

**Bangor University** 

MASTER OF PHILOSOPHY

A mixed methodological approach to investigating perceptions, and emotional outcomes, of stroke patients and carers

Jones, Elly

Award date: 2006

Awarding institution: Bangor University

Link to publication

#### General rights

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

• Users may download and print one copy of any publication from the public portal for the purpose of private study or research.

You may not further distribute the material or use it for any profit-making activity or commercial gain
 You may freely distribute the URL identifying the publication in the public portal ?

#### Take down policy

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

# A MIXED METHODOLOGICAL APPROACH TO

### **INVESTIGATING PERCEPTIONS,**

# AND EMOTIONAL OUTCOMES, OF STROKE

# PATIENTS AND CARERS.

# **Elly Jones**



A thesis submitted in fulfilment of the regulations for the degree of Master of Philosophy in the University of Wales; 2006

CONTENTS
----------

INDE	X OF FIGURES	. 3
ACK	NOWLEDGEMENTS	. 4
DEDI	CATION	6
SUMI	MARY	7
ABST	RACT	9
CHAI	PTER 1: MODELS OF HEALTH AND ILLNESS 1	0
1.1	The biomedical model	.0
1.2	BIOPSYCHOSCOCIAL MODEL OF HEALTH AND ILLNESS 1	2
1.3	Understanding disability and impairment 1	2
1	1.3.1 WHO Impairment-Disability-Handicap framework1	2
1	1.3.2 Social model of disability	4
1.4	Psychological models of illness and stress 1	5
1	1.4.1 Leventhals' self regulatory model 1	5
1	1.4.2 Lazarus 's Transactional model of stress	0
1.5	Chronic illness	2
1	.5.1 Impact of chronic illness on the patient	3
1	1.5.2 The loss of self	4
1	.5.3 Social support	5
1.6	IMPACT OF ILLNESS ON FAMILIES AND CAREGIVERS	8
1.7	CAREGIVER BURDEN AND STRAIN	4
1	.7.1 Objective measures of burden	6
1	.7.2 Subjective measures of burden	7
СНАР	TER 2 REVIEW OF STROKE AND CAREGIVING LITERATURE	2
2.1	INTRODUCTION TO STROKE4	2
2	1.1 Depression and anxiety post-stroke 4	3
2	.1.2 Perceived control over recovery	8
2	1.3 Perceptions of rehabilitation	9
2	.1.4 Family functioning	1
2.2	ГНЕ IMPACT OF STROKE CAREGIVING	1
2	.2.1 Burden	2
2	.2.2 Depression and anxiety	5

2.2.3 Positive aspects of caring
2.3 Relationship between patients and carers
2.3.1 Family functioning and interaction
2.3.2 Deficits in the caregiving literature
2.4 Summary
CHAPTER 3 STUDY 1: THE PSYCHOLOGICAL WELL-BEING OF STROKE PATIENTS AND THEIR CARERS AT ONE, THREE, AND SIX MONTHS POST STROKE
3.1 Introduction
3.1.1 Carer psychological well-being
3.1.2 Social support and well-being
3.1.3 Discrepant perceptions between patients and carers
3.1.4 Time-line and carer well-being
3.2 Aims of the study
3.3 Method
3.3.1 Participants
3.3.2 Procedure
3.3.3 Recruitment Phase 1
3.3.4 Recruitment Phase 2
3.3.5 Measures
3.4 Analysis
3.5 Cross sectional cohorts results
3.6 Results for the prospective sample
3.7 DISCUSSION
3.7.1 Differences between patients and carers
3.7.2 Demographic Differences
3.7.3 Differences across time
3.7.4 Caring appraisal scales
3.7.5 Prospective sample
3.7.6 Limitations and future research

#### CHAPTER 4 STUDY 2: COUPLES' ACCOUNTS OF LIVING WITH STROKE; CONVERSATIONAL STYLES AND ASSOCIATIONS WITH CARER DISTRESS121

4.1 Introduction	121
4.2 Method	128
4.2.1 Participants	128
4.2.2 Data collection	128
4.3 Analysis	129

4.3.1 IPA analysis and voice-relational analysis	
4.4 Results	
4.4.1 Results section part 1	
4.4.2 Results section part 2	
4.5 DISCUSSION	
4.5.1 Patient and carer themes and their relation to the literature	
4.5.2 Conversation styles	
4.6 Reflexivity	
CHAPTER 5 STUDY 3: A COMPARISON OF CAREGIVING CO	UPLES AND NON-

# 

5.1 Introduction	
5.2 Аімѕ	
5.3 Methods	
5.3.1 Participants	
5.3.2 Measures	
5.4 Procedure	
5.5 Results	
5.5.1 Results for depression, anxiety and marital intimacy	
5.5.2 Inter-rater reliability	
5.5.3 Interaction results	
5.5.4 Results of the Intra-class and Inter-class correlations	
5.7 DISCUSSION	
5.7.1 Benefits of the methodology	
5.7.2 Limitations	
5.7.3 Statistical considerations	200

# CHAPTER 6 STUDY 4: YOUNG ADULTS' PERCEPTIONS OF STROKE AND CARING FOR A STROKE PATIENT .....

202
202
204
210
210
213

6.5.2 Perceptions of Caring	
6.6. DISCUSSION	
6.6.1 Limitations of the research	
6.6.2 Future Research	
REFERENCES	224

#### **APPENDICES**

Appendix 1: Information letter: Study 1 Appendix 2: Consent form: Study 1 Appendix 3: Patient Questionnaire: Study 1 Appendix 4: Carer Questionnaire: Study 1 Appendix 5: Copy of the MSQ Appendix 6: Information Letter: Study 2 Appendix 6: Information Letter: Study 2 Appendix 7: Interview Schedule: Study 2 Appendix 8a: A Couple's Master Themes: Study 2 Appendix 8b: Conversation Schedule for Analysis: Study 2 Appendix 9a: Information Letter: Study 3 Appendix 9b: Questionnaire: Study 3 Appendix 10: Observation Scales: Study 3 Appendix 11: Scoring Form: Study 3 Appendix 12: Information Letter: Study 4

### **INDEX OF TABLES**

Table 3.1: Reliability Of Scales. 85
Table 3.2: Means Of Variables For Patients And Carers (Cross-Sectional)
Table 3.3: Patient Means On Variables According To Gender
Table 3.4: Carer Means On Variables According To Gender
Table 3.5: Means For Carer Impact Appraisal Scale (Cross-Sectional)
Table 3.6: Carers' Anxiety, Depression, Control And Caring Appraisal In Relation ToPast Caregiving Experience (Cross-Sectional)
Table 3.7: Carers' Anxiety, Depression, Control And Caring Appraisal In Relation To Type Of Carer
Table 3.8. Intercorrelations Between Patient And Carer Variables At The Acute Phase.
Table 3.9: Intercorrelations Between Patient And Carer Variables At 12 Weeks 100
Table 3.10. Intercorrelations Between Patient And Carer Variables At 24 Weeks 101
Table 3.11. Table Indicating The Background Information Of Patient And Carer      Dyads
Table 3.12: Means Of Variables For Patients And Carers (Prospective)      104
Table 4.1. An Overview Of The Themes For Patients And Carers In Relation To Talk About The Self And The Relationship133
Table 4.2. Carers' Depression And Anxiety Scores Examined In Relation To Their      Interactive Style.
Table 5.1. Results Of Inter-Rater Reliability For Caregiving And Non-Caregiving Couples On The Puzzle Task
Table 5.2. Results Of Inter-Rater Reliability For Caregiving And Non-CaregivingCouples On The Planning Task
Table 5.3. Descriptive Statistics Of Scores For The Puzzle Task For Caregiving And

Non-Caregiving Couples
Table 5.4. Descriptive Statistics Of Scores On The Planning Task For Caregiving And      Non-Caregiving Couples    187
Table 5.5 Correlations Between Interaction Scores On The Puzzle Task And      Depression, Anxiety And Intimacy.      189
Table 5.6 Correlations On The Interaction Planning Task And Depression, Anxiety      And Intimacy
Table 5.7 Intra-Scale Correlations On The Puzzle Task
Table 5. 8 Intra-Scale Correlations On The Planning Task
Table 5.9 Inter-Scale Correlations Between The Puzzle And Planning Tasks      193
Table 6.1 Means For The Illness Perceptions And Caring Appraisals For A Stroke      Patient As Held By A Young Adult Sample
Table 6.2 Intercorrelations Between The Ipq And Caring Appraisal Variables

### **INDEX OF FIGURES**

	Figure 1.1 The Flow Of Relations In The Icidh (1980) Adapted From Http://Www.3.Who.Int/Icf13
	Figure 1.2 The Model Of Functioning And Disability (Icf Model) From The International Classification Of Functioning, Disability And Health (Adapted From Icf Website)
	Figure 1.3 Lazarus's Transactional Model Of Stress Adapted From Lazarus & Folkman (1984)
	Fig 1.4 Categorization Of Chronic Illness By Psychosocial Type Source; Adapted From Rolland (1988)
	Figure 3.1: Disability Scores Of Patients And Carers Across Time
	Figure 3.2: Depression Scores Of Patients And Carer Across Time
	Figure 3.3: Anxiety Scores Of Patients And Carer Across Time
and the second second	Figure 3.4: Perceived Control In Patients And Carers Across Time 108
	Figure 3.5: Carer Work Satisfaction Across Time
	Figure 3.6: Carer Work Strain Across Time
	Figure 3.7: Carer Lifestyle Satisfaction Across Time
	Figure 3.8: Carer Relationship Satisfaction Across Time
	Fig 4.1: Proposed Model Of Dyadic Interaction In Distressed Caregivers

#### ACKNOWLEDGEMENTS

Firstly I would like to thank my supervisor, Val Morrison, for being supportive and encouraging throughout my thesis and various life events. I would particularly like to thank Val for all her feedback on my various ideas and drafts, which always improved my work greatly and helped me see where I was going. I would also like to thank Bob Woods, my second supervisor, for casting his critical eye over everything I sent him and for his humour which helped me keep a sense of perspective. I would like to thank all the members of the Stroke Team who put up with me at their team meetings and helped me navigate my way round the hospital and patient record system.

I would like to give a special thanks to all the people who took part in the studies. Many of the people who participated in these studies let me into their homes and lives and I will always be very grateful to them for taking the time and effort to share their experiences with me.

Throughout the thesis and other events in the last 5 years I was well supported by a number of friends and colleagues: Jaci Huws, Bethan Henderson, Harriet Fearnley, Trish Goater and Kate Jones. Special thanks are reserved for Jaci Huws and Bethan Henderson, who both helped me at various stages in my thesis: Jaci as a second coder for my qualitative data; she taught me a lot about qualitative analysis and friendship; Bethan for her baby wisdom, humour and formatting expertise.

I would finally like to thank all my family for their love and support. My Mum and Len for helping me through all the difficult times and for being such a lovely Mum, Stepdad, and Nain and Taid. Ernie and Joyce for always helping our family in every way and for being

brilliant grandparents. Dad and Sue for always expressing an interest in what I was doing, despite being very busy, and for always believing in me. I would like to give a big thank you to my husband, Owen, for living with the thesis as much as I have and especially for his love, support and typing of references. Finally I would like to thank my daughter, Celyn, for the beauty and love she brings to my life and for being the best distraction.

#### DEDICATION

This thesis is dedicated to my daughters, Celyn and Megan Jones-Hughes. I hope one day you will be proud that Mummy finally finished her work on the computer.

#### SUMMARY

Using a range of different methodologies this research attempts to address aspects of the caregiver-care-receiver relationship between individuals who have experienced a stroke and their (mainly spousal) carers. The research examines cognitions (control, perceived disability) appraisals and relational factors (marital intimacy and interaction quality) and their impact on psychological well-being (anxiety and depression) in stroke patients and their carers. Study 1 examined stroke patients' and carers' psychological distress in a crosssectional design. A small prospective sample of eight patient and carer pairs took part across all time-points. Results revealed that carers were more distressed than the stroke patients and perceived the person with stroke to have greater disability and less control over recovery. The correlations demonstrated the following: that appraisals of caring were associated with carer anxiety and depression; and that patients' perceived level of disability and control associated with depression and anxiety. The data from the small prospective sample was only descriptively analysed but the results for the dyads exhibit large variation, with the exception of relationship satisfaction which decreased in all dyads across time. The decrease in relationship satisfaction is interesting as those patient and carers that were married rated their marital intimacy as high and unchanged from pre-stroke ratings; this finding was thought worthy of further investigation.

**Study 2** examined qualitatively the impact of stroke on persons with stroke and their spouses, looking at the impact of the stroke on the patients' and carers' sense of self and relationship; Ten married couples took part in this study. The main themes found for patients and carers were: living with the aftermath of stroke; making sense; and negotiating care, with differing sub-themes for patients and carers. A second level of analysis in this study was the nature of the communication seen in these couples and the triangulation of couples' coded

communication styles with the quantitative data on depression and anxiety in Study 1. Those couples that exhibited conflicted or carer dominant styles of interaction had significantly more anxious carers than those with equal levels of interaction. To examine whether interaction differs as a result of caregiving, rather than as a normal variation in a relationship, it was thought important to use a different methodology to capture interaction.

**Study 3** piloted a novel observational technique to examine whether stroke caregiving wives to husbands with stroke exhibited different interaction patterns than non-caregiving wives; 14 couples took part in this study. There were specific differences in caregiving wives who displayed more dominant and depersonalising behaviour than non-caregiving wives on a puzzle task. Overall caregiving couples were more depressed than non-caregiving couples.

**Study 4** examined lay perceptions of stroke and caring using an adapted Illness Perceptions Questionnaire and Caring Impact Appraisal Scale with 83 adults. The results found gaps and confusion in the knowledge regarding stroke and this study addresses issues for health promotion and improved understanding by the wider population of stroke and its impact on individuals and carers.

#### ABSTRACT

This thesis addresses aspects of the caregiver-care-receiver relationship between individuals who have experienced a stroke and their (mainly spousal) carers. The thesis also attempts to elicit lay perceptions of stroke and caregiving. Study 1 examined stroke patients' and carers' psychological distress in a cross-sectional design. Results revealed that carers were more distressed than the stroke patients at all time-points. Carers perceived the person with stroke to have greater disability and less control over recovery. Study 2 is a qualitative account of the impact of stroke on couples' sense of self and relationship (N=10). The main themes found were: living with the aftermath of stroke, making sense, and negotiating care. Voicerelational analysis was used to examine interaction and communication in the couples' conversations. Those couples that exhibited conflicted or carer dominant styles of interaction had significantly more anxious carers than those with equal levels of interaction. Study 3 examined videotaped interaction in couples where the husband had experienced a stroke and healthy control couples. Caregiving wives displayed more dominant and depersonalising behaviour to their husband than non-caregiving wives. Overall the stroke couples were more depressed than the healthy couples. Study 4 examined lay perceptions of stroke and caring (N=83) using an adapted Illness Perceptions Questionnaire and Caring Impact Appraisal Scale. The results found gaps and confusion in the knowledge regarding stroke. The discussion addresses issues for health promotion and improved understanding by the wider population of stroke and its impact on individuals and carers.

#### CHAPTER 1:

#### MODELS OF HEALTH AND ILLNESS

#### 1.1 The biomedical model

The biomedical model of illness views every disease as having a primary underlying biological cause that is objectively identifiable. Diseases are perceived to be caused by internal or external factors. External factors are divided into physical, chemical and microbiological, and internal factors are divided into vascular, immunological and metabolic; behavioural acts are not generally assessed as part of the process of diagnosis. The biomedical model views health and illness as contrasting states of bodily function. Health represents the "normal" biological state of the organism, and illness represents a deviation from this norm. Diseases are identified by symptom patterns that relate to an underlying condition, and once a diagnosis has been made a suitable treatment can be sought. Illness is understood in terms of biology, and is treated by physiological intervention: by chemical, surgical, or radiation techniques. In Western societies the biomedical model predominates over medical practices.

The biomedical model incorporates a mind-body dualism that views the mind and body as distinct entities that have no influence over one another (Ogden, 1996). Social and psychological factors in illness and health are ignored in the biomedical model, and a biological explanation is sought to the exclusion of other factors (Ogden, 1996). The biomedical approach has had enormous success in understanding the pathophysiological basis of disease and appropriately treating it. The biomedical approach has played a large part in decreasing infectious diseases through innoculation (Beigel, Sales & Shulz, 1991). The decline in serious infectious diseases (e.g. measles, tuberculosis) and advancements in

treatments and technologies for dealing with acute illness events such as heart attacks, has led to an increase in life span. Advances in medical technology have increased the number of individuals who survive serious trauma and chronic illness (as cited in Biegel et al., 1991). The biomedical approach has had its limitations in the areas of chronic disease such as cancer, stroke, and myocardial infarction, all of which are on the increase and account for most of the adult deaths in Western societies in the 21<sup>st</sup> Century. Circulatory vascular disease (CVD) accounts for 44% of all deaths in the UK (British Heart Foundation, 1996) with the UK having the highest death rate for coronary heart disease (British Heart Foundation, 1996). Biomedical approaches have had little success in reducing the prevalence of these illnesses, as social factors (income, living conditions) and personality and behavioural factors (ability to cope with stress, type of employment, smoking or drinking) are believed to have associations with these diseases (Radley, 1994). Chronic illness impacts not only physiologically on the sufferer but also psychologically, with many sufferers reporting anxiety and depression e.g. cancer and stroke patients (as cited in Chapter 15, Morrison & Bennet, 2005).

Health seeking behaviour and treatment adherence are also influenced by social and psychological factors; health seeking behaviour is often determined by cultural norms and treatment adherence can be affected by psychological factors such as perceived control over treatment, and the gains or losses made by the patient when adhering to the treatment. Health psychologists believe in the inclusion of psychological and social dimensions in addition to biological dimensions, in order to understand illness, help-seeking behaviour, and treatment adherence in illness.

#### 1.2 Biopsychoscocial model of health and illness

The biopsychosocial model is a set of beliefs and values about health and illness which developed out of a dissatisfaction with the biomedical approach. Engel (1977) proposed the biopsychosocial model in recognition of the interaction of three factors on health, the biological, psychological and social. The 1970s was a time when a recognition emerged that lifestyle factors and psychosocial stress contributed to morbidity and mortality from cardiovascular disease, cancer, injuries and other leading causes of death in industrialized countries. The Black Report and the White Paper (as cited in Radley, 1994) on health inequalities showed that health and illness could not be explained by biology and that where someone lived, their lifestyle, gender and socioeconomic status was a large determinant of whether they were sick or ill. Nearly 30% of the global burden of disease can be attributed to five risk factors, the largest risk factor being associated with poverty and the remaining four being strongly related to lifestyle: unsafe sex, high blood pressure, tobacco and alcohol consumption (Ezzati, Lopez, Rogers et al., 2002). In the biopsychosocial model disease is an objective biological event whereas illness refers to the personal consequences of a disease in terms of the physical but also the social and emotional outcomes. The recognition of the importance of factors such as the severity of illness, duration and consequences of illness allowed for a more individualistic and diverse approach to studying patients' perceptions and responses to illness.

#### 1.3 Understanding disability and impairment

#### 1.3.1 WHO Impairment-Disability-Handicap framework

The WHO in 1980 developed the International Classification of Impairment, Disability and Handicap (ICIDH), as an instrument to measure disability. According to the ICIDH,

disability refers to any reduction or lack of ability, caused by impairment, to perform an activity in a way considered normal. ICIDH defines disablement in terms of levels of impairment, disability and handicap. The ICIDH assumes that the social environment is fixed and does not incorporate an assessment of the social barriers and facilitators which may significantly affect the overall disability of the patient. The ICIDH framework presents disability as a linear process that begins with an underlying cause that brings about impairment, which causes disability that may result in a handicap (Figure 1.1).

# Figure 1.1 The flow of relations in the ICIDH (1980) adapted from <u>http://www.3.who.int/icf</u>



The ICIDH was revised to the International Classification of Functioning, Disability and Health (ICF). The ICF was developed to provide assessment of disability associated with illness irrespective of diagnosis, using a biopsychosocial model, as well as the assessment of environmental factors and their role in disability. The ICF integrates four dimensions of disability, including structural and functional impairments, activity limitations, participation restrictions and environmental factors. In the ICF disability is understood to encompass the interaction between impairments and externally imposed activity limitations or participation restrictions. Another difference of the ICF is that the dimensions of disability incorporate the principle of universalism; the understanding that the dimensions of disability exist on a continuum with ability and that the individual, social and physical environments interact with one another to produce the handicap or impairment rather than a one way interaction as conceptualised in the original ICIDH (see Figure 1.2).

# Figure 1.2 The model of Functioning and Disability (ICF model) from the International Classification of Functioning, Disability and Health (adapted from ICF website)



#### 1.3.2 Social model of disability

The social model of disability views disability as an outcome of social and institutional practices (e.g. a deaf person may not perceive themselves as disabled but rather handicapped by society) rather than biologically determined and the causal link between impairment and disability as seen in the ICF is refuted. Despite disputes over disability as a concept, psychology researchers believe that researching disability and its association with distress is an important endeavour "while being accepting of the fact that disability can be a socially constructed source of oppression, but it is important not to deny the reality of the physical and psychological affects that chronic illness can cause. We can insist that society disables us by its prejudices and by its failure to meet the needs created by disability, but to deny the personal experience of disability is, in the end, to collude in our oppression" (Morris, 1996; as cited in The Psychologist, 2005).

The term disability in this thesis will be used to discuss the functional neurological impairments that have resulted in activity limitations that are measured by activities of daily living (ADL). The studies reported in this thesis are interested in the impact that a physical illness, such as stroke, has upon psychological well-being in the person surviving stroke and those caring for the survivor. For the purpose of this thesis and in line with the ICF model, impairment will refer to the physical insult to the brain that has resulted in effects such as cognitive impairment or hemiplegia, and disability as a term will be used to describe a person's inability to perform activities of daily living. Disability as a term in this thesis fits with the following definition: 'a person has a disability...if he has a physical or mental impairment which has a substantial and long-term adverse affect on his ability to carry out normal day-to day activities' (Disability Discrimination Act, 1995, s.1 (1)).

Research into physical diseases in the elderly population has found an association between physical disease and depressive symptoms (Dent, Waite, Bennet, Casey, Grayson, Cullen, Creasey, & Broe 1999). This research demonstrates that physical disease does not necessarily lead to depression, but if the physical disease results in disability, then the likelihood of developing depression is far greater. Empirical evidence pertaining to stroke and the impact upon the survivor's and carer's well-being will be presented further on in Chapter 2 of the thesis.

#### 1.4 Psychological models of illness and stress

#### 1.4.1 Leventhals' self regulatory model

The World Health Organisation's (1980) definition of health is "a state of complete physical, mental, and social well-being," which departs from the traditional medical view of health being a physical state only. This definition presents a multidimensional approach to health and is argued by Lau (1995) to represent how most people view health. Lau (1995) found that when young healthy adults were asked to describe in their own words what health meant to them, their beliefs about health could be understood in the following terms:

Physiological/physical e.g. good condition, having energy.Psychological e.g. happy, energetic, feeling goodBehavioural e.g. eat or sleep properly.Future consequences e.g. live longer.The absence of e.g. not sick, no disease and no symptoms.

Therefore Lau (1995) concluded that health is viewed as a multidimensional concept by the lay person. Lau (1995) went on to investigate beliefs about illness and asked participants what it means to be sick. Their answers indicated the dimensions they used to conceptualise illness:

Not feeling normal e.g. 'I don't feel right'. Specific symptoms e.g. physiological/psychological. Specific illnesses e.g. cancer, cold, depression. Consequences of illness e.g. 'I can't do what I usually do'. Time line e.g. how long symptoms will last. The absence of health e.g. not being healthy.

The dimensions of what it means to be ill were also described earlier on in the research literature in the context of illness cognitions by Leventhal (1980). He established a relationship between illness cognitions and subsequent responses to illness or health threats, defining illness cognitions as a 'patient's own implicit common sense beliefs about their illness'. Leventhal proposed that these cognitions provided patients with a framework or schema for 1) coping with and 2) understanding the illness, and 3) telling them what to look out for if they are becoming ill. Interviewing patients with hypertension and cancer enabled Leventhal (1980) to establish that patients build their illness representations around five key components: identity, cause, time line, consequences and controllability (similar to the later findings in the Lau 1995 study). The five components of illness cognitions together with the symptoms and signs of the illness make up what Leventhal termed Illness Representations.

Leventhal incorporated illness representations into a model that attempts to explain how an individual deals with illness. The model is named the self-regulatory model and includes: the illness representation (consisting of the five components of identity, cause, time line, consequences, and controllability); interpretation of the illness; coping with the illness; appraisal of the coping strategy; and the emotional response to the illness.

The stages of the self regulatory model can be explained as a series of stages with the first stage involving interpretation. The individual is confronted with a health threat either through symptom perceptions or by social messages (doctors diagnosis). The illness representation of identity, cause, time line consequence, and controllability/cure along with the symptoms and social messages will lead to interpretation of the illness. The illness representation will then in turn affect what coping strategy is employed and what emotional response the person may experience. When an individual receives a diagnosis of a chronic disease his/her immediate emotional response may be anxiety, and any subsequent coping strategies will relate to the illness representation and the emotional response. Leventhal, Nerenz & Steele (1984) studied patients who were being treated for malignant lymphoma and found those patients whose turnour reduced at the expected rate. Leventhal explains this in terms of his model; the patients had an illness representation and a belief about how long it would take to reduce the turnour, they in effect had a benchmark on which to appraise

their recovery; with a rapid reduction in the tumour the benchmark was lost and the individual was left without a clear understanding or expectation of the course of his/her illness.

The second stage involves coping. Once an illness representation has been constructed, the next stage in the model is the identification and development of coping strategies. Coping strategies are employed to return the person back to a state of equilibrium or normality. Physical illness may also disrupt an individual's established personal and social identity (Charmaz, 1983). The illness can cause changes for the individual in the following: their identity, role, social support, and their future. 'Crisis theory' has been applied to physical illness and suggests that individuals when thrown into a state of crisis will seek ways of returning back to their previous state of equilibrium or normality. Moos and Schaefer (1984) apply crisis theory to physical illness to examine the ways that individuals cope with this crisis. Whether physical illness is considered as a crisis or not, most individuals will employ coping strategies to reduce the impact of the illness (Scheier & Carver, 1987). There are two broad categories of coping strategies and they are approach coping (e.g. taking medication, visiting the relevant practitioners, discussing the problem with family or friends) and avoidance coping (e.g. denial, wishful thinking). There are also problem-focused coping and emotion-focused coping (Scheier & Carver, 1987) which are variations of approach and avoidance coping. Problem-focused coping involves the individual confronting the problem and reconstructing it as manageable. Problem-focused coping strategies involve learning specific procedures and behaviours to deal with the illness, identifying alternative rewards such as short term goals that provide alternative satisfaction to the rewards and goals set prior to the illness. Emotion focused coping involves managing emotions and maintaining emotional equilibrium. Three types of emotion focused coping have been identified as

effective: maintaining hope when dealing with a stressful situation; emotional release involving the discharge of feelings such as anger or despair; and resignation which involves the person accepting the inevitable outcome of the illness. Coping efforts have been found to influence psychosocial adjustment. Coping is affected by appraisals of helplessness, locus of control and perceived social support (Smith & Wallston, 1992).

Individuals will adopt a specific coping strategy in an attempt to return to the 'normal' healthy state. The strategy individuals use, and their positive or negative influence on adjustment is affected by: demographics and personal factors (age, sex, class, religion); physical and social factors (social support, the physical environment of a home or hospital, social stigma); and illness related factors (pain, disability and disfigurement). Despite the different categorisations of coping strategies, people may use a combination of approach and avoidance, and emotion and problem focused coping and so classification of types of coping and outcomes of these strategies may be difficult to establish. Coping strategies have been found to have stable and variable aspects dependant upon these factors, which makes measuring coping across time and its relationship to psychological outcome challenging (Folkman & Greer, 2000).

The third stage involves appraisal. Individuals will evaluate the effectiveness of their coping strategy in terms of their illness representation and emotional response. The individual's emotional response can influence the appraisal of the coping strategy, as well as being a benchmark for how well the coping strategy worked ( i.e. if depressed, the patient may evaluate the coping strategy negatively because of the depression, or if there is a reduction in feelings of depression the patient may evaluate the coping strategy to be effective).

All three stages interact with one another in order to return the individual back to a state of 'normality'. Leventhal's illness perceptions and their hypothesised role in patient outcome were implemented for research by the development of the IPQ (Illness Perceptions Questionnaire). Moss-Morris, Petrie and Weinman (1996) used the IPQ to measure illness cognitions and how they relate to outcome measures of disability and psychological wellbeing. Moss-Morris et al. (1996), in a multiple regression analysis, found that illness perceptions explained significantly greater variance in levels of disability and psychological well-being than measures of coping strategies adopted by patients to manage their condition. A strong illness identity, low perception of control, perception of serious consequences and causal attribution of stress were negatively associated with mental health and functional ability. There were however links found between illness perceptions and coping strategies with control strategies associated with positive reinterpretation of the illness by the patient, and emotion focused strategies associated with identity, consequences, and time line changes in perception of the illness. This work further established a link between illness cognitions and coping methods, and between illness cognitions of the patient and the outcome of the patient. Perceptions of control appeared to play a positive role in the interpretation of the illness.

#### 1.4.2 Lazarus's Transactional model of stress

One of the most popular accounts of how an individual's cognitions can lead to psychological distress comes from the work of Lazarus and his transactional model of stress (Lazarus & Folkman, 1984). Within this model, the determinant of whether any external event (such as the onset of chronic illness or becoming a caregiver) could cause psychological problems comes firstly from whether or not the individual appraises the event as being a stressor. This primary appraisal can vary between people and events, making the

perceived potential harm of any given situation unique to each person. If appraised as demand/threat/challenge, the individual then decides on a secondary appraisal, i.e. whether they have the resources available to defend against the negative effects.

A person's perception of the internal or external resources available to defend against a stressor is affected by social and personal variables such as having a significant relationship, age, gender, and life experiences of similar events. The secondary level of appraisal can have either direct or indirect effects on distress. In a direct relationship, it may be that through appraising an event as a stressor that they are unable to cope with, individuals become distressed (e.g. Barrowclough & Parle, 1997). Alternatively, appraisals themselves may determine what kind of coping method the individual tries to employ. When an event happens e.g. the onset of illness, individuals may have an actual ability to cope however, the perception of the demand and the perception of the ability to cope may differ from the actuality. If the demand is perceived as being high and the individual perceives themselves as being unable to cope with it they will experience stress (See Figure 1.3). In summary, Lazarus describes the idea of a primary and secondary appraisal. The primary appraisal is the assessment of the threat an individual is under and the secondary appraisal is the individual's perception of their ability to cope. According to Lazarus coping can serve two main functions: either it can alter the problem causing the stress or it can regulate the emotional responses through behavioural or cognitive approaches. People tend to use emotion focused methods when there is nothing they can do about the event e.g. a terminal illness (Kubler-Ross, 1969). Emotion focused coping can include behaviours such as drinking alcohol, watching TV, seeking support from friends. Problem focused coping is aimed at reducing the demands of the stressful situation or expanding the resources to deal with it (e.g. changing lifestyle, engaging in different activities or support groups).

Although now an older study, the research by Billings and Moos (1981) is still highly relevant. In their study 200 married couples completed a survey describing a recent personal crisis or negative life event that happened to them and then answered questions about their methods of coping. Both husbands and wives used more problem focused methods of coping overall but the wives used more emotion-focused methods than the husbands. People with higher income levels used more problem-focused methods. Coping with a death tended to be mainly emotion-focused. It would appear that when someone is powerless to bring about any change in their situation, such as when facing death or being diagnosed with a terminal illness, then emotion-focused coping strategies are preferred, but when there is an element of personal control over an event then problem-focused coping strategies are used. The results of this study show that coping strategies differ between individuals, in terms of gender, in the face of different stressors. The importance of both Lazarus's transactional model and Leventhal's self-regulatory model, lies with the emphasis that both place on individuals' cognitions in the illness experience. Lazarus's (1984) transactional model takes into account individual differences in the experience of stress unlike the past life events approaches to stress where certain life events, such as illness, had an objectively attributed level of stress thought to be associated with them, failing to take into account individual differences (Brown & Harris, 1978).

#### 1.5 Chronic illness

Chronic illness is on the increase in the Western world (WHO, 2005). This rise is due partly to increased life expectancy, as age increases the chances of experiencing a chronic illness such as Alzheimer's disease, a myocardial infarction, or a stroke increase (Biegel et al., 1991), but also partly because of improved medical treatment, meaning people live longer after experiencing a chronic illness.

### Figure 1.3 Lazarus's Transactional Model of Stress adapted from Lazarus & Folkman

(1984)



#### 1.5.1 Impact of chronic illness on the patient

Chronic illness can affect the whole of the sufferer's life-psychologically, physically, socially and economically (Hafsteindottir & Grypdonck, 1997). Chronic illness can be defined as:

"the irreversible presence, accumulation, or latency of disease states or impairments that involve the total human environment for supportive care and self care, maintenance of function and prevalence of further disease" (Biegel, Sales & Schulz, 1991: p145). Each individual's illness differs in its impact but common problems for the sufferer are: restrictions in lifestyle and activities; negative self perceptions; social stigma attached to the condition; intrafamily conflicts involving intimacy and sexual stress; increased dependency and decreased self sufficiency; and economic pressures resulting from work restriction or termination of work. These problems can lead to withdrawal from family and friends by the sufferer; lessened participation in social activities, lowered self esteem, and possibly depression and anxiety (Anderson & Bury, 1988; Biegel et al, 1991).

There are a number of variables that can affect the impact of chronic disease upon the sufferer and these are: type of disease; natural history of the disease; the stage of illness (prediagnosis, diagnosis, treatment, rehabilitation and reoccurrence); structure of family and social support; role of the ill individual (child, mother or father); the life stage the person is at; life stage of family; characteristics of ill individual; characteristics of carer; and economic circumstances of the ill individual and their family (Morrison & Bennet, 2005).

#### 1.5.2 The loss of self

The symbolic interactionist framework's central psychological feature of illness is loss of self "former self images crumble away without a simultaneous development of equally valued new ones" (Charmaz,1983; p168). Such viewpoints explicitly state that an understanding of illness requires an understanding of the social and cultural context. The social constructionist framework believes that reality is constructed between individuals through language, both verbal and non-verbal, and is an ongoing process. Social constructionism believes that the self can only be experienced through other's responses to the self. Therefore a stroke patient interprets others' responses as being an indicator to who they are and where they are in the world. An important factor in chronic illness is the social

support systems around an individual. The idea that social support from family and friends decreases the effects of stress is widely held (Rook, 1985).

#### 1.5.3 Social support

Social support is a well known concept relating to the emotional, instrumental and practical support that is provided by others in one's social network, often at times of crisis, and will not be thoroughly reviewed here (Saranson, Saranson and Pierce, 1990). A particularly salient aspect of support is that found in intimate relationships; an important aspect of social support seen by many is marriage. Many studies have found that under a range of stressors (including illness) married individuals fare better than non-married individuals, (Brown & Harris, 1978). Research has found that married men recovering from heart surgery have a higher level of post-surgical physical activity and resulting adjustment than non-married men (Schwarzer & Schroder, 1997b). This finding could be a function of the increased social network and support that is entailed by becoming married or the result of the marital relationship itself. The Schwarzer & Schroder (1997b) study however, did not show whether these married men are able to confide in their wives, what extra resources they have, or whether their beliefs about recovery are actually different from unmarried men.

There is evidence to show that gender affects the benefits of marriage, with women benefiting less than men when it comes to marital status. For example, patients who suffered from mild hypertension had measurements taken regarding their job strain, job status, marital status and lab and ambulatory blood pressure and overall it was found that marital status had a powerful moderating effect with married persons exhibiting higher systolic blood pressures than unmarried individuals on a mental stress test and in particular marital status impacted upon women, with married women having higher ambulatory blood pressure than single

women (Blumenthal, Towner and Siegel, 1995). Further evidence of the unequal benefits of marriage for women comes from the Hagedoorn, Bunk, Kuger, Wobbs & Sanderman (2000) study which found that when couples were dealing with cancer and it was the husband who was ill, females had increased distress levels but when it was the wife who was ill, husbands were not as affected as wives, reporting lower levels of distress. This result could be due to women being more expressive of their distress than men or that men are less likely to take on the "burden" of caring and therefore less likely to become distressed (Hagedoorn et al., 2000).

Theories put forward to explain the unequal benefits of marriage for men and women in stressful circumstances have focused mainly on the role identity explanation (Thotis, 1991) which states that women's increased distress when their partner is ill can be attributed to identity construction; their husband is a central part of their identity, and when their spouse is ill this identity comes under threat. It is unclear whether this may still be the case with higher percentages of women entering the work place. Role identity theory has been applied not only to studies looking at gender but also to caregiving studies, the wife takes on the role of carer and incorporates this role into her identity, Hagedoorn et al. (2000) measured self efficacy in caregivers and personal accomplishment and found there was greater distress in caregivers who had low personal accomplishment and low self efficacy in their role. Therefore evidence points to a psychological vulnerability for married women whose partners become ill whereas men seem less vulnerable when their wife becomes ill.

It would be misleading to give only details of studies that show females to fare worse in certain marital situations as evidence is by no means conclusive. Brown and Harris (1978) found that women living in the community who had no husband or boyfriend to act as a confidant were more likely to report symptoms of depression when faced with a stressful life

situation than those women with a partner. Coyne (2001) also found that married women fared better psychologically when making decisions about breast cancer screening than single women with marital quality being a stronger predictor of well-being rather than previous experience of breast cancer. Coyne (2001) also found that husbands were more important than sisters in decision making regarding the genetic testing, and overall, marital quality was a subtle pervasive influence on adjustment in the women, as those with good marriages adjusted faster.

Studies on marital quality and coping with physical and mental illness have shown the importance of marital functioning in illness adaptation and recovery. Sullivan, Mikail et al. (1992) found the emotional functioning of married and non-married individuals following a diagnosis of MS was not affected by marital status but was affected by marital quality; those couples with higher marital quality had better rates of adjustment. Couples with marital difficulties before the onset of MS had increased levels of depressive symptomatology in the MS sufferer and experienced strain as a couple relative to those couples without difficulties prior to the diagnosis. Earlier studies have also found that high levels of marital conflict predict relapse in a number of psychiatric disorders including schizophrenia (Vaughn & Leff, 1976) and major depression (Morris, Morris and Britton, 1988). Gilleard (1984) found the reported quality of the past relationship accounted for a significant proportion of the variance in predicting mental health for carers but other research has found no correlations between relationship quality and carer outcome (Gihooly, 1984). Morris et al. (1988) studied 20 spousal caregivers of persons with dementia and measured the level of intimacy both pre and post illness using the Marital Intimacy Questionnaire (Waring & Reddon, 1983) and also measured depression using the Beck Depression Inventory. The results found that past intimacy had dropped (72.6-54.6 out of a possible 120) and that the reduction in intimacy

correlated with depression and depression correlated with caregiver strain. No causality could be established in the Morris et al. (1988) study as it was cross-sectional, but the findings do fit with the later research evidence, mentioned above, concerning how a loss or lack of intimate relationships can be a vulnerability factor for depression should a stressful life event occur such as a chronic illness. It appears that marital quality or the availability of an intimate relationship is a factor that is important in determining well-being in those facing stressful life situations, such as experiencing a chronic illness or being a spouse to a chronically ill person. Marital quality is a factor that may have been missed in many studies simply by presuming marital status was the same construct as marital quality.

#### 1.6 Impact of illness on families and caregivers

Once a person becomes chronically ill, the prevention and management of the illness involves the patient and family in controlling the symptoms and carrying out prescribed regimens. Family members may also be involved in the management of problems encountered when carrying out the regimens and the prevention of, or living with, social isolation caused by the lessened contact with others due to the illness (Orbell & Gilles, 1993; Lee & Powers, 2002). The family will often be involved in attempts at normalizing interaction with others, adjusting to changes in the disease trajectory (whether the disease is in remission, or is progressing downwards) and finding the necessary means to pay for treatment or to live, despite potential losses in income due to partial or complete loss of employment of the sufferer. Both the patient and family must confront the psychological, marital, and family problems that may be present with the illness (Biegel et al. 1991).

The chronic illness therefore affects the whole family system of the ill individual and in recent reviews there have been calls for further research in how a family systems approach

to illness (such as stroke) can contribute to a better understanding of recovery (Palmer & Glass, 2003). Normal patterns of interaction are often disrupted by illness and there can be reassignments in the roles taken on by particular family members, Leventhal (1985 cited in Biegel et al 1991). The patient who previously may have been employed, may now stay at home, while the partner takes on the breadwinner role. The chronic illness alters the relationship not only of family members to the person who is ill, but also relationships between the family members.

The changes in family dynamics often involve activates such as household tasks, provision of family income, and interpersonal areas such as solidarity and belonging, sexuality and love. Role changes in these areas often cause tension in the family and may place strain on individual family members (Biegel et al., 1991; Zarit & Edwards 1996 as cited in Woods, 1996).

Family systems theory (Moos & Schaeffer, 1984) talks of equilibrium in the family and how the illness of one member disrupts the established balance of equilibrium. This disruption causes conflict, resulting in stress and strain within the system until adaptations or coping responses come into effect to restore the balance. When focusing on the impact of chronic illness on the family system it is also important to consider the different types of chronic illness, identifying the commonalities and diversities between diseases and the impact upon the patient and family.

Rolland (1988) categorized chronic illness into 4 major psychosocial variables: onset, course, outcome, and degree of incapacitation. These variables are important in assessing the similarities and differences of chronic illnesses and the impact they have on the patient and family; these variables are discussed in relation to five chronic illnesses (see Table 1.1).

Onset of disease can be either gradual or acute. Myocardial infarction and stroke have acute onsets whereas Alzheimer's disease and chronic mental illness have gradual onsets, both types of onset require adjustment by the family system but with a gradual disease onset there is more time for the family to adapt, whereas in acute onset, changes and adaptation by the family have to be made rapidly. The gradual onset of a disease such as Alzheimer's can allow greater time for acceptance and adjustment on the family's behalf, but the patient's symptoms may have caused anxiety before a diagnosis was reached.

Disease course can be progressive, constant, or relapsing. Progressive diseases such as Alzheimer's disease or cancer involve increments in impairment and resulting disability over time, so there are relatively few moments where the patient, or family, are relieved from coping with the illness (Zarit & Edwards, 1992). Additional caregiving roles may constantly be undertaken in a progressive illness and the danger of exhaustion may be increased for family caregivers. Alzheimer disease patients can experience plateaus in certain impairments but at the same time experience a decline in another aspect of functioning. These changes can often be more demanding for the caregiver as their role has to be dynamic and shift with need changes (Reese, Gross, Smalley & Messer, 1994). In a stable disease, an initial event such as a myocardial infarction or stroke will occur and disabilities involving movement, speech, or cognitive functioning will be present, stabilise, and then some recovery will usually begin. The condition will often stabilise, and although there may be some relapses the course is semi-permanent. Relapsing diseases such as cancer, rheumatoid arthritis, multiple sclerosis and chronic mental illness have stable periods where disease symptoms may be low, but then phases are experienced where the condition flares up and there can be reappearance of symptoms, often with increasing intensity (Walker, Jackson & Littlejohn, 2004). In a relapsing disease, families, patients, and carers, may experience periods of rest
from the presence of symptoms but strain may be placed on the family system by the unstable nature of the disease and the uncertainty of the recurrence.

The outcome in chronic illness can be classified as fatal, shortening the life span, or nonfatal. Rolland (1988 as cited in Biegel 1991) believes that a critical factor in family adaptation is the initial expectation of whether a disease is likely to be fatal or not, since both patient and family may experience anticipatory grief and may experience feelings of wanting to be closer to the patient but also wanting to pull away in preparation for their loss. Alzheimer's disease and metastatic cancer are fatal, whereas myocardial infarction and stroke can be non-fatal, but can be life-shortening by increasing the risk of sudden death through an additional infarct. Chronic mental illness as a disease is non-fatal.

The specific problems encountered by these 5 types of chronic disease sufferers, and the subsequent care they need can be simplified as follows: in Alzheimer's disease there is cognitive impairment and the carer may take control of family finances, driving and planning of future events; in chronic mental illness there are reality disturbances and social stigma, the carer may become involved in monitoring patient symptoms and adherence to medication and they may also be responsible for liasing between physicians and the sufferer. In stroke patients, paralysis and mobility problems are common and the carer may have to help the patient with tasks such as personal hygiene and mobility. In myocardial infarction, patients may need to change their diet and exercise behaviour to avoid further attacks and strenuous activity involving household tasks or car maintenance may be taken over by the carer. In cancer patients there is usually pain and a loss of energy and general household tasks or employment are taken over by the carer; the treatment regimen in cancer may result in weakness and exhaustion and pain medication may need to be regularly administered; as in myocardial infarction and stroke the carer undertakes duties that prior to treatment the

patient would have been able to do. However, all of these diseases and their impact on patient and carer share commonalties and overlaps in the assistance required by the sufferers. Alzheimer's patients will often require physical help with mobility and personal hygiene in the latter stages of the disease, as too will cancer patients, and stroke patients may suffer some degree of cognitive impairment and need help similar to that provided for Alzheimer's patients.

The psychological and immunological demands of caregiving for Alzheimer's patients, stroke patients, and Parkinson's patients have been compared and contrasted. Reese et al., (1994) compared 25 Alzheimer's disease carers and 25 stroke patients carers to 25 noncaregiving individuals and found that overall caregivers of Alzheimer's patients were more psychologically distressed and perceived greater burden than both the stroke and noncaregiving groups but both caregiving groups were more distressed than the non-caregiving group. Immunological functioning did not differ according to caregiver status suggesting that caregiving groups reported having fewer social resources and contacts but this was most affected in the Alzheimer's group of carers. The insidious onset of Alzheimer's disease makes comparing the onset of caring more difficult as, despite both these groups being given a similar diagnosis date, the Alzheimer's carers may have been providing care from a much earlier date.

Different incapacitation patterns will result in a differential impact on patients and family members. Diseases where both cognitive and physical impairment are present may need greater change and adaptation than those diseases which only involve one type of impairment. The onset and incapacitation will also result in different effects on families. Parkinson's disease and stroke have been compared because Parkinson's disease, like

Alzheimer's disease, is insidious in nature and brings about multifaceted impairments, in contrast to stroke which has an acute onset although it can leave large residual disabilities. Hermann, Freyholdt, Fuchs and Wallesch (1997) found no major differences in the psychosocial functioning of stroke patients compared to Parkinson's patients but did find that Parkinson's patients had more severe depressive symptoms than stroke patients. Both groups of patients experienced the greatest changes in 'work, household and everyday life activities' following the onset of their illness.

Stroke patients' impairments and corresponding disabilities are at their worst at onset, requiring fast and effective changes by family members, whereas Alzheimer's disease is gradual in onset and impairment increases over time which may give families more time to adjust and plan for the future. However, the burden of caring may become greater over time (Reese et al, 1994). These differences in disease variables are to be taken into account when looking at empirical investigations into the impact of chronic illness on patients, families and caregivers. Despite the differences in the typologies of disease, there are common problems faced by families dealing with chronic illness. Family members, if they are the main carer, will have reduced social activities, deal with the societal view of someone with a chronic illness, and be aware of the change in interpersonal interactions with the sufferer (Zarit & Edwards, 1992 as cited in Woods, 1996). It is often a family member that is the main carer for a chronically ill member at home (Department of Health (DOH), Carer's Act, 1996). The basic way of conceptualising the caregiving process and its impact on an individual carer is by using models that take into account functional and behavioural limitations of the patient as independent variables, carers appraisal of the situation and the contextual factors of the caregiving situation as mediating variables, and the dependent variable being carer outcome (i.e. mental health or well-being).

# Fig 1.4 Categorization of chronic illness by Psychosocial Type

## Source; Adapted from Rolland (1988).

ONSET	Acute	Requires affective and instrumental changes in short space of time Examples: stroke, myocardial infarction.
	Gradual	
		May take longer to diagnose which may cause anxiety, however, there is more time to adjust to the situation.
		Examples: Alzheimer's disease, cancer.
COURSE	Progressiv e	Continual adaptation and change is required by carer to the declining functions of the patient. However, Alzheimer's Disease can decline in one area and improve in another, though eventually this will stop occurring.
		Examples: Alzheimer's and cancer.
	Constant	A single episode that leaves semi permanent or permanent damage and change to the individual. The course of the illness is generally stable and predictable.
		Example: stroke, myocardial infarction.
	Relapse/ Episodic.	Characterised by stable, low symptom periods followed by disease relapses where symptoms flare up. Examples: Chronic mental illness.
OUTCOME	Fatal	Will eventually lead to the death of the individual.
		Examples: Alzheimer's disease, certain types of cancer.
	Reduction in life	Can reduce the life expectancy of the individual through damage caused by the illness, or associated illnesses.
	span	Examples: myocardial infarction, stroke
	Non-fatal	Where the disease does not by itself affect the individuals physical health.
		Examples: Chronic mental illness.

## 1.7 Caregiver Burden and Strain

Caregiving in terms of providing assistance and support by one family member to another is a regular and usual part of family interactions. What differentiates normal caregiving from

caregiving involving a chronically ill or disabled member of the family is the increment in care and nature of those caregiving tasks. In this thesis caregiving refers to informal carers only, those that are unpaid carers to their relatives who have experienced a stroke (DOH, 1996). Caregiving tasks may involve providing assistance or support for many aspects of the patient's life: physical, emotional, social, and economical, which go beyond what is considered normal or usual care in a family situation. Caregiving for a chronically ill family member involves expenditure of time and energy over long periods of time and involves tasks that may be unpleasant, uncomfortable and non-reciprocal. Becoming a family carer is often not anticipated and can bring with it additional roles such as: becoming a cook, maid, nursing assistant, transportation provider, administrator of medication, supervisor of medical equipment, provider of personal hygiene, and manager of exercise, some, or all of which, could be novel roles to the family member. This type of care, and the additional roles it brings, may be considered burdensome and result in stress or strain for the carer. Carers are often studied by examining three factors: the features of the actual carers (male/female carers, child carers); or the features of the care-receiver (stroke victim, person with dementia) or the relationship between carer and care-receiver (spousal, child-parent). This thesis although focusing on carers of persons with stroke will also address the nature of the relationship and the features of the cared-for person. A central concept that is used to measure the impact of caregiving on the carer is carer burden or strain (Montgomery, 1989).

Burden or strain can mean the load or responsibilities to be carried, and the term 'strain' indicates that this load is something that has a negative impact on the individual. Burden or strain has been conceptualised in two ways: as a broad concept assessing carers' general well-being or as a concept that deals with the tasks associated with taking care of the relative, taking into account the type and number of tasks, and the time involved in these

tasks. This division over the concept of burden can be clarified further by defining objective and subjective measures of burden. It is important to note that not all caring is perceived as negative and that there are reported positive aspects to this role such as satisfaction in providing care and support for a loved one (Kinney, Stephens & Norris, 1996) although these 'satisfactions' have tended to be captured in a qualitative manner, a recent questionnaire has been developed to provide a quantitative means of assessing the positive aspects of caring as well as the negative (Orbell, Hopkins & Gillies, 1993). However, the main body of empirical work on caregiving tends to focus on the negative outcomes of caring such as psychological distress and the relationship to burden or strain.

#### 1.7.1 Objective measures of burden

Objective concepts of burden consist of measuring the objective stressors thought to be important in carer burden. Typical measures included would be summary scores of the amount of time spent caring, types of service provided, and financial resources expended on behalf of the patient by the carer. Objective measures of burden are also related to measures of patient disability and cognitive impairment. The visible impairment in behaviour or physical functioning of the patient is another objective stressor that is thought to be important in carer burden. Alzheimer's disease and chronic mental illness involve symptoms that are likely to be problematic in a social context, which may have a large impact on the socialising of the patient and carer, reducing the social network of the carer (a measure of the amount of hours spent socialising is a possible objective measure of burden). The other factors likely to impact on carer burden are the nature of the disease; the onset, course, outcome, and degree of incapacitation (as mentioned in Rolland's 1988 categorization of chronic illness as cited in Biegel et al., 1991). Measures of objective stressors may also include the level of inconvenience or discomfort that is thought to be associated with

performing specific caregiving tasks. Researchers may predetermine which tasks are considered more burdensome than others. Objective measures of burden treat caregiving tasks as meaning the same to every carer, which would be inconsistent with Lazarus's transactional model of stress (Lazarus & Folkman, 1984).

