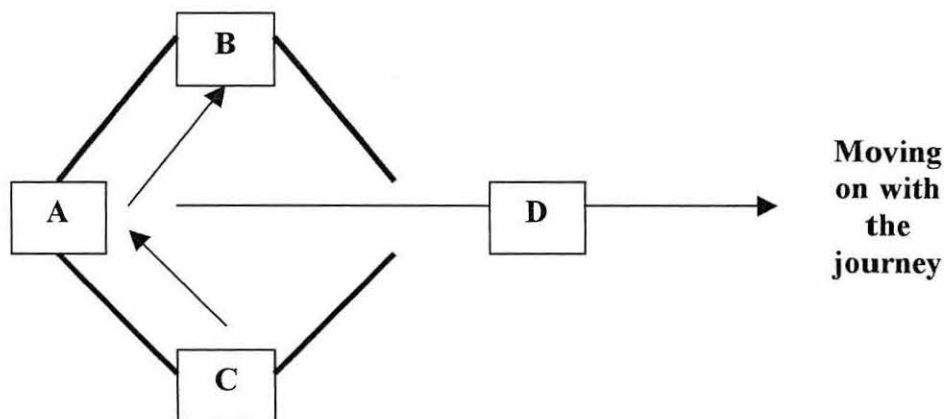
People may move 'around and around' A to B to C for some time or move through quickly A-B-C before progressing to D

7.5   Bridging failure and collapse

The dynamics of 'Bridging' represented in Figure 7.1 is subject to stressors at particular critical junctures and such stressors may result in delays in 'bridging' actions, leading from coming to terms-to- confirming-to- partnering as part of the journey with Alzheimer's disease. These failures or collapse may result in temporary, transient 'delays' or the process of bridging may extend over a prolonged period of

time (chronological) at each juncture. Also, the effects of failure or collapse may end the journey and require a return to a journey that is 'stuck' at the juncture of losing control and no further bridging may take place.

Figure 7.5 also illustrates the potential for failures at the critical junctures of losing (making mistakes), finding (diagnosis) and keeping (accepting) to enable continuing with the journey. As described earlier, the complex processes that underpin the journey from losing to keeping control involve a process of going 'round and round' as necessary before moving through to the next phase. These processes are subject to a possible collapse at any time and hence the collapse of bridging. The 'collapse' of the process, however, may be restored through a series of supportive events occurring or additional people (family/and or professionals) being involved.

7.6   Bridging: Fit, Work and Modifiability

Bridging should be viewed as a constant process and not a 'one off set' of events or stages. It can be argued that current biomedical approaches fail to appreciate the importance of bridging and narrative based biography as a way of helping us understand the early experience of Alzheimer's disease. The concept of 'bridging' explains why some people are more successful at coming to terms with their illness than others because of their past life experiences (biography). For instance, Grace adjusted quickly to her diagnosis and her current life is the happiest it has ever been. Current approaches and understanding of early Alzheimer's disease would have difficulty in explaining how Grace has come to terms with her current life in the way she has. However, a narrative based biography provides us with an insight into

Grace's past life and how she had learnt to 'bridge' over traumatic life experiences before and develop processes to help her adjust and accept her current situation. This explains why, for Grace, living with Alzheimer's disease was not the most insurmountable event her life.

The concept of 'bridging' provides opportunities for clinical intervention and practice development. The assessment process should be biographical and sensitive to the context within which Alzheimer's disease occurs. Clinical interventions should aim to support 'bridging' rather than the current emphasis on 'coping' or 'adapting' in Alzheimer's disease. Narrative and biographical based assessments should aim to determine the type of support required and care plans should be designed to identify the critical junctures with the aim of avoiding failure or collapse of the 'bridging' process.

7.7   Chapter Summary

Chapter 7 introduces the concept of 'bridging' as a theoretical explanation of the early adjustment and transition into a life with Alzheimer's disease. The concept of 'bridging' has been developed from the 4 'My Theories' and builds on the identified need to live life in control. The chapter argues that the concept of 'bridging' has a sense of capturing people's experiences far better than the traditional concept of coping and adaptation. This model acknowledges the importance of critical junctures in the process of early adjustment and describes a number of distinct phases: losing (making mistakes), finding (receiving a diagnosis) and keeping (accepting life after diagnosis). It is argued that failure at these critical junctures can inhibit successful

adjustment to a diagnosis of early Alzheimer's disease. The concept of 'bridging'

provides us with a way of understanding the complexities of the early experience of

Alzheimer's disease and explains why some people are more successful at coming to

terms with the illness than others. It is anticipated that the concept of 'bridging' will

have particular use in directing clinical intervention and practice development.

CHAPTER 8:

DISCUSSION

8.1 Introduction

This final chapter will discuss the findings from the study and highlight its

contribution to developing a greater understanding of the experiences of people living

with the onset and progression of Alzheimer's disease. The findings and the emergent

model of early adjustment developed during the study will be considered in the light

of recent developments in the field of dementia care, which will include the key areas

of early awareness and adjustment, memory clinics and relevant government policy

(up to mid 2007). The approach to constructivist grounded theory and a practitioner-

researcher model will be examined as part of the consideration of research methods

and the current evidence on practitioner-researcher and the involvement of patients as

partners in the research enterprise will be reviewed. Furthermore, the strengths and

weaknesses of the study will be discussed along with recommendations for future

practice, research and consider the implications for future policy in Wales and the

UK.

8.2 A model of early adjustment

The development of a model of early adjustment outlined in Chapter 7 has provided a greater understanding of the experiences of people living with early Alzheimer's disease; however, it remains an exploratory model and will require development through further empirical work and modification.

This proposed model of early adjustment of Alzheimer's disease described in terms of 'maintaining control' and 'bridging', describes basic life process as well as basic social process (Glaser, 1978) based on 'life language' (Spivak, 1997 cited in Lawler, 2003). However, the author argues that the use of diagramming has proved a more meaningful and accessible way of expressing the complexities of chronic illness than narrative alone. The conceptualisation and diagramming of 'bridging', which was developed from the 4 'My Theory' diagrams, has played a significant part in facilitating the emerging co-constructed grounded theory.

The inter-case grounded theory builds on what Osatuke *et al.* (2004) described as the role of narrative in making 'meaning bridges'. These 'meaning bridges' derived from narrative present a construct of the self (and its story) by the storyteller, centres on the 'semiotic glue' constructed of words, symbols and signs that hold our experiences together.

As Freeman (1993) highlights, any narrative account is a 'rewriting the self' and is itself an interpretive act and results in some 'submerged story threads' (Osatuke *et al.*, 2004). In this sense narratives address self-understanding (Freeman, 1993) and situate a sense of selfhood in a temporal frame, providing an interpretation of connections,

coherence, movement and direction (Gergen and Gergen, 1984) as part of what Spivak (1997 cited in Lawler, 2003) described as writing a running biography with life-language rather than 'word-language'. The task of accessing 'life language' requires the use of 'word language' and its careful interpretation and analysis in order to make sense of the storied narrative of individuals and wider communities.

8.3   How does the model of early adjustment fit with current literature?

The concept of 'bridging' is not one readily represented in the current literature. However, the experience of living with early Alzheimer's disease is presented in the literature as a highly individualized and complex consisting of several progressive phases, starting long before diagnosis (Steeman *et al.*, 2006).

