

Beliefs about Stroke:

Negotiating Shared Understandings

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Abstract

Studies suggest that the illness perceptions that individuals develop can affect their psychosocial adjustment, and that patients and carers may hold differing views about the illness. This 'discrepancy' in their views has been found to be predictive of a range of negative psychosocial outcomes. However, little is known about the illness perceptions of stroke patients and carers, so this study takes a longitudinal approach to examine the influence of discrepant illness perceptions on the psychological adjustment of both partners.

Aims: This thesis aims a) to examine the illness perceptions of patients and their carers; b) to examine the relationship between discrepant illness perceptions and emotional distress for both partners; c) to understand how couples negotiate a shared understanding of the stroke and how discrepant illness perceptions manifest in this process.

Method and Results

Study 1: Using Leventhal's self-regulatory model (Leventhal, 1980) as a framework, the illness perceptions, social support and relationship satisfaction of 42 stroke patients and their carers were examined approximately 3, 6 and 9 months post stroke. Emotional distress was assessed using the General Health Questionnaire. Discrepancy was common, with almost a quarter of couples classified as discrepant at time 1. Multilevel modelling was used to examine the utility of illness perceptions and discrepancy as predictors of patient and carer distress. Illness representations were found to be associated with concurrent distress, but not a good predictor of later distress. Discrepant illness perceptions were associated with increased distress for both partners.

Study 2: A qualitative study investigated how couples negotiate a way of adapting to the stroke over time. Data was collected from 16 couples using semi-structured interviews, and analysed using Interpretative Phenomenological Analysis. Four themes emerged: *entering an altered world*, *getting back to normal*, the *negotiation process* and *factors affecting the negotiation process*. Negotiation and adjustment styles varied across couples and each partner's illness beliefs played an important role in how the negotiation process was enacted by couples.

Discussion: The results suggest that although discrepancy is not a good predictor of later distress, it nonetheless affects the relationship between partners and this placed an additional burden on couples as they try to adjust to the stroke. The results of this research shows that significantly greater emphasis need to be placed on the dyad and the role of the dyadic relationship in order to help couples manage the impact of stroke and minimise its intrusion into their everyday lives.

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1 Literature Review: Stroke

1.1 Introduction

Stroke, also known as cerebrovascular accident (CVA) is the leading cause of long-term disability in adults, with more than half of survivors being left dependent on others (Wolfe 2000). This chapter describes the background to stroke and its impact on the patient and carer in terms of the prevalence and predictors of psychological distress. It goes on to describe how stroke survivors and families come to understand stroke and the role of social support in this process.

1.2 Definition

Stroke is a clinical diagnosis. The World Health Organisation (WHO) defines it as a clinical syndrome characterised by the sudden onset of focal or global disturbance of cerebral function, lasting more than 24 hours or leading to death, for which no cause can be found other than a disruption of the cerebral blood flow (World Health Organisation 1989). However, stroke is not a uniform entity, and includes cerebral infarction, intracerebral haemorrhage and subarachnoid haemorrhage, but not transient ischaemic attacks (TIA), which last less than 24 hours nor subdural or extradural haemorrhage (Bonita 1992).

1.3 Stroke Subtypes

In stroke, the blood supply to the brain is disrupted, damaging or destroying brain tissue, with two main categories of brain damage: ischaemic and haemorrhagic (Caplan, 1993). The most common type of stroke is ischaemic stroke (Warlow 1998), which accounts for about 70% of strokes (Caplan 1993). Ischaemic stroke occurs when the blood flow is disrupted by a blockage in an artery in the brain (cerebral thrombosis), a blockage which has occurred elsewhere in the vascular system and lodges in a blood vessel blocking blood flow to the brain (cerebral embolism) or a blockage of a smaller blood vessel in the brain (lacunar stroke) (Caplan 1993). When damage is permanent it is known as an infarction (Caplan 1993).

The second type of stroke is haemorrhagic stroke, and this occurs when a blood vessel bursts, causing bleeding between the brain and the skull (subarachnoid haemorrhage) or within

the brain (intracerebral or primary haemorrhage). Haemorrhagic stroke accounts for approximately 30% of strokes (Royal College of Physicians 2004) and is caused by a bleed in the brain which results in brain damage.

1.4 Stroke Incidence

Incidence refers to the number of new events (usually first ever) occurring within a specific period (Woodward 1999). UK National statistics (Office for National Statistics 2001) indicate that each year around 87,000 people in England and Wales have a first-ever stroke, and the risk of a recurrent stroke is 30%-43% within 5 years (Mant, Wade and Winner 2004). The incidence of stroke doubles with each successive decade over the age of 55, and lifetime risk is estimated at approximately one in five for women and one in six for men (Seshadri, Beiser, Kelly-Hayes, Kase, Rhoda, Kannel and Wolf 2006).

1.5 Case Fatality and Stroke Mortality

Stroke causes over 60,000 deaths each year in the UK (Office for National Statistics 2000). Older people are more likely to die after a stroke, with case fatality¹ twice as high in those over 85 years as below 65 years, with about two thirds of deaths occurring within the first week after stroke (Rothwell, Coull, Giles, Howard, Silver, Bull, Gutnikov, Warlow, Bamford and Anslow 2004).

1.6 Prevalence

Prevalence is defined as the number of people living at any time who have had a stroke, and statistics suggest that there are more than 900,000 people in England who are living with the effects of stroke, of which between 24% and 53% will be dependent on others for their everyday care (Royal College of Physicians 2004). It is also estimated that 80% of stroke survivors live with family members (Tyson 1995), suggesting significant burden on informal carers.

1.7 Risk Factors

Risk factors are attributes associated with the occurrence of a disease. A review in 2001 identified a significant number of risk factors for stroke (Goldstein, Adams, Becker, Furberg,

¹ Case fatality refers to the proportion of people who die within a specified period after the event (Bonita, 1992)

Gorelick, Hademenos, Hill, Howard, Howard, Jacobs, Levine, Mosca, Sacco, Sherman, Wolf and del Zoppo 2001), of which some are modifiable, whilst others are genetic or biological. The risk factors identified include biological factors, such as older age, male gender, Afro-Caribbean origin and family history; physiological deficits such as hypertension, hypercholesterolemia, atrial fibrillation, diabetes mellitus and obesity; behavioural risk factors, such as smoking tobacco, excessive alcohol intake, sedentary life-style, poor diet (high salt and fat) and use of oral contraceptives. Finally factors such as vascular problems, previous stroke or TIA, heart failure, carotid stenosis and vascular disease were also noted to increase the risk of stroke.

1.8 Diagnosis of Stroke

Stroke is a clinical diagnosis based on medical history, clinical examination and investigations (Royal College of Physicians 2004). Stroke location can be defined by subtypes, and one commonly used system is the Oxfordshire Community Stroke Project (OCSP) classification system (Bamford, Sandercock, Dennis, Burn and Warlow 1991), which classifies strokes into one of four main groups: total anterior circulation syndrome (TACS), which can result in hemiplegia, hemiparesis, hemianopia (visual field disturbance) and aphasia; partial anterior circulation syndrome (PACS), which can result in motor/sensory deficits and hemianopia, and aphasia; lacunar syndromes (LACS), infarcts which do not result in visual field deficits or loss of higher cerebral function, but do result in motor and/or sensory loss and can result in ataxia; and posterior circulation syndrome (POCS), which result in contralateral or bilateral motor or sensory deficits, visual problems and cerebellar dysfunction.

1.9 Treatment for Stroke

The National Clinical Guidelines for stroke (Royal College of Physicians 2004) recommend that all patients with ischaemic stroke be treated with aspirin, and thrombolysis is recommended when the patient is within three hours of stroke, as it has the potential to improve outcomes following ischaemic stroke within this period (Royal College of Physicians 2004). Initial management of haemorrhage (SAH) aims to prevent re-bleeding and reduce the risk of cerebral ischaemia. The guidelines therefore recommend diagnosis by CT scan and lumbar puncture, and that management of SAH should involve a neurosurgeon and specialist care (Royal College of Physicians 2004). The guidelines also recommend that secondary prevention measures should be followed for all patients. These include the treatment of high blood pressure and hypercholesterolemia, with treatment in place for life. Furthermore, patients should given appropriate health behaviour change such as smoking cessation, regular exercise,

diet and weight control, and reducing salt and alcohol intake (Royal College of Physicians 2004).

1.10 Consequences of Stroke

Stroke onset is generally without warning and can have major consequences for both the person experiencing the stroke and their family. Its effects vary depending on the part of the brain damaged, and the extent of the damage (Caplan 1993). For some, the effects will be minor and transitory, for others they will be more severe and may be permanent. Between a quarter and a half of survivors are left with some form of disability (Royal College of Physicians 2004). These disabilities can be physical, behavioural, cognitive, language-related, emotional or social. A recent analysis of data from the Office of National Statistics (Adamson, Beswick and Ebrahim 2004) concluded that stroke is associated with the highest odds of reporting a severe disability and can result in a greater range of disabilities than any other condition. The following section describes the main effects of stroke, and goes on to discuss the impact this has on the family.

1.10.1 Physical Disabilities

The most common physical impairments that limit activity are weakness and paralysis, loss of sensation, disturbed balance and coordination, with about half of patients reporting some loss of motor control (Widar, Samuelson, Karlsson-Tivenius and Ahlstrom 2002). Weakness and paralysis is usually, but not always confined to one side of the body, and can affect the face, an arm, a leg, or one side of the body. These disabilities can last a long time, and leave survivors dependent on others for their everyday care (Anderson, Linto and Stewart-Wynne 1995).

1.10.2 Cognitive Difficulties

Parts of the brain associated with memory, language, perception, attention, controlled action and executive functioning can be damaged (Royal College of Physicians 2004), and at least 35% of stroke survivors will have significant intellectual impairment (Tatemichi, Desmond, Stern, Paik, Sano and Bagella 1994). Problems with short term memory are common, affect the ability to make plans or decisions, learn new tasks, and can significantly affect rehabilitation and recovery potential (National Institute of Neurological Disorders and Stroke 2008). Individuals may be unable to acknowledge the existence or severity of their stroke (anosognosia), or experience perceptual problems resulting in difficulties recognising objects or knowing how to use them (NINDS 2008).

1.10.3 Language Difficulties

About one third of survivors will experience language problems after their stroke (Stroke Association 2006). Patients may have problems understanding language (receptive aphasia) or be unable to express their thoughts through words or writing (expressive aphasia) and so are unable to convey their needs or feelings, leaving them frightened, frustrated and isolated (Stroke Association 2008).

1.10.4 Other Difficulties

Other health related complications following a stroke include chronic pain (Gamble, Barberan and et al. 2002; Young, Murray and Forster 2003; Appelros 2006; Jonsson, Lindgren, Hallstrom, Norrving and Lindgren 2006), incontinence (Patel, Coshall, Rudd and Wolfe; Jorgensen, Engstad and Jacobsen; Brittain, Perry, Shaw, Matthews, Jagger and Potter 2006; Jonsson et al. 2006), falls (Anderson et al. 1995; Murray, Young, Forster and Ashworth 2003b; Young et al. 2003), swallowing problems (Stroke Association 2006), fatigue (Anderson et al. 1995; Carlsson, Moller and al. 2004a; Appelros 2006), and sexual problems (Korpelainen, Nieminen and Myllyla 1999).

1.10.5 Social Isolation

Social isolation refers to the lack of access to social contact or resources, and may be a consequence of reduced physical functioning, language or cognitive impairment, emotional problems or changes to relationships as well as external factors such as reduced access to transport and employment (Mukherjee, Levin and Heller 2006). A recent review found that almost half of the 23 studies examined reported that patients experienced negative changes in their social life (Murray et al. 2003b).

1.10.6 Identity Changes

Stroke can change how stroke survivors perceive themselves. The interaction between emotional, cognitive and physical changes experienced, as well as changes in social context and family dynamics all impact on stroke survivors' sense of identity (Stone, Townend, Kwan, Haga, Dennis and Sharpe 2004; Mukherjee et al. 2006). The stroke can take away the skills and activities which the person used to define themselves, (eg breadwinner, carer) and it has been argued that accepting the loss of these old identities which were previously central to one's sense of self, and the creation of new ones that provide satisfaction are key to adjustment (Heller, Levin, Mukerjee and Reis 2006; Mukherjee et al. 2006).

1.10.7 Personality Changes

Evidence suggests that some survivors will experience personality changes resulting from the brain damage caused by their stroke (Anderson et al. 1995; Martin, Dellatolas and

Viguiet 2002; Stone et al. 2004). Anderson and colleagues (1995) found that carers reported that patients demonstrated a range of abnormal behaviours at one year post stroke. These included withdrawal (49%), irritability (49%), unpredictability (35%), rudeness (23%) and odd behaviour (17%). However, not all changes are negative, with some studies noting that changes can also be in a positive direction (Stone et al. 2004). Patients and carers may also disagree as to the existence or nature of these changes, with one study finding that patients may deny that they have changed, which may result in stresses within the family (Anderson 1992).

1.11 Impact on the Family

As described above, stroke can affect individuals in very different ways, leaving patients with a range of problems. Although “acute stroke” is a term commonly used in clinical practice, for those left with post stroke disabilities it is more useful to consider stroke in terms of being a chronic condition (Young et al. 2003), as many of the difficulties encountered in the acute post stroke phase will remain as problems in the longer term. Increasingly stroke survivors are cared for in the community, with family members providing the bulk of the care (Tyson 1995; Royal College of Physicians 2004). Informal carers, who are more often than not spouses and adult children, have to deal not only stroke survivors’ physical and communication problems, but also with changes to the patient’s personality, mood and cognitive functioning (Han and Haley 1999). The psychological impact of caring for someone with a stroke is well documented (Han and Haley 1999; Low, Payne and Roderick 1999; Murray, Ashworth, Forster and Young 2003a; Young et al. 2003). The literature cited in these reviews highlights the complex and diverse problems faced by families, who often feel ill-equipped for caring for a disabled family member, especially during the first months after the patient is discharged from hospital (Teel, Duncan and Lau 2001).

Carers experience declines in their opportunities for social interaction (Anderson 1992; Anderson et al. 1995; Dale, Gallant, Kilbride and et al. 1997), especially when the patient and carer live together (Anderson 1992). Family members may have to give up work to become a full-time carer, resulting not only in a role change, but also financial strain on the family (Brocklehurst, Morris, Andrews, Richards and Laycock 1981). Others may have to combine going out to work and caring (McLean, Roper-Hall, Mayer and Main 1991). Carers also report adverse effects on family relationships resulting from the demands of caring for the stroke survivor (Anderson et al. 1995). For spousal carers especially, the onset of the stroke is a particular challenge as the usual balanced reciprocal relationship between spouses is disturbed, possibly on a permanent basis (Visser-Meily, Post, Gorter, Berdenis, Ven Den Bos and Lindeman 2006), and the support that the carer would have received from their spouse is no

longer available. Social roles are often affected, with families having to re-negotiate family-focussed roles to accommodate the stroke survivors' disability (Mukherjee et al. 2006). These negotiations may not always be successful, especially if other family members do not want to take on that responsibility, or the stroke survivor does not wish to relinquish the role (Carlsson et al. 2004a; Mukherjee et al. 2006).

The role of carer is not static, and may have to change as the circumstances of the family changes (Teel et al. 2001), and will certainly change during the first weeks and months after the stroke as the patient's health changes. It is important to recognise that family members will have different perceptions of the patient's abilities, and for some, this can be a source of conflict. The focus of this thesis is how the patient and carer come to terms with the stroke, and the impact that their beliefs about the stroke have on the emotional distress of both partners. However, not all patients and carers report difficulties. For some, the stroke has an empowering effect on the family, making it stronger and bringing to closer together (Schulz, Tompkins and Rau 1988; Draper, Poulos, Cole, Poulos and et al. 1992), and it is therefore important to understand how families come to understand stroke. The next section outlines the chronology of stroke in terms of how families come to understand it and introduces the role that illness cognitions play in this process, which will be discussed further in chapter 2.

1.12 How Families Come to Understand Stroke: The Role of the Stroke Pathway

The following section reviews the literature on psychological adjustment to stroke. It begins with how patients and carers make sense of the stroke before and after admission to hospital, and is followed by a section which details the psychological impact of stroke on patients and carers.

1.12.1 Before Admission to Hospital

Following the onset of symptoms, patients and carers have to make decisions about what the health threat is, and whether or not it is serious. Whilst one might expect the symptoms of a stroke to be easily recognisable, this is often not the case (Anderson et al. 1995), and can lead to delays seeking medical help (Yoon and Byles 2002; Carroll, Hobart, Fox, Teare and Gibson 2004; Moloczij, McPherson, Smith and Kayes 2008). Indeed, Carroll and colleagues (2004) found that whilst the majority of the general public said they would call an ambulance if they felt they were having a stroke, 80% of those experiencing a stroke called their GP.

The decision to seek medical help and the nature of that help is often not the sole decision of the patient. Studies have found that when medical help is sought, it is often family members, not the patient, who do this (Carroll et al. 2004). Indeed, Moloczji and colleagues (2008) found that at the onset of symptoms, individuals actively interpret their symptoms but also engage in a process of negotiation around help seeking, and the presence of family members can both facilitate and hinder this process, as well as influencing the type of help sought (Anderson et al. 1995; Carroll et al. 2004). The process of searching for and excluding possible diagnoses and attendant actions is explained by Leventhal's self regulatory model of illness (Leventhal, Nerenz and Steele 1984) which will be discussed in the next chapter. The evidence presented suggests that the actions taken at the onset of stroke may be best understood within the social context of the family, and that even at this early stage the actions of the individual may be guided not only by their own cognitive model of the health threat, but by others within their social network.

1.12.2 Knowledge of Stroke

Studies have shown a poor level of knowledge amongst patients and carers (Anderson 1988; Wellwood, Dennis and Warlow 1994; Anderson et al. 1995; Kothari and Sauerbeck 1997; Clark and Smith 1998; Carroll et al. 2004). One study to examine patients' knowledge of stroke found 39% unable to name any signs or symptoms, and 43% unable to name any risk factors, with older people, who are also those at most risk of stroke, having the poorest knowledge (Kothari and Sauerbeck 1997). One recent study to examine the knowledge of a group of UK carers found that knowledge of prevention and management was good, but risk factor knowledge was poorer (McKenzie, Perry, Lockhart, Cottee, Cloud and Mann 2007). This study also noted significant misconceptions in the beliefs of carers, with 78% of respondents believing that "taking it easy" would be beneficial to the patient, and 10% reporting that increased fruit and vegetables would not be beneficial, indicating significant gaps in carers' knowledge.

1.12.3 The Health-Care System

The responsibility for providing patients and family members with information in the early stages after the stroke lies with medical and other health professionals. The National Clinical Guidelines for stroke recommend that "*patients and families are prepared and fully involved in plans for transfer... given information about, and offered contact with, appropriate statutory and voluntary services*" (Royal College of Physicians 2004, pg 77). The phrasing of the guidelines suggests that this process should be a partnership between patients, families and health professionals, but research shows that this is not consistent with families' experiences (Wellwood et al. 1994; O'Mahoney, Dobson and al. 1995; McKenzie et al. 2007). Indeed, qualitative studies have found that whilst patients and carers feel it is the role of doctors and

health professionals to provide advice, guidance, information, and explanations, this need is not met (Pound, Gompertz and al 1994; Clark 2000; McKenzie et al. 2007). Instead, carers report that they struggle to get information on a range of topics, including the prognosis for recovery, benefits and services available after discharge, and local amenities available in their area (Anderson and Marlett 2004; McKenzie et al. 2007). Information leaflets provide a source of information for patients and carers, and are usually available on wards, and provided in discharge packs (Royal College of Physicians 2004). However, some patients struggle with the information provided because their stroke has left them with problems reading, comprehending or retaining information (McKenzie et al. 2007), and carers can also feel overwhelmed by the amount of information provided, much of which may not be appropriate to their specific needs. Even when information is available, patients and carers may fail to access it, which may mean that misconceptions and misunderstandings held by patients and carers are not addressed.

1.13 Summary of the Potential Changes Resulting from a Stroke

The functional, cognitive, behavioural and social limitations resulting from stroke may have significant implications for both the patient and the family. Its sudden onset can leave patients and carers struggling to come to terms with their new life situation, which may be permanently altered. It can also result in family roles and relationships having to be re-negotiated. Research evidence suggests that patients and carers have poor understanding of stroke, which can affect how they respond to the stroke, and during the recovery and rehabilitation phase families feel they have few opportunities to discuss their beliefs as a family with health professionals.

1.14 Mood Disorder after Stroke

Mood disorder after stroke is common, and a recent systematic review concluded that a third of patients demonstrate depressive symptoms after stroke (Hackett, Chaturangi, Parag and Anderson 2005), and a recent review suggests that depressive symptoms persist in about a quarter of patients beyond two years (Murray et al. 2003b). Criticism has been levelled at the existing literature base with regards to its methodological weaknesses (House 1987; Hackett et al. 2005), but the results of these studies are generally consistent across healthcare settings (Young et al. 2003). Different terms are used to describe mood dysfunction in patients, including depressive disorder, depressive symptoms and psychological distress. These terms are usually used to describe individuals who score above a pre-defined cut-off on self-report measures of mood. The terms major and minor depression are used when diagnosis has been made using a clinical interview to apply standard diagnostic criteria such as those in the DSM IV (American Psychological Association 2000). In addition to depressive symptoms, many

stroke survivors experience a range of other symptoms including apathy, withdrawal, loss of appetite, early waking, loss of libido, lack of energy, tiredness, irritability, and loss of interest (House, Dennis, Mogridge, Warlow, Hawton and Jones 1991) at levels which do not fulfil the criteria for “caseness” in research studies, but are nevertheless distressing for the patient and their family.

Anxiety disorders have been studied less often, but hospital-based studies suggest a prevalence of between 22% (Robinson 1998) and 28% (Astrom 1996). Feelings of fear and worry are common (Royal College of Physicians 2004) and may be provoked by situations such as the fear of falling when walking or transferring. Pathological emotionalism, or uncontrolled crying or laughing in response to neutral or trivial stimuli is relatively common after stroke, and occurs in 10-20% of a community sample (House, Dennis, Molneaux, Warlow and Hawton 1989).

1.14.1 Predictors of Mood Disorder after Stroke in Patients

Previous studies have shown statistical associations between depression after stroke and lesion size and location (Narushima, Keen-Loong, Kosier and Robinson 2003; Robinson 2003); cardiovascular risk factors (Brodaty, Witchall, Altendorf and Sachdev 2007); female sex (Carod-Artal, Egido, Gonzalez and de Seijas 2000); physical disability and stroke severity (Hackett and Anderson 2005); reduced activities of daily living (Eastwood, Rifat, Nobbs and al. 1989; Anderson 1992; Kotila, Numminen, Waltimo and Kaste 1999; Thomas and Lincoln 2008); reduced social activities (Anderson 1992; Carod-Artal et al. 2000), cognitive impairment (Hackett and Anderson 2005); aphasia or expressive communication impairment (Astrom, Adolfsson and Asplund 1993; Thomas and Lincoln 2008); recent life events (Morris, Robinson, Andrzejewski, Samuels and Price 1993); and personal control beliefs (Morrison, Johnston and MacWalter 2000; Morrison, Pollard, Johnston and MacWalter 2005; Thomas and Lincoln 2006).

However, a recent systematic review by Hackett and colleagues (Hackett and Anderson 2005) examined a range of demographic, social, medical, biological and physical variables associated with, or predictive of depressed mood after stroke. These authors concluded that the only factors which were consistently associated with patient depression were physical disability, stroke severity and cognitive impairment, although when considered together social support variables were also predictive. However, they acknowledge that the ability to draw firm conclusions regarding the predictors of distress after stroke “*is restricted by the methodological heterogeneity and limitations of the literature*” (Hackett and Anderson 2005 p 229).

1.15 Mood Disorder in Carers

The impact of stroke on carers is well documented, and a number of quantitative and qualitative reviews have been published in recent years which describe the range of difficulties experienced by carers (Han and Haley 1999; Morrison 1999; Young et al. 2003; McKevitt, Redfern, Mold and Wolfe 2004). The conclusions of these reviews suggest that carers experience significant burden in terms of their physical and psychological well-being. Prevalence of mood disorders in carers varies from 39% to 52% (Murray et al. 2003b), but significant differences exist between studies in terms of how distress is operationalised, the timing of assessments, the definition of carer, measures used and analysis techniques applied (Han and Haley 1999). One Australian study examining the emotional health of stroke carers one year after the patient's stroke found 55% of carers scored above the cut-off for emotional distress on the General Health Questionnaire (GHQ-28) and Hospital Anxiety and Depression scale (HADS) (Anderson et al. 1995). Half of carers reported feelings of depression, and 58% reported feelings of anxiety. Other commonly reported feelings were resentment (29%), impatience (25%) and guilt (10%). Overall, 79% reported emotional illness health and reduced social activities, and reduced leisure time and lower relationship satisfaction were also commonly reported.

1.15.1 Predictors of Mood Disorder in Carers

Whilst a considerable literature exists examining the predictors of distress in stroke patients, much less research has been directed at systematically identifying predictors of distress in informal carers. One review is particularly useful in identifying predictors of carer distress (Han and Haley 1999). This review concluded that carers were more distressed when they had concerns over the future and when the patient was more disabled. However, these were only predictive in the acute phase, and not in the chronic phase. Carers were more depressed when the patient was depressed, when carer's own health was poorer, and when the carer had fewer social contacts. However, as with the patient studies, significant heterogeneity exists in the literature, with selection bias (bias towards hospital samples and volunteer samples), small samples, different measurement tools, and the inclusion of different sorts of carer (spouse and non-spouse, experienced and new carers), which makes firm conclusions difficult. This review did not examine the role of illness perceptions on carer distress and few longitudinal studies were included, making its use limited in the present study.

Factors associated with carer distress may also vary over time. A longitudinal study by Schulz, Tompkins and Rau (1988) followed 140 spousal and non-spousal carers over the first eight-to-nine months after the patient's stroke, with data collected at seven weeks and six

months later. At baseline, stroke severity and fear for the future associated with concurrent distress, but by six months, age, carer health, a decrease in confiding relationships, and an increase in the negative changes in the patient's personality characteristics were associated with higher depression. This highlights the importance of longitudinal studies when considering predictors of distress in carers.

1.16 Social Support

Social support has been identified as a key factor in adaptation to illness (Coyne and Smith 1991), and research has found that social factors are associated with the risk of the onset of depression in stroke patients (Anderson 1992; Hackett and Anderson 2005; Townend, Whyte, Desborough, Crimmins, Markus, Levi and Strum 2007), and emotional distress in carers (Schulz et al. 1988; Han and Haley 1999). However, not all studies find support for such a link (McClenahan and Weinman 1998).

One explanation for these conflicting findings could be that *social support* is an ambiguous concept. Indeed, a common complaint which has been levelled is that there is no universally accepted definition (Coyne and DeLongis 1986). Furthermore, a wide range of measures are used to assess social support, which may also account for the conflicting findings (Schwarzer, Knoll and Rieckmann 2004). One commonly used definition refers to the number of people or sources of social support within an individual's social environment, which focuses on the level of social integration, or density of social networks and frequency of interaction (Schwarzer et al. 2004). Another definition, and the one which will be used in the present study focuses not to the sources of support, but their function and quality, as well as the perceived availability of support (Schwarzer et al. 2004).

The functions of social support can be further classified as: *esteem support* (feeling valued by others), *informational support* (eg advice), *social companionship* (being able to spend time with others socially and *instrumental support* (physical or tangible support that can be gained from others) (Cohen and Wills 1985). Unlike the functional approach, social support here is viewed in terms of the experienced quality of social relationships, and is exemplified by studies such as that by Brown and Harris (1978) who found that in a sample of working class women from London, the presence of a close confiding relationship during the life crisis was associated with a lower risk of depression.

1.16.1 Social Support and Chronic Illness

When one family member faces a stressor, such as the onset of a serious illness, other family members are affected too. Wortman & Conway (1985) make the point that whilst the patient will need more support when faced with the physical and emotional challenges associated with the health threat, the family, and especially the partner is also likely to have increased need for emotional and practical support. Research shows that many carers feel ill-equipped to care for the stroke survivor, making the first weeks and months especially stressful (Steiner, Pierce, Drahuschak, Nofziger, Buchman and Szirony 2008). Yet, whilst the well partner has to face the challenges of caring for an ill or disabled partner, they may also have less social support available to them. This is particularly true in the case of married and co-habiting couples when the well partner's main source of support may be the ill spouse (Thompson and Pitts 1992). At the same time, there is evidence that in the case of stroke, the network from which individuals draw their support reduces following the onset of chronic illness for both the patient (Knapp and Hewison 1998) and caregivers (Anderson 1992; Anderson et al. 1995).

1.16.2 Effect on Family Relationships

Studies of family interaction after stroke have found that both patients and carers report declines in family functioning during the year following stroke (Clark and Smith 1999a), but patients and family members differ in how they perceive the changes to other aspects of their relationship. For example, studies have shown that whilst spouses and carers report declines in relationship satisfaction in the year after the stroke (Anderson 1992; Anderson et al. 1995; Clark and Smith 1999a), stroke survivors often report increased closeness (Thompson, Bundek and Sobolew-Shubin 1990). Anderson (1992) found that at 18 months post-stroke, 59% of patients reported being very happy with their spouse, compared to only 30% of spouses who describe their relationship with the patient as very happy, suggesting that patients have a rosier perspective on their marriage than their well spouses.

1.17 Summary

The empirical evidence shows that for both patients and carers, mood disturbance after stroke is common. Systematic reviews of the literature have concluded that patient depression is most consistently associated with, or predicted by, physical disability, stroke severity, cognitive impairment and social support. Fewer studies have systematically examined factors associated with carer distress, but patient disability, the age and gender of the carer, patient depression and a lack of close confiding relationships have all been implicated. Therefore, in the present study social support and relationship satisfaction will be assessed as possible

predictors of patient and carer distress. In contrast to the focus on biological and medical predictors of patient depression after stroke, illness cognitions, the beliefs that patients and carers construct about the stroke have been rarely examined, and were not included as possible predictors of patient distress in a recent review (Hackett and Anderson 2005). There is however good evidence from a range of chronic conditions that how an individual comes to understand their illness is associated with psychological adjustment, and so the evidence for such an association in stroke will be examined in the next chapter.

2 Literature Review: Illness Cognitions

2.1 Introduction

The previous chapter examined the prevalence and predictors of emotional distress in stroke patients and carers. In studies examining distress in stroke patients, biological and medical risk factors have been implicated, but statistical analyses indicate that these factors are only modest predictors of distress, and indeed, not all patients become depressed. Fewer studies have systematically examined predictors of carer distress, but patient disability and patient depression and a lack of social contacts have been implicated. Again, not all carers become depressed.

An area which has been largely ignored as a possible predictor of distress in patients and carers is the appraisal process, that is, the cognitive understanding or representation constructed by patients and carers in response to the disease (Leventhal, Meyer and Nerenz 1980; Leventhal, Leventhal and Nguyen 1985). This chapter will introduce Leventhal's self regulatory model of health and illness (Leventhal et al. 1980) as a conceptual framework within which the way an individual represents their illness can be understood. There is good evidence from a range of conditions that the way an individual conceptualises their illness affects their physical recovery, psychological well-being and behavioural adaptation (Hagger and Orbell 2003). In order to place the present research into context, this chapter will briefly review some of the pertinent literature examining the role of illness cognitions in chronic illness and the evidence pertaining to stroke.

Leventhal's model (1980, 1984) proposes that illness representations are influenced by past experience, knowledge and the social context. However, it is only in recent years that researchers have turned their attention to examining the impact of carer perceptions in predicting patient outcomes, and the scant literature examining this will be presented. This will be followed by a review of the literature examining the discrepancy¹ between how patients and carers understand illness and its association with emotional distress. There is a dearth of literature examining this association within the context of stroke, and so evidence from a range of chronic conditions will be discussed.

¹ Discrepancy refers to differences in how partners understand and interpret the illness.

The focus of the present thesis is the impact that a lack of agreement (discrepancy) between partners has on their respective distress levels. However, a case will be put for examining the impact of discrepancy in the context of how the individuals themselves understand the illness. That is to say, it will be argued that when patients and carers disagree on aspects of the stroke, this is associated with increased distress for both partners. However, what each partner thinks about the stroke will also affect their distress levels and the impact of any disagreement should be considered within this context.

2.2 Leventhal's Self-Regulatory Model of Illness Cognition and Behaviour

Social cognition models provide a theoretical framework for the study of how individuals make sense of illness, and their behavioural response to a health threat (Hagger and Orbell 2003). One theoretical model which has dominated the literature is the self-regulatory model of illness cognition and behaviour (SRM), (Leventhal et al. 1980), shown graphically in Figure 2-1 (page 18), also called the "common-sense model" because it focuses on personal, common-sense beliefs about illness (Cameron and Moss-Morris 2004). It provides a framework for understanding and coping with illness, in which the individual is understood to be actively involved in the process of solving their own health problems (Leventhal, Benyamini, Brownlee, Diefenbach, Leventhal, Patrick-Miller and Robitaille 1997). As these beliefs are personal, they vary between individuals, both in terms of their medical accuracy and in the richness of the model the individual creates in response to the threat (Moss-Morris, Weinman, Petrie, Horne, Cameron and Buick 2002). Therefore, some individuals will have a rich and coherent model of their disease, whilst others may have a fractured and contradictory model (Leventhal et al. 1984).

2.2.1 Stage One: Interpretation

Individuals receive information about a potential health threat through two sources: symptom perceptions (eg weakness on side of body) or by social messages (eg medical diagnosis). According to the SRM, the health threat is given meaning by accessing the individual's illness cognitions, and symptoms and social messages form part of this cognitive model. In the literature, a range of different terms have been used to describe patients' cognitive models, including illness representations, implicit beliefs, illness perceptions, cognitive models. However, regardless of the labels used, the model identifies five components or dimensions of the illness representation, which are:

- 1) Illness identity, which refers to the label placed on the disease and is defined by the symptoms associated with it.

- 2) Consequences, which refer to the expected outcome of the disease, and the effect it will have on their life.
- 3) Perceived Cause, which refers to beliefs about its aetiology, which may be biological (eg a blockage in the brain), psychosocial (eg stress or overwork) or environmental (eg pollution).
- 4) Timeline, which refers to how long it is expected to last, whether it is perceived to be an acute or chronic illness.
- 5) Cure/control, which are beliefs about how amenable the disease is to treatment, and the degree to which the outcome is under their own control or other people's (eg health professionals).

These represent the problem and give it meaning, and thereby enable the individual to develop coping strategies to manage it.

2.2.2 Sources of Information

Leventhal and colleagues (Leventhal, Leventhal and Contrada 1998) distinguish three main sources of illness cognitions. Firstly, the individual's personal experience of the illness; secondly the societal and cultural beliefs about its aetiology and maintenance; and thirdly beliefs that are constructed through social communication about the illness. This last source of beliefs is of interest in the present study as it acknowledges the role of significant others in the development of illness beliefs, which may include sources such as family knowledge, beliefs and myths, personal experiences, and health professionals.

The previous chapter described the role of significant others in the decision to seek help following the onset of symptoms (Carroll et al. 2004; Molocziej et al. 2008). The network of individuals involved in the process of making sense of the health threat has been referred to as the "lay referral network" (Freidson 1960), and includes a range of individuals from family members through to health professionals. As discussed in chapter one, within the context of stroke there is good evidence that patients and carers diverge in their understandings of stroke, and this chapter will conclude with a review of the literature examining the effect that the discrepancy between patients' and carers' understanding of the patient's chronic illness has on their psychological adjustment.

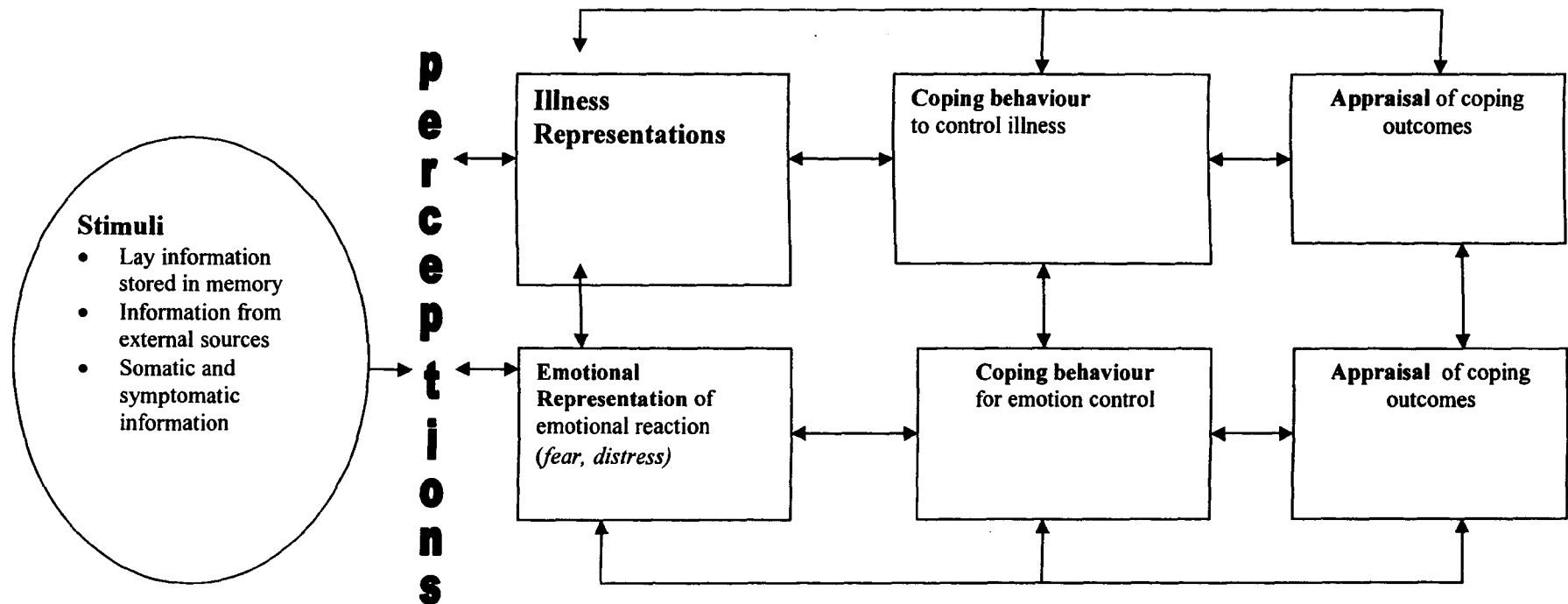


Figure 2.1 Leventhal's self-regulation model of illness cognition and behaviour; from Leventhal et al., 1984

2.2.3 Stage 2: Coping

In this stage the individual identifies and develops coping strategies. The coping response is dependent on the illness representation, and can take many forms. Two broad categories of coping strategies have been defined which incorporate a range of other strategies: approach coping (which incorporates talking about emotions, going to the doctor) and avoidance coping (for example: denial, distraction, wishful thinking) (Ogden 2000).

2.2.4 Stage 3: Appraisal of Coping

The third stage of the model is appraisal, which involves the evaluation of the effectiveness of chosen coping strategies. The self-regulatory model is an iterative model, as can be seen by the feedback loops shown in the diagram of the self-regulatory model shown in Figure 2-1. Therefore, each coping strategy is argued to alter the underlying illness representation, and thus changes later adaptive behaviours.