## 1.7.2 Subjective measures of burden

Subjective measures of the impact of caring involve the carer's perception of undertaking the role of carer, the inconvenience and discomfort associated with performing specific caregiving tasks, and the extent to which the carer feels that the caregiving causes strain in regard to work, social life, finances and emotional and physical status. Subjective stressors differ from objective stressors because the amount of impairment or disability of the patient is not the measure of burden, but how the carer interprets and appraises this as a stressor. There is growing evidence that the role of appraisal appears to be important in the experience of stress in carers. Orbell and Gillies (1993) analysed caring in terms of the Karasek model of job strain (1979), using the transactional model of stress (Lazarus and Folkman 1984, as cited in Orbell & Gillies, 1993), involving the appraisal of the resources and demands of a situation. Orbell and Gillies (1993) found that only at levels of high demand and low discretion was strain or burden felt, unlike in the workplace, where Karasek found that low levels of demand and discretion also resulted in job strain. The reason for the difference in findings could be that caring is not viewed as a job and, unlike in a work context, in the informal setting of caring there is no value to output and consequently there is less stress experienced. However, appraisal was found to be important in the experience of strain, with satisfaction experienced in the caring role up until the point that the carer appraised the demands as excessive. There is now a general consensus that it is not just the actual physical impairment of the patient, but the behaviour resulting from the disability and the carer's

appraisal of this (Orbell & Gillies, 1993), that causes the most strain in carers. Nolan, Grant and Ellis (1990) in a study investigating caregiver stress found that the most potent stressors, contrary to what had been previously assumed in some of the literature, were linked more to the subjective perceptions of events and circumstances of caregiving than to the objective features surrounding the caregiving. It was not necessarily the nature of the tasks that had to be carried out that could be attributed to the experience of stress but the perceived conditions under which they had to be carried out.

Research evidence points to an association between the perceived burden of the caring role and depression (Dennis, O'Rourke, Lewis, Sharpe & Warlow 1998), and an association between patient disability or impairment and emotional stress in the carer (Schulz & Beach, 1999). Schulz and Beach further conclude that "being a caregiver who is experiencing mental or emotional strain is an independent risk factor for mortality among elderly spousal caregivers". Research evidence points to significant emotional adjustment problems, physical strain, and financial problems amongst caregivers, but is relatively consistent in finding only a moderate relationship between the level of the care-receivers physical disability and resulting care-giver distress (Anderson, Linto, & Stewart -Wynne 1995, Greveson et al. 1991, Morrison, 1999) which lends support to the use of subjective measures (including appraisal) of burden or strain.

Using the transactional model of stress, different individuals will view carer tasks in differing ways; some carers may find personal hygiene tasks demanding and stressful, whereas for others cooking and cleaning may be more stressful. Harwood, Ownby, Burnett, Barker and Duara (2000) found that the role of appraisal was an important mediating variable in the carers experience of depression. Depression in the caregiver was correlated with the appraisal of the following objective measures: functional limitation of the patient;

behavioural disturbances of the patient; poorer perceived physical health of the patient; and lower levels of perceived environmental support. An interesting finding was that social support directly influenced depression with the lower the perceived support the more likely it was for the carer to experience depression.

Rapp & Chao (2000) found that positive appraisal played a buffering role by decreasing feelings of distress in the carer and this is an important finding as too often the literature concentrates on the negative aspects of caring with little attention paid to the positive aspects that caring can have (Chapter 2 will discuss this in more detail). In both these studies (Harwood et al. 2000; Rapp & Chao, 2000), as the design was cross-sectional, it is difficult to establish a causal relationship between the objective stressors, depression and appraisal. The caregiver's depression could distort their appraisal of the stressors, therefore the negative appraisals could be the result of depression.

The lack of consensus in the literature has lead to a confusing picture regarding correlates and causes of burden. What is required is consensus and consistency in the approach. Researchers now generally agree that burden is a subjective state, therefore caregivers are an appropriate source of data concerning burden. It is however important to measure both objective and subjective experiences of burden (i.e. the tasks involved such as the activities of daily living that the patient can or cannot perform and the carers appraisal of those tasks) to get the whole picture of the caring experience, and what tasks are appraised as causing burden or strain.

Although the literature has shifted the focus of burden to subjective stressors, clear distinctions need to be made between care-related problems and other influences. The carer being upset about physical decline in the patient is different from the carer being upset about

the time and effort expended to care for that relative. There are also problems with using global self report measures of carer well-being as an indicator of carer burden, as they lack the sensitivity of measures designed specifically for caregivers, and will not enable the researcher to disentangle the burden of caregiving tasks from other emotional variables. Psychiatric measures are also used as an assessment of carer burden, but models of caregiving advocate psychiatric measures as outcome measures (Montgomery, 1989), and burden or strain as a separate intervening variable impacting upon those outcomes. Measures of depression and anxiety are not viewed as measures of burden or strain but outcome measures of the carer, affected by levels of burden or strain.

Investigating carer burden involves not only the correct distinction between the types of carer stressors and how they are measured (objective and subjective) but also the inclusion of variables that mediate the impact of objective and subjective stressors.

Variables that may influence the extent to which stressors impact upon the carer are as follows: networks and support systems of carers, as it is hypothesised that the greater the social support the less likely the carer will feel isolated and burdened by caring tasks (Schwarzer & Schroeder, 1997a & 1997b); also the characteristics of the caregiver, such as socioeconomic status, health and gender; relationship to the patient (Cantor, 1983); and variables like optimism, perceived control, attitudes and appraisal of illness and caring for others (Schroeder & Schwarzer, 2001).

Longitudinal research is needed to investigate the impact of appraisal upon carer depression in order to establish causality. In the studies by Harwood et al. (2000) and Rapp et al. (2000) the patients had Alzheimer's disease, and so the carers of these patients will experience some uniquely different challenges to carers looking after other chronically ill patients (see

Rolland 1988). The following chapter discusses the research literature on stroke and caregiving in stroke, and the variables this thesis will investigate.

#### **CHAPTER 2**

## **REVIEW OF STROKE AND CAREGIVING LITERATURE**

#### 2.1 Introduction to Stroke

Differing chronic illnesses share some common features as shown in Chapter 1 but chronic neurological illnesses, such as a stroke, can cause irreversible life changes and their time frames and trajectories for recovery and rehabilitation can differ widely from other chronic illnesses. Stroke in medical terms is a cerebral vascular accident (CVA) and is defined as the sudden loss of blood supply to a region of the brain leading to permanent tissue damage (Robinson, 1998). As research has shown there are distinct differences in psychosocial outcomes and coping strategies for those patients who have experienced a stroke as opposed to patients with Parkinson's disease or other chronic illnesses (Herrmann, Freyholdt, Fuchs & Wallesch, 1997). Stroke is a major disabling neurological condition, which can impact hugely on the survivor and the family. Stroke has an acute onset and patients are suddenly entered into the sick role. Stroke is a chronic illness that is incurable, and although one third of survivors may suffer no long term disability, a third will die and two thirds will have some form of residual disability (Williams, Bruno, Rouch & Marriot, 1997; Robinson, 1998). In Britain stroke is the leading cause of physical disability (WHO, 2005). Disability can be extensive, affecting everyday tasks such as bathing, feeding, and walking. Approximately 70-80% of patients with acute stroke present with weakness or paralysis (Robinson, 1998; Williams et al. 1997). Following a stroke a high proportion of patients are discharged from hospital with continuing problems that can affect their physical, social, and emotional wellbeing (Wade, Leigh-Smith, & Langton Hewer, 1986). Residual disabilities frequently persist for long periods of time (from months to years) and can require considerable adjustment on

the part of the patient and the family (Morrison, 1999). Hafsteindottir & Grypdonck (1997) reviewed the literature on the physical and psychological outcome for stroke patients and found that stroke patients not only experienced physical changes - loss of mobility and loss of physical activity - but also experienced social and psychological changes. At the initial stages of the stroke there was extreme fear and shock at the weakness and paralysis that was experienced and this was often followed by feelings of loneliness as a result of lessened social contact with others and humiliation at the resulting disability. For stroke patients there can be a perceived and actual loss of control over their recovery. In hospital stroke patients may become dependent on physiotherapists and carers for their rehabilitation (Hafsteindottir & Grypdonck 1997). Stroke patients can often suffer setbacks on the path to recovery; fatigue can be a problem, as well as depression (Hafsteindottir & Grypdonck 1997). Residual disabilities and emotional distress frequently persist for long periods of time (Astrom, Adolfsson & Asplund, 1993). Quantitative research has tended to focus on the prevalence of depression, anxiety and disability in the stroke population whereas qualitative researchers have elucidated the phenomenon of living with a stroke from the individual's perspective. The impact a stroke has upon a person's sense of self and identity has been described phenomenologically in the articles of researchers such as Ellis-Hill & Horn (2000) and Nilsson, Jansson and Norberg (1997). The following chapter will draw upon both qualitative and quantitative research.

#### 2.1.1 Depression and anxiety post-stroke

Following a stroke, depression and anxiety have been cited as two of the most frequently associated emotional disorders (Robinson, 1998) for stroke patients and their relatives. Generalised Anxiety Disorder (GAD) post-stroke was examined across a range of 10 studies and was found to have a prevalence of between 5%-28%, and across all studies including

follow-up data as well as data from the initial evaluation, the mean prevalence of anxiety disorder was 14.4% (Robinson, 1998; page 342). The highest levels of anxiety were found in an acute hospital in 71 of the stroke patients (Astrom et al. 1996 as cited in Robinson, 1998). Lower levels of anxiety were found in community samples with a prevalence of 4-5% (House, Dennis, Mogridge, Warlow, Hawton, Jones, 1991). This difference may be due to the stage of recovery at which studies were conducted. The community studies consist of patients that have been discharged into the community when significant gains in function are likely to have been made following rehabilitation, whereas those patients hospitalised over the acute phase may still be adjusting to the impact of their stroke. The other difficulty with these studies is that some did not include the assessment of other co-morbid mood disorders such as depression and, as will be shown, depression is a far more prevalent mood disorder in stroke patients than anxiety. Factors that were found to be associated with anxiety were alcohol abuse, younger age at stroke onset and previous history of psychiatric disorder (Robinson, 1998).

It has been demonstrated that the degree of neuropsychological dysfunction and particularly aphasia can have a major impact on psychosocial functioning (Kinsella & Duffy, 1979) but the evidence for depression being associated with aphasia is unresolved as patients with severe comprehension deficits have been excluded from most studies (Robinson, 1998). The difficulty inherent in assessing the emotional outcome of stroke patients with aphasia is that it is difficult to elicit mood state through standardised self-report measures such as the Hospital and Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983). The following thesis and chapter details research that has been conducted on non-aphasic patients and their informal carers (as defined in Chapter 1).

In one of the earlier stroke studies, Wade et al. (1986) examined a community sample of

stroke patients and found that at 3 weeks post stroke 22% of patients were depressed, while another 11% were in the 'probable' range for depression. This is higher than the prevalence in the general population of 5% (Surveys of Psychiatric Morbidity, 2000). In research in rehabilitation hospitals the figures for depression are reported to be significantly greater (up to 50% as cited in Robinson 1998). In community studies of stroke patients, it would appear that depression is less common, approximately 25% of patients in the Wade et al. (1986) study were depressed following stroke. Further studies have attempted to investigate what predicts post-stroke depression.

Shulz, Tompkins and Rau, (1988) followed up 140 patient and carer dyads, interviewing them twice, at 10 weeks and then again at 6 months, to examine predictors of depression and carer burden. In this study 25% of patients were depressed at 10 weeks and 34% of patients were depressed at 6 months which suggests that the prevalence of depression increases across time. Supporting this are the findings of a three year longitudinal study assessing major depression, functional ability and social networks amongst 80 stroke patients at 3 and 12 months and again at 2 and 3 years post stroke (Astrom, Adolfsson & Asplund, 1993). In this study, the prevalence of depression in the stroke patients was as follows: 25% at the acute stage, 31% at 3 months, 16% at 12 months, 19% at 2 years and 29% at 3 years. The most important predictors of depression were found to be left anterior brain lesion, dysphasia and living alone. Dependency in activities of daily living was found to be an important predictor of depression at 3 months, and from 12 months onwards the most important predictors were found to be the patient having few social contacts outside the home and greater cerebral atrophy. This study is important, as previous research (Wade et al., 1986) has focused on shorter term outcomes (< 12 months) and the prevalence of depression appears to decrease at 12 months. The research by Astrom et al. (1993) shows that the

prevalence of depression actually increases at 3 years (16%-29%) and those patients that had not recovered from their early depression at 1 year were at a high risk of developing chronic depression. The results also highlight the important role in outcomes played by social support as those patients with fewer social contacts were found to be more likely to be depressed.

Kotila, Numminen, Waltimo and Kaste, (1998) conducted one of the larger stroke population investigations examining depression in relation to post-stroke care. They recruited 321 participants at 3 months and 390 at 12 months. The research looked at two stroke samples: one sample of stroke patients were in an active rehabilitation programme and another was in a treatment as usual. The Beck Depression Inventory was used to investigate depression in patients and their carers in the two groups and the results found that at 3 months there was a very slightly lower prevalence of depression in patients in the active program (41%) than amongst patients in the control group (42%) and these differences were maintained at 12 months. However no difference in depression prevalence in the corresponding carers was found. In addition, although it would appear that active rehabilitation resulted in a slightly lower prevalence rate of depression, the rate did not decrease further when assessed at 12 months. There was found to be no association between depression and lesion side, unlike previous research (Astrom et al.,1993).

Although the main focus has been clinical, social and demographic factors associated with depression in stroke patients, a study by Lofgren, Gustafson & Nyberg, (1999) found that depression amongst 47 stroke patients assessed 3 years after their stroke was associated with low scores on psychological well-being. The association between psychological well-being and depression was greater than that found between depression and social situation, functionality, age, gender and the need for help. However it should be noted that half of this

sample had high or middle range scores for psychological well-being and only low scores on psychological well-being were associated with depression. Therefore stroke may not cause depression directly but instead depression may be a result of low perceived well-being. The aspects of stroke that impact upon well-being may be better investigated from the individual's perspective

Oualitative research has demonstrated that the effects of stroke are not just confined to the physical and psychological outcomes of disability, depression and anxiety. Nilsson et al. (1997) found that stroke, as seen through the perspective of a developmental crisis, challenges the whole of the stroke patient's being, causing a break in their identity. Nilsson et al. (1997) interviewed patients on their experiences at 1 month and again at 2 months. The accounts spoke of stroke causing an identity crisis due to the loss of many abilities. As the hopes for a full recovery dissipate from 1 month to 2 months, those patients that had readjusted their hopes and aspirations at 2 months were found to report less depression than those patients who were unable to perceive their actual situation and clung onto their original hope of a full recovery. The loss of the self (as mentioned in Chapter 1) was found as a theme by Nilsson et al. (1997) but also in more recent qualitative research where a stroke was found to create a split between the perceived self and the physical and social self. The stroke patient had to deal with the loss of their personal and social self (Ellis-Hill & Horn, 2000). In other qualitative research physical and psychological changes have been found to occur to the stroke patient long after they have stopped becoming a patient and services have terminated. Kaufmann (1988b) found that transition for the stroke patient continues long after the six month period traditionally used as a marker for quantitative researchers and rehabilitation services.

Robinson (1998) has reviewed the literature on depression and other mood disorders in the

acute post stroke period and although many studies have shown depression to be associated with lesion location (i.e. left sided lesions; Astrom et al.,1993) depression does occur in stroke patients who have right sided lesions in both the acute and post stroke period (Robinson 1998). Factors other than lesion location may play a role in the development of major depression, for example there is mixed evidence as to the role of lesion size in predicting depression (Robinson, 1998), and factors associated with the caregiver have also been indicated.

Greater depression has been found in stroke patients who perceive their carer to help too much (Thompson, Sobolew-Shubin, Graham, Janigian, 1989). A more recent study (Newsom & Shulz 1998) of 288 spouse caregivers and their stroke patient care receivers found that when helping was perceived by the patient as under-helping, particularly when it was felt that there was a need for help, the patients had elevated tension and negative affect. Interestingly 'over' helping was not reported to have any negative effects on the patient, perhaps because the patient may still have felt in control of their situation. Perceptions of control over recovery are an important area for investigation.

#### 2.1.2 Perceived control over recovery

A cognitive factor considered to be important in the self-regulatory model (cf. Leventhal, described in Chapter 1) is perceived control. Stroke often, temporarily or permanently, results in a loss of functional independence, which can impact upon the stroke survivor's perceptions of himself/herself and the sense of autonomy and control. Perceived control over recovery, measured using the Recovery Locus of Control Scale (RLOC), has been shown to be predictive of disability levels in a sample of 71 stroke patients in a prospective 6 month study (Johnston, Morrison, MacWalter & Partridge, 1999). Those stroke patients with

greater perceived control over recovery at the initial stages of stroke had less disability at 6 months than those stroke patients who perceived they had less control over recovery. However, perceived control did not operate via coping as hypothesised and coping did not associate with physical or psychological outcomes. It therefore appears important to measure not only patient's individual goals regarding rehabilitation, but also their mental representation of whether they believe they can achieve these goals. Both these factors appear important predictors of disability, and disability is thought to be a mediating variable in the link between physical disease and depression (Morrison et al., 2000). Therefore the stroke patients' cognitions regarding control and recovery are important as well as their actual perceived level of functioning.

Due to the physical, psychological and social difficulties stroke patients face they often require physical assistance in carrying out everyday tasks, as well as ongoing emotional support. The physical changes that have taken place often impact on the social life of the stroke patient. Dependency of the patient can result in a failure to resume normal pre-stroke social activity. Successful rehabilitation and a resumption of pre-stroke Activities of Daily Living (ADL) and other social roles has been shown to be largely dependant upon the emotional and instrumental support that is received, the majority of which is provided in the community by informal carers, mainly family members (Palmer & Glass, 2003).

#### 2.1.3 Perceptions of rehabilitation

The recovery of a stroke patient can be very important to patient, carer and physiotherapist. For the patient recovery means independence and a return to the previous normal state, for the carer recovery means that he/she is less likely to be placed under excessive demands, and for the physiotherapists recovery of the patient means achieving their goal of helping the

patient return as much function as possible. Stroke patients often have personal goals that relate to improving their functional ability and returning to some of their former activities (Hafsteindottir & Grypdonck, 1997). The stroke patient has been shown to view recovery in terms of previously valued activity (Hafsteindottir & Grypdonck, 1997). Discrepancies have been found between patients and their physiotherapists in terms of patient recovery goals (Morrison & Dantanus 2000). The physiotherapist may view the patient's recovery in terms of more immediate functional goals i.e. washing, bathing, toileting, and place a high value on these, whereas the patient may regard the ability to perform tasks such as housework, shopping, and walking as more important and will often conserve energy for these tasks (Morrison & Dantanus, 2000). The discrepancies in patient and physiotherapist goals have been shown to have an adverse effect on patient adherence to rehabilitation programs, ultimately affecting the patient's recovery; although large scale research is still needed in this area (Morrison & Dantanus 2000). There is also some evidence to indicate that discrepancies in patients' and carers' thoughts and beliefs about the stroke, will also affect patient and carer outcome (Morrison, Hare & Horfield 2000). Knapp & Hewison (1999) investigated patient and carer pairs post stroke looking at discrepancies in the assessment of functional abilities pre-stroke and post-stroke. Patients were found to report significantly higher scores on the Barthel Index (a measure of functional independence in activities of daily living) than their carers, but assessments of the patient's functional independence pre-stroke did not differ from their carers. Greater discrepancies were found in more disabled patient and carer pairs. Neither patient nor carer mood, as measured by the HADS, was associated with discrepancies but the carers in discrepant pairs (where the carer rates the patient as less able) had higher carer strain scores. Carer strain has been shown to be a risk factor for poorer patient outcome and therefore discrepancies in perceptions between patients and carers on ADL is worthy of further investigation (Tompkins, Shulz & Rau, 1988).

#### 2.1.4 Family functioning

It has been shown that effective family involvement is important in helping the stroke patient to resume social activities and can result in earlier hospital discharge (Hafsteindottir & Grypdonck, 1997). Evans, Bishop, Matlock, Strananhan, (1987) studied 81 stroke patients and their families from admission to hospital and followed them up at 6 months and 1 year, assessing family functioning using a self report questionnaire. Family measures accounted for 28% of variance in a predictive model of re-hospitalisation at 1 year. Other variables such as lesion site, accounted for less than 10% of the variance. From the dimensions on the Family assessment, affective responsiveness was an important factor. Better problem solving and communication were associated with better patient adjustment and suggestions were made for interventions that used techniques that would improve communication and problem solving in families. The drawback of this study was that it relied on self report rather than observer ratings and that the cared for person's views were not elicited. In a recent review of family functioning post-stroke (Palmer & Glass, 2003) a strong argument is made for a family systems approach to stroke recovery rather than a focus on the individual.

#### 2.2 The impact of stroke caregiving

Whilst there has been a considerable amount of research on the impact of stroke on the survivor, and the cognitions associated with better outcomes (Johnston et al., 1999), there has been less prospective research looking at the effects of caring for a person surviving stroke (Han & Haley, 1999; Low, Payne & Roderick, 1999). The increase in stroke in industrialised countries across the world will have a corresponding effect on the number of people who will be required to become informal carers to these stroke patients (Audit Commission, 2004). In recent years there has been increased interest in informal carers,

those that are not paid or trained by statutory bodies but who provide care and support of a physical or emotional kind to their close family member who is experiencing illness, most commonly a spouse or parent. The important role these informal carers undertake has been highlighted in The Carer's Act (1995). Informal carers of stroke survivors are a valuable resource, without whom the burden of care placed on health and social services is estimated to be great (Palmer & Glass, 2003).

Studies have found that the rate of depression in informal carers is two and a half, to three and a half times greater than in the normal population (Shulz, Tompkins & Rau 1988). In the last 10-15 years researchers have begun to redress the balance and have started to focus on spouses who are carers, and how they cope with the caring role (Matson, 1994). Caring is generally viewed as a stressor i.e. something that is appraised by the individual as placing a demand on him/her, that requires him or her to utilise resources of an emotional, physical, financial, or social nature in order to cope (Morrison, 1999).

#### 2.2.1 Burden

Burden or strain is generally represented as a combination of objective and subjective factors as mentioned earlier (Chapter 1), although there has been differences in the interpretation of Burden as a concept. Generally Burden is perceived to be a different concept to depression or anxiety (Montgomery, 1989). Burden is often seen to be a mediator between objective task demands of caring and depression. Evidence points to an association between perceived burden or strain of the caring role and depression (Nolan & Grant, 1990), and an association between patient disability or impairment, and emotional stress in the carer (Schulz & Beach, 1999). Schulz & Beach further conclude that "being a caregiver who is experiencing mental or emotional strain is an independent risk factor for mortality among

elderly spousal caregivers". Stress Process models (Haley, Levine, Brown, Bartolucci, 1987) adapted from Lazarus & Folkman (1984), have been widely used to examine the relationships among caregiving stressors, psychosocial resources and caregiver well-being in other populations. Studies have found variables such as caregiving history, gender and socioeconomic characteristics are important predictors in caregiving appraisals (Pearlin, Mullan, Skemple, Skaff, 1990; Kane, Reimar, Penrod and Husk, 1999; Dennis et al. 1998). Kane et al. (1999) investigated 307 older people who were caring for individuals who had experienced a stroke or a hip fracture. Kane et al. (1999) found carers' difficulties and challenges were related less to specific tasks than to dealing with feelings, managing time and adjusting to caregiving. The levels of stress differed according to the length of time in the role or the individual's past experience of caring; those with past experience had less stress due to realistic appraisals of the task of caregiving.

Elmstahl, Malmberg & Annerstedt (1996) assessed carer burden three years after stroke, using a Caregiver Burden Scale. In this study they looked at what variables may be important predictors of Caregiver Burden (CB). They used three questionnaires with the stroke patient measuring: personality, quality of life and Activities of Daily Living (ADL). Their results were as follows: high CB was found with patients who had high improvements of ADL; and CB was high when carers and patients had a closer relationship, regardless of the living situation. There were negative correlations between a patients degree of extroversion and CB, and between their self-rated quality of life and CB.

Riedel, Fredman, & Langenberg (1998) measured ADL, and used open ended questions to address the difficulties and rewards of caregiving with a range of carers, examining how these factors contributed to caregiver burden. Higher levels of caregiver burden also associated with patients who had improved ADL and extroverted personality characteristics, which suggests that the increased mobility and activity of these patients may result in the need for increased vigilance on behalf of the carer. The same can be true of the relationship between extroversion in the stroke patient and carer burden. An extroverted patient may want to be involved in more social events, placing strain on the carer in terms of responsibility for involving the patient in social activities as the carer may be the sole transportation provider. These findings show how burden as a subjective concept is more effective in explaining findings such as this. Objective measures of burden would merely assess the amount of tasks and time spent on these tasks rather than the nature of the tasks. Improved activities of daily living would be expected to decrease burden from an objective perspective of burden but, as this study shows, to make such an inference would be incorrect.

Bugge, Alexander, Hagen, (1999) looked prospectively at 110 patient and carer pairs at three timepoints, 1, 3 and 6 months post stroke and the results found that caregivers spent more hours with the stroke patient over time; 13.5 hrs a day with stroke patient in 1<sup>st</sup> month, 16.6 hrs a day at 3 months and 16.4 hrs a day at 6 months. Strain increased across time and was predicted by the following factors: increased time helping, gender (i.e. if the caregiver was male), and the caregivers general health (i.e. if the caregiver's health was rated as being impaired they were more likely to experience strain). Strain increased over time and those caregivers who spent more time with patients with more severe strokes and are themselves in poorer health were at the greatest risk of strain. This research did not look at depression and the relationship between perceived strain and depression. In line with the transactional model of stress ( Lazarus & Folkman, 1984) if the caregiver perceives the task of caregiving to be causing strain then this should affect the well-being of the carer.

Reimer, Haan, Rjinders, Limburg, Bos, (1998) examined 115 partners of stroke patients at 3 years post stroke and there were higher levels of burden for those caring for partners with

greater disability. There were also greater levels of burden reported by those carers experiencing emotional distress and loneliness. There were also correlations between reported burden and the amount of informal care provided and unmet psychosocial needs and assistance in daily living. No relationship factors and no baseline as to what was going on before 3 years was recorded. It is important to know what was happening prior to the three years as other research has found that earlier depression in patients is predictive of later depression and this may be the case for stroke carers (Astrom et al., 1993).

#### 2.2.2 Depression and anxiety

Studies have found a large range of variables that, when combined, put the carer at a higher risk for depression (Draper, Roslyn & Ehrlich, 1995). These risk factors are: being a spouse; shorter length of time spent in the caring role; poorer overall self-rated health; physical disability of the patient; and behavioural and mood disturbances of the patient. Some studies have found that carers who are spouses of the patient have the highest risk of strain, and the impact is more severe than with other types of carers regardless of the physical disability or behavioural disturbances of the patient (Cantor 1983). An early study by Tompkins, Schulz & Rau (1988) followed up 140 patient and carer dyads, interviewing them twice, once at 10 weeks and then again at 6 months to examine predictors of depression and burden (burden only measured at 6 months). Depression at 6 months was predicted by age, decreased positive patient characteristics, decreased satisfaction with social contact and concern for future care at 10 weeks (explaining 23% of the variance in the regression model for depression). Income was an important factor, as carers with greater income experienced less depression at 6 months than carers with lower incomes. Additionally a decline in reciprocal relationships between patient and spouse-carer and in social contacts between 10 weeks and 6 months was predictive of higher levels of depression at 6 months. Thirty four percent of

carers and patients were depressed at 6 months and 25% of patients and carers were depressed at 10 weeks. No difference was found in carer depression that could be attributable to patients' neurological data such as site of lesion.

Other studies have found that the overall effect of the caring role is a drastic reduction in Quality of life (QOL) (Bethoux, Calmels, Gautheron, & Minaire, 1996). However, in this study the reduction of QOL did not correlate with depression. The Montgomery and Asberg depression rating scale (MADRS) was used in the Bethoux et al. (1996) study, and depression was seen as an inadequate reflection of the whole range of the spouses' psychological symptoms. In future studies it may be useful to use a measure such as the HADS, that not only measures depression but also measures anxiety. A measure of general well-being may be also be more appropriate for use with carers (Low et al., 2001). In the Bethoux et al., (1996) study, pre-existing relationship quality played an important role in the adaptation of the carer to the situation, so it may also be important to include both subjective and objective measures of the patient and carer relationship.

A study that has used the HADS was Anderson et al., (1995), this study was conducted prospectively and assessed stroke survivors' psychological outcome at onset, 4 months and 1 year post stroke and carers' psychological outcome at 1 year only. There was found to be a 44% caseness on the anxiety subscale of the HADS and 30% caseness for depression on HADS (with cut offs of 8 and above) for carers at 1 year. Carer distress arose more from patient behaviour than from physical impairment/disability and physical help with caring did not alleviate carer distress. Greveson, Gray, French & James (1997) found that 49 informal carers at 3 years post stroke reported emotional adjustment problems with 35% reporting physical strain, 25% financial problems and 30% exhibiting marked global strain as evaluated on the Caregiver Strain Index (CSI). The problem with this study is that carers will

have been in their role for 3 years and so little is known about the process that a carer may have gone through prior to these 3 years and how differing demands may be at this stage as opposed to the initial stages of stroke. There has been a lack of prospective research identifying carers early on in their caregiving. Identifying carers earlier on in their role allows examination of the differences in appraisals between and within carer groups, and whether earlier appraisals differ from later appraisals.

A study that did follow carers early on from the onset of their caring was Dennis, O'Rourke, Lewis, Sharpe & Warlow, (1998), they followed 231 stroke carers prospectively to the point of 6 months post-stroke, and using the HADS, 17% of carers were found to be depressed and 37% to be anxious. Older carers were more depressed and female carers were more anxious. Dependent activities associated with care, with the exception of dressing, did not predict carer anxiety. More recent literature (Warleby, Moller & Blomstrand, 2001) investigated spouses of first time stroke patients, and assessed carer well-being at approximately 10 days post stroke. There were 83 spouses under 75 years of age recruited and the results found no associations between carer age, sex or well-being. An open ended interview about traumatic life events, the stroke and the carers' ongoing life situation, as well as coping strategies and resources, resulted in a variable named 'view of the future'. Most carers felt decreased psychological well-being during the first phase of stroke and were worried about the future and it was this variable, worry for the future, that was associated with carer well-being. The carers' cognitive appraisal of their future life situation and coping capacity was important in their well-being. According to Lazarus & Folkman (1984), the cognitive activity of appraising a situation precedes the emotional response to a situation and the subsequent cognitive activity is affected by emotions. Uncertainty about the future in these carers had a negative impact on their well-being and concern about future care. Half of the carers felt they lacked information on the consequences of stroke.

One of the most recent studies on caregiving has taken a long term approach to studying caregiving, examining prospectively the caregiving experience over three years (White, Mayo, Hanley, Wood-Dauphinee, 2003). As incomplete recovery occurs in a about a third of stroke cases, caregiving is likely to continue indefinitely and it may take longer for a chronic stressor such as caregiving to affect carers' well-being. In this study (White et al., 2003) 97 patient and carer dyads were recruited and physical health, health related quality of life and burden were the dependant variables. In this sample the majority of the carers were women. Women caregivers were found to be the most affected by caregiving although male caregivers also scored below the norm on mental health. Women reported that there was not enough time for self, other responsibilities and that caregiving was impacting upon family relationships. Caregivers as a group scored on average 10 points lower on mental functioning compared to controls. There was little change in the mental health of caregivers over time and as in the previous study (Anderson et al., 1995) worry about the future was cited by carers but appeared independent of the stroke survivor's disability.

Evidence from the above studies appears to find that caregivers who report multiple difficulties have higher levels of stress, and carers who have reported social and emotional difficulties are more likely to experience burden. Reidel et al., (1998) found perceived carer burden and stress were lower in caregivers who only reported physical or financial difficulties. In this study relationship quality was correlated with rewards, the better the reported relationship quality, the more rewards they perceived caring to have, which is significant, as rewards modified the association between social and emotional difficulties and Caregiver Burden. However, in this study 40% of the carers reported no difficulties and this may reflect problems encountered in recruitment. Recruitment could have been biased, as those carers experiencing high levels of burden may not participate, as has been found in

other studies (Orbell & Gillies, 1991). Or, it may be the case that the perception of caring is biased by negativity on the part of the researcher, and that caring may not have as many costs as is believed. The inclusion of questions relating to positive aspects of the caring role will be beneficial to researchers in examining the role of rewards in modifying the association of caring to distress. Inclusion of neutral questions or questions addressing positive aspects of the caring role will also enable carers to talk about the positive experiences of caring, as well as the negative.

#### 2.2.3 Positive aspects of caring

Despite the focus on the negative aspects of caring in the literature seen so far, caring has different effects on different people and not all caring is perceived as bad or a burden or strain. Despite the focus on negative outcomes for carers such as depression, anxiety and morbidity, it is important to note that not all caring is perceived as negative and some studies have shown that there are positive aspects to this role. Carers have reported a sense of fulfilment, improved interpersonal relationships, and perceptions of 'togetherness' arising from the caregiving role (Kinney, Stephens & Norris, 1995). In the Kinney et al., (1995) study it was also found that behavioural and cognitive 'hassles' ( i.e. challenging behaviour, reminding the care-receiver to take medication) significantly predicted carer depression. Further research needs to address the issue of how caring is perceived by caregivers over time and incorporate not only measures of physical disability and carer tasks, but also the appraisals of caregiving and the caregiving-receiving relationship. Measures that allow both positive and negative appraisals will be important in providing a fuller picture of the caregiving role. Caregivers appraisals have been found to influence not only their own psychological well-being but also the care-receiver (Shroder & Shwarzer, 2000; Thomspon et.al., 2001).

Clearly there are varied responses and perceptions of the caring role by the carers themselves, but there are also differing responses to the care role by the recipient. In a study of 55 married couples, of which one had suffered a stroke, an association was found between patient perceptions of the care, and patient well-being, (Clark & Stephens 1996). Patient depression correlated with perceiving carer actions as unhelpful (Clark & Stephens, 1996) and patients having a positive affective state correlated with perceiving carer actions as helpful. It was found that the most helpful form of support was 'matched' support where the carer provided support specific to the stress being experienced. Other studies have found greater depression in stroke families where the family member is perceived to help too much (Thompson, Sobolew-Shubin, Graham, & Janigian, 1989). Discrepancies in perceptions of the nature and level of care required by the carer and care recipient would appear to be problematic and distressing for both parties, and has been found in other chronic illnesses such as cancer (Gurowka & Lightman 1995).

#### 2.3 Relationship between patients and carers

The relative most closely affected by a stroke may be the spouse, as they are living with the person who has experienced the stroke, will have shared finances and responsibilities and may also have shared dreams and hopes for their future. (Cantor, 1983). There is evidence that negative social interactions in intimate relationships can lead to depression (Shuster, Kessler, & Aseltine 1990). The Marital Intimacy Scale (Waring & Reddon, 1983) measures the past (pre-illness) and present (post-illness) levels of intimacy in a couple, and was developed for use with clinical populations. A lack of intimacy has been found in a couple where one or both spouses is suffering from a non-psychotic emotional illness (depression/anxiety), (Patton & Waring, 1984). Marital intimacy has also been shown to correlate with the mental health of spouses who are caregivers for dementia sufferers

(Morris, Morris & Britton, 1988). Carers who experienced a greater loss of intimacy from the past to the present had a higher level of depression, but reported no increase in perceived strain. Carers who reported lower levels of past intimacy and present intimacy were found to experience higher levels of depression and perceived strain. Morris et al., (1988) speculated that a poor pre-morbid relationship made caregiving more stressful because of the greater difficulty in performing the caregiving role. Research on communication and interpersonal factors on Alzheimer's patients, and their carers, is a growing area of knowledge that can be drawn upon for directions in research on stroke patients and their carers (Clare and Shakespeare, 2004).

As mentioned previously, there is evidence in the literature on caregiving that the behaviour of the patient is a better predictor of carer distress than the level of physical disability (Anderson et al 1995; Greveson et al., 1991; Morrison, 1999). Other studies have looked at the relationship of the caregiver to the carer, and found that the closer the relationship to the carer, the greater the perceived burden (Cantor, 1983), whereas other studies have found the reverse to be true (Zarit, Reever, & Bach-Peterson, 1980). Research on carers and patients and their relationship has been conducted in the belief that the more communicative and supportive the patient and carer perceives the relationship to be, the less stressed and troubled the caregiver (and patient) may feel.

The relationship and interaction between patient and carer may be important in determining the carer and care-recipient's well-being. Studies have examined carers of the elderly in Sydney, Australia (Broe , Jorm, Creasey, Casey, Bennet, Cullen, Edelbrock, Waite, & Grayson, 2000) and found the quality of the relationship fundamental in determining carer distress. Broe et al., (2000) found the main determinant of carer distress was a relationship in which the carer felt controlled by the elderly person (i.e. the carer feels that their life is dominated by the elderly person they are caring for). However this study was not focused on stroke victims, and carers of stroke victims often face unique challenges regarding the communication difficulties and mobility problems of the patient. Further exploration of relationship issues with stroke survivors and their informal carers is required because of the growing prevalence of stroke in an increasingly elderly population in Britain (Stroke Association, 2003).

In the past researchers have attempted to capture the subjective components of the caregiving experience and how it relates to psychological outcome by using questionnaire measures of psychological outcomes such as burden, (Zarit et al., 1980), strain (Cantor, 1983) and depression (Harwood et al., 2000). However, the inconsistency of findings in the literature on patient-carer relationships and the impact the relationship has on carer and patient outcome forces researchers to look closely at the dyadic interactions that take place. Questionnaire measures of relationship quality may be inadequate to capture relationship quality of patients and carers for a variety of reasons such as social desirability, carers may feel inhibited about reporting relationship difficulties to an outside agency. Loyalty may affect carers responses as the carer may feel guilty for betraying the person they are caring for by complaining about them. Cognitive dissonance may be experienced by the carer if they are expending time, effort and money on the care receiver but they admit that the relationship is poor. In this situation the carer could be left in a state of cognitive dissonance asking themselves 'why am I doing this ?'. In depth qualitative approaches where the carer is made to feel at ease and allowed to openly discuss problems may be suitable for this type of relationship research. Objective measures of relationship quality using observational techniques may also be an area for further research.

There is an apparent lack of research utilising combined qualitative and quantitative

techniques for the purpose of disentangling the interpersonal interactions in the caring relationship. Only a few studies have utilised a qualitative approach, and even fewer have looked at the interpersonal factors involved in caregiving (Hasselkus 1988; Pistrang, Clare & Barker, 1999). Hasselkus (1988) made an ethnographic investigation into caring and examined the interpersonal factors involved in the culture of caring, finding five main themes in the sense of self: managing, future, a fear of risk, and a changing role. A strong theme of tension was also found in the analysis. There was tension between the caregiver and health professional, and tension between the caregiver and other family members.

There has also been little research conducted into interaction and communication using observational techniques. Pistrang, Clare and Barker (1999) used a single case study to illustrate communication patterns between a husband and wife, where the husband had recently suffered a myocardial infarction, investigating help-intended communication in the couple. The limitations of this research are the fact that this was only a single case study not permitting generalisation, and that it used Brief Structured Recall (a psychotherapy intervention), therefore the findings are more applicable to clinical practice than informing researchers about the general characteristics present in carers and their partners. Although these qualitative studies lack generalisability, they can contribute to a deeper understanding of the carer's daily struggles and successes, and their relationship with the patient. Studies like Pistrang et al. (1999) help inform quantitative researchers of important areas of investigation, that may be present in the wider population of carers and patients. A study that captures the unique qualities of the caregiver and care-receiver relationship in stroke patients, using an approach that can be generalised, seems to be something that is urgently needed. Research conducted on populations other than stroke will be reviewed as there is a scarcity of research on relationship and interaction in stroke carer-care-receiver dyads.

#### 2.3.1 Family functioning and interaction

One of the first studies to observe family functioning in families where a member was caring for a person with Alzheimer's was Shields (1992). Poorer patient functioning was predicted by negative family affect toward patient and negative responses were predictive of poor marital satisfaction. Families of more depressed caregivers responded with more sadness when the caregiver experienced negative affect and responded with more anger when the caregiver expressed empathy and positive affect. Interactions between patients and carers in other populations have been investigated using qualitative analysis (Gurowka, & Lightman 1995), and by videotaping: in Alzheimer's (Niederhe 1990); alcoholics (Jacob &Leonard, 1992); and in training programs with formal carers (i.e. doctors and nurses) aimed at intervention (Kihlgren, Hallgren, Norberg, & Karlsson 1996). There have also been investigations into what support is perceived as helpful and unhelpful in a range of patients: cancer patients (Gurowaka & Lightman 1995); HIV patients (Ingram, Jones, Fass, Neidig, & Song 1999); and studies that have identified helpful and unhelpful behaviours of the social support networks of AIDS patients (Hays, Magee, & Chauncey, 1994).

There is evidence in the Alzheimer literature that there is a breakdown of communication skills between a PWD (person with dementia) and their caregivers (Kitwood, 1997). Caregivers' experience of stress has been attributed to this breakdown in communication and loss of intimacy with their partner (Morris et al., 1988; Kitwood, 1997). There appears to be inconsistency in the approach used to examine communication upon caregiver stress and this is partly due to the complex behavioural and conversational cues that make empirical observations problematic. Kitwood (1997) describes that a maintenance of self is important in the PWD and that this could be what is undermined in the interactions between persons with dementia or other illnesses and their carers, but few studies have looked at interaction and communication styles in stroke patients.

Attachment theory (Bowlby, 1969) states that following a threat an individual will seek proximity to other attachment figures. Stroke represents a threat to attachment in the sense that the person may die. In those cases where there has been a threat people will seek proximity to their partner and those individuals with secure attachment will be more successful in gaining and maintaining proximity and more aware of their own and partner's emotional needs. Those with insecure or avoidant attachment styles are more vulnerable to emotional difficulties during crises or periods of distress. Shields, Travis & Rousseau (2000) studied 28 cancer couples and 22 controls and found that greater security of attachment in wives associated with greater marital satisfaction for both husband and wives and greater perceived health for wives, but a securely attached husband when caring for his wife with cancer was found to be associated with poorer adjustment for wives to their illness, higher depressive symptoms and lower perceived health. These findings may fit in with the literature on women's "ethic of care" (Gilligan, 1982). When men have to take on the role of caring they or their wives may have poorer outcomes due to their lack of socialization into this role. Caregivers that have a poorer pre-morbid relationship with the care-receiver are also more likely to exhibit over-involvement and under-involvement of caring which is analogous to the constructs of enmeshment and disengagement found in the family systems literature and the literature on attachment. Observational methods that have examined styles of caregiving have been scarce but recently interest has grown in observational methods in dementia research.

Work by Gallagher –Thompson, Canto Dal, Darnley, Basilio, Whelan, & Jacob (1997) have shown that it is possible to systematically and meaningfully videotape interactions between Alzheimer patients and their carers. In the Gallagher-Thompson (1997) study they used the Marital Interaction Coding System (MICS) to analyse the interactions of Alzheimer patients and their carers on two tasks: a planning task and a mealtime task. In this study the Alzheimer's patient and their carer were filmed in their own home. Gallagher-Thompson et al. (1997) found the following results: a positive correlation between the amount of upset felt by the caregiver to the patients behavioural disturbances, and the number of negative responses made to the patient; the more expressive the interactions between patient and carer, the more likely they were to be negative; and the more depressed the caregiver was, the less likely they were to give positive comments. There was a significant correlation between the level of conflict in the marriage, and the frequency of positive codes observed in the wife (the carer) during the observations. This observational research needs to be replicated to investigate its efficacy for capturing patient-carer interaction.

A recent study in University College, London (UCL) used a set of scales to objectively measure interactions between mothers who had dementia and their daughters (carer) (Chisholm, 2000). The research was based on attachment theory (Bowlby, 1969) and was aimed at examining the relationship between mothers and adult daughters who are now their mother's carers. The research involved videotaping the dyadic interactions between mother and daughter at several time-points. The observed interactions correlated with validated questionnaire measures of stress and dementia ratings. Daughters that were stressed were more likely to be judged, as a dyad, to have lower overall communication quality, indicating criterion validity of the observational scales. This observational approach produced detailed, useful information, and may be modified for other chronic illnesses, such as stroke patients and their carers, in order to better capture relationship dynamics. The coding system designed by Chisholm (2000) and used in the mother and daughter study, is thought to be suitable for use with stroke patients and carers, as the main concepts of the coding system are measuring aspects of communication involved in a dyad consisting of a patient and a carer.
In stroke populations, to the best of the researcher's knowledge, only one published piece of research on stroke carers has used observational techniques to examine interaction. This study (Thompson, Galbraith, Thomas, Swan & Vrungos, 2002) investigated the link between the caregiver's interaction style and the care receiver's feelings of overprotection. The study used 4 tasks (videotaped) to look at overprotective care on behalf of the carer and its determinants using self report measures of feelings of overprotection, physical and mental functioning and caregiving related attitudes. Carer resentment was found to mediate the relationship between overprotection and overcontrolling caregiving styles. There were correlations between perceptions of underbenefit in the relationship by caregivers and overprotective ratings by patients. Pre-morbid relationship quality has been found to be under researched in a recent review of research on stroke informal caregivers (Low et al., 2001). In the review it was suggested that resentment on behalf of the carer may stem from pre-stroke relationship quality. Overprotection is seen to have a negative effect upon the receiver and also the caregivers who tend to be more distressed and resentful. Pre and postmorbid marital and relationship functioning would appear to be an important factor in distress in carers and patients and is worthy of further investigation.

# 2.3.2 Deficits in the caregiving literature

Han and Haley (1999) reviewed the stroke caregiving literature in relation to carer wellbeing,, examining 20 articles. Their review consolidated some of the findings in the literature outlined, which demonstrated that across studies caregivers had elevated levels of depression at both the acute phase and chronic phase compared to norms and comparison controls. During their review they identified deficiencies within the literature on caregiver samples. Recruitment was biased with caregivers past history and stroke survivors pre-morbid psychiatric history not being taken into account in recruitment. Often stroke patients who also had dementia were included in studies raising questions about disentangling the effects of stroke from other conditions.

Han and Haley (1999) also found only five studies which were longitudinal in design, the majority being cross-sectional, addressing only associations between variables but failing to make predictive analyses implicated in well-being. Another difficulty cited was the term burden, which was used as an outcome measure in six out of the twenty studies but was measured in each study using a different self report measure. The transferability of burden measures to non-caregivers is not possible and so makes comparisons of the outcomes of caregivers' appraisals to non-caregiving controls difficult; measures such as the HADS which has been developed to be used with a normal and also elderly population (Zigmond & Snaith, 1987) would enable levels of depression and anxiety to be compared to the noncaregiving populations. The HADS has been found to perform well in assessing the symptoms, severity and caseness of anxiety disorders and depression in a range of patients, both psychiatric and somatic, and has shown consistent alpha levels ranging between .67 and .93 across 747 research papers (Bjelland, Dahl, Haug and Neikelmann, 2002). Han & Haley (1999) report a tendency in the articles reviewed to pay little attention to the length of time post stroke as a factor in carer well-being. The impact of caregiving, as shown in previous research, is likely to be affected differently over time, due to the coping, adaptation and differing needs of the stroke patients across time. Five out of the twenty studies failed to state the mean interval time post stroke, making comparisons between studies difficult. The studies in this thesis will attempt to ensure that some of the methodological issues are considered, such as explicitly stating time post stroke, using a generic measure of depression and anxiety such as the HADS, excluding those stroke patients who have physical and psychiatric co-morbidity and attempting to recruit as many caregiver and care receiver dyads prospectively as possible.

## 2.4 Summary

As the empirical evidence has been referred to above, a brief descriptive overview of the chapter will be presented. Depression and anxiety are common features amongst individuals experiencing a stroke or caring for a stroke survivor. Studies have found variable rates in depression and anxiety but research suggests that it is important to examine psychological well-being across time. Appraisals of burden or strain would also appear to be important in influencing carer well-being. Positive aspects of caregiving or positive appraisals of caring would appear to have a protective aspect against negative psychological outcomes such as depression and anxiety. The level of disability appears to have a relationship to both patient and carer psychological well-being, as the more severe the stroke the greater the likelihood of the patient developing depression, though evidence for carer well-being and the association with objective levels of patient disability is more mixed. Discrepancies in perceptions and cognitions regarding disability, recovery and rehabilitation would appear to be problematic in patient and carer pairs and may lead to carer strain. In various illness populations, spouses in caregiving and care-receiving dyads appear to experience greater levels of depression and anxiety compared to other kin relationship dyads. The level of carer distress is often dependant upon the nature and quality of the relationship and style of interaction between patient and carer pre- and post- illness onset, similar findings may be important to investigate in stroke populations. Interaction and communication appear to be important influences in family functioning and psychological well-being in both patients and carers in various illness populations and in a recent stroke study.

Using a mixed methodological approach utilising both qualitative and quantitative analysis this thesis will examine the impact stroke has upon the survivor and the carer. The studies will examine depression and anxiety in patients and carers across time examining any discrepancies in perceptions of disability, control and marital intimacy. The thesis will also include a measure of both positive and negative aspects of caregiving including strain and satisfaction measures and their relationship to carer depression and anxiety.

# **CHAPTER 3**

# STUDY 1: THE PSYCHOLOGICAL WELL-BEING OF STROKE PATIENTS AND THEIR CARERS AT ONE, THREE, AND SIX MONTHS POST STROKE.

### **3.1 Introduction**

Rolland (1988) categorized chronic illnesses into 4 major illness variables: onset, course, outcome, and degree of incapacitation. These variables are thought to be important in assessing the similarities and differences of chronic illness and the impact they have on the patient and family. Stroke, unlike dementia or cancer, has a sudden onset and in the acute phase will require an immediate response and adjustment by family members or spouses. Thus the acute phase maybe a particularly difficult time for those relatives who are left with the impact of the stroke and the responsibility for caring for their loved one (Payne & Ellis-Hill, 2001). Depression rates have been observed to be high in both stroke patient and carer populations, almost half of a sample of 321 stroke patients and 195 caregivers were depressed post stroke (Kotila et al., 1998). Patients who have persisting physical impairment as a result of the stroke (i.e. hemiplegia) are more likely to be depressed than those without impairment following stroke onset. The likelihood of patients with residual disabilities being depressed at one year is higher than those without disability at one year (Wade et al., 1986). Over time, as there may be some spontaneous recovery or rehabilitation, there may be differing demands upon the caregiver; the potential stresses and strains of the caring role may vary depending on the stage the care-receiver is in their caregiving (White et al., 2003). Studies have found that the rate of depression in stroke carers is two and a half, to three and a half times greater than in the normal population (Han & Haley, 1999; Shulz, et.al., 1988) and that spousal carers, as opposed to other informal kin carers, are the carers that perceive the greatest burden or strain (Cantor, 1983; Bugge et. al., 1999). Research evidence points to significant emotional adjustment problems, physical strain, and financial problems amongst stroke caregivers, but is relatively consistent in finding only a moderate relationship between the level of the care-receivers' physical disability and resulting care-giver distress (Anderson et al., 1995; Greveson et al., 1999; Morrison et. al., 1999; Waleby et. al, 2001). Other studies have failed to find an association between patient disability and carer depression and therefore other factors may be important to examine (King et al., 2001). The nature and extent of disability a stroke can cause varies greatly as too does the potential for physical recovery, both these factors often depending on a range of variables such as the location of the stroke, whether it was an infarct or bleed and how timely was professional treatment (Williams et al., 1997). Psychological recovery from stroke has been shown to be partly dependent on the nature of care-received (Evans et. al., 1987; Thompson et. al., 1989) and also the level of disability (Dennis et. al, 1998). The nature and extent of disability, following a stroke, has been shown to be more strongly associated with psychological wellbeing in patients rather than other clinical indicators such as lateralisation (Kotila et al., 1998). Functional disability in terms of activities of daily living (ADL) is often measured as an indicator of the potential objective caregiver burden.