Losing

As previously rehearsed, the first phase of this model is characterised by a feeling of losing control due to the onset of early Alzheimer's disease. Mo, Grace, Jo and Linda describe early awareness as a highly individual and complex experience that starts with a gradual awareness that something is wrong expressed in terms of losing control. In Keady and Nolan's (1994) early temporal model this stage is described as one of slipping, suspecting and covering up. All the research participants describe feelings of 'changing as a person'. As Clare (2003) describes, losing control may result in loss of self-esteem and a changing sense of self. Early signs are individual, complex and wide ranging effecting emotions, senses and relationships. Mo describes the emotional impact of losing control and how she developed panic attacks when her

husband went to work and how she felt her head was about to 'explode'. Linda describes loss of control in terms of loss of mental agility and an altered sense of smell (the smell of fish and chips in her front room). Jo and Grace describe 'thought block' and 'writing block' and difficulty adding up numbers.

In Keady and Galliard's (1999) study on undiagnosed Alzheimer's disease they found that the research subjects described similar signs such as poor concentration, thought block, disassociation and a heightened sense of taste and smell. Linda describes intense feelings of anger, this emotional reaction is discussed in Clare's (2003) study where say concludes that anger can result from feelings of devaluation and being out of control. All four-research subjects reported that the frustration uncertainty and fear of developing early Alzheimer's disease placed a major degree of stress on interpersonal relationships. This was a finding noted by Pratt and Wilkinson, (2001) and Keady *et al.* (1995) who concluded that the reason for this was the inability to understand the changes they were experiencing and feelings of being out of control. The model shows that period between losing and finding control is dependent on a number of factors. Mo was unable to disclose her memory problems to her General Practitioner as she 'forgot' to tell him and it wasn't until her husband went on her behalf that specialist opinion was sought. Linda and her husband had a period of disagreement over the significance of her early signs and when they did decide to seek medical opinion her General Practitioner misdiagnosed a depressive illness and consequently it took four years for her to be referred to specialist services.

These experiences are evident in current literature. Keady and Gilliards (2002) process model describe the conditions necessary for a successful diagnosis as: a

willingness of the person to disclose their concerns; a family member to agree that there is a problem and that medical opinion is required; a General Practitioner and primary care team(s) to take the reported signs seriously and possessing the necessary skills to facilitate a diagnosis of early Alzheimer's disease; the availability of specialist services to confirm diagnosis and provide information and ongoing support. The present study would appear to confirm the robustness of this analysis.

Finding

Finding control is described in terms of coming to terms with the losses and changes being experienced by the person with early Alzheimer's disease. The formal provision of a diagnosis is crucial in this phase as it gives answers to what is wrong and why it has happened. After diagnosis, Grace, Mo, Linda showed positive signs of acceptance and adjustment. Jo found the process more challenging and took longer to come to terms with his diagnosis and appeared to go through a period of denial. This may, in part, be a result of his wartime experiences where discipline was important and weakness and vulnerability was discouraged. So individuals will differ in the way they respond to a diagnosis of early Alzheimer's disease and some are able to adjust more successfully than others (Pratt and Wilkinson, 2001). Individuals will also display a wide range of different coping styles that are the result of their personal characteristics and life experiences (Clare *et al.*, 2006). Linda and Mo describe the importance of the diagnosis in helping them coming to terms with changes they were experiences. In particular, they describe improvements to interpersonal relationships and their emotional and psychological health. Keady and Nolan (2003) report that sharing awareness before and after receiving a diagnosis and working together during the transitional period may strengthen relationships. Harris and Durkin (2002) report

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that after living through a negative crisis, a person with dementia may acquire a more positive attitude. The findings of this study support the notion that coming to terms and finding control may also be influenced by the age of the individual (Harman and Clare, 2006). In this study, Linda and Mo, 57 and 64 years of age respectively, displayed a pressing need to develop an understanding of their experiences and then to receive confirmation of the diagnosis of Alzheimer's disease. On the other hand, Jo aged 78, rationalised the changes he was experiencing as a natural part of growing old. As already discussed after his diagnosis he went through a period of 'denial' before he was able to accept what was happening to him.

Keeping

Keeping control is about the psychological and social acceptance by the person with Alzheimer's disease and their partner/family to their diagnosis and the ability to live normally within their limitations. As noted by Clare (2002) in her study of people living with early Alzheimer's disease, the importance of keeping control was dependant on the ability to cope well and lead a normal life. For Grace, Mo, Linda and Jo a normal life is about maintaining their independence and social networks. Of particular importance was the continued ability to have 'days out' and go on regular holidays. An important part of this phase was the decision to 'open-up' and talk about the diagnosis. For Linda, Mo and Jo this was a significant step in their psychological and social acceptance of their diagnosis of Alzheimer's disease. The literature shows the importance of sharing awareness as a prelude to seeking help and getting a diagnosis and is crucial in enabling movement from losing to finding control (Keady and Nolan, 2003). However, what this study shows is a further development of this

process and how the sharing of the diagnosis initially with close family members, then with friends and colleagues, and finally with members of the public that they come into contact with is a significant part of the keeping phase. An example of this is when Mo and her husband Pat go on holiday to Spain. Mo made the decision not to hide her diagnosis but to tell her fellow guests and hotel staff of her condition. As a result she fells more relaxed and in control. The employment of memory techniques and aids is also important in this phase. Linda describes the use of 'yellow stickies' and white boards as memory prompts placed in strategic places around the house. She stresses, however, the importance of moving these aids/prompts at regular intervals as she would cease to 'see them' after a period of time. Linda and Gary have also purchased a four by four car with a personalised number plate so Linda can easily locate the vehicle in the super market car park. A number of studies describe the importance of using innovative techniques in helping people to cope with their difficulties (Harris and Durkin, 2002; Keady *et al.*, 1995, Clare, 2002). Clare (2002) describes this process of normal living as alternating between self-protective strategies and integrative strategies. Self –protective strategies seek to normalise the situation and minimise difficulties and integrative strategies aim to confront the difficulties and adapt accordingly.

8.4 Terminology

The synthesised model of early adjustment discussed in chapter 7 provides 'user terminology' to describe how people articulate their early experience of Alzheimer's disease. The importance of acknowledging the significance of words or phrases used by people with dementia and their families to describe their experiences is largely missing from the literature. A key and recurrent term used by the co-researchers (Mo,

Linda and Grace) was 'making mistakes'. Making mistakes was a frequent term used to describe the early awareness of undiagnosed Alzheimer's disease. There was a strong association between making mistakes and the feeling of losing control. The recognition and understanding of user terminology becomes particularly significant in a number of areas in both practice and research. A good example of this is helping General Practitioner's to recognise the early signs of Alzheimer's disease.

As seen from a review of current literature, General Practitioners continue to find it difficult to recognise the early signs of dementia (Cahill *et al.*, 2006). It will be essential that General Practitioners acquire the necessary knowledge and expertise to identify individuals who may be presenting with early signs of dementia and refer to the memory clinics for further assessment. One of the key questions General Practitioners ask of the memory clinic team, which may appear an obvious question, but never the less a relevant one, is, 'how do you know if someone has early dementia'? The standard reply from the professional usually involves mention of poor memory, losing ones car in the car park or finding it difficult to master new technology, such as the mobile phone or DVD player. The reply to this explanation is usually 'well, that happens to me'! 'Does that mean I have early dementia'? What has become clear from the findings of the research is that the individuals' awareness of the early signs is often verbalised in a different way. When talking about early recognition the term 'making mistakes' is a common phrase used to describe early dementia – its much more subtle than just poor memory, car parks or DVD players. So, when General Practitioners ask the question regarding identifying individuals with early dementia, the findings of the study and the early adjustment model highlights

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the need to look for clues in *what* is being said by the individual and to look for key *phrases,* such as 'making mistakes'.