2.2.5 Emotional Pathway

Although the cognitive part of the model has received the most attention in terms of research, there is also an emotional pathway, such that emotions can change how the illness is interpreted (Leventhal et al. 1984). However, illness representations are not held only as abstract information; they can also include vivid, concrete memories of experiences (Cameron and Moss-Morris 2004), and these can affect the individual's response to the illness. A qualitative study by Gilmet and Burman (2003) found that the general public and professional carers had very enduring, negative images of stroke, with some feeling that death would be preferable to living with its consequences (Gilmet and Burman 2003). Negative concrete images can therefore trigger powerful emotional reactions. As can be seen in figure 2.1, the cognitive and emotional dimensions of the illness representation are bidirectional, and so whilst illness representations can activate emotions, the reverse is also true. Worry about a disease significantly influences illness representations and behaviour (Cameron 1997) promoting rumination about the illness which triggers the search for information to support this view, leading to a richer and more extensive illness representation. Anxiety too can influence how individuals attend to threat-related information, and to how information is processed, leading to the development of more threatening beliefs about the disease (Cameron 2003). Therefore, the self-regulatory model provides a framework not only for understanding how emotional distress can develop after stroke, but also how illness and distress are understood over time.

2.3 Measuring Illness Representations

Illness representations have been investigated using both qualitative and quantitative methods. Early studies were largely qualitative and used semi-structured interviews (Meyer, Leventhal and Gutmann 1985), a method which has also been employed successfully in more recent studies (Michie, MacDonald and Marteau 1996). However, the widespread use of the self-regulatory model can be attributed to the development of quantitative assessment tools such as the illness perception questionnaire (IPQ) (Weinman, Petrie, Moss-Morris and Horne 1996). The IPQ and its successor the IPQ-R (Moss-Morris et al. 2002) were developed to provide a quantitative assessment of the five dimensions of the illness representation described earlier. Its revision in 2002 addressed some minor psychometric problems with the original subscales, and resulted in the replacement of one scale (cure/control) with two scales (treatment control and personal control) and with the inclusion of two additional scales to provide an assessment of the emotional response generated by the illness, and to assess the degree to which individuals feel they understand their illness (coherence) (Moss-Morris et al. 2002).

2.4 Illness Representations in Chronic Illness

In 2003, Kaptein and colleagues (Kaptein, Scharloo, Helder, Kleijn, van Korlaar and Woertman 2003) published a selective review of studies examining illness representations in chronic illness. Studies were included if they explicitly assessed illness representations, and a dependent variable was included in the study. The illnesses examined were asthma, chronic obstructive pulmonary disease, neurological diseases (including Alzheimer's disease, Huntington's disease and epilepsy), cancer and cardiovascular disorders. The review found that different illness perceptions emerged as important correlates, or predictors, of outcomes in different chronic diseases. For example, in the neurological studies included in the review, identity and timeline emerged as associated with depression and wellbeing, whereas in the case of cardiovascular disease, personal control, causes, consequences and timeline were all implicated. This is in keeping with Leventhal's premise that individuals will exhibit characteristic illness representation profiles, depending on the illness symptoms and chronicity (Leventhal et al. 1980).

2.5 Illness Representations and Stroke

A search of the literature revealed only six studies examining the relationship between how stroke patients understand their illness and behavioural or emotional outcomes. The details of these studies can be found in table 2.1 (pages 22 - 23). Only two were specifically based on the SRM (Joice, Bonetti, MacWalter and Morrison 2003; Ford 2007), the other four studies

examine the role of control beliefs, using the Recovery Locus of Control (RLOC) (Partridge and Johnston 1989). The RLOC measures the role of control cognitions in recovery using Rotter's locus of control construct (Rotter 1966), which differentiates between internal control, i.e. 'believing that rewards are contingent on one's own behaviour' and external control, i.e. 'believing that events are outside one's own control', and therefore is similar in focus as the IPQ-R.

Both of the studies using the IPQ-R were unpublished cross-sectional, correlational studies which examined the illness representations of recently diagnosed stroke patients. Both studies assessed patients within 8 weeks of a first-ever stroke and considerable overlap was found in their findings. Higher depressive symptomology was associated with a strong illness identity, longer timeline and more severe consequence (Joice et al. 2003; Ford 2007). Whilst Ford (op. cit.) found low illness coherence to be associated with higher depressive symptoms, Joice (op. cit.) reports the opposite effect. In stroke, both associations are plausible, but as both studies found only bivariate correlational evidence for this relationship, further research is needed to explore this finding. The strength of both of these studies is that they recruited newly diagnosed patients, so tap their early understandings of their stroke. However, as with many of the studies cited in this review both studies were cross-sectional designs which means causal relationships cannot be determined.

A series of four related studies examined the role of control beliefs in predicting physical recovery and emotional distress in recently diagnosed stroke patients. These studies found that control beliefs (RLOC) at one month were predictive of physical recovery at six months (Johnston, Morrison, MacWalter and Partridge 1999) and that RLOC at six months was predictive of physical recovery at three years (Johnston, Pollard, Morrison and MacWalter 2004). Recovery locus of control at one month was correlated with, but not predictive of distress at six months. However a single item "recovery confidence" was found to be predictive of six month distress, (Morrison et al. 2000) but this association was not significant at three years post stroke (Morrison et al. 2005). Taken together these studies suggest that control cognitions are associated with physical recovery and emotional distress during the first months after a stroke, but that their predictive utility is restricted to physical recovery. In these studies, the RLOC and the IPQ-R personal control subscale were found to be generally unrelated to emotional distress scores. This is an interesting finding given that "recovery confidence" was predictive. One plausible explanation for the lack of predictive power for RLOC in the Morrison (2000, 2005) studies is a conceptual overlap between the two measures.

Table 2.1 : Summary characteristics and findings of studies examining the association between illness representations and distress in stroke

Study and date	Time since stroke Participant details	Design and analysis method	Assessment measures and outcome measure	Key Findings
Ford, 2007 unpublished thesis	2-6 weeks N= 40; 58% female Mean age 73yrs	Cross-sectional correlations	Demographic details IPQ-R, MMSE Outcome = HADS	Higher depression correlated with a stronger illness identity, longer timeline more serious consequences, lower coherence, stronger role for psychological factors as causal (all $p < 0.05$).
Joice, et al., 2003 BPS conference presentation	3 weeks post discharge n=106 n=50 female Mean age 65 yrs	Cross-sectional cohort correlations	IPQ-R, Outcome = HADS	Distress was significantly and positively associated with stronger illness identity, cyclical timeline, chronic timeline, negative consequences, higher coherence (all $p < 0.01$).
Johnston et al., 1999	Recruited 10-20 days post stroke. N=71 completers. N=35 female Mean age 69.4 yrs Assessed at 10-20 days post stroke, 1 & 6 months post discharge.	Longitudinal Cohort study Correlations and multiple regression	Exercise coping Orgogozo Index. RLOC HADS Outcome = BI and observed recovery measure.	RLOC at 1 month post stroke predicted recovery (BI) and observed recovery at 6 months post discharge ($p < 0.05$). Exercise and mood did not mediate this relationship.

Study and date	Time since stroke Participant details	Design and analysis method	Assessment measures and outcome measure	Key Findings
Johnston et al., 2004	N=40 from original cohort in 1999 study Re-assessed 3 years post stroke	Longitudinal cohort study Correlations and multiple regression	As Johnston 1999	Perceptions of control at 6 months post discharge (RLOC) were predictive of recovery (residualised Barthel Scores) ($p < 0.05$)
Morrison et al., 2000	N=71 as Johnston 1999	As above : Johnston 1999	As Johnston 1999, plus: Patient confidence in recovery, satisfaction with treatment and satisfaction with advice Outcome: HADS	Controlling for baseline depression and anxiety, satisfaction with treatment and confidence in recovery at 1 month were predictive anxiety at 6 months ($p < 0.001$). Satisfaction with advice and confidence in recovery at 1 month predictive of depression at 6 months ($p < 0.001$).
Morrison et al., 2005	As Johnston, 2004 3 year reassessment of cohort	As Johnston 2004	As Morrison 2000	Controlling for previous depression, only admission handicap, exercise frequency and anxiety predicted depression at 3 years. Recovery perceptions none-significant.

Key: BI = Barthel Index; HADS = Hospital Anxiety and Depression scale; IPQ-R = Illness perception Questionnaire- Revised; MMSE = mini-mental state examination; RLOC = recovery locus of control scale

However, the authors report only moderate inter- correlations between these variables indicating this is not the case, and suggests that the RLOC and recovery confidence measures tap different aspects of control. This has implications for the present study where personal control beliefs will be assessed. Recovery confidence was assessed using a single item in which patients rate how confident they are in making a full recovery, whereas the RLOC and IPQ-R assess the individual's own role in that process, which makes the lack of an association in these studies an area in need of further research.

In summary, these studies offer some tentative support for a correlational relationship between illness perceptions and distress, at least during the first few weeks post stroke. However, only control perceptions have been examined within a longitudinal setting, and only weak support has been found for a link between control perceptions and later distress. The lack of longitudinal studies testing other aspects of the SRM means that no conclusions can be drawn as to a causal relationship between illness perceptions and distress in stroke patients, and highlights the need for longitudinal studies able to test causal relationships in a stroke sample.

2.6 Carer's and Partner's Illness Representations

When faced with a health threat in a family member, others close to the patient also seek to create a cognitive framework within which they can come to understand the illness (Leventhal et al. 1985; Gray, Fitch, Phillips, Labrecque and Fergus 2000) and these illness perceptions also align with the dimensions of the illness representation proposed by the self-regulatory model (Leventhal et al. 1997). Although evidence from other illnesses have found that the perceptions of patients and carers can concur (Heijmans, De Ridder and Bensing 1999; Weinman, Petrie, Sharpe and Walker 2000), there is good evidence that stroke patients and carers differ in their illness perceptions (Clark 2000; Visser-Keizer, Mayboom-de Jong, Deelman, Berg and Gerritsen 2002; Hochstenbach, Prigatano and Mulder 2005), and so it is likely that family members will come to understand the illness in different ways. A search of the literature revealed only a small body of research examining the association between carers' illness perceptions and their health and well-being. Most of these studies have recruited individuals who have been caring for someone with a chronic illness over a long period, and include the carers of patients with stroke, myocardial infarction, Huntingdon's disease and schizophrenia (McClenahan and Weinman 1998; Barrowclough and Lobban 2001; Helder, Kaptein, Van Kempen, Weinman, Van Houwelingen and Roos 2002; Fortune, Smith and Garvey 2005; Kaptein, Scharloo, Helder, Snoei, Van Kempen, Weinman, Van Houwelingen and Roos 2007), with only one study examining the perceptions of new carers (Arefjord, Hallaraker, Havik and Maeland 2002).

The findings of these studies support the view that carer perceptions are associated with carer distress (see table 2.2 pages 26-27 for study details). Although significant differences exist between the studies, the most consistent finding is that carers are more distressed when they perceive there to be more negative consequences associated with the illness (Barrowclough and Lobban 2001; Fortune et al. 2005; Lobban, Barrowclough and Jones 2005b; Kaptein et al. 2007), that there are more symptoms associated with the condition (Fortune et al. 2005; Lobban et al. 2005b), that the illness will take a long time to recover from (McClenahan and Weinman 1998; Kaptein et al. 2007), and that the illness was caused by stress (Arefjord et al. 2002). Nevertheless, there are inconsistent findings. For example, in one study of the spousal carers of Huntington's disease patients, carer perceptions were found not to be good predictors of carer adjustment (Helder et al. 2002), but a later study by the same team, using the same measures, came to the opposite conclusion (Kaptein et al. 2007). One explanation for these conflicting findings is that there are differences in the demographics of the samples and in the analysis techniques used. However, the authors fail to discuss the differences in their findings, so no clear conclusions can be drawn.

2.6.1 Effect of Partner Perceptions on Patient and Carer Outcomes

It is also pertinent here to discuss briefly the relation between partner perceptions and patient and carer outcomes. This is a very new area of research and so few studies have been published. Five studies were found which examine the relation between carer perceptions and patient outcomes, and one which also examines the relation between patient perceptions and carer outcomes (see Table 2-3 pages 28-29 for details of the studies). These studies examine the direct or mediating effect of partner perceptions, and do not explicitly examine the impact of discrepancies in patient and carer perceptions, which will be discussed on page 32. Positive associations have been found between spousal perceptions and patient outcomes. Specifically, spousal perceptions have been found to be predictive of changes in exercise behaviour in recently diagnosed myocardial infarction patients (Weinman et al. 2000) and type II diabetic patients (Searle, Norman, Thompson and Vedhara 2007), patient and carer vitality in a sample of Huntington's disease patients and carers (Kaptein et al. 2007), improvements in physical functioning in a sample of recently diagnosed stroke patients (Molloy, Johnston, Johnston, Pollard, Morrison, Bonetti, Joice and MacWalter 2008), and physical recovery and psychological distress in a sample of recently diagnosed myocardial infarction patients (Figueiras 2000).

Table 2.2: Summary characteristics and findings of studies examining the association between illness perceptions and distress in carers

Study Illness	Time since diagnosis Participant details	Design	Assessment and outcome measures	Key Findings
Arefjord et al., 2002 Myocardial infarction	N=52 wives of patients. Mean age = 53.3 yrs (sd= 7.5) N=37 completers	Prospective Longitudinal Assessed at Acute stage & 3 months & 10 yrs post MI.	Causal beliefs Outcome: self report measure of anxiety, depression and irritability	Causal explanations showed little stability over time, with stress most commonly reported in the acute phase, and lifestyle causes more frequently reported at 10 yrs follow up. In the acute phase, attributing MI to husbands' personality was associated with anxiety and irritability (p<0.05). Blaming the patient was associated with depression and irritability (p<0.05). Attributions to stress in the acute phase was associated with higher depression and irritability at 3 months (p<0.05). Attributions were not associated with 10 year depression or anxiety.
Barrowclough et al., 2001 Psychosis	N=47 carers 53.2% parents 68% female Mean age: not reported Duration of patient's illness 14.3 yrs	Cross-sectional Correlational	Revised IPQ for psychosis Outcomes: GHQ-28, BDI, SBAS EE	Greater perceived consequences for the patient was associated with higher carer GHQ scores. Greater consequences for the carer were associated with higher distress (GHQ-28), depression (BDI) and burden (SBAS). Personal control was not associated with carer distress. Stronger illness identity was associated with higher GHQ-28 scores.
Fortune et al., 2005 Psychosis	N=42 carers 64% female Mean age 57.3 yrs (sd= 8.2) 93% parents duration of patient illness 2-14 yrs (Mean 6.1 yrs)	Cross-sectional study Correlations and regression analysis	Revised IPQ for psychosis Family questionnaire COPE Outcome : HADS	Higher distress was associated with stronger illness identity, (p<0.001), longer timeline (p<0.01), more severe consequences (p<0.01), belief that patient has higher personal control over symptoms (p<0.01), lower treatment confidence (p<0.001).

BI= Barthel Index, COPE= measure of coping mechanisms; FQ = frequency of problems; GSES= Generalised self-efficacy scale; GHQ= General Health Questionnaire; Revised IPQS= IPQ for psychosis; ; RCPM= Raven's coloured progressive matrices SBAS = Social behaviour assessment scale (subjective burden), SOS = significant others scale; STL = screening test for language; WAB = Western Aphasia battery;

Study Illness	Time since diagnosis Participant details	Design	Assessment and outcome measures	Key Findings
Helder et al., 2002 Huntingdon's disease	N=90 spousal carers. 49 females Mean age 53 yrs. 27% of patients were in Nursing homes	Cross-sectional Correlational and regression	IPQ COPE, Outcome :MOS SF-36	Spouses scores on SF-36 were not correlated with IPQ or COPE scores. IPQ did not explain any significant variance in SF-36 scores.
For Kaptein et al. 2007 see table 3				
Lobban et al., 2005 Psychosis	N=62 relatives. N=39 female. Mean age 53 yrs. N=37 were parents	Cross-sectional and longitudinal correlational study to assess psychometric properties of measure	Revised IPQS Outcomes: GHQ, SBAS, FQ	GHQ-28 scores were significantly correlated with more negative consequences and a belief that the illness is distressing to the patient. SBAS was significantly correlated with more negative consequences for both patient and relative. FQ was significantly correlated with stronger illness identity, more cyclical timeline, more negative consequences for patient and relative, and a belief that the illness is distressing to the patient.
McClenahan & Weinman 1998 Stroke	N=86 carers 69 spouses. Gender not reported Time since stroke= at least 11 months. Age not reported.	Cross-sectional correlational and regression	IPQ LOT, GSES, SOS, BI, WAB, STL, RCPM, Outcome: GHQ-12	A longer timeline was associated with higher distress ($p<0.009$), no other illness representations associated with distress levels. Carer distress predicted by GSES ($p<0.0015$), COPE (suppression) $p<0.017$, COPE (venting) $p<0.03$ and timeline ($p<0.02$)

Table 2.3: Summary characteristics and findings of studies examining the association between carer perceptions and patient outcomes

Study and date	Condition Illness/ sample	Participant details	Measures Focus of study	Key Findings & analysis technique used
Kaptein et al., 2007	Huntingdon's disease (HD)	<p>N=51 couples N=28 patients Male</p> <p>Mean age of both partners = 51 yrs (sd= 10) Married mean 25 yrs. 66% partners female. Duration of HD = 7 yrs (sd 5yrs)</p>	<p>Unified Huntingdon's disease rating scale MMSE IPQ MOS-36</p>	<p>Cross-sectional study Correlation, paired t-tests and Hierarchical multiple regression</p> <p>Patient QOL: spouse perceptions of longer timeline and weaker belief in cure added to prediction of higher patient vitality (p<0.05).</p> <p>Spouse QOL: Patient perceptions of control added to variance explained in spouse vitality scores, after controlling for spousal beliefs. Patient consequences perceptions added to spousal mental health scores, with fewer consequences associated with lower distress, but not significant.</p>
Molloy et al., 2009	<p>Stroke</p> <p>Prospective cohort study recruited via control arm of workbook intervention study (see Johnston 2007)</p>	<p>N=109 patients and spouses.</p> <p>85 male patients. Mean age = 67.7 yrs (sd 11.31) Spouse: mean age = 65.71 yrs (sd 10.83).</p>	<p>Outcome: FLP Spouse confidence Stroke survivor self-efficacy Stroke survivor self efficacy for recovery Received practical support Neurological impairment</p>	<p>Longitudinal Prospective cohort study Correlations and hierarchical multiple regression Time 1 = 2 wk post discharge; Time 2 = 6 wks later. Ambulatory recovery calculated as deviation of Time 2 scores from statistically expected score from time 1 score. Higher spouse confidence at Time 1 correlated with better than average recovery. Patient self-efficacy at time 1 not associated with recovery from activity limitations. Spouse confidence significantly predicted ambulatory activity recovery (p<0.05). Neurological impairment and practical support did not mediate this relationship.</p>

Study and Date	Condition/ illness Sample	Participant details	Measures Focus of study	Key Findings & Analysis technique
Searle et al., 2007	Type II diabetes patients Diagnosed at least 6 mo.	N=134 couples. Mean patient age = 67 yrs (sd = 10.5 yrs) Median years married = 38 yrs. N=37 patients used insulin to control diabetes. No information on spouses	IPQ-R Symptoms assessed using the PMDI Diet (HEA3) BHPAQ (physical activity) MARS	Longitudinal prospective study Paired t-tests, ANOVA Data collected at baseline and 12 months Patients reported lower illness coherence (p<0.01) and higher personal control (p<0.05) compared to partners. Patient and spouse perceptions of timeline, personal control, treatment control, illness coherence and causal beliefs were significantly correlated (p<0.01). Partner's only influenced levels of patient activity and aspects of diet. Timeline mediated patients' physical activity and fruit and fibre intake. Partners' personal control beliefs partly mediated physical activity
(Weinman, Petrie et al. 2000)	1 st time MI patients and spouses. prospective cohort study New Zealand	N=143 patients Mean age 53.2 yrs (sd 8.4 yrs) 87% male 89% European N=84 spouses Mean length of stay 6.8 days (sd 4.1) Follow-up @ 6mths – N=115 patients returned T2 data	IPQ (patients @ 3 wks & spouses @ 3 months) Health behaviour scale (baseline & 6 mths- patient only)	Prospective, longitudinal study. One-way ANOVA: Spousal attributions to cause of MI as due to lack of exercise, was associated with increased level of exercise by the patient @ 6mths (p=-.000). Reduction in patient alcohol intake associated with spousal belief in cause of MI being due to excess alcohol (p<0.04). Spouses lifestyle attributions was only variable to predict change in exercise patterns (p<0.01) explaining 11% of variance in behaviour.

These studies provide evidence that carer perceptions are associated with patient outcomes in a range of conditions. However, the focus of these studies is largely on physical, rather than psychological outcomes. This highlights the need to widen the research focus to examine the role of carer perceptions and patient distress. The paucity of research within a stroke context also makes it inappropriate to over-extrapolate these findings. These are generally well designed studies, but an emphasis on male patients and female carers makes it difficult to determine whether spousal influences on patient outcomes are due to partner or gender effects. They also examine the direct effect of partner perceptions and do not explicitly examine the impact of discrepancy. Finally, only one study was found which examines the relation between patient perceptions and carer outcomes (Kaptein et al. 2007). Although this study found patient perceptions were only related to one aspect of carers' quality of life, these findings do suggest that the impact of patient perceptions on carer outcomes is an area which is in need of further investigation.

2.7 Brief Critique of the Self-Regulatory Model

The SRM provides valuable information about the association between illness perceptions and patient outcomes, and evidence from a wealth of studies supports such a relationship (French and Weinman 2008). The results of a meta-analytic study concluded that the dimensions of the SRM are inter-related in a coherent and meaningful way (Hagger and Orbell 2003), and that illness perceptions are associated with a range of outcomes including physical recovery, emotional distress and behaviour change. However, although there is evidence from a range of chronic illnesses, there is a paucity of evidence pertaining to stroke. Given the relation between illness perceptions and distress found in other chronic illnesses there is a need to investigate this further.

The model predicts a causal relationship between illness representations and outcomes, mediated by coping. However, the present study will not examine the role of coping. In the present study the focus is on discrepancy in the illness perceptions of patients and their carers, and the assessment of coping in addition to illness representations and social support may risk over-burdening individuals, and so, given that the evidence to suggest that the relationship between illness perceptions and outcomes can be usefully assessed without investigating coping, a decision was taken not to assess coping in the present study.

The self-regulatory model further suggests that illness representations change over time as the individual learns more about the illness (Leventhal and Nerenz 1985) but the heavy reliance on cross-sectional studies means this hypothesis is rarely tested. Although a few

longitudinal studies exist, most are prospective studies which assess illness representations at baseline only, with few studies assessing how illness perceptions change over time (Weinman et al. 1996; Knapp and Hewison 1999). There is therefore a need for longitudinal studies to examine this relationship. The research to date has focussed on the intra-individual aspects of the SRM, and there have been few serious attempts to assess the role of significant others in patient recovery and adjustment. The few studies which do attempt this provide moderate support for a such a link. However, significant differences exist between the present study and those reviewed here. For example, the evidence is based largely on cross-sectional studies with a few prospective studies, and is biased towards three conditions (myocardial infarction, schizophrenia and Huntington's disease).

There is also a bias towards male patients and female spouses in the MI literature, which means that role and gender effects cannot be determined. The schizophrenia literature has recruited younger adults, and it is likely that the nature of the patients' illness and the age of both the patient and carer will affect carer perceptions. Also, in the schizophrenia studies, the carer samples have been biased towards female parents. In stroke, carers are more likely to be spouses or adult children. Therefore, although there is support for a link between partner beliefs and patient outcomes, overall conclusions are not easy to reach because the research has examined such different illnesses. It does however highlight the need for research which examines this issue in the context of stroke, although the likely predictors of carer distress cannot be predicted by the available evidence.

2.8 Summary

In conclusion, there is evidence to support a link between what patients and carers perceived about the patients' disease and their own emotional well-being. However, the literature reviewed highlights the lack of research using the SRM to examine the illness perceptions of stroke patients or carers, and a bias towards cross-sectional studies, limiting the conclusions that can be drawn. Furthermore, the lack of good longitudinal studies means no firm conclusions can be drawn on how illness perceptions change over time. Given the paucity of studies examining illness perceptions in stroke patients and carers, the present study will assess changes in illness perceptions over time, and will conduct both prospective and cross-sectional analyses to examine the relation between illness perceptions and patient and carer distress.

2.9 Literature Review: Discrepancy and Emotional Distress

In recent years, researchers have turned their attention to examining the idea that patients' and carers' psychological well-being is dependent not only on their own illness representations, but on whether those closest to them hold similar views. Empirical evidence indicates that stroke patients and their carers hold different views about the patient's stroke (Wellwood et al. 1994; Wyller, Sveen and Bautz-Holter 1996; Clark 2000; Tooth, McKenna, Smith and O'Rourke 2003a, b; Hochstenbach et al. 2005) but few studies have thus far examined the impact that not having a shared understanding of the stroke has on the psychological adjustment of the patient and carer (Knapp and Hewison 1999; Visser-Keizer et al. 2002). A literature review was therefore undertaken to examine the evidence base for an association between discrepant illness representations and psychological well-being.

A search for relevant articles was conducted on three databases (EMBASE, MEDLINE, PSYCinfo) for the period Jan 1995 to June 2008 (see appendix 1 for search strategy). Articles were selected if they fulfilled the following criteria: published in English; examined discrepancy between the illness representations of patients and informal carers (formal carers were excluded); stroke sample; adult populations, and dependent variable was psychological distress, psychological adjustment or well-being, or mood (depression, anxiety). The reference lists of those studies identified by the search process were searched for additional articles. This initial search revealed a paucity of studies fulfilling the inclusion criteria, so the search was re-run widening the inclusion criteria to include any chronic condition.

2.9.1 Findings

Whilst this is a growing area of research, no published reviews were found. The search identified ten empirical studies which fulfilled the inclusion criteria, of which one examines illness representations in two conditions (Heijmans et al. 1999). Only three longitudinal studies were found (Knapp and Hewison 1999; Figueiras and Weinman 2003; Sterba, DeVellis, Lewis, DeVellis, Jordan and Baucom 2008), of which only one assessed discrepancy at more than one time-point (Knapp and Hewison 1999). Most of the studies included in the review examine the illness representations of couples who have been living with the illness over a long period of time, and although stroke can be considered to be a chronic condition, the present study aims to examine the illness perceptions of patients and carers who have been recently diagnosed with a first-ever stroke, and so the findings should be viewed cautiously.

The studies identified form a heterogeneous evidence base and differ in terms of how discrepancy was defined, operationalised and analysed, making comparisons across studies difficult. The methods used by previous studies are of particular interest for the present research

as they form the basis of many of the analysis decisions taken here, and so these are discussed separately in chapter 4. Given the differences between studies, a narrative review of the literature is presented, and details of the studies included in the review are presented in table 2.4. The evidence is mixed with regards to providing support for a relationship between discrepant illness representations and psychological well-being in patients, with some studies finding good support (eg Heijmans et al. 1999) and others offering no support (eg Richards et al. 2004). Few studies have examined the relation between discrepancy and carer outcomes, so only tentative conclusions can be drawn, but these studies do suggest a link between discrepancy and well-being in carers.

Studies were included if they measured illness beliefs, and so measures in addition to the IPQ are included. Of those studies using the IPQ or IPQ-R, most do not test the full model, and instead focus on illness representations which are theoretically relevant to the illness under consideration. Furthermore, only two studies use the IPQ-R, and so discrepancy in the three newer subscales (timeline cyclical, coherence and emotional response) have been examined least often. A range of methodological issues were also identified, which will be discussed in detail at the end of review.

2.9.2 Impact of Discrepancy on Patients' and Carers' Psychosocial Adjustment

Two main groups of studies were found and will be discussed separately. The first group of studies examine the degree to which couples are discrepant in their perceptions (Heijmans et al. 1999; Visser-Keizer et al. 2002; Richards, Fortune, Chong, Mason, Sweeney, Main and Griffiths 2004; Kuipers, Watson, Onwumere, Bebbington, Dunn, Weinman, Fowler, Freeman, Hardy and Garety 2007), and examine the impact of two opposing patterns of discrepancy; spouse maximisation, (whereby the spouse is more pessimistic than the patient themselves), and spouse minimisation, (spouse minimises the impact of the illness, compared to the patient) (Heijmans et al. 1999). The second group take a discrete groups approach, and classify couples as having similar or discrepant views and use analysis of variance to determine whether the couples who are similar in their views differ from those with discrepant perceptions in the level of the outcome variable (eg Figuerias and Weinman, 2003).

The seminal paper in this research area is a cross-sectional study, in which the illness perceptions of chronic fatigue syndrome (CFS) and Addison's disease (AD) patients and those of their partners was compared (Heijmans et al. 1999). In this study, discrepancy was calculated as the difference between patient and partner perceptions. Discrepancy was only weakly associated with coping, but a strong predictor of adaptive outcome in patients, with stronger

effects in AD patients. Specifically, in AD couples, when the spouse reported more symptoms, a longer timeline, and worse consequences than the patient, patients were better adjusted. In the CFS patients, when spouses maximise the symptoms, and were more optimistic about the timeline for the illness, higher functioning was reported by the patient. A key finding from this study was that whilst dissimilarity was an important predictor of patient adaptation, its effect differed with both the dimension of the illness representation and the type of illness, with both spouse maximisation and spouse minimisation found to be detrimental.

In common with later studies, this study examines only the impact of discrepancy, and fails to examine the effect that similar negative perceptions may have on outcomes. The cross-sectional design, non-random sampling methods and gender-biased sample limit the generalisability of the study. Furthermore, the authors report low internal reliability on some scales, and the validity of the partner version of the IPQ had not yet been established. That said, later studies have found support for a relationship between discrepancy and patient adjustment in a range of other conditions including psychosis (Kuipers, Watson et al. 2007), rheumatoid arthritis (Sterba, DeVellis et al. 2008) and stroke (Visser-Keizer, Mayboom-de Jong et al. 2002). However, not all studies find a link between discrepancy and patient adjustment (Richards, Fortune et al. 2004). Three of these studies also examined the relation between discrepancy and carer outcomes, and each found support for such a relationship (Visser-Keizer et al. 2002; Richards et al. 2004; Kuipers et al. 2007).

In a cross-sectional study of patients who had recently experienced a first ever stroke, agreement between patients and carers over the cognitive, emotional and behavioural changes experienced by the patient was found to be only slight to fair, with better agreement for observable behaviour (Visser-Keizer et al. 2002). Correlational analyses revealed that both patients and carers were more distressed when they reported the presence of changes which were not reported by their partner. Severity of changes was not associated with distress. This study is one of only two to examine discrepancy in a stroke sample, and assesses this within the same time-frame as the present study, and so is of particular interest. It does not use the SRM as its theoretical framework, but it is one of the few to examine the impact of discrepancy in partners. However, there are some methodological limitations. The study fails to report any demographic data on partners, which limits the conclusions which can be drawn from the study, and it does not provide any validity data on the assessment measure used to determine patient and carer perceptions, beyond it having good internal reliability and being “*based upon clinical relevance according to both neuropsychological literature and interviews with partners of stroke patients*” (Visser-Keizer et al., 2002; pg 1034). The cross sectional design also means causal associations cannot be drawn, and the use of bivariate correlations means that other

factors which may be important, such as stroke severity, patient age and gender were not examined.

The second group of studies categorise couples as being similarly positive or negative, or discrepant in their illness representations, and compare these groups on the level of the dependent variable. As with the studies already discussed, these five studies examine the impact of discrepancy on patients, but only two examined associations between discrepancy and carer outcomes. As with the discrepancy studies already discussed, the results of the studies examining the beneficial effect of both partners holding similar beliefs (congruence) are mixed.

In a prospective study of men who had recently been diagnosed with a myocardial infarction (MI), Figueiras and Weinman (2003) found that at six and twelve months post MI, patients reported better physical and psychological well-being when both partners held similar positive (optimistic) perceptions of the illness identity and consequences of the MI. Conflicting perceptions about the level of control the patient had over their stroke was associated with patients reported lower social functioning at six months, but not associated with later psychological functioning. Discrepancy in causal attributions was not reported. The method used to classify couples as discrepant or congruent reduces continuous variables to categorical variables, and in doing so loses valuable information about the degree of difference between individuals (see chapter 4 for a discussion), which may account for the lack of effect of discrepancy as the thesis upon which this study was based found that carer perceptions were directly predictive of patient outcomes (Figueiras 2000).

Support for Figueiras and Weinman's (2003) findings comes from Franks and colleagues (2002) looking at the effects of couple congruence on the emotional well-being of elderly, male cardiac patients. This cross-sectional study found that patient well-being was better when both partners agreed in their rating of the patient's health, but in contrast with Figueiras and Weinman (2003) this study found discrepancy was detrimental. When wives rated the patient's health as poorer than that reported by the patient, this was associated with higher patient distress and lower positive affect. As with the Figueiras and Weinman (2003) study, the recruitment of male patients and their spouses means that the effect of gender on patient outcomes cannot be determined.

Other studies have also found both discrepancy and congruence to be important. An interesting, prospective longitudinal study, of a sample of female rheumatoid arthritis (RA) patients and their husbands, was conducted by Sterba et al (2008). She found that when partners were both positive about the wife's level of personal control the wife reported better

psychological adjustment. However, when partners disagreed about the cyclical nature of the timeline for the illness, wives reported higher distress, and when partners' minimized the consequences of the RA, wives reported better adjustment. This study is interesting because it examines both the congruence and discrepancy approaches and found both to be important. However, couples were highly congruent in their perceptions which limit the generalisability of the study. Also, as with the studies discussed thus far, the recruitment of single sex patient samples limits the conclusions which can be drawn about the effect of discrepancy on patients.

A cross-sectional study to examine the impact of discrepancy on rheumatoid arthritis patients examined discrepancy in their perceptions of the patient's physical functioning (Riemsma, Tall and Rasker 2000). Differences in partners' estimates were considerable, and patient distress was lowest when spouses' perceptions of the patient's functional ability matched their own. Both over-estimations and under-estimations by the spouse were associated with poorer mental health in the patient. This study was one of only a few to also examine the impact of discrepancy on spouses, and found that spouses who over-estimated the patient's functional disability, compared to the patient's own rating, reported poorer mental health. In this study, patients and carers were classified as congruent only if partners agreed absolutely in their rating of the patient's health, which fails to allow for natural variation in scoring. Nevertheless, these findings do suggest that when couples disagree about the functional ability of the patient, that this is associated with higher distress. This is also one of the few studies to look at the impact of discrepancy on carer outcomes.

Knapp and Hewison (1999) also examined the effect of discrepant perceptions of the patient's physical functioning. This prospective, longitudinal study investigated the effect of discrepancy in a sample of recently diagnosed stroke patients and their carers. Patient and carer ratings of the patient's functional ability were made using the Barthel Index as the independent variable, with assessments made at one month post stroke, one month post-discharge and six months post discharge. Couples were categorised as carer maximising (carer perceiving patient to be more disabled) and the second group comprised congruent couples and couples where the carer minimised the patient's disabilities. The study found systematic differences in patient and carer assessments of the patient's level of functioning, but these were small in magnitude, and not significantly related to patient or carer distress at any time-point. Differences in the partner's ratings of the patient's disability were related to carer strain at both assessment points post discharge. However, the Barthel index is a relatively insensitive measure, which may account for these disappointing findings. Other studies, using different measures have found large differences in the ratings of stroke patients and their carers, (Wyller et al. 1996), and so the lack of effect in this study may be due to the small sample size, resulting in a lack of power, or

more likely because the Barthel Index is a relatively insensitive measure and prone to ceiling effects.

2.9.3 Summary

The evidence presents a mixed picture, with some studies finding support for a link between discrepancy and higher patient distress (Riemsma, Tall et al. 2000; Franks, Hong et al. 2002; Visser-Keizer, Mayboom-de Jong et al. 2002; Kuipers, Watson et al. 2007), and others finding little or no support for such a link (Knapp and Hewison 1999; Figueiras and Weinman 2003; Richards, Fortune et al. 2004). Two studies found similar positive beliefs were beneficial to patient outcomes (Figueiras and Weinman 2003; Sterba, DeVellis et al. 2008), and one found that “shared appraisals” were associated with better outcomes (Franks, Hong et al. 2002). Fewer studies have focussed on the role of discrepant illness perceptions for carer outcomes, but all found some modest support for a link between discrepancy and carer distress, quality of life, or carer strain (Knapp and Hewison 1999; Riemsma, Tall et al. 2000; Visser-Keizer, Mayboom-de Jong et al. 2002; Richards, Fortune et al. 2004). Therefore, the results offer tentative support for the hypothesis that if the patient and carer interpret the illness differently, that this may have implications for carer outcomes. However, the literature also comes from a diverse range of conditions, and therefore a general critique of the literature is presented.

2.10 Critique of the Literature

The studies reported here differ in many respects, including the nature of the disease examined, time since diagnosis, status of the partner (carer versus spouse), method of operationalising discrepancy and analysis techniques used. Some studies find support for a link between discrepancy and outcomes and some do not. Given the range of illnesses examined, explanations for these differences are difficult, but they do suggest there is a need for more research into this area. Few studies have yet used the IPQ-R, so some illness representations have been rarely examined (eg illness coherence). Although studies have regularly assessed the illness representations of both partners, fewer examine carer outcomes, which is a significant limitation in the literature. There is now good evidence that carers form their own cognitive representation of the patient’s illness, and how the carer interprets the patient’s illness is associated with both patient and carer well-being, so there is a need for research examining this in more detail.

Illness representations are conceptualised as dynamic, and influenced by personal experiences and social communication (Leventhal et al. 1980), but changes in illness representations are rarely examined in the literature. The cross-sectional nature of many of the studies also limits the conclusions which can be drawn both in terms of the temporal ordering of

illness perceptions and outcomes, and of how illness perceptions and discrepancy change over time. Only one discrepancy study was found which examined how illness perceptions changed over time (Knapp and Hewison 1999), and this study focused on perceptions of physical functioning, so provides no evidence as to whether other illness representations converge or diverge over time. There is also a bias in the literature towards individuals who have been living with their illness for a long time, and this is an important issue as these studies may fail to capture the “natural history” of discrepancy from the time of diagnosis. There is therefore a need for longitudinal prospective studies which can examine these processes.

Most of the studies reviewed recruited participants who are younger than the average stroke patient, and age may play a part in the models that individuals construct of the illness (Leventhal et al. 1985), again limiting the usefulness of the existing literature. Sample sizes are generally small to medium, (ranging from 30 to 188, median = 56) which limit the generalisability of the findings. Studies recruiting spousal couples dominate the literature, and although spouses are generally the main source of support in married couples (Revenson 2003), in the context of stroke, which more commonly strikes in older people, other supporters may be relied upon (Anderson 1992), and it is pertinent to consider the impact of discrepancy in relationships other than husband-wife dyads. Sampling biases are common, with the majority of studies recruiting participants through doctors, clinics, and hospital in-patients, which may result in a bias towards more disabled individuals being recruited and those less disabled being excluded from the sample, whilst other studies recruit via support groups, which also limits the generalisability of the findings.