## 3.1.1 Carer psychological well-being

The term caregiver burden is derived from research that has attempted to quantify the nature of the caregiving experience. Terms such as 'carer burden' have an implied negativity and research has generally followed in examining negative outcomes of caring such as depression and anxiety. In the literature the term "carer burden" has been used to describe the objective and subjective "costs of caring" (Morrison, 1999). George and Gwyther (1986, p.253) defined caregiver burden as "the physical, psychological or emotional, social and

financial problems that can be experienced by family members caring for impaired older adults". Objective measures of burden often look at the level of disability and care that has to be provided to the care-receiver by the caregiver, most often in terms of activities of daily living (ADL). Research has shown an association between patient disability and emotional distress (e.g. anxiety and depression) in caregivers (Shulz & Beach, 1999). However other research has found only a moderate relationship between the level of physical disability and caregiver distress (Anderson et. al, 1995, Greveson et al., 1991, Morrison, 1999). In line with the transactional model of stress (Lazarus & Folkman, 1984) evidence shows that the care-receiver's appraisal of the level of care rather than the objective level of physical disability influences caregiver burden or strain (Orbell & Gillies, 1993; Dennis et. al., 1998; Harwood et al., 2000; Rapp & Chao, 2000)

### 3.1.2 Social support and well-being

Patients' psychological well-being has been shown to be affected by the level of disability that the stroke causes in the acute phase but this relationship diminishes over time (Tuomilheto et al., 1995; Astrom et al., 1993). Research has also shown that the level of distress a stroke patient and carer experience is also dependent upon age, gender and social support (as seen in Chapter 2). Social support has been measured in many ways from a simple summation of how much support is available to detailed scales assessing all forms of social support (Schwarzer & Schroeder, 1997a) and evidence is strong for social support being a good predictor of psychological well-being across time following a health threat or stressful life event (Schwarzer & Schroeder, 1997a and b; Brown et al., 1987). In this study the emphasis is on the support provided in the dyads as the patient's informal carer can be perceived to be the most important source of support they will experience. Likewise in an intimate relationship such as a marriage, carers may still perceive their partner to be their

most important source of support (Coyne, 2001). Many studies as, outlined in Chapter 2, have merely assessed marital status or measured the amount of social support (i.e. hours, etc) failing to examine the quality of this support or the relationship with those providing the support (Brown et al., 1987). The quality versus quantity distinction is clearly important, as research shows that relationship quality can be predictive of psychological distress in normal populations and those facing a health threat (Schuster et al., 1990; Shields et al., 2000). In this study relationship quality will be measured by both a Marital Intimacy questionnaire for those patients and carers who are married, and a carer relationship satisfaction scale for those unmarried/non-couple patient and carer dyads.

# 3.1.3 Discrepant perceptions between patients and carers

Discrepancies in perceptions of the level of disability that a patient has can lead to misperceptions in the perceived level of care required by the carer and care recipient . If patients perceive themselves to be more disabled than their carers, they may expect more 'help' and if it is not received this may lead to distress (Knapp & Hewison, 1999; Clark & Stephens, 1996). Discrepancies in perceptions regarding the nature and level of care required can be problematic and distressing for both care-givers and receivers as it has been found to be associated with overprotective caring styles (when carers perceive greater disability than their patients), depression in carers and a lack of physical activity in patients (Gurowka & Lightman, 1995; Clark& Stephens, 1996; Thompson et al; 1999; Knapp & Hewison, 1999).Therefore it is important to measure both patients' and their carers' perceptions about their level of disability and control over recovery.

Perceived internal control over recovery from a stroke was found to be related to physical outcome at 6 months in a sample of 72 stroke patients (Johnston et. al., 1999). As recovery

74

locus of control (RLOC) has been shown to be correlated with physical well-being (Johnston et. al., 1999) it will be examined in this study in relation to the psychological wellbeing of patients. Carers' perceptions of patients' control over recovery will also be measured to assess whether proxy ratings of control over recovery will associate with patient or carer well-being.

### 3.1.4 Time-line and carer well-being

This study is interested in measuring not just the level of disability patients have but the factors that affect caregivers' appraisal of their caregiving role and how these appraisals then associate with psychological well-being (depression and anxiety). It is thought important to look at all of the aforementioned factors according to length of time post stroke as the demands placed upon caregivers and care-receivers may change over time and time is a variable often neglected in carer research (Han & Haley, 1999). As mentioned previously, stroke is acute in onset and not necessarily fatal with the potential for recovery or stabilisation; most recovery taking place in the first six months after the acute period (Robinson, 1998). It is therefore important to look at differences taking place during this period of time (acute to six months) in terms of physical, emotional and interpersonal relationships between patients and carers. This information could provide important information for carer and patient targeted interventions aimed at reducing the 'costs' or 'burden' of caring and therefore at the same time promoting quality care for the carereceivers. Using the terminology of the transactional model of stress (Lazarus & Folkman, 1984), the primary stressors are seen as the stroke's impact in terms of disability and the resulting care that this entails. The primary appraisals of whether the stroke is a stressor are thought to be affected by relationship, gender, past experience and age (as found in the past literature). The primary appraisals are made up of whether stroke is a stressor and the

secondary appraisals of whether they have the resources to deal with the stressor will be affected simultaneously by how carers perceive this has impacted upon their life. Dependant upon these primary and secondary appraisals will be psychological well-being as measured by anxiety and depression.

#### 3.2 Aims of the study

- To identify: a) patients' and carers' perceptions of patient physical functioning and control over recovery b) To assess whether perceptions of control and physical functioning vary according to length of time post stroke and demographic data.
- To identify whether there are a) significant differences between stroke patients and caregivers in their experiences of anxiety and depression b) to examine whether there are differences in anxiety and depression depending on length of time post stroke and demographic data.
- To examine associations between carer depression and anxiety, and levels of disability, control, and care giving appraisals.
- 4. To examine specific dyadic pairs to capture quantitatively their experiences of living with stroke across time.

# 3.3 Method

The design of the study was originally prospective but was later changed to a cross-sectional cohort design. The change in design was due to low recruitment rates resulting from changes in hospital procedures and a failure to gain access to patients from another hospital site. Patient and carer dyads were recruited and interviewed at three time-points, the first interview, in the acute phase, being up to 5 weeks post stroke and following admission to hospital and then at 12 and 24 weeks post stroke. These time-points were chosen to correspond with previous research that has looked at psychological outcome at 12 and 24

weeks post stroke (e.g. Anderson et al 1995, Morrison et al., 2000).

### 3.3.1 Participants

For the acute cohort there were 18 patients (10 male and 8 female) and 20 carers, (6 male and 14 female). The mean age of patients was 76.33 (SD= 8.27, range 63-97) and for carers it was 61.30 (SD =12.67, range 25-77). The carers were made up of 10 spouses, 9 adult children and 1 cousin. In total 14 carers were married and 4 were single. Eight carers had previous caregiving experience ranging from 6 months to 12 years. Twelve carers were unemployed or retired and 8 were employed. All the patients were retired or unemployed prior to the stroke.

For the 12 week cohort there were 13 patients (9 male and 4 female) and 16 carers, (4 male and 12 female). The mean age of patients was 72.31 (SD = 9.45, range 57-86) and for carers it was 58 (SD= 12.61, range 25-77). 10 of the carers were spouses and 6 were adult children. Of the carers, 9 were unemployed or retired, 7 were employed and as before, all patients were retired or unemployed prior to the stroke.

For the 24 week cohort there were 18 patients, 10 male and 8 female, and 19 carers, 7 male and 12 female. The mean age of patients was 74.61 (SD = 8.27, range 57-97) and for carers it was 59.35 (SD= 14.64, range 25-77). Twelve of the carers were partners or spouses 6 were children and 1 was a cousin. Of the carers the 11 partners were unemployed, and the other seven were employed.

# 3.3.2 Procedure

Both North West Wales NHS Trust Research Ethics Committee and the School of Psychology, University of Wales, Bangor Ethics Committee granted ethical approval before

any data collection began. Recruitment was carried out in conjunction with the hospital's stroke team with the permission of the current Stroke Consultant. Recruitment took place between July 2001 and September 2002.

### 3.3.3 Recruitment Phase 1

Potential participants were contacted within 2 weeks of being admitted to the hospital and were provided with an information sheet detailing the aims of the study. Mostly patients were contacted first, as they were the most accessible, with permission sought to contact carers. However this did cause difficulties, as if patients were reluctant to take part it was then not possible to approach the carers. Ward recruitment also proved difficult with frequent changes in staff and changes in ward placement for the patients. These changes often resulted in repeated explanations of the purpose of the research and reason for the researcher's presence on each ward. The timing of recruitment and the interview would also clash with other activities such as lunch, ward rounds, visiting hours and often physiotherapy, which made it difficult to get the hour required to interview the patient. The difficulties in tracking patients resulted in the recruitment being conducted post discharge through postal recruitment.

### 3.3.4 Recruitment Phase 2

Postal recruitment involved gaining consent from the Stroke Team to access the addresses of the patients and their main caregivers (if different) and to be able to use them. Recruitment involved once a week attendance at Stroke team meetings, gaining information on who to exclude and who had been discharged, then sending a letter to recruit both the stroke patient and their main caregiver. If a reply had not been received after two weeks then a phone call was made or, for those without a telephone, a further prompt letter was sent. If after the reminder phone call consent was still not received then they were considered as not wishing to take part in the research. This method of recruitment resulted in a lessened likelihood of consent and a greater rate of non-replies than face-to- face interviews (face-to-face recruitment= 40% consent; postal recruitment= 25% consent).

Both methods of recruitment, bedside and postal, consisted of the same procedure once consent had been given. If willing to take part, an interview was arranged with the carerecipient and the caregiver was approached with the information sheet. All participants provided written consent before interview. The scales were administered in a large battery by structured interview. If patient and caregiver interviews took place at the same time they were performed separately from each other to ensure that responses would remain in complete confidence, and to avoid any approval effects. Acute interviews (up to 5 weeks) mainly took place in the hospital, most 12 week interviews and all 24 week interviews took place in the participants' homes.

During the recruitment period, 242 patients were referred to the stroke team and of those 98 were eligible to take part in the study. The change in recruitment style meant that less disabled stroke patients were more likely to be recruited as they had been discharged earlier. Reasons for recruitment exclusion were as follows:

- Patients deemed unfit to approach on advice of stroke team (26). Three of these cases were subarachnoid haemorrhages and as specified in ICD-10 this is classified separately from Stroke/CVA (168-ICD-10)
- 2. Death of patient (33)
- 3. No identifiable family or caregiver (21)
- 4. Cerebrovascular accident (stroke) unconfirmed (9)

- 5. After care to be in nursing home (17)
- 6. Patients whose residence was outside catchment area (e.g., tourists) (5)
- 7. Pre-stroke psychiatric problems identified in the medical notes by researcher (4)
- 8. Non stroke admission. Patient was admitted for other medical problems of which the stroke was secondary: i.e. Cancer, Chronic Obstructive Pulmonary Disease (COPD), (29)

Of the remaining 98 potential participants who were approached, 22 patients and 25 carers gave consent to take part at either one, two or all three time points. This gives an overall low recruitment rate (22.45%). This recruitment breaks down into 18 patients and 20 carers at the acute phase, 13 patients and 16 carers at 12 weeks and 18 patients and 20 carers at 24 weeks. Only 8 patient and carer dyads took part at all three time points. The 18 patients and 20 carers at 24 weeks are not the same 18 patients and 20 carers that took part at the acute phase (n= 10). The 8 prospective dyads' results are included in the overall results. The low levels of recruitment and lack of retention to the study has made a prospective statistical analysis of dyadic data impossible, but descriptive statistics will be used to examine the variables across time in the sample of 8 (section two).

Of the 73 patient and carers that did not give consent, analysis of the reasons for refusal to take part in the study by eligible patients were as follows:

- 1. Caregiver being too busy (11)
- 2. Patients denying access to contact their relatives (37)
- No contact established with either patient or carer due to incorrect address or no reply after second attempt to contact (23)
- 4. Interviews unavailable in Welsh (2).

80

In addition to the 73 patient and carer pairs that said 'no' an additional 3 patients, whose carers did consent, were unable to complete the questionnaire at the time of interview due to deterioration in their condition. Therefore only 22 patients as opposed to 25 were included in the study; as the carers of the excluded patients still wished to take part they were not excluded.

Potential participants were provided with an information sheet detailing the aims of the study. If willing to take part, an interview was arranged with the patient and care-giver. All participants provided written consent before the interview. The scales were administered in a large battery by structured interview.

### 3.3.5 Measures

Stroke patients and their carers completed a battery of questionnaires including demographic questions (see Appendix 3 and 4) and the following questionnaires: modified Barthel Index (Mahoney & Barthel, 1965), Recovery Locus of Control Scale (Partridge & Johnston, 1989) and Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1989). Additionally carers completed the Carer Impact Appraisal Scale (Orbell, Hopkins & Gillies, 1993) and those dyads that were comprised of spouses were administered the Marital Intimacy Questionnaire (Waring & Reddon, 1983) These measures (apart from Marital Intimacy) have been used successfully in previous studies involving stroke populations (e.g. Anderson et al., 1995, Morrison et al., 2000) and were therefore chosen to allow comparison to other findings.

# Patient disability

Mahoney and Barthel (1965) designed The Barthel Index of Activities of Daily Living, which is a well-validated self-assessment measure of general disability. It has been used previously in many studies of stroke patients (e.g., Bugge et al., 1999), though not previously for caregiver proxy ratings as far as can be determined. The scale has ten items (e.g., 'Can you walk on level surfaces?'), each with between two and four possible responses on a Likert scale of independence; the higher the score, the better the functional independence. The original Barthel scoring is out of 100 with a total score of 100 representing functional independence, though not necessarily normality. In this study an extra question was added 'How is your speech' or for a caregiver version "Can [patient name] speak normally' with a choice of three responses: normal, some difficulties, severe difficulties. With the additional question, it brings the Barthel score to a total of 120. Cronbach's alpha is reported in Table 3.1.

# Recovery Locus of Control

Designed by Partridge and Johnston (1989), the Recovery Locus of Control scale (RLOC) was used as it is the only locus of control scale to have been shown to have validity in a recovery-based situation. The scale has been used previously with stroke patients (e.g., Johnston et al.,1999), though not previously for proxy ratings as far as can be determined. The scale has nine items, five measuring internal locus of control cognitions and four measuring external and chance locus of control cognitions. The items are scored from one to five on a Likert scale, with the scores for the external items reversed before summation to give a total score reflecting level of internal representation (scores range from 5-45). Items were modified to determine the caregivers' patient-wise control cognitions (e.g., 'How [patient name] manages in the future depends on himself and not what other people can do for him') rather than the caregivers' beliefs about their own level of control over the care-recipient's recovery. Cronbach's alphas are reported in Table 3.1

# Anxiety and Depression

The Hospital Anxiety and Depression Scale (HADS) is a 14-item scale containing two equal subscales measuring either anxiety or depression. Zigmond and Snaith (1983) designed the scale, and it has since been well validated in different populations (Aylard, Gooding, McKenna, and Snaith, 1987), including stroke patients (Morrison et al., 2000) and stroke caregivers (Anderson et al., 1995). A review of the HADS found it to perform well in assessing anxiety and depression in somatic populations as well as psychiatric and primary care patients (Bjelland, Dahl, Haug, Neckelmann, 2002). Participants are asked to rate how much they agree with statements about themselves (e.g. for anxiety, 'I feel tense or wound up' and for depression, 'I have lost interest in my appearance'), with responses rated on a Likert scale from 0 to 3, the higher score indicating a worse state. On each subscale, the highest possible score is 21; a score of 0-7 indicates a non-case individual, 8-10 indicates a possible clinical disorder, and 11-21 indicates a probable clinical disorder. See Table 3.1 for Cronbach's alpha.

# Caring Impact Appraisal Questionnaire

The Caring Impact Appraisal Scale was derived from attempts to measure the subjective impact of caring, including both positive and negative appraisals (Orbell, et al., 1993). The 32 item questionnaire consists of four main factors: care work strain, care work satisfaction, relationship satisfaction and carer lifestyle satisfaction. Participants rate on a 7 point scale the extent of their agreement with the 24 statements. An example of a care work strain item is "caring means less energy than normal" and an example of a care work satisfaction item is "caring makes life better organised". An example of a lifestyle satisfaction item is "caring makes someone feel valued" and an example of an item for relationship satisfaction is

"caring makes me closer to the person I am caring for". High scores indicate greater perceived strain or satisfaction on a measure: care work strain (13-91); care work satisfaction (5-42); care lifestyle satisfaction (6-35), relationship satisfaction (5-45). See Table 3.1 for Cronbach's alpha.

### Marital Intimacy Questionnaire

The Marital Intimacy Questionnaire was specifically developed for use with elderly spousal caregivers (Patton & Waring 1984). There are 30 statements covering facets of intimacy, namely affection, cohesion, expressiveness, compatibility, conflict resolution, sexuality, autonomy and identity. The statements are rated on a 4 point scale to assess how much participants agree or disagree with each statement. Participants, both patients and carers, are asked to think of the relationship before and after the stroke. This study focuses only on the present intimacy rating. The higher the score the more intimate the relationship is perceived to be. The maximum score is 120 and the minimum score is 0.

#### **3.4 Analysis**

The data was screened for normality using Q-Q plots and only two sets of data violated the assumption of equal variances at a significant level (patients' disability ratings at 12 and 24 weeks). Patients' disability ratings at 12 and 24 weeks were subjected to a Levene's t-test. Independent sample t-tests were employed with all other variables to determine any differences in anxiety, depression, recovery locus of control, disability and perceived care-recipient disability between patients and carers at the three time-points (acute, 12 weeks, 24 weeks). Within each cohort, the above variables were also examined to determine whether there were any differences in caregivers' appraisals based on gender, relationship to care-recipient, or previous experience of caring.

Correlations were also performed within each cohort on all of the above variables to determine the relationships between all of the variables at each point in time. Between subject analysis of variance could not be computed on the data due to the violation of the assumption of independence as some patients and carers contributed scores to all the data points. Not all patients and carers contributed to every timepoint so a repeated measure analysis of variance could also not be computed. Separate t-tests are thought to be more suitable to this data set due to the increased robustness of t-tests in comparison to analysis of variance's F when there are unequal variances and low sample sizes. A second stage of analysis was performed on the data and this involved isolating the 8 couples that took part across all time points and includes descriptive prospective data on the 8 case studies.

	ALPHA									
CALE	Acute	Acute	12 wks	12 wks	24 wks	24 wks				
SCALE	Patient	Carer	Patient	Carer	Patient	Carer				
Barthel	.74	.94	.95	.95	.67	.91				
Anxiety	.81	.68	.89	.82	.93	.84				
Depression	.52	.77	.72	.80	.80	.84				
RLOC	.75	.07	.61	.78	.80	.73				
Marital Intimacy	.79	.75	.90	.85	.95	.86				
Work satisfaction	N/A	.84	N/A	.74	N/A	.77				
Work strain	N/A	.90	N/A	.95	N/A	.95				
Lifestyle satisfaction	N/A	.75	N/A	.76	N/A	.77				
Relationship satisfaction	N.A	.68	N/A	.95	N/A	.88				

Table 3.1: Reliability of scales.

#### 3.5 Cross sectional cohorts results

# Carer and patient differences

Overall across all time points patients were scoring highly on functional independence of activities of daily living (ADL) as measured by the Barthel and this was highest in the 24 week cohort (112.22). The Barthel appears to exhibit a ceiling effect in this study.

The mean scores for anxiety and depression show that patients and carers were not in the clinical range for anxiety or depression at any of the time-points though carer anxiety was in the borderline range (8.45). From the results in Table 3.2, it can be seen that at the acute stage carers were more anxious than patients (t=-3.25 (36), p<.05) but there was no difference in depression. There was no significant difference between patients and carers in depression or anxiety at 12 weeks or 24 weeks, but the means for carer anxiety are higher than patients at both 12 and 24 weeks (although not significantly). If just the means are examined in relation to the sample then the picture is misleading. Examining the frequencies of scores reaching 8 and above (borderline for suspected clinical significance) on the separate HADS scales for anxiety and depression it can be seen that: 16% of patients were anxious at the acute and 12 week cohort with an increase to 22% at 24 weeks; in terms of depression, 22% of patients were depressed in the acute cohort, 15.38% at 12 weeks and 33% at 24 weeks. Using the same criteria and cut off point of 8 and above for carers it can be seen that 55% of carers were anxious in the acute cohort, 37% at 12 weeks and 45% at 24 weeks. In terms of depression, 25% of carers were depressed in the acute cohort, 18.75% at 12 weeks and 30% at 24 weeks. Overall there are more anxious carers at all the time-points than patients and there are more probable cases of depressed carers in the acute cohort than patients. Lower numbers of patients and carers are depressed and anxious in the 12 week cohort compared to the acute and 24 week cohorts.

### Discrepancies in disability and control

Across all cohorts carers' proxy ratings indicated that they were caring for significantly more disabled patients than patients' ratings would suggest (t = 13.19, (36), p<.05; t = 4.32, (27), p<.05; t = 6.57, (36), p<.05). Control is significantly different at 12 and 24 weeks with patients rating themselves as having more control over their recovery than carers (t = 2.84, (27), p<.05; t = 2.10, (36), p<.05). Those carers and patients that were in a married relationship were assessed on an additional measure, Marital intimacy, and there were no significant differences found between patients and their carers at the acute (t = 1.48, df, 17, p>.05), 12 week (t = 1.06, df, 15, p>.05) or 24 week (t = 1.68, df, 9, p>.05) timepoints. There were no other significant differences found.

# Gender differences in patients and carers.

Table 3.3 and 3.4 show the variable means according to gender. Female patients perceived their disability as significantly higher than males' (t=2.73, (16), p<.05) in the acute cohort. Patients who were female were significantly more depressed at 12 weeks than male patients (t=-2.40,(11), p=<.05), there were no other differences in anxiety or depression for patients according to gender at the acute or 24 week cohort. There were no other gender differences in perceived disability at 12 or 24 weeks. No gender differences were found to be significant in carers' experiences of anxiety or depression (see Table 3.4). No other gender differences were found with any other variables.

		Patien	t	Carer				
	Max	M	SD	М	SD	t	df	p
Acute Cohort								
N=18 patients: $N=20$ carers								
Barthel*	120	111.6	11.11	87.25	36.11	13.19	36	.00*
Anxiety	21	4.39	4.13	8.45	3.56	-3.25	36	.00*
Depression	21	5.83	3.40	4.45	3.56	1.22	36	.23
RLOC*	35	34.05	6.69	31.70	3.58	1.37	36	.18
Marital Intimacy	120	88.00	13.39	80.10	9.71	1.48	17	.15
12 Week Cohort								
N= 13 patients: N=16 carers								
Barthel*	120	105.77	30.77	86.56	42.65	4.32	27	.05*
Anxiety	21	4.85	5.58	6.06	3.78	70	27	.48
Depression	21	3.31	2.72	3.75	3.57	37	27	.72
RLOC	35	38.31	4.11	31.87	7.25	2.84	27	.01*
Marital Intimacy	120	90.10	14.56	81.71	18.30	1.05	15	.30
24 Week Cohort								
N = 18 patients: $N = 20$ carers								
Barthel*	120	112.22	2 10.87	93.75	27.09	6.57	36	.02*
Anxiety	21	4.83	5.13	7.60	4.84	-1.71	36	.09
Depression	21	6.38	4.24	5.15	3.92	.93	36	.35
RLOC	35	36.39	6.02	32.40	5.67	2.10	36	.04*
Marital Intimacy	120	95.81	12.12	84.45	18.95	1.68	9	.11
* Homogeneity of variances violated; Levene's t-test used								

# Table 3.2: Means of variables for patients and carers (cross-sectional)

\*=p<.05

		Male		Femal	e			
	Max	М	SD	М	SD	t	df	р
Acute Cohort N= 10 male: N=8 female								
Barthel*	120	117.50	3.54	104.37	13.21	2.73	16	.02*
Anxiety	21	3.30	3.09	5.75	5.03	-1.27	16	.22
Depression	21	4.90	2.81	7.00	3.89	-1.33	16	.20
RLOC*	35	34.30	5.77	33.75	8.12	.17	16	.87
<b>12 Week Cohort</b> <i>N= 9 male: N= 4 female</i>								
Barthel*	120	105.00	35.79	107.50	18.93	13	11	.89
Anxiety*	21	3.00	2.81	9.00	8.29	-2.00	11	.24
Depression*	21	2.56	1.51	7.00	3.56	-2.40	11	.04
RLOC	35	38.11	4.46	38.75	3.77	25	11	.80
<b>24 Week Cohort</b> N = 10 male: N= 8 female								
Barthel*	120	114.44	7.26	110.00	13.69	.86	16	.40
Anxiety	21	3.78	5.19	5.89	5.15	87	16	.40
Depression	21	5.89	4.34	6.89	4.34	49	16	.63
RLOC * Homogeneity of variances violated; Levene's t-test used	35	36.33	4.72	36.44	7.40	04	16	.97

# Table 3.3: Patient means on variables according to gender

\*=p<.05

		Male		Female	e			
	Max	М	SD	М	SD	t	df	p
Acute Cohort								
N= 6 male: 14 female								
Barthel*	120	81.67	32.19	89.64	38.55	44	18	.66
Anxiety	21	8.83	2.99	8.28	3.87	.31	18	.76
Depression	21	4.67	2.16	4.36	4.08	.17	18	.86
RLOC*	35	31.83	3.25	31.64	3.83	.11	18	.92
Work Satisfaction	42	26.33	2.80	27.14	8.47	32	18	.75
Work Strain	91	45.67	14.65	41.64	19.31	.45	18	.65
Lifestyle Satisfaction	35	20.50	4.84	17.64	8.14	.97	18	.35
Relationship Satisfaction	45	44.00	6.32	40.50	6.86	1.11	18	.29
12 Week Cohort								
N=4 male: $N=12$ female								
Barthel*	120	82.50	47.87	87.91	42.98	21	14	.83
Anxiety*	21	6.00	.82	6.08	4.40	.95	14	.95
Depression	21	2.75	1.50	4.08	4.03	96	14	.35
RLOC	35	36.25	5.37	30.42	7.38	1.44	14	.17
Work Satisfaction	42	29.25	6.07	25.08	12.50	.63	14	.54
Work Strain	91	43.25	16.89	41.75	23.08	.12	14	.90
Lifestyle Satisfaction	35	20.00	3.92	22.67	7.47	67	14	.51
Relationship Satisfaction	45	35.75	6.70	40.91	7.63	-1.20	14	.25
24 Week Cohort								
N=7 male: $N=12$ female								
Barthel*	120	98.57	15.47	89.17	32.53	.71	17	.48
Anxiety	21	7.86	5.18	8.00	4.65	06	17	.95
Depression	21	5.00	3.91	5.67	3.93	36	17	.72
RLOC	35	34.71	4.19	31.25	6.37	1.28	17	.22
Work Satisfaction	42	30.86	7.84	23.83	9.46	1.65	17	.12
Work Strain	91	39.71	17.57	41.67	23.65	19	17	.85
Lifestyle Satisfaction	35	22.28	3.45	19.08	8.04	.99	17	.33
Relationship Satisfaction	45	38.86	10.10	34.83	8.98	.90	17	.38

# Table 3.4: Carer means on variables according to gender

\*=p<.05

### Carer variables across the cohorts

As there were small numbers and not all carers took part at all three timepoints a descriptive approach will be used in examining the scores. Across the cohorts (see Table 3.5) it appears that there is no variation in work satisfaction but work strain is greater in the acute cohort than at 12 weeks or 24 weeks and, at the same time, relationship satisfaction is greater in the acute cohort than at 24 weeks, with lifestyle satisfaction greater at 12 weeks than in the acute or 24 week cohort.

Carer Impact Appraisal Scale	Acute	(N=18)	12 Week	s (N=13)	24 Weeks (N= 18)		
Max scores ()	М	SD	М	SD	М	SD	
Work satisfaction (42)	26.90	7.16	26.13	11.20	26.90	9.35	
Work strain (91)	42.85	17.76	42.13	21.18	39.55	21.48	
Lifestyle satisfaction (35)	18.50	7.30	22.00	6.74	20.05	6.67	
Relationship satisfaction (45)	41.55	6.74	39.63	7.55	36.95	9.53	

Table 3.5: Means for Carer Impact Appraisal Scale (cross-sectional).

From Table 3.6, it can be seen that there are significant differences between caregivers with previous experience. Those caregivers with experience of caregiving have less anxiety in the acute cohort than those caregivers new to the role. A past history of caregiving has no effect on the other variables at 12 or 24 weeks. The only other significant difference is that of perceived control, with those carers with past experience rating patients as having more control over their recovery at 24 weeks. There were no gender differences found in carer variables in any of the cohorts however, there were significant differences found according to the nature of the relationship between caregivers and their patients (for the purposes of analysis the caregivers were divided into partners or adult children excluding the one cousin (Table 3.7)). There was significantly more work strain at the acute stage (M=55.62, t=-2.72,

df (16), <.05) and 24 weeks (M= 59.67, t=-2.80, (15), p<.05) in child caregivers than spouses. The increased work strain in the acute cohort may in part be explained by the significant difference in Barthel scores with child caregivers giving significantly lower scores than spousal caregivers (M= 70.62, t= 2.33, (16), p<.05), indicating that adult child caregivers perceive the care-recipient to be more disabled hence explaining why they perceive more strain than spousal caregivers. However, there was also significantly more relationship satisfaction perceived by the child caregivers than spouses at 24 weeks (M=42.83, t= -2.69, (15), p<.05).

# Table 3.6: Carers' anxiety, depression, control and caring appraisal in relation to past

								and the second second
		no		yes				
	Max	М	SD	М	SD	t	df	р
Acute Cohort $N=12$ no: $N=8$ yes								
Barthel*	120	75.83	36.04	104.37	30.64	-1.84	18	.08
Anxiety	21	9.83	3.29	6.37	3.02	2.37	18	.03*
Depression	21	5.42	2.94	3.00	4.11	1.54	18	.14
RLOC*	35	31.91	2.87	31.37	4.65	.32	18	.75
Work satisfaction	42	26.83	4.76	27.00	10.17	05	18	.96
Work strain	91	45.83	14.79	38.37	21.76	. 92	18	.37
Lifestyle satisfaction	35	19.17	5.64	17.50	9.63	.49	18	.63
Relationship satisfaction	45	40.58	7.06	43.00	6.40	78	18	.45
12 Week Cohort N= 11 no: N=5yes								
Barthel*	120	75.63	47.24	97.5	37.32	-1.03	14	.32
Anxiety	21	6.62	3.99	5.50	3.74	.58	14	.57
Depression	21	4.25	4.27	3.25	2.91	.55	14	.59
RLOC	35	29.12	5.27	34.62	8.21	-1.59	14	.13
Work satisfaction	42	27.25	9.21	25.00	13.46	.39	14	.70
Work strain	91	43.62	23.19	40.62	20.44	.27	14	.78
Lifestyle satisfaction	35	22.62	5.47	21.37	8.16	.36	14	.72
Relationship satisfaction	45	41.12	5.16	38.12	9.51	.78	14	.45
<b>24 Week Cohort</b> N=11 no: N= 9 yes								
Barthel*	120	80.90	27.82	109.44	16.48	-2.71	18	.01*
Anxiety	21	7.90	5.22	7.22	4.60	.31	18	.76.
Depression	21	6.09	4.35	4.00	3.20	1.20	18	.24
RLOC	35	30.09	5.81	35.22	4.23	-2.21	18	.04*
Work satisfaction	42	26.18	8.19	27.77	11.04	37	18	.71
Work strain	91	37.81	20.72	40.22	19.11	27	18	.79
Lifestyle satisfaction	35	18.81	3.99	21.55	9.00	91	18	.37
Relationship satisfaction	45	38.27	12.23	35.33	4.82	.68	18	.50

# caregiving experience (cross-sectional).

# Table 3.7: Carers' anxiety, depression, control and caring appraisal in relation to type

# of carer.

		Spous	e (Sp)	Adult (AC)	Chil	d		
	Max	М	SD	М	SD	t	df	р
Acute Cohort N= 10 Sp: N= 9 AC								
Barthel*	120	105.00	16.57	70.62	43.79	2.13	17	.03*
Anxiety	21	8.00	4.05	9.62	3.07	94	17	.36
Depression	21	4.70	4.22	5.00	2.73	17	17	.86
RLOC*	35	31.60	4.14	31.62	2.61	01	17	.98
Work satisfaction	42	28.50	9.03	26.62	3.50	.55	17	.59
Work strain	91	37.90	16.04	55.62	10.08	2.72	17	.01*
Lifestyle satisfaction	35	18.30	8.50	19.75	5.77	41	17	.68
Relationship satisfaction	45	40.20	7.89	42.00	5.61	54	17	.59
12 Week Cohort N= 10 Sp: N= AC	6							
Barthel*	120	98.50	33.50	66.67	51.74	1.51	14	.15
Anxiety	21	6.50	4.09	5.33	3.45	.58	14	.57
Depression	21	3.70	3.19	3.83	4.45	07	14	.94
RLOC	35	33.10	7.98	29.83	5.91	.87	14	.40
Work satisfaction	42	26.40	13.11	25.67	8.16	.12	14	.90
Work strain	91	37.80	19.50	49.33	23.68	-1.06	14	.31
Lifestyle satisfaction	35	22.90	8.22	20.50	3.21	.68	14	.51
Relationship satisfaction	45	38.40	8.43	41.67	5.92	83	14	.42
24 Week Cohort N= 12 Sp: N= - 4C	6							
Barthel*	120	102.27	17.37	80.00	38.47	1.67	16	.12
Anxiety	21	8.64	5.54	6.83	3.87	.70	16	.49
Depression	21	5.54	3.58	6.50	4.32	49	16	.63
RLOC	35	34.27	3.98	29.50	7.55	1.73	16	.10
Work satisfaction	42	27.36	9.89	22.50	6.97	1.06	16	.30
Work strain	91	35.18	18.90	59.67	12.37	-2.84	16	.01*
Lifestyle satisfaction	35	21.09	8.28	17.67	3.44	.96	16	.35
Relationship satisfaction	45	32.09	7.66	42.83	8.30	-2.69	16	.02*

# Correlations in the acute cohort (see Table 3.8)

# Carer-carer

Carer depression and anxiety scores were significantly positively correlated. Carers' work strain was positively correlated with anxiety and depression (i.e. greater strain is associated with higher levels of depression and anxiety). Proxy ratings of patients' control and work satisfaction appraisals were significantly positively correlated; the greater perceived control over recovery the patient had, the higher the level of care work satisfaction. Work satisfaction and lifestyle satisfaction were significantly positively correlated; carers who were satisfied with care work were also satisfied with their lifestyle.

#### Patient-carer

Patients' anxiety was negatively correlated with carers' ratings of disability; as the carer perceives the patient to be more independent the patient's anxiety decreases.

# Patient-patient

Patient depression and anxiety were positively correlated. Patients perceived recovery control and anxiety were significantly negatively correlated. As patients' perceived recovery over control decreases the patients' anxiety increases. Patient disability and anxiety were significantly negatively correlated so patients less functionally able had increased anxiety.

# Correlations in the 12 week cohort (see Table 3.9)

# Carer-carer

There were significant negative correlations between work strain and carer's proxy disability

ratings and work satisfaction. Life satisfaction was significantly positively correlated with work satisfaction and negatively correlated with work strain. Relationship satisfaction was significantly negatively correlated with work strain; the greater the level of perceived strain the lower the level of relationship satisfaction.

### Patient-carer

Patients' disability ratings were negatively correlated with care work strain; those patients who reported to be less independent had carers with increased strain. Carer's perceived patient control over recovery and work satisfaction were significantly negatively correlated as carers who perceived their patients to have control were less satisfied.

### Carer-patient

Patients' anxiety and depression were not associated with any variables. There was a positive correlation between carer disability ratings and depression, which appears to be a counter-intuitive finding, as the patient, was perceived to become more independent carers depression increased.

### Patient-Patient

There were no significant correlations with patients' anxiety and depression.

## Correlations at 24 weeks (see Table 3.10)

### Carer-carer

Carers' ratings of perceived patient recovery control were negatively correlated with carers' depression, so as patients were perceived to be more in control over their recovery

depression decreased. Carers' ratings of disability were also positively correlated with control; as independence increased so did perceptions of control. Work satisfaction was positively correlated with ratings of disability, and work strain was positively correlated with depression and negatively correlated with work satisfaction. Lifestyle satisfaction and work satisfaction were positively correlated.

## Carer-patient

There were no significant correlations with patient depression but there were significant positive correlations with patient anxiety and work and lifestyle satisfaction Carers with increased carer lifestyle satisfaction and work satisfaction had patients with increased anxiety.

### Patient-patient

There was a negative correlation with patient disability and patient anxiety as Barthel scores decreased (disability increased) patients anxiety scores increased.

# Correlations across the cohorts.

By examining the tables (3.8-3.10) it can be seen that there were similarities in the pattern of correlations across the cohorts. Carer and patient disability ratings were positively correlated across all time points. There were significant positive correlations between work satisfaction and control at the acute phase and 24 weeks post stroke. There were negative correlations between carer control and depression at 12 and 24 weeks. Carers' proxy ratings of disability were positively correlated with depression at 12 weeks so as disability is lessened and ratings on the Barthel increase carers are more likely to be depressed. However this is reversed in the 24 week cohort, with disability being negatively correlated with depression. As ratings increase on the Barthel the carers are less depressed at 24 weeks. Positive correlations with work strain and carer depression were found at all time points. Positive correlations between work satisfaction and lifestyle satisfaction were found at all time points. Negative correlations were found between work strain and work satisfaction in the 12 and 24 week cohorts. Carer depression and anxiety were positively correlated at the acute phase and at 12 weeks. Patients' disability and anxiety had a significant negative correlation at the acute phase so patients were less anxious if they were more independent.

	1	2	3	4	5	6	7	8	9	10	11
1 Anxiety (c)				39122 911-3233 INSA							
2 Depression (c)	.805**										
3 Control (c)	047	195									
4 Barthel (c)	377	168	.298								
5Work satisfaction	368	386	.466*	.343							
6 Work strain	.451*	.510*	.027	161	161						
7 Life satisfaction	232	296	.539*	.091	.735**	054					
8 Relat satisfaction	022	190	113	016	022	191	.028				
9 Anxiety (p)	.338	060	.004	590*	.034	.204	.034	139			
10 Depression (p)	.368	040	.125	367	.174	.234	.326	294	.650*		
11 Control (p)	140	.033	.268	.460	170	159	203	.068	636*	.033	
12 Barthel (p)	331	101	.170	.846**	.018	454	146	211	546*	366	.449

(c) = carer variables and (p) = patient variables: N= 20 carers; N= 18 patients: \*= p<.05 \*\*= p<.001

	1	2	3	4	5	6	7	8	9	10	11
1 Anxiety (c)											
2 Depression (c)	.826**										
3 Control (c)	277	550*									
4 Barthel (c)	426	.825**	.037								
5Work satisfaction	467	526*	.222	.338							
6 Work strain	.447	.559*	037	507*	573*						
7 Life satisfaction	253	244	064	.370	.592*	694*					
8 Relat satisfaction	286	063	253	.150	.246	506*	.298				
9 Anxiety (p)	088	099	.391	110	254	.195	261	194			
10 Depression (p)	262	045	292	.034	045	.088	058	.010	.338		
11 Control (p)	247	182	.256	.038	.038	395	.016	.401	.333	.089	
12 Barthel (p)	363	179	430	.966**	.434	586*	.520	.506	070	.134	.219

(c) = carer variables and (p) = patient variables; N= 16 carers: N= 13 patients: \*= p < .05 \*\*= p < .001

	1	2	3	4	5	6	7	8	9	10	11
1 Anxiety (c)						993 - 1991 (P. 1989) 1993 - 1995 (P. 1997)					
2 Depression (c)	.185										
3 Control (c)	163	495*									
4 Barthel (c)	331	543	.677**								
5 Work satisfaction	206	295	.436	.470*							
6 Work strain	085	.467*	178	386	436*						
7 Life satisfaction	.058	044	.187	.058	.665**	264					
8 Relat satisfaction	260	081	206	211	.008	.214	95				
9 Anxiety (p)	.017	.185	.080	170	.520*	059	.513*	204			
10 Depression (p)	216	.355	039	317	.120	.196	.247	346	.378		
11 Control (p)	.175	139	.232	.315	.109	361	.035	.018	125	262	
12 Barthel (p)	.051	230	.043	.597*	.042	324	121	577*	230	230	.498*

Table 3.10. Intercorrelations between patient and carer variables at 24 weeks.

(C) = carer variables and (p) = patient variable; N= 16 carers: N= 13 patients: \*= p<.05 \*\*= p<.001

# 3.6 Results for the prospective sample

Eight dyads took part at all three time points and a descriptive results section with some basic analysis will be provided. A summary of the age, gender, employment and relationship between patients and their informal caregivers can be found in Table 3.11. Table 3.12 presents the means for the patients and carers across time on all the key variables and independent t-tests have been used to examine any differences between patients and carers in each of the cohorts. To differentiate between the prospective and previous cross-sectional results the timepoints in this results section are labelled as acute, 3 and 6 months. The graphs that follow have been created to examine dyads across time on the following measures: disability (Figure: 3.1), anxiety (Figure: 3.2), depression (Figure: 3.3), control (Figure: 3.4) and the caring appraisals (Figures: 3.5-3.8). Comparisons between patients and carers within individual dyads are shown graphically. These give an understanding at the micro level of the changes in variables across time in patient and caregiver dyads. Due to the low numbers of cases per variable bivariate correlations were not calculated with this subset due to the risk of Type I errors (Cramer, 1998).

	Dyad 1:	Dyad 2	Dyad3:	Dyad 4:	Dyad 5:	Dyad 6:	Dyad 7:	Dyad 8:
Patient Age: Gender:	86 yrs Male	63 yrs Male	79 yrs Male	79 yrs Male	83 yrs Female	63 yrs Male	69 yrs Male	81yrs Male
Employment:	Retired Lecturer	Retired Concrete Laver	Retired Vet	Retired Guide	Retired Pharmacy	Retired Newsagent	Retired Engineer	Retired Farmer
Carer Age: Gender: Employment:	57 yrs Male Lecturer	52 yrs Female Care Worker	69 yrs Female Retired Teacher	74 yrs Female Retired Scientist	52 yrs Female Book keeper	64 yrs Female Retired Newsagent	59 yrs Female Care Worker	72 yrs Female Retired Shop Owner
Nature of Relation	Adult Child	Spouse	Spouse	Spouse	Adult Child	Spouse	Spouse	Spouse

Table 3.11. Table indicating the background information of patient and carer dyads
In this group the majority of the dyads were spousal and within these married couples patients and carers were retired. All patients were retired but those caregivers that were adult children were still employed. This may fit back in with the results of the cross sectional sample where the adult children had increased levels of anxiety and work strain. The adult child caregivers were younger and caring for the oldest patients in this group. The previous occupations of the stroke patients were a mixture of professional, manual and self-employed. The carers had a mixture of semi-skilled and professional backgrounds. The most striking aspect of this table is that the majority of patients were male with the exception of one female and the majority of carers were female with the exception of one male. This sample, although small, fits with the general trend found in stroke populations, with males experiencing an increased risk of stroke and females more likely to be caregivers (Lee, 2001).

#### Patient and Carer Differences

From examining Table 3.12, it can be seen that overall the patients scored highly on the Barthel and were able to be fairly independent. The mean scores for anxiety and depression indicated that as a group neither patients nor the carers were clinically depressed or anxious. Both patients and carers perceived a high degree of control over the recovery from the stroke. The only significant difference between patients and carers was at 3 months when carers perceived patients to have less control over recovery than patients themselves perceived (t= 2.25, (14), p<.05). Overall there were high levels of marital satisfaction (max score=120) in those couples that were married with no differences between patients and carers.

		Patient		Carer				
	Max	M	SD	М	SD	t	df	p
Acute N= 8 patients: N= 8 carers								
Barthel*	120	117.50	3.78	113.75	10.67	.94	14	.36
Anxiety	21	3.12	3.14	2.87	2.99	.16	14	.87
Depression	21	4.00	2.67	3.25	3.37	.49	14	.63
RLOC*	45	34.37	6.32	31.37	4.50	1.09	14	.29
Marital Intimacy	120	92.83	8.45	84.50	7.76	1.78	10	.10
3 months N= 8 patients: N= 8 carers								
Barthel*	120	115.63	4.17	111.25	5 10.60	1.09	14	.29
Anxiety	21	2.87	2.99	5.12	4.36	-1.20	14	.25
Depression	21	3.12	1.36	3.15	3.68	.29	14	.90
RLOC	45	38.50	4.47	31.87	7.04	2.25	14	.04*
Marital Intimacy	120	88.50	9.89	84.50	21.75	.40	10	.69
6 months N= 8 patients: N= 8 carers								
Barthel*	120	115.62	2 6.78	111.87	7 8.84	.95	14	.36
Anxiety	21	4.13	5.54	6.87	5.03	-1.04	14	.316
Depression	21	4.75	3.24	4.12	3.09	.39	14	.69
RLOC	45	35.75	5.99	34.00	4.54	.66	14	.52
Marital Intimacy	120	93.167	9.065	88.67	15.45	.62	10	.55
* Homogeneity of variances violated; Levene's t-test used								

# Table 3.12: Means of variables for patients and carers (prospective)

\*=p<.05

Figure 3.1: Disability scores of Patients and Carers across Time



Figure 3.1 demonstrates the ceiling effect that the Barthel Index appeared to have when used with a population with low levels of disability. Figure 3.1 shows no change in perceived disability across time for dyads 1 and 8. Dyads 6 and 7 show a decrease in disability at three months that returns to the initial level at six months; the carer in dyad 6 reported less independence than the patient at all the time points. In dyad 5 the carer perceived the disability to have decreased at six months whereas the patient perceived it to have increased. Dyads 2 and 4 perceived an increase in disability at six months as independence levels are perceived to have dropped. Although ratings were similar between patient and carer in dyad 2 at six months and the acute phase the carer rated independence as higher. In Dyad 3 patient and carer demonstrated similar ratings at the time-points but the pattern was different, with the carer perceiving independence to steadily increase across time and the patient perceiving a drop in independence at three months. Dyad 6 had the biggest discrepancy in ratings with the carer rating the patient as less independent at all timepoints. Referring back to Table 3.12, there appears to be no set pattern as to which patient will be most disabled, with the oldest patients and youngest patients rating themselves as very similar (Dyad 1 and Dyad 6).

There was also no set pattern as to which caregiver (spouse or adult child) would have the biggest difference in ratings with their patients. Both spouses and adult children demonstrated congruent and incongruent ratings.



Figure 3.2: Depression scores of Patients and Carer across Time

Examining Figure 3.2 it can be seen that depression over time was variable between dyads with three dyads reporting decreased depression from the acute phase to six months (Dyads 1,3 and 4) and four dyads exhibited increased or stable levels of depression across time (Dyads 2, 5, 6 and 8). Within dyads there were also differences in the pattern and level of depression between patients and carers. The patient in Dyad 2 had depression levels at the clinical level at 6 months and the carer also had elevated levels of depression from a score of zero (acute and three month phase) to seven at six months. The carer in dyad 4 had depression at the probable clinical level at the acute and three month stage which reduced at six months. The carer in dyad 6 had depression at the probable clinical level (8 and above) at three and six months as did patient 8 at six months.

There appears to be a lack of a consistent pattern in the dyads however, six dyads exhibited

higher levels of depression at the acute and three month stage than at six months. In relation to disability ratings those dyads with probable levels of clinical depression were not those uniformly with the lowest level of independence. Patient 2 had reduced levels of perceived independence at six months, as did carer 4 and carer 6, but only carers 2 and 6 had clinical levels of depression. Patient 8 who was also at the probable clinical level for depression, from looking at the previous graph, exhibited no change in disability/independence at six months to account for the depression.

Carers and patients in dyads 2 and 6, who in the previous Figure (3.2) exhibited elevated levels of depression, also had clinical levels of probable anxiety at six months (as seen in Figure 3.3). The findings replicate the high correlations found in the cross sectional cohorts between anxiety and depression. Anxiety is highest in carers at six months in 4 dyads (Dyads 1, 2, 4 and 6).



Figure 3.3: Anxiety scores of Patients and Carer across Time

There is no consistent pattern between dyads demonstrated. Some dyads have scores that increased over time and some decreased over time. Differences within dyads can be large also, as in dyad 4 where the patient scored zero for anxiety across time but whose carer scored at the clinical level for anxiety (8 and above) across all time-points.



Figure 3.4: Perceived Control in Patients and Carers across Time

Overall, this group of patients and carers demonstrated high levels of perceived internal control over recovery but there was variance regarding at which point control was at its highest. Most dyads seemed to show an increase in control over time but for some dyads patients rated less control over time and carers rated higher levels of control (Dyad 5) or the reverse (Dyad 4). There does appear to be a pattern between dyads, as those with low perceptions of control also demonstrated clinical levels of anxiety and depression. Although correlations have not been computed the graphs allow the dyads to be examined across the variables and across time. The patient and carer in dyad 2 had reduced perceptions of control at six months and the anxiety and depression graphs show that at six months both had high levels of anxiety and depression. The same pattern of low control and increased anxiety and

depression is found in dyad 7, at the acute phase there is low perceptions of control and high levels of anxiety and depression in the patient. Patient 5 was also a good example where perceived control is at its lowest at six months, and anxiety and depression (though not at clinically significant levels) are at their highest. Negative correlations between carer perceptions of control and depression were found in the cross-sectional data at 3 and 6 months and between patient perceptions of control and anxiety at the acute phase; this would fit with the pattern found in this sample.



Figure 3.5: Carer Work Satisfaction across Time

The carer variables of work, relationship and lifestyle satisfaction and work strain are graphically presented (Figures 3.5-3.8). Carer work satisfaction was seen to decrease from the acute phase to six months in carers 1, 3, 4 and 8 and remain stable in carer 2 and increase in 5, 6 and 7. Carer 2 had the highest level of care work and lifestyle satisfaction (see Figure 3.7) yet also reported the most anxiety across all timepoints (see Figure 3.3). There did not appear to be any immediate pattern amongst the carer variables (i.e. those reporting the most strain did not have the lowest satisfaction or highest levels of anxiety and depression) and there is great variability amongst carers in the variables and across time.

# Figure 3.6: Carer Work Strain across Time



Figure 3.7: Carer Lifestyle Satisfaction across Time



110



Figure 3.8: Carer Relationship Satisfaction across Time

Relationship satisfaction is uniformly low at six months (see Figure 3.8) as all carers reported a decrease in relationship satisfaction at six months from the acute phase. There appeared to be an inconsistent relationship between relationship satisfaction and work strain and work satisfaction scales. Carer 6 (lowest score at 6 months) had decreasing relationship satisfaction but increasing work satisfaction across time and decreasing work strain. Other carers (cf. carer 4) demonstrated decreasing relationship satisfaction across time which corresponded to increasing work strain and decreasing lifestyle satisfaction. Interestingly carer 6 had the lowest group relationship satisfaction at six months and highest anxiety and depression at six months

#### **3.7 Discussion**

In discussing the findings the results of the cross-sectional cohort will be discussed followed by the prospective results.

#### 3.7.1 Differences between patients and carers

The results show that patients and carers in this sample did differ on disability ratings across time-points and the difference in each cohort, despite the small number, indicate that patients perceive themselves to be more independent than their carers. The finding that relatives rate their patients as less functionally able on the Barthel Index has been found in other studies (Knapp & Hewison, 1999) and this discrepancy has associated with carer strain (Knapp & Hewison, 1999). Recovery over control is also perceived to be higher by patients than their carers at 12 and 24 weeks post stroke and carers are more anxious than patients at 12 weeks. Overall there were higher percentages of distressed caregivers than patients at all time points in line with previous findings (Shulz et al., 1988).

#### 3.7.2 Demographic Differences

Adult children perceived themselves to be caring for the most disabled patients in this sample and were experiencing more work strain than spousal caregivers in contrast to some research findings that have found spousal carers to experience the greatest strain (Cantor, 1983). This finding is in line with research that has shown adult –child caregivers are more likely to institutionalise their parent than spousal caregivers (George & Gwyther , 1986) and this may be as a consequence of caring for more disabled patients, but as the Barthel is a subjective measure there is no certainty that this is the case. Another explanation for greater perceived work strain in adult-child carers is their life stage. Carers that are adult children may have additional responsibilities and roles to fulfil such as dependants at home and employment, whereas spousal carers are similar in age and life stage to their partner and in this study were mostly retired. Research has found that women carers who have the optimum number of roles according to their life stage are in better physical and psychological health

(Lee & Powers, 2002). This large scale Australian research project looked at Australian women across the life span examining the optimum number of roles for best health (i.e. wife, mother, worker or caregiver). For young women the optimum number of roles was one whereas for middle age women this was three or more roles and for older women it was just one role. Older women (70-75) who were caregivers (be it for their partner or other family member) and had a partner were at greatest risk of poor health as they had two roles (i.e. wife and caregiver). In this study psychological health differences were found between women with the optimum number of roles and women with more or less roles than the optimum. Psychological health, which appears worse in adult-child caregivers, may be explained by the number of roles these caregivers have to manage. However the Australian research was based solely on women carers and whether these findings would be the same with a male population is unclear. Physical health of the caregiver was not a variable used in this study and may also be an additional variable that would account for some of the differences in caregiver's distress according to the nature of the caregiver relationship.

In this sample the majority of caregivers were female. Though no differences were found in anxiety and depression according to carer gender there were differences in stroke patients, with female patients found to be more depressed than male patients confirming the phenomenon in the normal population that women without brain injury have roughly twice the likelihood of developing depressive or anxiety disorders than men over the course of their lifetimes (Weissman and Klerman 1977; Kessler et al. 1994). Research in stroke populations has also found that women are more likely to experience anxiety disorders or depression following stroke (Shulz et al. 1998). Female patients also perceived themselves as more disabled than male patients which may also indicate greater somatisation.