8.4.1 Receiving a Diagnosis

A recurring theme in the life stories was the experience of receiving a diagnosis. The usual and accepted practice in Memory Clinics of sharing a diagnosis was not always seen in a positive light by those people on the receiving end, in particular Grace felt that the environment where the diagnosis was shared and the choice over whether cognitive tests should be undertaken were important issues. People with (undiagnosed and then diagnosed) dementia wanted the choice to have their neuropsychological assessments undertaken at home where they could exert some influence over the direction and timing of the procedures as well as feel more secure (safe) within the surroundings (Keady and Gilliard, 2002). Furthermore, on the issue of sharing the diagnosis of dementia, people with dementia placed a greater emphasis upon the positive relationship they had with the person sharing the news, rather than the fact that it had to be (in a professional construction of 'good practice') a medical practitioner. Pratt and Wilkinson (2003) suggest disclosure of a diagnosis needs to be supportive towards people with dementia and how the social context of the disclosure can lead to undue distress, in particular, medical practitioners need to examine the ways in which they may contribute towards this distress.

8.5   Co-constructing Constructivist Grounded Theory

A review of current literature on Constructivist Grounded Theory shows how this field continues to evolve (Glaser 2002, 2004; Charmaz 2006; Mills *et al.*, 2006 a,b,c). The literature seems to re-affirm the utility in examining the principles of constructivism as applied to a grounded theory, namely, a shift from the objectivist grounded theory standpoint, which tended to diminish the role/voice of the participant, to the re-positioning of the researcher as the participant's partner in the research process. However, the constructivist approach to grounded theory is disputed by Glaser (2002). He argues that the principles of constructivism as applied to grounded theory, with its joint build of an interactive interpreted produced data, is no more than an epistemological bias to achieve credible, accurate description of data (paragraph 10) and avoids the issue of confronting researcher bias (paragraph 11).

Charmaz (2003) questions the extent to which many researchers actually follow true (traditional) grounded theory. Charmaz (2006) argues the way theory is produced from grounded theory studies is subject to a variety of different views: 1) an empirical generalisation 2) a category 3) a predisposition 4) an explication of a procedure 5) a relationship between variables 6) an explanation 7) an abstract understanding 8) a description (page 133).

Traditional grounded theory is increasingly being viewed as limited due to its positivist assumptions and objectivist stance (Charmaz, 2001). Grounded theory needs to be more flexible without transforming it into rigid prescriptions concerning data collection, analysis, theoretical leanings and epistemological positions (Charmaz,

2006). There remain concerns regarding the interpretative nature of constructivist grounded theory and the reliability of qualitative data produced by this approach, however, Charmaz (2006) makes the point that the interaction between the researcher and participant is the strength of grounded theory. Charmaz (2006) sees grounded theory moving towards a more contemporary reflexive model with interaction at the centre of the approach developing on the strengths of Glaser and Strauss (1967) logic of grounded theory.

Therefore, grounded theory is evolving. As Charmaz (2006) summarises the guiding light continues to be Glaser and Strauss (1967) statement of the logic of grounded theory. Glaser (1978) version elaborated basic grounded theory strategies and expressed positivistic, objectivist leanings but spoke to fewer scholars. Strauss (1987) and Strauss and Corbin (1990 and 1998) immensely successful and accessible version of grounded theory attracted a wider audience, but made using it more technical and procedural. The aim of the constructivist approach is to 'loosen grounded theory from its objectivist foundations'. There remains ongoing debate about the interpretation that either Charmaz or Strauss or Corbin's direction is either advancing grounded theory or diverging from it (Charmaz, 2006, Mills *et al.*, 2006 b, c). Charmaz (2006) makes the point that Glaser's approach to grounded theory is also evolving and becoming more interpretive and taking account of participant feelings.

Mills *et al.* (2006 a, c) describes an evolving grounded theory and talks about adopting a constructivist approach. In doing so this will necessitate a rethink of the grounded theorist's traditional role of objective observer to one of developing a

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partnership with participants to mutually construct knowledge. Mills *et al.*, (2006 a p.9) suggests, a constructivist approach requires:

1. The creation of a sense of reciprocity between participants and the researcher in the co-construction of meaning and, ultimately, a theory that is grounded in the participant's and researchers experiences.

2. The establishment of relationships with participants that explicate power imbalances and attempts to modify these imbalances.

3. Clarification of the position the author takes in the text, the relevance of biography and how one renders participants' stories into theory through writing.

8.5.1 Research relationship

Constructivist grounded theory provides a structure to enable the person with dementia to be directly involved in the research process not only as co-collaborators but co-researchers in their lived experiences. This approach utilises the expertise of both the person with dementia and the practitioner-researcher. Such an approach recognises the in-depth first hand knowledge of the person with dementia along with the researchers knowledge and experience in the field under investigation and how to gather relevant data. This fits well with Glaser (1978) description of theoretical sensitivity. An important feature of grounded theory is theoretical sensitivity, which refers to a personal quality of the researcher and relates to understanding the meaning and subtlety of data. Theoretical sensitivity has been described by Glaser (1978) as the process of developing the insight with which the researcher comes to the research

situation and such insight should be conceptual and not concrete. This creative aspect of grounded theory is made possible by the researcher experience and expertise in the area of study. By gaining theoretical sensitivity the researcher will be able to recognise important data and formulate theory.

8.5.2 Building *emic* evidence

As the debate as to what counts as 'evidence' within 'evidence based practice' shows little signs of consensus (French 2002; Gabbay and le May 2004). There is a current shift towards recognising the emic perspective as a way of providing more meaningful evidence. As Evans (1999) states,

'An understanding of illness that reunites the psychological with the experimental will, it has been suggested, require a far richer and more varied conception of evidence than that previously at stake in 'evidence-based medicine', taking far more seriously patients' conceptions of their own values and goals.'

The emic perspective of individuals living with early-stage dementia will provide a framework for understanding their experience. Therefore it can be argued that constructivist grounded theory provides a heuristic research approach that will enable the construction of emic evidence.

8.6   Strengths and Weaknesses of the Study

8.6.1   Strengths

A framework for developing a better understanding of early adjustment

The strength of this model is that it is both innovative and participative. This is achieved by involving the participants as co-researchers working over time to develop their subjective account of a life with early Alzheimer's disease. The model provides a unique insight into the early experience of Alzheimer's disease and how the process of adjustment is rooted in biography and understanding life story is important to understanding adjustment. The study utilises a co-constructed grounded theory, which outlines a temporal model of early Alzheimer's disease that describes adjustment, decision-making and the key critical junctures from onset through to diagnosis. Temporal models that highlight aspects of change in awareness and coping styles over time have the potential to add an important dimension to understanding the subtlety and individuality of early stage Alzheimer's disease. This has major implications for maintaining well being and the provision of appropriate services (Clare *et al.*, 2005). The temporal perspective validates the model in that it takes account of individual variability and acknowledges physical, psychological and social factors and how people adapt to dementia related changes and consequences.

Narrative based methods

Co-constructed grounded theory and narrative based biography provides people with early dementia and their families an explanation of their experiences that will help them develop strategies and ways of adjusting and coping with their situation. By considering the three-stage process of losing, finding and keeping control, and the concept of 'bridging', this may provide a powerful tool that the person with dementia and their supporters can use to explain and manage their condition. As a result they are able to develop positive coping strategies, make use of available treatments and interventions, recognise difficulties and setbacks and adopt proactive and preventative strategies.