Table 2.4: Summary characteristics and findings of studies examining the association between discrepancy and patient and carer distress

Study and date	Condition Illness/ sample	Participant details	Measures Focus of study	Key Findings & analysis technique used	Discrepancy measured by?	Methodological issues
Figueiras & Weinman, 2003	1 st time MI patients & spouses Portugal Prospective cohort study- recruited patients in hospital	N=70 Couples Patients =Male Patient mean age= 53.2 (sd 8.8) Spouse mean age= 49.8 (sd 8.8) Assessed @ 3/6/12 mths post MI.	IPQ (reworded for spouse). SF-36 MHI scales (Psyc adjustment, health distress MOS: Sexual functioning SIP MOS: Marital functioning Diet change.	Longitudinal, prospective Assessed 3mth post MI to predict health outcomes @ 6/12 mths. Similar positive perceptions of identity & consequences = better patient functioning (physical, social, psychological & sexual functioning) Conflicting MI identity (symptoms) = poorer sexual functioning (but NS in post hocs). Conflicting perceptions of cure/control = lower social activities for patient at 6 & 12 mths.	Median score for each group (Patient & Spouse) calculated for each subscale. Individuals classified as above/below median for their group & compared to spouse placing. Couples classified as ++, -, +/-	(-) Patients = Male (+) novel way of assessing discrepancy. (-)Causal beliefs not used as predictors (-) No evidence of controlling for MI severity.
Franks, Hong et al. 2002	Heart disease Patients & spouses USA- Recruited via hospital research lab	N=66 Patients = Male Patient mean age =63.89 (sd 8.25) Spouses mean age= 61.77 (sd 8.66) Time Married = 35 yrs (sd 13.99)	NOT IPQ Global health rating (1 item) Bradburn affect balance scale QMI CES-D (depression) Positive Affect (Bradburn Affect Balance scale)	Correlations & Kappa for agreement on global health rating (t-tests to compare 3 groups** on Positive affect & depression. Hierarchical MR Kappa between P & S ($r=.54$, $p<0.001$), but absolute agreement in only ½ sample. Multiple Regression analysis found that patient outcomes (lower depression, higher positive affect & higher Marital satisfaction associated with spousal agreement with patient's self rated Global Health rating	global rating of patient health used to calculate min/max/congruent (-) couple had to get identical marks to be rated as congruent.	(-)Male patients (-) not based on SRM (-) time since diagnosis not reported. (-) x-sectional (-) no severity data. (-) patient outcome only 30% response rate (-) used t-test when 3 groups

Table 2.4 continued

Study and date	Condition Sample	Participant details	Measures Focus of study	Key Findings & analysis technique used	Discrepancy measured by	Methodological issues
Heijmans et al. 1999	Chronic Fatigue Syndrome (CFS) Addison's Disease (AD) Patient & spouse Netherlands Recruited via patient organisations	N=49 CFS patients (92% female) N=52 AD patients (72% female) Mean age 40 (sd 10yrs) Time with symptoms: CFS 7.6 yrs (sd 7.4yrs) AD: 16.5yrs (sd 13.3) No info on spouses.	IPQ Marital relationship questionnaire (not validated) Utrecht coping questionnaire	X sectional AD: Spouse maximisation of symptoms, timeline, and consequences= better patient functioning (psychological and physical). CFS: Spouse minimisation of the Timeline = better physical functioning in patient. ↑ dissimilarity in IPQ associated with ↓ marital relationship. Multiple Regression: AD: Spouse pessimism about Timeline and optimism about controllability = Patient better adjusted (p<0.05). Multiple Regression: CFS : Spouse minimization about symptoms & max role of env in causal role by spouse predicted poorer Patient outcomes (psychological adjustment) (p<0.05)	Dissimilarity scores calculated by subtracting spouse score from patient score – so spouse = min or max compared to patient. no congruent group Method of calculating discrepancy doesn't allow natural variation in scores (ie no congruent group).	Not controlled for illness severity (-) low inter-item reliability on timeline and PC (+) early study (-) biased sample on gender (-) biased sample on recruited (patient organisations) (-) assesses only timeline, consequences, control and causal perceptions.
Knapp & Hewison 1999	Stroke Patient & carer all 1 st time CVA patients UK	N=30 Patients = 14 female Median age = 72 yrs. Carers N=19 female. Age 30-81 More than half of carers were spouses	Barthel Index HADS Carer strain measure Assessed @ 1 mth, 1 mo post-discharge, 6 mo post-discharge	Longitudinal, prospective Agreement between patient & carer: ½ disagreed at each time point. Small number of carers rated patient functioning higher than did patient reported. Magnitude of disagreement small (2pts) Discrepancy not associated with patient or carer mood (HADS) Carers who maximised patient disability compared to Patient assessment reported higher carer strain (compared to those couples who agreed on BI)	Discrepancy calc as difference between Patient & Carer on BI scale.	(+) longitudinal (-)small sample. (-) only small differences on BI (-) ceiling effect on BI (-) not based on SRM

Table 2.4 continued

Study and date	Condition Sample	Participant details	Measures Focus of study	Key Findings & analysis technique used	Discrepancy measured by	Methodological issues
Kuipers et al. 2007	Psychosis Patient and carer Recruited from Trial participants UK	82 patients and carers Patients 72% male Patient mean age = 36.2 yrs Carers mean age = 52.4 yrs 69% female 50% parents	CFI RSS GHQ IPQ BDI BAI	Cross-sectional When carers were optimistic than patients about consequences – patient more anxious ($p < 0.003$), more depressed ($p < 0.001$) and had poorer self-esteem ($p = 0.001$). Carer optimism about illness persistence was correlated with higher patient anxiety ($p = 0.03$) When carers were more pessimistic about control of illness, patients had good self-esteem ($p = 0.02$), depression ($p = 0.02$) and lower self-esteem ($p = 0.001$).	Discrepancy calculated by subtracting patient from carer scores.	(+) clear inclusion criteria (-) cross-sectional (-) correlational (-) patient outcomes (-) does not assess all IPQ variables Assesses only timeline, consequences and personal control
Richards et al 2004	Psoriasis Patient & spouse- clinic sample UK	N=58 couples Patient mean age = 44 (+/- 12yrs) Partner Mean age = 47 (+/- 13 yrs) Mean time since diagnosis 18 yrs (+/- 11 yrs)	SAPASI (psoriasis severity index) HADS Penn worry questionnaire. IPQ-R (reworded for spouse)	x-sectional MANOVA- no difference in beliefs of patients & spouses (overall). Partners maximised external causes & minimized internal causes. Multiple Regression: Patients: Discrepancy not predictive of worry in patients. Spouses: Discrepancy about consequences and cyclical nature of timeline were significantly associated with worry in spouses ($p < 0.001$). Dissimilarity in emotional representations and timeline (acute/chronic) were independently associated with depression ($p < 0.01$)	Discrepancy calculated used Heijman's method - P-S = difference	(-) x- sectional (-) relationship factors not reported (+) controlled for medical variables (age/gender/ severity) (+) both patient and spousal outcomes (+) assesses all IPQ dimensions

Table 2.4 continued

Study and Date	Condition Sample	Participant details	Measures Focus of study	Key Findings & analysis technique used	Discrepancy measured by	Methodological issues
Riemsma et al., 2000	Rheumatoid arthritis Patient and spouse Clinic sample Netherlands	N=188 couples Patients 60% female Patient age 56 yrs (sd = 9.4) Spouse age 56.3 yrs (sd 9.5) Disease duration 11.3 yrs (sd 9.2)	M-HAQ AIMS2 Marital commitment	Cross-sectional Estimates of patient disability: 34% of couples differed by 1sd, 6% by more than 2sd Estimates of patient pain level: 38% differed by 1sd, 8% differed by 2sd Patients: Congruent perceptions were associated with better mental health. Over and under-estimates significantly related to poorer mental health (p<0.01) Spouses: Mental health significantly poorer when spouse over-estimated functional disability of patient – underestimation not related to mental health (p<0.01)	Discrepancy 2 methods a) Patient – spouse =difference 3 groups depending on difference in estimates of physical functioning and pain. Spouse over-estimate/ spouse underestimate – and equal scores	(-) equal scores needed to be classified as congruent, which does not allow for natural variation in scores. High rates of refusal and exclusions reported. (+) both patient and spouse mental health as outcomes.
Sterba et al, 2008	Rheumatoid arthritis patients and spouses USA Prospective panel study	N= 190 couples All patients = female Patient mean age = 49 (sd 12.9 yrs) Spouse mean age = 51 (sd 13.6 yrs) Time since diagnosis = 14 yrs (sd 14.9 yrs)	IPQ-R Psychological adjustment AIMS Physician ratings KMS QMI	4 months longitudinal study Patient and spousal perceptions significantly correlated (p<0.001) <u>Multiple regression</u> Patients were better adjusted when couples congruent in their beliefs about personal control (p<0.01), and timeline cyclical (p=0.05). Consequences and illness coherence congruence not significant. <u>ANOVA</u> Patients distress higher when couple discrepant on timeline cyclical, illness coherence, and consequences.	Congruence computed as difference score – then transformed into congruence score by deducting score from maximum score on IPQ. Median split to test whether level or direction of congruence important. 4 groups, ++, --, +/-, -/+	(+) controls for patient disability, time married, education and earlier adjustment in analysis (-) high levels of congruence. (+) looks at both discrepancy and congruence (-) volunteer sample (-) highly homogeneous sample (-) not examine distress in partners.

Study and date	Condition Sample	Participant details	Measures Focus of study	Key Findings & analysis technique used	Discrepancy measured by	Methodological issues
(Visser-Keizer, Mayboom-de Jong et al. 2002)	Stroke Patient & partner All 1 st time CVA Netherlands Cohort study	N=113 patients and partners. Mean age of patient = 67.1 (sd 12.7 yrs) 66% male Assessed 3 mo post stroke Mean time since stroke 115 days (sd 31 days) No info on spouses	Clinical interview HADS Neurological exam to look at memory, reasoning, language impairments.	Cross-sectional Agreement between patients and spouses on severity of symptoms poor to moderate (Kappa = 0.1 to 0.48). Mood & discrepancy: Significant correlations between changes noted by spouse and not by partners (discrepancy) & poorer partner mood (LH: rs=.37, p=0.03; RH: rs=.51, p<0.001). Significant correlation between patient mood & changes reported by patient & not by partner (LH: rs= .62, p<0.001 RH: rs=.36, p=0.04)	Discrepancy calc by P-S= difference. Discrepancy used in later correlational analyses	(-) x-sectional (-) correlational study (-) little information on partner. (-) no info to suggest controlled for other factors relating to distress. (+) assesses outcome for both patient and relative. (-) not based on SRM + 3 mo post stroke, patients & families just coming to terms with impact.

Key: AIMS2= Arthritis Impact Measurement scale 2; CES-D = Center for epidemiological studies: depression scale;HADS = Hospital Anxiety and Depression Scale IPQ= Illness perception questionnaire; IPQ-R= Illness perception questionnaire- Revised; KMS = Kansas marital scale; M-HAQ= Modified Health Assessment Questionnaire; MHI : Mental Health Index, MOS: Medical Outcomes survey; Mo = months; QMI= Quality of marriage questionnaire SIP= Sickness Impact profile; Vitality: MOS vitality scale; Yrs= years

2.11 Conclusion

These studies help establish the importance of illness perception discrepancy and congruence in patients and carers/spouses. However, the studies leave a considerable number of questions unanswered. The majority of studies have assessed the illness perceptions of both partners, but only examine patient outcomes, with few studies turning their attention to carers. Previous studies have also tended to examine discrepancy in only a few illness domains, which leaves questions unanswered. The few studies to examine discrepancy in stroke samples have focussed on physical, emotional and cognitive changes, (Knapp and Hewison 1999; Visser-Keizer et al. 2002), which taps some aspects of the SRM, but, again, leaves most areas unexplored.

The impact of discrepancy on outcomes is a research area which has been largely ignored in the context of stroke, but the evidence from other studies suggests that discrepancy and congruence are important to patient and carer adjustment. However, the literature examined at the beginning of this chapter is also important because it highlights what the discrepancy studies ignore, namely that the individual's own illness perceptions are important. Therefore, the current study intends to examine the association between discrepancy and patient and carer outcomes, whilst also examining the impact of the individual's own perceptions on their own outcomes.

2.12 Research Questions

This thesis is guided by Leventhal's Self-regulatory Model of Health and Illness (Leventhal et al. 1980; Leventhal 1984) and is concerned with understanding the nature of the illness perceptions constructed by first-ever stroke patients and their carers, and the impact of discrepant illness perceptions on the psychosocial adjustment of patients and carers. Research is becoming increasingly cognisant of the impact that other people's beliefs have on how patients come to understand and cope with chronic illness, but despite stroke being one of the most common chronic illnesses affecting older people surprising little is known about the illness perceptions of this group. The first aim of the research presented in this thesis is to increase knowledge, inform further research and contribute to the debate on the relation between illness perceptions and psychosocial adjustment to stroke. The research questions addressed by this thesis were driven by gaps in the literature identified in this chapter. In particular this thesis aims to examine the role of discrepant illness perceptions within the context of the individuals' own illness beliefs. The main research questions are:

1. To examine the nature of illness representations
 - a. Do patients and carers have a coherent model of stroke at baseline?
 - b. Do illness beliefs change over time?
 - c. What is the relation between illness beliefs and emotional distress?

2. To determine the extent of discrepant beliefs within the sample
 - a. To identify in which dimensions of the illness representation discrepancy is found.
 - b. To quantify the level of discrepancy within the sample.
 - c. To what extent is the maintenance of discrepancy associated with Time 1 socio-demographic variables?

3. To explore the relation between discrepant beliefs, distress, relationship satisfaction and social support.

4. How do discrepant beliefs affect the couple's adjustment following stroke and how do they affect how couples negotiate changes in their lives in response to illness?

This thesis is structured such as to explain the research process and present the findings of the thesis in a coherent manner. The quantitative study presented in chapters 3 to 7 is a longitudinal cohort study that assesses the illness perceptions of stroke patients and their carers. The IPQ-R was used to assess the illness perceptions of participants, and this was modified for the present study to make the measure more stroke-specific. Chapter 3 describes the modification process and how the reliability of the modified measure was tested. Chapter 3 goes on to describe the method and procedure for the main quantitative study in which the illness perceptions, relationship satisfaction, social support and emotional distress of 42 couples were assessed at 3, 6 and 9 months post stroke. Chapter 4 provides a rationale for the analysis techniques used in the study and chapters 5 and 6 present the main findings of the study. Chapter 5 presents the statistical analyses to answer research questions 1 and 2. Chapter 6 introduces the Actor-Partner Interdependence Model (APIM) which uses multi-level modelling to answer question 3. The results of this study are discussed in chapter 7 and are compared with those studies introduced and reviewed in chapter 2.

The dominant discourse about adjustment to stroke is situated in the quantitative literature, such as that presented in chapter one, in which adjustment is considered as an outcome variable. However, adjustment to stroke can also be considered in terms of an inter-

personal, psychosocial process. A few studies have examined the process of adjustment to chronic illness (Radley 1989) but none within the context of stroke, and none have considered the process of interpersonal communication that one can posit goes on between partners as they attempt to negotiate a shared understanding of how to live with and accommodate the impact of the stroke. The research presented in chapters 8 to 11 attempts to begin to fill this gap. Chapter 8 presents a brief introduction to the qualitative literature examining the experiences of patients and carers as they adjust to the impact of stroke. Chapter 9 presents details of the qualitative method. Sixteen couples were recruited to this qualitative study to explore the process of adjustment and the role of discrepant beliefs in this process. Couples were interviewed on two occasions, 7 – 8 months apart and semi-structured interviews were used to explore the adjustment process and the role that discrepant illness perceptions play in this and how these are negotiated by couples. Interpretative phenomenological analysis (IPA) was used to analyse the interview data. The method used for the study and the results of this analysis are presented in chapters 9 and 10. The results of this study are discussed in chapter 11. The final chapter to the thesis (chapter 12) discusses the findings of the two studies in relation to the research questions and the issue of discrepancy. Limitations to the studies and the clinical implications for the findings are discussed.

3 Study 1: A Quantitative Analysis of the Illness Representations of Stroke Patients and Carers

3.1 Introduction

This study investigates the relationship between the illness representations of stroke patients and their carers in a sample of patients (male and female) from Northern England. The aims of the study, which were outlined in the previous chapter, influenced the methods adopted and the choice of measures. The present chapter details the method used in the quantitative study and is divided into sections:

- Rationale for incorporating both quantitative and qualitative methods in the study
- Process of modification of the IPQ-R for stroke
- Procedure for testing the reliability of the modified measure
- Study design for the quantitative study
- Details of participants recruited to the study
- Selection of other measures used in the study
- Procedure for the study

A decision was taken to use the IPQ-R to assess the illness perceptions of patients and carers. However, at the time of the study no previous published study had used the measure with a stroke sample. Therefore the incorporation of the measure into the study was discussed with stroke survivors. Following these initial discussions, a decision was taken to modify the measure to make it more stroke-specific. The modification of the measure will be presented first, followed by the method for the main study. The statistical analyses used in this thesis will be discussed in chapter 4. Also, for clarity, the qualitative methodology will be discussed in chapter 9. The quantitative dimension of the project employs both cross-sectional and longitudinal methods, with identical measures used in both the cross-sectional and longitudinal studies. The results are presented in the order of the main aims of the study, which were presented at the end of the last chapter.

3.2 Rationale for a Mixed Methods Approach

As discussed earlier, the guiding theoretical framework for the thesis is Leventhal's Self-Regulatory Model of Health and Illness (SRM), a phenomenological model that focuses on the individual's "common sense" response to a health threat (Leventhal and Nerenz 1985). Although the model proposes that it is how the individual interprets threats to their health, and their own adaptive resources that guide behaviour, the SRM is also an inter-personal model, with cultural, social, personal and institutional factors all envisaged as influencing the individual's illness representations (Leventhal et al. 1998). It was this model and clinical observations that informed the basic research idea, which was to try to "understand how patients and carers understand (represent) stroke and how discrepant illness representations evolve and are resolved or maintained", and this guided the development of the research questions. Thus the research questions are grounded in theory and clinical experience, and this has driven the data collection methods and analytic strategies used in the study.

The research questions and the overall research design were complex, so different strategies were needed to answer the questions raised. The decision to use both quantitative and qualitative methods was a direct response to the demands of these questions. It was decided to follow a cohort of stroke patients and their carers using quantitative methods, from which patients and carers with discrepant illness representations could be selected for interview. The quantitative data investigates the level of discrepancy within couples, and tracks the levels of discrepancy over time, and also examines the relationship between discrepant illness representations and psychological distress in patients and carers.

Nested within the longitudinal quantitative study was a longitudinal qualitative study. In this, couples who were identified as having discrepant illness representations (identified quantitatively) were followed in order to explore their changing understandings of the stroke, and to investigate how couples negotiate a way of living with its impact. Thus the quantitative study acted as a filter to identify couples who fulfilled the interview criteria, as well as providing important data about how patients and carers conceptualised stroke. Thus the two methods were conceived as addressing complementary aims.

Much has been written about the differences between qualitative and quantitative approaches to research (Tashakkori and Teddlie 1998, 2003; Todd, Nerlich, McKeown and Clarke 2004). Many researchers conceptualise qualitative and quantitative research as competing paradigms and argue that it is inappropriate to combine the two approaches as they are underpinned by different philosophical assumptions, often referred to as the incompatibility

thesis (Kuhn 1970) or the “ontological divide” (Bryman 2007). However, in light of the questions posed by this thesis it was decided to take a *pragmatic* approach, which has been suggested as a framework with the potential to embrace both qualitative and quantitative approaches (Tashakkori and Teddlie 1998; Fishman 1999; Tashakkori and Teddlie 2003; Yardley and Bishop 2007). The pragmatic approach rejects the incompatibility thesis and avoids the use of metaphysical concepts such as truth and reality (Tashakkori and Teddlie 2003). For pragmatists, the aim of the inquiry is not to seek a truth that is independent from human experience, but to achieve a better, richer experience (Manxycy 2003; Yardley and Bishop 2007).

Therefore the methods chosen for the study have been selected because they fit the questions being asked. The quantitative questionnaire study allows couples to be compared, and enables the identification of couples who differ in their views about the stroke. Qualitative methods are then employed to explore how couples negotiate changes in their lives in response to the stroke. The use of semi-structured interviews in particular is much better suited to the study of negotiation within the family as this method permits problems and difficulties to be discussed in a non-confrontational way. The research questions form different components of a whole, with relevant methods employed to best suit the problem being addressed. Combining methods in this way allows different aspects of the research problem to be addressed in the most appropriate manner.

Whilst the project combines qualitative and quantitative approaches to answer a series of related research questions, the resulting data are analysed using the appropriate techniques, and the data will not be simply added together to create a “unitary truth”. The two methods are complementary, with each type of data seen as enhancing the other. The qualitative data analysis aims to elaborate upon the findings of the quantitative study; to answer questions that the quantitative analysis cannot, and thus provide complementary insights. It may also be the case that the quantitative and qualitative data are contradictory; that couples who appear discrepant in the quantitative study do not emerge as having problems coming to terms with the stroke in the qualitative study. Differences in the findings of the two studies will be discussed.

3.3 Modification of the IPQ-R for Stroke

The modification of the questionnaire was achieved by synthesising information from three sources. These were: a review of the stroke literature, data from two semi-structured focus group interviews with stroke survivors recruited from two local Stroke Clubs; and feedback from health professionals with experience working with stroke patients. The first stage of the

process involved a content analytic review of the largely qualitative literature to identify key illness perceptions and common myths and misconceptions about stroke as described by the general public and by stroke survivors and their families. The findings from the literature review were then mapped onto the existing IPQ-R domains to ensure the items were comprehensive, and potential new disease-specific items were created and added to the questionnaire blueprint (see appendix 2 for details of how the literature maps onto the original IPQ-R items and possible new items). Additional data was collected through two focus group interviews with stroke survivors recruited via the Stroke Association. The data collection from the focus group sessions is described below.

3.3.1 Focus Groups

During early 2005, two focus groups were formed, and met on three occasions. The goal was to collect material for the modification of the IPQ-R for stroke; and to test out the modified measure for its usability with this patient group. A main feature of focus groups is that participants present their own views, listen to those of others and reflect upon what is said to consider their own viewpoints. It is from the spontaneity arising from the social context that rich data can be derived (Ritchie and Lewis 2003). The focus groups allowed participants to discuss their diverse experiences and ensured that the items in the questionnaire had face validity for the intended respondents.

3.3.1.1 Participants

Participants came from two Stroke Clubs, one where members were aged over 65 and the other with members under 65. Five participants took part in each discussion group, which were moderated by the researcher. Participants were seven females and three males, aged between 44 and 85 years old. The mean time since their first stroke was 4.5 years.

3.3.1.2 Ethics

The research was carried out within the guidelines of the British Psychological Society's "Ethical principles for Conducting Research with Human participants" (British Psychological Society 1995). Ethical approval for the study was given by the Institute of Psychological Sciences, University of Leeds (see appendix 3). All members were invited to take part, and consent was recorded on a standard form. The information sheet and consent form informed participants of their right to withdraw from the study at any time. No participant withdrew consent retrospectively. The confidentiality of all data was ensured by keeping consent forms separate from the interview material and by using pseudonyms when transcribing the focus group material. These stroke survivors were involved throughout the early pilot work for which they were paid £15 to act as consultants.

3.3.1.3 Materials

The first meeting was driven by the IPQ-R and the literature review, and was designed to elicit beliefs about stroke. The questions focussed on encouraging participants to discuss their perceptions and experiences of stroke rather than using a question and answer format.

3.3.1.4 Procedure

The focus group sessions took place at their Stroke club so participants knew each other well which facilitated an informal atmosphere. The researcher described the purpose of the session, and emphasised that a diverse range of views were being sought in terms of their experiences of living with stroke. One focus group lasted 80 minutes and the other 65 minutes, and both were tape recorded and transcribed verbatim.

3.3.1.5 Analysis

An in-depth analysis of the focus group discussions was not conducted as the aim was to generate material for the modification of the IPQ-R. The group members were open in their discussions of their experiences of having a stroke and the impact they felt it had had on their family, and this was certainly enhanced by the fact that the participants knew each other well. Most participants were moderately disabled by their stroke, and were able to provide information about the symptoms that most affected their lives. A content analysis of the transcripts was used to identify important issues, which were then incorporated in the draft measure. The revised measure was then taken back to the group for discussion on two subsequent occasions. The original IPQ-R items and potential new items were discussed, adapted and refined by the group. This resulted in the rewording of some items and deletion of others which participants did not feel were relevant to stroke (see appendix 4). The self-regulation framework and the IPQ-R incorporate a degree of flexibility which allows the inclusion of additional items.

Questionnaire design is an iterative process, so the revisions made at each stage of the process were taken back to the focus group members and also discussed with the supervision team, and changes to the measure were made on the basis of these discussions. Feedback on the revised measure was also sought from health professionals. Copies of the draft measure were emailed to interested health professionals (doctors, nurses, occupational therapists and physiotherapists) experienced working with stroke survivors, and their feedback incorporated in the revision process. A final version of the modified measure was then taken forward to the reliability study, and this process is discussed in the next section.

3.3.2 Reliability Study

3.3.2.1 General Modifications

The IPQ-R uses the word *illness* and *symptoms* throughout. These terms are not necessarily appropriate for stroke where the patient experiences an acute incident after which they may be left with subsequent disabilities. Therefore, the word *illness* was replaced with the words *stroke* or *condition*.

3.3.2.2 Subscale Modifications

The following section provides a description of the modifications made to each IPQ-R subscale. Two scoring methods are used in the IPQ-R. The illness identity scale uses a yes/no scale, with participants asked whether they had experienced the symptom since their stroke, and whether they associated it with their stroke. The remaining subscales consist of a list of statements with respondents asked to indicate how much they agree with each statement. The final version of the measure uses a four-point³, *strongly agree (SA)* to *strongly disagree (SD)* (SD=1, D=2 A=3 SA=4) scale, and respondents were asked to rate each item as to how much they agree/disagree with this item with respect to their stroke. For each dimension (except identity) the score for each item was summated and a mean score calculated for the subscale, such that the scores range from 1 to 4. A slightly reworded version was used for the carers' perceptions of the patient's stroke, with the word "I" replaced with "they" (eg "they do not feel in control of their emotions").

Identity (24 items). The IPQ-R uses a generic list of 14 symptoms associated with common health problems, to which ten new items were added.

Causes (29 items). Bishop proposes that the use of open-ended questions enable patients to activate relevant illness beliefs (Bishop 1991). The original version of the IPQ-R

³ The original IPQ-R uses a five-point SA-SD scale, which includes a "neither" option. The preliminary testing of the questionnaire used this format. However, early analyses indicated a tendency for patients to over-use the neither option, so the questionnaire format was revised to incorporate a four-point response format for the Time 2 data (SA, A, D, SD). Although this simpler response format differs from that used in the original measure, Rust and Golombok (1999) suggest omitting the "don't know" option "*unless respondents are likely to become irritated by items they feel are unanswerable*" (p. 205). Discussions with the focus group members suggested that this was not a problem, so this option was removed.

addresses this by incorporating an open-ended question about causal attributions at the end of the questionnaire. However, a study by French et al. (2005) suggests that the use of open and closed-ended questions about participants' causal attributions elicits different responses. The study concluded that open questions require participants to recall possible causes, whereas the structured questionnaire requires participants to simply recognise potential causes. These authors acknowledge that their study sample constituted "well" individuals, rather than patients, and therefore the results may not be generalisable, but it was decided to move the open-ended question to the beginning of the measure, thereby tapping respondent's recall of potential causes, whilst ensuring respondents are not influenced by the causal items presented in the measure. In addition, fifteen stroke-specific causal items were added to the measure, reflecting known risk factors and common misconceptions.

Timeline (acute/chronic) (6 items). A high score on this scale indicated a chronic timeline. Minor modifications were made to each of the items.

Timeline Cyclical (4 items) A high score on this scale suggests that respondents perceive their stroke symptoms to change a great deal, and that there is a cyclical pattern to their recovery timeline.

Consequences (11 items). The six original items remain with minor amendments, and five additional items were added. The new items ask about specific consequences/ changes experienced by stroke survivors (*Since my stroke I fear becoming a burden on others*". *"My stroke has badly affected my relationship with my family"*, *"My stroke has strongly affected how I see myself"*, *"Emotional problems since my stroke are affecting my life"*, *"Memory problems since my stroke are affecting my life"*.) A high score on this subscale indicates a perception of severe consequences resulting from the stroke.

Personal Control (7 items) This subscale was subjected to minor modifications and two new items were generated to reflect common misconceptions about stroke (*"There is nothing I can do to prevent another stroke occurring"* and *"I need to avoid doing too much as this may cause another stroke"*) A high score on this scale denotes a perception of high levels of personal control over their recovery.

Treatment control (3 items). The original measure comprises five questions, but two items *"the negative effects of my illness can be prevented by my treatment"* and *"My treatment can control my illness"* were removed as early pilot work indicated patients often did not perceive themselves to have had any treatment, and thus did not understand the question. A high score indicates a belief that treatment will aid their recovery.

Illness coherence (5 items). The five original items of this scale were retained, and only minor modifications made to the wording. A low score on this subscale denotes a sense of not understanding their stroke.

Emotional response (10 items) All the original items were retained and three new items were added, two of which reflected the emotional impact of stroke on family members "*My stroke is very worrying for those closest to me*" and "*Those closest to me get very distressed about my stroke*". The final item reflected the impact that symptoms can have on self-identity "*I get embarrassed by the way I am since my stroke*". A high score on this subscale denotes a stronger negative emotional response to stroke.

3.3.3 Assessing the psychometric properties of the modified IPQ-R (Reliability Study)

3.3.3.1 Design

A cross-sectional and longitudinal correlational survey was used to assess the psychometric properties of the modified measure.

3.3.3.2 Participants

Participants were recruited using a postal questionnaire sent to the local organiser at twelve Stroke Clubs in West Yorkshire. Everybody who responded to the initial mailing was then sent a subsequent mailing eight weeks later and asked to complete the IPQ-R again in order to test the reliability of the modified measure over time.

3.3.3.3 Procedure

Time one questionnaires were distributed via Local Stroke Club organisers. Groups which agreed to take part were sent sufficient questionnaire packs for all their members, and they undertook to distribute them. Each questionnaire pack contained an information sheet and an invitation to participate in the study, two copies of the modified questionnaire and two demographic information sheets (one each for the patient and carer). The information sheet emphasised the voluntary and confidential nature of their responses, and reply-paid envelopes were included with each questionnaire to assist respondents with the return of completed questionnaires. Due to the method of distribution, non-respondents could not be followed-up directly, resulting in a lower than desired response rate. Using postal questionnaires also means that it cannot be ascertained whether patients and carers completed the measure individually, discussed their responses, nor indeed whether the questionnaires were completed by two individuals. Therefore, each "pair" (patient/carer) of responses were scrutinised by the researcher on receipt of the completed questionnaires and when responses were identical, both

questionnaires were excluded from the analysis, on the presumption that respondents were likely to have colluded. This resulted in the exclusion of 3 sets of data. Patients were asked to indicate the length of time it took them to complete the questionnaire, and the results indicate that 75% of respondents took less than 30 minutes to complete the measure.

As discussed earlier in page 52, the questionnaires distributed at time one used the original five-point Likert-type scale which utilised a “*neither/don't know*” option, but that stroke patients tended to over-use this “no opinion” choice. Therefore, it was decided that when the questionnaire was redistributed at time two, a revised four-point Likert-type format (SA, A, D, SD) would be used instead. Whilst this makes comparisons of the time one and time two data more difficult, it was decided that the problems encountered with the response format at time one needed to be addressed.

3.3.3.4 Analysis

Sixty-five stroke survivors completed and returned their questionnaires at time one (43% return rate), of which seven were largely incomplete and three were excluded from the analysis, leaving a sample of 55 patients. Forty-five carers responded (30% response rate). Only 39 patients and 24 carers responded to the second mailing. Item analysis of the data collected in this preliminary study was conducted to ensure that the new questionnaire items correlated with existing items in each of the subscales (Rust and Golombok, 1989). The number of questionnaires returned was insufficient for principal component analysis, so its factor structure cannot be adequately tested. As the questionnaire was amended between time one and time two, all analyses (with the exception of test-retest reliability analysis) were conducted on the time two data. In view of the low return rate, the data obtained from stroke survivors and carers were combined for the reliability analysis and test-retest analysis. In order to test the reliability of the modified measure over time, the time two data was recoded as follows SD=1, D=2, A=4, SA=5, so that the scoring at time two reflected as closely as possible that used at time one. It is likely that these revisions will reduce the test-retest reliability of scores, but the problems encountered with the format of the original measure made these amendments necessary.

3.3.3.5 Results of the Reliability Study

3.3.3.5.1 Patient characteristics

The mean age of respondents was 70.4 years (sd 10.0), range 52 to 88 years. Fifty-one percent of the sample (N=28) were male, 47% female (N= 26) and 2% (N=1) did not provide gender information. Fifteen percent had experienced stroke within the past year, and 36% had experienced stroke within last 1-5 years. The remaining 49% had experienced their first stroke over five years ago. Carers were younger than patients (Mean age: 61.55 years, SD=13.94: range 25-83), and 67.4% were females. At the 8-week follow-up, 38 patients and 23 carers responded to the second mailing.

3.3.3.5.2 IPQ-R Subscales: Descriptive statistics

Table 3.1 shows the mean item score (total score divided by number of items) and standard deviation for each subscale, based on the time two data. As discussed earlier, the response format was changed from time one to time two, and therefore the time two data is presented here.

3.3.3.5.3 Internal Consistency

Internal reliability (Cronbach's alpha) was calculated for all the subscales. As can be seen in Table 3.1 with the exception of timeline cyclical, subscales were found to be reliable ($\alpha=0.7$ to 0.9) (Streiner and Norman 1995). The Timeline cyclical subscale was lower than desired ($\alpha= 0.68$), but has only four items, which is likely to be partly responsible for the low alpha obtained.

Table 3-1: Mean Score and Cronbach Alpha for Modified IPQ-R

IPQ-R Subscale N=61	Number of items	Mean Score	SD	Alpha α
Identity	29	12.16	4.01	.72
Timeline cyclical	4	2.39	0.48	.68
Timeline acute/chronic	6	3.15	0.46	.84
Consequences	11	2.84	0.46	.84
Personal Control	7	2.67	0.47	.75
Treatment control	3	2.59	0.64	.75
Illness coherence	5	2.49	0.65	.86
Emotional representations	10	2.82	0.58	.91

*all scales (except identity) scored on a four-point scale.

3.3.3.5.4 Test-retest reliability

Testing the test-retest reliability of a scale requires participants to complete the same measure at two or more time-points. However, as discussed earlier, the time one data was scored on a five-point scale and the time two data were scored on a four-point scale, making direct comparisons difficult. In order to make some comparison over time, the time two data was recoded to reflect the scoring used at time one. Thus for this analysis only, strongly disagree = 1, disagree = 2, agree = 4 and strongly agree = 5. The test-retest reliability of the modified subscales was assessed over eight weeks. Bland and Altman (Bland and Altman 1986) argue that the correlation coefficient is an inappropriate method of looking at agreement as it measures the strength of the relationship, rather than agreement between scores. Therefore Altman-Bland plots were used to examine the differences in scores from time one (t1) and time two (t2). To do this, the difference in scores over time was plotted against the mean difference $(t1 + t2) / 2$ to determine the stability of the measure across time. This analysis also means that potential biased in scoring can be observed. However, the limited scale upon which the IPQ-R was scored made these plots difficult to interpret. Therefore, Pearson's correlation coefficients were utilized instead. The results of these analyses can be found in Table 3.2. These demonstrated that with the exception of the timeline cyclical subscale, the measure has good to very good reliability over the time-period.

Table 3-2: Pearson's Correlations to examine the test-retest reliability of the modified IPQ-R

IPQ Subscale	8 week test-retest correlations (p) (N= 61)
Identity (Symptoms)	.8 (<0.001)
Timeline cyclical	.6 (<0.001)
Timeline acute/chronic	.8 (<0.001)
Consequences	.74 (<0.001)
Personal Control	.67 (<0.001)
Treatment Control	.63 (<0.001)
Illness Coherence	.63 (<0.001)
Emotional representations	.82 (<0.001)

3.3.3.6 Discussion

The aim of the study was to modify the IPQ-R for stroke and to test the reliability of the modified measure. Feedback from participants indicated that the measure is acceptable to patients and carers. Insufficient responses were obtained for the results to be subjected to a principal component analysis in order to provide a robust test of the revised measure.

Nevertheless, the scale reliability data indicates that with the exception of the *timeline cyclical*

subscale, which has slightly lower than desirable reliability, the amended subscales have good internal reliability. The scales were also generally reliable over the 8 weeks test-retest period.

3.3.4 Assessing the Reliability of the Modified IPQ-R with recently diagnosed Patients and Carers.

To assess whether the modified scale provides a valid assessment of the components of the illness representation in recently diagnosed patients and their carers, the internal reliability of the IPQ-R subscales was tested using the data collected in the main study. This second analysis of the data revealed that the internal reliability of three subscales would be improved by the removal of items. The reliability data for each of the amended subscales can be found in Table 3.3 below.

Table 3-3: Illness Representation Subscales and their Internal Reliability

Illness Representation	Alpha coefficient	
	Patients	Carers
Illness identity	n/a	n/a
Timeline Acute/Chronic	0.68	0.72
Timeline Cyclical	0.78	0.8
Consequences	0.76	0.85
Treatment Control	0.8	0.62
Personal Control	0.59	0.79
Coherence	0.71	0.88
Emotional Response	0.8	0.92

N=42 couples

A list of all items included in the final analysis can be found in appendix 4. Items excluded are shown in parentheses. As can be seen by the results in table 3.3, most of the revised subscales show good internal reliability. However, three subscales are of concern. The Timeline acute/chronic subscale demonstrated lower than desired internal reliability for both the patient and carer data, and the Personal Control subscales demonstrate lower than desired reliability for patients, and the Treatment Control subscale was only moderately reliable for carers. However, removal of items did not improve the reliability of the scales.

3.3.4.1 Causal Attributions for Stroke

As discussed earlier, the causal component of the IPQ-R was measured using a list of 29 possible causal items, including generic and stroke-specific items. A factor analysis was conducted to determine whether factor scores could be derived which could be used in later analyses and allow comparisons to be made between patients and carers. In order to reduce the number of causal items to more interpretable dimensions, the method adopted by Weinman and colleagues (2000) was used, such that the ten causal items ranked most highly by patients were

subjected to an exploratory principal component analysis with varimax rotation. Three items (own behaviour, chance factors and aging) were omitted from the analysis, as they failed to load significantly onto any one factor (Field 2000). The remaining seven items were re-entered into the analysis, with Eigenvalues set at one or above, and 0.6 set as the point at which items could be considered as included in a factor. The analysis resulted in an interpretable two factor solution (see table 3.4), which explained 59.91% of the variance. The Kaiser-Meyer-Olim (KMO) measure of sampling adequacy was above the cut-off of 0.5 (KMO= 0.62), indicating that the sample size is adequate, but is lower than optimal (Kaiser 1974).

Table 3-4: Factor Structure of Causal Attributions for Stroke for Patients and Carers

Factor 1: Behavioural Risk Factors			Factor 2: Psychological Risk Factors		
	Patients	Carers		Patient s	Carers
High Cholesterol	0.76	0.85	Stress	0.66	0.88
Hypertension	0.88	0.88	Family worries	0.77	0.85
Lack of Exercise	0.7	0.65	Getting worked up emotionally	0.83	0.81
Diet	0.65	0.7			
Patients: 34.99% of variance explained Cronbach alpha = 0.75			Patients: 24.92% of variance explained Cronbach alpha = 0.64		
Carers: 38.79% of variance explained Cronbach alpha =0.78			Carers: 28.93% of variance explained Cronbach alpha = 0.79		

Bartlett's test of sphericity confirmed that factor analysis was appropriate for the data ($X_2=68.97$ (21) $p < 0.001$). The analysis was repeated using carer's data and the variables were found to load to the same factors. The KMO for carers was similarly low (KMO= 0.614), and the factors explained 67.72% of the variance explained.