Examining the correlations, disability was significantly correlated with patient and carer anxiety in the acute cohort. The greater the perceptions of disability the higher the levels of anxiety. There was a positive relationship between carers ratings of patient disability and depression at 12 weeks; as patients were perceived to increase in independence carers were more depressed. This counter-intuitive finding was not evident in the 24 week cohort and may be just a chance finding. No further correlations between disability and anxiety or depression were found for patients or carers suggesting that disability in terms of Activities of Daily Living is by itself inadequate for explaining differences in depression and anxiety, particularly in a sample with limited disability and where the measure used exhibits a plateau effect. Difficulties in using the Barthel Index for research purposes had been cited by others (Wade et al., 1988) and other variables such as gender may offer more in terms of explanation. These findings are in line with other research which has shown, over time, that the association between disability, depression and anxiety changes, with strong correlations in the acute period but no further associations at 1, 2 or 3 years follow up (Astrom et al. 1993).

#### 3.7.3 Differences across time

The percentages of depressed or anxious carers and patients was the same or lower at 12 weeks compared to the acute phase, which is to be expected, (Astrom et al., 1993) yet at 24 weeks there are more patients and carers reporting clinical levels of depression and anxiety and this is the highest percentage for carers (30%) compared to 12 weeks (18.75%) or in the acute phase (25%). There are similar findings in the percentages of patients reporting clinical levels of anxiety and depression at 24 weeks (Anxiety 22%, Depression 33%) which would suggest that there is an added stress or strain at this timepoint. Overall patients and carers as groups are least distressed in the 12 week cohort. The rise in depression and anxiety seen in

many couples in the prospective group and in the 24 week cohort fits in with literature that has found elevated levels of distress in caregivers at 6 months and at 1 year post stroke (Kotila et al., 1998). Research has demonstrated that patients and carers who have depression at 6 months continue to be depressed across time at two and three year follow ups and this is important to examine in this sample as more caregivers were anxious and depressed in the 24 week cohort (White et al., 2003, Morrison et al., 2005). Due to budgetary constraints many studies stop their follow up of patients and carers at 6 months, failing to address the long term impact of being a caregiver or care-receiver.

An explanation for a rise over time in distress could be the gradual realisation that the changes brought about by the stroke are permanent and expectations for the future are changed, contributing to depression (Worleby et al., 2001; Nilsson et al., 1997). However, it could be hypothesised that the reduction in percentage is due to those patients and carers who were depressed and anxious dropping out or refusing to take part at 12 weeks. Caution is required in interpreting the results, as this was a cross-sectional study, and the differing levels of anxiety and depression may be a facet of different couples. Future prospective studies would need to investigate levels of depression and anxiety in the same patient-carer pairs at the 3 time points.

Another possible explanation behind the increase in carers reporting depression and anxiety at 6 months is that those patients and carers functionally able to be discharged (as in this study) have returned home and are starting to face life with the impairment and difficulties that the stroke has brought them. At three months there has been little time since the hospital to re-adjust and take in the magnitude of what has happened. At six months there has been a more prolonged period in the caregiver-care-receiver roles and most recovery that will occur has generally been expected to have taken place; the residual impairment and disabilities may have to be accepted as things that may never improve. Nilsson et al. (1997) found that those stroke patients that had not accepted their situation were most depressed post stroke. There was no set pattern between those patients who perceived themselves to be most disabled at six months and levels of anxiety and depression. There may be other factors such as coping (c.f. Lazarus & Folkman, 1984), adjustment to disability and role changes not captured here, that may be important in explaining the rise in patients and carers reporting depression and anxiety at six months.

### 3.7.4 Caring appraisal scales

Interestingly in this study, carer variables of work satisfaction and life satisfaction correlated with patient anxiety at 24 weeks. High levels of patient anxiety were associated with higher levels of carer work satisfaction and lifestyle satisfaction which perhaps, in this sample of fairly independent stroke patients, with low levels overall of anxiety, is a chance finding. The high correlations within the carer appraisal scales suggest that there is an aspect of these two scales that may possibly be measuring carer adjustment to the caring role and at 24 weeks those carers that are more satisfied with their caregiving role have patients that are more anxious. In this sample, because patients are all generally scoring low on disability and are predominantly male, they may perceive themselves as not needing care, but if their carers' perceptions differ this may cause anxiety in the patient. The correlations found with appraisals of carer strain and depression fits with the transactional model of stress (Lazarus & Folkman, 1984) and Stress Process Models (Pearlin et al., 1990) that view strain as a secondary appraisal that determines whether psychological distress is experienced. The correlations across time between perceived control and the negative relationship between carer depression and positive relationship with work satisfaction fits in with the general

control literature conceptualising caring as a job and as such applying occupational psychology theories of strain such as Karasek's demand-control model of job strain (as cited in Orbell & Gillies, 1993). Those carers who perceive patients to have greater control over recovery have less depression and increased work satisfaction. The particularly interesting finding in this study is that the perceived control in this research is not the carer's own level of control as in other research (Molloy, Johnston, Johnston, Morrison & Pollard, 2005) but their patient's (proxy rating). Thus the influence of the patient's perceived level of control seems to affect carers. Carers across the cohorts rate control to be lower than patients and the reasons for this need to be explored. A tendency to perceive patients to have low control over recovery (in the carer's view) does this increase carer's feelings over control over the patient's recovery? Carers' own perceptions over recovery control would need to be measured in a future study.

#### 3.7.5 Prospective sample

As seen in the results for the prospective sample, there were variations between and within dyads with no set pattern of relationship with the variables of distress, except those seen in relation to recovery locus of control and relationship satisfaction. Examining this smaller sample it can be seen that the discrepancies or lack of discrepancies (in some dyads) in control and disability and the wide variation in anxiety and depression, that is not accounted for by disability, does show that individual care-receiver dyads do not necessarily conform at the micro level to the patterns demonstrated in larger samples. The discrepancy between the spousal dyads in disability ratings, and though not significant, marital intimacy, leads to questions regarding how these discrepancies exist and how this affects the caregiver-receiver relationship. Examining the prospective dyads in the results section it can be seen that there

are large variations in distress and carer appraisals and accounting for these differences using graphs and statistics may not add to the research literature but may be useful for interventions at the individual/dyadic level.

The increasing levels of anxiety and depression in the 6 month cohort, compared to the acute and 3 month cohorts in the larger sample of patients and carers, despite low levels of disability and higher levels of perceived control, leaves the explanation for these findings unaccounted for. Relationship quality and marital intimacy in the larger sample, variables that had been lacking in previous research, appear to contribute very little to explanations regarding distress. In the prospective sample there is a clear pattern amongst carers of a reduction in relationship satisfaction across time, and whether this is a real difference that could be found in a larger sample would need further investigation.

Examining the distribution of marital intimacy it can be seen that there is a ceiling effect within the data, with scores being skewed (though not significantly) towards the higher satisfied end of the scale. These results either mean that this group of individuals are highly satisfied and intimate in their relationships or that the tool for measuring intimacy is insensitive. When deciding to investigate marital intimacy and relationship satisfaction, care was taken to avoid a bias in reporting due to the presence of either spouse or relative; this was achieved by questionnaires being completed separately. This approach was not perfect as both carer and patient were, although in different rooms, often close enough to hear responses. Cognitive dissonance may occur if a patient reported that one's long term relationship with one's spouse was not intimate particularly when dependent on this person for care. Carers may also experience cognitive dissonance if reporting that their relationship is not satisfying whilst expending large amounts of time and effort caring for that person.

There needs to be a more objective means of examining relationship quality/intimacy. Some of the pioneering observational work of Gallagher-Thompson et.al (1999) and more recently Thompson et.al. (2002) has provided an avenue for the objective exploration of relationship quality and its correlation with distress, examining whether there are fundamental differences in caregiver-care-receiver relationships; this will be investigated in Chapter 5.

#### 3.7.6 Limitations and future research

In spite of the many interesting findings emerging from the two types of data, this study suffers from several limitations. The sample size was small, although small is not unusual for a dyadic study (Shields et al., 1992), the cross sectional study was not 100% dyadic. Patients were missing in two pairs but as these carers had spent time and energy contributing to the study their responses were not excluded. The attrition between timepoints and high refusal rate means generalisability is limited. The fact that the majority of patients were male, although in some ways representative of the wider stroke population, also influences the generalisability of the findings. Although care was taken to recruit only those who fitted the inclusion criteria, being a member of a stroke team ultimately led to biases in recruitment due to selection on behalf of the stroke team and in some cases there was self-selection by participants; those least disabled were more likely to take part in the research.

Patients appeared to try and protect their relatives with 37 patients refusing contact with relatives and which perhaps indicates that those patients who have caregivers experiencing the greatest level of distress will be selected out of this study by their patients. Co-morbidity was a large problem in recruitment of patients, reflecting the often complicated nature of the physical problems that stroke patients experience. Further research should try to embrace the multitude of health difficulties that stroke victims have to get a broader understanding of

how stroke impacts upon individuals already experiencing health difficulties (Han & Haley, 1999). The lack of range in disability, with Barthel scores being fairly high, means this study fails to examine the impact that patients and carers living with high levels of disability and dependency face. The site of the infarct or bleed was not used in this study and this maybe a factor to consider in other research. Neuropsychological research has shown that patients with differing neurological sites for the CVA have not only differing disabilities but also can have different emotional responses (Robinson, 1998). Unfortunately due to circumstances within the dynamics of the stroke team, clinical data was unobtainable.

The results have left many questions, particularly through examining the dyads' individual differences. The prospective dyads' relationship satisfaction decrease at 6 months requires a more in-depth examination of what is occurring, besides factors measured in this study, that would contribute to this. The rise in depression and anxiety at 6 months in the cross sectional cohort and the tentative hypothesis put forward (i.e. challenge of adjustment and acceptance to new roles) also needs further exploration. Research has been conducted looking qualitatively at the individual accounts of stroke patients (Nilsson et al., 1997) and stroke carers (Payne & Ellis-Hill, 2001) individually, but little research has been conducted on dyads, in particular qualitative research on dyads living with stroke. The next study (Chapter 4) looks in detail at the accounts of 10 married couples, four of which took part in the prospective part of this study (Dyads 3, 6, 7 and 8) and an additional six married couples from the cross-sectional cohorts. Qualitative data will be used in conjunction with the quantitative data to try and understand increases across time in anxiety and depression.

# **CHAPTER 4**

# STUDY 2: COUPLES' ACCOUNTS OF LIVING WITH STROKE; CONVERSATIONAL STYLES AND ASSOCIATIONS WITH CARER DISTRESS

#### 4.1 Introduction

A cerebral vascular accident (in medical terminology) threatens the neurological systems that provide life (Robinson 1998). A stroke's sudden onset and resulting impairments can leave survivors with emotional disorders (Wade et al., 1987) and impact upon the individual's role in society, as physical changes may lead to role changes (Hafsteindottir & Grypdonck, 1997). Therefore stroke represents a threat to the biological, psychological and social self. Previous research on chronic illness has found that patients' individual interpretations and narratives regarding their illness experience show that they organize and reorganize the self in response to the stress and emotion their illness brings (Pennebaker, Kiecolt-Glaser & Glaser, 1988; Charmaz, 1983). The emotional impact of stroke upon the self has been shown to be great, with depression being common among stroke survivors and enduring (Anderson et al., 1995); prospective research at three years shows that depression in victims increases over time (Astrom et al., 1993; Kotila et al., 1998). Despite the clinical knowledge of a high prevalence of mood disorders in stroke survivors, identifying which stroke survivors are at risk remains difficult. Statistics such as:150,000 people in the U.K will experience a stroke annually; two thirds are likely to survive; a significant proportion of survivors will live with residual disabilities (Robinson, 1998), fail to capture the lived experience of being a long term stroke survivor and do not help us to understand the influence of biological, psychological and social factors in stroke survivors' well-being.

Despite the seeming adoption of the biopsychosocial approach in Health Psychology, there is a lack of research that incorporates cultural and social factors. The social constructionist framework believes that reality is constructed between individuals through language and interaction, both verbal and non-verbal and is an ongoing process. Despite social constructionists emphasising the importance of others in the individuals experience of health and illness, applied psychological and physical interventions to reduce distress in caregivers and patients have, to date, tended to target the patient and carer as individual units, rather than as interacting dyads (e.g. Forster & Young, 1996; Grant, Elliott, Weaver, Bartolucci, Giger 2002). This may in part explain why patient satisfaction with stroke services is low and why psychosocial post-stroke interventions are often disappointing (Pound, Gompertz & Ebrahim, 1994, Rodgers, Atkinson, Bond, Suddes, Dobson, Curless, 1999; Johnston, Morrison, Bonetti, et al., 2002). Those rare studies that have attempted to address the influence of a partner on a stroke survivor have found that partners can play a pivotal role; for example, patient completion of a psychological therapy programme aimed at preventing depression was associated with the amount of positive contributions made by the stroke survivor's carer during therapy (Dempster, House & Knapp, 1998). Dempster et. al. (1998) concluded that assessment of the relationship between carer and patient may be an important indicator of the influence carers will have on patient outcomes.

In capturing the 'holistic' phenomenology of being a stroke victim it should be imperative to include the caregivers and in capturing the caregivers' role and experience of this role, it is important to examine the nature of the relationship between the stroke victim and stroke caregiver. Research has started to address the impact of others on the stroke survivor in terms of relationship quality, quality of care provided and the context of care. Considerable amounts of research have been carried out in the area of caregiver distress (see Chapter 2),

but yet again this has been largely carried out separately from patients. The past and current literature indicates that patients and caregivers should not be looked at in isolation from one another when examining well-being (Han & Haley, 1999; Palmer & Glass, 2003).

Stressful marital interaction in couples where one is a stroke survivor may contribute to reduced physical activities in stroke patients and stressful marital interactions have also been shown to relate to physiological arousal (Kiecolt-Glaser & Newton, 2001). Marital intimacy has been shown to correlate with the mental health of spouses who are caregivers for dementia sufferers (Morris et al., 1988), with carers who had experienced a greater loss of intimacy from the past to the present having higher levels of depression, but experiencing no increase in perceived strain. This was in contrast to carers who reported lower levels of both past intimacy and present intimacy but were found to experience high levels of depression and perceived strain. Morris et al. (1988) speculated that poor pre-morbid relationships made caregiving more stressful because of the greater difficulty in performing the caregiving role without resentment. A better pre-morbid relationship before caregiving has been hypothesised to make caregiving more intrinsically motivating (Yardley, 1997). The quality of the pre-morbid relationship has been shown to influence caregiver strain which has also been shown to be directly related to decisions to institutionalise the patient (George & Gwyther 1986). The dyadic relationship and interaction between patient and carer may well be fundamental to both carer and care-recipient's well-being, with the directionality of this relationship likely to be two-way. Severely depressed carers of Alzheimer's Disease patients have been shown to interact negatively with patients and their family (Shields et al., 1992), and in a study of carers to the elderly, the main determinants of carer distress were found to be relationship factors, in particular, one where the carer felt controlled by the elderly person (Broe et al., 2000).

Relationship quality can affect the patient, sometimes physically, by affecting the caregiver and thus influencing the quality of physical care received. Increasingly attention has turned to the type of care provided by family caregivers in predicting patient outcome. The nature of care provided by carer's to stroke patients has been shown to be a major determinant of patient-rated quality of life. Stroke survivors with overprotective care can experience negative consequences such as depression and lack of motivation in physical therapy programs (Hyman, 1971; Evans et al., 1987).

A recent study on stroke caregiving and overprotective care (Thompson et al. 2002) assessed carer attitudes towards the patient and their caring role. Patients and carers were observed performing four simple cognitive and motor tasks with each carer being asked to aid their patient but not to complete the task for them. Independent observers gave ratings on a Likert scale of these patient-carer interactions with caregivers given scores for babytalk, taking over task, interrupting task, frustration, and criticism. Patients were scored for: showing distress, asking for help and disengaging from the task. When examining prospectively the determinants of overprotective care, strong support was found for carer resentment towards the patient and their caring role being a crucial determinant of overprotective care. Stroke survivors' perceptions of overprotective care were found to associate with depression. However this study failed to address the source of carer resentment and how this was communicated to the patient in the act of caregiving.

Research so far has shown that relationship quality pre-and post morbidly, affects both patient and carer well-being and the type of care provided. Research on dementia caregivers has additionally found that it is not just the reported quality or intimacy of the relationship between care-giver and receiver, but the negative social interactions in intimate relationships that can lead to depression in care-receivers (Schuster, Kessler, & Asseltine 1990). In the dementia literature there is evidence that there is often a breakdown of communication skills between a person with dementia (PWD) and their caregivers (Kitwood, 1997). Caregivers' experience of stress has been attributed in part to the breakdown in communication with their partner and the resulting loss of intimacy (Morris et al., 1988). Kitwood (1997) describes a maintenance of self as important in the PWD and states that this is often undermined in the interactions between dementia patients and their carers, yet few studies have researched this in depth and so far only one study (Thompson et. al. 2002) has examined this in stroke survivors.

Negative interactions between caregivers and dementia patients has been termed 'malignant social psychology' by social interactionist theorists (e.g. Kitwood, 1997). Recently researchers have begun to examine the interactions and conversational rights of dementia patients and their spousal carers taking a conversational analysis approach. Clare & Shakespeare (2004) found that in a structured conversational situation between the PWD and their carer, the person with early stage dementia was already being positioned as less than equal in the conversation. This research has shown a way forward for including dyadic qualitative research into illness experience and caregiving. This dyadic interaction research. with the exception of Thompson et al. (2002), has been exclusively focused on dementia patients and their caregivers. The difficulty in extrapolating findings from dementia populations to stroke is that in using the biopsychosocial model all the elements of each of the domains (psychological, social and biological) have potential differences and consequences and the two conditions are not directly comparable (as cited in Chapter 1, Rolland, 1988). There is also inconsistency in the method used to examine the influence of communication upon caregiver and care-receiver distress. The complex behavioural and conversational cues that make empirical observations problematic may explain why there has been little research in this area with stroke patients.

Understanding more about how couples perceive a stroke, the care needed and how this is expressed in the context of an intimate relationship, may enable a better understanding of how matched care and optimum well-being in both stroke survivors and their carers can be achieved. Examining, as in the dementia studies, the conversational and interactional rights of the patients and carers will allow insight into how positive and negative emotions such as resentment (as found in Thompson et al., 2002) are communicated. To conduct this exploratory study into couples living with stroke, qualitative analysis has been chosen as the most appropriate form of analysis.

Interpretative phenomenological analysis has been shown to be extremely useful in capturing the lived experiences of those with chronic illness (Smith, Jarman, Osborn, 1999). Interpretative phenomenological analysis (IPA) is interested in exploring the individual's view of the phenomenon, in this case stroke, and is interpretative in nature as it acknowledges that the person's experience can only be elicited by the interaction of the researcher with the text; the researcher's beliefs and understanding play a major part in the interpretation. Past IPA papers have tended to deal with the single voice of the interviewee and this has enabled an exploration of individuals' perspectives. However in this current research it is considered important to capture the voice and perspective of the patient simultaneously with their carer, examining discrepancies in perspective and also the nature of dyadic communication and interaction. Conversational analysis is an approach used for examining discourse from a social constructionist philosophy, and has recently been applied to the conversations between community psychiatric nurses and dementia patients and their families (Adams, 2001). In line with the work of Clare & Shakespeare (2004), voicerelational analysis will be used to look at the communication styles of stroke survivors and their partners in this study.

Conversation analysis is philosophically juxtaposed with IPA. IPA seeks to understand the internal world of the person through close analysis of the text relating the text back to the person's internal thoughts and feelings in relation to the phenomenon under investigation (i.e. stroke). Conversation analysis views language as a behaviour in itself that can be used to further particular actions and does not directly relate to an individuals beliefs and cognitions. Smith (1999) explains that there does not necessarily have to be a gulf between the philosophies of phenomenology and social constructionism. Smith (1999) states that one can appreciate that language is a system of signs connected together through rules that convey meaning and value not just about the individual's internal world but also about society. In this study the mixture of the two methodologies allows the speech to become language that can be analysed and understood in relation to context, presentation and the self. The talk by participants in the study is recognized to have multiple layers of meaning that can only be understood truly in relation to speaker, receiver and the wider societal context to which the researcher and participants belong.

Brown and Gilligan (1993) developed the voice-relational method as a means of helping to 'understand how those not represented as full human beings within the dominant system of our society exist and resist, how they create and maintain their humanity both above ground and underground.' (p12). Brown and Gilligan (1993) interviewed school-age girls and found that there were threats to their ability to express an authentic voice which resulted in two types of resistance, psychological and political. This type of methodology is relational, dealing with issues of power. This type of analysis has traditionally been used as a way to hear the voices of those marginalised and has been successfully applied with dementia patients (Proctor, 2001; Clare and Shakespeare 2004) and professional dementia caregivers (Adams, 2001). It is used here as stroke survivors are dependent on their carer and although they may not be marginalised as a result of their dependency, power issues as a result of their dependency may be important to address.

#### 4.2 Method

This qualitative study investigates 10 conversations between individuals who have experienced a stroke and their partners who are identified as their informal caregivers.

#### 4.2.1 Participants

Eleven cohabiting married couples who had taken part in the previous quantitative study and had provided data at either two or three time-points were invited (see Study 1). One couple had to be excluded due to the patient contributing very little to the conversation and on later testing with the Mental Status Questionnaire (MSQ) had to be excluded due to moderate to severe cognitive impairment. The analysis therefore focuses on the remaining 10 couples (numbered 1-11 with the exclusion of couple no. 7). The date of stroke was calculated from the date of admission to hospital and the couples ranged from 1.4 to 2.3 years post stroke. Ages of patients ranged from 58 to 81, and carers ages from 56 to 77. All participants were white and of UK origin, reflecting the nature of the geographical area from where they were recruited. The partners who had experienced a stroke were eight men and two women. All stroke patients and their partners were retired prior to the stroke.

#### 4.2.2 Data collection

The couples were interviewed in their homes by the researcher and the interview took the format of a conversation with encouragement and facilitation by the researcher. There was a semi-structured interview schedule of open-ended questions used as a prompt for specific areas of interest. Each interview lasted between 40 minutes and 60 minutes. The interview

questions were usually arranged so that a brief update on what the couple had been doing since the last time the researcher had visited them was used as the starting point for the conversation and the more personal questions asked once the interview had become established (for the schedule see Appendix 7). Plans for the approaching Christmas holiday were discussed last to conclude the interview with a prospective look at the future. On conclusion of interviews, interviewees were given the contact numbers of the local Stroke Family Support Team and Carer's Outreach in case they felt that the interview had raised issues or needs that they wanted addressed. The participants were also informed that they could contact the researcher for further information or if they had any questions; no interviewee exercised this option. The interviews were audio recorded and the microphones were switched on once all participants felt comfortable and had consented to the interview. The audio tapes were transcribed in line with recommendations for qualitative analysis using IPA (Smith et al. 1999). The focus of this research was to look at the content of the interactions and to be able to trace the voices of the participants, therefore in line with other research (Clare, 2003) transcription followed IPA guidelines rather than the guidelines of conversation analysis.

#### 4.3 Analysis

Two levels of analysis were employed. The first level of analysis involved the qualitative interview data, using IPA (Smith et al., 1999) and voice-relational analysis (Brown and Gilligan, 1979). The first level explored the themes and voices of the patients and carers in relation to themselves, their relationship, and societal representations. Voice-relational analysis also examined the roles that are taken by each member in the conversation and the type of communication formats and interactions that each member exhibited. Voice-relational analysis looks at discursive practices at the individual and, in this study, dyadic

level. This research is particularly focused on how stroke patients and their partners use their discursive resources in interpersonal interaction to maintain or achieve certain objectives. A second level of analysis triangulated the qualitative data with the quantitative data presented in Study 1. Types of interaction were classified into conversational styles and were examined for differential associations with the quantitative measures of anxiety and depression in patients and in carers.

# 4.3.1 IPA analysis and voice-relational analysis.

The transcripts were read many times whilst listening to the tapes. The transcripts were analysed by noting relevant descriptions or units of meaning down the left hand margin for each conversation (e.g. lack of ability). The transcripts were then re-read and emergent themes were identified and noted down on the right hand side of the transcript (e.g. loss). The emergent themes were then listed on a separate sheet of paper for each couple under the headings patient and carer. Each couple's interview data was read to elicit new themes and to further confirm or elaborate on themes that emerged in previous transcripts. Once each couple had a list of themes then the lists were amalgamated into one summary list of themes that covered all the participants' transcripts. (see Appendix 8a for an example of a list of themes for a couple).

A master table of themes was compiled using IPA, and then the transcripts were subjected to voice-relational analysis. To elucidate the individual perspectives, thoughts and cognitions the patients' and carers' voices were traced through each transcript. Using Brown & Gilligan's (1993) voice relational method (as applied by Clare and Shakespeare, 2004; and Proctor, 2001) the interactions and communication between the couples were investigated.

Voice-relational analysis has four stages, with the first stage of familiarisation with the text

and noting themes already performed using IPA. The second stage of voice-relational analysis involved tracing the stroke patients voice through the transcript examining their voice in relation to themselves and their relationship and to dominant societal representations (i.e. ageing discourse, gender stereotypes, disability discourse). This process was repeated with the partner/carer. The different voices are traced using colour-coding and then grouped together under separate headings, as shown in the Conversation Schedule ( see Appendix 8b). The next stage involved noting down the communication formats (e.g. prompting) and nature of the interaction (e.g. parent-child) with separate colour coding for patients and their partners.

Once all the stages had been completed a conversation schedule was developed for each interview transcript, which included key heading and themes, with extracts from the transcript included as examples (see Appendix 8a). The analysis then moved onto an investigation into the similarities and differences between the conversation schedules for the ten couples. A master schedule was produced for all ten couples that included all the themes and issues identified with the relevant excerpts listed by each one. This final schedule formed the basis for the narrative account of the findings. The analysis of the communication formats and interactive styles of the patients and carers were classified for each couple. Looking at the amount of codes that were positive and negative in terms of communication formats and interactive styles for each couple allowed three styles of interaction to be identified; descriptions and examples are given in the findings. Triangulation of the qualitative data was conducted with the HADS (Zigmond & Snaith, 1983) scores given by the patients and carers in the quantitative study (CH 2). As not every couple took part at each time point (1month, 3 month, 6 months) in the quantitative study (Study 1) there are differing numbers in the table, not every couple had data for anxiety and depression scores at each time point (see Table 4.2)

#### 4.4 Results

The first section reports on the themes that emerged using IPA and voice-relational analysis. The themes are ordered under patients' and carers' voices regarding the self and the relationship, societal representations and communication formats. The second results section deals with the overall nature of interaction and communication in these couples and their association with distress. To ensure anonymity, participating couples are identified in the account presented here as either P (the person who has suffered the stroke) and C (for the carer/partner), with a shared number between 1 and 11 denoting each couple (except couple 7 whose data are excluded), and in each case an indication of whether the person speaking is a man (m) or a woman (f). There is also the use of the term partner when describing the perception of patients' and carers' to their spouse, as most would not view their partners in patient/carer terms.

#### 4.4.1 Results section part 1

The table below gives an overview of the stages across time that patients and their carers travel through in the domains of self and relationship. The master themes fitted under these headings and in the accounts there is a temporal aspect to these themes/stages but each stage can be re-visited and does not necessarily follow in a straightforward linear fashion. Patients and carers may have accepted their situation but return to the aftermath and bear witness to their losses on a daily basis. For this reason the table serves to summarise the findings under the topics of self and relationship, but a detailed description of the results with quotes follows.

# Table 4.1. An overview of the themes for patients and carers in relation to talk about

Patient	Aftermath Loss Frustration Anger	Making Sense         • Downward Comparison         • Ageing discourse         • Stressing competencies	<ul> <li>Negotiating Care</li> <li>Burden</li> <li>Praise and Criticism</li> </ul>		
Carer	Aftermath	Attributing a cause     Making Sense	Negotiating Care		
	<ul><li>Anxiety</li><li>Uncertainty</li><li>Loss</li></ul>	<ul> <li>Living in the moment</li> <li>Acceptance</li> <li>Attributing a cause</li> </ul>	<ul> <li>Adjustment</li> <li>Responsibilities</li> <li>Frustration</li> </ul>		

#### the self and the relationship

# Patient's voice in relation to self:

Throughout the interviews there was the theme of **loss**; this was in relation to physical and cognitive abilities, and competencies that were previously taken for granted. The stroke had also impacted upon leisure activities and socialization.

P3m: Yeah. And another thing, simple things like erm.. cleaning your teeth, y'know, I couldn't, I just couldn't fathom, get a brush and put toothpaste on..

P8m: I used to read, I used to paint, a lot and I don't do either now...

P11m: I can't do stocks and shares anymore, I used to be quite expert at that as well you know.

When the interests and capabilities had been a large part of the person's life defining "who they were" there was a greater impact of the stroke, threatening their perceived identity, many reporting "I've changed".

P1f: Hard working all my life, like any person as you'd imagine...but em, I'm not that person anymore, it's gone.

P6f: I dunno, I'm..I suppose I've changed since I've had the stroke, y'know, I don't want to go out and join things the same as I used to and it..gives me, I've got to think a lot about going to anything public like, y'know. Not like I used to be.

P8m : -Cus I always used to feel like, I was painting, always felt y'know, y'know..cus you look at things in a different way being an artist, you, the way you look at things, differently.

*P8m: I don't know, though its[painting] not something you usually stop.. you do it more in later years, I dunno* 

Those patients with specialized skills such as P8m were often left with a void in their life. Often there had been an expectation that these interests would be developed over retirement, rather than lost. Although physical impairments as a result of the stroke limited a lot of activities most patients spoke of losing interest and confidence in these activities despite being capable of performing them.

P6f: Yes but I don't, I've lost my confidence, y'know, in driving.

P6f: I used to knit a lot and I used to do cross-stitch but I've given that up, oh, I dunno, I got fed up with it. But I used to do a lot of cooking, but I don't cook cakes and things anymore.

Loss was often accompanied by **frustration** and **anger** at oneself when simple tasks took longer or proved difficult to perform. These patients tended to have accounts that were absent from self comparison or used comparisons with present self to their old self, positioning themselves in a worse situation. P10m: Devastated and frustrated

P1f: I don't like to be [inactive], but I can't that's the frustrated, that.

P5m: Mmm. So, I've been fed up at not having, not being able to do as much as I was able to do.

P2m: That's right because of the er....I er.....I never feel satisfied with my performance day by day [laughs] virtually.

P10m: Frustrated most of the time, can't do things I could do before

**Social comparison** in other accounts helped the stroke patients to gain a sense of perspective. The patients perceived others to be worse off than them, despite experiencing physical impairments as a result of the stroke and in many cases having developed or been diagnosed with other health conditions post-stroke (e.g. diabetes). The downward comparison of self to others helped the patients accept their own problems and in some cases patients even considered themselves fortunate. These patients, by their very nature self-selecting for research, may be less functionally impaired than others. However, P10 and P3 had developed other life threatening conditions by the time of interview (e.g. cancer) yet maintained their position of being 'lucky'.

P3m: The thing is, when you go there [stroke association meeting], alright, I had memory loss, I recovered 90% of it but there's some people there who are suffering really with it. They lost use of their limbs and y'know. Must be hard for people like that, really... cus mentally, they're ok but they can't use their legs or can't walk properly.

P9m: I'm so lucky, my mate had a stroke, GC, he had a stroke, y'know, and he's really bad. I feel sorry for him. I'm lucky in a way, like that.

P10m: There's one erm....he's an old colleague of \*\*, he's had a terrible stroke, much worse than me.

In most of the accounts patients stressed their **competencies** in addition to their losses, some mentioned the process of recovery and the regaining of control; this was often in small steps such as being able to brush one's own teeth or by getting their driving licence back. One husband demonstrated that despite losing his ability to drive or cook he could still be useful (extract P5).

## P5m:I can wash up though!

Being able to drive symbolized independence and a return to a valued aspect of the prestroke self in all of the interviews regardless of gender. As in the extract below, the independence from driving is almost priceless.

P1f: We had all the adaptations. But we had to pay seven hundred quid...so, but its been worth it...and I can now be independent again and go out.

In the next extract the patient recounts an example where he had the upper hand on the medical doctor and not only remembered the answers to the memory questions but remembered that he hadn't been asked all the memory tests.

P3m: So at the end of it, I said [laughs], I said at the end, I said, 'You forgotten to ask me something' before I left like, he says 'Oh what's that?', 'You've forgotten to ask me where all the five states, the three states', 'Oh yes' he says 'Do you know them?', I said 'Yes!' [all laugh], 'Oh' he said 'Your memory's better than mine!

The stressing of competencies by the patient promoted a positive attitude towards their position in life reaffirming that they were still competent adults.

P4m: I have a heck of a lot to be thankful for. I can get up and down those stairs like a two year old. No problem. Can get in and out of the bath no problem. Better than she can!

In some patients' conversations, despite having made gains in recovery, they focused on their difficulties. In three accounts there were the themes of **anxiety**, **isolation** and **exclusion**, which were attributed in part to the stroke. Stressful past life events were later revealed in these conversations, which the stroke may have exacerbated. These three patients had experienced the loss of a child, bankruptcy and a disappointment in their career. These individuals were also those whose accounts did not use downward comparison.

P6f: I hate the wind and erm, another thing, don't like being here all day by myself, y'know, if [husband] away at the sales or anything. I don't like being on my own.

P1f: Yeah I should imagine but, another thing is, people, other people don't see me anymore cus I don't go out see?....I mean none of my family come to see me.

P2m: So you do feel, I do feel disheartened as regards not being able to be involved actually with interesting activity.

#### Patient's voice in relation to the relationship:

In three accounts there was the appearance of the word **burden**, specifically patients spoke of their desire not to become a burden on their partners. Patients expressed anxiety over the impact their needs had on their partner.

P6f:I thought it was too much for him to drive to Durham, y'see.

Plf: I don't want to burden [husband] with my problems...because he's got enough to cope with as it is. *P8m:* Get on your nerves sometimes?.... so I do feel like I'm in the way quite a lot of the time.

Some patients were aware that they were placing demands on their carers but were frustrated because they were dependent on their partner. The tension this causes can be felt in the extract below (P2m). In this account the patient wants to attend an event that his wife does not, yet she also does not wish to drive him.

P2m: Yes, yes, but the point is, she's talking about me driving on my own to Bangor, you see, this is what she's on about. I think I will have to because she can't sit out in that cold car park [whilst he attends a lecture].

Despite conflicting needs and interests as seen above, all the patients **praised** their carers and their attempts to look after them.

#### P6m:Oh he looks after me very well, fair play to him.

However, there was a fine line between care that was wanted and care that was deemed to be interfering. In P2m's account he is cross because his wife has given some timber away. P8m shows his frustration with his wife who is concerned with him falling and often tries to catch him. Praise could quickly be switched back into criticism as can be seen in P2m's extracts which made expressing gratitude perfunctory rather than a true expression of the patient's feelings.

P2m: she really does look after me, things like that and she's very generous, paying for these sort of things to be done. She's really done a good job, with this builder here, she's erm....there's a lovely plank upstairs on the top floor there that she's given away...

P8m: She mithers me! ... She interferes ... with things
When asked directly if the stroke had any impact on the relationship the majority of the patients' accounts said the stroke had no impact on their relationship, despite evidence within the accounts that there was concern by patients about the burden they placed on their carers and the evidence in the accounts of areas of conflict (P2m; P8m).

I: What effect has the stroke had on your relationship?

C4f: Well, I dunno really ....

P4m:Oh, not really, no different is it

C4f: No.

I: Has the stroke had an effect on your relationship?

P5m: No, I don't think anyway, learnt to live with each other, haven't we?

C5f: Yes [laughs]

There was the general view by the couples that their relationships were so long standing that they were impermeable to the effects. Only one female patient reported a change, and that was regarding intimacy (P1f). Intimacy problems may be under –reported due to the presence of a young female researcher, especially as the majority of stroke patients were male.

Plf: Y'know, but we haven't kissed and cuddled since I've had the stroke, no

I: And do you miss that?

P1f: Oh yeah, I do yeah.

As we see later on in the accounts of the carers there are reported intimacy and communication problems.

## Patients' voice in relation to societal representations

In some of the accounts there was the discussion of feeling **stigmatized** and standing out as a result of the stroke. Patients often felt embarrassed or awkward in social situations. Two patients specifically mentioned the social impact of their stroke.

P11m: That's what it is, I didn't like that I was different, I didn't want them to see me [patient is embarrassed when meeting old colleagues].

P1f: So I don't want other people to say 'oh look at that one there, having her dinner cut up for her.'

In P1f's account she decides to change her choice of meal when eating out at a restaurant because her preferred choice, steak, would have to be cut up for her by her husband. P1f would rather manage her dinner herself so as not to draw attention to her disability.

In the accounts there was an inherent sense that the patients had lowered expectations for themselves as they got older, with many problems being attributed to old age. Old age was seen as being a time of poor physical health, **marginalisation** (P11m) and an expected **deterioration** in the self.

P3m: No, no, I don't know, it's a combination of things, I think you get older, you, y'know, like swimming when I was younger like, but, you get older, like, you're not so active are you? Tend to put weight on as well, when you get old. Bad thing

P9m: That's my, that's my age, gone, brain cells have gone!

P 11m: Anyhow you get close to seventy or over seventy they[ medical profession] are not so bothered.

In P11m's account he talks of a feeling of being 'written off', of marginalisation by the medical profession due to age. In addition to the acceptance of deterioration in old age, quite a few patients openly spoke of preparation for, and acceptance of, pending death.

P10m: [laughs] Yes! I mean, I'm going to die soon and, and....it doesn't matter, erm, I'm eighty-one.

In the accounts there was reference to the stroke as ageing the survivor, and ageing was a negative process.

P8m: I think, you think these things...it ages you, y'know.

P2m: I'm walking like a very old man aren't I?. .....I feel my age now. I mean previously, before the stroke, I didn't feel my age, did I?

The negative perceptions of ageing held by some participants lessened the perceived impact of the stroke. The expectation that old age brings ill health and cognitive deficits allowed the impact of the stroke and the resulting problems to be normalized or minimized. Still being alive was seen as an achievement in itself, despite severe health problems.

P10: Not really, it doesn't bother me, because I'm seventy, well, y'know...the way I look at it anyway, I mean to say, we all we're going to die sometime, aren't we?

P2: Well I'm too old now, at my age, at any case.

P4: Well, good as anybody's I think at eighty-three! [laughing]

Old age seems to be typically considered a time of sickness, infirmity and impending death which may be due to negative social images associated with old age. However these images or representations may make the experience of a stroke in old age less traumatic and more easily accepted.

When patients were asked what had caused their stroke their causal attributions of stroke fell into three categories: stroke was due to stress, chance or to medical problems.

I: what do you think caused it?

#### Stress:

P5f:Yes,[carer's ill-health] that frightened me, I think, y'know.....Yes, yes I was (stressed prior to the stroke). I worry about everything, y'know.

## Chance:

P3m: But as you say, you don't really know, you see. Y'know, [the wife] was saying, thousands of people have heart attacks and it just happens, y'know? Like I didn't have a warning, I went to bed, I was fine, y'know.

## Medical problems:

P11m: I had an operation to my bladder and I think clots.

#### Patients' communication formats

Patients were often less involved in the conversations than the carers and in some cases this was mainly due to the patient being slower to respond. Patient involvement could still said to be equal if opportunities were created and their voice was allowed to be heard. Carers would often provide prompts to allow the patients to be involved and the patients would often mirror responses by the carers. The interview extract below gives an example of a conversation where the patient was positioned as an equal partner in the conversation with turn-taking evident in constructing the story they wish to tell.

P5f: The \*\*\*\*Hotels we usually stay at, what was the other one we stayed at?

C5m: The \*\*\*Hotel

P5F: The \*\*\*Hotel, we used to stay at, yes

C5m: They recommended us to go to\* \*\*, they didn't have room so...

P5f: so they gave us the number of ..

C5m: number of the \*\*\*Hotel and it was..

P5f: It was lovely.

In some conversations patients used **Resistance** against concerns that were raised by their carers. This resistance often took the form of not giving a response or by moving the conversation to a different topic:

C4f: I think that'll be the crunch time, when he's..

P4m:Pardon?

C4f:..if and when he can't drive.

P4m: Well, I can't complain, y'know, still driving at eighty-three, I've had a good innings.

C4f:Mmm..but you don't walk do you?

P4m:Pardon?

C4f:I mean, you, its no good saying T've got a bus pass' because you couldn't...

P4m:I've got a sofa haven't I?

C4f: That what I'm dreading! [laughing] that'll I'll have to go out in the afternoon!

Despite the majority of conversation formats showing positive interactions there were interviews where signs of malignant interaction (c.f. Kitwood, 1997) were present in the patients' communication. These conversations often had tension or conflict, in one account (see below) the patient uses sarcasm and resistance to assert himself. The conversation is about an upcoming holiday he wishes to go on but involves a trip on a ferry:

C8f: I can't swim and I don't like the water see.

P8m: You aren't supposed to swim! You are supposed to sail!

C8f: I know!

P8m; You sit on it, you sit down and you.

C8f: I don't like flying either

P8m: You won't be flying down the Danube.

In another account the patient asserts himself in the conversation by stating his wishes emphatically:

P2m; Well, yes, I'm not as active and not as, I can't go to many lectures now at all, but this one...

C2f: Well there's not many lectures to go to

P2m: But this one is available and I'm certainly not missing that one

## Carers voice in relation to self:

Carers spoke of coping with the initial effects of the stroke and the anxiety over the future and the unknown. Sometimes this anxiety was exacerbated by their dealings with medical professionals or the social services and in some cases there was anger directed at these services (C6m).

C8f: Just stresses you, you know me

C10f: It was an awful shock to me

C6m: Every little bit adds on, doesn't it? Y'know, they, Rapid Response [stroke team] is supposed to be there, to take stress off, doesn't it? But you, instead of taking stress off, it was adding on. I was mad with that.

For some carers the stroke put their **life in perspective** and materialistic or other concerns about the future became irrelevant in the face of the challenges in the present.

C3f: And all of a sudden your life's in perspective and you think 'Well, you've got plenty of money, what the hell is it good for you when you haven't got your health?' y'know

All the carers spoke of coping with the resulting **aftermath** of the stroke. The general consensus amongst carers was that it was important to accept what had happened and to live day by day. The right way to cope was seen to be **living in the moment** and avoiding looking ahead at the difficulties.

C4f: Yes, just got on with it [laughs], we just took things gently and er..I didn't go out for long periods, y'know, just to the shops and back, things like that. And then gradually you got adjusted and a bit steadier.

C5f: Erm, I think I just take each day as it comes really.

The initial grief at the loss of the future or at least the certainty of a future, was acute and painful early on, something to be railed against (C3f) but this abated as expectations were brought into line and adjusted (C4f).

C3f: And I think you see your life then. Like last year, I think, I was looking at my life,

I'm never going to have a holiday again, he's never going to be able to drive far again. Its in the back of mind, all the time. It isn't now for me, its gone.

C4f: Erm, well I suppose, really, you go with the flow, you have to, you can't fight against things like that, can you? You just have to cope with it, at the time

**Uncertainty** regarding the cause of the stroke and the threat of a further stroke was a recurrent fear. There was plenty of analysis and questioning by the carers, but most of the questions were merely rhetorical by this stage. Carers were resigned and accepting that there was no specific answer as to why the stroke occurred. The second extract from C8f\* sums up what all the carers felt and feared.

C9f: So whatever it was, it was only very very minor but we, we, to this day, don't know exactly.... what was the cause of it, do we?

*C3f:* But then, as we said before, y'know, at times it is always in the back of your mind isn't it? y'know

*C8f:* He's only been once and I was a bit frightened, cus after he'd been, he had this stroke [another stroke] a few days after but it can't be physiotherapy can it?

C11f: I mean he wasn't under any stress, couldn't be caused by stress could it, we hadn't got anything to worry about had we?

\*C8f: Well we just don't want anymore but you can't say can you

There was much talk about **change**, as carers took on more responsibility. These new roles, although challenging, were often looked upon as having a positive effect on their sense of self. In many instances wives of stroke survivors had gender stereotyped roles prior to the stroke such as cooking and cleaning. Pre-stroke many of the husbands had taken care of financial issues and driving and after the stroke the wives had been forced to adapt and take on the 'man's' roles.

C11f: I'm a lot more confident in things like that aren't I, doing business things, over the phone things, I used to be hopeless

C4f:Not now, no, I'm erm...I'm more confident myself now...because before all this happened he always did the driving, didn't you?

All the carers talked of **acceptance** and of **adjustment to** their new roles with a positive progression made by most of the carers.

C4f: Well, last year I found it very tiring. But this year, I've coped much better

*C3f:* No, I feel now, erm, you've got to, I think you've got to change your sort of attitude and your lifestyle and everything, y'know its...erm, I dunno

Social support was very important to the carers and this came in the form of family and friends but also organisations such as the Stoke Association's family support team. Many carers felt they had a confidant in their family support worker. Events held by the stroke team allowed comparisons that helped most patients and their carers gauge their social position, with most viewing themselves as better off than others. The downward social comparison as mentioned in the patients' accounts boosted their perception of themselves and it also helped carers to get out and meet others.

C3f: Mind you, the Stroke Association they've been brilliant really, haven't they?...and we still, we still keep in touch cus we go to what they call this 'Young Stroke Group', y'know, they meet every month. I like going there and meeting the people and sharing notes...you know.

## Carers' voice in relation to relationship:

Carers tended to talk more of changes and problems in their relationship than patients. The problems ranged from intimacy and communication, to a general sense of having lost part of their partner.

C8f: But he doesn't speak very much, y'see...doesn't talk to me at all! [laughs].

C8f: Switch him up [laughs].

C4f:No, not upset. I mean, sometimes, I wish that you could...come to Llandudno and walk up and down the street with me but [laughs] erm.. there's no, not much hope of going shopping together is there?

There was a mixture of **frustration** and **concern** over the **loss** of activities for patients with carers often talking of pushing the patient to do more activities within their own capabilities.

C2f: But you see, when he's sat in here, on his own, and thinking, he's making himself miserable and that's when I want him to snap out of it. But I don't mean snap out of the chair and jump up and run out. I mean out of here [pointing to head of patient]. This is where all the trouble is with R, its not his legs, its here. He is brooding all the time.

C6m:But erm, M's biggest problem really...she can't motivate herself to take an interest in anything, in doing anything, y'know, if she was doing anything... knitting, for example. It would take a couple of hours, a couple of hours would go without her thinking, wouldn't it? I can't get her interested in anything to do.

C8f: Well, its made it more distressing because I don't like seeing him not doing the things that he used to do, do you know what I mean?

C8f: Well, just ordinary, really, I find a lot to do but I think, it gets, it gets a bit, I don't like him keep watching the telly all the time, I like him to go out a bit more y'know.

The carers often felt that if their partners could be involved in activities or hobbies then the patients would be happier. Only when the desires of the patient were congruent with the carer's wishes for them was there agreement on a course of action as seen in the extract below.

P4m: I think so, yes, I think I ought to read more..

C4f:Yes, I'd like to see you reading more, I think it would be a bit more....and if you get into a good book the day can go quickly can't it?

C4fF:No, I think we'll have to see if we can organise a bit of [laughs] reading.

In many instances the patients resisted the attempts by carers to **motivate** them and some attempts by the carers to get the patient more active were counterproductive, and often resented (P2m). In one account the patient speaks of not completing the crosswords that his wife wants him to, and in doing so he exercises control (P8m). This extract seems to represent in an allegorical way the loss of power this man feels and the level of control others have over him, his refusal to be 'in their ball game' is a way of asserting himself.

P2m: ..the thing is, I can only take things at a slower rate than I did before and E doesn't seem to want to accept that. Although she does say that she appreciates it, when it comes down to the crunch of actual activities she doesn't accept it, particularly the way she behaves.

C8f: No, but I think its good for the brain, y'know, to do things like that. (talking about crosswords)

P8f: I don't like them. They're a waste of time...they make, they're making you..you know you're in their ballgame, y'know, it's all their problem, the way they've formed it and I don't really need that.

In the accounts there was a sense that the carers were **responsible** for many different aspects of their partner's life and had many differing roles in their relationship; dietician, nurse, driver. This was sometimes bringing carers and their partners/patients into conflict with one another.

C9f: But now keeping off, he does have some fat but I'm trying to keep chips and fish and things like that, y'know, not have them and....

P9m: Have nothing

C11f: But I have got him sorted out now, so in the evening he's got them altogether [medication pills] so that's brilliant isn't it, only a pot to swallow (laughs).

This 'care' was not always easily accepted by the patients especially when it came to driving with male stroke survivors having to allow their partners to drive. Role reversal often caused minor conflict as most of the relationship roles prior to the stroke were gender specific.

C11f: No, he'll see lights coming up and he'll go "red".

P11m: It's wonderful really

C11f: Wonderful! I do get irritated by that.

C9f: Perhaps the most frustrating thing was when I had to drive [laughs] He didn't like me driving

C9f: [laughs] No. No, the thing was, I mean, he loves his driving, y'know, he always has done and the fact that I had to drive, he got a bit frustrated about that, didn't you?

These two conversations show the contrast in the understanding and tolerance that each wife shows to their husband. C9f empathises with her husband's frustration and intolerance whilst C11f expresses her irritation.

Overall there were general positive comments made by carers towards their partners and their relationship. For some couples the struggles made them closer and appreciative of one another. Other carers felt that there was no time or energy to argue and so they got on better with their partner and these carers often reported enjoyment and increased confidence from their new roles. C11f's relationship with her husband had always been characterised by his dominance pre-stroke but since the stroke he was 'very easy'. One carer reported no change for the better or worse in the relationship (C2f).

C3f: Y'know erm... well I dunno, I don't want to tell him in his face, you feel so proud he can do things he couldn't do twelve months ago, y'know, like.

*C8f:* Because y'know, it frightens you and you think, y'know, something could happen to him and y'know..it upsets you and makes you think, y'know, you're lucky that he's here, y'know, it does, doesn't it?

C8f: No, I don't think its, hasn't affected us at all...made us a bit closer, perhaps?

C11f: We get on alright, we don't have the energy to argue (laughs) he's very easy to do it, he's always very grateful, he always says thank you don't you.

C11f: I don't know really, the same I've always looked after him haven't I. In some ways he's easier to look after than he used to be

C2f: No I still don't like him, I love him but I don't like him [laughs].

There was a sense of constancy throughout the talks regarding the relationship. Difficulties within the relationship (e.g. C2f) were long standing in nature and present pre-stroke. Likewise those relationships that had always had an element of 'caring' to them appeared to have changed little (C11f). The relationships that had grown and flourished in the face of the stroke were reported to have been supportive and positive pre-stroke (C3f).

## <u>Carers' voice in relation to societal representations:</u>

Carers spoke of gaining advice from others and many were allied with medical staff in the treatment and management of their partner. In line with patients, general perceptions regarding the cause and control of the stroke fell into the same categories; chance, stress and diet. As found in the patients accounts, carers' accounts were filled with ageing discourse and this was used to explain most of the difficulties and may have been a form of reassurance.

C9f: The only thing is that you do get, sometimes you do get a little bit unsteady but then he's, y'know, when you're older you do have that.

C8f: Yeah and people think he's older than he is, y'see, cus he's got the stick and it's affected his speech a little bit, but not much...so.

Attributions of difficulties to age minimised the importance of these changes.

C4f: Well, and of course, we're both getting older anyway aren't we?

Patients spoke of being written off at a certain age, whereas carers' utilisation of services was often influenced by their perceptions of limited resources and limited treatment for stroke patients.

C9f: I mean, had that not started to, I could see a difference, then I think I would've made a bit of a noise and said 'Look, he needs to see someone'. I, I, actually someone did ring, they ring, I believe, if I can think back....I think they did ring and we said erm, 'No, its all ok, its fine' y'know, I thought, well, there's other people that will probably need their attention...[talking about physiotherapy].

C11f: but definitely stroke, there's nothing they can do perhaps, perhaps they feel hopeless, do you think? [medical professionals].

This carer's statement (C11f) sums up the feelings that come across in most accounts, that stroke is associated with old age, and at times it can feel hopeless trying to maintain the perception that the person they once knew pre-stroke will return. The female carers talked of gender roles and particular difficulties that face older women whose husbands have experienced a stroke and this was also a form of social comparison. Using downward comparison the carers could feel positive about their additional responsibilities. C6f: But I'm very glad I did [ drive] because it would've been very very difficult otherwise. It must be awful if the woman can't drive and, I mean, in my generation that isn't all that unusual, is it.

C10f: I don't understand why a lot of women, particularly my age, seem to be so frightened about everything, afraid to go out on their own, y'know, hardly drive anywhere on their own, don't walk on their own, I don't know..

Visible disability had the negative connotations as found in the patients' accounts. The use of a wheelchair is seen as a symbol of disability and deterioration rather than an aid to mobility. Aided mobility is seen as giving up and succumbing to the disability, giving up hope for future improvement.