User involvement in the research process

The approach described in this research study provides a method that will allow the person with early stage Alzheimer's disease and their families to be actively involved in the research process. The actions and language of constructivist grounded theory and its use of diagrams to help explain potentially difficult concepts in a simplified, effective and meaningful way that the person with dementia as research participant can not only understand, but facilitates an active partnership in the research process.

Practitioner researcher model

For the researcher, in particular the novice researcher, constructivist grounded theory provided a more accessible and meaningful method of conducting qualitative research

inquiry. In response to the call for clinically effective practice, nurses are being encouraged to engage in research and for many this is a daunting prospect. Constructivist grounded theory provides a user-friendly methodology that nurses will be able to employ and integrate into routine practice.

Life story work

An additional strength of this research design is the use of life story work. Life story has proved a powerful and accessible tool for generating a better understanding of the experience of people living with early Alzheimer's disease. However, it could be argued that a potential weakness of this study is the use of the researcher practitioner model, and how this may adversely effect the relationship between researcher and research participant as the researcher is also the research participants nurse and key worker. To help redress potential imbalances and inequalities in the research relationship and in line with constructivist principles of interviewing, the sharing and exchange of life stories promoted a closer research relationship and level of trust; discovery was a partnership and not a mutually exclusive event. There was evidence towards the end of the study that one of the research participants (Jo), if he required a clinical intervention, would bypass the research practitioner and seek advice from other members of the memory clinic team so as 'not to interfere' with the research visit.

8.6.2   Weaknesses

Sample size

The small sample size may be viewed as potential weakness and affect the generalisabilty of the study. However, the study aim and methodological intention was not to generalise but obtain rich in-depth information by utilising a case study approach, a longitudinal design and a co-constructed method.

Accessibility

A potential weakness of early awareness models is that they are dependent on research participants who have accessed services, been told of their diagnosis, who have accepted their diagnosis, able to retain information and willing to talk about their experiences. Many people with similar difficulties may not have access to specialist services or may attend for assessment and not be told their diagnosis or who may not be able to take in or retain information. As a result this study may not (with early stage Alzheimer's disease) be totally representative of all people.

Constructivist grounded theory and more advanced dementia

The use of constructivist grounded theory with people with dementia can present with particular challenges. For instance, such an approach may have limited value, benefiting only a small group of people with early Alzheimer's disease becoming impractical as their cognitive condition deteriorates. Whitlach, Feinberg and Tucke (2005) argue that it is possible to maintain involvement of people with dementia with

significant cognitive impairment through an appropriate research design. The author would suggest that constructivist grounded theory has the potential to meet this need. However, as yet, constructivist grounded theory has not been tested on people with more advanced dementia and this is an area to be explored.

The appeal of constructivist grounded theory

Constructivist grounded theory will not suit everyone. This methodology, with its constructivist principles (partnership working, relationship formation, biography and sharing of narrative) may prove potentially threatening to the nurse/researcher, patient/research subject. For instance, the nurse, who's traditional training and culture of working, is one that encourages professional distance and cautions against closer involvement with their patients. As a result, the threat of losing the power relationship and an adoption of a more egalitarian relationship, whether in the clinical setting or in the research field, may challenge and question their own beliefs and ways of working. Patients/ research participants may also find a closer working relationship difficult to come to terms with as they might also expect a degree of professional distance and therefore find it difficult to actively participate in constructivist grounded theory.

Cultural bias

The location of this research was in Wales, however none of the research participants were of Welsh origin or spoke the Welsh language. To avoid cultural bias it is recommended that a similar study be carried out using the Welsh language.

8.7 Grounding change in practice

The early adjustment model and its use of life-story work to capture 'meaning making' and 'mental construction' of events and experience is, as we have found, an effective way of working alongside people with dementia and their families and provides a sense of shared enterprise and discovery in the life journey. As a result, an opportunity to engage people with a new and early diagnosis of dementia (and their families, as appropriate) in the documentation of their life-story has provided valuable insight into their experience of services. The author has a clinical role (Specialist Nurse) as well as an academic role (research-practitioner) and has a pivotal role in developing memory clinic services in the counties of Conwy and Denbighshire, and, as a result, has been able to assimilate the findings of the study into the development of two new clinics in Llandudno and Ruthin:

- Offer a pre-screening multidisciplinary home assessment wherever possible.

- Obtain informed consent from the person with memory loss and their family to participate in, and proceed with, the assessment process.

- Carry out an initial holistic assessment of the person and their family within the context of their home environment and their significant relationship.

- Assess and offer prompt intervention with safety and risk factors e.g. gas and fire safety, non-compliance with medication, mobility issues, and carer stress.

- Establish a therapeutic alliance (relationship) in the person's own 'territory', where they are more relaxed and less threatened. This makes subsequent visits to the clinic where there is a familiar face less daunting.

- Carry out assessments in the home to introduce the concept of 'testing' in a less formal way and reduce performance anxiety. Some people are anxious for the screening process to begin immediately, and are very happy to complete assessments on this first visit.

- Assess the approach and timing that will be individually required in each situation i.e. sharing the diagnosis. Control of the sharing of the diagnosis is given to the client/family, where appropriate, they can choose who shares the diagnosis with them i.e. doctor, nurse, occupational therapist. The person can also choose the location of this procedure i.e. their own home.

- Facilitate an understanding that memory clinic involves a full psychosocial service, as well as offering medication.

- Joint assessments: can provide staff with increased professional confidence and reassurance, resulting from 'shared wisdom' and 'shared memory'

- Less reliance on the use of objective measures of 'assessment testing'

(Keady *et al.*, 2005)

The sharing and documentation of a life-story also provides a living document of choice, experience and history for when, a little further along the road, people with dementia may have more difficulty in communicating their needs and wants through language alone. The use of life story work will also prove a useful and meaningful clinical and therapeutic tool. Life story work will involve both clinician and patient in developing a shared understanding of lived experience. Interventions can be jointly developed building on the concept of 'bridging' the traditional clinical emphasis centring on coping and adapting the nurses interpretation of deficit and risk.

8.8 Recommendations and policy and practice implications

The study has shown the importance of actively involving people in the research process and how co-constructed research findings can inform and transform practice. The primary aim of utilising constructivist grounded theory is to provide a way to involve the person with dementia and their families in the research process and help to create mutual knowledge and a shared understanding of the early experience of Alzheimer's disease. Increasingly, the voice of people living with dementia is influencing political and social/health care systems and the findings of this study will add to the debate on early intervention in dementia care. As previously rehearsed, the concept of bridging has provided new ways of thinking about the experience of early Alzheimer's disease and will provide opportunities for clinical intervention and assessment driven by narrative based biography. The findings of the research have shown how crucial early intervention services are to a modern dementia care service, noticeably the shift from crisis management to preventative approaches. Where local areas do not have a Memory Service they will need to develop one, in line with the evidence that such services are effective in reducing stigma and reducing crisis and carer distress as the illness progresses.

8.8.1 Service Issues

Early intervention services should aim to integrate with community mental health teams and provide a comprehensive service including post diagnostic interventions. It is recommended that Older People Mental Health Services should take the lead in

developing multi professional protocols for diagnosis and early intervention in dementia. This should include guidance on skills needed to make formal diagnosis and sharing the diagnosis; a template on the type of information to give people with dementia and their families, including what to expect as the disease progresses and the professional support available.

There is also need to develop criteria and referral pathways from primary care and for moving people from the 'early intervention stream' to the 'serious mental illness stream'. Early intervention services should begin by offering the opportunity for people to discuss their experiences by using such methods as biography and narrative. As Pearce *et al.* (2002) outline, it will be important for services to be guided by the person with dementia and their families as to how much information they want, how they wish to receive it, and at what time it is most appropriate and useful to them.