3.4 Design for Quantitative Study

3.4.1 Participants

This is a prospective, cohort study of first-time stroke patients. The patients were assessed at baseline (3-16 weeks post stroke), and at 3 and 6 months post recruitment, using a repeated measures design. In order to maximise recruitment, patients were approached as soon as deemed well enough by their Consulting Physician, providing this was within 4 months of their first-ever stroke. Carers were approached once informed consent was obtained from the patient. In order to track changes in illness representations over time, all measures were completed by patients and carers at all time-points. In addition to the prospective analysis, the relation between the independent variables and dependent variables was assessed cross-

sectionally for each time-point. In order to examine the predictors of patient and carer distress, the independent variables for the study were socio-demographic factors, patient disability, illness representations, discrepancy in illness representations, social support and relationship satisfaction. In addition, as the study also intended to examine factors associated with the maintenance of discrepancy over time, for these analyses illness representations became the dependent variable.

3.4.2 Study Setting

Cumbria is located in the North West of England and is the country's second largest county. In terms of health coverage, the county is separated into two areas, North and South. North Cumbria, where the study is located, covers an area of 2000 square miles and has a population of 315,000 (Office for National Statistics 2001). It is sparsely populated, with a population density of 0.72, compared to 3.77 in England overall, and can therefore be defined as non-urban (Department of Health 2007). Cumbria has areas of affluence, but also some of the highest levels of deprivation in England (DOH, 2007) with areas of low income, high unemployment and poor health. Participants were drawn from both the most affluent and the most deprived areas of the County.

3.4.3 Ethics

Ethical approval for the project was granted by the North Cumbria Local Research Ethics Committee on 11 April 2005 (appendix 5) for access to patients admitted to the Stroke Unit of the Cumberland Infirmary, in Carlisle. However following a service reorganisation which resulted in some patients not being admitted to the Stroke Unit ethical approval was applied for, and granted, to extend the study to include patients seen via the Neurovascular clinic and those patients admitted to other wards. Approval for this extension to the study was granted on 21 December 2005 (appendix 6). A further extension to the study was granted in June 2006 to extend the project to West Cumberland Hospital, Workington.

3.4.4 Confidentiality and Data Protection

Participant confidentiality and data protection was ensured by assigning each participant an identification number and this was used on all questionnaires. All data containing personal information was kept in a locked cabinet within the university. Computer files were password protected and the key connecting the participants' names and identification numbers was kept in a password controlled file on the university computer system. Significant ethical and confidentiality issues exist when collecting data from couples. It was therefore necessary to ensure that individuals were assured that information divulged in the quantitative questionnaire study would not be disclosed to their partner. There are also ethical issues pertaining to interviewing couples together, and care was taken not to raise the issue of their quantitative

questionnaire responses during the qualitative interviews. There are also ethical issues surrounding the discussion of topics whereby information which has hitherto been kept secret is revealed. To address this issue, all couples were advised on the information sheet that the qualitative study involved joint interviews, and that they should consider how they feel about discussing the stroke with their partner present.

3.4.5 Potential for Distress

Although attempts were made to minimise distress, focussing on illness representations may be distressing for some. Therefore it was agreed that if a patient became distressed during data collection then it would be terminated and staff informed. However, on some occasions patients voiced a desire to continue with the process despite their distress. The wishes of the patient were acknowledged, data collection stopped, and the patient was given time to collect their thoughts. Data collection only continued if the patient consented to this. Patients and carers were informed on the information sheet that they may find the interview process distressing. The consent form was therefore designed such that couples had to opt into the qualitative interview study, rather than opt out. Fifteen couples declined to take part in this part of the study. During the interview couples were given the opportunity to not talk about topics which they found distressing, and some couples chose to do this.

3.4.6 Detection of Possible Mood Disorder

The possible consequence of screening participants' mood was identifying individuals with possible mood disorder. A protocol was therefore put in place such that if a mood disorder was suspected, participants were informed. If the participant was an in-patient their permission was sought to discuss this with their clinician. If the participant was a carer, the issue was discussed with them, information about possible sources of support provided (eg Stroke Association, Mind), and they were advised to contact their GP. If the participant was judged to be suicidal their clinician (either consultant or GP) would be informed immediately.

3.4.7 Inclusion Criteria

Patients were approached if they met the following inclusion criteria: a) the first-ever diagnosed stroke occurred within the past 8 weeks; b) the patient was well enough to be interviewed; c) the patient had sufficient language (assessed by speech and language therapist); d) the patient was assessed as cognitively able to take part (assessed by MMSE conducted by clinician); e) a named carer was willing to take part; f) patient would be discharged home; g) the patient lived within 50 miles of the hospital; h) written consent was obtained. Carers were approached once consent had been obtained from the patient.

3.4.7.1 Defining the “Carer”

The majority of stroke patients are over 65, some stroke survivors may not have a marriage partner, and others may have partners who have their own health problems and so may be unable to take part in the study. Therefore to ensure the highest levels of recruitment a broad, inclusive definition of “carer” was needed. A review of the literature found different research groups adopted very different definitions of carer. Some studies include only spouses (Hooker, Monahan, Shifren and Hutchinson 1992; Scholte op Reimer, de Haan, Rijnders, Limberg and van den Boss 1998; Clark 2000), others extended the definition to include other family members (Lobban, Barrowclough and Jones 2006), whilst a third group include non-family carers, such as friends and neighbours (Cantor 1983; Anderson 1992). The most inclusive definition, and the one that was most useful for the present study is that provided by Anderson who, in his study of the experiences of stroke patients and carers, asked patients to identify an individual who was “*the person who, in general, gives you most help and support*” (Anderson 1992 p 18). He uses the term “supporter” rather than “carer”, but by using these criteria it acknowledges that “a carer/supporter” is not necessarily an individual who provides practical help for the patient, but also that support can come in the form of emotional support. It also does not define a kinship relationship.

In the present study it was decided that it was important to exclude as few patients as possible, and so the definition of “supporter” formulated by Anderson (1992) adopted. Patients were asked to nominate an individual whom they felt fulfilled this definition. Carer/supporters were approached on the basis of whom the patient felt closest to, rather than on the basis of kinship. By taking this approach, it was hoped to minimise the number of patients excluded this basis. Although Anderson uses the term supporter, the term “carer” will be used in the present study.

3.4.8 Recruitment Data

Patient recruitment was from consecutive admissions to the wards of two hospitals (Carlisle and Workington), and from their respective out-patient clinics. Recruitment from the Stroke Unit at the Cumberland Infirmary (CIC) lasted for 19 months, recruitment from the Neurovascular Clinic (NVC) and other wards lasted 14 months, and recruitment from West Cumberland lasted for 9 months. Recruitment from all sources ended in March 2007. At the end of the 19 month recruitment period (Sept 2005 – March 2007) a total of 95 patients and carers had been invited to participate (see figure 3.1 for details). A total of 44 patients (46.32% of those invited; 25 Males, 19 Females), and 44 carers (13 Males and 31 Females) consented to take part.

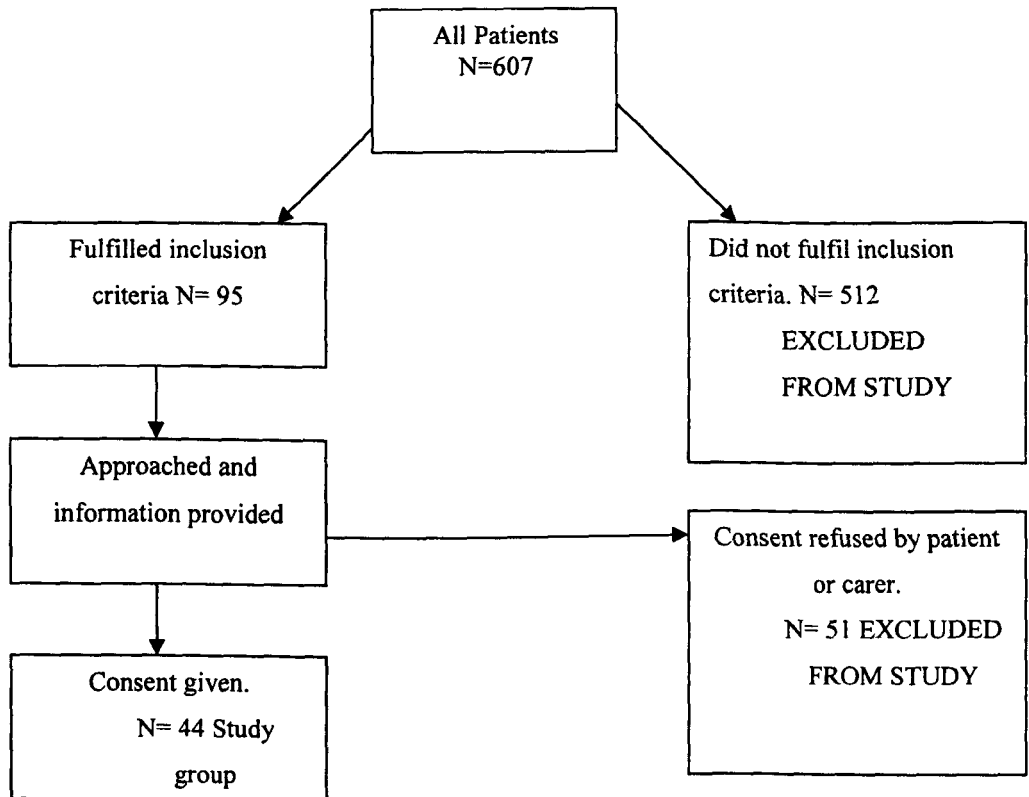


Figure 3-1: Flow diagram of Recruitment Process

Five hundred and twelve patients with stroke did not meet the criteria for inclusion. The main reasons for exclusion were; not first ever stroke ($n=157$), died ($n=73$), aphasic ($n=52$), too frail ($n=53$), impaired cognition ($n=45$), no carer identified ($n=41$), not able to confirm stroke ($n=40$). A further 31 patients who did meet the inclusion criteria refused to participate, as did 20 carers, giving a total of 51 refusals. Reason for refusing given by patients were feeling too old to take part ($n=4$), not interested ($n=18$), personal reasons ($n=2$), in denial of stroke ($n=1$), no response to letter of invitation ($n=6$). The main reason given by carers was that they felt it was too much for them or the patient to undertake ($n=14$). One patient died post recruitment, but before data was collected, and one patient experienced a second stroke before data was collected. Baseline data was therefore collected from forty-two patients (24 male, 18 female). Participants were aged 47 to 87 (mean = 65.12 years (sd 10.27), median 64 years). Only eight patients were recruited via the West Cumberland hospital and the remainder from the Cumberland Infirmary, reflecting the longer recruitment period and hospital size. The mean length of stay as an in-patient was 35.52 days (sd 47.95 days; range 0 days to 230).

The majority of carers were spouses of the patients ($n=34$), whilst seven were adult children, and one was a friend. Seventy-one percent of carers were female and the median age of carers was 60 years, although three carers did not provide this data. Before the stroke, 34

patients and carers were co-resident, a figure that did not change post-stroke. Of the 42 patients completing the baseline data collection, five patients withdrew from the study at time two, two had experienced a second stroke and so were dropped from the study, and three were ill and so did not complete their questionnaires, resulting in 32 sets of data being collected. At time three, three patients withdrew, and three patients who failed to return their data at time two due to illness returned the time three assessment, resulting in 32 sets of data. Therefore, 29 patients and carers completed questionnaires at all three time points in the study.

3.4.9 Selection of Measures used in the Study

3.4.9.1 Illness Representations Measure

The Illness Perception Questionnaire (Revised) (IPQ-R: Moss-Morris et al. 2002) was used to measure the components of the patient's and carer's illness representation. As discussed earlier, the measure had not been used within a stroke population, and so a revised version of the measure was designed for the study. This has already been discussed and will not be discussed here.

3.4.9.2 Measure of Psychological Distress

One of the aims of the quantitative study is to consider the relationship between patient's and carer's illness representations and their emotional distress. Given the range of measures available to screen for anxiety and depression, it was decided that the selected measure should fulfil specific criteria. A review of screening measures for anxiety and depression had recently been undertaken by Bennett and Lincoln (2004) and this was used to guide the selection process. Measures that assessed only depression or anxiety were excluded. The measure had to be acceptable to patients, both in terms of length and format, and have simple response categories which did not challenge their memory functioning. It had to be applicable to both hospital and community-based samples and for both patients and carers. It needed to be a self-report measure which could be completed by participants independently and returned through the post. It was also important that there was good evidence for its validity and reliability, not only for the general population, but for stroke patients. The application of these criteria resulted in three measures being considered for use in the study. These were the Hospital Anxiety and Depression Scale (Zigmond and Snaith 1983), the General Health Questionnaire 12/28/30 (Goldberg and Williams 1988) and the Wimbledon Self-Report Scale (Coughlan and Storey 1988).

3.4.9.2.1 Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith 1983)

The Hospital Anxiety and Depression Scale has been widely used with stroke patients. It is a short measure comprising seven items assessing depression and seven items assessing anxiety. However, it has been found not to be suitable for distinguishing between depressed and non-depressed participants in research settings because of its high mis-diagnosis rate, (Aben, Verhey, Lousberg, Lodder and Honig 2002) and so a decision was taken not to use this measure in the present study.

3.4.9.2.2 Wimbledon Self-Report Scale (Coughlan and Storey 1988)

The Wimbledon Self-Report Scale (Coughlan and Storey 1988) has 30 items, and is designed to measure general mood disturbance, both in the general population and in patient samples. A high score on this measure indicates unpleasant feelings, but the measure has been rarely used with stroke populations, and therefore was excluded on this basis.

3.4.9.2.3 General Health Questionnaire (GHQ) (Goldberg and Williams 1972)

The General Health Questionnaire is a self-administered screening test aimed at detecting psychiatric disorders in community settings and non-psychiatric settings, and assesses two aspects of a psychiatric episode: the inability to pursue normal functions of daily living, and the appearance of new symptoms which lead to a state of psychological distress (Richard, Lussier, Non and Lamarche 2004). Patients assess their state in the past weeks compared with their usual state, making it sensitive to transitory states, and able to detect deterioration in psychological functioning (Lincoln, Nicholl, Flannaghan, Leonard and Van der Grucht 2003).

Three versions of the measure were considered for the study; the GHQ-12, 28 and 30 (Goldberg and Williams 1988). The format for each of these measures is the same, comprising a question asking whether the participant has recently experienced a particular symptom, and uses a four-point response format, ranging from “less than usual” to “much more than usual”. It can be treated as a Likert-type scale or can use a bi-modal response format, often termed the *GHQ method*, where items are scored 0-0-1-1, such that 0 is given for “not at all” and “same as usual” responses and 1 is assigned when the patient responds with “rather more than usual” or “much more than usual”.

The GHQ-12 was excluded from consideration because at the time of the study there was little evidence in terms of the reliability and validity of the measure with stroke patients (Bennett and Lincoln 2004). A decision was taken to use the GHQ-28 for the study (see

appendix 7). The main advantage of the GHQ-28 over the GHQ-30 is that because it was derived from factor analysis it has four subscales, each measuring a dimension of psychological distress: somatic symptoms, anxiety and insomnia, social dysfunction and severe depressive symptoms (Goldberg & Hiller, 1979) providing potential for the analysis of these dimensions. However, Bennett & Lincoln (2004) note that the subscales represent dimensions of ‘symptomology’ and are not independent of one another, nor do they necessarily correspond to psychiatric diagnosis. Studies have found the GHQ-28 to be a reliable and valid measure in stroke samples (sensitivity 0.81 and specificity 0.68) (Lincoln et al., 2003), and Bennett and Lincoln (2004) concluded that the GHQ-28 is a useful measure of distress, able to detect mood problems later after stroke. In the present study the GHQ method of scoring was adopted, giving a total GHQ score of 0 – 28.

3.4.10 Recovery-Related Measures

3.4.10.1 Relationship Functioning Scale

A measure of relationship functioning was needed in order to determine whether differences in illness representations expressed by patients and their carers were due in part to poorer relationship functioning. The study intended to look at both spousal and non-spousal carers, so the measure needed to be able to assess relationship functioning across a range of relationship types. Furthermore, given the package of measures used in the study it also needed to be short, so as not to over-burden patients, and needed to be able to be completed and returned by post.

3.4.10.2 Medical Outcomes Study: Relationship Functioning Subscale

The relationship functioning subscale of the Medical Outcomes Study (MOS) (Sherbourne and Kamberg 1992) is a short (six item) measure of relationship satisfaction, which asks respondents to rate how true or false each statement was about their relationship over the previous four weeks (see appendix 8 for copy). The measure focuses on how much the respondent feels they can communicate with their partner (eg “*We said anything we wanted to say to each other*” and how much support they feel their partner was able to offer them (eg “*My spouse or partner was very supportive of me*”). The MOS had recently been used successfully in a study of illness representations of myocardial infarction patients and spouses (Figueiras and Weinman 2003). The subscale uses a five-point response format from 1 (definitely true), 3 (don’t know), 5 (definitely false). The measure requires the recoding of three items, after which a higher score reflects better relationship functioning. After reverse scoring of the items, a

mean score is then calculated for the subscale. For this sample, the internal reliability for the scale was computed as $\alpha = 0.69$ for patients and $\alpha = 0.71$ for carers.

3.4.11 Social Support Measure

The short version of the Significant Others Scale (SOS: B) (Powers, Champion and Aris 1988) was selected for use in the present study (see appendix 9 for copy). It measures practical and emotional support, as well as actual and ideal support, and is flexible enough to use with non-spousal relationships. It is designed to examine the quality of the individual's most significant relationships (Powers et al. 1988), whilst allowing respondents to nominate supporters. The version used in the present study is the shortened SOS which assesses two emotional support functions (*sharing feelings* and *relying on people in times of difficulty*) and two practical support functions (*obtaining practical help* and *spending time with them socially*) in a maximum of three individuals. This abridged version has been used with stroke carers (McClenahan and Weinman 1998), and also fulfils the criteria of not over-burdening participants.

The measure uses a seven-point rating scale, from *never* (1) to *always* (7). Respondents rate each supporter on the level of support they perceive to be available from this person, and also score the person on what their ideal level of support should be available from such a relationship (Powers et al. 1988). Separate scores are obtained for emotional and practical support. The scores are summated and divided by the number of supporters named by respondents, to give a mean score on that subscale. Mean support ratings are available for a number of different groups, and data suggest that there is no difference in the ratings of actual support (Powers et al. 1988), but that depressed participants have higher ratings for their ideal levels of emotional and practical support than do non-depressed individuals. There is however no normative data on large samples (Johnston, Wright and Weinman 1995). The SOS can be used to assess the gap between perceived support need and perceived available support. In the present study, however, few patients completed this part of the assessment. Following informal discussions with patients it became clear that they found it difficult to conceptualise the difference between desired support and available support. Therefore the discrepancy data for this measure was not analysed due to high levels of missing data. For this sample, the internal reliability of the emotional support subscale was calculated as $\alpha = 0.63$ for both patients and relatives. The internal reliability for the practical support subscale was calculated as $\alpha = 0.63$ for patients and $\alpha = 0.78$ for carers.

3.4.12 Activities of Daily Living (ADL)

Since there is some evidence that dependence in activities of daily living is associated with patient depression in the early post stroke period (Thomas and Lincoln 2006), a measure of patient disability was needed. In the present study it was decided that an assessment of the patient's physical functioning should be made by the researcher at the beginning and end of the study. However, physical disability and ADL is not the main focus of the present study, so a brief measure was required that would provide an indication of the level of patient functioning, without requiring the involvement of health professionals in the assessment process.

3.4.12.1 Barthel Index (BI) (Mahoney and Barthel 1965)

The Barthel Index (Mahoney and Barthel 1965) was chosen as a measure of the functional ability of the stroke survivor (see appendix 10). It was originally developed to monitor functional independence before and after treatment and to determine the level of nursing care needed (McDowell and Newell 1987), and has been widely used in studies of stroke patients and in clinical practice (Dromerick, Edwards and Diringier 2003). It measures the level of independence in ten basic physical functions including dressing, walking, and bowel and bladder control. The original paper does not stipulate how the data for the assessment should be collected, but in clinical practice the information is usually collected during a patient interview (Sinoff and Ore 1997), and Wade (1992) recommends that information collected should pertain to the past 24 hours and be obtained from the best source (patient or carer). Knapp and Hewison (1999) found patients and carers differed in their assessments of the patient's functioning and so for consistency, data was collected from the patient. Granger, Albrecht et al, (1979) report a test-retest reliability of 0.89 with severely disabled adults, and McDowell and Newell (1987) report the scale to have good predictive validity. The original scoring system uses a 0-100 scale, but the modified 0-20 scale will be used in the present study. The Barthel Index is restricted in its scope, and does not cover speech and mental functions. It also suffers from both floor and ceiling effects, and cannot detect small deficits. Nevertheless, it is a widely used measure and therefore allows comparisons to be made across studies, and provides a brief and basic assessment of patient functioning.

3.5 Layout and readability of measures

As already discussed, the measures used in this study were carefully selected to ensure that they contributed to answering the research questions posed and allowed comparisons against other studies. It was also important that the measures used were acceptable to, and understandable by participants. User involvement in the early stages of the study meant that

that the measures and their instructions were assessed for readability, font size and layout. This resulted in the layout and font size of all measures being adapted to enable individuals to read the questions easily and meant that most participants could complete them independently, although some participant still opted to have assistance in completing the measures.

3.6 Procedure

The participants in the study completed assessments at baseline (3-16 weeks post stroke) and at three and six months post-recruitment. All patients admitted with a first ever confirmed stroke were considered for the study if they fulfilled the inclusion criteria (see page 61). The original protocol stated that patients would be approached one to four weeks post stroke, with the first assessment taking place two to four weeks post stroke. However, this resulted in the exclusion of large numbers of patients who were not well enough to be seen within this time. The protocol was therefore revised so that patients excluded initially on the basis of stroke severity or aphasia were reassessed at four, eight and 12 weeks post-stroke. The recruitment process was also much slower than envisaged, and most patients were recruited into the study two to three weeks after being first approached. The researcher attended the wards each week throughout the recruitment period (unless on leave or the ward was closed due to viral outbreaks). The researcher was therefore able to answer questions from both staff and patients. Notices were also placed on the wards to tell patients and staff when the researcher would be available to answer questions.

3.6.1 Accessing Patients

Eligibility was confirmed by the Consulting Physician, and patients were only approached with the Consultant's agreement. The time-point at which patients were initially approached was dependent on stroke severity and presence of aphasia. Waiting for approval to approach patients built in delays in terms of data collection, but ensured patients were aware of the study, and well enough to take part, prior to being approached by the researcher. Eligibility was then confirmed by discussion with patient.

3.6.2 Informed Consent

The Information Sheet (appendix 11) reassured patients that their responses would be confidential, that participation was voluntary and non-participation would in no way affect their care. Participants were given a week to read the information sheet before deciding whether or not to take part. Contact details were provided on the information sheet, and patients were informed that questions could be asked of the researcher either in person or by phone.

3.7 Recruiting Participants

All eligible patients were given the information sheet, and the nature of the study explained orally. Patients were encouraged to discuss participation with their family, and written patient consent (see appendix 12) was sought on the second visit. Patients who were discharged before they were seen, or before consent obtained, were approached by letter one to two weeks post-discharge. Included with the letter was a duplicate information sheet and consent form. A freepost envelope was provided for the return of signed consent forms. Patients who did not respond within three weeks were then followed up with a telephone call. Patients recruited via the Neurovascular clinic were not approached in the clinic, but were approached by letter (see appendix 13) two weeks after their stroke had been confirmed to them. Consent was obtained from patients to approach their appointed carer. Contact was made either on the ward or by letter as appropriate. A pack containing an invitation to take part, an information sheet, consent form and freepost envelope was given or sent to the carer (see appendix 14 and 15). Carers who did not respond within three weeks were followed up by telephone to ascertain whether or not they were interested in taking part in the study. Recruitment of carers proved particularly difficult and consent was generally given four to six weeks after the first approach was made.

3.7.1 Completing the Measures

It was important that the questionnaire package did not over-burden patients and carers. Feedback on the time taken to complete the modified IPQ-R had already been sought from participants who took part in the reliability study, and the first ten patients recruited to the main study were also asked to provide feedback on completing the measures to ascertain whether participants had any difficulties completing them. The reason for this second check was that participants in the reliability study were 1-19 years post-stroke, so were unable to provide accurate information with respect to the difficulties that acutely ill patients may have with the measures. Feedback indicated that older and more disabled participants found the measures tiring, and so participants were invited to complete the measures in two sessions if needed. Baseline data was collected once consent had been obtained from both the patient and carer. Patients were given the option of completing the questionnaires themselves (at home if discharged or in hospital) or with the researcher's assistance. The two main reasons for choosing to have assistance completing the questionnaires were that the patient needed assistance completing the questionnaires due to physical or visual disabilities. The patient was still quite poorly, and the burden of completing the questionnaire package in one session was too much. In these instances the questionnaires were given in the form of an interview and split

over two sessions, such that during the first session the IPQ-R and the BI were completed and the remaining measures completed during the second session (SOS, MOS, GHQ-28).

3.7.2 Stages of Data Collection

Once consent was obtained baseline demographic information was obtained from the patient and carer. Data was collected from patients and carers at time one (3-16 weeks post stroke), time two (3 months later) and time three (six months post recruitment). The measures included at each time point are presented in table 3.5. If the questionnaires were sent via the post, a freepost envelope was provided for their return. A covering letter was enclosed with the measures which reminded participants that there are no right or wrong answers to the questions asked, and asked participants to complete the questionnaires independently, and not to discuss their responses with their partner until after they had completed and returned the questionnaires.

Table 3-5: Measures used and times of assessment

Measures	Time 1	Time 2	Time 3
Demographic information	PC		
Barthel Index (BI)	P		P
Illness representations (IPQ-R)	PC	PC	PC
Relationship functioning (MOS)	PC	PC	PC
Social Support (SOS)	PC	PC	PC
Psychological distress (GHQ-28)	PC	PC	PC

P= patient C= Carer

3.8 Statistical Screening and Analysis

Statistical analysis was carried out using SPSS version 15 for windows. Descriptive statistics for all measures for all time-points were produced to assess normality and to detect outliers prior to conducting the analyses. All data was tested for normality and skewness using the Shapiro-Wilk W test for normality (Shapiro and Wilk 1965), as recommended by Altman (Altman 1991).

Most but not all of the IPQ-R dimensions fulfilled the assumptions of normality, as did the MOS. The SOS displayed a significant negative skewness, and the GHQ-28 which is the dependent variable in the present study was significantly and positively skewed, (Patients: $W = 0.92$, $p < 0.005$; Carers: $W = 0.93$, $p = 0.02$). Where appropriate, data transformations were attempted, but these failed to normalise the distributions, and so data analyses have been conducted on the non-transformed data. Therefore for analyses comparing the GHQ-28 scores of patients and carers non-parametric tests will be used. A decision was taken to use parametric

tests for all independent variables as the significance values obtained for the normality tests were generally small, since there is good evidence that parametric tests are robust to the violation of parametric assumptions (Havlicek and Peterson 1977). To look at the relationship between patient and carers views in more detail a series of Pearson's product-moment correlations and bi-point serial correlational analyses were conducted. A decision was taken to use Pearson's as there is good evidence that inferential tests of correlation coefficients are robust against the violations of the assumptions of normality (Havlicek and Peterson 1977; Fowler 1987). In light of the small sample size and the skewness of some data, the test results for the inferential statistics must be interpreted with caution. However, following statistical advice, the Bonferroni correction was not used as this is very conservative when used with small samples, resulting in the increased likelihood of Type II errors, and instead a significance level of $p < 0.01$ was adopted.

3.8.1.1 Data Screening

A missing value analysis was conducted on the measures to identify variables with more than 5% missing values as recommended by Tabachnick and Fidell (1989). The Significant Other Scale (SOS) was found to have significant amounts of missing data. Participants are asked to identify three individuals who are able to offer them emotional and practical support. Three patients and carers (7.1%) provided details of only one support person, and 19% ($n=8$) of patients and carers could name only two supporters. Therefore a new variable was created which indicated the number of sources of support an individual reported. However, this failed to be significantly associated with the outcome in any analysis and so is not reported further.

3.8.1.2 Sample Size and Power Calculation

Due to the exploratory nature of the study, no power calculation was conducted before data collection commenced. Based on past research (Figueiras and Weinman 2003; Morrison 2003; Morrison et al. 2005) it was predicted that a sample of approximately 70 couples would be needed for the study. Based on the available data, it was estimated that 500 patients would be available via the Cumberland Infirmary over a 12 month recruitment period, of which one-third would be eligible. However, due to the reorganisation of stroke services in North Cumbria this figure could not be achieved. The study was extended (discussed earlier) resulting in a total of 607 patients available to the study, of which only 15.6% ($n=95$) were eligible for inclusion in the study, from which $n=44$ patients were recruited. This left the study potentially underpowered.

4 Methodology: Defining, Measuring and Analysing Discrepancy

4.1 Introduction

The focus of this thesis is to examine the nature of discrepant illness perceptions and the impact these have on the psychological well-being of patients and their carers. From the literature reviewed in the chapter 2 it became clear that despite a decade of research, little agreement exists in how discrepancy is defined, operationalised, and analysed. Therefore, the purpose of this chapter is to review these aspects of the literature to:

- a) Consider how different research groups have defined discrepant and congruent perceptions within couples.
- b) Examine the ways in which discrepancy and congruence have been operationalised in the literature, and critically evaluate these methods.
- c) Critically examine the analysis techniques used by the different research groups.

On the basis of the evidence collected by this review, a number of methodological decisions will be made with respect to the present thesis. These include: how “discrepancy” will be defined for this study; selecting a method of operationalising discrepancy, and choosing appropriate analysis techniques to apply to the data.

4.2 The Review Process

Literature examining the illness perceptions of patients and carers was examined as part of the literature review discussed in chapter 2. This chapter focuses on the methodologies employed by previous research groups in order to answer the above questions. Studies were included if they were empirical studies focussing on the discrepancy between how patients and carers perceive a current health threat and the impact these differences have on psychological well-being in one or both partners. Therefore, studies which simply identify the existence of discrepant views without relating these to health outcomes (for example patient proxy scores) are excluded, as were studies which do not examine discrepancy directly but instead look at the separate contributions made by the patient’s and carer’s beliefs in predicting the patient’s outcome (Weinman et al. 2000; Searle et al. 2007).

The present study uses the IPQ-R to assess illness perceptions, but as the focus is on identifying how discrepancy is operationalised and analysed, studies that assess the difference in patient and carer illness perceptions (Heijmans et al. 1999; Figueiras and Weinman 2003;

Benyamini, Gozlan and Kokia 2004; Richards et al. 2004; Lobban et al. 2006; Benyamini, Medalion and Garfinkel 2007; Kuipers et al. 2007; Olsen, Berg and Wiebe 2007; Sterba et al. 2008), their views of the patient's physical functioning (Knapp and Hewison 1999), the patient's emotional adjustment (Klinedinst, Clark, Blanton and Wolf 2007), perceptions of the patient's pain (Riemsma et al. 2000; Riley-Doucet 2005) and how the couples rate the patient's health (Franks, Hong, Pierce and Ketterer 2002) have been included. Five studies were identified which examined the impact of discrepancy on both partners (Knapp and Hewison 1999; Riemsma et al. 2000; Benyamini et al. 2004; Richards et al. 2004; Benyamini et al. 2007; Olsen et al. 2007), other studies look at the impact of discrepancy on the patient only (Heijmans et al. 1999; Franks et al. 2002; Sterba et al. 2008).

4.2.1 Defining Discrepancy

In an effort to understand what researchers *mean* when they talk about discrepancy, a search was made for the terms used by the different research groups. This revealed that discrepancy was not defined explicitly, but rather studies have previously discussed it only in terms of how it was operationalised. A related set of literature was also identified, which is pertinent here, namely studies that assess the impact that having similar illness perceptions has on outcomes. The terminology used by different studies was largely dependent on the focus of the study, but it was not uncommon for studies to examine both the difficulties associated with discrepancy and the impact of having similar views (eg Benyamini et al. 2007).

Discrepancy: defined as “*a failure (eg sets of information) to correspond or to be the same*” (Chambers 2008). This was the most commonly used term found in the literature and will be used in the present study (Knapp and Hewison 1999; Lobban et al. 2006; Benyamini et al. 2007; Kuipers et al. 2007). Other related terms include “*divergent beliefs*” (Richards et al. 2004), “*divergence*” (Riemsma et al., 2000), and “*dissimilarity*” (Olsen et al. 2007), “*incongruence*” (Benyamini et al. 2004), and “*disagreement*” (Knapp and Hewison 1999).

Congruence: The literature review also identified studies which focus on the impact that similar beliefs have on patient and carer outcomes. The most commonly used term was “*congruence*” (Benyamini et al. 2004; Riley-Doucet 2005; Benyamini et al. 2007; Klinedinst et al. 2007), meaning *suitability or appropriateness; agreement*” (Chambers 2008). This will be the term used in this study to indicate similarity of views. Other terms included “*similarity*” (Figueiras and Weinman 2003), and “*shared perceptions*” (Franks et al. 2002).

4.2.2 Operationalising Discrepancy

Discrepancy has been operationalised in the literature in two main ways; the discrete groups approach and the difference score approach, and each of these will be described in brief, and their advantages and disadvantages discussed.

4.3 Discrete Groups Approaches

Five studies were found to use this approach, and two different methods were used to classify couples into groups. The first approach uses a median split technique (Figueiras and Weinman 2003; Benyamini et al. 2007; Sterba et al. 2008). The median score for each group (patients and carers) on each illness perception subscale is calculated, and individuals classified as above or below the median on that subscale. This gives rise to four possible groupings; couples with shared positive perceptions (both above the median for their group), couples who have shared negative perceptions, (both below the median for their group) and two groups where the patient and carer are classified differently, indicating that they have discrepant perceptions. In this instance the patient is positive and the carer negative, or vice versa. In a study using this approach, Figueiras and Weinman (2003) found relatively few couples were classified as discrepant and so these were collapsed into one “conflicting perceptions” group, whereas Benyamini et al. (2007) and Sterba et al. (2008) had relatively large samples and were able to retain four groupings, thus were able to compare the impact of the carer being more positive or more negative than the patient.

Two studies (Knapp and Hewison 1999; Riemsma et al. 2000) classified couples into groups on the basis of whether the patient scored higher or lower than their carer on the independent variable. In a study of the perceptions of stroke patients’ physical functioning, Knapp and Hewison (1999) used this approach to create two groups, one where the patient’s assessment of their functional ability was higher than their carer’s, and the other group comprised those couples who were congruent in their perceptions and those where the difference was in the opposite direction. This split means that the impact of similar beliefs cannot be assessed, but the focus here was on patients who rated their functional ability higher than their carer. In contrast, Riemsma et al. (2000) created three groups; carers scoring higher than the patient (maximising), carers scoring lower (minimising) and couples who scored exactly the same on the predictor variable (congruent). The measure used in this study employed a 3 point scale, and so absolute agreement is useful here. However, as a general rule, whilst this method has the advantage of having a congruent group, this criterion is probably too stringent for most purposes as it does not allow for any natural variation in scoring.

4.3.1 Critique of the Discrete Groups Approach

This approach has the advantage of being able to consider the effect of having similar or discrepant views. It is also a simple and straight forward method of categorising couples, especially when the predictor variables are categorical, but larger samples are required, especially when looking for interactions (Aiken and West 1991). This method also results in a significant loss of statistical power when the predictor variables represent continuous variables. The two methods of creating discrete groups achieve a very different balance in terms of the number of couples classified as congruent and discrepant, with few couples identified as discrepant using the first method, and few classified as congruent using the latter. The choice of how to split the data is determined by the focus of the study, but will have a significant impact on the results of any analysis.

4.4 Difference Score Approaches

The second approach is to create a *difference score* which indicates the degree of discrepancy between the patient and carer. One method of achieving this is to subtract the carer's score from the patient's score to create a continuous variable that describes the difference between the carer and patient, using the patient score as an "anchor", thus creating a *mean difference* score. This approach was pioneered by Heijmans and colleagues (1999), and has been widely adopted (Benyamini et al. 2004; Richards et al. 2004; Lobban et al. 2006; Benyamini et al. 2007; Kuipers et al. 2007; Olsen et al. 2007). From this perspective, the carer can be viewed as maximizing (ie scoring higher than the patient) or minimizing (scoring lower than the patient) on any given measure. The second method is to calculate an *absolute difference* score which is calculated as above, but ignores the direction of difference between the partners' scores (Lobban et al. 2006; Kuipers et al. 2007; Sterba et al. 2008).

4.4.1 Critique of the Difference Score Approaches

The mean difference score was the most common method of operationalising discrepancy found in the literature reviewed. One advantage of this approach is that it uses the whole range of scores, and allows hypotheses to be tested with regard to the direction of the difference. The mean difference score has been used in two ways: firstly to form discrete groups, and secondly as a continuous variable in correlation and multiple regression analyses (Heijmans et al. 1999; Richards et al. 2004). When the multiple regression method is adopted, one significant disadvantage emerges. Conceptually, when estimating the effect of the patient's and carer's illness representations on the dependent variable, this is a linear additive model (Field 2000). That is to say, the predicted score on the dependent variable is a linear

combination of each of the predictor variables. When discrepancy is calculated by subtracting the carer's score from the patient's score (mean difference score) this is a transformation of the additive model (W Cook, personal communication, February 2008). The mean difference score is linearly dependent on the patient's and carer's scores on that illness perception domain, which increases multicollinearity⁴ in the regression model if all three predictor variables (patient's score, carer's score and discrepancy score) are included in the model. It is the directionality of the difference score that is problematic. When the absolute difference score is used, this link is broken as they are not linearly related to the patient and carer score, reducing multicollinearity. However, the absolute difference score approach results in a loss of information in terms of the direction of discrepancy, and it may be important to consider the impact of the direction of the difference.

One general criticism of the difference score approach is that it contrasts couples where carers are more positive than the patient against couples where carers are more negative compared to the patient, and ignores what may happen if the patient and carer have similar positive or similar negative views. Indeed, there is evidence that when the patient and carer have similar negative perceptions this has a detrimental impact on the well-being of the patient (Figueiras and Weinman 2003). However, the creation of three or four discrete groups would require a larger sample size than is available in the present study, and so the absolute difference score approach will be used in the present study as it utilises the range of scores but without increasing multicollinearity.

4.5 Analysing the Data

The main techniques that have been applied to data generated from discrepancy studies are correlations, analysis of variance (including ANOVA, paired t-tests and non-parametric tests), and linear regression. It is not the purpose of this section to describe how these analysis techniques are conducted, but the way in which they have been applied to discrepancy data will be discussed, and the advantages and disadvantages considered.

⁴ Multicollinearity: a strong correlation between two or more predictors in a model. As collinearity increases so do the standard errors of the β coefficients. High collinearity increases the chances of type II error as it increases the risk that good predictors are found non-significant (Field, 2000).