C5f:Well, that's what I felt, yeah, I thought 'Ooh, I wonder if a wheelchair would be any help?' and I thought 'No!' [laughs] No.

C5f:No. I think that [laughs] that's a retrograde step isn't it? [laughs]

## Carers' communication formats:

The style of interaction exhibited by carers when talking about the care needed by the patients, and their new roles since the stroke, often resembled a parent and child relationship. This style could be seen in five of the interviews, however this didn't necessarily mean the overall conversation was dominated by the carer. Often these parent-child roles were only evident when the talk turned to the care received by the patient. These interviews were often filled with humour and a shared narrative and understanding of events. Congruent thoughts and shared narrative combined with the use of humour and validation of the patient by the carer indicated that despite their parent-like role, carers helped patients to maintain an overall level of communication and equal status.

#### Parent-child role

C6m: And she comes, I'll be watching, y'know, if I've gone up there to do some cattle or anything like that, she'll come past the van, that way, and like a naughty school girl [Mrs G laughs] looking round the corner to see if I'm all right! [P and C laughing]. And then I'll just shout and point 'House!' [P and C laughing].

In this extract explicit reference is made to "school girl" demonstrating that there is an explicit awareness of the more superior and dominant role the husband plays in the relationship. Carers facilitated their patients in the conversation by providing the **scaffolding** into the conversation and by picking up and elaborating on their contributions. Posing facts as questions allowed patients to respond and therefore engage in the conversation.

## Scaffolding:

C6f: We were in the old house, that's it, erm...Well, I think you managed, getting up stairs and so on, didn't you?

P6M: Yes

Elaborating:

I: What things do you enjoy doing together?

P10m: Music.

C10f:..and music yes, the opera...

Overall patients contributed less in the interviews than the carers and this meant that most carers took on the role of directing the conversation and **facilitating** the patient in partaking in the conversation. Facilitation was achieved by prompts and directing questions towards their partner. Here is an example of agreement by the carer that helps validate the patient as someone competent and who has something worthwhile hearing:

P5m: I can wash up though!

C5f: Yes! [laughs] he's a dab hand at washing up! [laughs] which is worth a lot.

In some conversations there was a lack of **validation** or facilitation occurring, with carers **monopolizing** the conversations and **interrupting** or **ignoring** the patients' contributions. Often the topic of conversation would be re-directed by the carer.

In the extract below the carer re-directs the conversation. Carers whose patients had cognitive difficulties often managed the conversation and this influence was usually subtle but in this instance the carer had been upset when speaking about her husband and their relationship and to avoid further upset or embarrassment steers the conversation away from the topic. Although the carer in this extract ends the conversation she does at least acknowledge the patients contribution.

P9m When we first met something in my eyes, said 'I don't want you!' [laughs]

C9f: Yeah, well, they don't want to be hearing that story!

In the extract below (C11f) the carer fails to pick up on the patients' contribution and does not acknowledge or elaborate upon his point. She fails to collaborate with him in the conversation in contrast with C9f and P9m. I: What do you both have in common?

C11f: We've been married for fifty years

P11m: We are quite happy together

C11f: yes, well I'm not very interested in Rugby but I put it on for you don't I.

Carers would often bring up the difficulties and problems faced by the patient and then together they would discuss it and talk about improvements. However, some carers' talk reinforced the patients' limitations. In Couple 11 the carer's talk places emphasis on the patient's memory problems and is quick to presume that the patient has forgotten things, in some instances before the patient has had chance to reply:

C11f: And on Saturday he's decided he wants to go on what is it? You've forgotten it haven't you?

And this occurs yet again in this couple when the patient is trying to recall how many plants he has put in the garden.

C11f; Oh no I think it's in the fortysomethings, I think you have forgotten that.

These communication formats were seen in couples where there was dominance by the carer as opposed to just directing conversation. These conversations tended to have a parent-child interaction style throughout the interview.

*P11m: The one's in the living room, I haven't touched them have I, Two bars (chocolate).* 

C11f: How long have they been there G

C11f: about a week, but I feel so mean.

P11m: But I haven't touched them

C11f: But you do though don't you, fair do's I am right aren't I G.

P11m: I'm sure you are

The extract above shows that the patient tries to resist the accusation but this fails and he passively accepts the carer's point of view. Conversations where carers displayed a dominant style of interacting also included **mockery** and **conflict** by either patient or carer and in some cases **infantilization** of the patient by the carer .

## Belittling/mockery:

C2f: He's always having them (referring to MI).

C2f: The things he does you have to laugh, but he isn't laughing.

C2f: And, of course he wasn't very pleased, you have to laugh, if you didn't laugh at him, you'd cry.

Below is an example of conflict. The carer laughs off patients' criticism over the 'new' diet she has put in place for him, but the patient is not laughing and is quite serious.

## Conflict:

I: What do you have now? P9m; have nothing C9f: have more [laughs] P9m: have nothing that's what it means

## 4.4.2 Results section part 2

Analysis of the roles taken by the carers and patients in relation to one another and the communication formats used resulted in the couples being classified into three groups: Dominant, Equal or Conflicted. The number of negative and positive contributions noted in the conversations contributed to the classification distinction of conflicted and equal. The contribution by each partner in the conversation also indicated whether a conversation was equal or dominant. Once the 10 couples were classified into the three groups, the anxiety and depression scores of the patients and carers recorded in the previous study (Ch 3) at 1 month, 3 months, and 6 months were analysed. Table 4.2 shows the individual scores of the couples at these time points. Dominant and conflicted couples were put together in a group and those that exhibited low levels of conflict or dominance were placed in another group, to examine whether there were any significant differences between the conversation styles and levels of previously measured depression and anxiety. The mean scores for anxiety and depression lacked normality therefore non-parametric Mann-Whitney tests were performed (see results in Table 4.2 ). Descriptions of conversational styles follow:

#### <u>Dominant</u>

Dominant conversations involved tutting, direct criticism or sarcasm directed by the carer to the patient. Carers held roles that were similar to a parent and the patient as a child, or a teacher and pupil dynamic. In this style there may be patronizing behaviour exhibited by the carer. In the conversation suggestions by the patient for new topics are dismissed or not acknowledged. The patient is not encouraged to take an active role in the interview. Questions are closed or rhetorical and there is interrupting by the carer or not enough time given for the patient to respond. Patients are passive and when attempts are made to resist or disagree with the carer's viewpoint they fail.

## **Conflicted**

Conflicted conversations may have overlaps with the dominant conversations yet in this style both carers and patients may exhibit dominance. In this style both patient and carer try to establish their views and voice but they are often incongruent with their partners The communication formats show there is a lack of agreement, mirroring or reflection shown by the couple. There may also be a lesser form of conflict present, which shall be termed resistance, this may be used by the carer or patient and is in response to the statements or views of the other. Resistance can be subtle in conversation i.e. switching topics, or failing to acknowledge a topic that is introduced, or obvious, by undermining the other's account by providing evidence contrary to the speakers viewpoint.

#### Equal

Both patient and carers take part equally in the conversation. Either partner can introduce new topics or direct the conversation. There is a mix within the transcript of questions and statements and shared guidance of the conversation. Patients are addressed as adults and are helped by carers to maintain equal status in the conversation by the use of prompting through open ended questions. Both speakers are allowed to finish sentences and if the other is struggling may be guided to complete the sentence. In this style of conversation viewpoints are acknowledged and often shared. These couples have shared narratives involving the stroke and the impact, views are mostly congruent. Both speakers may use empathy to convey understanding and validation of the other.

# <u>Results for conversation style and distress</u>

There were no significant effects found at any of the time points between interactive group and depression and anxiety for the patients but there were significant differences found in

160

carers. Carers who are in the conflicted/dominant interaction group had significantly higher levels of depression and anxiety at 1 month post stroke and significantly higher levels of anxiety at 6 months post stroke than those carers exhibiting equal interaction styles

 Table 4.2. Carers' depression and anxiety scores examined in relation to their interactive style.

Time Point	Equal Couples	Conflict/Dominant Couples	Z scores
C1 Anxiety	4.25 (n= 4)	12.66 (n=3)	2.22*
C1 Depression	1.00 (n= 4)	8.66 (n= 3)	2.14*
C2 Anxiety	4.8 (n=5)	10.00 (n= 2)	1.56
C2 Depression	2.00 (n= 5)	6.5 (n= 2)	1.79
C3 Anxiety	4.8 (n= 5)	14.00 (n= 3)	2.25*
C3 Depression	3.4 (n= 5)	7.00 (n= 3)	1.38

C1=1 month post stroke, C2 = 3 months post stroke, C3 = 6 months post stroke

\* Significant at p<.05

## **4.5 Discussion**

## 4.5.1 Patient and carer themes and their relation to the literature

Results from the IPA analysis have elicited many important themes in terms of how stroke patients make sense of and interpret meaning in their illness experience. Patients understood the stroke and their inabilities by anchoring themselves to old age; this allowed minimization and normalization of their problems. By constructing their accounts through ageing discourse they could bolster their self perception and through social comparison most patients believed they were in fact fortunate in their experiences. This finding is similar to other recent qualitative and quantitative research on other older adult populations with and without dementia (Clare, 2003; Beaumont & Kenealy, 2004). In a community sample,

downward social comparison was found to be a dominant strategy for 78% of older adults and associated with increased perceptions of Quality of Life (Beaumont & Kenealy, 2004). In the Beaumont & Kenealy (2004) study downward comparison was also used by older adults who were carers but not as often. Social comparison theory (Bower, 1991) and the selective affect-cognition priming model emphasizes how individuals that are depressed experience dysphoria which will prime negative thoughts about the self, and will engage in upward social comparison (viewing others in a more favourable light). This upward social comparison will in turn decrease subjective well-being resulting in further feelings of dysphoria and thus maintaining negative thoughts about the self and increase engagement in upward social comparison. It would be important to take into account patients' depression and anxiety scores to look at whether those patients who are depressed, compared to those who are not, engage in more upward social comparison. The quantitative data of Chapter 3 found that overall the stroke patients recruited for this study scored low as a group for depression, which would fit with the overall tendency of patients in this sample to use downward social comparison which would lend support to the affect-cognition model. A sample of stroke patients that score low on depression is also of interest as depression has been found to have a high prevalence in stroke populations (Robinson 1998).

The downward social comparison that many patients engaged in when discussing the consequences of their stroke is said to be characteristic of high self-esteem individuals who often engage in more self-enhancing comparisons (Wheeler & Miyake, 1992). In this group there were retired professionals who had experienced a stroke and, in their own accounts, had lost a great deal of highly skilled and valued activity, yet despite this in many accounts there was downward comparison. This finding may fit with Wheeler and Miyake's (1992) research. Despite patients' loss of self, their self esteem in relation to their past achievements

may still be present and as a cognitive habit allowing the individual to engage in downward comparison. This type of comparison bolsters self- esteem which helps the person to be euthymic, and in line with Bower (1991), the euthymia would promote positive thoughts about the self. Those individuals that did not use downward comparison were individuals who had experienced negative life events. Stressful life events in addition to the experience of the stroke appear to influence perceptions, cognitive style and coping. Those individuals with stressful life events were least likely to engage in downward comparison. Research demonstrates that older adults may be at greater risk of stressful life events (i.e. ill health, loss of loved ones) and therefore be vulnerable to the additive impact on psychological well-being (Knight, 1996).

In contrast to patients' accounts carers' accounts tended to highlight problems in their life as a result of the stroke, and although in general making sense of the stroke was through the focus of ageing, some carers showed a marked resistance to attribute patients' difficulties to ageing. The normalisation of patients' problems, using ageing discourse, may undermine carers' sense of struggle and invalidate their anxieties. Anxiety was in fact far more common in the carers' accounts than in the patients, with most of the fears centering on the unexpected nature of stroke and whether a second stroke may occur. Linked to this fear of a second stroke was the uncertainty regarding the cause of stroke. Fear of a second stroke has been shown to be associated with an increase in emotional distress in carers which would fit with the high levels of anxiety reported by the carers rather than patients (Hanger & Molley, 1993).

The most common area of concern for carers was regarding the patients' loss of activity. Carers believed that getting patients to do more was a positive and worthwhile endeavour despite resistance by the patients. The parent-child role was most clear when carers spoke of

163

attempts to get the patient involved in activity. Often carers were allies of the medical professions and adhered to their advice and dominant representations of the causes of stroke, disregarding the patients' perspective. In contrast to findings by Clare & Shakespeare (2004), in studies of dementia patients and their partners, the caregiving spouses in this study were not over-protective towards their care-receiving partner. Clare & Shakespeare (2004) found partners protected their relatives, in terms of denying difficulties and compensating with other activities, but in this study the carers wanted the patient to be more aware of their limitations and to work harder to improve, even when in some cases this view was not shared by the care-receiver. Conflict arose when incongruent views over activity level were expressed to one another and this was generally when a caregiver would become dominant conversationally.

Individual's attitudes to such things as assistance by others (e.g. cutting up one's food) or the use of a wheelchair seemed to fit with negative societal representations of disability. Assistance with activities of daily living had negative connotations for both patients and carers. Rather than seeing aid (such as a wheelchair) as enabling a person to return to previously valued activities, such as accompanying their partner when shopping, aid was seen as stigmatizing and embarrassing. Disability aids perhaps trigger schemas (Bartlett, 1930) related to disability and social stigma and as such are regarded as negative and are resisted by both patients and carers alike. At the societal level the lack of positive elderly and disabled role models in the media is an issue that would need to be addressed. Many stroke patients are left with disabilities that are chronic in nature and without aid may have their quality of life reduced.

## 4.5.2 Conversation styles

Carers were generally in control of the conversations and when conflict arose they would either concede to the patient by enabling the patients' view to be heard or become more dominant in the conversation by using infantilisation, mockery or by interrupting. This level of control exhibited in the interactions in this study would fit with the general literature on overprotective and over-controlling caring (Thompson et al., 2002). There is evidence in previous research that carers exhibiting dominant styles of caregiving have higher levels of depression and anxiety, both in stroke couples and couples living with dementia, supporting the findings in this study (Thompson et al. 2002; Clare and Shakespeare 2004). The interesting finding in this study is that the style of interaction appears not to be associated with the levels of self reported distress by patients. What is not known and difficult to ascertain is whether the anxiety and depression are precursors of poor interaction style and possibly marital problems or a result of interactions that are conflicted or dominant. What is interesting to note is that patients' depression and anxiety scores were not significantly different in relation to conversation style. Therefore carers and patients exhibiting these interactive styles may not be equally affected. It may be that carers who are struggling with anxiety find it more difficult to interact in an equal way or that this style of interacting exacerbates the already difficult task of caring; either way it would be misleading to say one preceded the other as that is not possible without detailed analysis of conversations and interactive styles at T1(< 1 month post stroke). As mentioned in the introduction, those relationships that have pre-stroke difficulties may not give caregivers the intrinsic sense of reward that caring for a close and intimate partner would, thus caring may feel more burdensome (Yardley, 1997).

The literature on dementia suggests that dominant and conflicted styles of interaction with elements of 'malignant social psychology' (Kitwood, 1999), a term which encompasses an environment that is unsupportive and hostile to the person, may in the long term have detrimental effects on the individual patient and their struggle to retain a sense of mastery and well-being (Thompson et. al. 2002, Clare & Shakespeare, 2004); this may be true for stroke patients. Results in this study appear to show evidence of malignant social interaction taking place (Kitwood, 1997).

Based on the findings in this study and on the recent literature looking at interactions and communication in caregivers and care-receivers in intimate relationships, the literature would point to an association between caregiver depression, poor interaction style and poor perceived care of the stroke patient. This relationship has been simplified in a diagram (see Figure 4.1). The diagram shows where the literature fits in and the hypothesized links between depression, dominant and conflicted types of interaction and caregiving. As the literature has shown in caregivers, to both stroke and dementia populations, the depressed caregiver interacts less positively with their partner, and are more resentful leading to carereceiver dissatisfaction. Care receiver's dissatisfaction would be evident in interactions with their caregiver and may feed back into the caregiver's depression by undermining and devaluing the care that they provide. (Martire, Schulz, Keefe et al., 2003). Based on such a small sample and by amalgamating different research findings with different populations and methodologies this model is only a tentative means of explaining the results and incorporating them into the existing literature. Further research would need to be conducted to address whether this is an appropriate model and also to assess whether these results would be found in non-caregiving samples (i.e. interaction style effects mood in close relationships regardless of whether caregiving or non-caregiving). In the next study patients

and their carers, along with age-matched controls, have been filmed interacting on two tasks, and the results will be examined in relation to anxiety and depression in controls and stroke patients and carers at 6 months post-stroke.

The proposed model of interaction in line with these findings and the evidence from previous research (Martire et. al. 2003) follows the diagrammatic representation:



Fig 4.1: Proposed Model of Dyadic interaction in Distressed Caregivers.

(Schultz et al (2003); Jones & Morrison, 2004

## 4.6 Reflexivity

The researcher's presence in the interview introduced an element of competition for participants to have their voices heard. Both patient and carer were familiar with the researcher from involvement in previous research or from being contacted for recruitment in the hospital. Participants may have been expecting the researcher to interview them separately, as previously conducted in earlier research (Study 1). To minimize any bias in perspective questions were directed to both partners and it was made clear at the start that the researcher was interested in hearing both voices. How the patients and carers dealt with sharing the conversation was not seen as a complication to the analysis but as an enrichment in capturing the dynamics between patient and carer as they managed turn-taking and questioning by the researcher. Despite some benefits of the researcher's presence, the communication seen in these interviews may deviate from a representation of their everyday conversations.

A secondary issue of interviewing both partners simultaneously was that either one may have felt inhibited by the presence of their partner and may have failed to disclose any problems or difficulties. Dealing with sensitive issues in front of significant others makes social desirability a problem in the research responses. In the previous quantitative research in Study 1, questionnaires on marital intimacy were completed separately by patients and carers to address this problem. Participants were given privacy to respond, without their partner, but only high levels of marital intimacy were reported. On examination of the scores the Marital Intimacy scale exhibited a ceiling effect which may indicate the impact of social desirability and is a problem difficult to overcome regardless of methodology. The researcher being female may have inhibited some responses regarding any intimacy or sexuality issues as the majority of stroke patients in this sample were male. The results do

168

contain disclosures of difficulties by patients and carers and conflict did arise within conversations despite the presence of the researcher. Therefore the conversations are nonuniform and suggest validity in regards to capturing differing experiences and realities. The familiarity of the researcher in having met these patients and carers on several previous occasions was an asset in the data collection though care has been taken to avoid bias in the analysis by the use of a rater unfamiliar with the couples.

## **CHAPTER 5**

# STUDY 3: A COMPARISON OF CAREGIVING COUPLES AND NON-CAREGIVING COUPLES ON MARITAL INTIMACY, DISTRESS AND INTERACTION USING A NOVEL OBSERVATIONAL TOOL.

## **5.1 Introduction**

Research carried out with non-caregiving couples has shown that marital closeness and satisfaction is reported to increase with age (Brubaker, 1990; Cartensen, Gottman & Levenson, 1995). Older couples have been observed to express less negativity and more affection than younger couples. Given these findings, it is important to ask what will happen when one partner is taken ill and the other becomes a carer. Will it be the case that the relationship will be detrimentally affected (Reese, 1994), or will the marital closeness in this age group act as a buffer against negative life events? As discussed in Chapter 2, stroke can pose a significant challenge to close relationships within the family system. Stroke can present challenges as a result of the emergence of new patterns and roles that persons with stroke and their partners often experience (as seen in the qualitative accounts in chapter 4). Family members that are now having to act as caregivers may have to adjust to a different way of communicating and interacting with the person with a stroke. A factor that may be crucial not only in carer well-being, but also in patient well-being, is the quality of the relationship between the patient and the carer. Studies have been conducted with informal carers of older adults examining carer distress (Broe et al., 2000). The results (Broe et al., 2000) found the quality of the relationship between caregiver and receiver fundamental in determining carer distress. Carers who felt they were in a relationship controlled by the caring for reported more distress.

Intimate, close relationships have been shown to have beneficial effects at times of stress and the absence of intimate relationships has been associated with depression (Brown, Bifulco & Harris, 1987). In the caregiving literature low levels of marital intimacy, as assessed by the Marital Intimacy Questionnaire, were found to be associated with depression in spousal caregivers (Morris et al., 1988). Relationship quality has also been found to play an important part in stroke patients' physical recovery; the better the family dynamics the less time the patient spends hospitalised (Evans et al., 1987). A study on stroke couples found the most helpful form of support for stroke patients to be 'matched' support, where the carer provides support specific to the stress being experienced (Clark & Stephens, 1996). In this study patient depression was found to be correlated with perceiving carer actions as unhelpful while patients having a positive affective state were more likely to perceive carer actions as helpful (Clark & Stephens, 1996). Other studies have also found greater depression in stroke patients where the family member is perceived to help too much, with the type and appropriateness of the care provided by family members reported to be a major determinant of quality of life for stroke survivors (Thompson et al, 1989).

Over-protective care has been linked to negative consequences in patients', for example, depression and lack of motivation in physical therapy programs (Hyman, 1971; Evans et al 1984; Dempster et al., 1998). Researchers have recently acknowledged the importance of significant others on patient outcomes (Morrison 2001; Schwarzer & Schroder, 1997; Dempster et al., 1998).

Partners' resources have been shown to be important in patient social support, social integration and quality of life (Schroeder & Schwarzer, 2001) and discrepancies between patients and their carers regarding recovery, associated with patient and carer depression and

anxiety (Morrison, Hare, Horsfield & Bates, 2001). The quality of the relationship between patient and carer, and their perceptions of the illness and care required, would appear to be important factors in both patient and carer well being (as seen in Chapter 3).

Research on marital quality has relied mainly on self-report measures. where each member of a couple reports answers to questions on their relationship. In a questionnaire format, responses could be influenced by social desirability or by cognitive dissonance; in other words if the carer expends large amounts of time and energy on the care-receiver, but simultaneously reports the relationship to be poor, there is a discrepancy between thoughts and actions. Direct observation of couples interacting could reduce the potential for social desirability bias or cognitive dissonance and could provide a valuable insight into the nature of interaction between carer and care-receiver. Gallagher-Thompson et al. (1997) demonstrated the feasibility of videotaping dementia patient-carer dyads in their own home. Their analysis found a positive relationship between distress and marital conflict, as well as an inverse relationship between distress and the frequency of positive interactions in persons with dementia and their caregivers.

As far as could be determined, only one published piece of research on stroke carers has used observational techniques to examine interaction. This study (Thompson et al., 2002) investigated the link between the caregiver's interaction style and the care receiver's feelings of overprotection. The study used four tasks, which were videotaped, to identify overprotective care on behalf of the carer. This study attempted to identify determinants of overprotective care using self report measures of feelings of overprotection, physical and mental functioning and attitudes related to caregiving. Carer resentment was found to mediate the relationship between observed overcontrolling caregiving styles (as rated by

researchers) and patients' feelings of overprotection. Carers higher in resentment were more likely to have overcontrolling caregiving styles that were rated by the patients as overprotective. Caregivers' perceptions of benefiting less in the relationship were positively correlated with overprotective caring. The question this study raises is where does carer resentment stem from? Is it the result of perceiving less from the relationship when in the caregiving role? If so, then all carers may be resentful and exhibit this in interactions, alternatively it may be an aspect of the past relationship that makes caring difficult. Premorbid relationship quality has been found to be under-researched in a recent review of research on stroke informal caregivers (Lowe et al., 2001). In the review it was suggested that resentment on behalf of the carer may stem from pre-stroke relationship quality. Earlier research supports this, such as the study by Clark & Stephens (1996), who found that married stroke patients who were less satisfied with their marriage judged that their partners engaged in more unhelpful behaviours. However in this study, as in the Thompson et al. (2002) study of carer resentment and overprotection, no control group was used. A control group is ideally required in order to examine whether some of these behaviours were specific to a caregiving relationship or are to be found in age matched controls and may be a facet of relationships in older adults. The majority of the caregivers in the Thompson et al. (2002) study were women (65%) however there were no gender differences detected, except that male patients were more likely to have dependent attitudes than women. As the majority of caregivers tend to be women, it would be important to disentangle the effects of being a wife and being a caregiving wife when looking at interaction in this age group.

A larger body of observational work has been undertaken with caregivers and care-receivers in dementia care and there have been some successful and ongoing research projects looking at the feasibility of videotaping caregiving dyads with dementia in their own environment and a research environment (Gallagher-Thompson et al., 1997, 2001). The aim of this research is to apply similar techniques to those used in the Thompson- Gallagher et al. (1997) study but with stroke patients and their carers, and to validate a set of interaction scales (Chisholm, 2000). This study will explore whether there are any correlations between observed interactions and self reported marital intimacy and distress. In addition, this study will address past as well as current marital intimacy and will evaluate whether there are specific differences in interaction associated with caregiving or non-caregiving status.

## 5.2 Aims

- To examine differences between caregiver/care-recipient couples and non-caregiving couples on measures of distress intimacy and interaction.
- To investigate whether observed interaction, as rated by a set of interaction scales, correlate with validated measures of distress and relationship quality.

#### 5.3 Methods

#### 5.3.1 Participants

There were 10 stroke couples and 10 non-caregiving couples that took part in filling in the questionnaires. 10 stroke couples also took part in the videotaping section of the study but unfortunately 3 tapes were void because of a failure of equipment on two occasions and the other couples' seating arrangement obscuring the video. Therefore the videotapes of 7 stroke couples were utilised as well as the videotapes of the 7 healthy elderly couples which were used as a control group. In total there were 40 individual participants in this study of which 28 took part in the videotaping.
All caregiving and non-caregiving couples were married and had been married on average 30.1 years (s.d.= 10.7). The caregiver wives had a mean age of 67.20 (s.d. 7.57) and non-caregiving wives had a mean age of 62.50 (s.d. 8.77); this age difference was not significant (t=1.27, (18), p>.05). Caregiving wives were caring for husbands who had a mean age of 72.60 (s.d. 6.33) and non-caregiver wives had husbands with a mean age of 64.30 (s.d. 8.97); this was a significant age difference (t= 2.39, (18), p<.05). Mean level of disability at the time of videotaping was 107.12 (s.d. 16.01). The range of disability was from 70-120 on the Barthel (the higher the score the less the disability on activities of daily living). The average length of time post stroke for the caregiving couples when taking part was 5.5 months.

The caregiving couples were recruited from a local District General Hospital and were identified as having had a stroke by the Stroke Team. The person with stroke was approached by the researcher in hospital and their spouse was sent a letter regarding the study. If both the stroke patient and carer consented they were contacted by phone and a home visit arranged by the researcher. The second group consisted of 10 older (aged over 55) married couples in which neither spouse had a physical or mental health condition (as identified by self-report) and perceived themselves to be currently healthy. Non-caregiving couples were recruited from the School of Psychology Participant Panel and were matched as closely as possible to the caregiving couples on key sociodemographic details. This study focuses on comparisons between wife caregivers and wife non-caregivers as all of the stroke couples with valid videos consisted of a husband who had experienced a stroke and a wife who was the carer. Due to the nature of the tasks, dysphasic or aphasic patients were not recruited (as in the previous study in chapter 3). The exclusion criteria used in this study were identical to those in Study 1.

#### 5.3.2 Measures

### <u>Disability</u>

Mahoney and Barthel (1965) designed The Barthel Index of Activities of Daily Living, which is a well-validated self-assessment measure of general disability. It has been used previously in studies of stroke patients (e.g. Morrison et al. 2000). The scale had ten items originally, with two further items added for this study (i.e. How is your speech?; How is your eating?). Each item has between two and four possible responses on a Likert scale; the higher the score, the better the functional independence. Total scores can range from 0 to 120, a score of 120 represents functional independence, though not necessarily normality. Carers were asked to give a proxy rating for the patient (as reported in Study 1).

### <u>Distress</u>

The Hospital Anxiety and Depression Scale (HADS) consists of 7 items measuring anxiety and 7 measuring depression. Zigmond and Snaith (1983) designed the scale, and it has since been well validated in different populations including stroke patients (Morrison et al., 2000) and stroke caregivers (Anderson et al., 1995). On each subscale, the highest possible score is 21; a score of 0-7 falls in the non-clinical range, 8-10 indicates a possible clinical disorder and 11-21 indicates a probable clinical disorder. The sum of depression and anxiety scores reflects distress levels. Maximum score for distress is 42, minimum is 0. Alphas for Depression and Anxiety, in this study, were 0.741 and .883 respectively, reflecting good levels of internal reliability.

### Marital Intimacy Questionnaire

The Marital Intimacy questionnaire was specifically developed for use with elderly spouse

caregivers (Waring & Reddon, 1983). There are 30 statements covering facets of intimacy, namely affection, cohesion, expressiveness, compatibility, conflict resolution, sexuality, autonomy and identity. Participants are asked to think of their relationship before and after the stroke. The higher the score the more intimate the relationship is perceived to be. The maximum score is 120, minimum score is 0. The scale takes a past and present rating on the 30 statements. The alpha in this study for Marital Intimacy present and past was .970. The scale has been used in Study 1 and was found to have ceiling effects; it is used here in conjunction with the observational scales to examine criterion validity of the observational scales.

### **Observational** Scales

A set of scales designed to capture communication and interaction between care-receivers and their caregivers was developed by Chisholm (2000). These scales require researchers to rate video clips of the dyad working together on two tasks (puzzle completion and planning a trip together). Each interactional dimension is rated on a scale of 1-4, (1-2 represents a low score on a dimension, 3-4 high). The care-recipients (and the non-caregiving husbands) were rated on the following dimensions: engagement in task, positive affect and negative affect. The caregivers (and the non-caregiving wives) were rated on: engagement in task, positive affect, negative affect, dominance, sensitive responsiveness, depersonalising behaviour and problem solving. Each couple were also rated on two global dimensions: emotional atonement, interactive style and communication quality. In total there are 12 dimensions for each dyad. For a full explanation of the dimensions of the scales and how they were rated refer to Appendices 10 and 11.

### 5.4 Procedure

Videotaping took place in the couples' homes and consisted of filming the couples on two tasks: planning a trip together and completing a jigsaw puzzle. Before filming began rapport was established with the participants, and some of the questionnaire measures (demographic details, Barthel Index, HADS) were administered to the husband and wife before filming began. The first filmed task involved completing a 32 large piece jigsaw puzzle of a Renoir painting obtained from an Occupational Therapy catalogue. The instructions were for the couple to work together to complete the jigsaw puzzle and that they were not under any time limit; the researcher then left the room. The second task involved the couple planning a trip. The couples were asked to plan a hypothetical or real trip or holiday for themselves to go on in the near future. They were told it could be a day trip, a visit to family or friends, or a holiday. They were asked to think of things they would like to do and see, and to discuss any relevant arrangements that would need to be made including: what they would need to bring; how they would get there; and anything else they thought would need to be taken care of. They were told they had approximately 10 minutes for the task and then the researcher left the room. At the end of the planning task the camera was switched off and packed away while the couples were allowed to discuss their thoughts and feelings towards the task. The remainder of the questionnaires were then completed with both husband and wife.

The tasks were chosen in line with published research on people with dementia and carer couples (Thompson, Gallagher, et al. 2001) and in consultation with researchers (Woods, Bruce, Orrell & Russell, 2003) who had previous experience of using these techniques with people with dementia.

### 5.5 Results

### 5.5.1 Results for depression, anxiety and marital intimacy

There was no significant difference in anxiety scores between husbands with stroke and their mean score of 4.10 (s.d. 2.06) and healthy husbands whose mean scores was 4.5 (s.d. 3.89) (t=-.24, (18), p>.05). There was no statistically significant difference between depression scores for husbands with stroke, mean of 5.2 (s.d 3.42) and husbands who were healthy, who had a mean score of 2.8. (s.d. 1.98), (t=1.92, (18), p>.05), though this was close to statistical significance (p=.07). When examining the depression scores on the HADS, 3 out of the 10 husbands with stroke had scores at or above the suspected clinical borderline of 8, whereas none of the healthy husbands scored at or above 8 for depression. Only one husband with stroke scored 8 or above for anxiety whereas 2 healthy husbands scored 8 or over.

The wives' mean anxiety scores were 8.2 (s.d. 5.53) for the caregivers and 4.5 (s.d. 4.50) for the non-caregivers. This difference approached statistical significance (t=1.87, (18), p=0.06). The wives' mean depression scores were 4.8 (s.d. 3.79) for the caregivers and 3.00 (s.d. 1.56) for the non-caregivers; this difference was not statistically significant (t=1.39, (18), p>.05). None of the non-caregiving wives scored 8 or above on depression or anxiety whereas 4 out of 10 caregiver wives scored 8 or above for depression and 5 out of 10 scored 8 or above for anxiety. None of the couples reported any change in intimacy from the past to present, therefore the present intimacy rating is used throughout the remainder of this analysis. Husbands with and without stroke and caregiving and non-caregiving wives all report moderate to high levels of marital intimacy.

There were no significant differences between marital intimacy scores of husbands with stroke (M=90.10, s.d. 14.35) and healthy husbands' marital intimacy scores (M=87.78, s.d.

11.20); the data were significantly skewed exhibiting a ceiling effect, therefore the groups were compared using a Mann Whitney test (z= -.4084, (18), p>.05).

There were no significant differences between caregiving wives' marital intimacy scores (81.80, s.d. 14.93) and non-caregiving wives' intimacy scores (77.89, s.d. 18.18) (t=.51, (17), p>.05). The mean scores of disability as rated by caregiving wives and their husbands with stroke, were different; wives rated their husbands as more disabled, mean Barthel score of 105.50 (s.d.15.36) whilst the husbands with stroke rated themselves as less disabled with a mean score of 115.00 (s.d. 7.07), close to the maximum score obtainable on the Barthel (max=120). This husband and wife difference, unlike in chapter two, was not statistically significant (t= 1.78, (18), p>.05). The Barthel scores indicate that the stroke patients are close to independence.

### 5.5.2 Inter-rater reliability

Inter-rater reliability data was obtained using three raters who have experience of working with older adults. The first rater was the researcher and the other two raters were trained postgraduate research Psychologists. The training session for the raters comprised of watching the videos of three couples completing the puzzle and planning tasks; these couples had been recruited to the pilot phase of the study and their data is not included in this study. During training each rater scored each couple and the scores were then openly discussed. Guidance was given by the first researcher and any discrepancies were clarified. Once this training session had been completed the seven stroke and healthy couples were rated. The first five minutes of each task were rated by each of the three researchers independently and the scores were not discussed. As the sample size was small all seven couples were rated by all three researchers but the order in which they were rated was randomised. Only the main

researcher rated couples on both tasks, the other two raters were assigned only one task per couple to avoid a carry over effect from having rated the same couple on two tasks. Intra class correlations (ICC) were used to calculate reliability instead of Pearson's r as ICC is preferred when sample size is small (<15) or when there are more than two raters (Shrout & Fleiss, 1979) but is still a measure of association. ICC is the ratio of between groups variance to total variance (Shrout & Fleiss, 1979). ICC will approach 1.00 when there is no variation within subjects (i.e. all raters give the same ratings). Tables 5.1 and 5.2 show the inter-rater reliability scores on the Puzzle and Planning tasks. Acceptable reliability is reported to be approximately 0.70 (Shrout & Fleiss, 1979).

### Inter-rater reliability results

Overall the planning task elicits more acceptable reliabilities than the puzzle task and reliabilities on the puzzle task were generally lower for the caregiving couples than the non-caregiving couples (see Table 5.1 and 5.2). There was a high level of agreement for husbands' and wives' engagement in task and negative affect on both tasks. Positive affect was low in reliability for husbands with stroke on the puzzle task and caregiving wives' negative affect had less reliability among raters on the planning task. Dominance, sensitive responsiveness, depersonalising behaviour and problem solving for caregiving wives on the puzzle task all achieved a low level of correlation among raters ranging from .200 to .530. Emotional attunement and interactive style and communication quality achieved modest to high levels of correlation amongst raters on both tasks.

### 5.5.3 Interaction results

The observational tasks and the differences reported between caregiving and non-caregiving couples can be seen in Tables 5.3 and 5.4. A mean score was taken of the three raters' scores

to provide one score per dimension and per task for each subject. Tables 5.3-5.4 show that on some dimensions there were a broad range of scores used and on other dimensions there was no range. Overall there was a more restricted range of scores used for the non-caregiving couples which partly explains the differences in inter-rater reliability between caregiving and non-caregiving couples on the puzzle task (i.e. there was greater variability in interactions in the caregiving couples than the non-caregiving couples). The results show that on both puzzle and planning tasks both caregiving couples and non-caregiving couples were highly engaged in the tasks. As both husbands and their wives, whether care-giving or non-caregiving consented to take part in the study they are likely to be motivated to engage in the tasks

### Caregiving and non-caregiving couples on the puzzle task

Husbands without stroke appeared more engaged in the task (though this failed to reach significance) and exhibited less negative affect than husbands without stroke. Caregiving wives and non-caregiving wives were both equally engaged in the task and exhibited equal levels of positive affect. The mean and range for negative affect for caregiving wives was broader than non-caregiving wives but was not significant. Caregiving wives were significantly more dominant and used more depersonalising behaviour (p<.05) than non-caregiving wives. In fact none of the non-caregiving wives received scores of greater than one on dominance or depersonalising behaviour. Although no other significant differences between the scales was found, the means indicate that non-caregiving wives received higher scores on problem solving and overall non-caregiving couples had higher mean scores for interaction style and communication quality than the caregiving couples.

### Caregiving and non-caregiving couples on the planning task

Husbands without stroke and husbands with stroke showed no significant differences in engagement in the task, negative affect or positive affect. Caregiving wives and non-caregiving wives were equally engaged in the task, but caregiving wives exhibited more negative affect than non-caregiving wives, non-caregiving wives did not score greater than one on negative affect. Non-caregiving wives' scores appear to suggest that they exhibited more sensitive responsiveness, though this missed statistical significance (p<.077). Unlike on the puzzle task there was no difference in dominance and depersonalising behaviour between caregiving wives and non-caregiving wives. Although the non-caregiving couples gained higher scores on emotional attunement and interaction quality this was not significantly different from the caregiving couples.

# Table 5.1. Results of inter-rater reliability for caregiving and non-caregiving couples on

# the puzzle task

Measurement Scales-	Intra-	Measurements	Intra-class
Puzzle Task: Husband	class	Scales-Puzzle Task:	correlatio
with Stroke	correlatio	Husband without	n
	n	stroke	
Engagement in task	1.00	Engagement in task	1.00
Mood rating-positive affect	.350	Mood rating-positive affect	.500
Mood rating-negative affect	1.00	Mood rating-negative affect	1.00
Caregiving Wife		Non-caregiving Wife	
Engagement in task	1.00	Engagement in task	1.00
Mood rating-positive affect	.949	Mood rating-positive affect	.857
Mood rating-negative affect	.888	Mood rating-negative affect	1.00
Dominance	.500	Dominance	1.00
Sensitive responsiveness	.200	Sensitive responsiveness	.780
Depersonalising	.530	Depersonalising	1.00
behaviour		Behaviour	
Problem solving approach	.421	Problem solving approach	.889
Husband and Wife		Husband and Wife	
Emotional Attunement	.842	Emotional Attunement	.778
Interactive style and	.600	Interactive style and	.887
Quality		Communication Quality	

# Table 5.2. Results of Inter-rater reliability for caregiving and non-caregiving couples on the planning task

Measurements Scales-	Intra-class	Measurements Scales-	Intra-class correlation
Planning Task:		Planning Task:	contonation
Husbands with Stroke		Husbands without stroke	
Engagement in task	1.00	Engagement in task	.950
Mood rating-positive affect	1.00	Mood rating positive affect	.741
Mood rating-negative affect	.857	Mood rating negative affect	.892
Caregiving Wife		Non-caregiving Wife	
Engagement in task	1.00	Engagement in task	1.00
Mood rating-positive affect	.952	Mood rating-positive affect	.701
Mood rating-negative affect	.667	Mood rating-negative affect	1.00
Dominance	.889	Dominance	.980
Sensitive responsiveness	.727	Sensitive responsiveness	.892
Depersonalising behaviour	.907	Depersonalising Behaviour	.883
Problem solving approach	1.00	Problem solving approach	.790
Husband and Wife		Husband and Wife	
Emotional Attunement	.789	Emotional Attunement	.778
Interactive style	.842	Interactive style	.878
Communication Quality		Communication Quality	

# Table 5.3. Descriptive statistics of scores for the puzzle task for caregiving and non-

# caregiving couples

Measurement	Ca	regivir	ng Coup	les	Non-Caregiving Couples							
Scales Puzzle Task		N	=7		N= 7							
N=14												
Husband	Mi	Max	Mea	SD	Mi	Max	Mea	SD	Т	Sig.		
	n		n		n		n					
Engagement in task	3	4	3.86	.38	4	4	4.00	.00	1.00	.337		
Mood rating positive affect	1	4	243	.84	2	3	2.28	.76	.33	.743		
Mood rating negative affect	1	2	1.28	.48	1	1	1.00	.00	1.55	.147		
Wife												
Engagement in task	4	4	4	.00	4	4	4.00	.00	Na	Na		
Positive affect	1	4	2.50	1.0 4	1	3	2.43	.78	.14	.887		
Negative affect	1	3	1.21	.57	4	4	1.00	.00	1.00	.337		
Dominance	1	3	1.50	.41	1	1	1.00	.00	3.24	.007*		
Sensitive responsiveness	1	4	2.43	.84	2	3	2.71	.48	78	.451		
Depersonalising behaviour	1	2	1.21	.27	1	1	1.00	.00	2.12	.05*		
Problem solving approach	1	4	2.36	.80	3	4	3.00	.57	-1.72	.111		
Husband and Wife												
Emotional attunement	2	4	2.93	.73	3	4	2.28	.48	-1.07	.304		
Interactive style and Communication Quality	1	4	2.57	.84	2	4	3.28	.75	-1.67	.120		

\*=p<.05

186

# Table 5.4. Descriptive statistics of scores on the planning task for caregiving and non-

# caregiving couples

Measurement	Ca	aregivir	ng Coup	oles	Non-Caregiving Couples							
Scales Planning task N=14		N	[=7		N= 7							
Husband	Mi n	Max	X	SD	Mi n	Max	x	SD	T	Sig		
Engagement in task	2	3	3.21	.91	3	4	3.85	.38	-1.73	.109		
Mood rating positive affect	1	4	2.64	1.0 3	1	3	2.00	.81	1.29	.220		
Mood rating negative affect	1	3	1.71	.80	1	2	1.14	.38	1.69	.116		
Wife												
Engagement in task	3	4	3.86	.38	4	4	4.00	.00	-1.00	.337		
Positive affect	1	4	2.71	.90	1	4	2.00	1.0 0	1.40	.18		
Negative affect	1	3	1.64	.75	1	1	1.00	.00	2.27	.042 *		
Dominance	1	3	1.28	.76	1	1	1.71	1.2 5	77	.454		
Sensitive responsiveness	1	4	2.50	.96	3	4	3.28	.48	-1.93	.077		
Depersonalising behaviour	1	1	1.00	.00	1	2	1.14	.38	-100	.337		
Problem solving approach	1	3	2.57	.73	1	4	3.14	.66	-1.50	.159		
Husband and Wife												
Emotional attunement	2	4	2.93	.60	3	4	3.14	.69	62	.549		
Interactive style and Communication Quality	2	4	3.07	.73	3	4	3.43	.53	-1.04	.318		

\*=p<.05

187

### Correlations between interaction, depression, anxiety and marital intimacy

Due to the limited number of significant differences found between caregiver couples and non-caregiver couples on the interaction scales it was decided to combine all the couples' data in order to examine associations between the observational scores and levels of anxiety, depression and intimacy.

The puzzle task's observational scales show that negative affect of husbands or wives is associated with depression and anxiety. In addition, higher levels of marital intimacy in wives is associated with less negative affect. Higher levels of problem solving and emotional attunement are associated with lower levels of depression and higher levels of depression and higher levels of depression behaviour are associated with higher levels of anxiety. Wives' engagement in the puzzle task was not correlated with depression, anxiety or marital intimacy as there was no variation, all wives scoring the maximum score of four (refer back to Table 3.5).

On the planning task there was no relationship between husbands' negative affect and depression and anxiety but negative affect in wives was positively associated with higher levels of depression and anxiety. Sensitive responsiveness and problem solving were significantly negatively correlated with depression and anxiety indicating that those wives who were less depressed and anxious exhibited more sensitive responsiveness and problem solving behaviour during the task. Interaction quality was significantly negatively correlated with depression is associated with better quality interactions. Those correlations that failed to reach significance all appeared to indicate appropriate directionality (in line with previous research).

Marital intimacy correlations failed to show construct related directionality indicating that this scale does not correspond with the observed interactions and fails to lend criterion validity to the observational scales. As shown earlier in the results, the marital intimacy scale fails to show much variation in scores on either past or present intimacy in caregiving or non-caregiving couples and this lack of discrimination will have affected the correlations.

To further examine the nature of the scales in relation to each task and each dimension Inter and Intra-Scale correlations were performed on the data and tables 5.7-5.9 show the correlation matrices.

	Observationa	l Scales-Puzzle Tas	k (N=28)
Husbands	Depression	Anxiety	Intimacy
Engagement with Task	327	232	161
Positive Affect	028	038	.053
Negative Affect	.558**	.491**	157
Wives			
Engagement in Task	NA	NA	NA
Positive Affect	269	371	.102
Negative Affect	.432*	.435*	375*
Dominance	.348	.322	013
Sensitive responsiveness	375*	249	139
Depersonalising Behaviour	.355	.458*	104
Problem Solving	460*	173	009
Emotional Attunement	435*	321	.156
Interaction Quality	315	237	294

 Table 5.5 Correlations between interaction scores on the puzzle task and depression,

 anxiety and intimacy.

\*=p.05, \*\*=p.01

# Table 5.6 Correlations on the interaction planning task and depression, anxiety and

# intimacy

Observational Scales-Planning Task (N=28)										
Husbands	Depression	nning Task (N=28)onAnxietyIntimacy $177$ $244$ $.065$ $.093$ $.109$ $023$ $161$ $232$ $212$ $.115$ $.459*$ $215$ $088$ $.262$ $403*$ $.073$ $.131$ $139$ $239$ $053$								
Engagement with Task	091	177	244							
Positive Affect	244	.065	.093							
Negative Affect	.231	.109	023							
Wives										
Engagement in Task	327	161	232							
Positive Affect	339	212	.115							
Negative Affect	.384*	.459*	215							
Dominance	205	088	.262							
Sensitive responsiveness	573***	403*	.073							
Depersonalising Behaviour	.275	.131	139							
Problem Solving	497**	239	053							
Emotional Attunement	326	165	.042							
Interaction Quality	411*	225	.099							

<sup>\*=</sup>p<.05, \*\*=p<.01, \*\*\*=p<.001

Puzzle	Puzzle	1	2	3	4	5	6	7	8	9	10	11
1 Husband Eng	agement Task			- 34(- 0)								
2 Husband Pos	itive Affect	.751*										
3 Husband Neg	ative Affect	645*	553*									
4 Wife Engager	ment Task	NA	NA	NA								
5 Wife Positive	Affect	.635*	.812**	820**	NA							
6 Wife Negativ	e Affect	.167	.037	.645*	NA	424						
7 Wife Domina	nce	540*	487	.418	NA	588*	.001					
8 Wife Sensitiv	e Responsive	.752*	757*	757*	NA	.955**	225	730*				
9 Wife Deperso	nalising Beh	471	106	.730*	NA	299	.471	.382	292			
10 Wife Proble	m Solving	.746*	730*	666**	NA	.949**	196	636*	.847**	222		
11 Emotional A	ttunement	.559*	.669*	866**	NA	.820**	559*	279	.670*	548*	.689*	
12 Interaction Q	Quality	.827**	.898**	669*	NA	.907**	037	731*	.957**	266	.948**	.689*

Planning	Planning	1	2	3	4	5	6	7	8	9	10	11
1 Husband Eng	agement Task											
2 Husband Posi	tive Affect	.140										
3 Husband nega	ative Affect	016	843**									
4 Wife Engager	nent Task	.591*	.704*	428								
5 Wife Positive	Affect	.290	.676*	584*	.834**							
6 Wife Negative	e Affect	114	.131	.147	210	544*						
7 Wife Dominat	nce	104	.153	389	.167	.139	379					
8 Wife Sensitive	e Responsive	.480	.592*	430	.691*	.768*	290	230				
9 Wife Deperso	nalising Beh	NA	NA	NA	NA	NA	NA	NA	NA			
10 Wife Probler	n Solving	.476	.814**	663*	.947**	.915**	326	.258	.773**	NA		
11 Emotional A	ttunement	.562*	.685*	726**	.674*	.713*	249	.052	.573*	NA	.763*	
12 Interaction Q	Quality	.421*	.424*	443*	.559*	.514*	615	.381	.416	112	.767*	.731**

Puzzle	Planning	1	2	3	4	5	6	7	8	9	10	11	12
1 Husband Eng	gage Task	.590*											
2 Husband Pos	sitive Affect	.751*	.593*										
3 Husband Ne	gative Affect	161	426	.452									
4 Wife Engage	ement Task	NA	NA	NA	1.00**								
5 Wife Positive	e Affect	.044	.583*	396	.635*	.883*							
6 Wife Negativ	ve Affect	NA	.382	.153	.156	347	.800*						
7 Wife Domina	ance	563*	099	252	540*	450	.136	.540*					
8 Wife Sensitiv	ve Responsive	.188	.593*	281	.752*	.846**	247	255	.831**				
9 Wife Deperso	onalising Beh	565*	NA	.138	471	565*	.863**	NA	489	NA			
10 Wife Proble	em Solving	.164	.736*	459	.946**	.852**	169	196	.868**	NA	.801**		
11 Emotional A	Attunement	.152	.513	603*	.559*	.906**	.559*	.043	.654*	NA	.711*	.736*	
12 Interaction (	Quality	.360	.662*	334	.827**	.854**	152	301	.831**	NA	.805**	.585*	.397

### 5.5.4 Results of the Intra-class and Inter-class correlations

#### <u>Puzzle</u> <u>Task</u>

As expected interaction quality exhibits a large number of associations with the other scales in the puzzle task. Those couples who have higher levels of interaction quality are more engaged in the task, have more positive affect and less negative affect. In couples with high levels of interaction quality, wives are less dominant, have greater sensitive responsiveness and problem solving and as a couple are more emotionally attuned. Emotional attunement was also strongly correlated with the other scales in a similar fashion to interaction quality except that emotional attunement was also negatively correlated with wives' negative affect and problem solving behaviour. Engagement in the task for the puzzle (husbands only) and planning tasks (husbands and wives) was correlated with positive affect in husbands and wives. Negative affect in husbands was associated with lower engagement in the task. Wives' positive affect was positively correlated with husbands' positive affect and husbands engagement in the task and negatively correlated with husbands' negative affect. Negative affect was positively correlated between husbands and wives. As found in the correlations between depression, anxiety and dominance those wives that are dominant are less likely to exhibit positive affect. Dominance was also negatively correlated with husbands' engagement in the task and their positive affect. Sensitive responsiveness was positively correlated with husband engagement in task but negatively correlated with husband negative affect. These correlations demonstrate how each partner's interaction affects the other and how the measures of emotional attunement and interaction quality were indicators of the general level of interaction. Due to the lack of variance in scores, wives' engagement in the puzzle task could not be used for the purposes of correlation.

### <u>Planning</u> Task

As found in the intra-scale correlations for the puzzle task, interaction quality and emotional attunement in the planning task exhibit a large number of associations with the other scales and these associations are in the same direction as observed in the puzzle task. Problem solving had significant positive correlations with husbands' positive affect, wives' engagement, wives' positive affect and sensitive responsiveness and a significant negative correlation with husbands' negative affect. Depersonalising behaviour could not be included due to the lack of variance in scores on this task.

There were no significant correlations between dominance and any of the other dimensions, unlike in the puzzle task where dominance did have significant intra-scale correlations. Wives' negative affect was negatively correlated with positive affect as was expected but this was not found in the puzzle intra-scale correlations. Wives' positive affect was positively correlated with husbands' engagement in the task and husbands' positive affect was negatively correlated with husbands' negative affect. Husbands' negative affect was negatively associated with positive affect. As found in the puzzle intra-scale correlations there is a high level of significant multidimensionality in the planning scales and the scales all appear to exert influence on one another.

There were strong inter-scale correlations as expected, which would indicate the evidence of both tasks tapping into the same aspects of communication and interaction (see Table 5.9). Despite the significant and strong correlations in a number of areas in the inter-scale correlations, there are differences between the puzzle and planning tasks data, supporting the idea that both tasks are addressing slightly different aspects of interaction and communication.