Early intervention services are provided by memory clinics and, as previously rehearsed, these services continue to develop without specific guidance or funding. As a result, there is a growing debate as to the most suitable model. The traditionalists advocate a more integrated approach provided by community mental health teams and a move away from the specialist 'stand alone' memory clinics, which they believe, have diverted resources way from high quality integrated care.

The results of this study have advocated the importance of early intervention and the provision of services for individuals with early Alzheimer's disease. The suggestion that working with individuals in the early stage is the 'easy part' of the disorder or the impression that there is little that can be offered at this stage is not supported by

current literature or this study. Early identification, sharing a diagnosis, pre and post diagnostic support, patient and carer counselling and education along with audit and research is complex, specialist work and should be recognised as such. It is recommended that a way forward is to develop more integrated services fronted by old age psychiatry and the community mental health team, which will include early intervention work. The valuable expertise developed by the specialist memory clinic team should not be lost and be transferable to all team members through specific training and instruction. The aim, therefore, will be to provide a modern dementia service to people with dementia and their families through all stages of the disorder.

It is also recommended that in addition to the formal memory clinic services the importance of support groups and the development of 'cafes' and social events should be recognised. Such facilities will provide opportunities for people with dementia to speak to professionals and other service users to compare and contrast experiences that help to maximise coping strategies.

8.8.2   Individual practitioner issues

Modern specialist mental health services are becoming increasingly focused on understanding the experience of early dementia and developing appropriate interventions to support this group of people and their family.

As previously rehearsed, biographical and life story approaches can help practitioners understand the experience of early Alzheimer's disease and inform practice development (Keady *et al.*, 2005). The findings of this study have provided new

insights into the complex biographical base experiences and responses to the onset, diagnosis and adjustment to Alzheimer's disease. Crucial to this model is the identification of 3 key phases of losing, finding and keeping balance and the critical junctures between them. The process of identifying the key phases and the 'bridging' of the critical junctures has the potential to inform individual nursing practice in this service area.

Utilising a life story/biographical/narrative approach to the nursing assessment will provide a powerful tool for building understanding and relationships. The assessment will need to identify the individual experiences of Alzheimer's disease, the critical junctures and support the process of bridging by anticipating potential failure and collapse.

In the losing phase the aim of the nursing intervention is to help the individual come to terms with their memory problems and seek a diagnosis. The role of the nurse will see them working closely with colleagues in primary care to assist in the early identification and referral to specialist services. In the finding phase, the aim of the nursing intervention will be to support the person and their family come to terms with the diagnosis, by making sense of what is happening and start the process of reconstructing their lives, daily events and future aspirations. In the keeping phase the aim of the intervention is to help the person and their families accept what is wrong with them, why it has happened and what can be done about it. Nursing interventions will provide support and partnering and help the person and their families live their lives within new horizons, continuing with and developing new interests and maintaining quality of life.

To support the bridging process and transition through the stages the nurse will need to provide strong psychological and social support and a close and meaningful relationship. Failure of bridging denotes frailty in the process and is a result of the person not having access to support and advice at the critical junctures. The ultimate aim of the nursing intervention should be to minimise the biographical and chronological time that people with (undiagnosed and then diagnosed) Alzheimer's disease spend in the stages of losing and finding balance, whilst maximising the time in the stage of keeping balance.

8.9   Concluding Thoughts

This thesis commenced with a reflection of the author's life story and the reasons for embarking on this study. The author will now conclude with a refection on where this journey has taken me.

Recently, Ironside *et al.* (2003) observed that long-term conditions cannot be understood as a series of changes in functional status, but, instead, need to be seen in the context of each person's 'concerns and commitments'. Importantly, Ironside *et al.* (2003) continue by asking 'but how do clinicians ascertain the touchstones of meaning for clients within chronic illness?' (p.180). As the use of constructivist grounded theory demonstrates, especially the formation of the life story and 'My Theory', the author would suggest that it is through prolonged and sustained engagement with a narrative account of people's lives that the practitioner will be best able to understand the 'touchstones of meaning' for people with dementia and their

families. Furthermore, a narrative process and research relationship needs to be underpinned by shared values and language (Zgola, 1999) if the ideals of a constructivist grounded theory are to be met (Charmaz, 2000). In the presented 'My Theories' Mo, Linda, Grace and Jo describe their need for 'a life in control' and a sense of 'balance', and by further analysis the concept of 'bridging' was developed as a theoretical explanation of early adjustment and transition into a life with Alzheimer's disease. Such descriptions provide a meaningful discourse from which to plan supportive interventions. Furthermore, an individual's life story has the potential to be a 'living document' as the research participants continue on their journey through Alzheimer's disease

As noted by McAdams and Janis (2004), a narrative configures an individual's understanding of self and the construction of identity has a degree of purpose and unity. The weaving of the 'synchronic' and 'diachronic' elements of identity into a temporal dimension presents a construction of self that can be understood separately as occurring in the past, but also synthesized into the present into a temporally organized whole (McAdams and Janis, 2004). As illustrated by Mo, Linda, Grace and Jo this provides a powerful platform for understanding the complexity and relatedness of responses to Alzheimer's disease and how adjustment is constructed. *Making mistakes* and *balancing* related to the formative experiences of people with dementia during the initial period of their 'illness' (Mo's description) and describe their affective response and feelings within a relational context. Both *making mistakes* and *balancing* were characterised as responses in relationship with others and mapped out the broader canvas of the early experience of Alzheimer's disease. It would be interesting to see if these conditional statements/generic concepts have meaning to

others living through a similar situation and form an important dimension of a collective theory in constructivist grounded theory.

As Gubrium and Holstein (1997) argue, human beings 'theorise as we talk'; however, the use of an approach such as constructivist grounded theory with people with dementia may present particular challenges. As I have described, I embedded constructivist grounded theory in an approach that acknowledged issues regarding cognitive impairment and consent, but affirmed the importance of the person's active involvement as co-researchers. The adoption of process consent (Dewing, 2002) facilitated the need to 'get to know the person' in order to establish and re-establish consent at each clinical visit. This element links up with the area of relationship-building that is embedded in constructivist approaches (Charmaz, 2000). The usefulness of constructivist grounded theory with people with more advanced dementia is a study that remains to be conducted and it is important to note that the life story does not need to be compiled in words alone - communication is deeper and more dynamic that this (Killick and Allan, 2001) - and it is up to the research community in partnership with stakeholder groups to come up with imaginative, informative and inclusive research designs.

Finally, the actions and language of constructivist grounded theory have, to date, proven to be understandable to participants and have helped to make accessible some of the rather complex and mystifying analytical and coding procedures used in traditional qualitative research methods. Whilst the use of theatrical and dramaturgical metaphors is by no means unique within the qualitative research canon (see, for example, Bowers, 1988; Mienczakowski, 1995; McCall, 2000; Schneider, 2005), I

have found that people with dementia and their families (and participants living with other long-terms conditions) can readily, and creatively, grasp, identify and apply their meaning in order to engage in co-construction and the mutual generation of knowledge.

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APPENDIX 1

APPROVAL FROM THE HEAD OF THE AUTHOR'S COMMUNITY MENTAL HEALTH SERVICES MANAGER

Ymddiriedolaeth GIG Siroedd Conwy a Dinbych
Conwy & Denbighshire NHS Trust

Dear John,

Re: **Support for John Hughes-Roberts, currently employed by Conwy and Denbighshire NHS Trust, to undertake a Masters Degree under the supervision of the University of Bangor.**

I am writing to support the proposal for John Hughes-Roberts to undertake research at a Masters degree level in respect of memory clinic work. I am also happy to agree for him to have a certain amount of service time on a monthly basis to assist him to do this.