4.5.1 Correlations

Correlational analyses (Pearson's product moment correlations and Spearman's ranked correlations) were commonly used to examine the association between discrepancy and outcomes. These correlations are discussed and other correlations which would be useful in illuminating this association are also discussed. Some, but not all studies reviewed the correlation between discrepancy scores and the dependent variable. Those studies reporting this correlation found significant associations between discrepancy scores and patient outcomes on some, but not all illness perception domains (eg Heijmans et al. 1999, Kuipers et al. 2007, Olsen et al., 2007; Sterba et al. 2008). Whilst no causal inferences can be made from these analyses, these correlations are a good way of building a picture of the relationship between discrepancy and outcomes.

Three studies reported the correlation between the illness perceptions of the patient and their carer (Franks et al. 2002; Benyamini et al. 2007; Sterba et al. 2008). This correlation is important if the data is to be used in multiple regression analyses, as the predictor variables included in models should not correlate strongly (Field 2000), since this increases the risk of type II errors. In these studies, the strength of the correlation between the illness perceptions of patients and their partners differed depending on the illness perception domain, and the study. In their study, Sterba and colleagues found strong positive and significant correlations in all the domains examined (all $p < 0.001$). In contrast, Benyamini found only a weak relationship between partner's perceptions of personal control ($r = 0.05$, NS), but a strong relationship between partner's perceptions of the illness identity ($r = 0.52$, $p < 0.001$). Therefore it is likely that the illness perceptions of patients and carers in the present study will be inter-correlated, and so the correlations between patient's and carer's predictor variables are reported in the present study.

No study was found which examined the correlation between the patient's and their carer's outcome variables. This is an important correlation. If the scores of the two partners do correlate significantly, it indicates interdependence in their scores, and statistical tests such as ANOVA and regression assume independent observations in the dependent variable (Altman 1991). If patient's and carer's dependent variables are strongly correlated, this assumption may be violated, in which case there is a *non-independence of observations*, which is problematic in terms of inferential testing. A method of analysing data which allows for inter-correlations between the patients and carers independent and dependent variables will be discussed in chapter 6. Correlations measure the strength of a relationship and not agreement (Bland and

Altman 1986). Indeed correlations can be perfect, but this does not mean the scores are equal, or that the couple are congruent in the level of their beliefs, just that the difference between them is systematic and linear and therefore correlations should be used in conjunction with inferential statistics.

4.5.2 ANOVA

Both cross-sectional and longitudinal studies have used ANOVA to examine the impact of discrepancy on outcomes. These studies use the discrete groups approach (described earlier) to examine whether couples with different or similar beliefs differ significantly in their scores on the dependent variable. Whilst there is inconsistency in the way in which couples are categorised as congruent or discrepant, there is evidence that discrepancy is associated with poorer patient outcomes (Riemsma et al. 2000; Figueiras and Weinman 2003; Sterba et al. 2008), and poorer carer outcomes (Knapp and Hewison 1999), and that similar positive beliefs appear to be beneficial whilst similar negative perceptions appear detrimental (Figueiras and Weinman 2003; Benyamini et al. 2007; Sterba et al. 2008).

4.5.2.1 Critique of ANOVA Method for Dyadic Data

Whilst ANOVA is a straightforward approach, it is also associated with substantial costs (Aiken & West 1991) when used in discrepancy analyses. Reducing continuous variables, such as IPQ-R scores, into categorical variables loses valuable information, and may result in the loss of statistical power because the full range of scores is not used (Cohen and Cohen 1983). This makes it more difficult to detect significant effects when they are present, which is a problem when, as in the present study, samples are small. Also, when interaction terms are used, larger sample sizes are needed compared to the sample size required for multiple regression models (Aiken and West 1991). ANOVA also assumes independent observations on the dependent variable (Altman 1991) and data from couples may violate this assumption, resulting in lower reliabilities in terms of the significance of the test statistic (Kenny and Judd 1986). However, ANOVA is a useful tool for examining whether perceptions change over time, and whether there are group level differences between patients and carers and so ANOVA will be used in that context in the present study.

Other studies have used paired t-tests and their non-parametric equivalents to test whether discrepancy impacts on the dependent variable. These studies have found significant differences between the beliefs of patients and carers (Benyamini et al. 2007). However, t-tests are problematic when multiple analyses are required, such as when analysing the IPQ-R which utilises multiple subscales as this increases the risk of type I errors. The usual solution to this is

to use a correction technique such as Bonferroni, but this increases the risk of type II errors (Bland and Altman 1986). Therefore, in the present study, when paired t-tests are used a significance level of $p < 0.01$ will be adopted to reduce the risk of type I errors, without significantly increasing the risk of type II errors.

4.5.3 Multiple Regression

Multiple regression was the most commonly used analysis technique applied to discrepancy data, but despite this, little methodological commonality can be found. As can be seen by Table 4-1 at the end of this chapter, discrepancy was generally operationalised as a *difference score*, with most studies using the *mean* rather than the *absolute* difference score, and one study using a product term. When both the patient's and carer's outcomes were assessed, this was achieved by running two separate regression models. These studies differ in terms of the number of variables included as predictors in each regression model, with some studies running a separate regression model for each illness perception domain, and others including all illness perceptions in one model. Some studies have controlled for background variables (Heijmans et al. 1999) whilst others did not (Benyamini et al. 2007). Finally, studies varied in terms of the regression method used (hierarchical, forced entry). The methods used will be discussed in brief, and the advantages and disadvantages of each method examined.

4.6 Testing the Impact of Discrepancy: Creating the Model

As can be seen by table 4.1, two studies of these studies (Heijmans et al. 1999; Richards et al. 2004) tested the impact of discrepancy on outcomes, but did not control for either the individual's own illness perceptions or those of their partner in the model. This approach is problematic as it risks inflating the effect of discrepancy on outcomes, where discrepancy may only be significant because the confounding effects of the actor and partner have not been removed. Specifically, Kenny and Cook argue that when a discrepancy score is calculated "*the components that make up the discrepancy should also be included in the analysis. Thus when an actor-partner interaction is estimated, the actor and partner effects should also be estimated*" (Kenny and Cook, 1999 pg. 438).

A second group of studies tested the impact of discrepancy alongside (or after) examining the impact of the participant's own illness perceptions on their outcomes. For example, Sterba and colleagues (2008) examined the impact of discrepancy as the main predictor of the patient's emotional distress, and so entered discrepancy scores at step one, and the patient's own illness perception score was entered at step two. This approach offers a more stringent test of the impact of discrepancy, and does not significantly increase the risk of

multicollinearity. However, whilst testing for discrepancy, it does not address the issue of the effects of the partner's perceptions on the actor's distress. The final method, and the one recommended by Kenny and Cook (1999) involves regressing the actor's outcome score onto the actor's and partner's predictor scores, and then assessing the impact of discrepancy, using either an absolute difference or patient x carer interaction score as the metric for discrepancy. This method was adopted by one study (Benyamini et al. 2007), and is the most stringent test of the impact of discrepancy as it controls for both actor and partner effects.

Studies differed in terms of the number of illness perception dimensions included in the final regression model(s). Some studies (Benyamini et al. 2007; Olsen et al. 2007; Sterba et al. 2008) conducted a series of regression analyses, one for each illness perception dimension examined, and usually, but not always, controlled for other background variables. This method has the advantage of testing the independent contribution made by each illness perception to the variance explained by the model, but has the disadvantage of not assessing the shared variance between predictors. The only studies that included all significant predictors in one regression model were those that included only discrepancy scores as predictors (Heijmans et al. 1999; Richards et al. 2004). The rationale for running one model including all predictors, or conducting separate analyses for each illness representation is not explicitly discussed by any of the studies authors. One possible reason for the differences between studies may have been the differences in the sample sizes of the different studies, as Tabachnick and Fidell (1989) recommend a 15:1 ratio of participants to predictors in multiple regression models, which preclude the inclusion of large numbers of predictors in the models. However, this is not reported explicitly by any study.

4.6.1 Multicollinearity

One method of limiting the extent of multicollinearity is to centre the variables at their means by standardising them (Cohen and Cohen 1983), a method adopted by Benyamini and colleagues (2007). In doing so, the correlation that exists between the illness representations of patients and carers is significantly reduced, allowing models to be tested which examine the impact of discrepancy whilst controlling for the patient's and carer's own beliefs.

4.6.2 Critique of Multiple Regression Models

The studies discussed above all test the impact of discrepancy on outcomes, but the way in which the analysis is approached varies significantly. Despite a decade of research, no consensus was found in the literature in terms of how the multiple regression models were constructed and how discrepancy was tested. The discrepancy-only approach pioneered by Heijmans and colleagues (1999) constituted the first examination of the impact that differences

in patient and carer beliefs have on patient outcomes, and proved to be a springboard for later studies. However, these studies are limited because of their focus on discrepancy only. The ANOVA approach has the flexibility of examining the impact of both similar and different views has on health outcomes, but larger sample sizes are required than are available in the present study. The multiple regression approach which tests the impact of actor, partner and discrepancy seems to bridge the gap between the ANOVA and discrepancy-only approach by looking not only at discrepancy but the impact of each partner having positive or negative views about the stroke.

4.7 Conclusions

The aim of this chapter was to identify terms to be used to describe the difference and similarity between patients and their carers; to choose a method of operationalising discrepancy for the present study, and to identify a method of analysing data produced by this study. Therefore in the present study the term “Discrepancy” will be used to describe the differences between patient’s and carer’s illness representations. “Congruence” will be used to describe the similarities between patient’s and carer’s illness representations. Discrepancy will be operationalised as the absolute difference between the illness representations of patients and carers, due to the difficulties associated with linear coupling between the patient, carer and mean difference scores. Correlations will be used to describe the inter-relationship between the variables in the study. They will be used to examine the inter-relationships between the individual’s own illness representations; between their illness representations and their own dependent variable, and between their discrepancy scores and their own dependent variable. ANOVA is rejected as a method of assessing the impact of discrepancy on outcomes in the present study because a) the small sample size available in the present study results in a significant loss of statistical power, b) patients and carers scores on the dependent variables in the present study correlate significantly, thus the assumptions of ANOVA are violated. However, mixed ANOVA will be used to assess group level changes in the perceptions of patients and relatives over time. The multiple regression approach which tests the impact of actor, partner and discrepancy effects seemed to offer the best approach to conceptualising discrepancy and was initially chosen to analyse the data in the present study. This approach was chosen because it meant discrepancy could be examined within the context of what each partner thought about the stroke. However, the significant correlations between the patient’s and carer’s predictor and outcome variables proved problematic, and, as will be discussed in chapter 6, a new approach was sought to analyse the data generated in the present study.

Table 4-1: Studies using Multiple Regression to Analyse Discrepancy

Study details	Illness	Actor beliefs	Partner beliefs	Discrepancy calculated as	Background variables included?	Both partners outcomes measured?	Separate model/ one model	Findings
Benyamini (2007)	Heart disease	Yes	Yes	patient x carer product term & Mean difference term	No	Yes	Separate models	Discrepant perceptions of the Timeline and Attributions to lifestyle associated with perceived support. Discrepant perceptions of controllability associated with reported undermining by the spouse
Sterba et al., (2008)	Rheumatoid Arthritis	Yes	No	Absolute difference	Yes	No	Separate models	Congruent beliefs about timeline and consequences – associated with better patient adjustment
Olsen et al., (2007)	Diabetes	Yes	No	Mean difference	No	Yes	Separate models	Discrepancy did not predict the patient (adolescent's) negative adjustment When mother perceived greater coherence than her child, she reported greater negative adjustment
Heijmans et al., (1999)	Chronic Fatigue syndrome Addison's disease	No	No	Mean difference	Yes	No	One model	AD: Spouse maximisation associated with better patient adjustment. CFS: Spouse maximisation associated with greater emotion focussed coping by patient. A more positive timeline by spouse was associated with better functioning in patient.
Richards et al., (2004)	Psoriasis	No	No	Yes	Yes	No	One model	Discrepancy was not a good predictor of patient worry. Discrepant beliefs about the consequences and cyclical nature of psoriasis was significantly associated with greater worry in partners.

5 Quantitative Results

5.1 Introduction

The first section provides descriptive statistics of the study sample, and the predictor and outcome measures. The second section presents the aims of the thesis and the statistical analyses which test the research questions of the study.

5.2 Descriptive Statistics

5.2.1 Sample Demographic and Clinical Information

At time one, 42 patients and carers completed the first assessment, of whom 23.8 % (n=10) of patients were still in hospital. At time two, three months post recruitment, 32 patients and carers completed the second assessment. At this time 7% (n=3) of patients were still in hospital, and the remainder completed their assessments by post, and at time 3, 6 months post recruitment, 32 patients and carers completed their final assessment. Twenty- nine patients and carers completed all three assessments.

5.2.2 Attrition

To test whether there was any difference between those who completed and those who dropped out, a series of independent t-tests was conducted on the data. There were no significant differences between the two groups in terms of the age, gender, disability level (Barthel Index), relationship satisfaction (MOS), social support (SOS), or level of psychological distress (GHQ-28). Therefore, the time one cross-sectional analyses are conducted on all 42 patients and their carers. Longitudinal analyses are conducted on the 29 complete data sets.

5.2.3 Severity of Stroke

Disability was assessed using the Barthel Index (0 to 20 scale), with a higher score indicating lower levels of residual disability in activities of daily living. For this sample, the baseline mean BI score for male patients was 17.29 (sd 3.65), range 7 to 20, and for female patients the mean BI was 15.83 (sd 3.42), range 6 to 20, indicating that female patients were marginally more impaired than male patients. Overall the sample is skewed to the more able end of the scale. Disability levels declined over time, but female patients were still more disabled (Time 3: Mean Male score: 19.38 (sd 1.02); Mean Female score: 17.85 (sd 3.73)).

5.2.4 Emotional Distress

The dependent variable in the study is the GHQ-28, a measure of emotional distress. This was administered at each assessment point. The mean and standard deviation scores for the 29 couples returning all three sets of data are presented in Table 5-1 below. Carers were more distressed than patients at all three assessment points, but strong positive correlations were found between patient and carer scores indicating that their scores co-vary. The scores of spousal and non-spousal carers were compared and no significant differences were found in their distress levels at any time-point so the groups were collapsed into one overall "carer" group. Patient and carer scores were found to be significantly and positively skewed (Patients: $W = 0.92, p=0.005$; Carers = $0.93, p=0.02$). Therefore the Wilcoxon matched pairs test was used to examine whether patients and carers scores differed significantly at each assessment point. The results indicate that the emotional distress levels of partners do not differ significantly.

Table 5-1: Mean GHQ-28 Scores for patients and carers

GHQ Subscale (n=29)	Time 1 Mean (sd)	Time 2 Mean (sd)	Time 3 Mean (sd)
Patient GHQ 28 total	6.76 (6.41)	8.1 (5.38)	7.03 (6.49)
Carer GHQ-28 total	7.97 (6.25)	9.48 (6.0)	8.13 (6.07)
Correlation between patient and carer	.66 ($p<0.001$)	.68 ($p<0.001$)	.64 ($p<0.001$)

5.2.5 Changes in predictor variables over time

5.2.5.1 Relationship Satisfaction (MOS)

The scale ranges from 1 to 5, with a higher score indicating better relationship functioning. As can be seen by table 5.2 below, relationship satisfaction declined over time for both patients and carers. An analysis of variance showed that the effect of time was significant ($F(2, 112) = 13.98, p<0.001$). Within-subjects contrasts revealed that whilst the drop in relationship satisfaction between time one and time two was non-significant, the drop from time two to time three was significant ($F(1,56) = 20.18, p<0.001$). However, no time x role interaction was found indicating that patients' and carers' relationship satisfaction scores did not differ significantly ($F(1, 56) = 1.07, p= 0.3$).

Table 5-2: Mean (sd) Relationship Satisfaction (MOS) and Social Support scores for patients and carers

(n=29)	Time 1 Mean (sd)	Time 2 Mean (sd)	Time 3 Mean (sd)
MOS: Patient	4.13 (0.69)	4.05 (0.77)	3.39 (1.01)
MOS: Carer	3.96 (0.6)	3.99 (0.54)	3.53 (0.82)
SOS: (ES): Patient	12.19 (1.74)	12.37 (1.53)	12.29 (1.76)
SOS: (ES): Carer	12.11(1.82)	12.54 (1.41)	12.09 (1.44)
SOS: (PS) Patient	12.03 (1.61)	11.92 (1.46)	12.3 (1.7)
SOS (PS) Carer	11.44 (1.83)	11.36 (1.86)	11.17 (1.95)

MOS= Relationship Satisfaction; SOS (ES) = Emotional Support SOS (PS) = Practical Support

5.2.5.2 Significant Other Scale (SOS)

Social support is scored on a 1-14 scale and scores remained high at all three assessment points (see table 5.2) however, there is no normative data on large samples with which to compare the data. Patients reported higher levels of practical support than carers, which increased over time, whilst carers reported a slight drop in support over the same period. An analysis of variance showed that the effect of time was not significant for ratings of emotional support ($F(2, 112) = 1.14, p = .32$, equal variances not assumed), or for practical support ($F(1, 56) = 1.04, p = .35$, equal variances not assumed). No significant interaction was found between role and time for either analysis.

5.2.6 Time One Illness Perceptions (IPQ-R subscales) of Patients and Carers

The mean and standard deviations (sd) of the patients' and carers' baseline illness perceptions for all 42 pairs of patients and carers are presented in table 5.3. Carers perceived the stroke more negatively at baseline than did patients. They reported that the patient had significantly more symptoms associated with the stroke (stronger illness identity), and thought that the stroke was more distressing for the patient than the patient themselves perceived it to be. They also reported a more cyclical timeline and more severe consequences (non-significant at $p < 0.01$). Comparisons between patients' and carers' illness perceptions were not statistically significant for treatment control and personal control, with both patients and carers reporting positive perceptions. Patients and carers also held similar views about the role of behavioural factors in causing the stroke, with neither group making strong attributions towards the role of behavioural risk factors as causal. Carers were more pessimistic about the time it would take for the patient to recover (timeline acute/chronic); they were less confident about how much the patient understood their stroke (coherence), and held stronger attributions towards a psychological cause than did patients, but these differences were not statistically significant.

Patients' and carers' scores on eight of the illness representation domains are positively and significantly correlated (illness identity, timeline acute/chronic, timeline cyclical, coherence, emotional response and both of the causal attribution subscales (behavioural and psychological). However, patients' and carers' views about the personal control and treatment control dimensions were not significantly correlated, and their views about the timeline (cyclical) was only modestly correlated ($r = .3$, $p < 0.05$), suggesting that patients and carers views on these issues are largely unrelated at this time-point. However, even if the correlation between two variables is large, indicating that they covary systematically, the difference between the two scores may still be significant. Therefore, paired t-tests were used to determine whether the mean difference between the scores differs significantly.

Table 5-3: Descriptive Statistics for patients and carers Illness Representations at Time One

Illness Representation	Patient Mean (SD) n=42	Carer Mean (SD) n=42	Correlation* (p-value)	t* (p-value)
Illness Identity	7.69 (3.89)	9.5 (5.24)	.74 (p<0.001)	3.32 (p=0.002)
Timeline Acute/Chronic	2.38 (0.49)	2.45 (0.61)	.47 (p<0.002)	0.8, (p=0.43)
Timeline Cyclical	2.11 (0.48)	2.33 (0.53)	.3 (p<0.05)	2.38 (p=0.02)
Consequences	2.46 (0.43)	2.61 (0.53)	.56 (p<0.001)	1.97 (p=0.05)
Treatment Control	3.06 (0.58)	3.00 (0.6)	.05 (p=0.77)	0.8 (p=0.43)
Coherence	2.66 (0.55)	2.59 (0.67)	.4 (p<0.01)	0.51 (p=0.62)
Personal Control	2.94 (0.38)	2.86 (0.43)	-.09 (p=0.54)	0.62 (p=0.54)
Emotional Response	2.48 (0.48)	2.76 (0.63)	.56 (p<0.001)	3.47 (p<0.001)
Behavioural Cause	2.37 (0.69)	2.36 (0.65)	.69 (p<0.001)	0.16, (p=0.87)
Psychological Cause	2.36 (0.65)	2.47 (0.83)	.59 (p<0.001)	1.39 (p=0.17)

*Significance values shown in brackets

Comparisons of the results of the correlational analyses and the t-test results suggests that whilst patients' and carers' illness representations co-vary, as indicated by positive significant correlations between patients and carers, they also differ significantly in some dimensions (eg illness identity, consequences, timeline) in terms of the strength of those perceptions. Therefore, some illness representations are both related (correlated) and systematically different in terms of the strength at which they are held. Conversely, the views

patients and carers hold about personal and treatment control were neither significantly correlated, nor significantly different. In these dimensions, patients and carers hold views which are neither related nor systematically different in strength.

5.2.7 Gender Differences in IPQ Variables

To test whether there were any gender differences in patient perceptions, a series of independent group t-tests were conducted on the IPQ-R subscales. The only significant gender differences in IPQ-R scores were found in the consequences and emotional representation subscales. Female patients were significantly more likely to report serious consequences resulting from their stroke (Mean Male score: 2.56, sd: 0.55; Mean Female score: 2.67, sd: 0.5), ($t=-2.02$, df, 40, $p<0.05$). Female patients were also more likely to report more negative emotional representations than male patients (Mean Male score 2.28, (sd 0.42); Mean Female score 2.73, (sd 0.45) ($t=-3.34$, df 40, $p=0.002$).

5.2.8 Correlations between Socio-Demographic, Family Factors and Emotional Distress (GHQ-28)

Pearson's Product-Moment Correlations were used to test the association between the continuous predictor variables (age, patient disability level, practical support, emotional support and relationship satisfaction) and emotional distress. Bi-point serial correlation was used to examine the association between emotional distress and gender. Given the small sample size, the correlation coefficients must be considered cautiously (Bland 2000) and the significance level is set at $p<0.01$. As can be seen in Table 5.4 below, strong positive correlations were found between the reported emotional distress levels of the patients and carers and patient disability (BI). Both patients and carers were more distressed when the patient was more disabled. Female gender was weakly associated with higher distress in patients, but gender was unrelated to carer distress. Social support and relationship satisfaction was largely unrelated to emotional distress levels, with only one modestly significant correlation found, which was between carer's distress and emotional support at time one.

Table 5-4: How personal and social factors correlate with GHQ-28 scores for patients and carers

GHQ Scores for Patient and Carer						
	Time 1 N=42		Time 2 N=29		Time 3 N=29	
	Patient r	Carer r	Patient r	Carer r	Patient r	Carer r
Personal Factors						
Age	-0.05 (0.73)	-0.06 (0.69)	-0.002 (0.93)	-0.11 (0.53)	-0.11 (0.56)	-0.3 (0.09)
Gender	0.27 (0.09)	0.02 (0.88)	0.32 (0.07)	0.05 (0.79)	0.48 (0.006)	0.07 (0.69)
Patient Disability (BI)	-0.33 (0.03)	-0.53 (< 0.001)	-0.63 (<0.001)	-0.6 (<0 .001)	-0.53 (0.002)	-0.35 (0.05)
Family Factors						
SOS Practical Support	-0.02 (0.89)	-0.15 (0.34)	-0.02 (0.92)	-0.25 (0.18)	0.19 (0.29)	-0.28 (0.12)
SOS Emotional Support	-0.13 (0.41)	-0.35 (0.03)	-0.3 (0.10)	0.14 (0.44)	0.13 (0.49)	-0.19 (0.2)
Relationship satisfaction (MOS)	0.08 (0.6)	-0.23 (0.13)	-0.25 (0.16)	-0.25 (0.17)	0.002 (0.99)	0.21 (0.24)

Significance values shown in brackets.

5.2.9 Summary of Key Findings from the Descriptive Statistics

- Patients and carers associated the stroke with high levels of symptoms and moderately negative consequences. They believed recovery would take time, and that the stroke was moderately distressing.
- Both patients and carers believed the patient had good control over their recovery, that their treatment would be reasonably effective, and that they understood the stroke. However, large variance scores suggest that some pairs have very positive views, whilst other pairs are negative, which reflects the range of disability levels in the sample.
- Female patients were more disabled than males, but overall patients' disability levels were skewed towards the higher functioning end of the scale.
- Carers were slightly more distressed than patients at all time-points, but these differences were not significant.
- Relationship satisfaction declined for both patients and carers over time, but was not associated with concurrent distress levels.
- Mean average social support scores remained high at all time-points. Lower emotional support at baseline was associated with higher distress in carers, but this did not reach

significance. Social support was not related to distress levels in patients. No other associations were found.

- At baseline, carers conceived the stroke to be more negative than patients did. However, with the exception of control perceptions, patient's and carer's illness representations were strongly correlated, indicating that their views are both related and systematically different in strength.
- Patient and carer views about the controllability of the stroke (personal and treatment control) were uncorrelated, but paired t-tests also revealed that they were not systematically different in strength, suggesting that the perceptions of patients or carers are not influenced by the views of their partner.

5.3 SECTION 2: TESTING THE RESEARCH QUESTIONS

The results are presented in the order of the main aims of the study, which are:

Aim 1: To examine the nature of illness representations

- a. Do patients and carers have a coherent model of stroke at Time One?
- b. Do illness perceptions change over time?
- c. Do patients' and carers perceptions converge or diverge over time?
- d. What is the relationship between illness perceptions and emotional distress?

Aim 2: To determine the extent of discrepant perceptions within the sample

- a. To identify in which dimensions of the illness representation discrepancy is found.
- b. To quantify the level of discrepancy within the sample.
- c. To what extent is the maintenance of discrepancy associated with Time One socio-demographic variables?

Aim 3: To explore relations between discrepant perceptions, distress, relationship satisfaction and social support. This question will be answered in chapter 6.

5.4 Aim 1: To Examine the Nature of Illness Representations

5.4.1 Question 1a: Do Patients and Carers have a Coherent Model of Stroke at Time One?

Pearson's Product-moment correlation coefficients were computed to investigate the inter-relationships between IPQ-R dimensions and examine whether patients and carers have a coherent model of stroke. The significance values reported in the next section are those

obtained in the analysis, and only correlations where $p < 0.01$ are viewed as significant, and correlations where $p > 0.01$ should be interpreted with caution.

5.4.1.1 Correlations between Patients Illness Representations

Table 5-5 presents patients' time one illness representations. The results reveal a picture of patients struggling to understand their stroke. There is evidence of a developing model that is coherent⁵ in terms of the negative connotations surrounding stroke. Positive correlations were found between illness identity, consequences, and emotional response, indicating that patients who reported more symptoms perceived there to be more negative consequences and were more distressed by their stroke. Negative consequences were also associated with a longer timeline and lower personal control and a poorer understanding (coherence). However, with this exception, control perceptions were largely unrelated to other illness domains, suggesting that even when patients believe they have control over their recovery, this is unrelated to other attributions they have regarding the stroke. The implications of this will be considered in the discussion chapter. Causal attributions for a behavioural cause were unrelated to any other illness representation component, suggesting that these attributions do not play an important role in understanding the stroke at this point. In contrast, patients who had a stronger belief in the role of psychological factors as causal in their stroke had more negative timeline perceptions, perceived there to be more negative consequences, felt they had a poorer understanding of their stroke, and had a more negative emotional response to the stroke.

5.4.1.2 Correlations between Carer's Illness Representations

Table 5-5 shows that at time one, as with the patient data, carer's perceptions about the impact of the patient's stroke were coherent in terms of their negative connotations. Carers who report that the patient had a lot of symptoms associated with the stroke were also likely to report that the patient's recovery would take longer, that the consequences were more severe, and that the patient was more distressed by their stroke. The treatment control and personal control subscales were strongly associated with each other, but only one significant correlation was found between control perceptions and any of the more negative illness representations, with higher personal control negatively correlated with a longer timeline. Carer's perceptions about the patient's control over their recovery were otherwise unrelated to their other perceptions about the stroke.

⁵ Coherent = consistent, harmonious, holds together or logically connected Chambers 21st Century Dictionary (Standard) (2008). Chambers Harrap Publishers.

Table 5.5: Correlations of patients and carers illness representations of stroke at baseline (n=42) couples

Carers \ Patients	1 Id	2 TLA	3 TLC	4 Cons	5 TC	6 PC	7 Coh	8 ER	9 Beh	10 Psyc
1. Illness identity (Id)	.74 (<i><.001</i>)	.33 (.04)	.44 (.004)	.62 (<i><.001</i>)	.2 (.19)	.14 (.37)	-.23 (.15)	.55 (<i><.001</i>)	.03 (.85)	.23 (.15)
2. Timeline acute/chronic (TLA)	.24 (.13)	.47 (.002)	.52 (<i><.001</i>)	.74 (<i><.001</i>)	-.25 (.11)	-.33 (.03)	-.38 (.01)	.76 (<i><.001</i>)	.07 (.66)	-.02 (.9)
3. Timeline cyclical (TLC)	.28 (.07)	.39 (.01)	.3 (.05)	.5 (<i><.01</i>)	.03 (.87)	-.17 (.27)	-.32 (.04)	.62 (<i><.001</i>)	.02 (.91)	.17 (.3)
4. Consequences (Cons)	.62 (<i><.001</i>)	.4 (0.009)	.49 (<i><.001</i>)	.56 (<i><.001</i>)	-.13 (.4)	-.21 (.17)	-.4 (.009)	.85 (<i><.001</i>)	.001 (.99)	.15 (.35)
5. Treatment control (TC)	.08 (.62)	.04 (.83)	.34 (.03)	-.06 (.73)	.05 (.77)	.66 (<i><.001</i>)	.34 (.03)	-.03 (.85)	-.16 (.31)	.16 (.3)
6. Personal control (PC)	.03 (.83)	-.01 (.5)	-.05 (0.7)	-.032 (.04)	.44 (.003)	-.09 (.54)	.5 (<i><.001</i>)	-.19 (.23)	-.05 (.74)	-.05 (.76)
7. Coherence (Coh)	-.1 (.51)	-.02 (.2)	-.26 (0.1)	-.45 (.003)	.15 (.31)	.28 (.07)	.4 (.01)	-.45 (.003)	-.003 (.98)	-.2 (.2)
8. Emotional rep (ER)	.52 (<i><.001</i>)	.29 (.06)	.36 (.02)	.77 (<i><.001</i>)	-.02 (.88)	-.27 (.08)	-.61 (<i><.001</i>)	.56 (<i><.001</i>)	-.09 (.59)	.09 (.58)
9. Cause: Behaviour (Beh)	.05 (.73)	-.01 (.94)	-.08 (.64)	.09 (.6)	.19 (.22)	-.22 (.15)	-.1 (0.54)	.03 (.85)	.69 (<i><.001</i>)	.1 (.53)
10. Cause: Psychological (psyc)	.12 (.44)	.32 (.04)	.35 (.03)	.53 (<i><.001</i>)	-.06 (.7)	-.21 (.18)	-.49 (<i><.001</i>)	.57 (<i><.001</i>)	.08 (0.6)	.59 (<i><.001</i>)

Patient correlations presented in lower diagonal; carer's correlations presented in upper diagonal. Figures italics and in greyed in boxes represent correlations between patient and carer views on same illness representation domain. Significance levels are in parentheses. Figures in bold indicate correlations of over $r=0.5$

This suggests that carers have a coherent model of stroke in terms of its negative connotations, but that these perceptions are largely unrelated to their views about the patient's role in their recovery (personal control). Illness representations regarding both a behavioural and psychological cause for the stroke failed to correlate with any other illness dimension, indicating that carers do not have a coherent causal model for the stroke during this sub-acute post-stroke period.

5.4.2 Question 1b: Are there Significant Changes in the Illness Perceptions of Patients and Carers over Time?

5.4.2.1 Patients' Perceptions of Stroke over Time

Patients' illness perceptions were assessed at three assessment points. The mean and standard deviation scores for patients' representations of stroke, as well as significant differences over time are presented in table 5.6. One way ANOVA was used to assess changes in perceptions over time. Patients' perceptions of treatment control and personal control change significantly over time and by time three patients hold more negative control perceptions. Illness coherence perceptions also decline over time, with patients reporting that they understand their stroke less by time three than at time one, but this was only significant at $p < 0.05$, so should be interpreted with caution due to the small sample size. Other illness perceptions did not change significantly over time, suggesting some stability in their views over this time period.

Table 5-6: Patients' IPQ-R scores at baseline and 3 and 6 months post recruitment, and significant difference over time (n=29)

	Time 1 Mean (sd)	Time 2 Mean (sd)	Time 3 Mean (sd)	ANOVA
Identity	7.48 (4.01)	6.89 (4.54)	6.86 (3.89)	0.2
Timeline Acute/chronic	2.32 (.47)	2.39 (.44)	2.47 (.42)	0.87
Timeline Cyclical	2.11 (.51)	2.07 (.55)	2.19 (.52)	0.32
Consequences	2.42 (.43)	2.41 (.47)	2.41 (.53)	0.005
Treatment Control	3.13_{ab} (.56)	2.36_b (.49)	2.47_a (.45)	19.74***
Coherence	2.69 _a (.51)	2.46 (.49)	2.4 _a (.36)	3.35*
Personal Control	2.97_{ab} (.37)	2.54_a (.31)	2.54_b (.38)	14.43***
Emotional Representation	2.43 (.46)	2.36 (.41)	2.33 (.46)	0.37
Cause: Behavioural	2.33 (.71)	2.25 (.8)	2.45 (.7)	0.53
Cause: Psychological	2.23 (.66)	2.21 (.74)	2.23 (.81)	0.009

Means sharing a common subscript differ significantly from one another by Bonferroni's test.

*= $P < .05$; ** = $p < .01$; *** = $p < .001$

5.4.2.2 Carers' Perceptions of Stroke over Time

Carers' illness perceptions were assessed at the three assessment points. The mean and standard deviation scores for carers' representations of stroke, as well as significant differences over time are presented in table 5.7. One way ANOVA was used to assess changes in perceptions over time. Carers' views of treatment control and the patient's personal control over their recovery change significantly over time, and by time three, carers, like patients, are significantly less confident about the efficacy of treatment and the level of personal control the patient has over their recovery.

Table 5-7: Carers' IPQ scores at baseline and 3 and 6 months post recruitment and significant differences overtime (n=29)

	Time 1 Mean (sd)	Time 2 Mean (sd)	Time 3 Mean (sd)	ANOVA
Identity	9.97 (5.43)	8.45 (5.77)	8.38 (5.94)	0.71
Timeline Acute/chronic	2.42 (.53)	2.47 (.32)	2.52 (.46)	0.68
Timeline Cyclical	2.33 (.53)	2.12 (.59)	2.29 (.61)	0.39
Consequences	2.58 (.47)	2.56 (.48)	2.54 (.47)	0.05
Treatment Control	3.00_{ab} (.63)	2.32_a (.48)	2.32_b (.43)	16.33***
Coherence	2.62 (.7)	2.53 (.51)	2.4 (.51)	1.08
Personal Control	2.84_{ab} (.41)	2.46_a (.36)	2.51_b (.27)	10.25***
Emotional Representation	2.74 (.54)	2.57 (.53)	2.53 (.56)	1.18
Cause: Behavioural	2.35 (.66)	2.36 (.73)	2.35 (.65)	0.002
Cause: Psychological	2.52 (.86)	2.36 (.85)	2.44 (.79)	0.27

Means sharing a common subscript differ significantly from one another by Bonferroni's test.

* = $P < .05$; ** = $p < .01$; *** = $p < .001$

5.4.3 Question 1c: Do the Illness Representations of Patients and Carers Change (converge or diverge) over Time?

The aim of this analysis is to consider whether the illness representations of patients and carers converged or diverged over time. As discussed earlier, partners' illness representations correlate significantly at time one, but significant differences in the strength of partners' representations were also found. The previous analysis revealed that with the exception of control perceptions and patient coherence scores, patients' and carers' perceptions do not change significantly over time. Therefore analysis of variance (ANOVA) was used to examine whether there is any evidence that patients' and carers' views converge or diverge over time. The following analyses are conducted on data from the 29 couples returning data at all 3 assessment points. Due to the small sample size only results which are significant at least $p < 0.01$ are considered significant.

A series of two-way (role x time) repeated measures ANOVAs, were used to assess changes over time in the whole sample. There was a significant main effect of time, with changes in illness identity, illness coherence, emotional response, and treatment and personal control perceptions. The results of all analyses are shown in Table 5-8. Over time, both groups reported fewer symptoms associated with the stroke, and felt that the patient was less distressed by their stroke (lower emotional response scores), had lower personal control over their recovery and that the treatment would be less effective. Patients and carers also reported the patient understood the stroke less (lower coherence), but this was significant only at the $p < 0.05$ level. Although few significant between-groups differences were found, this does not mean that changes did not occur at the level of the couple. Tests of between subjects' effects revealed a main effect of role for perceptions of emotional response, but this was only significant at the 95% significance level ($F(1,56) = 3.95, p < 0.05$), with patients reporting lower emotional response scores at each time-point, compared to how carers perceived they were feeling. No significant interactions were found.

Table 5-8: Means and Standard Deviation scores for Patients and Carers Illness Representations at baseline, 3 and 6 months (n=29 couples)

	Time 1 Mean (sd)		Time 2 Mean (sd) n=29		Time 3 Mean (sd) n=29		ANOVA Sig*
	Patient	Carer	Patient	Carer	Patient	Carer	
Identity	7.48 (4.01)	9.97 (5.43)	6.89 (4.54)	8.45 (5.77)	6.86 (3.89)	8.38 (5.94)	5.17**
Timeline	2.32 (0.47)	2.42 (0.53)	2.39 (0.44)	2.47 (0.32)	2.47 (0.42)	2.52 (0.46)	1.81
Timeline Cyclical	2.11 (0.51)	2.33 (0.53)	2.07 (0.55)	2.12 (0.59)	2.19 (0.52)	2.29 (0.61)	0.14
Consequences	2.42 (0.43)	2.58 (0.47)	2.41 (0.47)	2.56 (0.48)	2.41 (0.53)	2.54 (0.47)	0.15
Treatment Control	3.13 (0.56)	3.00 (0.63)	2.36 (0.49)	2.32 (0.48)	2.47 (0.45)	2.32 (0.43)	10.03***
Coherence	2.69 (0.51)	2.62 (0.7)	2.46 (0.49)	2.53 (0.51)	2.4 (0.36)	2.4 (0.51)	3.14*
Personal Control	2.97 (0.37)	2.84 (0.41)	2.54 (0.31)	2.46 (0.36)	2.54 (0.38)	2.51 (0.27)	23.4***
Emotional Representation	2.43 (0.46)	2.74 (0.54)	2.36 (0.41)	2.57 (0.53)	2.33 (0.46)	2.53 (0.56)	5.18**
Cause: Behavioural	2.33 (0.71)	2.35 (0.66)	2.25 (0.8)	2.36 (0.73)	2.45 (0.7)	2.35 (0.65)	0.96
Cause: Psychological	2.23 (0.66)	2.52 (0.86)	2.21 (0.74)	2.36 (0.85)	2.23 (0.81)	2.44 (0.79)	0.66

* $p < 0.05$ ** $p < 0.01$, *** $p < 0.001$

5.4.4 Question 1d : Are Illness Representations Associated with Emotional Distress?

Pearson's correlations were conducted to determine whether patients' and carers' illness representations were associated with concurrent emotional distress levels (GHQ-28 scores) at each time-point. In order to compare the correlation patterns over time, only couples who had returned data at all three time-points were included in the analysis (n=29).

At time one, patients' distress was significantly and positively associated with both their own and their carer's illness perceptions (Table 5-9). Patients were more distressed when they and their carer reported that the patient displayed more symptoms (stronger illness identity), and when the patient perceived the stroke to be more emotionally distressing (emotional response). Carers were more distressed when they and the patient perceived there to be more symptoms associated with the stroke and when the carer perceived there to be more negative consequences resulting from the stroke.