### 5.7 Discussion

The first aim of this study was to examine differences between caregiving and noncaregiving couples on measures of distress and intimacy. The self-reported measures found no significant differences between caregiving wives and non-caregiving wives or between the husbands with or without stroke on depression or anxiety. However, when examining the data closely it would appear that a number of caregiving wives were at risk of depression and anxiety, according to their individual scores, than non-caregiving wives and there may have been statistically significant differences observed had the numbers been greater. Another possible explanation for the lack of significant differences, is that caring is not affecting these women's mood. Caring has been shown in other studies to have positive aspects (Kinney et al., 1995) and caring does not necessarily lead to negative outcomes, which was reported in carers accounts in study 3. Overall the levels of distress in husbands with stroke and healthy husbands showed less variation than that found amongst caregiving wives. None of the couples reported any change in intimacy ratings from the past to the present. The intimacy measure failed to discriminate any changes over time and also exhibited ceiling effects with the husbands in both caregiving and non-caregiving couples. The similarity in self reported distress and intimacy between the groups may demonstrate that despite the differences in roles, caregiving couples have the same level of intimacy as couples in the same age cohort and that a chronic illness does not necessarily result in distress or reduced marital intimacy. The husbands who had experienced a stroke were all scoring highly on independence and therefore had low levels of disability, this could mean that the healthy husbands and stroke husbands may be similar in ability.

The second aim of the chapter was to examine whether there were observed differences in interaction between caregiving and non-caregiving couples.

There were clearly difficulties in rating the puzzle task as shown by some of the low ICC's and this could be due to the nature of the task which was predominantly a non-verbal motor task in contrast to the planning task which was a verbal non-motor task. It appears harder to gain reliability when rating caregiving couples than non-caregiving couples on the tasks, in particular on the puzzle task. The results may therefore indicate that interaction is less visible/audible for coding purposes on the puzzle task and this would need further investigation. However, there were significant differences shown between caregiving wives and non-caregiving wives on a range of behaviours and characteristics. Caregiving wives were more dominant and used more depersonalising behaviour and exhibited more negative affect. Various theories have been used to explain the relationship between carers and carereceivers in intimate relationships. Attempts have been made to explain why caregivers experience more distress which in turn is associated with greater overprotection and negative styles of caregiving. One such theory that has attempted to explain findings for overprotection by the caregiver is the 'Exchange Theory' (Bekowitz & Walster, 1976) which states that in a relationship there is reciprocal sharing of benefits and burdens but that in caregiving relationships the exchange breaks down as the caregiver has to give more and more time and energy for less; caregivers and care-receivers in this dynamic can then have perceptions of underbenefit or overbenefit which leads to a lack of satisfaction in the relationship. The person who is 'underbenefitted' is more likely to feel less communal or attached to the relationship and also to experience anger towards the other partner (Bekowitz & Walster, 1976; Thompson et al., 1995). Caregivers may feel underbenefitted (as found in the Thompson et al, 2002 study) and this may then spill into interactions with the carereceiver in negative ways.

The scales used in this study are highly inter and intra-correlated and the correlations give support to the idea that these scales are measuring common aspects of interaction and communication. As the main researcher rated the same couple on both tasks there is the risk of ratings from the first task being carried over to the second task. In future studies all judges that rate the puzzle task should be different from those that rate the planning task. The slight differences in the patterns of intra-scale correlations between the puzzle and planning tasks suggest that these tasks have differing demands tapping different aspects of interaction.

The third aim of this chapter was to investigate whether observed interaction correlated with self reported measures of distress and marital intimacy. Results show that wives (caregiving or non-caregiving in this study) who are more depressed and anxious exhibit (as one would expect) more negative affect, less sensitive responsiveness, more depersonalising behaviour and poorer problem solving behaviour, and are less emotionally attuned with their husbands. From these results it can be concluded that mood is seen to impact upon how a wife interacts with her husband, whether the wife is in a 'caring' role or not.

The significant correlations between depression and anxiety and negative affect, problem solving, emotional attunement and depersonalising behaviour fit with the results found in study 3 (Chapter 4) where significant correlations were found between conflicted or dominant conversation styles and caregiver anxiety and depression. It would have been interesting to separate out the caregiving couples from the non-caregiving couples when examining the correlations but this was not possible due to the increased risk of Type I errors and would be an avenue for future research.

### 5.7.1 Benefits of the methodology

The problems with some of the past studies that have examined family interactions (Evans et al., 1987), was the reliance on caregivers to report patient adjustment rather than seeking self-ratings from patients themselves. Furthermore, there has been a lack of age matched control groups to compare interaction between caregiving and non-caregiving couples (Thompson et al., 2002); both of these limitations were addressed in this study. The person who had experienced the stroke completed their own self report measures and this study also used an age matched control group.

The study had low costs in terms of time, with each task taking only approximately 10-15 minutes and the coding of the tapes taking only 5 minutes. The ease of training and low time involvement is one of the main positive aspects to the set of scales. The scales were also developed specifically for caregiving couples unlike measures such as the MICS which is generic to married couples regardless of health status (Marital Interaction Coding System as cited in Gallagher-Thompson et al., 2000). The MICS requires a long period of training and a low number of codes have been generated when used to code dementia caregiving couples, with suggestions that the MICS may not be suitable for such caregiving dyadic research (Gallagher-Thompson, 1997). Despite the small sample size in this study, the results show the ability to identify associations between mood and interaction styles. Hopefully these results will add to the body of research that has started to show that interactions between caregivers and care-receivers (Thompson et al, 2002) can be videotaped in the home environment and that the data derived from observations relate to well used and validated self report measures.

#### 5.7.2 Limitations

Those couples that chose to take part may be above average in adjustment to stroke, as well as in health, as shown by the high ratings on the Barthel demonstrating that these individuals may have low levels of disability. The couples volunteering to take part are also more likely to be satisfied with their relationship as shown by the high levels of marital intimacy reported. Due to difficulties with recruitment and time pressures the sample size is limited and it is possible that more significant differences between the caregiving wives and noncaregiving wives and husbands with and without stroke may have been found if numbers had been greater. Furthermore a bigger sample that included couples other than white Caucasian couples may enable a better understanding of whether the results are purely a facet of this sample or whether these interactions may also be found in other caregiving and noncaregiving couples.

There was no possibility of blinding the raters to health status as in some cases the nature of the stroke disability was visible. Therefore each rater knew which couples were in the clinical group and which were healthy. Perhaps all raters were primed to rate the caregivers as higher scoring on certain dimensions (i.e. dominance, depersonalising behaviour) due to knowledge of the literature as all raters were psychologists. There is a difference on interrater scores between the puzzle and planning tasks for caregiving couples suggesting that the raters were picking up on 'actual' differences in the task and not just a difference between groups.

### 5.7.3 Statistical considerations

Post hoc analysis and statistical considerations need to be considered with such low numbers. The number of correlations in comparison to the number of participants increases the risk of Type 1 errors, resulting in the necessary precaution of adjusting the alpha levels. There is a need to be cautious when examining the correlations looking in particular for the strength of the correlation. On closer inspection of the data the argument can be made for the application of nonparametric statistics if the scales were considered ranks instead of intervals along a continuum consequently a correlation coefficient derived from Spearman's rho may have been more appropriate. The scales are rated on a scale of 1-4 and on some of the dimensions the whole range of scores was not used. This may mean that on some dimensions raters may just be indicating whether there is a high or low level of that aspect of communication. If this is the case than a non-parametric analysis may have been more appropriate. In the original development of the scales researchers used both Pearson's r correlations on the scales and Spearman's rho and found that intra and inter scale correlations and their significance were unaffected according to the statistic used (Chisholm, 2000).

Despite the limitations there is a strength to this research in that a combination of methods were used; depression, anxiety and intimacy were assessed using self-report measures and the interactions scales were observational. It is hoped that further investigation of these scales and their validity in this population will be an area for future research.

201

### **CHAPTER 6**

# STUDY 4: YOUNG ADULTS' PERCEPTIONS OF STROKE AND CARING FOR A STROKE PATIENT

### **6.1 Introduction**

In everyday life people will have direct or indirect experiences of illness and through these experiences they will build up a future representation of that illness (see Chapter 1). Leventhal and colleagues (Leventhal, Meyer & Nerenz, 1980) proposed that these cognitive representations of illness, or common-sense models of illness, provide people with a framework or schema for symptom perception, and for understanding and coping with illness. Leventhal's idea of disease schema was explored in hypertension and cancer patients (Leventhal et al; 1980, 1984). Cancer patients were found to gauge likely treatment effectiveness by the size of their tumour. However, patients whose tumour reduction exceeded the expected rate had higher levels of distress. Leventhal argued that the patient's implicit model of cancer and the tumour was implicated in the patient's distress. The cancer patients' implicit representations of treatment and recovery were no longer valid when the tumour reduction exceeded their expectations and therefore they did not have a benchmark from which to monitor the effectiveness of their treatment. Following such early studies further research grew in the area of illness representations using interviews to establish that patients, as well as health professionals, viewed health and illness as a multidimensional concept (Lau & Hartman, 1995). Research on beliefs regarding illness in lay populations supported five illness representations of: identity, cause, timeline, consequences and controllability. Leventhal incorporates these dimensions into the Self-Regulatory Model (see Chapter 1) which proposes that individuals' beliefs about health and illness are based on

prior symptom episodes and ongoing physical experiences and that these beliefs influence subsequent coping reactions and that these coping reactions are dependent on the outcome of the initial processing. The illness representations of the self-regulatory model have been shown to be important in determining adjustment and coping in patient populations (Chronic Fatigue Syndrome; Rheumatoid Arthritis) (Moss-Morris, Petrie, Weinman, 1996; Shawaryn & Blum, 1998).

Research has demonstrated that individuals' representations of illness effect future health seeking behaviour, response to treatment, behaviour change and delays in seeking health care (Lau et al., 1983; Moss-Morris et al., 1996; Weinman, Petrie, Sharpe, Walker, 2000; Walsh, Lynch, Murphy & Daly, 2004). Mental representations of health and illness therefore play a critical role in health related behaviour (exercise, healthy eating, smoking etc) (Skelton & Croyle, 1991). Illness representations and their hypothesised role in the outcome for patients were further investigated with the development and implementation of a standardised instrument, the IPO (Illness Perceptions Questionnaire; Weinman et al., 1996). Morris (1996 as cited in Cooper 1998) used the IPQ to measure illness cognitions and how they relate to outcome measures of disability and psychological well-being. Morris (1996 as cited in Cooper 1998), in a multiple regression analysis, found that illness perceptions explained significantly greater prospective variance in levels of disability and psychological well-being than measures of coping strategies adopted by patients to manage their condition. A strong illness identity, low perception of control, perception of serious consequences and causal attribution of stress were negatively associated with mental health and functional ability. Links were also found between illness perceptions and coping strategies; beliefs regarding internal control led to positive reinterpretation of the illness by the patient, and emotion focused strategies were associated with identity, consequences, and time line changes in perception of the illness and effective coping. This work established important links between illness cognitions and coping methods, and between illness cognitions of patients and their psychological outcome, thus supporting the self regulation model as described by Leventhal et al. (1984) many years earlier.

### 6.1.1 Illness perceptions in stroke

As far as can be determined. very little research has been conducted on illness representations in stroke and none have used the IPQ; only two (Australian) studies have examined perceptions of stroke in patient and lay populations (Yoon, Heller, Wiggers, Levi, Fitzgerald, 2001;Yoon & Byles, 2002), neither of these studies used the IPQ and both are qualitative in their methodology. Through the data collection for the current PhD, contact with the general public revealed some misperceptions of stroke which led the researcher to investigate the understanding of what a stroke is in a lay population. The research extract below (Ellis-Hill, 1998 as cited in Payne & Ellis-Hill, 2001) sums up some of the difficulties that people who are living with stroke face when trying to convey the impact of stroke.

'Bob had one stroke and they can't do anything to put him right. And yet when you say heart attack people automatically think-waah, terrible. And it is terrible. But they can mend that. And yet they can't mend a stroke. And yet people dismiss strokes, as though it's er not so serious. That's what amazes me. That, that's the thing that really, and, and I find myself, because I think where people don't understand it, they're inclined to think that, what's all this fuss about, why are still backwards and forwards to the hospital. And you think, well you just don't understand.' (Ellis-Hill 1998 as cited in Payne & Ellis-Hill 2001, p.53)

When examining the literature there was evidence to show that stroke was poorly understood, not only by the general public, but also by individuals who had actually

experienced a stroke. Perceptions regarding stroke were elicited from the general public and from stroke patients in Australia (Yoon & Byles, 2002) and evidence was found of an overall lack of information for individuals in the community which translated into a difficulty in recognising stroke symptoms. The causes of stroke as cited by these participants were stress, diet, high blood pressure, age and smoking which fits with some of the cited risk factors in the British lay literature for stroke survivors (Stroke Association: 2003). However, understanding of symptoms was less clear, with many stroke patients reporting that they had failed to recognise their symptoms as indicative of a stroke; their symptoms had not fitted in with their understanding of stroke symptoms or they had very little understanding of what stroke symptoms were. These findings would relate to theories on prototypical representations of diseases as first described by Bishop & Converse (1986). Prototypical representations are an organised mental model of a disease built of symptoms against which new symptoms are matched for identification, for example a person may have a 'flu' prototype that consists of a fever and achey joints and when a fever arrives it is matched against this prototype before a person would interpret their symptoms as an illness or not. Disease prototypes therefore act as standards or "family resemblances" for symptoms. Evidence from a number of studies (Bishop & Converse; 1986 as cited in Skelton & Croyle, 1991; Lengerke, 2005) have shown that diseases that have high levels of consistent prototype symptoms and distinctiveness, are quicker to be recognised and identified. The existence and content of prototypes appear to influence the processing of underlying states from symptoms as well as the processing and recall of information about illness episodes (Lengerke, 2005). The difficulty with stroke is that often the early signs (i.e. headache) are not distinctive enough to allow identification.

It is hypothesised that a British study of lay perceptions of stroke would find similar symptoms cited to those found in the Australian study, such as paralysis, fainting and numbness. The interesting finding in Yoon and Byles (2002) is that the general public groups placed little importance on symptoms of stroke. Some participants reported that in reaction to symptoms of numbness, tingling sensations and weakness or paralysis of one side of the body, they would just lie down and take a couple of paracetamol. Patient and community groups in these studies all wanted community education about recognising stroke and the appropriate responses for those people experiencing a stroke.

Lay perceptions of stroke may often contain inaccurate information, as shown in these Australian studies. Inaccurate perceptions of stroke can have two predominant illness related outcomes. Firstly, inaccurate perceptions of stroke and the cause of stroke leads to the failure of individuals to take preventative measures to decrease their own risk of stroke, having implications for preventative health promotion. Secondly, inaccuracies in symptom perception have been shown to result in delays in seeking medical attention (Williams et al.,1997; Yoon & Byles, 2002), having serious implications for survival and recovery as treatment is most efficacious within 3 hours of stroke (Williams et al., 1997). If, as in the Australian study, symptoms are not correctly identified as fitting a prototype of stroke then the appropriate response (i.e. call an ambulance, visit the G.P. etc.) would not take place and the result could be increased disability or worse still death.

There are nearly 150,000 new cases of stroke reported in England and Wales each year, and at any one time in England and Wales there are approximately 300,000 people living with the effects of a stroke (Stroke Association, 2003). Residual disabilities frequently persist for long periods of time and can require considerable adjustment on the part of the patient and their family (Greveson, Gray, French, James, 1991; Anderson, Linto, Stewart-Wyne, 1995; Morrison, 1999). The importance of understanding lay perceptions of stroke is evident in terms of treatment and health promotion. However, in terms of the prevalence of stroke, with stroke being the leading cause of major disability in Britain (WHO, 2005), gaps in knowledge and inaccurate perceptions regarding stroke would have direct implications for the NHS.

As outlined above, there appears to be misunderstanding amongst the general public and stroke survivors regarding symptoms and severity in Australian populations (Yoon & Byles, 2002) and in American stroke populations (Williams et al., 1997). If there are misconceptions regarding the nature of stroke by stroke patients and the general public, then there may also be little understanding of what is involved in caring for a stroke patient.

The Caregivers Act (1996) recognised the important and vital roles that informal carers such as relatives play in caring for those with both physical and mental health difficulties. Once a stroke patient is discharged into the community, the responsibility for the patient's wellbeing generally falls on a community caregiver, typically a spouse or adult child (Morrison, 1999). It is generally accepted that prolonged caring for a chronically ill relative can have a detrimental effect on the carer's own physical and mental health through increased levels of stress (Hooker, Monahan, Shifren, Hutchinson, 1992; Shewchuck, Richards, Elliott, 1998); with depression and anxiety consistently more prevalent amongst caregivers than would be expected in a normal, age-matched population (Anderson et al., 1995). In line with the transactional model of stress (outlined in Chapter 1 and 3), the factors that may affect stress are the appraisal of the caregiving role which in turn can be affected by demographics such as age, gender and relationship to patient (i.e. is caring appraised as a threat or challenge). Differences in emotional responses to caregiving are also in part attributable to the

207

caregiver-receiver relationship, for example spouse caregivers have reported more physical and emotional strain than adult child caregivers (Cantor, 1983). The results of Study 1, found that adult child caregivers, in contrast to Cantor (1983), were experiencing the most strain at the acute phase and that a possible explanation for this may be that adult child caregivers may be caring for more disabled patients. Adult child caregivers may also be those with the least contact with chronic illness in terms of their age cohort; therefore investigating younger adults' perceptions of stroke and caregiving may be important as this group may have the least experience of stroke and may be at most risk for developing strain within a caregiving role.

The younger adult age group are also less likely to have caregiving experience (Lee, 2001). The carer's past experience of illness or caring is also likely to influence situational appraisals of their role as reported in Study 1. Gender differences may also exist in perceptions of illness with recent research on MI patients' illness representations (Walsh, Lynch, Murphy Daly, 2004) using the IPQ (Weinman et al. 1996), finding that males report more severe consequences of an MI than females and as a result have significantly less delay in attending hospital for treatment. Gender is also thought to affect caregiving appraisals with the majority of informal carers in our western society being women (Radley, 1994). Men may see caregiving as a typically female role to undertake and therefore perceive this role to be negative. Alternatively it has been found that female carers (Hagedoorn et al., 2000) express more distress when caring for their ill male partner than males caring for their ill female partners, and in the case of carers for family members that have experienced brain injury, a stroke or dementia, females reported a greater level of burden than male caregivers (Morris, Woods, Davies and Morris, 1991); female caregivers have also been reported to be more anxious than male caregivers (Dennis et al., 1998). These findings have been

explained in two ways: firstly in terms of females being more expressive of their emotions than males; and secondly, that females are more likely to assume an intensive personal role and are less likely to maintain outside interests than male caregivers (Radley 1994). It will be interesting to investigate whether these gender differences appear in hypothetical appraisals of caregiving in a younger sample.

Appraisals of control have also been suggested to play a role in caregivers' distress. In high demand situations, caregivers perceiving themselves as having less discretion over their actions appraise themselves as experiencing more strain (Orbell & Gillies, 1993). A higher perceived estimate of care-recipient disability by the caregiver has also been shown to correlate with caregiver burden, although objective disability is commonly not associated with burden (Morrison, 2001). Identifying individual and demographic differences that may affect perceptions of caring, prior to the potential uptake of the caring role, enables identification of those carers that may enter the role with increased risk of negative outcomes.

Illness perceptions in part shape our engagement in health risk or health enhancing behaviours (Weinman et al., 2000), behaviours that can reduce or increase later risk of stroke. Perceptions of caring and of illness are shown to affect well-being and distress as shown in Chapter 3. This study sets out to identify perceptions of stroke and stroke caregiving amongst a sample of young British adults who may be the potential stroke victims or carers of the future. The study will compare the results of caregiving appraisals in the lay population with those appraisals found in actual stroke caregivers (Chapter 3). A further aim of this study is to identify potential targets for intervention and health education regarding stroke amongst young people.

### 6.2 Aims

- 1. To investigate young adults' illness representations regarding stroke and caring for a stroke patient and to compare the hypothesised caregiving appraisals with actual caregivers' appraisals.
- 2. To examine the factors that influence stroke representations and hypothesised caregiving appraisals.

### 6.3 Method

### 6.3.1 Participants

There were 83 first year psychology undergraduate students at the University of Wales, who Bangor completed the questionnaire. The only criterion for taking part was that students had to have heard of stroke; if they responded that they had never heard of stroke they did not complete the rest of the questionnaire. Participants were aged between 18 and 57 years with the majority of students being in their early twenties (M=22.07, SD = 8.63). The students comprised of 70 females and 13 males and were predominantly Caucasian. The majority of participants were single (62%). In terms of illness, 22% had experienced or were currently experiencing a chronic illness. Fifteen students had been an informal carer, 13 for a chronic illness (including a stroke, n=1).

### 6.3.2 Measures

### <u>All participants completed the following battery of measures.</u>

### **Illness** Perceptions

The Illness Perception Questionnaire (IPQ), (Weimman, Petrie, Moss-Morris, Horne, 1996) was developed to enable researchers to compare illness representations across illness
populations (e.g. Shawaryn & Blum, 1998; Fortune, Richards, Main, Griffiths, 2000). The IPQ has shown good internal reliability (Weinman et al., 1996). There are five subscales of the IPO: Identity, Time line, Cause, Control and Consequences. The IPO can be adapted to specific illness populations and in this study has been adapted to stroke. Identity comprises of 19 items (e.g. weakness, paralysis, nausea) that the participant endorses as being part of the illness. In addition an open-ended question to address identity was included, 'In your own words please state what you think a stroke is'. Items for the remaining scales are rated by the participant on a 5-point scale ranging from 1 (strongly agree) to 5 (strongly disagree). Timeline comprises 3 items, example: "The effects of stroke will last for a long time". Cause comprises 10 items and is broken down into four specific causal subscales: Chance (1-5); Patient (4-20); Environment (4-20); and Genetic (1-5). An example of a Causal Patient item is "Strokes are largely due to individual behaviour". Control/Cure comprises 5 items. An example of an external control item is "Recovery from stroke is largely dependent on chance or fate". An example of an internal control item is "There is a lot a person can do to control the symptoms of stroke". Consequences comprise 7 items. An example of a consequences item is "Stroke is a serious condition". Scores for the Identity, Timeline, Consequences and Cure/Control scales are obtained by summing all the scale items: Identity (0-19); Consequences (7-35) high scores indicate greater consequences; Cure/Control (5-25); a high score indicates perceptions of internal control and a low score indicates perceptions of external control; Timeline (3-15); the higher scores indicate a more chronic timeline. IPQ scales showed satisfactory reliabilities (i.e. Cronbach alphas ranging from .55 to .72) with the exception of Cause Environment (.48), which is therefore treated with caution. Additionally Cause Genetic and Chance are one item subscales.

### Caring Impact Appraisal Questionnaire

The Caring Impact Appraisal Scale was derived from attempts to measure the subjective impact of caring, including both positive and negative appraisals (Orbell, Hopkins, Gillies, 1993). The 32 item questionnaire consists of four main factors: care work strain, care work satisfaction, relationship satisfaction and carer lifestyle satisfaction. This study uses only three of the four (sub) scales; relationship satisfaction was excluded due to difficulty in transferring the measure for hypothetical use. Participants rate on a 7 point scale the extent of their agreement with the 24 statements. Examples of the scale items are: care work strain, "caring means less energy than normal"; care work satisfaction, "caring makes life better organised"; and lifestyle satisfaction, "caring makes someone feel valued", with high scores indicating greater perceived strain or satisfaction. Care work strain scores are 13-91; care work satisfaction scores are 6-42 and care lifestyle satisfaction scores are 5-35. The Caring scales show high internal reliability (i.e. Cronbach Alpha's range .72 to .92).

#### 6.4 Analysis

The responses to the open-ended question regarding stroke identity were analysed using content analysis and subsequently categorised. Individual statements for the IPQ and Caring Impact Appraisal Scale were summed and means calculated. The individual items were then summed and an overall mean was calculated for each of the five components (Identity, Timeline, Control, Consequences and Cause) of the IPQ and the three components for the Caring Impact Appraisal scale (work strain, work satisfaction and lifestyle satisfaction). Demographic and individual differences in the IPQ and Caring Appraisals were assessed using independent sample t-tests. The relationship between the IPQ and Caring Appraisals were analysed using bivariate Pearson correlations.

212

#### 6.5 Results

### 6.5.1 Perceptions of Stroke

When examining the total scores for the IPQ sub scales (see Table 6.1) it can be seen that participants perceived there to be numerous symptoms associated with stroke, believed the consequences to be great and of a chronic duration and were unsure of the potential for control and cure. Participants identified loss of strength, mobility problems and speech problems as more likely to occur than nausea or an upset stomach although they did not rate paralysis as symptomatic of stroke. In response to the open-ended question regarding stroke identity, 74.7% mentioned neurological damage and cited disruption to the blood supply to the brain as a cause, 10.1% responded that a stroke was a heart attack and a further 2.5 % cited heart problems as causing a problem in the brain. A further 12.6% responded to the question by listing symptoms without mentioning a cause.

Participants agreed with the consequences statements "There are major consequences to stroke" and "Stroke is a serious condition", but paradoxically they also agreed with the statement "Stroke has little impact on one's life". Participants recorded uncertainty regarding whether stroke had a financial or social impact and were also uncertain as to whether it affected a stroke victims self-perception. Cause was identified as most likely to be stress and least likely to be germs, overall participants perceived patient behaviour (e.g. "Diet plays a major role in causing stroke") and genetics (e.g. "Stroke is hereditary, it runs in families") to be the most likely causes of stroke. Participants disagreed with statements regarding chance or patient control over recovery, therefore patients' control over recovery from stroke is perceived as low.

### Table 6.1 Means for the Illness Perceptions and Caring Appraisals for a stroke patient

Illness perceptions	Mean (s.d.)				
Consequences	(35)	28.75 (2.65)			
Cure/Control	(25)	15.59 (2.62)			
Timeline	(15)	11.89 (1.93)			
Identity Sympton	15				
Number	(19)	16.55 (3.01)			
Cause					
Chance related	(5)	2.77 (1.09)			
Patient related	(20)	13.42 (2.60)			
Environment	(20)	8.73 (2.21)			
Genetic	(5)	3.54 (1.03)			
<b>Caring Appraisal</b>	s				
Work strain	(91)	58.63 (15.29)			
Work satisfaction	(42)	34.49 (5.92)			
Lifestyle satisfaction	20.40 (6.80)				

as held by a young adult sample.

Intercorrelations between Identity, Timeline, Consequences, Control and the sub domains of Cause, are shown in Table 6.2. Timeline and Control were significantly negatively correlated. If participants perceived stroke to be of a chronic timeline, their perceptions regarding the patient's control over the illness decreased. The causal items were all significantly inter-correlated. The influence of individual factors on perceptions was assessed using t-tests. By examining the t-tests it can be seen that having a chronic illness or having been previously dependent on another person had no significant effect on stroke perceptions. There was also no effect of previous caring experience on stroke perceptions. A gender

effect was found with males perceiving stroke consequences as greater than females (t=2.63,(81);p<0.01) but there was no gender effect for the other four IPQ factors.

#### 6.5.2 Perceptions of Caring

Participants perceived there to be a moderate to high strain (M=58.63, SD = 15.29) involved in caring but they also perceived there to be high levels of care work satisfaction (M = 34.49, SD = 5.92) and moderate levels of lifestyle satisfaction (M= 20.40, SD = 6.80). The three caring dimensions were highly inter-correlated as expected from Study 1 and the literature (Orbell et al., 1993) (see Table 6.2). The caring dimensions were then correlated with the IPQ (Table 6.2). Carer lifestyle satisfaction and patient control were significantly negatively correlated (-.263, p<0.05) as was work satisfaction and patient control (-.228, p<0.05). As the patient is perceived to have more control over recovery, carer lifestyle and work satisfaction is perceived to decrease. Carer work satisfaction was positively correlated with perceptions of cause-chance (.217, p<0.05) and work strain was significantly negatively correlated with perceptions of cause-chance (-.226, p<. 05), cause-chance perceptions therefore associate with greater carer work satisfaction and less carer strain. Individual differences were again assessed using t-tests. Previous care work experience significantly reduced perceived care work satisfaction (t=-.2.22, df= 80; p<0.05) but had no effect on the other caring appraisals. No effect of gender was found on the caring appraisals.

### 6.6. Discussion

As shown in previous research there appears to be misunderstanding regarding what a stroke is and what part of the body is affected. From this sample, 12.6 % believed stroke to be a problem with the heart, which then affected the brain, some identifying stroke as a heart attack. The confusion between heart attacks and strokes has been found in lay populations and stroke populations in other studies (Yoon & Byles, 2002). Heart attacks appear to be more recognisable in society with stroke being a lesser known or understood disease. The danger in misperceptions is that heart attacks are perceived as a pain or numbness in the chest or arm (Yoon & Byles, 2002), which is very different from the warning signs associated with stroke and thus stroke symptoms may go unrecognised.

With the exception of paralysis, symptoms associated with stroke such as loss of strength and mobility problems were correctly identified. Participants' failure to attribute paralysis as a symptom could be due to the term itself; paralysis may be associated with complete body paralysis rather than specific paralysis of areas of the body or may be due to confusing a stroke with a heart attack (Myocardial Infarction). This finding is surprising, whatever the reason, given that paralysis is the most visible of stroke consequences and other research has found paralysis to be one of the main perceived symptoms of stroke (Yoons & Byles, 2002).

	1	2	3	4	5	6	7	8	9	10
1. Identity										
2. Timeline	.032									
3. Consequences	.225	.145								
4. Control/Cure	.135	277*	.027							
5. Cause-Chance	.095	.052	.182	.117						
6. Cause-Genetic	079	069	176	175	303*					
7. Cause-Environ	.112	079	074	.192	.025	.092				
8. Cause Patient	024	072	.184	.083	537***	.316*	.300*			
9. Work strain	138	067	.076	.117	226*	.038	.051	.0119		
10. Work satisfaction	.028	007	111	228*	.217*	.004	154	149	441***	
11. Life satisfaction	042	.035	167	263*	.159	.053	.021	119	474***	.504***

\*p < .05. \*\*p < .01. \*\*\*p < .001.

Appropriate attributions were made regarding cause of stroke: stress, diet, hereditary factors and individual behaviour. Causal attributions of stress and diet have been associated with appropriate health behaviour change following a heart attack (Weinman et al., 2000). When individuals rate their own behaviour as a causal factor, health behaviour change is more likely than when patients believe their illness is caused by hereditary or uncontrollable factors. Believing serious illness (e.g. cancer) to be hereditary has been associated with a fatalistic view of illness and low uptake of preventative behaviours in healthy older women (Savage & Clarke, 1998). Therefore, these young adults may be more proactive in reducing their own risk of stroke so long as their perceptions of cause indicate the role of the individual over hereditary/ genetic factors.

There was an unclear picture regarding young adults' perceptions of consequences and timeline. The participants agreed that a stroke would have major consequences for a person's life and that stroke was a serious condition, however they also agreed with the statement 'stroke has little impact on someone's life', although there was a greater standard deviation for this statement (1.02). Participants were uncertain as to whether they agreed with the statements: 'stroke has serious financial consequences' and 'stroke affects the way someone perceives themselves'. The overall mean for consequences indicated that the young adult sample believed there were serious consequences associated with stroke. Males in this study perceived the global impact of stroke to have more severe consequences than females. However, examination of gender differences is limited by the low numbers of males in this study; furthermore those males who did take part are unlikely to be representative of young males in their age group due to their level of education and choice of degree subject.

As for timeline, young adults equally agreed with the statements that suggested the effects of stroke would last for a short time and long time and that the effects would be permanent, suggesting some confusion over the effects of stroke. However, this finding could represent the broad spectrum of disability and recovery reflected in stroke patients; some stroke patients may make a near full recovery and others will suffer serious disability and handicap for the rest of their lives (Robinson, 1998).

Participants rated patients as having low amounts of control over their recovery. This could be due to a lack of knowledge regarding treatment and rehabilitation, although this was not investigated, and may fit in with recent research that has shown lay perceptions of chronic illness differ from those living with illness. Buick and Petrie (2002) looked at healthy women's perceptions of breast cancer and compared them to women undergoing breast cancer treatment. The results showed a marked incongruity between healthy women's perceptions and actual patients' experiences of the disease and its treatment. Healthy women overestimated patients' distress, perceived the consequences of breast cancer to be more severe, and were more likely to believe that patients used denial and disengagement strategies. Healthy individuals may perceive the consequences of chronic illness such as stroke as more negative than patients experiencing illness, as they do not have knowledge of the support systems that are made available to those with chronic illness. In the Australian study comparing healthy participants and stroke patients on their perceptions of stroke (Yoon & Byles, 2002), healthy participants had little knowledge of stroke organisations or the availability of educational/rehabilitation materials. Individuals with little to no experience of stroke may therefore perceive the consequences as more severe and less controllable than those who have had experiences directly or indirectly of stroke or chronic illness.

Perceptions of control have previously been associated with a wide range of health outcomes in stroke patients, with internal control beliefs predictive of better physical recovery (Johnston, Morrison, MacWalter, Partridge, 1999; Morrison, Johnston, MacWalter, 2000; Reich & Zatura, 1989). Entering a situation believing there is low personal control could have negative effects on the individual's emotional well-being and recovery. This group of young adults may therefore be vulnerable to poor physical and psychological outcome should they experience a 'young' stroke, the prevalence of which is on the increase (Stroke Association, 2003).

Perceived patient control was found to be negatively correlated with perceived carer lifestyle and work satisfaction which may seem counterintuitive; it is possible that as the participants perceived patients to have control over their situation, participants perceived the carer's role to be undermined, leading to a perceived reduction of caring rewards. In Chapter 3 (Study 1) actual caregivers' ratings of patients' control over recovery were positively correlated with carers' work satisfaction, so as the carers perceived the patients to have more control their actual satisfaction in caring increased. Therefore this may reflect a discrepancy in what is perceived to be satisfying about caring in lay populations or may just simply be a reflection of the different measures of control used (control as rated in the IPQ and RLOC as rated by patients and carers in Chapter 3).

Another interesting finding was that perceptions of the cause of stroke being due to chance were associated with greater perceived care work satisfaction and reduced carer strain. If stroke is seen to be unpredictable then participants in this sample perceived carers to be more satisfied with care work and less strained. Perhaps carers could be perceived to feel less responsible for the prevention / recovery of further strokes if there is no definitive cause, which may differ if the cause of stroke was attributed to stress or diet. A recent study of family carers of stroke patients found that carers who relinquished their own perceptions of control over the patient's recovery, when patient demands upon them increased, exhibited lower levels of depression and anxiety than those carers who maintained perceptions of control (Molloy, Johnston, Johnston, Morrison, Pollard, Bonetti et al., 2004). This is an interesting finding and in Study 1 there were no illness perceptions rated by the patients or carers and this may be an important area to investigate in relation to patient and caregiver well-being. The primary goals of support workers and health workers is often to increase the independence and control of the stroke patients in collaboration with carers. However this may carry costs to carers if they feel responsible for the patient's recovery.

The relationship between causal perceptions of chance and satisfaction in caring, if replicated in studies with actual stroke patients and their carers, will have implications for health workers and family support workers. In Chapter 4 (Study 2), the accounts of carers and patients cited similar causal factors to stroke as in this lay population (stress, diet etc.). The carers' accounts were filled with uncertainty regarding the chance of another stroke with some carers reporting that they were leaving it down to fate. Many of the carers accounts reported that they just lived "day to day", suggesting that there is an element of chance in actual caregivers' attributions regarding the likelihood of stroke occurring.

Overall, participants made accurate estimates of levels of carer strain relative to studies of actual carers and to carers in chapter three (Orbell et al., 1993). However, they also rated caring satisfactions higher than actual carers (Orbell et al., 1993), which may reflect an unrealistic optimism regarding the perceived satisfactions of caring. In this study carers' work strain was rated as moderate to high by the students and high levels of strain have been

found in 37% of actual stroke carers (Bugge, Alexander, Hagen, 1999). However, many studies have also shown that there are carers that do not feel any strain and experience positive benefits (Silliman et al.,1987) but this may not be well publicised and the negativity surrounding the demands of full time unpaid caring may be primed in the public's mind as it is in the research literature (Montgomery 1989).

#### 6.6.1 Limitations of the research

There can be limited generalisations from this sample, which is not representative as it focuses on students, whose acquired knowledge may be greater than the general population. The sample is also biased in terms of age and gender. Gender and other demographic differences have to be interpreted with caution, but despite the biased nature of the sample, some of the findings fit with previous literature on random community samples (Yoon & Byles, 2002). This study provides a tentative step in examining lay perceptions of stroke and caregiving using the IPQ and Caregiving Impact Appraisal Scale (Orbell & Gillies, 1993). Examining the sources of information (i.e. television, charities etc.) that had informed perceptions regarding stroke would have been useful in comparing British findings to other research and also to look at gaps in information provision to young adults (Yoon & Byles, 2002).

#### 6.6.2 Future Research

As far as can be determined there is a lack of research that has applied illness perceptions as a way of studying caregiving perceptions and willingness to care. As individuals build up their illness representations from direct or indirect experience, those without experience of caregiving or chronic illness may have very different perceptions from those that have experience, and this may ultimately affect willingness to take on a caring role in the future. Studies have looked at willingness to care as a simple measure of whether the individual is in favour of taking on the caring role and have generally looked at predictors to care such as demographics of carers, (Colerick and George 1986, as cited in Biegel 1991) and levels of emotional distress or burden associated with caregiving tasks (Anderson Linto, & Stewart - Wynne 1995; Greveson et al 1991; Morrison, 1999). Very few studies address the caregivers' perceptions/understanding of the illness and how this may affect their appraisal of caregiving and willingness to care. It would have been interesting to have included this in this study.

Future research would need to include a more representative sample and a broader age range to incorporate those in the lay population who may be more likely to experience a stroke (middle to older aged men; Stroke Association, 2003) or enter the caring role. Middle aged women's perceptions of a stroke and caring for a stroke patient and how this relates to willingness to care would be important to look at as this group are most likely to become carers or have peers who are carers (Lee, 2001).

As there is also a lack of research on actual British stroke patients and their illness perceptions, this is, another area that needs further investigation to examine whether misperceptions of stroke are evident in patient samples as well as in lay populations. As research has shown (Williams et al., 1997; Yoon & Byles, 2002; Walsh et al., 2004) understanding lay and patient populations' illness perceptions could have major implications for health promotion and treatment.

#### REFERENCES

- Adams, T. (2001). The conversational and discursive construction of community psychiatric nursing for chronically confused people and their families. *Nursing Inquiry*, 8, 98-107.
- Anderson, C. S., Linto, J., & Stewart-Wynne, E. G. (1995). A population-based assessment of the impact and burden of caregiving for long term stroke survivors. *Stroke*, 26, 843-849.
- Anderson, R. (1988). The quality of life of stroke patients and their carers. In R. Anderson and M. Bury (Eds.), *Living with chronic illness: the experience of patients and their families*. London: Unwin Hyman.
- Anderson, R. (1992) The aftermath of stroke: the experience of patients and their families. Cambridge: Cambridge University Press.
- Astrom, M., Adolfsson, R., & Asplund, K. (1993). Major depression in stroke patients: A 3year longitudinal study. *Stroke*, 24, 976 – 982.
- Audit Commission, (2004). Carers UK (2003). Missed Opportunities: The impact of new rights for carers. London: Carers UK.
- Aylard, P. R., Gooding, J. H., McKenna, P. J., & Snaith, R. P. (1987). A validation study of three anxiety and depression self-assessment scales. *Journal of Psychosomatic Research*, 31, 261 – 268.
- Barrowclough, C., & Parle, M. (1997). Appraisal, psychological adjustment and expressed emotion in relatives of patients suffering from schizophrenia. *British Journal of Psychiatry*, 171, 26 – 30.
- Bartlett, F. C. (1930). <u>Experimental method in psychology</u>. *The Journal of General* <u>Psychology</u>, 4, 49-66.
- Beaumont, J. G., & Kenealy, P. M. (2004). Quality of life perceptions and social comparisons in healthy old age. Ageing & Society, 24, 755-769.

- Berkowitz, L., & Walster, E., (1976). Equity theory; Toward a general theory of social interaction. *Advances in experimental social psychology*. Academic Press, Vol. 9.
- Bethoux, F., Calmels, P., Gautheron, V., & Minaire, P. (1996). Quality of life of the spouses of stroke patients: a preliminary study. *International Journal of Rehabilitation Research*, 19, 291-299.
- Biegel, D. E., Sales, E., & Schulz, R. (1991). Family caregiving in chronic illness: Alzheimer's disease, cancer, heart disease, mental illness, and stroke. London: Sage Publications.
- Billings, A. G., & Moos, R. H. (1981). The role of coping responses and social resources in attenuating the stress of life events. *Journal of Behavioral Medicine*, 4, 139 – 157.
- Bishop, G. D., & Converse, S. A. (1986). Illness representations: A prototype approach. *Health Psychology*, 5, 95 – 114.
- Bjelland, I., Dahl, A. A., Haug, T. T., & Neckelmann, D. (2002). The validity of the Hospital Anxiety and Depression Scale: An updated literature review. *Journal of Psychosomatic Research*, 52, 69 – 77.
- Blumenthal, J. A., Towner, E. T., & Siegel, W. C. (1995). Contribution of job strain, job status and marital status to laboratory and ambulatory blood pressure in patients with mild hypertension. *Journal of Psychosomatic Research*, 39, 133 – 144.
- British Heart Foundation (1996). *Heartwise Campaign*, as accessed on: <u>www.BHF.org.uk</u> (October 10<sup>th</sup> 2005).
- Bower G. H. (1991). Mood congruity of social judgment. In J. Forgas (Ed.), *Emotion and social judgement* (pp. 31-54). Oxford: Pergamon Press.
- Bowlby, J. (1969). Attachment and loss. Vol. 1: Attachment. New York: Basic Books.
- Broe, G. A., Jorm, A. F., Creasey, H., Casey, B., Bennet, H., Cullen, J., Edlebrock, D.,
  Waite, L., & Grayson, D. (2000). Carer distress in the general population: results
  from the Sydney older persons study. *Age and Ageing*, *28*, 307-311.

- Broome, A., & Llewelyn, S. (1995). *Health psychology: Processes and applications* (2<sup>nd</sup> ed.). London: Chapman Hall.
- Brown, G., Bifulco, A., & Harris, T. (1987). Life events, vulnerability and onset of depression: some refinements. *British Journal of Psychiatry*, 150, 30-42.
- Brown, L. M., & Gilligan, C., (1991). 'Listening for Voice in Narratives of Relationship' in
   M. Tappan and M. Packer (ed.s) Narrative and Storytelling: Implications for
   Understanding Moral Development (New directions for child development, No. 54.
- Brown, L. M., & Gilligan, C. (1993). Meeting at the crossroads: Women's Psychology and Girl's Development. *Feminism & Psychology*. Vol. 3(1) 11-35.
- Brown, G. W. & Harris, T. (1978). Social origins of depression: A study of psychiatric disorder in women. London: Tavistock Publications.
- Brubaker, T. H. (1990). Families in later life: A burgeoning research area. A Journal of Marriage and the Family, 52, 959-981.
- Bugge, C., Alexander, H., & Hagen, S. (1999). Stroke patients' informal caregivers: Patient, caregiver, and service factors that affect caregiver strain. *Stroke*, 30, 1517-1523.
- Buick, D., & Petrie, K. J. (2002). "I know just how you feel": The validity of healthy women's perceptions of breast-cancer patient receiving treatment. *Journal of Applied Social Psychology*, 32, 110 – 123.
- Cantor, M. H. (1983). Strain among caregivers: A study of experience in the United States. *The Gerontologist, 23*, 597-604.
- Cartensen, L., Gottman, J., & Levenson, R. (1995). Emotional behavior in long-term marriage. *Psychology and Aging*, *10*, 140-149.
- Charmaz, K. (1983). Loss of self: a fundamental form of suffering in the chronically ill. Sociology of Health and Illness, 5, 168-195.
- Chisholm, B. (2000). A new set of communication scales that describe and quantify interaction between mother with dementia and daughter caregiver dyads.

Unpublished M.Sc. Thesis. London: University College London.

- Clare, L. (2003). Managing threats to self: awareness in early stage Alzheimer's disease. Social Science and Medicine, 57, 1017-1029.
- Clare, L., & Shakespeare, P. (2004). Negotiating the impact of forgetting: dimensions of resistance in task-orientated conversations between people with dementia and their partners. *Dementia*, 3, 211-232.
- Clark, S. L., & Stephens, M. A. P. (1996). Stroke patients' well-being as a function of caregiving spouses helpful and unhelpful actions. *Personal Relations*, 3, 171-84.
- Cooper, A. F. (1998). Whose illness is it anyway? Why patient perceptions matter. International Journal of Clinical Psychology, 52; 551-556.
- Coyne, J. C. (2001) Husbands' anticipated reactions to wives' genetic testing for risk of breast cancer. *Proceedings: British Psychological Society*. Division: British and European Health Psychology.
- Crossley, M. L. (2000). Introducing narrative psychology: Self trauma and the construction of meaning. Birmingham: Open University Press.
- Crossley, M. L. (2000). *Rethinking health psychology*. Milton Keynes: Open University Press.
- Dempster, C., House, A, & Knapp, P. (1998). The collaboration of carers during psychological therapy. *Mental Health Nursing*, 18, 324
- Dennis, M., O'Rourke, S., Lewis, S., Sharpe, M., & Warlow, C. (1998). A Quantitative study of the emotional outcome of people caring for stroke survivors. *Stroke*, 29, 1867-1872.
- Dent, O. F., Waite, L. M., Bennet, H. P., Casey, B. J., Grayson D. A., Cullen J. S., Creasey, H., & Broe, G. A. (1999). A longitudinal study of chronic disease and depressive symptoms in a community sample of older people. *Aging and Mental Health*, *3*, 351-357.

- Department of Health. (1995). Disability Discrimination Act. Policy guidance. London: Department of Health.
- Department of Health. (1996). Carers' (recognition and services) Act: Policy guidance. London: Department of Health.
- Department of Health. (2001). Involving patients and the public in healthcare: Response to the listening exercise. London: Department of Health.
- Draper B. M., Roslyn, P. G., & Ehrlich, F. (1995). Risk factors for stress in elderly caregivers. *International Journal of Geriatric Psychiatry*, 11, 227-231.
- Ellis-Hill, C. S. (1998). New world, new rules; life narratives and changes in self Concept in the first year after stroke. Unpublished PhD manuscript. University of Southampton.
- Ellis-Hill, C. S., & Horn, S. (2000). Change in identity and self-concept: A new theoretical approach to recovery following a stroke. *Clinical Rehabilitation*, 14, 279 287.
- Elmstahl, S., Malmberg, B., & Annerstedt, L. (1996). Caregiver's burden of patients 3 years after stroke assessed by a novel Caregiver Burden Scale. *Archive Physical Medical Rehabilitation*, 77, 177-182
- Engel, G. L. (1977). The need for a new medical model: A challenge for biomedicine. *Science*, 196, 129 – 136.
- Evans, R. L., Bishop, D. S., Matlock, A. L., Stranahan, S. (1987). Predicting post stroke family function: A continuing dilemma. *Psychological Reports*, 60, 691 – 695.
- Ezzati, M., Lopez, A. D., Rodgers, A., Hoorn, S. V.,, & Murray, C. J. L. (2002). The comparative risk assessment collaboration group; selected major risk factors and global and regional burden of disease, *Lancet*, 360: 1347-60.
- Folkman, S. & Greer, S. (2002). Promoting psychological well-being in the face of serious illness: When theory, research and practice inform each other. *Psycho-oncology*, 9, 11-19.

Forster, A., & Young, J. (1996). Specialist nurse support for patients with stroke in the community; a randomised controlled trial. *British Medical Journal*, *312*, 1642-1646.

- Fortune, D. G., Richards, H. L., Main, C., & Griffiths, C. E. M. (2000). Pathological worrying, illness perceptions and disease severity in patients with psoriasis. *British Journal of Health Psychology*, 5, 71-82.
- Gale, L., Bennett, P. D., Tallon, D., Brooks, E., Munnoch, K., Schreiber-Kounine, C., Fowler, C., Sammon, A., Reyter, Z., Farndon, J., & Vedhara, K. (2001). Quality of partner relationship and emotional responses to a health threat. *Psychology, Health* and Medicine. Vol. 6, 373-386.
- Gallagher-Thompson, D., Canto Dal, P. G., Darnley, S., Basilio, L. A., Whelan, L., & Jacob, T. (1997). A feasibility study of videotaping to assess the caregivers and their interaction style. *Aging and Mental Health*, 1, 346–355.
- Gallagher-Thompson, D., Canto Dal, P. G., Jacob, T., & Thompson, L. W. (2001). A comparison of marital interaction patterns between couples in which the husband does or does not have Alzheimer's disease. *Journal of Gerontology*, 56B, 140-150.
- George, L.K., & Gwyther, L.P. (1986). Caregiver well-being: A multidimensional examination of family caregivers of demented adults. *Gerontologist*, 26, 253-259.
- Gilhooly, M. I. M. (1984). The impact of caregiving on caregivers. Factors associated with the psychological well-being of people supporting a dementing relative in the community. *British Journal of Medical Psychology*, *57*, *35-44*.
- Gilleard, C.J. (1984). Problems posed for supporting relatives of geriatric and psychogeriatric day patients. *Act Psychiatrica Scandinavia*, 70, 198-208.
- Gilligan, C. (1982). In a Different Voice. Harvard University Press.
- Grant, J. S., Elliot, T. R., Weaver, M., Bartolucci, A. A., & Giger, J. N. (2002). Telephone intervention with family caregivers of stroke survivors after rehabilitation. *Stroke*, 3, 2060-2065.

- Greveson, G. C., Gray, C. S., French, J. M., & James, O. F. W. (1991). Long term outcome for patients and carers following hospital admission for stroke. Age & Ageing, 20, 337-344.
- Gurowka, K. J., & Lightman, E. S. (1995). Supportive and unsupportive interaction as perceived by cancer patients. *Social Work in Health Care, 21*, 71-88.
- Habermann, B. (2000). Spousal perspective of Parkinson's diseases in middle life. *Journal of* Advanced Nursing, 31, 1409-1415.
- Hafsteindottir, T. B., & Grypdonck, M. (1997). Being a stroke patient: a review of the literature. *Journal of Advanced Nursing*, 26, 580-588.
- Hagedoorn, M., Buunk, B. P., Kuijer, R. G., Wobbes, T., & Sanderman, R. (2000). Couples dealing with cancer: Role and gender differences regarding psychological distress and quality of life. *Psycho-Oncology*, 9, 232 – 242.
- Haley, W. E., Levine, E. G., Brown, S. L., & Bartolucci A. A. (1987). Stress, appraisal, coping, and social support as predictors of adaptational outcome among dementia caregivers. *Psychology and Aging*, 2, 323 – 330.
- Han, B., & Haley, W. E. (1999). Family caregiving for patients with stroke: Review and analysis. *Stroke*, 30, 1478-1485.
- Hanger, H. C., & Mulley, G. P. (1993). Questions people ask about stroke. *Stroke*, 24, 536-538.
- Harwood, D. G., Ownby, R. L., Burnett, K., Barker, W. W, & Duara, R. (2000). Predictors of appraisal and psychological well-being in Alzheimer's disease family caregivers. *Journal of Clinical Geropsychology*, 6, 279-297.
- Hasselkus, B. R. (1988). Meaning in family caregiving: Perspectives on caregiver/professional relationships. *The Gerontologist, 28*, 686-691.
- Hays, R. B., Magee, R. H., & Chauncey, S. (1994). Identifying helpful and unhelpful behaviors of loved ones: the PWA's perspective. *Aids Care*, 6; 379-392.

- Herrmann, M., Freyholdt, U., Fuchs, G., & Wallesch, C. W. (1997). Coping with chronic neurological impairment: A constrastive analysis of Parkinson's disease and stroke. *Disability and Rehabilitation: An International Multidisciplinary Journal, 19*, 6 – 12.
- Holbrook M., & Skilbeck, C. E. (1983). An activities index for use with stroke patients. Age & Ageing, 12, 166-170.
- Horner, K. L. (2001). Personality and intimate support influences on prospective health status. *Psychology, Health & Medicine, 6*, 473 479.
- Hooker, K., Monahan, D., Shifren, K., & Hutchinson, C. (1992). Mental and physical health of spouse caregivers: The role of personality. *Psychology of Aging*, *7*, 367-375.
- House, A., Dennis, M., Mogridge, L., Warlow, C., Hawton, K., & Jones, L. (1991). Mood disorders in the year after first stroke. *British Journal of Psychiatry*, 2: 211-221.
- Hyman, M. D. (1971), Social isolation and performance in rehabilitation. Journal of Chronic Disease, 25, 85-97.
- Ingram, K. M., Jones, D.A., Fass, R. J., Neidig, J. L, & Song, Y. S. (1999). Social support and unsupportive social interactions: their association with depression among people living with HIV. *Aids Care*, 3, 313-329.
- Jacob, T., & Leonard, K. (1992). Sequential analysis of marital interaction involving alcoholic, depressed, and non-distressed men. *Journal of Abnormal Psychology*,101, 647-656.
- Johnston, M., Morrison, V., & Bonetti, D. (2002). SWOT: (Stroke Workbook Outcomes Trial) – A randomised controlled trial of a workbook-based intervention for stroke patients and carers. *Cerebrovascular Diseases*, 13, Suppl 3, 62.
- Johnston, M., Wright, S., & Weinman, S. (Eds.) (1995). *Measures in health psychology: A* users portfolio. Windsor: NFER-Nelson.