I think John's research is an essential part of the work needed to ensure that the new memory clinic services are effectively delivered by the Trust.

Yours sincerely,

Jim Brooks
Team Manager
Mental Health Services
For Older People
Denbighshire

APPENDIX 2

APPROVAL FROM THE NORTH WALES CENTRAL RESEARCH ETHICS COMMITTEE

North Wales Central Research Ethics Committee

Gweinyddwraig Etheg /
Ethics Administrator, Ystafell1038 / Room 1038,
Ysbyty Glan Clwyd,
Rhyl, Denbighshire LL185UJ
8th April 2003

Dear Mr. Hughes-Roberts,

CONFIRMATION OF FULL ETHICS APPROVAL

Re: 3.4.03 Positive coping with Memory Loss: A longitudinal study approved by Chairman's action @ 3.4.03 - for formal ratification

Further to our letter of 5th April 2003 confirming Chairman's approval for the above mentioned study and following a meeting of the North Wales Central Research Ethics Committee on 8th April 2003 can now provide full ethics approval for this study, on condition that:

- approval from the Trust R & D Committee Internal Review Panel has been obtained
- the protocol is followed as agreed
- the project commences within 3 years of the date of this letter
- the committee is notified of all protocol amendments and serious adverse events as soon as possible
- the committee receives annual progress reports and/or a final report within 3 months of completion of the project.

The Committee reserves the right to audit local research records relating to the above study. Ethics approval is granted on this basis.

The Committee aims to be fully ICH / GCP compliant. Please find attached a copy of our working constitution and a list of members for your information and retention.

Mr. C. Penfold, Chairman,

NW Central Research Ethics Committee

APPENDIX 3

APPROVAL FROM THE CONWY AND DENBIGHSHIRE NHS TRUST RESERCH AND DEVELOPMENT COMMITTEE

Conwy & Denbighshire NHS Trust

Mr John Hughes Roberts Glan Traeth Day Hospital Royal Alexandra Hospital RHYL , 29th July, 2003

Dear John

--Re-:-Trust Approval to Proceed

    Project Title   **Positive coping with memory loss, a longitudinal study**

    Project Reference   **2003/mentalhealth/098**

I am pleased to inform you that, following the Research Review Panel held on 29 July 2003 your project has obtained approval to proceed at the Conwy and Denbighshire NHS Trust.

As part of regular monitoring undertaken by the Trust R&D Committee, you will be required to complete a short progress report. This will be requested on a six monthly basis. However, please contact me sooner should you need to report any particular successes or problems concerning your research. Whilst the Trust is keen to reduce the burden of paperwork for Researchers failure to produce a progress report may result in withdrawal of approval and any allocated funding.

Details of the funding allocated to your project and how to access it can be obtained by contacting Shelagh Evans or Dave Stafford Management Accounts in the Finance Department, H M Stanley Hospital.

All research conducted at Conwy and Denbighshire NHS Trust must comply with the Research Governance Framework for Health and Social Care in Wales (November 2001). An electronic link to this document is provided on the Trusts R&D webpages. Alternatively you may obtain a paper copy of this document via the Trust R&D Office.

I trust this is in order. If you would like further information on any of the points covered by this fetter, please do not hesitate to contact me. On behalf of the R&D Committee, may I wish you every success with your research .

Yours sincerely
Lona Tudor Jones, R&D Manager

APPENDIX 4

GUBRIUM'S LIFE STORY INTERVIEW FORMAT

Background to the study

Aims

Reaffirm consent procedure

Reaffirm consent to tape record interview

Right to stop the interview/life history at any time and withdraw from the research

Confidential nature of the research interview

Topics to Cover:

Life in general

1. Everyone has a life story. Tell me about your life in about twenty minutes or so if you can. Begin wherever you like and include whatever you wish.

2. What were the most important turning points in your life?

3. Tell me about the happiest moments in your life.

4. What about the saddest points.

5. Who've the been the most important in your life?

6. Who are you closest to now?

7. What does your life look like from where you are at now?

8. If you had the opportunity to write the story of your life, what would the chapters be about? (Probe about the last chapter).

Self

How would you describe yourself when you were younger?

How would you describe yourself now?

Have you changed much over the years? How?

What is your philosophy of life? Overall, what is the meaning of life to you?

APPENDIX 5

PATIENT INFORMATION SHEET AND EXPRESSION OF INTEREST FORM

Version 2: April 2003.

Positive Coping with Memory Loss

Participant/Family Information Sheet

The Study

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends, relatives and your GP if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Consumers for Ethics in Research (CERES) publish a leaflet entitled 'Medical Research and You'. This leaflet gives more information about Medical Research and looks at some questions you may want to ask. A copy may be obtained from CERES, P. O. Box 1365, London. N16 0BW.

What is the purpose of the study?

Whilst we have some knowledge about best practice in sharing a diagnosis of dementia, we have relatively little understanding about how people with the diagnosis, and their close family member, then cope and adapt to their new-found situation. By listening closely to your experiences over an 18-month period, this study will try and understand what you think is important and how you went about adjusting to the news. You will receive a visit at home at least once a month from Mr

John Hughes-Roberts, Clinical Nurse Specialist at the Conwy and Denbighshire Memory Clinic, to hear your views. After the 18-month period of contact you will continue to have a visit from a member of the support service, should you wish it. The study will also develop ways in which services can work with people with an early diagnosis of dementia.

The North Wales Research Committee, a local funding body, has agreed to help support the study. The study is being completed by Mr John Hughes-Roberts, Clinical Nurse Specialist at the Conwy and Denbighshire Memory Clinic, Dr. John Keady, Senior Lecturer in Nursing Research at the School of Nursing, Midwifery and Health Studies, University of Wales, Bangor and Dr. Terry Crowther, Consultant Psychiatrist at the Conwy and Denbighshire Memory Clinic

Why have I been chosen?

You have been approached as we are looking to recruit participants who have adjusted in a positive manner to the diagnosis. We are looking to recruit between 5-8 people with an early diagnosis of dementia and a close family member, to take part in the study.

Do I have to take part?

It is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide not to take part in the study, this will not effect the standard of care you receive now or in the future. If you decide to take part you are still free to withdraw at any time and without giving a reason. This will not effect the standard of care the patient and their family receive now or in the future.

What will happen to me if I take part?

If you decide to take part, Mr. John Hughes-Roberts will make a convenient appointment to see you at home. The aim of the research will be explained once more and if you are happy to proceed after this visit, then you will be a participant in the

project. Mr. John Hughes-Roberts will then visit you at home at least once a month for eighteen months to discuss how you are getting on. This contact will be face-to-face and organised at your convenience. You may well wish to have these meetings at your home. In addition to the visit, Mr. Hughes-Roberts will ask your permission to tape-record the interview to help him recall what was said during your time together. This information will be strictly confidential so only those involved in the research will know exactly what you have said. Your name will not be used on labelling these tapes or in any report. The tapes will be stored securely and destroyed when the project has ended. This procedure, and your right to refuse this request, will be explained more fully should you express an interest in participating in the study.

What if new information becomes available?

This is a study that tries to better understand your individual and family adjustment to the diagnosis and how this impacts upon your day-to-day life. However, the participation of your loved one will not stop them receiving any new drug or therapeutic treatments that their doctor feels would be of benefit. If a new treatment becomes available, Dr. Crowther will tell your loved one about it and discuss with them whether or not they wish to continue in the study. If they do decide to withdraw, Dr. Crowther will make arrangements for the care to continue.
Also, on receiving new information Dr. Crowther might consider it to be in your best interests to withdraw your loved one from the study. If this does happen, Dr. Crowther will explain the reasons and arrange for their care to continue.