Table 5-9: Significant Correlations identified between Illness Representations and concurrent GHQ-28 scores

Illness representation	Time 1 N=29		Time 2 N=29		Time 3 N=29	
	Patient's GHQ	Carer's GHQ	Patient's GHQ	Carer's GHQ	Patient's GHQ	Carer's GHQ
Patient's symptoms	.43 (0.02)	.4 (0.03)	.8 (<0.001)	.55 (0.002)	.57 (<0.001)	.44 (0.02)
Carer's symptoms	.36 (0.05)	.4 (0.03)	.76 (<0.001)	.57 (0.001)	.66 (<0.001)	.39 (0.04)
Patient's Timeline Cyclical	.17 (0.37)	.07 (0.7)	.47 (0.01)	.2 (0.57)	.47 (0.009)	.23 (0.2)
Carer's Timeline cyclical	.27 (0.16)	.13 (0.48)	.54 (0.003)	.4 (0.02)	.52 (0.004)	.39 (0.04)
Patient's Consequences	.28 (0.14)	.2 (0.26)	.7 (<0.001)	.3 (0.1)	.56 (0.002)	.4 (0.03)
Carer's Consequences	.2 (0.29)	.4 (0.02)	.69 (<0.001)	.7 (<0.001)	.68 (<0.001)	.62 (<0.001)
Patient's Emotional Response	.3 (0.08)	.25 (0.18)	.6 (<0.001)	.36 (0.06)	.54 (0.002)	.3 (0.11)
Carer's Emotional Response	.07 (0.7)	.2 (0.29)	.67 (<0.001)	.53 (0.003)	.66 (<0.001)	.47 (0.009)
Carer's Cause (psychological)	-.15 (.43)	-.05 (0.8)	.68 (<0.001)	-.02 (0.93)	.41 (0.03)	.27 (0.15)

(significance values in brackets, correlations significant at $P < 0.01$ or more in bold)

Over time, a picture emerges of an association between illness representations and GHQ-28 scores. The weaker correlations at time one suggest that early distress may be largely

unrelated to illness representations, but the time two and time three correlations suggest that illness representations may be important in terms of later distress. However, the nature of correlational analyses means that no causal relationships can be explored, and these are first-order correlations, and do not control for other factors which may be important predictors, or may moderate these associations. The results suggest that the level of distress experienced by patients may be strongly influenced by the views of their carers, but that patient perceptions impact much less on carer's distress. None of the positive illness representation domains (eg personal control) was associated with GHQ scores at any time-point. The significance of this lack of association will be considered in the discussion. No significant correlations emerged between patient GHQ-28 scores, relationship satisfaction and social support.

5.4.5 SUMMARY FROM AIM 1 QUESTIONS

- At baseline, patients and carers have a fairly coherent model of stroke in respect to the negative dimensions of their understanding (ie consequences, identity, emotional response, timeline).
- Control perceptions were unrelated to other illness representations at any time point indicating that even when patients and carers have positive control perceptions this does not translate into more positive perceptions about other aspects of the stroke.
- Patients' and carers' perceptions about stroke remain generally stable over time, although the strength of their perceptions about the controllability of the stroke (personal and treatment control) decline significantly. The results also indicate that by 6 months post recruitment, patients feel they have a significantly poorer understanding of the stroke than they felt they had at baseline.
- Patients' and carers' perceptions about the consequences, emotional response, and behavioural and psychological causes were positively and significantly correlated at each assessment point. ANOVA revealed that these perceptions were stable over time, with carers reporting slightly worse consequences, and a stronger belief that the patient was distressed by their stroke (emotional response) and stronger causal perceptions.
- Patients' and carers' illness identity perceptions were positively and significantly correlated at each assessment point, and both partners reported significantly fewer symptoms to be associated with the stroke over time.
- Patients' and carers' treatment control and personal control perceptions were poorly correlated at each assessment point, and scores declined significantly for both partners. This suggests that whilst at a group level, patients and carers are similar overall in their views, this is not the case within couples, and that, at the level of the couple, partner's views may differ significantly.

- Patient distress is strongly and positively associated with patients and carers having more negative perceptions of the stroke, with stronger associations developing over time. The results suggest that the level of distress experienced by patients is strongly influenced by the perceptions of their carer.
- Carer distress levels were most strongly associated with their own illness perceptions, with patient perceptions more weakly associated with carer distress.

5.5 Aim 2: To determine the extent of Discrepancy within Couples

One aim of the present study is to quantify levels of discrepancy *within* couples, and to track the evolution of discrepant illness representations over time. With this problem in mind, a number of different options were explored to identify a method that would enable an exploration of discrepancy within rather than between couples. It was decided to proceed with a simple classification system based on the *absolute difference* score for each couple on each subscale in order to identify couples who were similar or discrepant in their illness representations. (The rationale for using this method is discussed in chapter 4).

5.5.1 Operationalising “Discrepancy”

Couples were categorised as being discrepant in their illness representations if, at time one, the difference between their scores for that illness representation dimension was more than two standard deviations from zero (congruent)⁶. This cut-off was selected as a conservative measure of discrepancy. It classifies only those couples with large differences in their views as discrepant, and classifies couples who are congruent or “averagely discrepant” as congruent. It will therefore miss couples who have moderate levels of discrepancy, but will identify those couples who are most different. To allow comparisons to be made across time, this analysis was confined to those couples who returned all 3 sets of data (n=29). Due to the small sample size the results of the parametric tests must be viewed with caution.

The next section aims to answer the following questions:

- In which dimensions of the illness representation is discrepancy found, and what is the extent of discrepant perceptions within couples?
- To what extent is the maintenance of discrepancy predicted by socio-demographic variables at time one?

⁶ Using this method of quantifying discrepancy both patient < carer and patient > carer are included.

5.5.2 Question 2a: Identifying Dimensions of the Illness Representation in which Discrepancy is found

Table 5-10 presents the time one mean “absolute difference scores” for couples on each subscale. The absolute difference⁷ between patients’ and carers’ scores for all scales except illness identity, (which is a summated scale) can range from 0 to 3 (with zero difference indicating that the patient and carer obtained the same score on that subscale, and 3 being the largest discrepancy possible on the subscale). The data shows that mean difference scores in couples’ illness representations were small, but the large standard deviation scores indicate moderate to high levels of discrepancy within some couples. The table also illustrates the number (and percentage) of couples identified as discrepant at each time-point. Discrepancy at time one was most common in the illness identity, consequences, personal control and causal attributions subscales. By time three, illness identity and personal control representations had converged for most couples, but discrepancy was still common for causal attributions, with a quarter of couples still discrepant at this time.

Table 5-10 : Frequencies (%) of couples identified as discrepant at each time point (n=29 couples)

Illness representation	Time 1	Discrepancy range	2 sd cut-off	% of couples identified as discrepant		
	Mean Abs. Diff			Time 1 N=29	Time 2 N=29	Time 3 N=29
Identity discrepancy	3.24	0 to 9	4.54	9 (31%)	7 (24.1%)	4 (13.8%)
Timeline Acute discrepancy	0.42	0 to 1.75	0.81	2 (6.9%)	5 (17.2%)	1 (3.4%)
Timeline Cyclical discrepancy	0.5	0 to 2	1.02	2 (6.9%)	5 (17.2%)	1 (3.4%)
Consequences discrepancy	0.38	0 to .91	0.66	5 (17.2%)	4 (13.8%)	4 (13.8%)
Treatment Control Discrepancy	0.57	0 to 2.33	1.12	3 (10.3%)	0 (0%)	1 (3.4%)
Coherence Discrepancy	0.51	0 to 3	1.00	2 (6.9%)	0 (0%)	0 (0%)
Personal Control Discrepancy	0.48	0 to 1.57	0.96	5 (17.2%)	1 (3.4%)	1 (3.4%)
Emotional Resp. Discrepancy	0.5	0 to 1.4	0.9	4 (13.8%)	1 (3.4%)	2 (6.9%)
Behavioural Cause Discrepancy	0.37	0 to 1	0.74	6 (20.7%)	3 (10.3%)	7 (24.1%)
Psychological Cause Discrepancy	0.5	0 to 2	0.94	7 (24.1%)	7 (24.1%)	7 (24.1%)

⁷ Calculated as the absolute difference between the patient’s and carer’s score on the subscale.

5.5.3 Question 2b: Quantifying Levels of Discrepancy within Couples

The above analysis revealed that some couples failed to agree in their views about the stroke. The next stage was to examine whether couples who were discrepant in one dimension disagreed on other illness representations. To answer this question, the number of illness representation dimensions in which each couple was discrepant was calculated for each time-point. As can be seen by table 5-11 at time one, only 31% of couples were congruent in all dimensions of their illness representation, and 24.1% of couples were discrepant in three or more dimensions (out of a possible ten), indicating that some level of discrepancy was an issue for over two-thirds of couples. By time three, 20% of couples have moved from the incongruent to congruent group, and only 10.3% of couples (n=3) are discrepant in three or more illness representations, indicating that for a good proportion of couples, discrepancy resolves over time. However, this means that for almost half of all couples (48.3%), some residual discrepancy persists more than eight months after the stroke.

Table 5-11: Number of illness representations dimensions in which couples are discrepant at each time point

Number of illness representation domains discrepancy found	Time 1 N=29	Time 2 N=29	Time 3 N=29
0 (Congruent)	9 (31%)	11 (37.9%)	15 (51.7%)
1	8 (27.6%)	11 (37.9%)	5 (17.2%)
2	5 (17.2%)	1 (3.4%)	6 (20.7%)
3	4 (13.8%)	4 (13.8%)	1 (3.4%)
4	2 (6.9%)	2 (6.9%)	2 (6.9%)
5	1 (3.4%)	0 (0%)	0 (0%)

5.5.4 Question 2c: To what extent is the maintenance of Discrepancy associated with Time One Socio-Demographic variables?

The maintenance of discrepancy was operationalised as couples who were discrepant in at least one illness representation dimension at each time-point, and where the number of dimensions of the illness representation in which discrepancy was found did not reduce by time three. In order to examine possible predictors of the maintenance of discrepant perceptions over time, a dichotomous measure of discrepancy was created, in which couples who had been identified as being congruent at all time points and couples whose representations converged over time were categorised as "congruent" (n=18). Couples who were discrepant at all three time-points were categorised as "incongruent" (n=11). Only those couples with full data sets were included (n=29). As these were planned comparisons, a significance level of $p < 0.05$ is

considered significant. Independent t-tests were used to compare the two groups. These analyses revealed that the two groups did not differ significantly in terms of age or gender of the patient, disability level of the patient; patient distress (GHQ-28), relationship satisfaction (MOS) or social support (SOS) scores. However, carers in the incongruent group were significantly more distressed at time one than carers in the congruent group (Mean for incongruent = 11.29 (4.69); Mean for congruent = 5.94 (7.25); $t=2.4$ (27) $p=0.046$; two tailed, equal variances not assumed).

5.5.5 SUMMARY FROM AIM 2 QUESTIONS

- In this sample of couples, discrepancy resolves over time for most but not all illness representation dimensions, with discrepancy in causal attributions common at time three.
- At time one, almost 70% of couples differed in their illness representations in at least one dimension.
- At time three, almost half of all couples were still discrepant in at least one dimension.
- Discrepancy is more likely to be maintained over time in couples where the carer is distressed at time one.
- Relationship satisfaction at time one is not associated with the maintenance of discrepancy.

6 Actor-Partner Interdependence Model (APIM) Analysis: Predicting Patient and Carer Distress

6.1 Introduction

Chapter 4 outlined the difficulties inherent in the methods that have been employed to analyse discrepancy in the past. The present study differs from most of those examined in the literature review in that it looks at the impact of discrepancy on both partners. The descriptive statistics reported in chapter 5 indicate that strong positive correlations exist between the dependent variable scores of patients and carers, thus violating the assumptions of independence upon which ordinary least squares approaches are based. Therefore a search was made for an analysis technique which could manage correlated data and model intra-individual and inter-individual effects, both cross-sectionally and longitudinally. The following section introduces a dyadic data-analytic method, the Actor-Partner Interdependence Model (APIM), which was first proposed by David Kenny and colleagues (Kenny and Judd 1986; Kenny and Acitelli 1988; Kenny 1996; Kenny 1996; Kashy and Kenny 1999; Kenny and Cook 1999; Kenny, Kashy et al. 2006) as a conceptual framework for collecting and analysing dyadic data, which also considers the interdependence that may exist between the two partners. The issue of non-independence will be discussed first. The model will then be introduced and the types of variable considered in dyadic studies will be described. Finally, methods of analysing the APIM will be discussed.

6.2 Nonindependence

Married couples and parents and children are not simply two individuals, but have a long shared history, and often influence each other's cognitions, emotions and behaviours (Campbell and Kashy 2002). Indeed, close interpersonal relationships have significant potential for mutual influence (Kelley, Berscheid, Christensen, Harvey, Huston and al. 1983), and this notion is central to most theories of romantic relationships, such as attachment (Bowlby 1969, 1973, 1980), equity (Walster, Walster and Berscheid 1978), and interdependence (Kelley and Thibaut 1978). Interdependence theory has its roots in theories such as game theory, social exchange theory and social learning theory (Rusbult and Van Lange 2003), and provides an account of interaction and relationships by examining ways in which social situations influence both intraindividual and intraindividual processes (Kelley and Thibaut 1978). The theory argues that interaction partners affect their own and one another's well-being (Rusbult and Van Lange 2003), and so one consequence is that the perceptions or attributes of one individual can

impact on the outcomes of the other partner. The theory uses matrices to represent the way in which the needs of individuals are achieved (or not) during an interaction to analyse the situation structure (Kelley and Thibaut 1978). The analysis describes the degree to which an individual is dependent on their partner, and how much their outcome is influenced by their partner's actions (Rusbult and Van Lange 2003). The connection between the qualities of one partner and the outcomes of the other is what defines a "relationship" (Kelley et al. 1983). Therefore to understand the impact of illness perceptions on both partners it is important to understand the interdependent nature of close relationships.

6.2.1 Sources of Nonindependence

Kenny and colleagues (2006) use the term "nonindependence" to describe when two individuals share something in common, and offer this conceptual definition.

"if the two scores from the two members of the dyad are nonindependent, then those two scores are more similar to (or different from) one another than are two scores from two people that are not members of the same dyad" (2006, p.5).

Nonindependence occurs through a number of difference processes (for a discussion see Kenny & Judd, 1986), such as voluntary linkage (a bond that develops over time) and kinship linkage (links through being family members) (Kenny, Kashy et al. 2006). Couples may also be similar on factors such as age, socioeconomic status, education, etc (Kenny and Cook 1999), and this similarity may influence the outcome variable. Partner effects refer to the degree to which one member of the dyad affects the outcome of the other partner. This may occur in the present study when the patient's disability affects the mood of the carer. Mutual influence occurs when the views of each partner mutually affect the other through a process of feedback. In the present study this may occur when the mood of each partner affects that of the other.

In the present study, Leventhal's self regulatory model provides the underlying theoretical framework (Leventhal, Leventhal et al. 1985; Leventhal, Benyamini et al. 1997). As the model predicts that illness perceptions are derived from both personal experience and from the social milieu, each of the forms of non-independence described above is implied within the model, albeit not made explicit. However, although patients and carers may hold similar views on some aspects of the stroke, the results presented in the previous chapter suggest that some couples do not have a shared understanding of the stroke. The focus of the present study is the impact of discrepancy on outcomes and so this analysis will model not only actor and partner effects, but the impact of discrepancy on each actor's dependent variable.

6.2.2 Statistical Nonindependence

Traditionally, social science research has focussed on the individual, and yet as already discussed, many of the phenomena studied are interpersonal in nature. One factor which has contributed to this focus is the reliance on statistical methods such as analysis of variance and multiple regression. However, both of these methods assume that observations are independent, commonly known as the independence assumption (Kenny, Kashy et al. 2006). Ignoring this potential non-independence and treating the person as the unit of analysis could bias the results and produce either type I or type II errors (Kenny, Kashy et al. 2006).

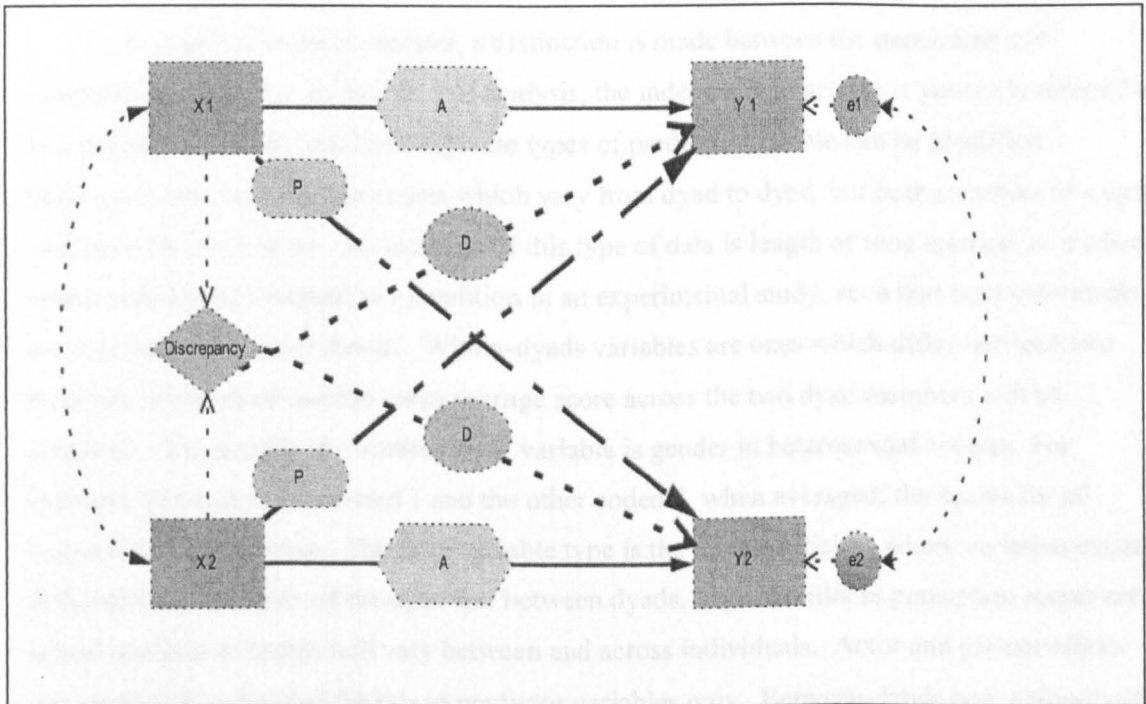
6.3 The Actor-Partner Interdependence Model (APIM)

The APIM is a model of dyadic data analysis which uses the dyad as the unit of analysis, and integrates the concept of interdependence between patient's and carer's relationships with appropriate techniques for measuring and testing it (Cook and Kenny 2005). The model suggests that one partner's independent variable score affects both his or her own dependent variable score (known as the actor effect) and his or her partner's dependent variable score (known as the partner effect) (Campbell and Kashy 2002). The APIM is an extension of the traditional multiple regression model to the case where each member of the couple is conceptualised as an individual "nested" within a couple/dyad. This allows for the estimation of both individual and dyadic factors. In the simplest version of the APIM the partners are interchangeable, but in the present study each partner can be distinguishable, both by their role (patient or carer) and by their gender, although in the present analysis, the main distinguished variable will be the individual's role and gender effects will not be modelled due to the small sample size.

6.3.1 The Model

Figure 6.1, provides a graphical representation of the model. There are four main variables in the model. The two dependent or outcome variables are labelled Y1 and Y2 and represent the GHQ-28 scores for the patient and carer, respectively. The X1 and X2 variables are measures of the patient's and carer's predictor variables. The two central components of the model are the actor and partner effects. An actor effect measures how much the person's perceptions affect their behaviour, this is represented by the solid arrow from X → Y (labelled A). However, the model proposes that in order to be measured accurately, actor effects should be estimated whilst controlling for partner effects (Cook and Kenny 2005). Partner effects refer to the degree to which the actor is influenced by a partner, although only a predictive and not causal relationship can be assumed (Cook and Kenny 2005). Partner effects are shown in figure

6.1 as dotted lines, and are labelled (P). It is partner effects that measure a form of interdependence, and as these are by definition dyadic, they cannot be measured within the individual (Cook and Kenny 2005). In the present study there are two other important parameters, and these model the relationship between discrepancy scores (D) and each partner's outcomes (Y).



Key: X1 and X2 = predictor variables Y1 and Y2 = Outcome variables

A = actor effect, P= partner effects, D= discrepancy effect e1 and e2 = correlated residuals.

Figure 6-1: Actor-Partner Interdependence Model

In the APIM, discrepancy is modelled as an interaction between each partner's scores. All interactions are modelled whilst controlling for the main effects in the model. Therefore, the impact that discrepancy has on each partner is assessed whilst controlling for both actor and partner effects, thus offering a stringent test of the role of discrepancy. Discrepancy is modelled as the absolute difference between the x1 and x2 scores (as recommended by Cook, personal communication), and has a direct effect on the outcome of each partner, but has no partner effect. The impact that discrepancy has on each partner will differ between dyad members. Two further features of the APIM are important. These are the correlations between the patient's and their carer's independent variables. The correlation between the two independent variables is indicated by the curved double headed arrow between X1 and X2. This correlation means that if either the patient's or carer's X variable predicts a Y variable, it is done whilst controlling for partner effects. Correlations are also found between the residual variables. The

curved, double headed arrow connecting e_1 and e_2 indicate that the unexplained variance in the dependent variable may be correlated, even after the covariance explained by the partner effect is controlled.

6.4 Types of variable in Dyadic Designs

In standard research designs, a distinction is made between the dependent and independent variables. In dyadic data analysis, the independent variable is generally referred to as a predictor variable, and three separate types of predictor variable can be identified. Between-dyads variables are scores which vary from dyad to dyad, but both members of a dyad will have the same score. An example of this type of data is length of time married, or studies where couples are assigned to a condition in an experimental study, such that both individuals are exposed to the same stimuli. Within-dyads variables are ones which differ between two members of the dyad, but the mean average score across the two dyad members will be identical. An example of a within-dyads variable is gender in heterosexual couples. For example if one partner is coded 1 and the other coded 2, when averaged, the scores for all couples will be the same. The third variable type is the mixed variable, where variation exists both between members of the dyad and between dyads. Age and illness perception scores are mixed variable as scores will vary between and across individuals. Actor and partner effects can be directly estimated for mixed predictor variables only. Between-dyads and within-dyads variables are estimated using interaction terms.

6.5 Statistical Analysis of the APIM

There are different ways of examining APIM effects, including pooled regression analyses, structural equation modelling (SEM) and hierarchical linear models (multi-level modelling: MLM). Kashy & Kenny (2000) propose a model using pooled regressions, whereby the results of two regressions are combined to estimate the APIM effects. However, this model is inflexible, and Kenny recommends the use of MLM and SEM approaches over the pooled regression approach (Kenny, Kashy et al. 2006). It was therefore decided to use multi-level modelling (MLM) in the present study. MLM, also referred to as hierarchical linear modelling, allows the management of non-independent observations.

6.5.1 Two Intercept Model

There are several ways to model dyadic processes using MLM, and the present study will use the two intercept approach which was first introduced by Raudenbush and colleagues (1995). At its most basic level, this model has six independent variables. The model has no

ordinary error term, instead, two dummy variables are created to use as intercept variables for the patient and carer respectively. These dummy variables are used to create predictor variables that measure and test for actor and partner effects (see Cook & Kenny 2005 for a full description). The intercept variables have a fixed component, which is the intercept, and a random component. The correlation between the random components for the patient and carer variables models the residual covariance (e_1 and e_2 in the model). For a full description of how to define and analyse this model see Cook and Kenny (2005). The other four main variables in the model are the two actor variables and the two partner variables. In the present study two additional variables are included which model the impact of discrepancy on each partner. Estimation of these coefficients is the goal of the analysis. The main advantage of the two intercept model is that actor and partner effects for each partner can be read directly from the output.

6.5.2 Specifying the Model

The two-intercept model tests the following equation for member j of dyad i :

$$Y_{ij} = a_i X_{1i} + b_i X_{2i}$$

Using the dummy variables described above X_1 is 1 for the patient and 0 for the carer, whereas X_2 is 0 for the patient and 1 for the carer. Within the model, the effect of X_1 and X_2 are random variables, (as indicated by the i subscript to a and b), and, as already mentioned, there are two intercepts. All predictor variables are multiplied by each of the two dummy X variables, so that the effect of each predictor (X) variable can be tested for both members of the couple (Kenny, Kashy et al. 2006).

6.5.3 Actor-Partner Interactions

Discrepancy is modelled as an interaction term. These can be created using the typical multiplicative form (eg gender x IPQ score), or, as in the case of discrepancy scores, using an absolute difference score (Kenny and Cook 1999; Kenny, Kashy and Cook 2006). All models will be first estimated without discrepancy in the model (Aiken and West 1991), and discrepancy will be modelled at step two to test whether this adds to the explanatory power of the model, whilst controlling for the main actor and partner effects.

6.5.4 Application of the APIM to health settings

The APIM is being increasingly used in the social sciences to examine the impact of partner scores on outcomes, with studies looking at topics as diverse as emotion (Butler, Egloff, Wilhelm, Smith, Erickson and Gross 2003), psychological adjustment among bereaved parents (Wijngaards-de Meij, Stroebe, Schut, Stroebe, van de Bout, van der Heijden and Dijkstra 2007) anxiety and emotional distress in women with breast cancer and their partners (Segrin, Badger,

Dorros, Meek and Lopez 2007), fear of cancer recurrence (Mellon, Kershaw, Northouse and Freeman-Gibb 2007), the impact of social support in couples undergoing in-vitro fertilization (Knoll, Kienle, Bauer, Pfuller and Luszczynska 2007), and the impact of couples therapy (Cook and Snyder 2005). The model has also been recommended in the study of family adaptation (Rayens and Svavarsdottir 2003).

6.6 Summary of the APIM Approach

The impact of illness representations on patients and carers will be examined using the Actor-Partner Interdependence Model (APIM). The analysis will be conducted using hierarchical linear modelling using SPSS 15, and the two-intercept approach will be used to assess the impact of actor, partner and discrepancy on each partner's outcomes. The impact of discrepancy will be modelled whilst controlling for actor and partner effects.

6.7 Analysis

This section presents the results from the quantitative study in relation to the aim number 3 set out in chapter 2. The overall aim is to examine the relation between discrepant illness representations, emotional distress and relationship satisfaction. However, as discussed earlier, it is important to consider discrepancy within the context of what each partner thinks about the illness, and so the present study will test the following research questions:

1. Are illness representations associated with concurrent or later distress in patients and carers?
2. Do the illness representations of one partner influence the distress experienced by the other partner?
3. Are discrepant illness representations associated with concurrent or later emotional distress in patients and carers?

To examine whether relationship quality is associated with patient and carer distress, or moderates the illness representations → emotional distress relationship, the analysis will also examine the following questions:

4. Is relationship satisfaction associated with patients' and carers' concurrent or later emotional distress?
5. Does relationship satisfaction moderate the illness representations → emotional distress relationship?

6.8 Data Analysis Plan

To answer these research questions, cross-sectional (time one, two and three) and longitudinal models (time one → time two; time two → time three) were examined. The impact of each illness perception dimension on self-reported emotional distress was **analysed separately** using APIMs. The data organisation and syntax required to analyse the APIM using SPSS have been documented by Cook and Kenny (2005) and Kenny, Kashy and Cook (2006), and will be discussed in brief.

The data is contained in a two-level model, with individuals (level 1) nested within couples (level 2). SPSS was used because of the ease of modelling within-subjects non-independence in longitudinal models. In order to increase the interpretability of the regression coefficients, all continuous predictor variables are grand mean centred prior to analysis. This involves calculating the variable mean across the whole sample (patients and carers), and deducting this from all scores (Aiken and West 1991). Centring makes the intercept more interpretable, as, when the variables are centred, the expected Y is when all predictors are at their mean, rather than at zero. All discrepancy scores are also centred since this makes the first order terms (actor and partner effects) more interpretable, and reduces colinearity. Actor and partner effects are presented in the model as unstandardised regression coefficients. Measures of r^2 are not reported because the present analysis uses the two-intercept model, and Kreft and De Leeuw caution against citing r^2 for anything other than random intercept models due to the difficulty in defining estimates of variance (Kreft and De Leeui 2006). The parameters of the APIM were estimated in stages, as recommended by Aiken and West (1991). Firstly a series of main effects models were estimated. These test for actor and partner effects, but do not contain discrepancy scores. For each analysis, two equations are modelled simultaneously, one for each partner's dependent variable. The same variables are specified as predictors in each model. In the present study the effect of each IPQ-R dimension is tested separately.

Therefore, each main effects model includes:

- significant background variables (e.g. BI, SOS, MOS, age)
- one IPQ-R dimension (i.e. illness identity, Timeline (Acute/ chronic and cyclical), Consequences, Coherence, Control (Personal & Treatment), Emotional Response, or causal perceptions (psychological and behavioural)).

The emotional response scale of the IPQ-R was only modestly correlated with patients' and carers' GHQ-28 scores indicating that this scale is not just a reflection of the emotional distress (Moss-Morris, Weinman et al. 2002), and so a decision was taken to include emotional

response as a predictor in the models. Discrepancy was tested in later analyses. As discussed earlier, discrepancy is modelled as the absolute difference between the patient and carer scores.

6.8.1 Constructing the Models

Separate models were constructed to examine the unique contribution that each of the IPQ-R dimensions provided in explaining the variance in patient and carer distress. It is important to rule out alternative explanations for the variance explained in GHQ-28 scores, so at step one, an APIM was constructed regressing each of the background variables (i.e. social support, Barthel index, relationship satisfaction, patient's and carer's ages) onto the dependent variable (GHQ-28 scores). This allowed for the identification of significant predictors ($p < 0.05$) which were then included as control variables in later models testing the impact of each of the illness representation dimensions. Earlier emotional adjustment (t-1 GHQ-28 scores) is included in all models (except time one) to control for the confounding effect of past distress on current distress. The results of this baseline model testing the impact of background variables on the dependent variable is presented in the top section of each APIM table.

Once relevant background variables were identified and entered into the model, the impact of each of the IPQ-R dimensions was analysed. All significant results are shown in the 3rd and 4th columns of the following tables (main effects). Therefore, for example, table 6.1 presents the results of six separate models, which constitute all the significant models where illness representations were associated with emotional distress. In these models, the impact of illness representations on distress is therefore tested after controlling for patient disability and emotional support (SOS).

Separate models were run because the data set is too small to test all the IPQ-R dimensions in one model. Furthermore as well as significant correlations between patients and carers dependent variables the inter-correlation between patient's and carers' IPQ-R scores on most of the IPQ-R subscales were also found to be significantly correlated at each time point (see table 5.5 for time one correlations, and appendix 16 for time two and time three correlations), suggesting high levels of shared variance. Testing the impact of illness representations using separate models also allows the unique contribution of each dimension to be examined.

6.8.2 Testing for the Impact of Discrepancy

The second stage of the analysis involved the inclusion the discrepancy scores into each of the main effects models. In each case, the impact of discrepancy was tested after controlling

for the main effects in the model. The impact of discrepancy on outcomes and the changes to the main effects models are shown in columns 5 and 6 of the tables. Only significant models are shown. When discrepancy was found to be significant the results were plotted using simple plots. In each case, values of X (the IPQ-R predictor variable) were chosen as one standard deviation above and below the mean and simple plots generated by substituting these values. Separate lines were used to represent the impact of high and low discrepancy on distress when the participant scored high or low on that subscale. However, initial plots indicated less variance in the data for female participants, and so a 3rd value, the mean, was included in the plots. Where appropriate, these plots are presented in the results.

6.8.3 Testing for Moderation Effects

Finally, relationship satisfaction (MOS) was examined as a possible moderator (Z) of the illness representation – emotional distress (XY) relationship using strategy recommended by Aiken and West (Aiken and West 1991). In this analysis the predictor (IPQ-R dimension) and potential moderator (MOS) variable were multiplied together to form a new term (XZ). A new regression model was then tested using the three predictor variables (X, Z and XZ) to determine whether the interaction between the two predictor variables is significant. Then, following Cohen and Cohen (1983) values of Z (the moderator variable) were chosen as one standard deviation above and below the mean, and simple regression lines then generated by substituting these values. No significant interactions were identified, and so no results are presented.

6.9 Time 1 Cross Sectional Models

6.9.1 Impact of Background variables on GHQ-28 Scores

As discussed in the previous section, at step one, background variables were tested as predictors of GHQ-28 scores using the APIM. Patient disability (BI: Barthel Index) and emotional support (SOS) were significant predictors of time one GHQ-28 scores. These variables then formed the basic APIM within which each of the IPQ-R variables in turn were tested. As can be seen in columns 3 and 4 of Table 6-1, patient disability (BI) exerted a significant actor and partner effect, with lower BI scores (higher disability) associated with higher emotional distress in both partners. Emotional support exerted a significant actor and partner effect for carers but not patients. When the carer perceived lower emotional support to be available to them this was associated with higher distress in both the patient and carer.

Table 6-1: APIMs for Time One Cross-Sectional Analyses predicting GHQ-28 Scores

APIM Parameters		Main Effects		with Discrepancy	
		Patient β	Carer β	Patient β	Carer β
Model : Background variables					
Emotional support					
Main Effects	Actor Effect	-0.18	-1.06*		
	Partner Effect	-0.45	-1.23**		
Barthel Index					
Main Effects	Actor Effect	-0.56*			
	Partner Effect	-0.89***			
Models: Illness Representations					
Model 1: Timeline Cyclical					
Main Effects	Actor Effect	1.76	0.6	2.77	-1.44
	Partner Effect	-0.24	1.7	1.21	0.29
Discrepancy				3.28	4.74*
Model 2: Consequences (Cons)					
Main Effects	Actor Effect	2.64	5.13**		
	Partner Effect	-2.87	0.43		
Model 3: Coherence (Coh)					
Main Effects	Actor Effect	-3.25*	-0.25	-3.25*	0.27
	Partner Effect	-0.4	2.38	-0.43	2.68*
Discrepancy				2.21	3.93*
Model 4: Personal Control (PC)					
Main Effects	Actor Effect	-1.92	-2.08	-1.93	-1.73
	Partner Effect	1.05	-0.6	1.01	-0.44
Discrepancy				1.71	3.74*
Model 5: Emotional Response (ER)					
Main Effects	Actor Effect	4.6*	2.38		
	Partner Effect	-1.51	-0.59		
Model 6: Psychological Cause (Psyc)					
Main Effects	Actor Effect	3.21*	-0.52		
	Partner Effect	0.76	-2.39		

Only significant models are shown. * $p < .05$; ** $p < .01$, *** $p < .001$. (n=42 couples)

6.9.2 Impact of Illness Representations

A series of APIMs were then conducted to examine the unique contribution made by each of the IPQ-R dimensions to the variance explained in GHQ-28 scores. Significant results are shown in Table 6-1. The inclusion of illness representations into the models had no significant effect on the emotional support – GHQ-28 association, or on the partner effect for BI, but did result in a modest reduction of the BI- GHQ-28 relationship, suggesting that patient's illness representations are more closely linked to their disability level than are those of their partners (changes to the emotional support –GHQ association after the inclusion of illness representations are not significant and are therefore not shown).

Columns 3 and 4 presents the APIM results for each of the significant models, after controlling for the effect of background variables, and without discrepancy in the model. For patients, significant actor effects were found for illness coherence, emotional response and psychological cause. Better understanding (higher coherence) was associated with lower distress, and a more negative emotional response and a stronger perception in a psychological cause were associated with higher distress in patients. One significant carer actor effect was found, with more negative consequences associated with higher carer distress. The results suggests that even after controlling for the impact of emotional support and the patient's initial level of disability, illness representations are associated with concurrent distress.

6.9.3 Impact of Discrepancy

IPQ -R discrepancy scores were then added to each of the main APIMs. The inclusion of discrepancy resulted in three significant models (timeline cyclical, coherence, personal control). The changes to the main actor and partner effects resulting from the inclusion of discrepancy, and the regression coefficients for the discrepancy scores are shown in the two right hand columns. Although patients and carers are not directly influenced by their own or their partners timeline cyclical perceptions, when the partners are discrepant this is associated with a significant increase in carer distress.

Discrepancy with respect to illness coherence also had a significant impact on patient and carer distress. The inclusion of discrepancy in the model increased the partner effect from carers to patients, such that when the carer felt the patient understood their stroke, this was associated with higher patient distress ($\beta = 2.68, p < 0.05$). Discrepancy also had a significant direct effect on carer distress, such that when the couple disagreed, this added to the carer's distress ($\beta = 3.93, p < 0.05$). When the carer felt the patient had personal control over their recovery this was associated with a non-significant decrease in their distress level (actor effect),

but higher discrepancy was associated with significantly higher carer distress, such that a one unit increase in discrepancy was associated with a 3.74 unit increase in carer's GHQ-28 scores.

6.10 Time 2 Cross-Sectional Models

6.10.1 Impact of Background Variables on GHQ-28 Scores

None of the background variables tested was predictive of time two GHQ-28 scores, so were excluded from the analyses. To control for the confounding effects of past distress, time one GHQ-28 was included in the later models. The results of this analysis can be found at the top of table 6.2.

6.10.2 Predictive ability of Past Distress on Present Distress

The results of this APIM showed past distress levels were predictive of later distress in carers, but not patients (actor effect). Actor effects measure intra-individual changes, so this could be taken as suggesting some stability in carers' distress levels which is not found in patients' distress levels. Significant bidirectional effects were also found. When patients are more distressed at time one, this was associated with lower carer distress at time two, but when carers are more distressed at time one, this is associated with higher distress in patients at time two.

6.10.3 Impact of Illness Representations on Concurrent Distress

Separate APIMs were then conducted to examine the impact of each illness representation domain on concurrent (time two) distress, controlling for past (time one) distress. The main effects models found significant actor effects for both patient and carer (see columns 3 and 4). For patients, a stronger illness identity, a longer timeline, more negative consequences, a more negative emotional response and a stronger perception in the role of psychological causes were all significantly and positively associated with patient distress. Only one significant actor effect was found for carers, with more negative consequences associated with higher carer distress. No significant partner effects were found.

Table 6-2: APIM for Time Two Cross-Sectional Analyses predicting GHQ-28 Scores

APIM Parameters		Main Effects		with Discrepancy	
Model : Time 1 GHQ- 28 Scores		Patient	Carer	Patient	Carer
		β	β	β	β
Main effects	Actor Effect	0.07	1.05***		
	Partner Effect	-0.41**	.044*		
Models: Illness representations					
Model 1: Illness Identity					
Main Effects	Actor Effect	0.62**	0.06		
	Partner Effect	0.35	0.17		
Model 2: Timeline Acute					
Main Effects	Actor Effect	5.89**	0.73		
	Partner Effect	0.32	0.28		
Model 4: Consequences					
Main Effects	Actor Effect	5.90***	4.17*	7.87***	2.46
	Partner Effect	0.37	2.45	1.74	-0.001
Consequences Discrepancy				5.21	3.63
Model 5: Coherence					
Main Effects	Actor Effect	-1.26	2.08	-0.13	2.44
	Partner Effect	-1.47	2.61	-0.97	3.42
Coherence Discrepancy				-7.73*	-3.41
Model 7: Emotional Response					
Main Effect	Actor Effect	5.58**	-0.76		
	Partner Effect	2.7	1.23		
Model 8: Psychological Cause					
Main Effect	Actor Effect	3.38*	-0.46		
	Partner Effect	1.25	-1.29		

p<.05, ** p<.01, *** p<.001 n=32 couples

6.10.4 Impact of Discrepancy

The APIMs revealed that for patients, the impact of discrepancy was significant with respect to illness coherence and approaching significance for consequences. Patient distress was unrelated to their own illness coherence score, as indicated by the non-significant regression coefficients for actor main effects. However, the significant regression coefficient for discrepancy indicates that high discrepancy is associated with lower patient distress at time

two. Plotting this interaction revealed that when patient coherence is low (indicating poor understanding), distress is low and discrepancy has little effect (see figure 6.2). When the patient feels they understand their stroke (high coherence), low discrepancy is associated with higher distress, and high discrepancy with low distress.