- Johnston, M., Morrison, V., MacWalter, R., & Partridge, C. (1999). Perceived control, coping and recovery from disability following stroke. *Psychology & Health*; 14, 181-192.
- Jones, E & Morrison, V. (2004) Making sense of illness: Couples accounts of living with stroke. Proceedings: British Psychological Society. Division: British and European Health Psychology, p 36.
- Kane, R. A., Reinardy, J., Penrod, J. D., & Huck, S. (1999). After the hospitalization is over: A different perspective on family care of older people. *Journal of Gerontological Social Work*, 31, 119 – 141.,
- Karasek, R. (1979) Job Demands, Job Decision Latitude, and Mental Strain: Implications for Job Redesign. Administrative Science Quarterly, Vol. 24, 285-308.
- Kaufman, S. (1988). Stroke rehabilitation and the negotiation of identity. In Reinharz, S, and Rowles, G, (eds). *Qualitative Gerontology*.
- Kiecolt-Glaser, J. K., & Newton, T. L. (2001). Marriage and health: His and hers. *Psychological Bulletin*, 127, 472-503.
- Kilhgren, M., Hallgren, A., Norberg, A., & Karlsson, I. (1996). Disclosure of basic strengths and weaknesses in demented patients during morning care, before and after staff training: Analysis of video- recordings by means of the Erikson theory of "eight stages of man". *International Journal of Aging and Human Development*, 43, 219-233.
- King, R. B., Carlson, C. F., Bares, K.K., Roth, E. J., & Heinman, A. W. (2001) Transition to home care after stroke: Depression, physical health and adaptive processes in support persons. *Research in Nursing and Health*, 24, 307-323.
- Kinney, J. M., Stephens, M. A. P., & Norris, V. K.(1995). Stresses and satisfactions of family caregivers to older stroke patients. *Journal of Applied Gerontology*, 14, 3-21.
- Kinsella, G. J., & Duffy, F. D. (1979) Psychosocial readjustments in the spouses of aphasic patients. Scandinavian Journal of Rehabilitative Medicine, 11, 129-132.

Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Buckingham: Open University Press.

Knapp, P., & Hewison, J. (1999). Disagreement in patient and care assessment of functional abilities after stroke. *Stroke, 30,* 934-938.

Knight, B. G. (1996). Psychotherapy with older adults. Thousand Oaks, CA:Sage.

- Kotila, M., Numminen, H., Waltimo, O., & Kaste, M. (1998). Depression after stroke: Results of the Finn stroke study. *Stroke*, 29, 368-372.
- Kubler-Ross (1969). Death and Dying. New York, Macmillian
- Lau R. R. (1995). Cognitive representations of health and illness. In: D Gochman (ed.) Handbook of Health Behavior Research, Vol 1. New York: Plenum Press.
- Lau, R. R., & Hartman, K. A. (1983). Commonsense representations of common illnesses. *Health Psychology*, 2, 167-185.
- Lazarus, R. S., & Folkman, S. (1984). Stress, appraisal, and coping. New York: Springer.
- Lee, C., & Powers, J. R. (2002). Number of social roles, health and well-being in three generations of Australian women. *International Journal of Behavioural Medicine*. *Special Issue: Women's health*, 9, 195 – 215.
- Lengerke, T. V. (2005). Distinctiveness of disease prototypes in lay illness diagnosis: An exploratory observational study. *Psychology, Health & Medicine, 10*, 108 121.
- Leventhal, H., Meyer, D., & Nerenz, D. (1980). The common sense representations of illness danger. In S. Rachman (Ed), *Contributions to medical psychology* (Volume 2). New York: Pergamon.
- Leventhal, H., Nerenz, D. R., & Steele, D. J. (1984). Illness representations and coping with health threats. In A. Baum, S. E. Taylor & J. E. Singer (Eds.), *Handbook of psychology and health* (Volume 4). Hillsdale, NJ: Erlbaum Associates.
- Lofgren, B., Gustafson, Y., & Nyberg, L. (1999). Psychological well-being 3 years after severe stroke. *Stroke*, *30*, 567-572.

- Low, J. T., Payne, S., & Roderick, P. (1999). The impact of stroke on informal carers: a literature review. *Social Science & Medicine*, 49, 711-725.
- Mahoney, F. J., & Barthel, D. W. (1965). Functional evaluation: The Barthel Index. Maryland State Medical Journal, 14, 61-65.
- Martire, L. M., Schulz, R., Keefe, F. J., Starz, T. W., Ostal, T. A., Dew, M. A., & Reynolds, C. F. (2003). Feasibility of a dyadic intervention for management of osteoarthritis: A pilot study with older patients and their spousal caregivers. *Aging and Mental Health*, 7, 53-60.
- Matson, N. (1994). Coping, caring and stress: A study of stroke carers and carers of older confused people. *British Journal of Clinical Psychology*, *33*, 333-334.
- Molloy, G., Johnston, D.W., Johnston, M., Morrison, V., Pollard, B., Bonetti, D., & MacWalter, R . (2005). Extending the Demand-Control model to informal caregiving. *Journal of Psychosomatic Research*, 58, 243-251.
- Montgomery, R. J. V. (1989). Investigating caregiver burden. In Markides, K. S., Cooper, C. L., eds. Aging, stress and health, 201-18.
- Moos, R.H. & Schaefer, J. A. (1984). The crisis of physical illness: An overview and conceptual approach. In R. H. Moos (ed.), *Coping with physical illness: New perspectives*. Vol. II. New York: Plenum Press.
- Morris, J. (Ed) (1996). Encounters with strangers: Feminism and disability. The Psychologist, 2005, 18 p423-425
- Morris, L. W., Morris, R. G., & Britton, P. G. (1988). The relationship between marital intimacy, perceived strain and depression in spouse caregivers of dementia sufferers. *British Journal of Medical Psychology*, 61, 231-236.
- Morris, R. G., Woods, R. T., Davies, K. S., & Morris, L. W. (1991). Gender differences in carers of dementia sufferers. *British Journal of Psychiatry*, 158, 69 74.
- Morrison, V. (1999). Predictors of carer distress following stroke. *Reviews in Clinical Gerontology*, 9, 265-271.

- Morrison, V. (2001). The need to explore discrepant illness cognitions when predicting patient outcomes. *Health Psychology Update*, 10, 9-1.
- Morrison, V., & Bennett, P. (2006). An Introduction to Health Psychology. Harlow, Pearson Prentice Hall.
- Morrison, V., & Dantanus. K (2000). Adherence to physical therapy amongst elderly stroke survivors: are discrepant patient-physiotherapist goals predictive? *Final Report to the Nuffield Foundation*. November 2000.
- Morrison, V., Hare, J., Horsfield, D., & Bates, A. (2001). Discrepant cognitions and illness outcomes: stroke patient-carer analysis. *Proceedings: British Psychological Society*. *Division: British and European Health Psychology*, p 50.
- Morrison, V., Pollard B., Johnston M., & MacWalter R. (2005). Depression and anxiety following stroke: Demographic, clinical and psychological predictors of 3-year outcome. *Journal of Psychosomatic Research*, 59: 209-213.
- Morrison, V., Johnston, M., & MacWalter, R. (2000). Predictors of distress following an acute stroke: Disability, control cognitions and satisfaction with care. *Psychology & Health*, 15, 1-13.
- Moss-Morris, R., Petrie, K. J., & Weinman, J. (1996). Functioning in chronic fatigue syndrome: Do illness perceptions play a regulatory role? *British Journal of Health Psychology*, 1, 15-25.
- National Service Framework- Consultation Document (July 2005). http:// www.wales.nhs.uk/nsf. (accessed 10th October 2005)
- Newman, S. (1984). The social and emotional consequences of head injury and stroke. International Review of Applied Psychology, 33, 427-455.
- Newsom & Schulz. (1998) Caregiving from the recipient perspective: negative reactions to being helped. Health Psychology, 17, 172-81.
- Niederehe, G. N., (1990). Communication patterns and care giver distress in senile dementia. Paper presented at the 43<sup>rd</sup> Annual Scientific Meeting of the Gerontological Society of America, Boston.

- Nilsson, I., Jansson, L., & Norberg, A. (1997). To meet with a stroke: patients' experiences and aspects seen through a screen of crises. *Journal of Advanced Nursing*, 25, 953-963.
- Nolan, M.R., & Grant, G. (1990). Stress is in the eye of the beholder: reconceptualising the measurement of carer burden. *Journal of Advanced Nursing*, 15: 544-55.
- Ogden, J. (1996). Health Psychology: A Textbook. London: Open University Press.
- Orbell, S., & Gillies, B. (1993). What's stressful about caring? Journal of Applied Social Psychology, 24, 272-90.
- Orbell, S., Hopkins, S. N., & Gillies, B. (1993). Measuring the impact of informal caregiving. *Journal of Community & Applied Social Psychology*, *3*, 149-163.
- Palmer, S., & Glass, T. A. (2003). Family function and stroke recovery: A review. *Rehabilitation Psychology*, 48, 255 – 265.
- Partridge, C. J., & Johnston, M. (1989). Perceived control and recovery from physical disability. *British Journal of Clinical Psychology*, 28, 53-60.
- Patton, D., & Waring, E. M. (1984). The quality and quantity of marital intimacy in the marriages of psychiatric patients. *Journal of Sex and Marital Therapy*, *10*, 201-206.
- Payne, S., & Ellis-Hill, C. (Eds.). (2001). Chronic and terminal illness: new perspectives on caring and carers. Oxford: Oxford University Press.
- Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M., (1990). Caregiving and the stress process; An overview of concepts and their measures. *The Gerontologist*, 30, 583-594.
- Pennebaker, J. W., Kiecolt-Glaser, J. K., & Galser, R. (1988). Disclosure of traumas and immune function: Health implications for psychotherapy. *Journal of Consulting Clinical Psychology*, 56, 239-245.
- Pistrang, N., Clare, L., & Barker, C. (1999). The helping process in couples during recovery from heart attack: A single case study. *British Journal of Medical Psychology*, 72, 227-237.

- Pound, P., Gompertz, P., & Ebrahim, S. (1994). Patients' satisfaction with stroke services. *Clinical Rehabilitation*, 8, 7-17.
- Putten, van der, J. J. M. F., Hobart, J. C., Freeman, J. A., & Thompson, A. J. (1999). Measuring change in disability after inpatient rehabilitation: comparison of the responsiveness of the Barthel Index and the Functional Independence Measure. J Neural Neurosurgery Psychiatry, 66, 480-484.
- Radley, A. (1994). Making sense of illness: The social psychology of health and disease. Thousand Oaks, CA: Sage Publications Inc.
- Rapp, S. R., & Chao, D. (2000). Appraisals of strain and of gain: Effects of psychological wellbeing of caregivers of dementia patients. *Aging & Mental Health*, 142 – 147.
- Reich, J. W., Zatura, A. J. (1989). A perceived control intervention for at- risk older adults. Psychology of Aging, 4, 415-424.
- Reimer, Scholte op, W. J. M, de Haan, R. J., Rijnders, P. T., Limburg, M., van den Bos, G.
   A. M. (1998). The Burden of Caregiving in Partners of Long-Term Stroke Survivors. Stroke, 29, 1605-1611.
- Reese, D. R., Gross, A. M., Smalley, D. L., & Messer, S. C. (1994). Caregivers of Alzheimer's disease and stroke patients. Immunological and psychological considerations. *The Gerontologist*, 34, 534-540.
- Robinson, R. G. (1998). Cognitive, behavioural and emotional disorders following vascular brain injury. *The Clinical Neuropsychiatry of Stroke*.
- Rodgers, H., Bond, S., & Curless, R. (2001). Inadequacies in the provision of information to stroke patients and their families. *Age & Ageing*, *30*, 129-133.
- Rolland, J. S. (1988). A conceptual model of chronic and life threatening illness and its impact on families as cited in Biegel, D. E., Sales, E., & Schulz, R. (1991) Family caregiving in chronic illness: Alzheimer's disease, cancer, heart disease, mental illness, and stroke. London: Sage Publications, 231-241.

- Rook, K. S. (1985). The functions of social bonds: Perspectives from research on social support, loneliness and social isolation. In I. G. Sarason & R. R. Sarason (eds). Social Support: History, Research, and Applications, 243-267.
- Sarason, B.R., Sarason, I.G., & Pierce, G.R. (1990). Traditional views of social support and their impact on assessment. In B.R. Sarason, I.G. Sarason, & G.R. Pierce (Eds.), *Social Support: An Interactional View*. Wiley: NewYork.
- Savage, S. A., & Clarke, V. A. (1998). Older Women's representations of cancer: A qualitative study. *Health Education Research*, 13, 529-544.
- Scheier, M. F., & Carver C. S. (1987). Dispositional optimism and physical well-being: The influence of generalized outcome expectancies. *Journal of Personality*, 55, 169-210.
- Schiaffino, K. M., Shawaryn, M. A., & Blum, D. (1998). Examining the impact of illness representations on psychological adjustment to chronic illnesses. *Health Psychology*, 17, 262-268.
- Schröder, K. E. E., & Schwarzer, R. (2001). Do partners' personality resources add to the prediction of patients' coping and quality of life? *Psychology & Health, 16,* 139-159.
- Schröder, K. E. E., Schwarzer, R., & Endler, N. S. (1997). Predicting cardiac patients' quality of life from the characteristics of their spouses. *Journal of Health Psychology*, 2, 231-244.
- Schuling, J., de Haan, R., Limburg, M., & Groenier, K. H. (1993). The Frenchay Activities Index. Assessment of functional status in stroke patients. *Stroke*, *24*, 1173-1177.
- Schulz, R., & Beach, S. R. (1999). Caregiving as a risk factor for mortality: The caregiver health effects study. *Journal of the American Medical Association, 282, 2215-2219.*
- Schwarzer, R., & Schröder, K. E. E. (1997a). Social and personal coping resources as predictors of quality of life in cardiac patients. *European Review of Applied Psychology*, 47, 131-135.
- Schwarzer, R., & Schröder, K. E. E. (1997b). Effects of self-efficacy and social support on post-surgical recovery of heart patients. *Irish Journal of Psychology*, 18, 88-103.

- Seddon, D., & Robinson, C. (2001). Carers of Older People with Dementia: Assessment and the Carers Act. Journal of Health and Social Care in the Community, 9, (3): 151-158.
- Shawaryn, M. A., & Blum, D. (1998). Examining the impact of illness representations on psychological adjustment to chronic illnesses. *Health Psychology*, *17*, 262-268.
- Shewchuck, R. M., Richards, J. S., &Elliott, T. R. (1998). Dynamic processes in health outcomes among caregivers of patients with spinal cord injuries. *Health Psychology*, 17, 125-29.
- Shields, C. G. (1992). Family interaction and caregivers of Alzheimer's disease patients: Correlates of depression. *Family Process*, *31*, 19-33.
- Shields, C. G., Travis, L. A., & Rousseau, S. L. (2000). Marital attachment and adjustment in older couples coping with cancer. *Aging & Mental Health*, *4*, 223-233.
- Schulz, R., Tompkins, C. A., & Rau, M. T. (1988). A longitudinal study of the psychosocial study of the psychosocial impact of stroke on primary support persons. *Psychology* and Aging, 3, 131-141.
- Schuster, T. L., Kessler, R. C., & Aseltine, R. H. (1990). Supportive interactions, negative interactions, and depressed mood. *American Journal of Community Psychology*, 18, 423-438.
- Shrout, P. E., Fleiss, J. L., (1979). Intraclass correlations: Uses in assessing rater reliability. *Psychological Bulletin*, 86, 420-428.
- Silliman, R., Fletcher, R. H., Earp, J. L., & Wagner, E. H. (1986). Families of Elderly Stroke Patients. Effects of Home care. *Journal of the American Geriatrics Society*, 34, 643-648.
- Skelton, J. A., & Croyle, R. T. (Ed.). (1991). Mental Representations in health and illness. New York Press: Springer-Verlag.

- Smith J. A. (1999). Identity during the transition to motherhood: An interpretative phenomenological analysis. *Journal of Reproductive and Infant Psychology*, 17, 281-229.
- Smith, J. A. (1996). Beyond the divide between condition and discourse: Using interpretative phenomenological analysis in health psychology. *Psychology and Health*, 11, 261-271.
- Smith, J. A., Jarman, M., Osborn, M. (1999). Doing interpretative phenomenological analysis. In M. Murray, & K. Chamberlain (Eds.). *Qualitative health psychology: Theories and methods* (pp. 218-240). London: Sage.
- Smith, C., & Wallston, K. (1992). Adaptation in partners with chronic Rheumatoid Arthritis: application of a general model. *Health Psychology*, 11, 151-162.
- Surveys of Psychiatric Morbidity among Adults in Great Britain, *Better or worse: a* longitudinal study of the mental health of adults living in private households in Great Britain. Office for National Statistics. <u>www.statistics.gov.uk</u> (accessed 10<sup>th</sup> Oct 2006)
- Strauss, A., & Corbin, J. (1998). Basics of qualitative research: Techniques and procedures for developing grounded theory (2<sup>nd</sup> Edn.). Thousand Oaks: Sage.
- The Stroke Association. Stroke-facts and figures. <u>www.stroke.org.uk/noticebaord/facts.htm</u> (accessed 7th October 2003).
- Thompson, S. C., Galbraith, G. T., Thomas, C., Swan, J., & Vrungos, S. (2002). Caregivers of stroke patient family members: Behavioural and attitudinal indicators of overprotective care. *Psychology & Health*, 17, 297-312.
- Thompson, S. C., Sobolew-Shubin, A. S., Galbraith, M. E., Schwankovsky, L., & Cruzen, D. (1993). Maintaining perceptions of control: Finding perceived control in low-control circumstances. *Journal of Personality and Social Psychology*, 62, 293-304.
- Thompson, S. C., Sobolew-Shubin, A. S., Graham, M. A., & Janigian, A. S. (1989). Psychosocial adjustment following a stroke. Social Science and Medicine, 28, 239-47.

- Thotis, P. A. (1991). On merging identity theory and stress research. Social Psychology Quarterly, 54, 101-12.
- Tompkins, C. A., Schulz, R., & Rau, M. T. (1988). Post-stroke depression in primary support persons: Predicting those at risk. *Journal of Consulting and Clinical Psychology*, 56, 502-508.
- Tuomilehto, J., Nuottimaki, T., Salmi, K., Aho, K., Kotila, M., Sarti, C., & Rastenyte, D. (1995). Psychosocial and health status in stroke survivors after 14 years. *Stroke*, 26, 971-975.
- Vaughan, C. E., & Leff, J. P. (1976). The influence of family and social factors on the course of psychiatric illness: A comparison of schizophrenic and depressed neurotic patients. *British Journal of Psychiatry*, 129, 125-137.
- Wade, D. T., Leigh-Smith, J., & Langton Hewer, R. (1986). Effects of living with and looking after survivors of a stroke. *British Medical Journal*, 293: 418-20.
- Wade, D.T., & Collin, C. (1988). The Barthel ADL index: a standard measure of disability? International Disability Studies, 10, 64-67.
- Walker, J. G., Jackson, H. J., & Littlejohn, G. O. (2004). Models of adjustment to chronic illness: Using the example of rheumatoid arthritis. *Clinical Psychology Review*. 24, 461-488.
- Walsh, J. C., Lynch, M., Murphy, A.W., & Daly K. (2004). Factors influencing the decision to seek treatment for symptoms of acute myocardial infarction. An evaluation of the Self-Regulatory Model of illness behaviour. *Journal of Psychosomatic Research*, 56, 67-73.
- Waring, E. M., & Reddon, J. R. (1983). The measurement of intimacy in marriage: the Waring Intimacy Questionnaire. *Journal of Clinical Psychology*, 39, 53-57.
- Warleby-Forsberg. G., Moller A., & Blomstrand, C (2001). Psychological well-being of spouses of stroke patients during the first year after stroke. *Clinical Rehabilitation*, 18, 430 - 437.

- Weinman, J. (2001). Spouses following first time myocardial infarction and subsequent lifestyle changes. *British Journal of Health Psychology*, *5*, 263-273.
- Weinman, J., Petrie, K. J., Moss-Morris, R., & Horne, R. (1996). The illness perception questionnaire: A new method for assessing the cognitive representation of illness. *Psychology and Health*, 11, 431-445.
- Weinman, J., Petrie, K. J., Sharpe, N., & Walker, S. (2000). Causal attributions in patients and spouses following first time myocardial infarction and subsequent lifestyle changes. *British Journal of Health Psychology*, 5, 263-273.
- Weissman, M. M., & Klerman, G. L. (1977). Sex differences and the epidemiology of depression. Archives of General Psychiatry, 34, 98-111.
- Wheeler, L., & Miyake, K. (1992). Social comparison in everyday life. Journal of Personality and Social Psychology, 62, 760-773.
- White, C. L., Mayo, N., Hanley, J. A., & Wood-Dauphinee, S. (2003). Evolution of the caregiving experience in the initial 2 years following stroke. *Research in Nursing & Health, 26,* 177-189.
- Williams, L. S., Bruno, A., Rouch, D., & Marriott, D. J. (1997). Stroke patients' knowledge of stroke: Influence on time to presentation. *Stroke*, 28, 912-915.
- Woods, R.T., Bruce, E., Orrell, M., & Russell, I.T. (2003). Reminiscence groups for people with dementia and their family caregivers. Trial platform. *MRC strategic grant*.
- World Health Organisation. (1980). International classification of Impairments, Disabilities, and Handicaps. WHO, Geneva.
- World Health Organisation. (2001). The International Classification of Functioning, Disability and Health ICF. WHO, Geneva.
- Yardley, L., (1997). Material discourses of health and illness. London: Routledge.
- Yoon, S. S., & Byles, J. (2002). Perceptions of stroke in the general polic and patients with troke: A qualitative study. *British Medical Journal*, 324, 1065.

- Zarit, S. H., Reever, K. E., & Bach-Peterson, J. (1980). Relatives of the impaired aged: correlates of feelings of burden. *Gerontologist*, 20, 649-655.
- Zarit, S. H., & Edwards, A. B., (1992). Family Caregiving: Research and Clinical Intervention. as cited in R.T. Woods (Eds.) (1996). Handbook of the Clinical Psychology of Ageing. Chichester: Wiley.
- Zigmond, A. S., & Snaith, R. P. (1983). The Hospital Anxiety and Depression Scale. Acta Psychiatrica Scandinavica, 67, 361- 370.

# **APPENDIX**

- Appendix 1: Information Letter: Study 1
- Appendix 2: Consent form: Study 1
- Appendix 3: Patient Questionnaire: Study 1
- Appendix 4: Carer Questionnaire: Study 1
- Appendix 5: Copy of the MSQ
- Appendix 6: Information Letter: Study 2
- Appendix 7: Interview Schedule: Study 2
- Appendix 8a: A Couple's Master Themes: Study 2
- Appendix 8b: Conversation Schedule for Analysis: Study 2
- Appendix 9a: Information Letter: Study 3
- Appendix 9b: Questionnaire: Study 3
- Appendix 10: Observation Scales: Study 3
- Appendix 11: Scoring Form: Study 3
- Appendix 12: Information Letter: Study 4
- Appendix 13: Questionnaire: Study 4



e-mail: pss029@bangor.ac.uk http://www.psych.bangor.ac.uk/

# Information Sheet (Carer)

You are being invited to take part in a research study. Before you make a decision, it is important that you understand why the research is being done, and what it will involve. Please take time to read the following information carefully and feel free to discuss it with friends, and family, before you decide whether or not you wish to take part

**Title of Study:** Patient-carer interactions following stroke; the effect on patient and carer outcome.

Who is running the study? Dr Val Morrison, a health psychologist at the University of Wales, Bangor, with Miss Elly Jones, a PhD student in the School of Psychology, University of Wales, Bangor.

Why are you a suitable person to take part in the study? You are caring for someone who has recently had a stroke and is living with you.

What is the study about? This study is interested in what psychological factors are important in patient and carer well-being following stroke. This study will follow patient and carer pairs over a 6 month period. Questionnaires will measure the patient and carers thoughts and feelings about the stroke, the caring role, and the relationship between the patient and carer. These questionnaires will be administered to the patient and carer within 21 days of the patient being admitted to hospital for a stroke, and then at 3 months and 6 months post-stroke. It is hoped that the measures at 21 days, and at 3 months, will help us predict patient and carer well-being at 6 months.

# If you agree to take part, what will it involve?

If you agree to take part in the study, Elly Jones will arrange an appointment to visit you at home, or on the hospital ward within 21 days of the stroke. Elly Jones and a student assistant will then interview you and the person you are caring for separately, using a range of questionnaires. The questionnaires will ask you a set

of questions about yourself and the person you are caring for; the effects the stroke has had on you, and the person you are caring for ; your recovery expectancies and future goals for the person you are caring for; and the care you feel is necessary to help the person you are caring for recover. There will also be some personal questions regarding your relationship with the person you are caring for, before and after the stroke. The questionnaires will take about 1 hour to complete with you, and 1 hour to complete with the person you are caring for. Elly will then contact you and the person you are caring for 3 months and 6 months later, to arrange for the follow up interviews at your home, or in the Psychology Department, dependent on which is convenient for you.

## Are the interviews available in Welsh?

Unfortunately, the questionnaires only currently exist in a validated form in English.

## What are the possible benefits of taking part in this research?

There are no direct benefits to you and the person you are caring for, but the information that you provide may inform clinicians about the impact of stroke on both patient and carer. This information may be used in future interventions to reduce the distress of future stroke patients and their families.

# What are the possible dangers of taking part in this research?

No harm is likely. The answers you give to the questionnaires will be kept strictly confidential, that is, your name will not appear on your answer sheet and no-one except you and the research team will know your responses to the questions we asked you. You can stop at any point during the interview. You can change your mind during the interview and stop answering questions, or refuse to answer particular questions if you wish to. You do not have to give us a reason for pulling out of the study, and your health care and that of the person you are caring for, will not be affected in any way should you choose to do so.

# What will happen when the study finishes?

The questionnaire sheets will be stored in a safe place and destroyed when the study is completely finished.

# What will happen to the results of the research study?

It is hoped that the results of the study will be subsequently published. At the end of the research period a report will be prepared for both of the participating NHS trusts. Your identity will not be published in any paper resulting from your participation. If you and the person you are caring for agree to take part in this study, then you will be informed of any publications and how to obtain them.

Thank-you for considering taking part in this study.

*Questions:* If you have any questions to ask about the study before you decide whether or not to take part, please phone Miss Elly Jones on 01248 383664 or alternatively on 07970 004647.

*Complaints:* In the case of complaints about how the study is carried out, you should write to either: Mr K.Thompson, Chief Executive, North Wales NHS Trust, Ysbyty Gwynedd OR
Professor C.F. Lowe, Head of School of Psychology, University of Wales Bangor, Gwynedd LL57 2DG.



e-mail: pss029@bangor.ac.uk http://www.psych.bangor.ac.uk/

#### **Information Sheet (Patient)**

You are being invited to take part in a research study. Before you make a decision, it is important that you understand why the research is being done, and what it will involve. Please take time to read the following information carefully, and feel free to discuss it with friends, and family, before you decide whether or not you wish to take part

Title of Study: Patient-carer interactions following stroke: the effect on patient and carer outcome.

Who is running the study? Dr Val Morrison, a health psychologist at the University of Wales, Bangor, with Miss Elly Jones, a PhD student in the School of Psychology, University of Wales, Bangor.

Why are you a suitable person to take part in the study? You have recently experienced a stroke and are being cared for by someone you live with.

What is the study about? This study is interested in what psychological factors are important in patient and carer well-being following stroke. This study will follow patient and carer pairs over a 6 month period. Questionnaires will measure the patient and carers thoughts and feelings about the stroke, the caring role, and the relationship between the patient and carer. These questionnaires will be administered to the patient and carer within 21 days of the patient being admitted to hospital, and at 3 months, and 6 months post stroke. It is hoped that the measures within 21 days and at 3 months, will help us predict patient and carer well-being at 6 months.

#### If you agree to take part, what will it involve?

If you agree to take part in the study, Elly Jones will arrange an appointment to visit you at your home or on the hospital ward within 21 days of being admitted to hospital. Elly Jones and a student assistant will then interview you and your carer separately, using questionnaires. The questionnaires will ask you a set of questions about you and your stroke: the effects it has had on you; about your recovery expectancies and future goals; and the care you feel is necessary to help you recover. There will also be some personal questions regarding your relationship with the carer before and after the stroke. The questionnaires will take about 1 hour to complete with you, and 1 hour to complete with your carer. Elly will then contact you and your carer 3 months and 6 months later, to arrange for the follow up interviews at your home or in the Psychology Department, dependent on which is convenient for you.

#### Are the interviews available in Welsh?

Unfortunately, the questionnaires only currently exist in a validated form in English.

#### What are the possible benefits of taking part in this research?

There are no direct benefits to you and your carer, but the information that you provide may inform clinicians about the impact of stroke on both patient and carer. This information may be used in future interventions to reduce distress of future stroke patients and their families.

#### What are the possible dangers of taking part in this research?

No harm is likely. The answers you give to the questionnaires will be kept strictly confidential, that is, your name will not appear on your answer sheet and no-one except you and the research team will know your responses to the questions we asked you. You can stop at any point during any of the interviews. You can change your mind during the interview and stop answering questions, or refuse to answer particular questions if you wish to. You do not have to give us a reason for pulling out of the study, and your health care and that of your carer will not be affected in any way should you choose to do so.

#### What happens when the study finishes?

The questionnaire sheets will be stored in a safe place and destroyed when the study is completely finished.

#### What will happen to the results of the research study?

It is hoped that the results of the study will be subsequently published. At the end of the research period a report will be prepared for both of the participating NHS trusts. Your identity will not be published in any paper resulting from your participation and if you and your carer agree to take part in this study, then you will be informed of publications and how to obtain them.

Thank-you for considering taking part in this study.

*Questions:* If you have any questions to ask about the study before you decide whether or not to take part, please phone Miss Elly Jones on 01248 383664. *Complaints:* In the case of complaints about how the study is carried out, you should write to either: Mr. K.Thomson, Chief Executive, North West Wales NHS Trust, Ysbyty Gwynedd OR

Professor C.F. Lowe, Head of School of Psychology, University of Wales Bangor, Gwynedd LL57 2DG.

## **APPENDIX 2**



http://www.psych.bangor.ac.uk/

Research Consent Form

YOU SHOULD COMPLETE THE WHOLE OF THIS SHEET YOURSELF.

Please tick your answer below as necessary:

# 1) Have you read and understood the information sheet or has someone

#### explained the study to you verbally?

YES \_\_\_\_ NO \_\_

2) Have you had a chance to ask questions about the study?

YES \_\_\_\_ NO \_\_\_

3) Have you been given enough information about the study?

YES \_\_\_\_ NO \_\_\_

4) Do you understand that you are able to pull out of the study: at any time;

without having to give a reason;

and without it affecting your future medical care in any way?

YES\_\_\_\_NO \_\_\_

5) Do you agree to take part in the study?

YES	NO		
Signed:		Date:	
NAME in capital letters			



# Appendix 3 Patient Interview

Interviewer ID	
Case ID	

These first few questions are to find out general background information.

1.	Gender:		Female				
2.	Age:						
3.	Marital status:						
	Married		Separated				
	Single		Widowed				
	Divorced		Partner				
4.	Are you employed'	?	Yes			No	
5.	If 'no', when were ye	ou last employ	ved?	Yrs		Mts.	
6.	What were/ are you	employed as	?				
7.	Other than your main	n carer, do you	ı have family w	vho live	in you	r area?	
			Yes	;		No	
8.	If yes, how often do	you see them	1?				
	Daily	A.	t least weekly	Πa	t least	monthly	<i>y</i>
11.	Were you right hanc	led before you	ır stroke?	Yes		No	
12.	When did you suffer	your present :	stroke?	Yrs		Mts	
13.	Is this your first stroke	∋?		Yes		No	
14.	If 'no' how many hav	e you had?					



15. When did you have those strokes?

Yrs.....Mts.....

16. Please will you indicate in the boxes the extent to which you are confident that you will make a full recovery, with 1 being 'not at all confident' and 5 being 'very confident'.

1	2	3	4	5

17.	Have you had physiotherapy?	Yes 🗀 No 🗀
18.	If 'yes', how many hours per week?	
19.	For how many weeks?	
20.	When did this finish?	



21. Are you currently receiving any medication other than that prescribed for your stroke?

Yes	No	

22. If 'yes' what for?

**Barthel Index** 

The next set of questions are interested in what you can do physically. Think of yourself in the last 24 Hrs

#### 1. Can you walk on level surfaces?

Independent (may use aid)
Walk with the help of a person (verbal/physical)
Independent (in wheelchair)
Unable

2. Can you dress? (All fasteners, etc.)

L			
L			
	_		

Independently (zips, buttons, etc)



Needs help, but does at least half

Dependent



3. Can you transfer yourself? (from chair to bed and vice versa)

 Independent

 Minimal help

 (verbal or physical)

 Can sit with major help

 unable

 4. Can you handle toilet duties on your own? (transfer, clothes, wipe, flush, etc.)

 Independent

 Needs some help

 Dependent

 Dependent

## 5. How is your bowel control?



Continent



Occasional accident

Incontinent

# 6. How is your bladder control?



Continent



Occasional accident



Incontinent (Catheterised)



#### Can you manage personal hygiene? (washing face, combing hair, 7. shaving, teeth etc.)



8.

Dependent

Independent

Can you bath yourself?



Independent

Dependent

#### 9. Can you feed yourself?

Independent

	Need (cuttir
1	, D

s some help ng food, spreading etc.)

Dependent

10. How is your eating? (e.g. chewing, swallowing)





Some problems



#### 11. Can you go up and down stairs?



Independent



Needs help (verbal/physical)

Unable



#### 12. How is your speech?

Normal

Some difficulties

Severe difficulties

### HAD Scale

The next questions are interested in how you have been feeling in the last seven days. As before there are no 'correct' or 'Incorrect' answers. Please answer according to your **own feelings**, rather than how you think 'most people' would answer

#### 1. I feel tense or 'wound up':

	Most of the time	
	A lot of the time	
	From time to time, occasionally	
	Not at all	
2.	I still enjoy doing the things I used to enjoy:	
	Definitely as much	
	Not quite so much	
	Only a little	
	Hardly at all	
З.	l get sort of frightened feeling as if something a about to happen:	wful is
	Very definitely and quite badly	
	Yes, but not too badly	
	A little, but it doesn't worry me	
	Not at all	



4.	I can laugh and	see the funny side of things:	
	As r	nuch as I always could	
	Not	quite so much now	
	Defi	nitely not so much now	
	Not	at all	
5.	Worrying though	nts ao through my mind:	
	A gr	reat deal of the time	
	A lot	t of the time	
	From	n time to time but not too often	
	Only	coccasionally	
6.	I feel cheerful:		
	Not a	at all	
	Not	often	
	Som	netimes	
	Mos	t of the time	
7.	I can sit at ease a	and feel relaxed:	
	Defir	nitely	
	Usua	ally	
	Not o	often	
	Not a	at all	



8.	I feel as if I	am slowed down:	
		Nearly all the time	
		Very often	
		Sometimes	
		Not at all	
9.	l get a sort	of frightened feeling like 'butterflies' i	n the stomach:
		Not at all	
		Occasionally	
		Quite often	
		Very often	
10.	l have lost i	interest in my appearance:	
		Definitely	
		I don't take as much care as I should	
		I may not take quite as much care	
		I take just as much care as ever	
11.	I feel restle	ss as if I have to be on the move:	
		Very much indeed	
		Quite a lot	
		Not very often	
		Not at all	



12.	I look forward with enjoyment to things:	
	As much as I ever did	
	Rather less than I used to	
	Definitely less than I used to	
	Hardly at all	
13.	I get sudden feelings of panic:	
	Very often indeed	
	Quite often	
	Not very often	
	Not at all	
14.	l can enjoy a good book or radio or TV programm	ne:
	Often	
	Sometimes	
	Not often	
	Very seldom	



#### R.L.O.C.

These are statements other people have made about recovery. Please will you indicate the extent to which you agree or disagree with them in the appropriate columns below each question.

# 1. How I manage in the future depends on me not what other people can do for me.

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree

# 2. It's often best just to wait and see what happens.

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree

# It's what I do to help myself that's really going to make all the difference.

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree

4. My own efforts are not very important, my recovery really depends on others.

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree



# 5. It's up to me to make sure that I make the best recovery possible under the circumstances.

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree

#### 6. My own contribution to my recovery doesn't amount to much.

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree
				-

# 7. Getting better now is a matter of my own determination rather than anything else.

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree

#### 8. I have little or no control over my progress from now on.

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree



# 9. It doesn't matter how much help you get, in the end it's your own efforts that count.

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree

#### Marital Intimacy

Please say whether you strongly agree, agree, are undecided, disagree, or strongly disagree with each of the following statements as they apply to you AT PRESENT. It is best not to spend too long thinking about your answers. Please tick the word that corresponds to you. Then think back to the time before (insert name) was ill and say whether you would have strongly agreed, agreed, been undecided, disagreed, or strongly disagreed with the same statements. Please tick the PAST statement in the boxes underneath.

#### 1. The feelings I have for my partner are warm and affectionate.

Strongly	Agree	Undecided	Disagree	Strongly
agree			-	disagree

PAST

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

# 2. My partner and I find it difficult to agree when making important decisions.

agree



#### PAST

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

## 3. I am very committed to my partner

		PRESENT		
Strongly agree	Agree	Undecided	Disagree	Strongly disagree

### PAST

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

#### 4. My Partner makes unreasonable demands on my spare time PRESENT

Agree	Undecided	Disagree	Strongly disagree
	Agree	Agree Undecided	Agree Undecided Disagree

### PAST

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

### 5. All my partners habits are good and desirable ones.

Strongly agree	Agree	Undecided	Disagree	Strongly disagree



Strongly agree	Agree	Undecided	Disagree	Strongly disagree

#### I enjoy pleasant conversations with my partrner. 6.

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

## I wish my partner was more loving and affectionate. PRESENT 7.

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

		PAST		
Strongly agree	Agree	Undecided	Disagree	Strongly disagree

#### My partner has helped me to feel that I am a worthwhile person. 8.

Strongly	Agree	Undecided	Disagree	Strongly
agree		6		disagree



Strongly agree	Agree	Undecided	Disagree	Strongly disagree

#### 9. I am unable to tell my partner in words that I love him/her.

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

PAST

Agree	Undecided	Disagree	disagree
	Agree	Agree Undecided	Agree Undecided Disagree

# 10. On occasion, I have told a small lie to my partner.

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

PAST

	17.61						
Strongly agree	Agree	Undecided	Disagree	Strongly disagree			

# 11. My partner is liked and accepted by my relatives

Strongly agree	Agree	Undecided	Disagree	Strongly disagree



Strongly agree	Agree	Undecided	Disagree	Strongly disagree

12. I look outside my marriage for things that make my life worthwhile and interesting

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

PAST

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

13. When I am unhappy about some aspect of our relationship I am able to tell my partner about it.

PRESENT

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

Strongly	Agree	PAST Undecided	Disagree	Strongly
agree				disagree

14. My marriage has "smothered" my personality.

disagree	Disagree	Undecided	Agree	agree



Strongly agree	Agree	Undecided	Disagree	Strongly disagree

I sometimes have thoughts and ideas I would not like to tell my 15. partner.

disagree

agree	disagree

I am happy with the physical relationship I have with my partner. PRESENT 16.

Strongly agree	Agree	Undecided	Disagree	Strongly disagree
		DAGT		

Δ	S	т	
1	0		_

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

My partner does not understand the way I feel. 17.

agree	Agree	Undecided	Disagree	Strongly disagree



Strongly agree	Agree	Undecided	Disagree	Strongly disagree

18. My relationship with my partner is the most important and meaningful relationship I have.

	 disagree
-	

PAST

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

19. I wish my partner worked harder to make our relationship more satisfying for us both.

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

 Strongly agree
 Agree
 Undecided
 Disagree
 Strongly disagree

20. I have never had an argument with my partner.

Strongly agree	Agree	Undecided	Disagree	Strongly disagree



Strongly agree	Agree	Undecided	Disagree	Strongly disagree

# 21. My partner confides his/her inmost thoughts and beliefs to me.

Agree	Undecided	Disagree	disagree
			Dibugico

PAST

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

22. I have become angry, upset or irritable because of things that occur in my marriage/relationship

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

# 23. My partner and I enjoy several mutually satisfying outside interests.

		PRESENT		
Strongly agree	Agree	Undecided	Disagree	Strongly disagree



Strongly agree	Agree	Undecided	Disagree	Strongly disagree

## 24. I am unable to say to my partner all that I would like.

agree	disag	Disagree	Undecided	Agree	Strongly agree

PAST

agree		2	disagree

# 25. I sometimes boast in front of my partner.

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

PAST

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

### 26. My partner and I share views on what is right and proper conduct.

		PRESENT		
Strongly agree	Agree	Undecided	Disagree	Strongly disagree



Strongly agree	Agree	Undecided	Disagree	Strongly disagree

### 27. My partner is critical of decisions I make.

Strongly	Agree	Undecided	Disagree	Strongly
				uisagiee

ugi oo	disagree

28. My marriage/ relationship helps me to achieve the goals I have set myself in life.

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

29. My marriage/relationship suffers from disagreement concerning matter of leisure and recreation.

Strongly agree	Agree	Undecided	Disagree	Strongly disagree



Strongly agree	Agree	Undecided	Disagree	Strongly disagree

#### 30. Once in a while, I lose my temper and get angry with my partner. PRESENT

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

That is the end of the questions.

Thank you for your time and effort on this project Do you have any questions or comments?

	Prifygal Cymres University of Wales B A N G O R
	APPENDIX 4
	Carer Interview
Interviewer ID	
Case ID	

These first few questions are to find out general background information.

1.	Gender:	Mal	e 🗌	Female			5	
2.	Age:							
З.	Marital status	:						
	Married			Separate	əd			
	Single			Widowe	d			
	Divorced			Partner				
4.	Are you emp	oloyed?		,	Yes		No	
5.	If 'no', when	were you la	st employ	ved?		Yrs	Mts	
6.	What were/ a	are you emp	loyed as	?				
7.	Other than yo	our patient/p	artner, do	o you have	e farr	nily who li	ve in your ai	rea?
					Yes		No	
8.	If yes, how o	ften do you	see them	ו?				
		Daily	At	least wee	kly		At least m	onthly
11.	How long hav	/e you been	caring fo	r <i>(insert p</i>	atier	nt's name	)?	
	How long hav	ve they beer	n dischar	ged home	)	Yrs Wks	Mts Days	
12.	Have you bee	en a carer b	efore?			Yes	No	
13.	lf 'yes', then a) how	v long ago v	vere you a	a carer?		Yrs	Mts	
	b) for l	now long?				Yrs	Mts	



14. Please will you indicate in the boxes the extent to which you are confident that (*insert patient's name*) will make a full recovery, with 1 being 'not at all confident' and 5 being 'very confident'.

4	0	•		_
1	2	3	4	5

15. Are you currently receiving any medication?

Yes	 No
100	

16. If 'yes', what for?

2



### **Barthel Index**

The next set of questions are interested in what (*insert name of patient*) can do physically. Think of (*insert name of patient*) in the last 24 Hrs

#### 1. Can they walk on level surfaces?



#### 2. Can they dress? (All fasteners, etc.)

Independently (zips, buttons, etc)



Dependent



3. Can they	transfer themself? (from chair to bed and vice versa)
	Independent
	Minimal help (verbal or physical) Can sit with major help
	unable
4. Can they I flush, etc.)	nandle toilet duties on their own? (transfer, clothes, wipe,
	Independent
	Needs some help
	Dependent
5. How is the	eir bowel control?
	Continent
	Occasional accident
	Incontinent
6. How is the	ir bladder control?
	Continent
	Occasional accident
	Incontinent (Catheterised)



7. Can they manage personal hygiene? (washing face, combing hair, shaving, teeth etc.)



Independent



Dependent

# 8. Can they bath/shower themselves?



Independent

Dependent

### 9. Can they feed themself?

L		
Г	-	

Independent

Needs some help	
(cutting food, spreading etc.)	

Dependent

10. How is their eating? (e.g. chewing, swallowing)





Some problems



## 11. Can they go up and down stairs?



Independent



Needs help (verbal/physical)

Unable

2 12 K



12. How is their speech?



### HAD Scale

The next questions are interested in how you have been feeling in the last seven days. As before there are no 'correct' or 'Incorrect' answers. Please answer according to your **own feelings**, rather than how you think 'most people' would answer

**\_\_\_** 

1.	l feel	tense	or	'wound	up':
----	--------	-------	----	--------	------

	Most of the time	
	A lot of the time	
	From time to time, occasionally	
	Not at all	
2.	I still enjoy doing the things I used to enjoy:	
	Definitely as much	
	Not quite so much	
	Only a little	
	Hardly at all	
3.	I get sort of frightened feeling as if something a about to happen:	wful is
	Very definitely and quite badly	
	Yes, but not too badly	
	A little, but it doesn't worry me	
	Not at all	



4.	I can laugh and s	see the funny side of things:	
	As r	nuch as I always could	
	Not	quite so much now	
	Defi	nitely not so much now	
	Not	at all	
5.	Worrying though	its go through my mind:	
	A gr	eat deal of the time	
	A lot	t of the time	
	Fron	n time to time but not too often	
	Only	occasionally	
6.	I feel cheerful:		
	Not a	at all	
	Not o	often	
	Som	etimes	
	Most	t of the time	
7.	I can sit at ease a	and feel relaxed:	
	Defir	nitely	
	Usua	ally	
	Not c	often	
	Not a	t all	



8.	I feel as if I am slowed down:	
	Nearly all the time	
	Very often	
	Sometimes	
	Not at all	
9.	I get a sort of frightened feeling like 'butterflie	s' in the stomach:
	Not at all	
	Occasionally	
	Quite often	
	Very often	
10.	I have lost interest in my appearance:	
	Definitely	
	I don't take as much care as I should	
	I may not take quite as much care	
e	I take just as much care as ever	
11.	I feel restless as if I have to be on the move:	
	Very much indeed	
	Quite a lot	
	Not very often	
	Not at all	

-



12.	I look forward with enjoyment to things:	
	As much as I ever did	
	Rather less than I used to	
	Definitely less than I used to	
	Hardly at all	
13.	l get sudden feelings of panic:	
	Very often indeed	
	Quite often	
	Not very often	
	Not at all	
14.	I can enjoy a good book or radio or TV programn	ne:
	Often	
	Sometimes	
	Not often	
	Very seldom	



## R.L.O.C.

These are statements other people have made about recovery. Please will you indicate the extent to which you agree or disagree with them in the appropriate columns below each question.

# 1. How *(insert name of patient)* manages in the future depends on himself/ herself, not on what other people can do for him/ her.

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree

#### 2. It's often best just to wait and see what happens.

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree

3. It's what *(insert name of patient )* does to help himself/ herself that's really going to make all the difference.

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree

4. *(insert name of patient)* efforts are not very important, his / her recovery really depends on others.

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree




5. It's up to *(insert name of patient)* to make sure that he/she makes the best recovery possible under the circumstances.

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree

# 6. *(insert name of patient)* own contributions to his/her recovery don't amount to much.

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree

# 7. Getting better now is a matter of *(insert name of patient)* own determination rather than anything else.

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree

8. *(insert name of patient)* has little or no control over his/ her progress from now on.

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree



# 9. It doesn't matter how much help *(insert name of patient )* gets, in the end it's his/her own efforts that count.

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree

### Caring Impact Appraisal Scale

To what extent do you feel each of the statements below applies to how you feel about yourself and your situation?

Show how you feel by circling a number from -3 ('strongly disagree') to +3 ('strongly agree'). The more you feel the statement applies to you, the higher the number you should circle. The less you feel the statement applies to you, the lower the number you should circle.

Se	ction A							
		Strongly Disagree						Strongly Agree
1.1	Because of my caring, my social life has got better.	-3	-2	-1	0	1	2	3
2. I	Because of my caring, I have more opportunities to be with my loved one.	-3	-2	-1	0	1	2	3
3.	My life is better organised because of my caring.	-3	-2	-1	0	1	2	3
4. I	Because of my caring, I am more 'alive' than I used to be.	-3	-2	-1	0	1	2	3
5. I	My caring means that my relationships with other family members are closer and richer.	-3	-2	-1	0	1	2	3
Se	ction B	Strongly Disagree						Strongly Agree
1.	Because of my caring, I don't have as much energy as I used to have.	-3	-2	-1	0	1	2	3
2.	Because of my caring, I am no getting enough sleep.	t-3 -2	-1	0	1	2	3	



	Stro Disa	ongly agree						Strongly Agree
3.	Because of my caring, I am physically tired.	-3	-2	-1	0	1	2	3
4.	Because of my caring, I take part less in social activities.	-3	-2	-1	0	1	2	3
5.	Because of my caring, I don't have enough time for myself.	-3	-2	-1	0	1	2	3
6.	Because of my caring, my health has suffered.	-3	-2	-1	0	1	2	3
7.	I feel emotionally drained because of my caring.	-3	-2	-1	0	1	2	3
8.	Because of my caring, I don't keep in touch with my friends the way I used to.	-3	-2	-1	0	1	2	3
9.	I have too much to do to do everything well.	-3	-2	-1	0	1	2	3
10	I have trouble with my nerves because of my caring.	-3	-2	-1	0	1	2	3
11.	I feel like I am being pulled in different directions because of my caring	-3	-2	-1	0	1	2	3
12	. I feel trapped because of my caring.	-3	-2	-1	0	1	2	3
13	. Because of my caring, I feel like I have lost control of my life.	-3	-2	-1	0	1	2	3



Se	ection C	Strongly						Otaraala
		Disagree						Agree
1.	My relationship with the persor I care for is strained.	ı -3	-2	-1	0	1	2	3
2.	The person I care for lets me know how much s/he appreciates what I do.	-3	-2	-1	0	1	2	3
3.	The person I care for doesn't appreciate what I do as much as I would like.	-3 -2	-1	0	1	2	3	
4.	I feel irritable/grouchy when I am around the person I care for.	-3	-2	-1	0	1	2	3
5.	I wish I had a better relationship with the person I care for.	o -3	-2	-1	0	1	2	3
6.	Caring has made me closer to the person I care for	-3 -2	-1	0	1	2	3	
7.	I feel that the person I care for asks for more help than s/he needs.	-3	-2	-1	0	1	2	3
Se	ction D							
		Strongly Disagree						Strongly Agree
1.	Caring for this person makes me feel good about myself.	-3	-2	-1	0	1	2	3
2.	The responsibility of caring gives me an important sense of satisfaction.		-3	-2	-1	0	1	2 3
З.	Caring makes me feel valued	-3	-2	-1	0	1	2	3



		Strong Disag	gly ree						Strongly Agree
4.	Caring for this person is a real source of pleasure to me.	-3	-2	-1	0	1	2	3	
5.	I find my caring activities fulfilling/rewarding.	-3	-2	-1	0	1	2	3	
6.	Caring for this person makes n happy.	ne	-3	-2	-1	0	1	2	3

### Marital Intimacy

Strongly

agree

Please say whether you strongly agree, agree, are undecided, disagree, or strongly disagree with each of the following statements as they apply to you AT PRESENT. It is best not to spend too long thinking about your answers. Please tick the word that corresponds to you. Then think back to the time before (insert name) was ill and say whether you would have strongly agreed, agreed, been undecided, disagreed, or strongly disagreed with the same statements. Please tick the PAST statement in the boxes underneath.