What if something goes wrong?

If you both decide to take part in the study you will receive home visits from Mr John Hughes-Roberts, Clinical Nurse Specialist at the Conwy and Denbighshire Memory Clinic. As Mr. Hughes-Roberts is an employee of the Conwy and Denbighshire NHS Trust, any complaints about treatment by members of Trust staff can be made directly to the Trust; a complaints procedure will be immediately provided for this purpose. It is important to point out, however, that if you are psychologically harmed by taking part in this research project then there are no special compensation arrangements. If you are harmed by someone's negligence, then you may have grounds for a legal action but you may have to pay for it. Regardless of this, if you wish to complain

about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms may be open to you.

What do I have to do next?

If you are interested in taking part in the study, please complete the attached 'Expression of Interest' form and return it to Dr. Terry Crowther at the Conwy and Denbighshire Memory Clinic in Rhyl. A stamped addressed envelope is attached for this purpose. Once this Form is received, Dr. Crowther will inform Mr. John Hughes-Roberts of its receipt, and Mr. Hughes-Roberts will make an appointment to see you at home to discuss the project further. Only after this visit will you be asked to decide if you wish to take part in the study.

Will my taking part in this study be kept confidential?

All information that is collected about you during the course of the research will be kept strictly confidential unless you specify differently. With your permission, we will tell your GP that you are taking part in the study.

What will happen to the results of the research study?

On completion of the study Mr. John Hughes-Roberts will compile a short report on the experiences of all those who participated in the study for the North Wales Research Committee, wider publication will be sought in National and International Journals but patient confidentiality will be respected at all time. Your loved one will not be named in this report and you will be given a copy of it. This study will also go towards John Hughes-Roberts completing an M.Phil. Degree

Who has reviewed the study?

This study has been reviewed and approved by the North Wales Health Authority Research Ethics Committee (Central).

Contact for further information

Thank you for taking the time to read this Family Information Sheet. If you are still interested in being considered as a research participant in the study, could you complete the attached 'Expression of Interest' form and return it to Dr. Crowther in the pre-paid envelope. Mr John Hughes-Roberts will then make contact with you to discuss your participation. This will mean Mr. Hughes-Roberts visiting you at home.

Please keep this Information Sheet for your records. If you do decide to participate in the study, Mr. John Hughes-Roberts will bring the appropriate Consent Form with him to your meeting. If you decide to sign it, a copy of the Consent Form will be left for your attention and records.

Thank You

If you would like to discuss any aspect of the study please contact:

Mr. John Hughes-Roberts *at*

Conwy and Denbighshire NHS Trust

Division of Mental Health and Learning Disability

Glan Traeth Day Hospital

2 Alexandra Road

Rhyl

Denbighshire. LL18 9AS

Tel: *01745 443270*

Email john.hughes-roberts@cd-tr.wales.nhs.uk

Mr Hughes-Roberts is available between 9am and 5.00pm Monday to Friday

Positive Coping with Memory Loss: Expression of Interest

Yes, I would be interested in hearing more about the study:

Name: _____

Address: _____

_____

_____

Post Code: _____

Telephone Number: _____

Email address (if any): _____

Best time to Contact you? Please tick one box:

Morning   ☐

Afternoon   ☐

Early evening   ☐

Anytime   ☐

Now, please place this form in the provided pre-paid envelope and post it to Dr. Terry Crowther.

THANK YOU VERY MUCH.

APPENDIX 6

RESEARCH CONSENT FORM

Patient Research Consent Form

Title of Study: Positive Coping with Memory Loss

(The patient should complete the whole of this sheet himself/herself).
(Please cross out as necessary)

Have you read the Patient Information Sheet?	YES / NO
Have you had the opportunity to ask questions and discuss this study?	YES / NO
Have you received satisfactory answers to all of your questions?	YES / NO
Have you received enough information about the study?	YES / NO
Do you understand that I will seek your permission to be part of the research project during each visit I make to your house and that you are free to withdraw from the study at any time?	YES/NO
Do you understand that I will tape record our conversation during the 18 months of the study and that you are free to discontinue this arrangement at any time?	YES/NO

Do you understand that you are free to withdraw from the study:

☐   at any time

☐   without having to give a reason

☐   and without affecting your future medical care?   YES / NO

Do you agree to take part in this study?   YES / NO

Signed: _____   Date:

_____

Family Member

Family Member Research Consent Form

Title of Study: Positive Coping with Memory Loss

(The family member should complete the whole of this sheet himself/herself).
(Please cross out as necessary)

Have you read the Family Information Sheet?	YES / NO
Have you had the opportunity to ask questions and discuss this study?	YES / NO
Have you received satisfactory answers to all of your questions?	YES / NO
Have you received enough information about the study?	YES / NO

Do you understand that I will seek your permission to be part of the research project during each visit I make to your house and that you are free to withdraw from the study at any time? YES/NO

Do you understand that I will tape record our conversation during the 18 months of the study and that you are free to discontinue this arrangement at any time? YES/NO

Do you understand that you are free to withdraw from the study:

☐   at any time

☐   without having to give a reason

☐   and without affecting your future medical care?   YES / NO

Do you agree to take part in this study?   YES / NO

Signed: _____   Date:

_____

APPENDIX 7

CONSENT TO TAPE RECORD INTERVIEW

CONSENT TO TAPE RECORD INTERVIEW (Patient)

Name:	
Address:	
Telephone Number:	

Do you understand that:

Permission to tape record the interview is under your control
and can be discontinued at any time.   YES/NO

You are free to turn off the tape recorded at any time during the interview. You can
either do this on your own or ask for it to be done.   YES/NO

Permission to tape record the interview will be sought at the start of each visit.
Only if permission is given will the tape recorder be used.   YES/NO

Signed: _____   Date: _____

(NAME - in block letters) _____

Signature of Witness: _____   Date: _____

CONSENT TO TAPE RECORD INTERVIEW (Family Member)

Name:	
Address:	
Telephone Number:	

Do you understand that:

Permission to tape record the interview is under your control
and can be discontinued at any time.   YES/NO

You are free to turn off the tape recorded at any time during the interview.
You can either do this on your own or ask for it to be done.   YES/NO

Permission to tape record the interview will be sought at the start of each visit. .
Only if permission is given will the tape recorder be used.   YES/NO