Discrepancy with regards to the consequences of the stroke had a weak effect on patient distress ($\beta = 5.21$, $SE = 2.67$, $p = .06$). Plotting the impact of discrepancy revealed an additive effect. Whether the patient perceived high or low consequences, higher discrepancy increased distress levels (see figure 6.3).

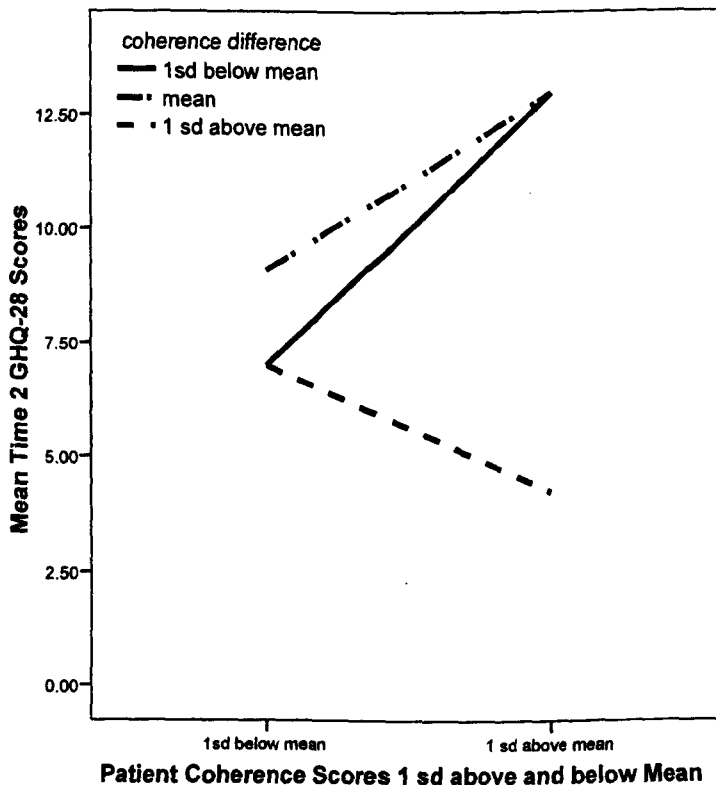


Figure 6-2: Interaction between Patient Coherence Scores, Discrepancy Scores and GHQ-28 Scores

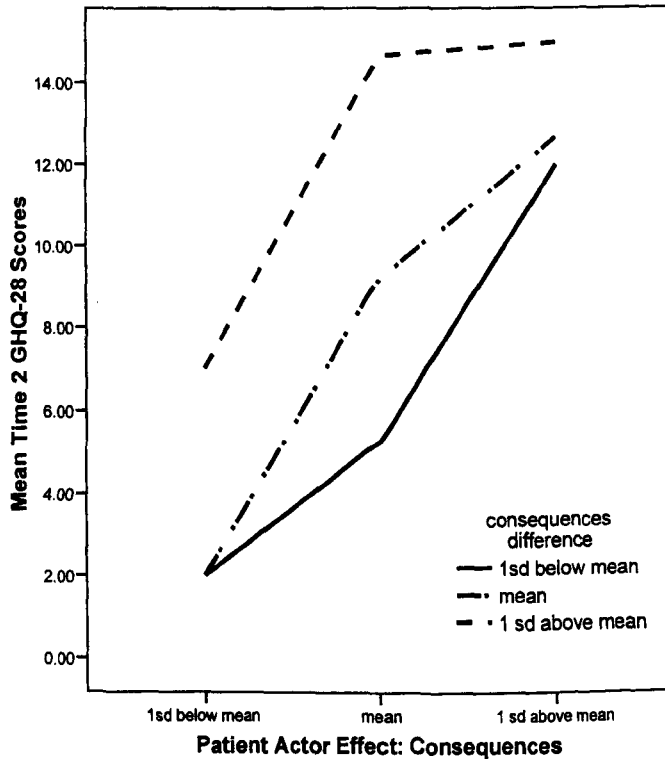


Figure 6-3: Interaction between Patient's Consequences scores, discrepancy and GHQ-28 Scores

6.11 Time 3 Cross –Sectional Analysis

6.11.1 Impact of Background Variables on GHQ-28 Scores

Initial APIMs identified background variables which were independently associated with patients' and carers' distress. Time three practical support, emotional support, disability (BI) and patient age were unrelated to time three GHQ-28 scores. A significant effect was found for carer's relationship satisfaction (MOS), and so this was included as a control variable. Time two GHQ-28 scores were also included to control for earlier distress. The results of these analyses are shown at the top of table 6.3. Patients' and carers' own earlier distress was positively and significantly predictive of their own later distress. No significant partner effects were found, suggesting that patient's and carer's distress levels were not significantly influenced by one another by this time.

Carers who reported higher relationship satisfaction (time three MOS) were also more distressed. However, no causal relationship can be established for this relationship due to the cross-sectional nature of the model. Patients' relationship satisfaction scores were not

associated with their own distress levels, but when the patient is less satisfied with their relationship this is associated with higher distress in the carer (partner effect).

Table 6-3: APIMs for Time 3 Cross-Sectional Analyses predicting GHQ-28 Scores

APIM Parameters		<i>Main Effects</i>		<i>with Discrepancy</i>	
<i>Model : Background variables</i>		Patient	Carer	Patient	Carer
		β	β	β	β
Time 2 GHQ-28					
Main Effect	Actor Effect	0.73***	0.68***		
	Partner Effect	0.13	0.15		
Relationship Satisfaction					
Main Effect	Actor Effect	-0.57	2.19*		
	Partner Effect	-1.68*	1.76		
Illness Representations					
Model 3: Coherence					
Main Effect	Actor Effect	1.03	-0.47	1.44	0.41
	Partner Effect	-0.94	-1.82	0.01	-1.45
<i>Coherence Discrepancy</i>				3.01	7.08**

* $p < 0.05$, ** $p < 0.01$ *** $p < 0.001$ $n = 32$ couples

6.11.2 Impact of Illness Representations

The main effects models failed to identify any significant actor or partner effects for the any illness representation dimension.

6.11.3 Impact of Discrepancy

The inclusion of discrepancy into each of the APIMs identified only one significant effect. Discrepancy with respect to illness coherence had a detrimental effect on carer's mood. However, the main actor effect for the carer's own perceptions was not significant, and so the interaction between own perceptions and discrepancy was plotted. This revealed that regardless of the carer's own perceptions, if discrepancy is low, the carer reports lower distress, and when discrepancy is high this is associated with high distress in the carer.

6.12 Summary of results of Cross-Sectional APIM Analyses

Time One Cross-Sectional Models

- Patients and carers are more distressed when the patient is more disabled (BI), with disability having a stronger impact on carer's distress (partner effect).
- Patients and carers are more distressed when the carer perceives that low emotional support is available to them, with low support having a stronger effect on patients (partner effect).
- Patients and carers are affected by their own illness representations (actor effects) but not by their partner's illness representations (partner effect).
- Discrepancy is associated with higher distress in carers, but not patients.
- Relationship satisfaction is not associated with distress levels in patients or carers.

Time Two Cross-Sectional Models

- Earlier distress is predictive of later distress in carers, but not patients.
- Patients and carers are affected by their own illness perceptions, but not by those of their partner.
- Discrepancy is associated with distress in patients, but not in carers.
- Relationship satisfaction is not associated with distress levels in patients or carers.

Time Three Cross-Sectional Model

- For each partner, earlier distress is predictive of own later distress, but not predictive of distress in the other partner.
- Illness representations were not associated with concurrent distress.
- Higher discrepancy with respect to whether the patient understands their stroke (coherence) is associated with higher distress in carers.
- Relationship satisfaction has a direct and indirect effect on distress levels in carers, but not patients. When carers report better relationship satisfaction this is associated with increases in own distress. When patients report lower relationship satisfaction this is associated with higher distress in carers.

6.13 Longitudinal Models: Predicting Time 2 Distress

6.13.1 Impact of Background variables on GHQ-28 Scores

Background variables (MOS, SOS, age, BI) were excluded from the model as they failed to exert any influence on time two distress (GHQ-28). Time one GHQ-28 scores were included to control for the confounding effects of earlier distress. The results of this initial APIM are shown in the upper section of table 6.4, and show that earlier distress is predictive of later distress for carers, but not for patients. When carers were more distressed at time one, this is translated into higher distress in patients at time two (partner effect), but the partner effect from patients to carers had the opposite effect; higher distress in the patient at time one was associated with lower partner distress at time two. The later APIMs tested the impact that each of the illness representations in turn exerted on time two distress. The significant results are shown in Table 6-4. The inclusion of each of the illness representation variables into the models did not affect the significance level of this initial model.

Table 6-4: APIM's for Time One - Time Two Longitudinal Analyses

APIM Parameters		Main Effects		with Discrepancy	
<i>Model:</i>		Patient	Carer	Patient	Carer
		β	β	β	β
<i>Time 1 GHQ-28 (control variable)</i>					
Main Effects	Actor Effect	0.07	1.05***		
	Partner Effect	-0.4**	0.44*		
Illness Representations					
Model 1: Timeline Cyclical					
Main Effects	Actor Effect	1.62	-2.49*		
	Partner Effect	0.39	-3.9**		
Model 3: Emotional Response					
Main Effects	Actor Effect	1.19	-2.47*		
	Partner Effect	0.81	-2.37		
Model 4: Psychological Cause					
Main Effects	Actor Effect	-1.81	1.24	-1.28	0.16
	Partner Effect	-2.65*	-0.76	-2.02	-1.67
Discrepancy Causal Attributions				2.05	2.39

* $p < 0.05$, *** $p < 0.01$, **** $p < 0.001$ $n = 32$ couples

6.13.2 Impact of Illness Representations

Patients' illness representations were not associated with their own distress levels (no significant actor effects). Carers were more distressed at time two when they reported a less cyclical timeline at time one, but less distressed when they felt the patient had a lower emotional response to the stroke at time one (actor effects). When carers reported a less cyclical timeline at time one, patients were more distressed at time two (partner effect from carers to patients). Similarly, when patients reported a stronger belief in the role of psychological factors in causing the stroke at time one; this was associated with lower distress in carers at time two. No other illness representations were significantly associated with time two distress.

6.13.3 Impact of Discrepancy

When patients and carers disagreed with respect to attributing the stroke to psychological factors, this had a relatively weak effect on carer distress ($\beta = 2.39$, $SE = 1.24$, $p = 0.06$), with higher discrepancy associated with higher distress. However, as the effect is marginal and the sample size small, this must be interpreted cautiously.

6.14 Predicting Time 3 Distress from Time 2 Illness Representations

6.14.1 Impact of Background variables on GHQ-28 Scores

Initial APIMs revealed that only time two relationship satisfaction (MOS) was associated with time three distress, so all other background variables were excluded from the analysis (BI, SOS, patient age, SOS). Time two GHQ-28 scores were included to control for the confounding effect of past distress. The results of this analysis can be found at the top of table 6.5. Patient's and carer's mood was significantly predicted by their own earlier mood, but not by their partner's mood, suggesting no interdependence between patient's and carer's level of distress by time three. Later models tested the impact of illness representations controlling for the impact of earlier GHQ-28, and MOS.

Patients were more distressed at time three when they reported lower relationship satisfaction (MOS) at time two (actor effect). Carers' relationship satisfaction was unrelated to their own time three distress levels. However, carers were more distressed at time three if patients reported lower relationship satisfaction at time two (significant partner effect). The effect of relationship satisfaction on later distress was largely unaffected by the inclusion of illness representations into later models, suggesting that it is independently associated with distress. The data does not suggest "interdependence" between the feelings of patients and carers, but a unidirectional association, with both partners affected by the patient's views.

Table 6-5: APIMs Predicting Time 3 Distress from Time 2 Illness Representations

APIM Parameters		Main Effects		with Discrepancy	
Model : Background variables		Patient β	Carer β	Patient β	Carer β
Time 2 GHQ-28					
Main Effects	Actor Effect	0.57*	0.8***		
	Partner Effect	0.01	0.27		
Relationship Satisfaction (MOS)					
Main Effects	Actor Effect	-3.03**	1.98		
	Partner Effect	-3.2**	0.25		
Illness Representations					
Model 1 : Illness Identity					
Main Effects	Actor Effect	0.55	-0.38		
	Partner Effect	0.65*	0.15		
Model 2: Consequences					
Main Effects	Actor Effect	0.44	4.01		
	Partner Effect	-0.88	8.67***		
Model 3: Coherence					
Main Effects	Actor Effect	0.74	-1.48	-0.06	-2.48
	Partner Effect	-0.09	0.89	-1.27	0.25
Coherence Discrepancy				3.68	5.83*
Model 5: Emotional Response					
Main Effects	Actor Effect	1.65	0.86	-2.18	2.06
	Partner Effect	-0.81	5.61**	-2.42	8.5***
Emotional Response Discrepancy				-8.38**	-3.52

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$ $n = 32$ couples

6.14.2 Impact of Illness Representations

The main effects model revealed that each partner's illness representations were not predictive of their own distress levels. However, three significant partner effects were found. When patients reported more symptoms (stronger illness identity) at time two, carers reported higher distress at time three. When carers report more severe consequences associated with the stroke, or believed the patient was distressed by their stroke (high emotional response score on IPQ-R) at time two, this was associated with higher patient distress at time three.

6.14.3 Impact of Discrepancy

Discrepancy with regard to illness coherence was significantly and positively associated with carer distress, with higher discrepancy at time two associated with higher time three distress. Plotting the interaction (not shown) revealed that regardless of the carer's own illness perception, when discrepancy was high, this was associated with high distress.

Discrepancy with respect to the way the patient and carer perceive how the stroke has affected the patient emotionally was associated with a significant decrease in patient's time three GHQ-28 scores. Plotting this interaction (not shown) revealed that when the patient felt the stroke was not distressing, discrepancy had no impact, but when the patient reported higher emotional response scores at time two, high discrepancy was associated with a large decrease in patient distress at time three.

6.15 Summary of Results of Longitudinal APIM Analyses

Time 1 – Time 2 Longitudinal Models

- Past distress was a good predictor of later distress in carers, but not in patients.
- Patient disability was not predictive of later distress for patients or carers.
- Patients' illness representations were not predictive of their later distress, but when carers were distressed at time 1 this was associated with higher distress in patients at time two (partner effect).
- Carers' distress was predicted by both their own illness representations (actor effect) and by those of the patient (partner effect).
- Discrepancy was not predictive of patient distress, and was only marginally associated with distress in carers, suggesting that discrepancy is not a good predictor of patients and carers emotional states.
- Relationship satisfaction was not associated with patient's or carer's distress levels.

Time 2 – Time 3 Longitudinal Models

- For both partners, time three distress was predicted by their own past distress, but not by their partner's earlier distress.
- Illness representations exerted no significant actor effects for either partner, suggesting mood is not directly associated with their own perceptions.

- Significant partner effects from carers to patients indicate that what the carer believes affects how the patient feels (partner effect).
- Discrepancy is associated with both partners' later distress levels, but different illness perceptions are important. When patients and carers disagree about whether or not the patient understands their stroke (coherence) this is associated with higher distress for carers. However, when partners disagree about how much the stroke has upset the patient (emotional response) this is associated with lower patient distress at time three.
- When patients report lower relationship satisfaction this is associated with higher distress in both partners.

7 Quantitative Discussion

The first section of the discussion is organised according to the research questions as set out in the introduction. Each section will present the findings and links will be made to existing research. The second section will discuss the strengths and limitations of the study and will examine the use of multilevel modelling as an approach for analysing discrepancy data. The final section will consider implications for clinical practice in stroke care and future research.

7.1 Level of Distress in the Sample

The results show that level of distress within the sample changed little over the assessment period, and patients' distress levels were significantly and positively associated with the distress experienced by their partners' at all three assessment points. This is consistent with previous research (Schulz et al. 1988; Dennis, O'Rourke, Lewis, Sharpe and Warlow 1998; Kotila, Numminen, Waltimo and Kaste 1998; Klinedinst et al. 2007). Moreover, the fact that distress levels of patients and carers did not decline significantly over the time of the study, has also well reported in the literature (Murray et al. 2003b; Berg, Psych, Paolmaki, Lonnqvist, Lehtihalmes, Phil and Kaste 2005).

As well as being significantly correlated, patient and carer distress levels exerted a significant influence on one another, although this effect was only observed for time two distress levels. Specifically, early carer distress is predictive of higher patient distress at time two, suggesting a within-couples effect running from carers to patients. This finding is supported by empirical evidence which shows that people's anxiety levels can be influenced by a partner, even when that partner is not facing the same threat (Gump and Kulik 1997). This finding has also been found in studies examining the effect of partner distress on women suffering from breast cancer (Maly, Umezawa, Leake and Silliman 2005; Segrin et al. 2007) which found women with cancer were less distressed when they had a family member who was less anxious. These findings underscore the importance for patients of having a well partner who is less distressed while the couple cope with the challenges of the stroke.

A decision was taken not to use cut-off criteria for the GHQ-28 scores, but to use the scores themselves as the dependent variable. This decision was taken for two reasons. Firstly because using cut-off scores reduces the data to dichotomous variables and thus loses valuable information; and secondly because there is the lack of agreement over the optimal cut-off for

caseness in stroke samples. Previous studies using the GHQ-28 have used different cut-off levels to define “cases” of distress. Adopting the 11/12 cut-off used by Lincoln and colleagues (2003) resulted in 23.8% of patients defined as cases whereas using the lower 8/9 adopted by Lykouras and colleagues (1996) results in 50% of patients defined as cases. These rates fall below and above the 36% prevalence rate calculated by Hackett and colleagues (2005) in a recent systematic review of the literature. Applying the lower 5/6 cut-off for carers indicates that 59.5% of relatives score above the “caseness” cut-off for mood disturbance at time one, which is higher than that found by many studies, (Schulz et al. 1988; Dennis et al. 1998; Han and Haley 1999), with the Han and Haley review reporting rates of between 39% and 42%, although this difference likely reflects the different methods and assessment times.

7.2 Do Patients and Carers have a Coherent Model of Stroke at Baseline?

It has been proposed that the cognitive models that individuals construct about an illness have an internal coherence (Leventhal, Diefenbach and Leventhal 1992; Hagger and Orbell 2003). The pattern of intercorrelations found in the illness representations of patients and carers in the present study provides some support for this assertion. At baseline, the pattern of inter-correlations between illness representations provided evidence of a coherent model in terms of the negative connotations surrounding stroke, with positive correlations between the more pessimistic illness beliefs, but the more positive illness representations were not well-integrated into patients’ model of stroke. Thus these findings only partly support the idea of internally coherent model.

Illness identity showed some, but not all of the anticipated associations, with the more pessimistic illness representations. Strong, positive associations were found between a stronger illness identity, more negative consequences and a stronger emotional response to the stroke, but failed to correlate strongly with a more chronic timeline. This suggests that when the stroke is perceived to be severe in terms of high symptomology, it is distressing and is associated with negative consequences. However, the number of symptoms patients associated with the stroke did not influence how long patients felt it would take to recover. This lack of association is not unexpected as previous experiences of illnesses lead us to develop a model of illness which is acute and curable (Leventhal, Brissett and Leventhal 2003) and initially it may be this stereotypical schema which is triggered. Most patients believed that recovery would be relatively fast which confirms the findings of earlier studies of stroke survivors (Joice et al. 2003; Ford 2007), and these beliefs did not change significantly over the study period.

However, in the present study the patient's timeline acute/chronic subscale had lower than desired internal reliability ($\alpha = 0.68$), which may account for this result.

A stronger causal attribution towards psychological factors (stress, family worries and getting worked up emotionally) was associated with more negative consequences, lower coherence, longer timeline and a stronger emotional response to the stroke. It therefore seems that holding beliefs about a psychological cause for the stroke is associated with perceiving it generally more negatively. As stress is a common causal attribution made by stroke survivors and those at risk of stroke (Gupta and Thomas 2002; Truelsen, Nielsen, Boysen and Gronbaek 2003; Carroll et al. 2004) this relationship is interesting and worthy of further research. In contrast, attributions towards a behavioural cause were not associated with any other illness dimension. The lack of relationship between causal attributions and other illness representations is not an uncommon finding (Heijmans and De Ridder 1998a) and in the present study is likely to reflect the tendency for patients to make at least one attribution towards a behavioural cause, such as hypertension and hypercholesterolemia, which may weaken the observed relationship between this behavioural causes and other illness dimensions.

Patients held quite positive personal control beliefs. However, personal control correlated only with beliefs about the consequences of the stroke and not with any other illness dimensions. This finding is counter to the majority of research which finds personal control beliefs to be negatively correlated with the more pessimistic illness representations (Heijmans and De Ridder 1998a, b; Moss-Morris et al. 2002; Rutter and Rutter 2002; Fortune et al. 2005; Treharne, Kitas, Lyons and Booth 2005). However, all these studies examine the illness perceptions of patients who have long term diagnoses, so are not directly comparable with the present study. One explanation for the lack of association between personal control and other dimensions in the present study may be due to the low internal reliability of the subscale, or may reflect a lack of statistical power. However, that these findings are similar to those found in other stroke (Joice et al. 2003; Ford 2007) suggests these results are not a statistical artefact.

The low internal reliability of the control subscale may indicate that patients do not conceptualise personal control as a unitary construct, which could weaken the statistical link between control and other illness dimensions. French and Weinman (2008) use the example of diabetes to make the case that because of the generic nature of the IPQ, the control subscale can be interpreted in different ways, and argue that the notion of control may be ambiguous. The same case can be put for stroke where recovery encompasses more than reduction of physical deficits. Furthermore, the same lack of association between control perceptions and other

illness representations has also been found in studies examining other complex, multifaceted illnesses such as schizophrenia and Huntington's disease (Lobban, Barrowclough and Jones 2005a; Kaptein et al. 2007) which supports the idea that beliefs about control may not be tapped adequately by quantitative methods. It may therefore be fruitful to use qualitative methods to explore how patients perceive issues of personal control, and this is an area worthy of further research.

An important aspect of this study was to examine not only what the patient thinks about the stroke, but to consider how the carer understands it, and to examine differences and similarities in their perceptions. At baseline, carers reported that the patient had a lot of symptoms associated with their stroke, but the recovery would be moderately quick, and without severe consequences. They also felt it was quite distressing for the patient, that the patient had a reasonable understanding of the stroke and good control over recovery. Carers did not hold strong causal beliefs towards either a psychological or behavioural cause for the stroke, and their causal beliefs were not correlated with other aspects of the carers' illness representation.

In common with patients, carers' illness representations of the stroke were coherent in terms of its negative connotations. Again, as with the patient results, beliefs about controllability were unrelated to the other dimensions of the illness representations, and the reasons discussed above may be posited as potential explanations for these findings. The inter-relationship between aspects of carers' illness representations have been seldom examined systematically, so there is little data to compare with these findings. However, two studies, both examining the illness representations of schizophrenia carers, report similar findings to the present study (Barrowclough and Lobban 2001; Lobban et al. 2005b).

7.3 Relationship between Patient and Carer Perceptions

Overall, with the exception of beliefs about personal control and treatment control, patients and carers illness representations were moderately to strongly correlated. Similar findings have been reported in a range of conditions, including myocardial infarction (Weinman et al. 1996), type 2 diabetes (Searle et al. 2007), Huntington's disease (Kaptein et al. 2007), and rheumatoid arthritis (Sterba et al. 2008), and likely reflect the similarities in their experiences, and in the information given to both parties by health professionals. In common with previous research, patients tended to hold more positive views about the stroke than carers did (Knapp and Hewison 1999; Visser-Keizer et al. 2002; Hochstenbach et al. 2005). It seems likely that

these findings reflect a lack of knowledge about the stroke (Hanger and Mulley 1993; Wellwood et al. 1994), and carers' more negative interpretations may be a reflection of this. However, the stroke also places significant extra burden onto the carer who may feel ill-equipped to cope with the additional responsibility of caring for the patient (Brocklehurst et al. 1981; Visser-Meily et al. 2006), and these more pessimistic views of the stroke may be a reflection of this strain.

7.4 Do Illness Representations Change over Time?

The present study found that patients' illness representations remained relatively stable over time, with significant changes only in beliefs about personal control and treatment control, which became significantly more negative over time, but given the low internal reliability of these scales these should be interpreted cautiously. However, the finding that stroke patients and carers initial optimism for recovery declines over time is supported by other studies (Morrison et al. 2000; Johnston et al. 2004), and may reflect the slowing down of recovery experienced by many stroke survivors (Doolittle 1991; Burton 2000). Patients also perceived that their understanding (coherence) of their stroke declined over time, but this was only significant at the 5% significance level, so this too should be interpreted with caution.

No other aspects of patients' and carers' illness perceptions were found to change over time. This apparent lack of change in their illness representations contrasts with the expectations both of Leventhal's self-regulatory model (Leventhal et al. 1980) and the findings of other studies (Weinman et al. 1996). One possible explanation for the apparent lack of significant changes in patients' illness representations over time is that the results may be an artefact of the way in which the data was analysed. Analysis of variance was used to examine changes over time, but this is based on changes in group level scores, which may mask individual level differences. In the case of stroke, where knowledge has been found to be poor (Wellwood et al. 1994), and the deficits left by the stroke can be wide ranging (Young et al. 2003), it is reasonable to expect that illness perceptions would change over time, and although there are few longitudinal studies, these provide some evidence that both patient and carer perceptions change over time (Knapp and Hewison 1999; Clark 2000).

Although the group level data revealed few changes over time, an attempt was made to examine discrepancy at the level of the couple. In common with other studies (Heijmans et al. 1999) the results revealed that whilst most carers held more pessimistic views of the stroke than did patients, a significant minority of carers were more positive than the patient. Therefore, an

attempt was made to devise a measure of discrepancy which would identify those couples who were most discrepant in their illness representations, regardless of whether the carer was more positive or more negative than the patient. To achieve this, absolute difference scores were calculated and this was used to classify couples as congruent or discrepant in their perceptions.

The results revealed that at time one, only 31% of couples were congruent in all dimensions of their illness representation, indicating that in this sample discrepancy was quite common, a finding which was masked by the ANOVA results. Couples diverged in the number of symptoms they attributed to the stroke, its perceived consequences, the level of control the patient had over their recovery and the causal attributions they made, which is similar to the findings of other studies (Figueiras and Weinman 2003; Richards et al. 2004). By time three, few couples were discrepant in their perceptions of the symptoms resulting from the stroke or the patients' personal control. These findings support the idea that at the level of the couple, there is some degree of change in illness perceptions over time. However, no comparable, longitudinal data was found with which to compare these findings. The number of couples who were discrepant in their causal attributions did not change, and a significant minority of couples were still discrepant in their perceptions of the consequences of the stroke.

Discrepancy in the causal perceptions of patients and carers remained high throughout the study. No quantitative studies were found with which these results could be compared, but qualitative studies have found there to be little correspondence between the causal beliefs of stroke patients and carers (Thompson 1991; Clark 2000). In the present study discrepancy in the causal attributions of partners towards a psychological cause was associated with higher carer distress, but not with patient distress. Previous research has found support for a link between discrepant causal attributions and patient distress (Heijmans et al. 1999), but significant differences between the two studies in terms of illness and time since diagnosis may account for the contradictory findings. No previous study was found which examined the impact of discrepancy on carer distress but as causal perceptions are hypothesised to guide coping behaviours (Leventhal et al. 1984) this provides a potential area for an intervention to reduce carer distress as well as improve secondary prevention behaviour in patients.

One explanation for the high level of divergence in couples' illness representations at time one is that, initially, patients and carers hold illness perceptions which are based on prototypic information (Bishop 1987). Therefore the early divergence in their views could be attributed to a lack of knowledge about stroke. However, research into family communication within the context of cancer shows that families often actively avoid talking about the patient's

illness because they feel to do so is not in the patient's best interests (Vess, Moreland, Schwebel and Kraut 1988; Coyne and Smith 1991; Faulkner and Maguire 1994). The avoidance of difficult discussions may also be a coping strategy enacted to manage the emotional impact of sudden illness (Coyne and Smith 1991). One form of which is "protective buffering", the term Coyne and Smith used to describe couples who actively avoided talking about some aspects of the illness in order to protect their partner. The results of the quantitative study cannot shed light on whether the couple talked about the stroke or not, but it is plausible that during the weeks and months after the stroke some families may avoid open communication about the stroke, which would contribute to the maintenance of discrepancy, as misconceptions and misunderstandings would be less likely to be resolved (Rolland 1994). This will be explored within the qualitative study.

There is good evidence, that at least in the short term, not talking openly about the trauma of the stroke may actually be beneficial. Experiencing a stroke is a traumatic event, and a recent Cochrane review of the post-traumatic stress literature concluded that there is evidence to suggest that early debriefing following a trauma may not be beneficial and may indeed be harmful (Rose, Bisson, Churchill and Wessely 2002). Therefore the avoidance of difficult discussions during these early weeks may maintain discrepancy in their illness perceptions, but may also serve a protective function whilst the couple manage the emotions triggered by the trauma of the stroke.

7.5 Convergence in Illness Representations over Time

The discrepancy analysis provided good evidence that couples illness perceptions became more similar over time. A number of possible explanations for convergence over time can be posited. One explanation is that as patients and carers gain knowledge and experience they develop richer and more complex representations (Hampson and Glasgow 1996), which changes their understandings of the stroke. Another possible explanation for the convergence in partners' illness representations over time comes from the cognitive dissonance literature (Festinger 1957). Festinger proposed that individuals are influenced by those within their social network, such that when individuals within a group (couple) hold different attitudes or, in this instance, illness perceptions, this causes a state of tension within the group such that an individual is driven to change their views to that of the group or the more influential group member (Ross and Nisbett 1991).

However, this hypothesis raises two key questions. Firstly, which partner is deemed to be the more influential group member, and secondly what mechanisms are implicated in the reduction of cognitive dissonance? Is the reduction of dissonance driven by normative pressures, for example to establish positive relations with one's partner, or perhaps because one partner is perceived by the other to be more dominant within the relationship? Alternatively is dissonance reduction driven by informational pressures, for example because one partner feels the other is better informed? This quantitative study is ill-equipped to answer these questions, but the issue of negotiation of beliefs will be examined in the qualitative study.

Empirical studies using student populations have found that dissonance induced by group disagreement can be reduced through a range of interpersonal strategies including persuasion and changing one's own position (Matz and Wood 2005). However, few studies have applied this theory to real-life health issues. One qualitative study was identified which described changes to the illness perceptions of couples where the husband has been diagnosed with chronic heart disease (Patterson 1989). In this study the illness perceptions of patients were found to move towards those of their well partner in response to the persuasive attempts of the well spouse. Using a case study approach, Patterson described cases where the ill partner's views changed because they were influenced by the views of their wife, who was perceived by the patient to hold expert knowledge. Other patients were found to change their views about their disease in response to lifestyle changes imposed by their wives, such as changes to their diet and exercise regimes. This was a qualitative study and was not specifically examining the issue of dissonance, but the findings are nevertheless interesting as they provide some tentative evidence for at least two methods of cognitive change in couples. However, as all patients were male it is unclear whether the apparent persuasiveness of well spouses was due to their role or gender.

7.6 Maintenance of Discrepancy

A quarter of couples still differed in their perceptions of the causes and consequences of the stroke at time three. Divergence in their perceptions of the consequences of the stroke was towards carers over-estimating the consequences compared to patients, which accords with the findings of other studies (King, Shade-Zeldow, Carlson, Knafl and Roth 1995; Clark 2000). In this sample, the maintenance of discrepancy over time was not associated with the age or gender of the patient or carer, the level of patient disability or the level of relationship satisfaction at time one. Indeed, the only factor associated with the maintenance of discrepancy over time was the presence of symptoms of emotional distress reported by the carer at time one. This finding

is in keeping with the results of a review examining predictors of discrepancy in the context of cancer, which found greater discrepancy in the couples' perceptions of the patients' quality of life occurred when the carer reported high levels of burden (Lobchuk and Degner 2002). Cognitive models of depression suggest that depressed people show dysfunctional cognitive processing (Abramson, Seligman and Teasdale 1987) and selectively attend to negative information even in the presence of positive information. It is therefore plausible that maintenance of discrepancy in some couples is due to maladaptive thinking on the part of these carers, which results in pessimistic illness perceptions, which is then maintained through the selective attention to negative information.

The present study found no support for a link between the maintenance of discrepancy and lower relationship satisfaction. To date, studies have only examined the relationship between concurrent discrepancy and relationship satisfaction, and the findings are contradictory, with some studies finding support for such a link (Heijmans et al. 1999), and others finding no support (Figueiras and Weinman 2003). The maintenance of discrepancy in illness perceptions has been rarely examined (Knapp and Hewison 1999), and no study was found which used the IPQ or IPQ-R to examine changes in discrepancy over time. Therefore, the lack of convergence found in some couples in the present study must be viewed cautiously as it may be an artefact of the sample size. Furthermore, it cannot be certain whether the maintenance of discrepancy in these domains is typical of families or specific to the present sample. To determine this, there is a need for further research to replicate these findings.

7.7 Correlations between Illness Representations and Emotional Distress

At time one, patients were more distressed when they perceived more symptoms to be associated with the stroke. However, bivariate correlational analyses found no other significant associations between patients' illness representations and distress levels. This was an unexpected finding as studies have consistently found such an association in patients who have recently been diagnosed with a range of conditions including stroke (Joice et al. 2003; Ford 2007), epilepsy (Kemp, Morley and Anderson 1999), rheumatoid arthritis (Sharpe, Sensky and Allard 2001; Llewellyn, McGurk and Weinman 2007) and cancer (Treharne et al. 2005).

In the present study the only variable to show any significant association with patient or carer distress at time one was patient disability (Barthel Index) which remained significant at each assessment point which supports previous research (Schulz et al. 1988; Hackett and

Anderson 2005). The lack of any obvious association between illness perceptions and distress in stroke patients contradicts the findings of Ford (2007) and Joice et al. (2003). The differences in these results are difficult to explain given the apparent similarities between the studies, but as neither study was published unreported differences may exist between the samples. Alternatively the lack of association may be due to small sample size. However, as will be discussed in the next section, the APIM analyses did find statistically significant, albeit modest ($p < 0.05$) associations between patients' illness representations and patient distress at time one, after controlling for the effect of patient disability.

At time two and time three, the expected pattern of relationships between the negative illness representations and patient distress emerged (Hagger and Orbell 2003). Patient distress was significantly and positively associated with a stronger illness identity, more cyclical timeline, more negative consequences and a more negative emotional response. However, control beliefs were not associated with patient distress at any assessment point. Evidence from studies examining the association between personal control and distress in stroke patients is mixed, with two studies finding personal control to be unrelated to emotional distress (Joice et al. 2003; Ford 2007), and one study finding support for a link (Morrison et al. 2000). Evidence from other illnesses support a link between patient and carer perceptions and outcomes in individuals with longer-term diagnoses (Murphy, Dickens, Creed and Bernstein 1999; Edwards, Suresh, Lynch, Clarkson and Stanley 2001; Groarke, Curtis, Coughlan and Gsel 2005; Knibb and Horton 2008), making the inconsistent results from studies of stroke patients is interesting and worthy of further study. However, as discussed earlier, personal control may not be a unitary construct and therefore the different findings may be a reflection of different ways in which control is conceptualised by individuals who have been recently diagnosed compared to individuals with long term diagnoses.

Examining the relationship between carer perceptions and patient distress reveals a number of significant correlational relationships. At time two and time three, patients were more distressed when the carer perceived there to be more symptoms associated with the patient's stroke (stronger identity), a more cyclical timeline, more negative consequences, felt the patient was distressed by the stroke (emotional response) and reported a stronger belief in the role of psychological factors as causing the stroke. These findings are in the expected direction and support previous research (Barrowclough and Lobban 2001; Arefjord et al. 2002); (Lobban et al. 2005b; Kaptein et al. 2007). As Weinman and colleagues note, carer perceptions can have a direct effect on patient outcomes (Weinman, Heijmans and Figueiras 2003), and also influence how carers interact with patients. As the associations in the present study are

correlational only, no causal relationships can be assumed. The emergence of correlational links between patient and carer illness representations and distress in both partners indicates the importance of cognitive mediators in understanding psychological adaptation to chronic illness. It also suggests that specific illness representations may be important and therefore provide potential targets for therapeutic intervention.

7.8 Actor Partner Interaction Model (APIM) Analyses

The aim of this analysis was to explore the relations between discrepant illness perceptions, social support, relationship satisfaction and distress. However, it was also identified as important to examine the impact of discrepancy within the context of what each partner thought about the stroke, thus offering a more stringent test of the impact of discrepancy on distress. To achieve this aim a multi-level modelling approach was adopted which provided a novel way of assessing the impact of discrepancy, without increasing colinearity between predictor variables. This approach considers partners as individuals nested within couples, which allows micro-level relations to be examined (Kenny et al. 2006). This study demonstrates the plausibility of using multilevel modelling to overcome the difficulties inherent in examining only discrepancy, and the problems of multicollinearity found in standard regression models. However, there were no sustained trends found in the data, but instead different illness representations emerged as significantly associated with distress at each time-point. The large number of analyses, lack of consistent findings, and the small sample size in the present study means that the relationships reported in the next section should be interpreted cautiously and need to be replicated before any firm conclusions can be drawn.

The results show that each partner's illness representations were associated with their own distress level and their partner's perceptions exerted much less influence. This contrasts with Kelley's assumptions of interdependence within couples (Kelley and Thibaut 1978; Kelley et al. 1983), as there seems to be little interaction between the illness perceptions of one partner and the distress reported by the other partner. However, after controlling for patient and carer illness representations, discrepancy was related to higher distress in both partners. The APIM analyses found that patients' illness representations were significantly associated with the patient's concurrent distress level, but not predictive of later distress. This finding was unexpected as other studies have found patient beliefs to be predictive of a range of outcomes including later distress (Morrison et al. 2000; Sharpe et al. 2001; Groarke et al. 2005; Llewellyn et al. 2007) and physical recovery (Petrie and Weinman 1997; Johnston et al. 1999), in a range of illnesses, including stroke. In the present study, significant associations between illness

representations and patient distress at time one were not expected given the weak bivariate correlational results discussed earlier. However, after controlling for the level of patient disability, significant associations were found. Specifically, patients were more distressed when they reported more symptoms, a longer timeline, more negative consequences, a stronger emotional response, lower coherence and a stronger role for psychological factors in causing the stroke. As discussed earlier, these findings support those found in other studies (Ford 2007), although the fact that this pattern only emerged after controlling for patient disability is more difficult to explain, and so the results should be viewed as tentative.

The strongest associations were found at time two, reflecting the stronger bivariate correlations at this time-point. However, this pattern was not replicated at time three (three months later) when, despite strong positive correlations between patient's illness representations and patient distress, no significant associations were found in the APIM analyses once past distress and relationship satisfaction were controlled for. The lack of association between illness representations and distress at time three is unexpected, but may reflect the importance of the role of relationship satisfaction which was used as a control variable in this analysis.