# 1. The feelings I have for my partner are warm and affectionate.

	PRESENT		
Agree	Undecided	Disagree	
Agree	Undecided	Disagree	

Strongly

disagree

	PAST	
	TAOT	

Strongly agree	Agree	Undecided	Disagree	Strongly disagree



# 2. My partner and I find it difficult to agree when making important decisions.

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

PAST

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

# 3. I am very committed to my partner

Strongly	Agree	Undecided	Disagree	Strongly
agree	Agree	onacolaca	Disagree	disagree

PAST

Strongly agree	Agree	Undecided	Disagree	Strongly disagree
37				

### 4. My Partner makes unreasonable demands on my spare time PRESENT

Strongly agree	Agree	Undecided	Disagree	Strongly disagree		

Λ (	C	T
A	5	
	A	AS

Strongly agree	Agree	Undecided	Disagree	Strongly disagree



## 5. All my partners habits are good and desirable ones.

Strongly agree	Agree	Undecided	Disagree	Strongly disagree
				×

### PAST

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

# 6. I enjoy pleasant conversations with my partrner.

		PRESENT		
Strongly agree	Agree	Undecided	Disagree	Strongly disagree

### PAST

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

# 7. I wish my partner was more loving and affectionate.

### PRESENT

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

Strongly agree	Agree	Undecided	Disagree	Strongly disagree



#### My partner has helped me to feel that I am a worthwhile person. 8.

agree	Agree	Undecided	Disagree	Strongly disagree

### PAST

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

#### I am unable to tell my partner in words that I love him/her. 9.

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

### PAST

Agree	ondecided	Disagree	disagree

### On occasion, I have told a small lie to my partner. PRESENT 10.

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

Strongly agree	Agree	Undecided	Disagree	Strongly disagree



# 11. My partner is liked and accepted by my relatives

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

PAST

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

12. I look outside my marriage for things that make my life worthwhile and interesting

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

PAST

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

13. When I am unhappy about some aspect of our relationship I am able to tell my partner about it.

 Strongly agree
 Agree
 Undecided
 Disagree
 Strongly disagree

ugico	disagree



#### My marriage has "smothered" my personality. 14.

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

## PAST

Strongly agree	Agree	Undecided	Disagree	Strongly disagree	

I sometimes have thoughts and ideas I would not like to tell my 15. partner. DDEOENIT

isagree	dis	Disagree	Undecided	Agree	agree

### PAST

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

### I am happy with the physical relationship I have with my partner. PRESENT 16.

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

Strongly agree	Agree	Undecided	Disagree	Strongly disagree



# 17. My partner does not understand the way I feel.

isagree

### PAST

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

18. My relationship with my partner is the most important and meaningful relationship I have.

		PRESENT		
Strongly agree	Agree	Undecided	Disagree	Strongly disagree
		there is all the second		

		PAST		
Strongly agree	Agree	Undecided	Disagree	Strongly disagree



#### I wish my partner worked harder to make our relationship more 19. satisfying for us both.

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

PAST

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

#### I have never had an argumnet with my partner. 20.

agree

PAST

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

# My partner confides his/her inmost thoughts and beliefs to me. PRESENT 21.

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

Strongly agree	Agree	Undecided	Disagree	Strongly disagree



in

# 22. I have become angry, upset or irritable because of things that occur my marriage/relationship

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

### PAST

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

# 23. My partner and I enjoy several mutually satisfying outside interests.

Agree	Undecided	Disagree	Strongly disagree
	Agree	Agree Undecided	Agree Undecided Disagree

## PAST

Strongly agree	Agree	Undecided	Disagree	Strongly disagree
	ę			

### 24. I am unable to say to my partner all that I would like.

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

Strongly agree	Agree	Undecided	Disagree	Strongly disagree



# 25. I sometimes boast in front of my partner.

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

PAST

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

# 26. My partner and I share views on what is right and proper conduct. PRESENT

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

PAST

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

# 27. My partner is critical of decisions I make.

PRESENT

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

Strongly agree	Agree	Undecided	Disagree	Strongly disagree



28. My marriage/ relationship helps me to achieve the goals I have set myself in life.

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

PAST

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

29. My marriage/relationship suffers from disagreement concerning matter of leisure and recreation.

agree	Agree	Undecided	Disagree	Strongly disagree

Strongly agree	Agree	Undecided	Disagree	Strongly disagree



30. Once in a while, I lose my temper and get angry with my partner.

Strongly agree	Agree	Undecided	Disagree	Strongly disagree
			1	

### PAST

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

# That is the end of the questions.

Thank you for your time and effort on this project Do you have any questions or comments?

### **APPENDIX 5**

# MSQ

### Introduction to Test

"Before we start I would just like to check your memory. I will ask you some questions and I would like you to tell me the answers. Don't worry if you can't answer some questions or have forgotten the answers, just try your best."

Then proceed to ask the participant the following:

- 1) Address/name of place they reside at
- 2) Their age
- 3) Their Year of birth
- 4) Their month of birth
- 5) Today's date
- 6) The Month
- 7) The Year
- 8) Name of Prime Minister
- 9) Name of previous Prime Minister

Answers can be given in writing or verbally.

# **APPENDIX 6**



e-mail: pss029@bangor.ac.uk http://www.psych.bangor.ac.uk/

### **Information Sheet**

You are being invited to take part in a research study. Before you make a decision, it is important that you understand why the research is being done, and what it will involve. Please take time to read the following information carefully and feel free to discuss it with friends, and family, before you decide whether or not you wish to take part

Title of Study: Couples personal accounts of stroke.

**Who is running the study?** Dr Val Morrison, a chartered health psychologist at the University of Wales, Bangor, with Miss Elly Jones, a PhD student in the School of Psychology, University of Wales, Bangor.

Why are you a suitable person to take part in the study? You are a couple of which one has experienced a stroke and have taken part in one of Elly's previous studies.

What is the study about? The study is interested in couples' personal accounts of stroke, their relationship and their experiences since the stroke. This is the final stage of Elly's research.

### If you agree to take part, what will it involve?

If you agree to take part to this final aspect of Elly's study, it will involve her coming to visit you at your home to have an informal interview. The interview will be audio-recorded with the both of you and Elly will ask you some questions about your experiences of stroke and the impact stroke has had on your lives. There will be opportunity for you both to talk about your personal experiences and to put across your own views and opinions. This part of the study involves discussion NOT questionnaires.

### Are the interviews available in Welsh?

Elly has conversational Welsh but unfortunately will not be able to transcribe the interviews if they are conducted in Welsh, she therefore asks if the interviews can be conducted in English for the purpose of the research.

### What are the possible benefits of taking part in this research?

There are no direct benefits to you and your carer, but you may enjoy being able to share and discuss your experiences. The aim of the study is to gain a deeper understanding of

couples experiences folowing a stroke.

### What are the possible dangers of taking part in this research?

No harm is likely. The tape recordings will be kept strictly confidential, that is, your name will not appear on the tape cassettes and no-one except you and the research team will have access to the tapes. You can change your mind during the interview and stop answering questions, or refuse to answer particular questions if you wish to. You do not have to give us a reason for pulling out of the study, and your health care will not be affected in any way should you choose to do so.

### What happens when the study finishes?

The tape cassettes will be stored in a locked filing cabinet and will be destroyed once all the research has been completed.

### What will happen to the results of the research study?

It is hoped that the results of the study will be published at the end of the research period. Your identity will not be published in any paper resulting from your participation. Extracts of what you say may be used in subsequent reports but will not contain personal details that might compromise your anonymity. If you agree to take part in this study, then you will be informed of publications and how to obtain them.

Thank you for considering taking part in this study.

*Questions:* If you have any questions to ask about the study before you decide whether or not to take part, please phone Miss Elly Jones on 01248 383664 or 01492 572057.

*Complaints:* In the case of complaints about how the study is carried out, you should write to: Professor C.F. Lowe, Head of School of Psychology, University of Wales Bangor, Gwynedd LL57 2DG.

### **APPENDIX 7**

Interview Schedule.

Impact of Stroke

Can you tell me about what has happened in the last year/two years since I last saw you both?
Has anything changed?
How do you feel now?

Think back to the stroke, how did the stroke affect you both?
How did you both feel after the stroke?
How was returning home after the stroke?
What has helped you both since the stroke?
What has hindered you since the stroke?

Identity

-How would you describe yourself as a person? addressed to both carer and stroke patient

-Has the stroke made a difference to how you see yourself?

What about compared to before the stroke

-How do you think others see you?

Couple Questions

- -What does your everyday routine involve? Has this changed, who does what?
- -What do you enjoy doing together? Has this changed?
- -What do you enjoy doing separately? Has this changed?
- -What frustrates/upsets you?
- -What do you both have in common?
- -How much do you talk about problems?
- -What affect has the stroke had on your relationship?
- -What plans do you have for the future?

# **APPENDIX 8A**

### Patient content and voice

Themes

Voice: talking about self. I: *Have you accepted it? P: No.* 

P: I used to write essays and things and I used to do things straight away.

P: Frustrated and dependant person
Comparison to self before
P: That's what it is, I didn't like that I was different.
Reminiscence
P: I used to do 30 mile walks.
Voice talking about relationship:
Positive, happy
P: We are quite happy together I think

P: Well we haven't any problems really

P: Without M I'd be lost

Representations and dominant societal voices: Ageing discourse P: Anyhow you get close to seventy or over seventy they are not so bothered. Burden P: He was overworked anyhow. Illness representations P: I've never had a headache in my life touch wood

I: what do you think caused it? P: I had an operation to my bladder and I think clots.

### Patient communication formats and interactions

Role taken in relation to other person Patient is Interviewee, wife interviewer C: Well I can't see what else is stopping you, you've got all the time in the world, haven't you ? P: Attitude

C: What is it, you've forgotten haven't you? P: No. Grateful recipient: P: M's helpful, not helpful she's brilliant.

Passive: P: Not so argumentative C: No he doesn't argue anymore, no, not really. ( interview is characterised by lots of "yes" in this interview on behalf of patient).

Types of conversational interaction (e.g. questioning, negotiating, disagreeing) Agrees/ passive. P: yes (numerous times in script) Short sentences/answers P: That's it P: I'm not sure. Interrupted: P: Thing is... C: but we've decided we can't wait until the new Year Attempts to join in: P: I planted all the chryth.... C: but, yes I know he's planted all the .. in little pots Asserting oneself C: And you wanted to go didn't you? P: I did go Agreeing-failed resistance. P: The one's in the living room, I haven't touched them have I, Two bars. C: How long have they been there G C: about a week but I feel so mean. P: But I haven't touched them C: But you do though don't you, fair do's I am right aren't I G. P: I'm sure you are

### Carer content and voice

<u>Themes</u> Conflict with medical world C: Doctor never turned up did he and it was only quarter ten at night...he's only five minutes away, but he didn't come.

C: No she was away or sick or something and every time we went there we saw somebody different. So you couldn't ask and it's, was bloody hopeless I must say.

Conflict with patient C: And I can't get him out through the front door now Partner is now driving but patient interferes C: No, he'll see lights coming up and he'll go red. P: It's wonderful really



C: Wonderful! I do get irritated by that. Uncertainty/panic at stroke C: We didn't know what had happened to him

C: panicky, you panic, well I know I do'

C: Well I don't think I realized what had happened to him at that time in a way. I didn't think it was anything. I didn't think it would affect this much .And then I couldn't get him home quick enough and that was a mistake probably I should have tried to keep him there. But I didn't think that he was that bad

Voice talking about self: Changed roles

C: Now I am a lot more interested in gardening, I really enjoy doing the gardening now Confidence

C: I'm a lot more confident in things like that aren't I, doing business things, over the phone things, I used to be hopeless

Comparison to others, upwards.

C: No we're fortunate, it's a good job, it would be awful wouldn't it

C: I tell you we've been so lucky in a way not to go to hospital in a way. <u>Voice talking about relationship</u> Neutral C; Well we don't talk, only health problems and that C: We get on alright we don't have the energy to argue (laughs) he's very easy to do it, he's always very grateful, he always says thank you don't you. Improved

C: I don't know really, the same I've always looked after him haven't I. In some ways he's easier to look after than he used to be.

*P: That's right.C: We're o.k as long as nothing happens to me aren't we?* 

Societal representations

Negativity towards stroke C: And that's the other one yeah, but definitely stroke, there's nothing they can do perhaps, perhaps they feel hopeless, do you think? Search for cause C: I mean he wasn't under any stress, couldn't be caused by stress could it, we hadn't got anything to worry about had we?

### Carer Communication formats and interactions

Role taken in relation to other person

Parent-child relationship C: He's always managed to shave himself and em he has to get dressed and take his pills and that takes half an hour, I've timed it. C: We get on alright we don't have the energy to argue (laughs) he's very easy to do it, he's always very grateful, he always says thank you don't you. Manager/carer-in control C: But I have got him sorted out now, so in the evening he's got them altogether so that's

brilliant isn't it, only a pot to swallow (laughs).

P: Not so argumentative
C: No he doesn't argue anymore, no, not really.
Narrator/translator for patient
C: Strange that he's interested in it, most of us study and forget it, but he's always been. he still feels it obviously.

C: Well I think he just wanted to come home, we, you do don't you, anybody wants to come home."

Types of conversational interaction Contradicts/undermines point of view C: Oh no I think it's in the sixties C; Oh no I think it's in the fortysomethings, I think you have forgotten that. Resistance by carer I: So how at the moment, do you both feel now about the stroke: P: Devastated and frustrating C: We manage Ignores-re-directs I: What do you both have in common? C: We've been married for fifty years P: We are quite happy together C: yes, well I'm not very interested in Rugby but I put it on for you don't I. Interrupts P: She was brilliant, occupational... C: very good P: he was a pupil of mine, he... C: He's in Bangor university now Directs patient C; The pulleys good you said didn't you? C; And now it's once a fortnight. Don't know if it's any use really, perhaps it is perhaps it isn't. What do you think? Directs conversation to highlight what's important/changed C: And on Saturday he's decided he wants to go on what is it? You've forgotten it haven't you? C: You don't read quite as many books

C: You don't read quite as many books P: I've only read two since C: I know, (sigh, tut) Negotiating. C: I don't know, I 'm not all that at the moment, I don't really, I don't think it would be worth the hassle would it? P: I'm not sure

### **APPENDIX 8b**

### **Couple Conversation Analysis Schedule**

To elucidate the individual perspectives, thoughts and cognitions by the participants their voices were traced through each transcript and IPA was used to create themes. Then using Brown & Gilligan's voice relational method as applied by Clare and Shakespeare (in press 2003) and Proctor (2001) and on conversation analysis methods as applied by Adams (2001) the interactions and communication between the couples were investigated.

The categories are also informed by Kitwood's "Malignant Social Psychology" in dementia care mapping-see my handout

For both PATIENT (P) and PARTNER/CARER (C)

Content and voice Themes Voice: talking about self Voice: talking about relationship/other Representations of dominant societal voice (e.g. ageing discourse, burden, medical model) Communication formats and interactions Role taken in relation to other person Types of conversational interaction (e.g. questioning, negotiating, disagreeing)

Patient –content and voice PINK Patient-role and interaction YELLOW Carer-content and voice GREEN Carer-role and interaction ORANGE

### **APPENDIX 9a**



Information Sheet

e-mail: pss029@bangor.ac.uk http://www.psych.bangor.ac.uk/

You are a registered member of the School of Psychology's Participant Panel and we are contacting you to see if you would like to be involved in our study. Please take time to read the following information carefully and feel free to discuss it with others before you decide whether or not to take part.

Who is running the study? Two research students, Jayne Swift and Ruth Edwards, are conducting the study in collaboration with Elly Jones, a PhD student in the University of Wales, Bangor and Dr Val Morrison, a chartered health psychologist and lecturer, who is the study Supervisor.

Who are suitable persons to take part in the study? Married or co-habiting couples that consider themselves healthy and are aged 55 years or older.

Why is the study being conducted?

We are interested in the associations between couples interaction, personal characteristics, life goals and mood. Elly Jones has been conducting a study of stroke patients and their carers, and this new study will allow us to establish whether 'stroke couples' interactions, goals and mood differ from healthy couples of the same age. Ultimately we hope to be able to identify factors of benefit to mood in healthy couples or those dealing with illness such as stroke.

If you agree to take part what will it involve?

The study involves you and your partner being filmed working together to complete a jigsaw puzzle and then being filmed discussing/planning a future event. We then give you each a questionnaire to complete which you and your partner fill in individually with the aid of Jayne and Ruth. The questionnaire measures mood, general outlook on life, your goals and your relationship with your partner, and should take no longer than 40 minutes to complete

Are the interviews available in Welsh?

Unfortunately, the questionnaires only currently exist in English, but the research students will help explain anything to you if this is necessary.

What are the possible benefits of taking part in this research? You and your partner will each be paid  $\pounds$ 5 for taking part in the study and the information you provide will be used along with information from stroke patients and carers to inform clinicians and future researchers.

What are the possible dangers of taking part in this research? No harm is anticipated. The video-recording and your questionnaire answers will be kept strictly confidential, that is, your name will not appear on your answer sheet or videotape. You can change your

### **APPENDIX 9a**

mind during the interview and stop answering questions, or refuse to answer particular questions if you wish to. You do not have to give us a reason for pulling out of the study and both you and your partner are free to do so at anytime.

What will happen when the study finishes? The questionnaire sheets and videotapes will be stored in a safe place and destroyed when the study is completely finished.

What will happen to the results of the research study?

It is hoped that the results of the study will be subsequently published. Your identity will not be published in any paper or report resulting from your participation. If you and your spouse/partner agree to take part in this study, then you will be informed of any publications and how to obtain them.

If you are happy to take part, please indicate 'yes' on the reply slip overleaf, and provide your contact details. Post back this reply slip as soon as possible in the FREEPOST envelope, and then one of the researchers will contact you to arrange a suitable appointment.

If you do NOT wish to take part, please indicate 'No' on the reply slip and return as above. We will not contact you again in relation to this study.

Thank you for your consideration.

*Questions:* If you have any questions to ask about the study before you decide whether or not to take part, please phone Elly Jones/Val Morrison on 01248 383664 or 382485.

*Complaints* : If you have any complaints about how this study has been conducted, please contact: Professor C.F. Lowe, Head of School of Psychology, University of Wales Bangor, Brigantia Building, Penrallt Rd, Bangor, Gwynedd LL57 2DG.

# **APPENDIX 9a**

# PLEASE COMPLETE AND POST BACK IN FREEPOST ENVELOPE

....

••••••	
Names	S
	<b>NO</b> , I cannot take part in this study as I do not fit the criteria for your study (i.e. am single, or aged under 55, or I do not consider myself to be healthy)
	NO, my spouse/partner and I would not like to take part in this study.
	YES, my spouse/partner and I would like to take part.
Please	contact me on
If no te shortly	elephone or email contact, please give your address and we will write to you

APPENDIX 9b Bangor University Research Team
Interviewer ID Case ID
These first few questions are to find out general background information.
Gender: Male Female
Age: Marital status:
Married Partner
Are you employed? Yes No
If 'no', when were you last employed? YrsMts
What were/ are you employed as?
Other than your partner, do you have family who live in your area?
Yes No
If yes, how often do you see them?
Daily At least weekly At least monthly
How many times a month do you socialise?
Never Once at most Twice at most More than this
Have you ever suffered a chronic illness? (diabetes, asthma, arthritis, stroke, heart attack, mental illness)
Yes No No All All All All All All All All All Al

b) Have you ever been dependent upon a family member to care for you because of an illness (period of time must exceed 7 days).

APPENDIX 9b
Have you ever been a carer for someone who was dependent on you (period of time must exceed 7 days and excludes paid care) YesNoNoNoNoNoNO
If yes how long for? yrsmnthswks
Please state whether they were a friend or family member and the reason they needed care
Are you currently receiving any medication? Yes No D

# **APPENDIX 9b**

### HAD Scale

The next questions are interested in how you have been feeling in the last seven days. As before there are no 'correct' or 'Incorrect' answers. Please answer according to your **own feelings**, rather than how you think 'most people' would answer

1.	I feel tense or 'wound up':	
	Most of the time	
	A lot of the time	
	From time to time, occasionally	
	Not at all	
2.	I still enjoy doing the things I used to enjoy:	
	Definitely as much	
	Not quite so much	
	Only a little	
	Hardly at all	
3.	I get sort of frightened feeling as if something about to happen:	awful is
3.	I get sort of frightened feeling as if something about to happen: Very definitely and quite badly	awful is
3.	I get sort of frightened feeling as if something about to happen: Very definitely and quite badly Yes, but not too badly	awful is
3.	I get sort of frightened feeling as if something about to happen: Very definitely and quite badly Yes, but not too badly A little, but it doesn't worry me	awful is
3.	I get sort of frightened feeling as if something about to happen: Very definitely and quite badly Yes, but not too badly A little, but it doesn't worry me Not at all	awful is
3.	I get sort of frightened feeling as if something about to happen: Very definitely and quite badly Yes, but not too badly A little, but it doesn't worry me Not at all I can laugh and see the funny side of things:	awful is
3.	I get sort of frightened feeling as if something about to happen: Very definitely and quite badly Yes, but not too badly A little, but it doesn't worry me Not at all I can laugh and see the funny side of things: As much as I always could	awful is
3.	I get sort of frightened feeling as if something about to happen: Very definitely and quite badly Yes, but not too badly A little, but it doesn't worry me Not at all I can laugh and see the funny side of things: As much as I always could Not quite so much now	awful is

		APPENDIX 9b	
		Not at all	
5.	Worrying th	noughts go through my mind: A great deal of the time	
		A lot of the time	
		From time to time but not too often	
		Only occasionally	
6.	I feel cheer	ful:	
		Not at all	
		Not often	
		Sometimes	
		Most of the time	

7.	APPENDIX 9b I can sit at ease and feel relaxed:		
	Definitely		
	Usually		
	Not often		
	Not at all		
8.	I feel as if I am slowed down:		
	Nearly all the time		
	Very often		
	Sometimes		
	Not at all		
9.	I get a sort of frightened feeling like 'butterflies'	in the stomach:	
	Not at all		
	Occasionally		
	Quite often		
	Very often		
10.	I have lost interest in my appearance:		
	Definitely		
	I don't take as much care as I should		
	I may not take quite as much care		
	I take just as much care as ever		

1.5

11.	APPENDIX 9b I feel restless as if I have to be on the move:	
	Very much indeed	
	Quite a lot	
	Not very often	
	Not at all	
12.	I look forward with enjoyment to things:	
	As much as I ever did	
	Rather less than I used to	
	Definitely less than I used to	
	Hardly at all	
13.	I get sudden feelings of panic:	
	Very often indeed	
	Quite often	
	Not very often	
	Not at all	
14.	l can enjoy a good book or radio or TV program	me:
	Often	
	Sometimes	
	Not often	
	Very seldom	

# **APPENDIX 9b**

### Marital Intimacy

These next set of questions ask about your relationship with your partner as before there are no right or wrong answers. Please say whether you strongly agree, agree, are undecided, disagree, or strongly disagree with each of the following statements as they apply to you AT PRESENT. It is best not to spend too long thinking about your answers. Please tick the word that corresponds to you.

### 1. The feelings I have for my partner are warm and affectionate.

Strongly agree	Agree	Undecided	Disagree	Strongly disagree
				-

# 2. My partner and I find it difficult to agree when making important decisions.

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

### 3. I am very committed to my partner.

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

4. My partner makes unreasonable demands on my spare time.

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

### 5. All my partners habits are good and desirable ones.
Strongly agree	Agree	Undecided	Disagree	Strongly disagree

6. I enjoy pleasant conversations with my partner.

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

7. I wish my partner was more loving and affectionate.

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

8. My partner has helped me to feel that I am a worthwhile person.

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

9. I am unable to tell my partner in words that I love him/her.

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

10. On occasion, I have told a small lie to my partner.

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

### 11. My partner is liked and accepted by my relatives.

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

12. I look outside my marriage for things that make my life worthwhile and interesting.

Strongly agree	Agree	Undecided	Disagree	Strongly disagree
			*	

13. When I am unhappy about some aspect of our relationship I am able to tell my partner about it.

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

### 14. My marriage has "smothered" my personality.

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

# 15. I sometimes have thoughts and ideas I would not like to tell my partner.

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

### 16. I am happy with the physical relationship I have with my partner.

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

### 17. My partner does not understand the way I feel.

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

## 18. My relationship with my partner is the most important and meaningful relationship I have.

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

## 19. I wish my partner worked harder to make our relationship more satisfying for us both.

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

### 20. I have never had an argument with my partner.

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

21.

My partner confides his/her inmost thoughts and beliefs to me.

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

## 22. I have become angry, upset or irritable because of things that occur in my marriage/relationship

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

### 23. My partner and I enjoy several mutually satisfying outside interests.

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

### 24. I am unable to say to my partner all that I would like.

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

### 25. I sometimes boast in front of my partner.

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

26. My partner and I share views on what is right and proper conduct.

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

### 27. My partner is critical of decisions I make.

Strongly agree	Agree	Undecided	Disagree	Strongly disagree
		3		

## 28. My marriage/ relationship helps me to achieve the goals I have set myself in life.

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

## 29. My marriage/relationship suffers from disagreement concerning matter of leisure and recreation.

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

30. Once in a while, I lose my temper and get angry with my partner.

Strongly agree	Agree	Undecided	Disagree	Strongly disagree

### Observational Guidelines Chisholm (2000)

Rating Scales to assess mother with dementia and daughter caregiver dyads on puzzle building and meal planning tasks.

## **Rating the Daughter**

- Engagement in the Task
- Mood rating- positive affect
- Mood rating- negative affect
- Dominance
- Sensitive Responsiveness
- Depersonalising behaviour
- Problem solving approach

6

11

### Engagement in the Task

#### Behaviour to watch for:

Time spent on puzzle building/meal discussion Gazing around room Distracted activity

#### Description

Raters are asked to judge the extent to which participant was attentive and contributory to the task that they agreed to participate in. When referring to the puzzle task attention should be given to how much time is spent actually doing the task, compared to discussion about other things, drinking tea, looking out the window etc. For the meal planning consideration of how much conversation is directly based around this topic, compared to any other topic, or action. When judges are rating the daughter, they are reminded that their "task" can also be referring to aiding the mother to do a task.

#### **Examples of mark allocation**

#### Score of 1-3

A person with a lower score in this category would not have been attentive to the task in hand or appeared interested. She may have been fiddling with other objects, discussed other topics or staring around the room.

#### Score of 4-6

A person scoring in the top end of the scale would mean that the person participated and was interested in the task for all or most of the time being assessed. There was a feeling of involvement and the participant was fully contributing to the designated task.

#### Frequencies

Non topic discourse Looking around the room

### Mood rating- positive affect

#### Behaviour to watch for

Facial expression Positive comments Laughter

### Description

This measures how positive a mood the participant is in. Although raters are asked to look for examples of laughter, smiling, and positive emotion facial expressions they should also consider how genuinely they reflect the mood state of the individual. Participants may be adopting a "grin and bear it" approach and not really be in a very positive mood. Raters are directed towards considering what is said by the participant as well as their non-verbal communication. Comments may be directed at the situation or at the other person.

#### **Examples of mark allocation**

#### Score of 1-3

A low score would reflect the absence of positive affect and not necessarily a negative mood. Participants who displayed few occurrences of positive mood facial expressions such as smiling, laughing or grinning and made little or no positive comments would not score highly on this scale.

#### Score of 4-6

Higher scores would typically include examples of laughter and smiling as well as cheerful comments. Raters are reminded that it is possible for one participant to have a high rating of *Positive Affect* and the other to have a low score

<u>Frequencies</u> Laughter Smiling Positive comments

### Mood rating- negative affect

#### Behaviour to watch for

Facial expression Negative comments Anger Tears Resentment Distress

#### Description

This measures the amount of negativity present in the participant's mood. As stated in the positive mood rating scale the rater should pay attention to possible negative affect despite the presence of smiling, and positive emotion facial expressions. Participants may be adopting a "grin and bear it" approach and not really be in a very positive mood. Again, raters are directed towards considering what is verbalised by the participant as well as their non-verbal communication. As with *Positive Affect* comments may be directed at the situation or at the other person.

#### **Examples of mark allocation**

#### Score of 1-3

A low score would reflect the absence of negative affect and not necessarily a positive mood. Participants who displayed few occurrences of negative mood facial expressions such as frowning, sadness or anger and made little or no negative comments would not score highly on this scale.

#### Score of 4-6

Higher scores would typically include frowning, scowling, anger as well as discouraging or critical comments. Raters are reminded that it is possible for one participant to have a high rating of *Negative Affect* and the other to have a low score

#### Frequencies

Frowning Negative comments Crying Anger

### Dominance

#### Behaviour to watch for

Positioning of the puzzle pieces Interrupting Physical contact. Criticism Sarcasm and patronising comments directed towards the mother Facial expression

#### Description

This attempts to score dominating behaviour in the daughter. This is sometimes done in the spirit of helping, but the daughter may demonstrate frustration. Dominating behaviours to be vigilant for are whether the puzzle pieces are under the daughter or mother, who determines what is for dinner, and who is coming. Watch to see whether these decisions are made after some discussion, or merely stated by the daughter. Does the daughter use open or closed questions? Raters should consider the nature of the physical contact directed at the mother. Either an absence of physical contact of or rough contact would contribute towards a higher score. Tutting or direct criticism of the mother would also be indicative of *Dominance*. Also look for examples of scowling, sarcasm or patronising behaviour directed towards the mother.

Any body language considered by the rater to be imposing, such as standing over the mother, or grabbing an item from the mother is particularly relevant. Particular attention should also be paid to obvious display of frustration directed towards the mother.

#### **Examples of mark allocation**

#### Score of 1-3

A low score would indicate a lack of dominating behaviour from the daughter. She would be trying to encourage independence in her mother by allowing her time to express herself and carry out her tasks appropriately.

On the puzzle building task the pieces are likely to be either under the mother or between the two of them. The daughter has at least ensured that her mother can reach them. On the meal planning task the mother would be allowed and perhaps even encouraged to take an active role in deciding who is coming and what would be served.

#### Score of 4-6

A score high *Dominance* score would mean that the daughter did not allow the mother to make suggestions, or if she did they would be not listened to or dismissed as foolish. The daughter may have completed a lot of the puzzle and she may have planned the meal as well. The daughter's body posture might be slightly intimidating to the mother.

The puzzle pieces may be positioned under the daughter and out of reach from the mother. The daughter may take pieces from the hand of the mother. Dominating behaviour does not have to be done in an intimidating manner but is can manifest itself under the guise of helping.

In conversation she may not give the mother time to reply, or overly encourage a response.

<u>Frequencies</u> Taking an item from Mother's hand Open Vs closed questions Interrupting the mother

### Sensitive Responsiveness

#### Behaviour to watch for

Attending to needs Demonstration of understanding of impairment Aiding word finding Being patient but instructive during perseveration

#### Description

This seeks to measure the level of understanding and empathy the daughter displays to mother regarding her cognitive impairment. This would include giving the mother time to express herself, but aiding word finding if necessary. The daughter should be sensitive to the stress that her mother may be feeling and help her to overcome some of her difficulties caused by her cognitive impairment without showing frustration. The scale also assesses whether the daughter allows time to see if her mother can accomplish a task or finish a sentence, and not just assuming that she can't.

Raters who feel that there was a lack of support given when some aid was appropriate should take this into consideration when scoring. However, any support should be tailored to dementia severity and not appear to be patronising. She should also use language so that they were appropriate to the cognitive state.

#### **Examples of mark allocation**

#### Score of 1-3

Daughters who received a low score may have ignored the stress and difficulties her mother experienced due to the dementia. However, the daughter may not ignore them but be frustrated by them, and possibly still not help. She may have been communicating in such a way that her mother does not understand her.

#### Score of 4-6

Higher scores will be reflective of the daughter's attention that has been paid to the needs of her mother. The daughter will have ascertained whether her mother was comfortable both mentally and physically and made some effort to help her if necessary. The daughter may have aided comprehension by repeating herself or adjusting her explanation/question so that it could be more easily understood.

### Depersonalising behaviour

#### Behaviour to watch for

Criticism-distinguishing between constructive and non-constructive Condescending comments Treating the mother like a child Not listening to comments Not allowing the mother any independence Infantalising comments

#### Description

This is trying to asses how much attention the daughter is paying to the struggle of the mother to maintain a concept of the self. Attention should be addressed towards how much independence is given. Not acknowledging communication from the mother, or attempting to understand ambiguous comments are the sorts of behaviours to be vigilant for. Try to assess how much effort is made to understand the mother, and how much she is being treated like an adult rather than a small child, or someone who "isn't all there".

The daughter should be attending to the needs of her in a non-intrusive or patronising way.

#### **Examples of mark allocation**

#### Score of 1-3

Daughter's in the lower scoring range will have paid attention to the needs of the mother to have a concept of self by addressing her as an adult, paying attention to what she had to say and attempted to understand anything that did not make sense. The mother would have been allowed independence in making decisions and completing the puzzle.

#### Score of 4-6

Little independence is granted to the mother. The puzzle pieces may be slightly out of reach from the mother, and she would not be allowed much time to try to place them. The daughter would address her as if she were a small child, and ignore any ambiguous comments. In the meal planning task the decisions would all be made by the daughter without attempting to listen to the mother. The daughter's speech would be characterised by a series of statements, or semi-rhetorical questions such as "You like that don't you?", and then moving on not waiting for an answer. There may even be slight resentment in the daughter's voice.

#### Example of a high score

The puzzle building has so far been characterised by the mother putting little effort into building the puzzle. Every time she picks up a piece and attempts to place in the puzzle the daughter takes it from her hand and places it for her. D: What do you think this piece is? M: I don't know. D: It's his hand. M: hmmm.

### Problem solving approach

#### Behaviour to watch for

Use of concrete and specific instructions. Evidence of providing clear instructions geared to Mother's cognitive capacity. Whether level of functioning enhanced or hindered by approach. Provision of feedback.

#### Description

This attempts to score the nature of the daughter's behaviour in the daughter-mother problem solving partnership. It is based on Cavanaugh et al's (1989) theory that function is improved when the caregiver applies scaffolding (Bruner,1975) techniques, and adheres to the 'zone of proximal development' (Vygotsky, 1978).

These terms are borrowed from developmental psychology in the parent/infant relationship and applied to the daughter care-giver/dementing mother relationship. The zone of proximal development refers to the theory that a child's potential performance is enhanced if guidance is provided by someone more skilled. The role of the more knowledgeable (or in this case functional) other is to raise the functional development of the child's ability by providing structure and direction. Scaffolding refers to 'the support that others can contribute to the learner's behaviours, providing guidance, hints or advice, and offering feedback about the performance and correction as needed (Cavanaugh et al 1989).

The measure therefore is a score of how much guidance, feedback, and concrete specific instructions enhances the mother's performance. The daughter's flexibility in changing her approach if it is not working and the use of tools in constructing the puzzle are also important. Independence is considered important as the scale is assessing the improvement of the mother's performance by providing such feedback.

When assessing the puzzle the problem referred to is completion of the puzzle. In the meal planning task it is deciding who is coming and what is going to be eaten

#### Examples of mark allocation

#### Score of 1-3

The daughter has not provided any direction when it was needed. She was rigid in her approach to explaining something or solving the problem. The daughter provides little or no feedback or guidance.

#### Score of 4-6

The daughter would be less rigid and try new approaches to communicate and problem solve. She has provided ample feedback, and allowed her mother to demonstrate her skill.

Daughters scoring highly may still be very different to one another in their approach. A mother and daughter may work closely together on the puzzle building task in one group, each placing an equal number of pieces and in another equally high scoring pair the daughter may give the mother an equal amount of help, but allow her to place all of the pieces herself.

### **Rating for the Mother**

- Engagement in Task
- Mood rating positive affect
- Mood rating negative affect

### Engagement in the Task

#### Behaviour to watch for:

Time spent on puzzle building/meal discussion Gazing around room Distracted activity

#### Description

Raters are asked to judge the extent to which participant was attentive and contributory to the task that they agreed to participate in. When referring to the puzzle task attention should be given to how much time is spent actually doing the task, compared to discussion about other things, drinking tea, looking out the window etc. For the meal planning consideration of how much conversation is directly based around this topic, compared to any other topic, or action.

#### Examples of mark allocation

#### Score of 1-3

A person with a lower score in this category would not have been attentive to the task in hand or appeared interested. She may have been fiddling with other objects, discussed other topics or staring around the room.

#### Score of 4-6

A person scoring in the top end of the scale would mean that the person participated and was interested in the task for all or most of the time being assessed. There was a feeling of involvement and the participant was fully contributing to the designated task.

#### Frequencies

Non topic discourse Looking around the room

### Mood rating- positive affect

#### Behaviour to watch for

Facial expression Positive comments Laughter

#### Description

This measures how positive a mood the participant is in. Although raters are asked to look for examples of laughter, smiling, and positive emotion facial expressions they should also consider how genuinely they reflect the mood state of the individual. Participants may be adopting a "grin and bear it" approach and not really be in a very positive mood. Raters are directed towards considering what was said by the participant as well as their non-verbal communication. Comments may be directed at the situation or at the other person.

#### **Examples of mark allocation**

#### Score of 1-3

A low score would reflect the absence of positive affect and not necessarily a negative mood. Participants who displayed few occurrences of positive mood facial expressions such as smiling, laughing or grinning and made little or no positive comments would not score highly on this scale.

#### Score of 4-6

Higher scores would typically include examples of laughter and smiling as well as cheerful comments. Raters are reminded that it is possible for one participant to have a high rating of *Positive Affect* and the other to have a low score

<u>Frequencies</u> Laughter Smiling Positive comments

### Mood rating- negative affect

#### Behaviour to watch for

Facial expression Negative comments Anger Tears Resentment Distress

#### Description

This measures the amount of negativity present in the participant's mood. As stated in the positive mood rating scale the rater should pay attention to possible negative affect despite the presence of smiling, and positive emotion facial expressions. Participants may be adopting a "grin and bear it" approach and not really be in a very positive mood. Again, raters are directed towards considering what is verbalised by the participant as well as their non-verbal communication. As with *Positive Affect* comments may be directed at the situation or at the other person.

#### **Examples of mark allocation**

#### Score of 1-3

A low score would reflect the absence of negative affect and not necessarily a positive mood. Participants who displayed few occurrences of negative mood facial expressions such as frowning, sadness or anger and made little or no negative comments would not score highly on this scale.

#### Score of 4-6

Higher scores would typically include frowning, scowling, anger as well as discouraging or critical comments. Raters are reminded that it is possible for one participant to have a high rating of *Negative Affect* and the other to have a low score

#### Frequencies

Frowning Negative comments Crying Anger

## **Rating Mother and Daughter Interaction**

- Emotional attunement
- Interactive style and communication quality

### Emotional attunement

#### Behaviour to watch for

Eye contact Shared emotional expression Evidence of mirroring Evidence of ability to anticipate communication.

#### Description

This attempts to quantify the amount of empathy and emotional communication the pair has. The rater is asked to look for examples of anticipating emotional response, the level of understanding a communication each has of the other, and how attuned they are to the emotions that the other may be feeling.

#### **Examples of mark allocation**

#### Score of 1-3

The daughter does not seem sensitive to the mother's affective state (and vice versa). There is some kind of disparity present in what each is communicating- verbally and non-verbally- to the other. The rater believes that neither person feels what the other feels.

#### Score of 4-6

High scores would have a high frequency of eye contact during discussion. Emotional expression would be similar throughout the interaction, and there would be some evidence of an ability to predict emotional affect.

One person may indicate using non-verbal communication that they have predicted what the other is going to say. The person speaking demonstrates that she has a good idea of what the effect it will have on the other person.

#### Example of a high score

M: What do you think we should have for dinner?
Eye contact has been established, and both have a neutral expression
D: Well, you know that I like pork.
M: Pork?
D: Yes.
Mother begins to smile, as does daughter.
M: You would eat the whole roast if I cooked it, (daughter's smile begins to widen) and not leave any for the others.
Both break into laughter

### Interactive style and communication quality

### Behaviour to watch for

Is there an equal amount said? Is there a response to the questions? Is there a mix of initiation of subject matter? Are commands or questions given? Is there discussion or a series of statements? Is there an understanding?

#### Description

This examines the overall quality of the communication between mother and daughter. It seeks to assess the level of understanding that each has of the other as well as the nature of the discourse. It seeks to find examples of conversation and discussion rather a series of statements, rhetorical questions or commands. It also assesses whether the conversation is dominated by one person, or is a shared dyad.

This scale basically seeks to assess how receptive and understanding each is what the other is communicating. It should consider whether the conversation flows or is disjointed. The score awarded by the rater should not reflect the type of mood the pair may be in. Good communication is possible even if both are angry or unhappy.

#### **Examples of mark allocation**

#### Score of 1-3

A low score would reflect the poor communication between mother and daughter. The rater may have a sense that each did not understand the other, or that they were not interested in what the other was attempting to communicate.

It may be that one person did all the talking, and possibly used a series of statements rather than inviting discussion by using open questions. Their body language may be closed, and they display few cues that demonstrate interest and comprehension of what the other is saying (such as eye contact and nodding).

#### Score of 4-6

Scores in the higher range mean that questions were always answered in a way that demonstrates at least some understanding. There was sufficient pause for reply, and there was a mix of questions, statements, and some commands. There was similar amount spoken by each, and non-verbal communication indicates attention (nodding, smiling etc). A shared guidance of the discourse and not one person initiating all ideas was also evident.

### <u>Codes</u>

### Appropriation of scores

Examples of the types of behaviours to look for, as well as an overall description of the scale are provided for the rater. When the rater is considering what score to give in a given scale they are asked to consider the extent to which the study participant conforms to the scale description. Examples of possible combinations of behaviour are provided to aid the rater in a score assignment. The rater is invited to consider how close these behaviours reflect what the participant is actually doing. Raters should take into consideration the intensity and frequency of any behaviour they are focussing on when assigning a score.

There are separate rating scales for the mother, the daughter, and two are used to describe an interaction between mother and daughter.

#### Rating the Mother

- 1. Engagement in the Task
- 2. Mood rating- positive affect
- 3. Mood rating- negative affect

#### Rating the Daughter

- 1. Engagement in the Task
- 2. Mood rating- positive affect
- 3. Mood rating- negative affect
- 4. Dominance
- 5. Sensitive Responsiveness
- 6. Depersonalising behaviour
- 7. Problem solving approach

### Rating Mother and Daughter

- 1. Emotional attunement
- 2. Interactive style and communication quality

2

Rater number:

Participants number:

Task:

**Engagement in task** 

Mood rating-positive affect

Mood rating negative affect

**Enagagement in task** 

Mood rating positive affect

Mood rating negative affect

Dominance

Sensitive responsiveness

**Depersonalising behaviour** 

Problem solving approach

#### Patient and Carer

**Emotional attunement** 



Interactive style and communication quality

Care	<u>er</u>

Patient











e-mail: pss029@bangor.ac.uk http://www.psych.bangor.ac.uk/

### Information

This study is being conducted as part of a PhD project investigating illness and caring perceptions in a student population. The questionnaire measures perceptions about stroke and caring for someone who has had a stroke. If you agree to take part you will be asked what a stroke is, what care you think is important for someone who has had a stroke and the impact of stroke on carers. There will also be some questions asking you about any prior experience you have of illness or caring for someone. The questionnaire will take about 30 minutes to complete and once the questionnaire is completed it can be handed in at your next lecture, or placed in a box in the Wheldon Learning Resource Centre. This study is completely voluntary and you have the right to withdraw at any time or to refuse to answer certain questions. The information you give will be kept confidential, only your Psu number is recorded so that print credits can be given. A debreifing sheet will be handed out once all the questionnaires have been completed. If you have any questions regarding the study then please do not hesitate to contact me at: psp810@bangor.ac.uk

Thank you for your help and co-operation.

Elly Jones.

Ph.D. Student/ Teaching Assistant.

Psu number:					
These first few questions are to find out general background information.					
1. Gender: Male Female					
2. Age:					
3. Marital status:					
Married Separated					
Single Widowed					
Divorced Partner					
4. Living arrangements.					
Sharing Alone					
5. Have you ever suffered a chronic illness? (diabetes, asthma, arthritis, stroke, heart attack, mental illness) Yes No a)If yes please state what					
b) Have you ever been dependent upon a family member to care for you because of an illness (period of time must exceed 7 days).					
Yes No If yes please state what condition you were being cared for					
6. Have you ever been a carer for someone who was dependent on you (period of time must exceed 7 days and excludes paid care) Yes No If yes please state whether they were a friend or family member and the reason they needed care.					
<ul> <li>7A. Have you ever heard of the illness "stroke"?</li> <li>Yes if yes, please proceed to fill out the rest of the questionnaire.</li> <li>No if no, stop here and thank you for taking part.</li> </ul>					

7B. In your own words please state what you think stroke is.

Please tick how often you think stroke patient's experience the following symptoms.

STROKE SYMPTOMS	ALL THE TIME	FREQUENTLY	OCCASIONALLY	NEVER
Nausea				
Breathlessness				
Weight Loss				
Fatique				
Stiff joints				
Wheeziness				
Headaches				
Loss of strength				
Speech problems				
Mobility problems				
Memory Loss				
Confusion				
Altered Mood	140			
Social restrictions				
Reduced sexual activity				
Chest pains				
Incontinence				
Paralysis				
Upset stomach				

I am interested in your own personal views on stroke. Please indicate how much you agree or disagree with the following statements about stroke.

	STRONGLY AGREE	AGREE	NEITHER AGREE NOR DISAGREE	DISAGREE	STRONGLY DISAGREE
A germ or virus causes stroke					
Diet plays a major role in causing stroke					

	STRONGLY AGREE	AGREE	NEITHER	DISAGREE	STRONGLY
			OR		
Pollution of the environment			DISAGREE		
causes stroke					
Stroke is hereditary-it runs in					
families.					
It is just by chance that					
people get stroke.					
Stress is a major factor in					
causing stroke					
Strokes are largely due to					
individuals behaviour					
Other people play a large					
role in causing stroke.					
Stroke is caused by poor					
medical care					
The state of mind of an					•
individual plays a major part					
in causing stroke.					
The effects of stroke will last					
for a short time					
The effects of stroke are					
likely to be permanent rather					
than temporary					
The effects of stroke will last					
for a long time					
Stroke is a serious condition					
Stroke has major					
consequences for someone's					
Ille Stroke goto oppier to live with					
Stroke gets easier to live with					
Stroke has little impact on					
Stroke cap strongly affect the					
way other people perceive					
the person who has had a					
stroke					
Stroke has serious financial					
and economic consequences					
Stroke strongly affects the					
way the person sees					
themself					

	STRONGLY AGREE	AGREE	NEITHER AGREE OR DISAGREE	DISAGREE	STRONGLY DISAGREE
The symptoms of stroke will improve in time					
There is a lot a person can do to control the symptoms of stroke					
Treatment will be effective in curing stroke					
Recovery from stroke is largely dependent on chance or fate					
What a person does can determine whether they get better or worse.					

Perceptions of helpful and unhelpful caring actions.

a) What care from a friend or relative do you think would be particularly helpful for a person who has suffered a stroke?

b) What care from a friend or relative do you think will be particularly unhelpful for a person who has suffered a stroke?

#### **Recovery Goals.**

Imagine you are caring for someone who has had a stroke. How important do you think it would be for them to achieve the following: Please indicate by placing a tick in the appropriate box below each question.

#### 1 Being able to eat normally.

Not important	Slightly important	Quite important	Very important	Extremely important

### 2. Being able to feed without assistance.

Not important	Slightly important	Quite important	Very important	Extremely important

#### 3. Being able to move from his / her wheelchair without any assistance.

Not important	Slightly important	Quite important	Very important	Extremely important

#### 4. Being able to perform personal hygiene tasks.

Not important	Slightly important	Quite important	Quite important Very important	

#### 5. Being able to go to the toilet unassisted.

Not important	Slightly important	Quite important	Very important	Extremely important

### 6. Being able to bath himself / herself without any assistance.

Not important	Slightly important	Quite important	Very important	Extremely important

#### 7. Being able to walk on a level surface without any assistance.

Not important	Slightly important	Quite important	Very important	Extremely important
	No. 21			

#### 8. Being able to go up and down stairs without any assistance.

Not important	Slightly important	Quite important	Very important	Extremely important	

#### 9. Being able to dress or undress without any assistance.

Not important	Slightly important	Quite important	Very important	Extremely important	
	N				

#### 10. Being able to control bowels.

Not important	Slightly important	Quite important	Very important	Extremely important

#### 11. Being able to control bladder.

Not important	Slightly important	Quite important	Very important	Extremely important

#### 12. Being able to speak normally.

Not important	Slightly important	Quite important	Very important	Extremely important

#### 13. Being able to actively pursue a hobby.

Not important	Slightly important	Quite important	Very important	Extremely important

### 14. Being able to prepare meals.

Not important	Slightly important	Quite important	Very important	Extremely important

#### 15. Being able to engage in light housework.

Not important	Slightly important	Quite important	Very important	Extremely important

### 16. Being able to carry out house-hold/garden/car maintenance.

Not important	Slightly important	Quite important	Very important	Extremely important

#### 17. Being able to shop locally.

Not important	Slightly important	Quite important	Very important	Extremely important

#### 18. Being able to walk out side for more than 15 minutes.

Not important	Slightly important	Quite important	Very important	Extremely important

#### 19. Being able to drive a car/travel on public transport.

Not important	Slightly important	Quite important	Very important	Extremely important

#### 20. Being able undertake social occasions.

Not important Slightly important	Quite important	Very important	Extremely important	

#### 21. Being able to do any gainful work.

Not important Slightly important		Quite important	Very important	Extremely important

#### 22. Being able to live with complete independence.

Not important	Slightly important	Quite important	Very important	Extremely important

### **Recovery Goals Ranking**

Please study the following list, and consider which three goals in your opinion a stroke patient would view as most important in their recovery.

- 1. Being able to eat normally.
- 2. Being able to feed without assistance.
- 3. Being able to move from his/ her wheelchair without any assistance.
- 4. Being able to perform personal hygiene tasks.
- 5. Being able to go to the toilet unassisted.
- 6. Being able to bath himself/ herself without any assistance.
- 7. Being able to walk on a level surface without any assistance.
- 8. Being able to go up and down stairs without any assistance.
- 9. Being able to dress or undress without any assistance.
- 10. Being able to control bowels.

- 11. Being able to control bladder.
- 12. Being able to speak normally.
- 13. Being able to actively pursue a hobby.
- 14. Being able to prepare meals.
- 15. Being able to engage in light housework.
- 16. Being able to carry out house-hold/garden/car maintenance.
- 17. Being able to shop locally.
- 18. Being able to walk out side for more than 15 minutes.
- 19. Being able to drive a car/travel on public transport.
- 20. Being able undertake social occasions.
- 21. Being able to do any gainful work.
- 22. Being able to live with complete independence.

Most important	
Second most important	
Third most important	

### Caring Impact Appraisal Scale

Imagine someone (a friend or family member- not a health professional) caring for a stroke patient, to what extent do you feel each of the statements below would apply.

Show how you feel by circling a number from -3 ('strongly disagree') to +3 ('strongly agree'). The more you feel the statement applies to carers, the higher the number you should circle. The less you feel the statement applies to carers, the lower the number you should circle.

Section A

	Strongly Disagree					Stro Agre	Strongly Agree	
<ol> <li>Because of caring a person's social life will get b</li> </ol>	-3 better.	-2	-1	0	1	2	3	
2. Caring makes more opportunities to be with loved ones	-3	-2	-1	0	1	2	3	

<ol> <li>Caring makes life better organised</li> </ol>	-3	-2	-1	0	1	2	3
<ol> <li>Caring can make people more 'alive' than they used to be.</li> </ol>	-3	-2	-1	0	1	2	3
5. Caring means that relationship with other family members are o and more richer	os -3 closer	-2	-1	0	1	2	3
Section B	Stron Disag	gly Iree				Strong Agree	gly
1.Caring means less energy than normal	-3	-2	-1	0	1	2	3
2. Caring means a person will not be getting enough sleep.	-3	-2	-1	0	1	2	3
3.Caring makes a person physically tired	-3	-2	-1	0	1	2	3
4. Caring makes someone take part less in social activitie	-3 s	-2	-1	0	1	2	3
5.Caring means less time for oneself.	-3	-2	-1	0	1	2	3
6. Because of caring a person's health will suffer.	-3	-2	-1	0	1	2	3
7. Caring makes a person feel emotionally drained	-3	-2	-1	0	1	2	3
8.Because of caring people won't keep in touch with their friends like they used to.	-3	-2	-1	0	1	2	3
<ol> <li>Carers will have too much to do to do everything we</li> </ol>	-3 II	-2	-1	0	1	2	3

10 Caring causes people to have trouble with their nerv	-3 /es	-2	-1	0	1	2	3
11.Because of caring a person can feel like they are being pulled in different directions	-3	-2	-1	0	1	2	3
12 Caring can make someone feel trapped	-3	-2	-1	0	1	2	3
13 Because of caring a person can feel like they have lost co of their life	-3 ontrol	-2	-1	0	1	2	3
Section C/D							
	Stron	gly				Stron	gly
.1. Caring for someone can make someone feel good abou themself	Disag -3 It	ree -2	-1	0	1	Agree 2	3
2. The responsibility of caring can give a person an important sense of satisfaction	-3 nt	-2	-1	0	1	2	3
3. Caring makes someone feel valued	-3	-2	-1	0	1	2	3
<ol> <li>Being a carer can be a real source of pleasure for a per</li> </ol>	-3 erson	-2	-1	0	1	2	3
5. Caring activities can be rewarding and fulfilling	-3	-2	-1	0	1	2	3
6. Caring for a person can make someone happy	-3	-2	-1	0	1	2	3

That is all the questions thank you for your participation in this study.