Signed: _____   Date: _____

(NAME - in block letters) _____

Signature of Witness: _____   Date: _____

APPENDIX 8

TABLE OF GRACE'S CO-RESEARCH VISITS

Family E		Date of Interview	Biography Grace lives alone supported by partner Chris until Nov. 04. DOB: 13/12/36: 68yrs. Diagnosed with AD: September 2002	MMSE Av: 27	GDS Av: 2
Grace	1	18 / 03 / 04	Life history patient – (Grace and Chris) – Using Gubriums Interview	27	6
	2	20 / 04 / 04	Life history carer - (Grace and Chris) - Using Gubriums Interview		
	3	25 / 05 / 04	My life history – Exchange of life stories – (Grace & Chris)		
	4	21 / 06 / 04	More detailed discussion regarding patients life story looking at the chapters – (Grace, Chris and son Peter)		
	5	16/08/04	*Clinical review*		
	6	22/10/04	Closer examination of chapter 1 & 2 'childhood & teenage years'– (Grace and Chris)	30	0
	7	12 / 11 / 04	Closer examination of chapter 3 – 'working life'– (Grace and Chris)		
	8	17 / 01 / 05	Closer examination of chapter 4 & 5 – 'Married life & Life after death of husband'– (Grace)		
	9	11 / 03 / 05	Closer examination of chapter 6 – 'Joan & the fellowship' - (Grace)		
	10	18 / 03 / 05	*Clinical review*		
	11	29 /04 / 05	Closer examination of Chapter 7 – 'Current life' - (Grace)		0
	12	20 / 05 / 05	Signed of Life Story Script – (Grace)		
	13	06 / 06 / 05	Exploration and discussion of 'My Theory' Diagram – Draft 1 - (Grace)		
	14	08 / 08 / 05	Exploration and discussion of 'My Theory' Diagram – Draft 2 - (Grace)		
	15	12 / 09 / 05	Exploration and discussion of 'My Theory' Diagram – Draft 3 - (Grace)	29	
	16	31/ 10 / 05	Exploration and discussion of 'My Theory' Diagram – Draft 4 - (Grace)		
	17	12/ 12/ 05	Discussion – Version 1 – 'My Theory' Diagram – (Grace)		
	18	15 / 02 / 06	Follow up visit – (Grace)		
	19	20 / 03 / 06	Follow up visit – (Grace)	27	2

APPENDIX 9

TABLE OF MO'S CO-RESEARCH CONTACTS

Mo & Pat	Interview Number	Date of Interview	Biography	MMSE	GDS
Family A	1	10 / 10 / 03	Semi-structured interview with Mo & Pat – Introductory visit	24	7
	2	19 / 01 / 04	2nd semi-structured interview building on key points of first interview with Mo	30	
	3	29 / 04 / 04	Life history with Mo & Pat		
	4	24 / 05 / 04	Life history with Mo – using Gubriums Interview		
	5	30 / 06 / 04	Life history with Pat (Told me *personal* story)		
	6	18 / 08 / 04	Life history – researcher – Exchanging stories	28	2
	7	24 / 09 / 04	In depth analysis of chapter one – childhood (Mo & Pat)		
	8	12 / 11 / 04	In depth analysis of chapter two – working life		
	9	2 / 12 / 04	In depth analysis of chapter three – raising my family		
	10	21 / 01 / 05	In depth analysis of chapter four - retirement		
	11	25 / 02 / 05	In depth analysis of chapter five – my illness	25	0
	12	22 / 04 / 05	In depth analysis of chapter six – moving on		
	13	6 / 05 / 05	Signed off life story script - (Mo & Pat)		
	14	10 / 06 / 05	Exploration and discussion of first 'My Theory' Diagram – Draft Version 1 - (Mo & Pat)		
	15	08 / 07 / 05	Visit became – Clinical Visit - (Mo & Pat)		
	16	22 / 08 / 05	Exploration and discussion on 'My Theory' Diagram – Draft Version 2 - (Mo & Pat)		3
	17	3 / 10 / 05	Exploration and discussion on 'My Theory' Diagram – Draft Version 3- (Mo & Pat)		
	18	07 / 11 / 05	Clinical Visit- (Mo & Pat)		
	19	28 / 11 / 05	Discussion – Version 1 – Mo's Personal Theory Diagram	23	3
	20	29 / 03 / 06	Follow on visit		
	21	08 / 06 / 06	Follow on visit	Av: 25	Av: 3

APPENDIX 10

TABLE OF LINDA'S CO-RESEARCH CONTACTS

Linda	Interviews	Date	Biography	MMSE	GDS
Family B	1	10 / 11 / 03	Semi-structured interview with Linda & Gary – Introductory meeting	27	5
	2	12 / 01 / 04	2nd semi-structured interview building on key points of first interview with patient with Linda and Gary		
	3	23 / 02 / 04	Life history with Linda and Gary	28	4
	4	29 / 03 / 04	Clinical review		
	5	29 / 07 / 04	Life history with Linda using Gubriums Interview		
	6	16 / 08 / 04	Life history with Gary		
	7	20 / 09 / 04	Life History – Researcher – Exchange of life stories		
	8	25/10/04	*Clinical review.*		
	9	6/12/04	Closer examination of Linda's life story – chapter one, **'Growing Up'**. (Linda & Gary)	28	4
	10	17/ 01/ 05	Closer examination of client's life story, chapter 2 – **'Working Life'** (Linda & Gary)		
	11	14/ 02/ 05	Closer examination of Linda's life story – chapter 3, **'Getting Married'**. (Linda & Gary)		
	12	21/03/05	Closer examination of client's life story, chapter 4 – 'The Illness' (Linda & Gary)		
	13	11 / 04 / 05	Clinical Review		
	14	25 / 04 / 05	Signed off Life Story Script – (Linda & Gary)		
	15	30 / 05 / 05	Exploration and discussion on 'My Theory' Diagram draft 1 – (Linda & Gary)		
	16	20 / 06 / 05	Exploration and discussion on 'My Theory' Diagram draft 2 – (Linda & Gary)	30	
	17	18 / 07 / 05	Exploration and discussion on 'My Theory' Diagram draft 3 – (Linda & Gary)		
	18	24 / 07 / 05	Exploration and discussion on 'My Theory' Diagram draft 4 – (Linda & Gary)		
	19	14 / 11 / 05	Discussion – Version 1 – Linda's 'My Theory' Diagram – (Linda & Gary)	26	6
	20	30 / 01 / 06	Follow up visit	Av: 28	Av: 4

APPENDIX 11

TABLE OF JO'S CO-RESEARCH CONTACTS

Jo and Gwen		Date of Interview	Biography	MMSE Av: 25	GDS Av: 2
	1	14th April 2004	Life history – Client – Using Gubriums Interview – (Jo & Gwen)	27	2
	2	25th May 2004	Life history – Carer – Using Gubriums Interview – (Jo & Gwen)		
	3	17th June 2004	Exchange of life stories		
	4	28th July 2004	Developing life history with client – closer examination of life chapters – (Jo & Gwen)		
	5	25th August 2004	Clinical review		3
	6	29th September 2004	Meeting with family to discuss life story work and to introduce the concept of a life story book and co – construction of future interviews – (Jo & Gwen)		
	7	2nd December 2004	Closer examination of life history – Chapter 1 – 'childhood'– (Jo & Gwen)	22	4
	8	14th January 2005	Closer examination of life history – Chapter 2 – 'Wartime experiences'– (Jo & Gwen)		
	9	4th February 2005	Closer examination of life history – Chapter 3– 'The Royal Airforce'– (Jo & Gwen)		
	10	28th April 2005	Closer examination of life history – Chapter 4 – 'Work After the RAF' – (Jo & Gwen)		
	11	18th May 2005	Closer examination of life history – Chapter 5 – 'Marriage & children'– (Jo & Gwen)		
	12	29th June 2005	Closer examination of life history – Chapter 6–'Retirement' & chapter 7 'My Illness'– (Jo & Gwen)		
	13	27th July 2005	Signed-off Life Story Script. – (Jo & Gwen)		
	14	31st August 2005	Clinical review	25	3
	15	22nd November 05	Exploration & discussion of storyboard		
	16	16th December 2005	Exploration & discussion of storyboard	25	
	17	17th January 2006	Exploration & discussion of 'My Theory' – draft 1		
	18	17th February 2006	Exploration & discussion of 'My Theory' – draft 2		
	19	24th April 2006	Discussion – Version 1 – Jo's 'My Theory' Diagram		
	20	3rd July 2006	Follow up visit		