Carer perceptions were also found to be associated with patient distress. At time one, when the carer perceived that the patient understood their stroke (high coherence) this was associated with higher concurrent patient distress. This can be contrasted with the patient's own illness perceptions, where high coherence was associated with low distress. Illness coherence emerged as an important factor in the present study and will be discussed in more depth in the next section. Carer beliefs were also predictive of patient distress prospectively. When carers reported a less cyclical timeline at time one this was related to higher patient distress at time two, and when carers reported more negative consequences at time two, this was associated with higher patient distress at time three. These results are in line with previous research which has found spousal beliefs to be predictive of behavioural outcomes in patients (Weinman et al. 2000; Kaptein et al. 2007; Searle et al. 2007; Molloy et al. 2008). However, this is the first study to find carer perceptions are predictive of patient distress, and as such more research is justified to examine the unique contribution of carer perceptions to patient distress.

Carers were more distressed when they perceived there to be more negative consequences associated with the stroke. This association is in keeping with previous research which suggests that certain stressful appraisals affect carer distress (Barrowclough and Lobban 2001; Fortune et al. 2005; Kaptein et al. 2007). However, in the present study no support was found for a relationship between a more chronic timeline and higher carer distress, which

contradicts the findings of the only other study examining the illness perceptions of stroke carers (McClenahan and Weinman 1998). However, significant differences exist between these studies in terms of sample and design which may account for the lack of association in this study. These studies highlight the role that maladaptive illness cognitions play in carer distress, and suggest the potential for a role for therapeutic interventions to reduce carer distress.

Patient beliefs were unrelated to concurrent carer distress, and few predictive associations were found, although a stronger belief in the role of psychological factors on the part of the patient at time one was found to be associated with lower carer distress at time two, and when patients reported more symptoms at time two this was associated with higher carer distress at time three. However, these relationships were only significant at $p < 0.05$ level and so must be interpreted cautiously. Overall these analyses indicate that patients and carers who are more positive about the stroke report lower concurrent distress levels, but that illness representations show little predictive power. Patients and carers are more distressed when they hold negative views about the stroke, but there was little evidence of mutual dependence (Kelley and Thibaut 1978) in their illness perceptions.

7.9 The Predictive Utility of Discrepancy

Although partners' illness representations did not exert any direct influence on each other's distress level, when partners disagreed in their illness representations of the stroke, this was associated with both patient and carer distress. Specifically, at time one, when patients and carers disagreed about the level of (personal) control the patient had over their recovery, and the cyclical nature of the timeline, carers reported higher concurrent distress. In both of these models the perceptions of the carer were not directly associated with distress, but level of disagreement between partners was significant. This is important because it suggests that dissonance in the perceptions of partners has a direct impact on distress, regardless of the individual's own illness perceptions.

Illness coherence was found to be associated with both patient and carer well-being. However, these associations proved to be complex. Bivariate correlational analyses found that the illness coherence scores of patients and carers were not strongly correlated, and only weakly associated with distress levels. However, the APIM analyses revealed that when partners did not agree, this was associated with both patient and carer distress. Specifically, the results show that when the patient felt they understood their stroke (high coherence) this was associated with lower distress. This finding is in keeping with the idea that stronger coherence provides some

sense of control over the illness (Moss-Morris et al. 2002), and has some support from previous studies (Ford 2007), although the opposite finding has also been reported (Joice et al. 2003). When partners disagreed, this affected patient distress, such that when the patient felt they understood their stroke but their carer did not, the patient reported low distress, suggesting that discrepancy has little effect. However, when discrepancy is low because both partners reported high patient coherence this was associated with higher patient distress.

This finding appears paradoxical, and indeed contrasts with the only other study to examine the impact of coherence discrepancy on patient outcomes in which similar positive beliefs were associated with lower patient distress (Sterba et al. 2008). However, significant differences exist between these two studies in terms of illness, patient gender and time since diagnosis which may account for the differences in these findings. One possible explanation for these results is that when the carer feels the patient understands their stroke this may be associated with a reduction in supportive behaviours on the part of the carer which increases patient distress. However, neither social support nor relationship satisfaction scores were associated with illness coherence discrepancy scores, indicating that discrepancy is not a reflection of a poorer relationship in this sample. To date, few studies have examined the association between discrepant illness representations and psychological outcome, and the findings are contradictory, with Heijmans and colleagues (1999) finding support for such as link in a sample of long-term diagnosed chronic fatigue and Addison's disease patients, and Figuerias and Weinman (2003) finding no support for a link in a sample of recently diagnosed myocardial infarction patients. However, differences in terms of sample, gender and time since diagnosis makes comparisons inappropriate.

It may well be that the link between discrepancy and poorer relationship satisfaction develops over time, but more studies are needed to test this, and therefore the current results need to be replicated to discover if this is an artefact of the present analysis or a stable finding. Finally, the cross-sectional nature of these analyses means that the causal links suggested here cannot be tested. However, these results do hint at the possibility that congruence of illness perceptions may not always be beneficial to the patient. Discrepant perceptions of illness coherence also had a significant impact on carer distress such that regardless of the carer's own illness perceptions, if the partners disagree the carer reported higher distress. Furthermore, discrepancy in illness coherence was associated with carer distress both concurrently and prospectively suggesting that this is an area worthy of further investigation.

7.10 Social Support

Substantial evidence points to the benefits of social support during recovery from stroke (Palmer and Glass 2003). In the present study social support scores were stable over time, and there were no significant differences in the levels of support reported by partners, which is a positive finding in light of the decline in social support over time often reported in the literature (Anderson 1992), and the buffering effect of social support against negative outcomes (Brown and Harris 1978; Monroe, Connell, Bromet and Steiner 1986). However, the sample was characterised by the presence of social support because patients were only recruited to the study if they could identify a named carer. As such, the consistent pattern of support may be partly methodological. In the present study, practical support was unrelated to emotional distress in either partner, and emotional support was only associated with time one distress. Specifically, when the carer perceived themselves to have low support this was associated with higher distress in both partners. This finding lends support to the idea that the presence of emotional support is protective of distress in carers (Kerr and Smith 2001; Bakas, Austin, Okonkwo, Lewis and Chadwick 2002) at least during the first months after the stroke. Social support was not directly associated with patient distress, and did not emerge as a significant predictor in later models, which is contrary to previous research (Knapp and Hewison 1998).

Ordinarily, social support is considered to have a buffering effect on distress. However, one explanation for the lack of association between social support and emotional distress comes from the matching hypothesis (Cohen 1988) which posits that different types of social support are beneficial when they match the contextual features of the stressor. Evans and Northwood (1983) found that support was most effective when the recipient judged that it met their emotional needs. The Significant Other Scale used in the present study operationalises support as the availability of emotional and practical support from three named individuals. This does not mean that respondents have accessed or indeed would access these individuals for support for any given stressor, and this may be an important distinction. Social support may also have different effects on different stressors. For example, Revenson and colleagues (1983) found that for individuals with significant disability the receipt of support had negative consequences because it highlighted their inability to reciprocate that support. Therefore, different forms of support may have a differential effect on distress. This has clinical implications for the management of both patient and carer distress.

7.11 Relationship Satisfaction

Relationship satisfaction declined over time, with larger declines between time two and time three. These results correspond with the findings of other stroke studies which show that personal relationships become more strained over time (Anderson 1992; Clark and Smith 1999a). Studies of other illness groups (Heijmans et al. 1999; Northouse, Mood, Templin, Mellon and George 2000) have shown that couples can have very different patterns of adjustment to illness. One question which arose at the beginning of the study was whether good communication between the patient and carer would buffer the relationship between more negative illness perceptions and distress, and to examine this, the MOS was included to assess the interaction between the patient and carer. However, the results of this study yielded a complex and contradictory picture of the role of relationship quality and distress. Furthermore, given the sample size of the study, the results should be considered preliminary.

In general, the results showed the expected relationships as when patients reported lower relationship satisfaction at time two this is associated with higher patient and carer distress at time three (Briscoe and Smith 1973; Coyne, Thompson and Palmer 2002; Lemmens, Buysse, Heene, Eisler and Demyttenaere 2007). The direction of the effect supports the view that relationship strain precedes and is causally related to distress (Beach, Sandeen and O'Leary 1990). Furthermore, there was a significant interpersonal effect which was also in the expected direction, with carers reporting lower emotional distress to the extent that their ill partner was satisfied with their relationship. No comparable data was found with which to compare this finding, but the results suggest that there is some influence from how the patient interprets their relationship and distress experienced by well partners, highlighting the importance of considering both partners when examining predictors of distress. In contrast, when carers reported feeling high levels of relationship satisfaction at time three, this was associated with increased concurrent distress. Ordinarily, relationship quality has a buffering effect (Coyne and Smith 1991; Florian, Milulincer and Hirschberger 2002) and so this finding is paradoxical. This relationship was only found in one cross-sectional model, so the findings need replication. However, it is plausible that the stress of coping with the stroke may have dominated the carers' psychological landscape, making them more distressed by the thought of losing their loved one, and this is a potential area for research.

7.12 Strengths and Limitations of the Study

A major strength of this study is that it recruited both patients and carers to examine the illness perceptions of a key NHS priority population (Royal College of Physicians 2004). Patients were only recruited if they had experienced a first-ever stroke and clear diagnosis of stroke could be made. Including both spousal and non-spousal caregivers provided a significant advantage because female stroke survivors tend to be older and less likely to have a living marital partner. Extending the recruitment criteria to include non-spousal carers also ensured the fewest individuals were excluded. However, few very old patients (over 80 years) agreed to participate in the study, which limits the generalisability of the findings. A common reason given by older patients for not taking part was that they did not wish to involve their family in the study because they felt that they were “doing enough” already. Only eight carers were not spouses, which meant that analyses comparing the perceptions of spousal and non-spousal carers could not be conducted.

The study aimed to recruit at least 70 couples to the study, but recruitment was halted at 44 couples because of time constraints. The number of eligible patients was overestimated and despite extending the study to a second hospital, the original recruitment levels could not be reached. Specifically, the number of patients admitted with a second stroke was much higher than anticipated. Extending recruitment to include out-patients seen in the neurovascular clinics was intended to boost recruitment levels. However, this strategy was only partly successful as recruitment via clinics yielded few participants. Overall, refusal rates were quite high and this has implications in terms of the power of the study and its ability to identify significant relationships, and also in terms of the generalisability of the findings. High refusal rates have also been reported by other studies involving stroke patients (Bennett and Lincoln 2004). In the present study, in-patients were approached in person and clinic patients were approached by letter some weeks after their clinic appointment. In the case of clinic patients, timing may have been an issue as the salience of the event was reduced, and so the topic may have failed to engage these individuals (Shaughnessy, Zechmeister and Zechmeister 2000). Also, no face-to-face contact was made with clinic patients as it was agreed not to approach patients in the clinic as no confirmation of stroke could be made at this point. Although recruitment rates were low, only five couples (12%) dropped out of the study for reasons other than patient illness, suggesting that the measures were acceptable to patients and carers.

As discussed earlier, multi-level modelling was used to test the main research question because this allows the testing of complex relationships, whilst controlling for the

interrelationship between patient and carer beliefs and mood. However, the modest sample size in the present study is a problem for the multivariate statistics. Advice was sought on the ability of the APIM to produce reliable results with a modest sample size (William Cook, personal communication) which resulted in the creation of separate models to test the impact of each illness representation on distress. This approach has been used successfully in other studies (Benyamini et al. 2007; Olsen et al. 2007), but a significant limitation of this method is that it does not allow for the identification of shared variance between illness perceptions.

Furthermore, the use of absolute difference scores means that the direction of difference in discrepant illness perceptions is not known, and this is a weakness as the results of other studies suggest that the direction of difference may be important (Heijmans et al. 1999). However, by using absolute difference scores, the impact of discrepancy could be assessed after controlling for both actor and partner effects, which makes this a much more stringent test of the role of discrepancy. The small sample size may have had insufficient power to detect small effects, and the sample size may also have affected the stability of the regression analyses. The low recruitment levels also meant that gender differences could not be examined. Therefore replication of the results is needed to confirm the stability of these results, and the findings should be viewed as preliminary only.

The self-regulatory model (Leventhal et al. 1984) is conceptualised as a dynamic, iterative model in which illness perceptions change through experience, social interaction and over time. However, the stroke literature has been dominated by cross-sectional studies which do not allow for the examination of causal relationships or focus on the role of early control perceptions as predictors of later outcomes (Johnston et al. 1999; Morrison 1999; Johnston et al. 2004; Morrison et al. 2005). In this study, patients were approached during the first four to twelve weeks post stroke, and then followed for 6-7 months. Targeting recruitment to first time patients and recruiting them as soon as possible post stroke meant that their first tentative understandings could be examined, and also allowed for changes in perceptions to be assessed.

In the present study the percentage of patients and carers found to have mood problems were similar to the rate identified by earlier reviews (Han and Haley 1999; Hackett et al. 2005). These reviews have identified a number of variables associated with or predictive of patient distress (Hackett and Anderson 2005) including physical disability, stroke severity, cognitive impairment and social support. In the present study, two of these variables (cognitive impairment and stroke severity) were not included as predictors of distress. Individuals were excluded from the study if they had significant cognitive impairment, and lesion location was not included due to lack of information on the lesion location in some patients. Therefore,

stroke patients were treated as a homogeneous group which limits the reliability of the models. However, none of the published reviews included studies examining the association between illness representations and distress, and so this study adds to the small, but growing body of evidence to support such a relationship. Much less attention has been paid to predictors of carer distress, and few consistent predictors have been identified so the present study adds to this literature. Furthermore, these findings suggest that it may be important to consider post stroke distress as a dyadic, interpersonal issue, especially given the strong positive correlation between patient and carer distress.

7.12.1 Generalisability

As with earlier research, the present study excluded patients with significant cognitive and language problems, which reduces the generalisability of the study findings. However, individuals who were initially excluded were reassessed regularly and invited to take part when it could be certain that the patient was able to give their informed consent to participation. Patients with some degree of expressive aphasia were included in the sample if it could be ascertained that they could give informed consent. This included two patients who had pre-existing language difficulties as they had no cognitive problems.

7.12.2 Design Issues

The study was based on the self-regulatory model which hypothesises that coping mediates the illness representation- outcome relationship. As discussed in chapter two, few studies have examined the illness perceptions of stroke patients or their carers, and so it was decided to focus on the primary appraisal process, and how couples differ in their perceptions. Research examining secondary appraisal processes have traditionally examined how individuals adapt to chronic illness by considering the coping strategies adopted by each partner, but despite a long history of research into coping, the focus still tends to be on the individual, rather than on the couple, although recent developments in this area have been made (Revensen, Kayser and Bodenmann 2005). Therefore, a decision was taken to focus on primary appraisal (Lazarus and Folkman 1984) because of a lack of evidence pertaining to either primary or secondary appraisal in the context of couples coming to terms with stroke. The decision not to examine coping strategies may mean that important dyadic coping processes have been ignored (Coyne and Smith 1991), and this is an area for future research. A second reason for not examining coping was that the addition of a coping measure to the package of measures may over-burden patients and carers who were actively coming to terms with a recent significant, negative life event, and may indeed add to their distress and lead to higher drop-out rates.

7.12.3 Measurement Issues

A significant strength of the present study is the development of a stroke specific version of the IPQ-R. Stroke survivors and health professionals were actively involved in the modification process, and the resulting measure was found to have good face validity with stroke survivors and health professionals. However, insufficient questionnaires were returned to formally test the factor structure of the modified measure. Comparing the internal reliability of the subscales against the original IPQ-R reliability data (Moss-Morris et al. 2002) revealed that reliability of most subscales were similar to the original, but that the timeline acute/chronic subscale was lower than desirable for both patients and carers, the personal control subscale was low for patients and the treatment control subscale was low for carers, which may affect the reliability of the results.

The GHQ-28 was selected as a measure of emotional distress for the study. It is a self-report measure, but has good psychometric properties (Lincoln et al. 2003). It has been widely used with stroke patients, although fewer studies have used it with stroke carers. However, the GHQ-28 is a screening tool, rather than a diagnostic measure, so results reflect severity of depressed mood, not a diagnosis of depression or generalised anxiety. A strength of the study is that all measures were assessed at all three time-points, and the perceptions of patients and carers were assessed at the same time, such that changes in each partners' perceptions could be assessed during the critical first months after a first-ever stroke. As the time two and time three data was collected largely by post, the possibility that partners completed the measures together cannot be discounted, but the high levels of discrepancy in IPQ-R questionnaires suggests this was not the case. Participants were asked to complete the measures independently, but as participants completed these at home this cannot be assumed.

7.12.4 Ethical Issues

An important ethical issue in the present study was that patients and carers were asked to think about the stroke. This is an important point, especially as the IPQ-R asks them to think about how the stroke makes them feel, which could engender feeling of distress, even if this is transient. To address this issue, patients and carers were given the opportunity to see the measures before consenting to the study so that they could decide if completing them would cause them distress. When emotional problems were identified a protocol was put in place to refer these issues on. However, unless there were significant concerns for the safety of the patient, this meant getting the participant's permission to refer on, and some participants chose not to be referred to services. The two hospitals taking part in the study differed in the level of

psychological support available, with good support available in one hospital, and little available in the other. This meant referring participants to either their GP or consultant.

7.13 Implications for Clinical Practice

Despite the limitations of this study, the findings suggest a number of potential implications for clinical practice. Stroke is being increasingly considered to be a family illness (Palmer and Glass 2003) and therefore professional support should be directed at both partners, not only because carers experience high levels of distress and therefore have a legitimate need to support in their own right, but also because carer distress has a significant negative impact on patient distress. The National Clinical Guidelines for Stroke (Royal College of Physicians 2004) recommend screening for mood disorders in patients within one month of their stroke. These findings suggest that the family and patient should be the focus of attention. To date, much less attention has been focussed on understanding predictors of carer distress, and this study provides evidence to support the view that carer distress is associated with specific patterns of negative illness perceptions. Considering predictors of carer mood is also important because it has an impact on the patient in terms of the carer being able to support the patient.

This research suggests that health professionals need to engage with patients and carers in order to assess and challenge maladaptive illness perceptions. The present study indicates that carers are significantly more pessimistic about the stroke than patients. Therefore devising strategies that can identify partners who have maladaptive illness perceptions, and those couples who have different understandings of the stroke, and who are therefore at risk of adjustment problems would seem beneficial. As discrepant illness coherence beliefs were associated with both patient and carer distress, special attention may need to be given to whether partners feel they understand the stroke and what it means to their lives. In doing so, it may be useful to draw on the existing therapeutic models for mental health to develop family-based interventions which can facilitate adaptation to physical illness. For example, devising interventions which provide a safe environment in which families can discuss their beliefs and concerns may alleviate some of the myths and misconceptions surrounding stroke.

7.14 Implications for Future Research

There are several implications for future research arising from this study. First, the findings require replication with a larger sample in order to confirm the role of illness perceptions as predictors of patient and carer distress. For some couples, perceptions of the

causes and consequences of the stroke did not converge over time. The study has identified that discrepancy is common in the early weeks after the stroke, but research is still needed to investigate the sources of discrepant illness perceptions, and this will be explored in study two. The mechanisms which facilitate convergence in illness perceptions need to be identified and examined. It is also useful to consider whether beliefs change as a result of negotiation between the patient and carer, which will be considered in study two.

The lack of statistical association between the personal control dimension of the IPQ-R and mood in this and in previous studies (Joice et al. 2003; Ford 2007) is of interest, and worthy of further study. Previous research has found that the RLOC (recovery locus of control) is a good predictor of physical recovery (Johnston et al. 1999), but the relationship between personal control beliefs and mood still much less clear. French and Weinman (2008) hypothesise that personal control beliefs may not be a unitary construct in some instances, and it is therefore important to examine how patients and carers understand the notion of control in the context of stroke. The assessment of illness coherence is relatively new, and few studies have examined the role of this illness representation in adaptation to illness. This study found that discrepancy within couples was low (less than 2sd), but it emerged as an important predictor of abnormal mood, suggesting that couples do not have to disagree by a great deal before this become distressing for one or other member of the couple. It would therefore appear to be a fruitful area for future research.

Finally, as discussed above, an important future direction would be to design interventions aimed at changing negative and maladaptive illness perceptions, particularly those which are associated with negative outcomes. Interventions designed to change the personal control cognitions of stroke survivors have had some limited success (Franks, Johnston, Morrison, Pollard and MacWalter 2000). Furthermore, motivational interviewing in the early post stroke period has been shown to support and build patients' motivation to adjust and adapt to having had a stroke (Watkins, Auton, Deans, Dickinson, Jack, Lightbody, Sutton, van den Broek and Leathley 2007). Therefore, intervention studies guided by the SRM may provide valuable insights into how patient and carer adaptation may be enhanced.

7.15 Conclusion

In conclusion, the findings from the quantitative study indicate that patients and carers perceive the stroke negatively. Over time the number of symptoms they associate with the stroke declines, but, more importantly, both patient and carer become more pessimistic about

the efficacy of treatment (treatment control) and the patient's personal control over recovery. Discrepancy between the illness representations of the patient and carer were common, and almost half of couples still disagreed about at least one aspect of the stroke at time three. Discrepancy on causes and consequences of stroke were most common, and a quarter of couples still disagreed about cause at the final assessment point.

Patients and carers levels of distress are positively and significantly correlated, and distress levels did not decline over time. Patient distress levels were associated with their own and their carer's beliefs about the stroke as well as with the carer's perceptions of the level of emotional support available to them at time one. Carer distress was associated with their own illness representations. However, both patient and carer were more distressed when they disagreed about how well the patient understood the stroke. The only predictor of the maintenance of distress was carer distress at time one, which makes this a potentially important target for therapeutic intervention.

8 Study Two: Negotiating “Shared Understandings”

8.1 Introduction

The quantitative, empirical study described in study one was informed by Leventhal’s self-regulatory model of illness (1980, 1984) described in chapter two. The study operationalised successful adjustment as the absence of emotional distress, and proposed that psychological adjustment to chronic illness was influenced by cognitive appraisal processes. The quantitative approach taken by study one provided a descriptive account of the structure of patients’ and carers’ illness representations and assessed the level of discrepancy between partners. The study tested the hypothesis that illness representations, and specifically the discrepancy between the illness perceptions of patients and their carers would be associated with patient and carer distress. The results of the quantitative study found that patients’ and carers’ illness perceptions became more negative over time. Patients’ and carers’ emotional adjustment was associated with their own and their partner’s illness perceptions, and that when patients and carers held different illness perceptions, this was associated with higher concurrent distress, especially for carers. The study also found that discrepancy levels declined over time, but that distress did not. The deductive methods used by the quantitative study provided generalisable results from which causal inferences can be drawn (Shaughnessy et al. 2000). The results of the quantitative study provide some answers to the research questions set by this thesis, and detail the structure of the illness representations held by this sample of patients and carers and how these relate to distress as an indicator of adjustment. However, the deductive, data reduction approach taken by quantitative methods cannot provide information on the process of adjustment.

The purpose of this qualitative study is to answer the final research question posed by this thesis, which is to try to provide some insight into the adjustment process and the role of discrepant beliefs in this process. To do this, a qualitative approach is taken because the inductive, interpretative nature of qualitative methods are well suited to examining the process of adjustment (Mason 1994). The inductive approach taken by qualitative methods is well suited to examining the meanings that participants ascribe to their experiences of coming to terms with the stroke and also to examining how couples negotiate with one another as they attempt to construct a ‘shared understanding’ of how to manage its impact. This qualitative study therefore widens the discussion of psychosocial adjustment to stroke from one which focuses on quantitative outcomes (e.g. emotional distress), to a more holistic, interpersonal

approach that considers adjustment as a social process involving the family. The quantitative and qualitative studies therefore have complementary aims and consider the nature of adjustment from two perspectives, as an outcome and as a process.

Examining adjustment as a process necessitates examining how couples negotiate changes in their lives in response to illness, and therefore this study examines the communication and negotiation strategies adopted by couples as they come to terms with the impact of the stroke. In this way, this study will try to elucidate the meanings that couples ascribe to the recovery and adjustment process, how discrepant illness beliefs are represented in their accounts, and the role they play in the negotiation process. It is however appropriate to briefly examine the concept of adjustment and how it has been defined and operationalised, and also examine the concept of negotiation in order to situate the reader to the research question.

8.2 Adjustment to Chronic Illness

As already discussed, quantitative studies have defined psychological adjustment to chronic illness as an outcome (De Ridder, Geenen, Kuijer and Van Middendorp 2008). However, the qualitative literature has defined it as a process (Radley 1989; Radley 1994; Wright, Watson and Bell 1996; Wright and Kirby 1999), leading Wright and Kirby (1999) to conclude that adjustment to illness remains an “elusive and ill-defined” construct. In this study, the term ‘adjustment’ will be used to refer to the process couples go through as they come to terms with the impact of the stroke. Radley (1988) examined the process of adjustment in couples where the husband had coronary heart disease. A cohort of 42 couples were followed from before the surgery until one year post-surgery to examine how couples adjusted from the time of diagnosis through until after the operation to correct the condition. Couples were interviewed five times during this period, and different styles of adjustment to illness examined (Radley 1989). He found that the men’s style of adjustment to illness was consistent with the way in which the couple could, or could not negotiate how to cope during the period of the man’s treatment, thereby placing the partner central to the process of patient adjustment in a way which cannot be observed using quantitative methods.

Using Herzlich’s (1973) descriptions of styles of adjustment, Radley and Green (1985) developed a conceptual framework by which a person’s adjustment style could be characterised. This framework has two dimensions within which four different styles of adjustment can be situated. The horizontal dimension refers to the *loss or retention of participation in society* and the other refers to the *relation of illness to the self*. This produced four modes of adjustment, but the authors argue that any individual’s style of adjustment is a balance between the four

modalities, and because one modality dominates, this does not mean the others are unavailable to the individual (Radley and Green 1985). The first dimension contains two aspects, active-denial and resignation. These both represent opposition to the illness. *Active-denial* involves the individual resisting the illness by participating in normal life as much as possible. *Resignation* still involves opposition to the illness, but here the illness is perceived to permeate all aspects of the individual's life. In contrast, accommodation and secondary gain reflect the complementary relation to illness. By *accommodating* the illness, the individual accepts and works round it and in doing so they try to remain well. *Secondary gain* refers to positive reappraisal in which the positive gains that can be derived from the illness are highlighted, such as being able to withdraw from the difficulties of life.

Radley (1989) found that couples differed in their acceptance of the illness, with some patients and spouses dealing with the illness by opposing it, and others adjusted by making joint adaptations to their lives. Some couples were found to make some limited adjustments to their life in order to fight the illness, whilst others were forced to make adjustments in order to overcome the illness. However, resisting and accepting the illness was part of the process for both patients and spouses, and couples may not have a joint perspective on how to manage the impact of the illness. This theoretical approach places the individual within a social framework and is thus a useful way of conceptualising adjustment to illness in the present study. In this model, adjustment to illness is influenced not only by internal factors, but also by significant others and the resources available to the individual.

8.3 Adjustment to Stroke

The dominant models of adjustment to stroke have taken a quantitative approach, and the literature pertaining to psychological adjustment as an outcome has been discussed in chapter one and will not be considered again here. However, in recent years there has been a move towards a qualitative approach which considers adjustment to stroke as a process. Some studies have examined adjustment in the context of patient recovery (Burton 2000; Dowswell, Lawler, Dowswell, Young, Forster and Hearn 2000; Wiles, Ashburn, Payne and Murphy 2002). Other researchers have examined the process of adjustment by considering the concept of loss (Mumma 1986; Anderson 1992; Folden 1994; Ellis-Hill and Horn 2000) whereby the stroke is conceptualised as a disruption to the biographical flow of the patient and carer resulting in a discontinuity to their lives to which they need to adjust. These studies and others mention the role of the spouse, carer or family in the adjustment process (Cox, Dooley, Liston and Miller 1998; Carlsson, Moller and Blomstrand 2004b; Oloffson, Andersson and Carlberg 2005). However, most of these studies have interviewed only one participant, usually the patient, and

extrapolated from the patient's descriptions, the role the family play in this process. Few studies have sought input from family members and are therefore of limited use in terms of considering the process of adjustment by couples.

A few studies have interviewed patients and carers, either together or separately to examine the process of patient adjustment. However, even when both partners are present during the interview, the voice and experiences of carers is not always represented. A longitudinal study of UK stroke patients by Dowswell et al. (2000) interviewed 30 stroke survivors and 15 carers to gain an understanding of their experiences of the recovery process during the first year after stroke. Patients and carers were interviewed separately on four occasions over the space of a year in order to allow partners to be open about the difficulties the patient was faced with. The focus of the study was on patient adjustment and recovery, and the data was analysed using a thematic analysis. The results provide an insightful narrative, grounded in the data which shows that both patients and carers perceive the impact of the stroke to be "serious, severe and predominantly negative" for the patient (p. 513). However, although data was collected from 15 carers, the focus was on patient recovery and missing from the picture is any sense of the effect of the stroke on carers' adjustment. It is also not clear whether there were any discrepancies in their descriptions of how they were coping together with the stroke, or whether these differences of opinion affected the patient's adjustment. Couples were interviewed separately which provided the opportunity for discrepancies to emerge, but if they did these were not reported.

An American qualitative study interviewed 51 male stroke survivors and their caregivers during the month after discharge from hospital (Rittman, Faircloth, Boylstein, Gubrium, Williams, van Puymbroeck and Ellis 2004), to explore the process of the transition home for stroke survivors. Patients and carers (75% spouses) were interviewed together a month post-discharge to identify changes in routines and strategies developed to manage the transition home. The main themes identified map to the questions asked, suggesting that it is likely that a thematic rather than the reported grounded theory approach was used to analyse the results. The key themes identified were changes to the temporal order of daily routines; disruptions to sense of self; and strategies for managing time during the transition phase. They found stroke survivors and carers were faced with re-establishing daily routines in the context of changes in the survivors physical functioning, and that when routines were not established this impacted negatively on both partners. Carers often took responsibility for establishing these routines, and this was described in terms of being an ongoing process of negotiation, influenced by the fluctuating nature of the recovery process. However, as all carers were female it is

unclear whether this was because they were the well partner, or related to gender role issues. A major challenge to families was reordering their daily routines to fit with the limitations of the patient, and the daily fluctuations in patient functioning posed particular problems for couples during this transitional phase. However, the focus was on adjustment for the patient not the carer, and so this aspect of adjustment is missing from this narrative.

A Canadian study of stroke patients and carers followed 20 couples for two years following a first stroke (Stanton 2000). In this study, partners were interviewed separately on up to five occasions over a 2 year period. Using in-depth interviews and a grounded theory analysis, a story of a transition emerged. Their findings indicate that the actions of each partner can have a huge impact on the adjustment of the other partner. Tracking couples over time, they examined the process couples went through in their “journey towards normality” (p. 55). They found that disagreements initially occurred between partners about the provision of care, and what and how much the survivor could do. Over time couples started “venturing out” (p. 55), and came face-to-face with the realities and limitations of the survivor’s disability. This prompted a process of negotiating of new roles, and also meant that partners had to come to terms with the changes brought about by the stroke. By the end of the study couples had come to describe their lives as normal. Although their lives had changed and things were different, they had a sense of what was possible.

This study identified two recurring patterns of behaviour, which will be explored in the present study. One pattern facilitated adaptation, and was characterised by good communication through which couples shared feelings and solved problems. Here, both partners encouraged each other; carers encouraged survivors to take up new activities, and survivors helped carers take on new roles and responsibilities. The other pattern constrained partners, and resulted in frustration. Partners were less well able to communicate, and this affected their ability to solve problems. Unfortunately the brevity of the report means that no direct quotes are used, so although the findings make intuitive sense and the narrative provided is vivid and insightful, it cannot be determined if the results are indeed grounded in the data. Furthermore, although the study examines couples over time, the results do not make clear whether patterns of communication were unchanging and perhaps reflected pre-stroke relationship functioning, or whether they changed over time. Nor is it clear whether couples could move between being facilitative or constraining in their relationship style or whether these too were fixed from the outset.

Finally, an American study took a content analysis approach to examine the process of adjustment to stroke in older couples (Robinson-Smith and Mahoney 1995). This cross-sectional study conducted conjoint interviews with seven couples 6-12 months after the stroke. The major themes produced by the study were: the impact of physical changes for both partners, feeling down and worried about the future, being restricted by the stroke, and seeking equilibrium in their relationship. All but one couple had been married over 40 years and couples were aged 60 - 79 years. Couples were found to cope together, and although all couples experienced changes to their relationship, the authors found that most approached the adjustment process using a collaborative approach, and only one couple reported any significant conflict. The themes identified were raised by most couples, but a few couples talked about few issues, and these differences were not elucidated in the results or discussed. Although this was a content analytic study, and therefore limited in terms of richness of description, the results nevertheless suggest that adjustment to stroke is a dyadic process, with both partners faced with having to make changes to adjust.

The findings of these studies suggest that the process of adjustment for patients is not straightforward and that well partners play an important role in this process. However, the largely cross-sectional nature of the existing literature means the dynamic nature of adjustment is missing. The studies cited are heterogeneous in nature and differ in terms of the time since the onset of the stroke, the age of the patients, and the nature of the patient-carer relationship (e.g. spousal, non-spousal). The type of analysis applied to the data also varied across studies, as did the quality of the reporting of the results. Whilst all report conducting in-depth interviews, some lacked transparency in their methodology (Dixon-Woods, Shaw, Agarwal and Smith 2004) with the main difficulty being studies labelled as grounded theory when there was no evidence of this (Rittman et al. 2004), and there was also a lack of information about participants in some studies, for example, few studies reported whether participants had experienced a stroke previously, or how participants were recruited. Some studies provide a picture which suggests that patients find a way of living with the stroke over time (Robinson-Smith and Mahoney 1995; Pound, Gompertz and Ebrahim 1998b, a; Stanton 2000) whereas others suggest that patients struggle to adapt (Dowswell et al. 2000).

What is largely missing from this picture is the impact of the stroke on the well partner, or the couple. All of the studies reported here recruited carers or reported they were present during the interviews which formed the basis of the analysis, but because the focus is on patient adjustment, the voice of carers is largely missing from the final reports. There is also little sense of how spouses and carers affect the patient's adjustment process, despite some studies

conducting separate interviews with patients and carers which would facilitate the collection of such data. Indeed, it is sometimes unclear to the reader why carers were involved at all, beyond them being there to support the patient during the interview process, or clarify or translate when the patient had language problems (Rittman et al. 2004). Several of these studies did report that couples had to negotiate coping strategies to manage the impact of the stroke (Robinson-Smith and Mahoney 1995; Stanton 2000; Rittman et al. 2004), but not how couples achieved this. There is therefore an urgent need to explore the experiences of couples as they come to terms with the stroke to try to understand this process more clearly. Taking a process-based approach which is interested in couple-level adjustment necessarily has to examine issues of communication and negotiation within couples, as it will be through these processes that partners influence one another, and the literature pertaining to this will be examined next.

8.4 Negotiation

The focus of the negotiation literature has moved in recent years from an approach which is exemplified by business theory and practice (Pruitt 1972; Sheppard 1995) whereby negotiations are studied as one-off interactions between strangers, to one in which the relationship between partners is part of the picture of the negotiation process (McGinn 2006). Taking this second approach, individuals are seen as social decision makers, in which negotiations affect, and are affected by, the relationship within which they are embedded. Taking this approach, negotiation constitutes one way of “*getting things done*” (Strauss 1978), with other ways including coercion, persuasion and manipulation (Finch 1989). The implication of this definition is that a negotiated settlement does not necessarily imply full agreement but that it is a way of working “it” out (Finch 1989). In negotiations, individuals have room for manoeuvre, but their actions and the potential outcome of any negotiation may be constrained by other factors. Indeed, in practice things are not infinitely negotiable (Rolland 1994), and feelings such as a desire not to rock the boat or upset the other party will influence the negotiation process (McGinn 2006), as will a knowledge of what *should* be done in the circumstances (Finch 1989).

As highlighted by the literature reviewed in chapter one, the stroke brings with it physical, emotional and behavioural limitations which will influence what can be negotiated, and what has to be accepted and worked round. Families also have ‘ways of doing things’, which develop over time, but which define them as a family (Finch 1989). However, the onset of the stroke may challenge these long held routines and ways of doing things, and couples may struggle to explore new approaches and alternatives because they are restricted by their ongoing ways of relating to one another (McGinn 2006).

Negotiation can take both *explicit* and *implicit* forms. Finch (1989) argues that explicit negotiations involve individuals sitting round the table to openly discuss a specific problem. Open discussion allows a common understanding to be arrived at and moves things toward an agreed upon settlement. In contrast, *implicit* negotiation occurs without open negotiation, such that individuals find ways of communicating responsibilities over time (Sillars and Kalbflesch 1988; Finch 1989). In her study of the negotiation of family responsibilities, Finch (1989) found that three-quarters of families described how they used explicit forms of negotiation, and talked about how they had got together to make decisions. However, the authors note that this is not necessarily the way in which things *get* negotiated, because implicit forms of negotiation are more difficult to describe, and so may be under-reported by families. This is not to say that explicit negotiation does not happen, but Finch argues that the balance between the two forms of negotiation may be less clear-cut than first assumed.

Sillars and Kalbflesch (1988) describe a range of implicit decision-making strategies which may also be relevant, including conflict avoidance, stoicism and silent awareness of decisions. These authors argue that *implicit agreement* emerges because in long-term relationships communication styles develop which mean that many things do not need to be openly discussed because partners know one another well enough to know what the other would accept or want (Sillars and Kalbflesch 1988). These authors suggest that in marital relationships, explicit styles of negotiation and decision making are less common, because relationship maintenance goals take precedence over the content of decisions. Instead they argue that explicit styles of decision making are more commonly used when couples are undergoing a crisis. This is of relevance because it suggests that the degree to which couples rely on implicit or explicit forms of negotiation may change, both over time, and dependent on the salience of the issue.

A small-scale empirical study by Zietlow and Sillars (1988) compared the communication styles of 49 couples, classified as young, middle-aged or retired, as they discussed a range of issues including an issue which was a cause of conflict in their relationship. These discussions took place without the presence of the investigator and were tape recorded for analysis. The study found that when discussing non-salient topics, middle-aged and retired couples used non-conflictive, topic management and non-committal statements in their discussions. However, when the topic was salient and reflected an unresolved problem, older couples became confrontational, but the discussion failed to resolve the issue. In contrast, middle-aged couples were much more flexible in their negotiation style. When the issue was

salient these couples moved between analytic and confrontational approaches, and used strategies such as disclosing and seeking disclosure, to de-escalating the conflict without terminating the discussion. The authors attribute these differences to cohort and life-stage differences, and it must be borne in mind that the study is now 20 years old. Nevertheless, these findings suggest that participants may use a range of negotiation strategies depending on the salience of the topic, and age may be a factor in the negotiation process.

Although Sillars and Kalbflesch (1988) found older couples were confrontational in their approaches to difficulties, other studies have found that older couples do make decisions together (Dorfman and Hill 1986; Padula 1996). A survey of decision making in older American couples, Padula (1996) found that where health-related decisions were concerned, couples tended to make health decisions together. However, they also noted that if a final decision was needed it was the wives who were the primary decision makers (Padula 1996). This study also found that wives often tried to change their spouse's behaviour and described how wives used discussions and reminders to try to achieve this goal, although their husbands tended to interpret this behaviour as nagging. This study concluded that couples rely on their partners when making health decisions and "often make them jointly" (p. 684). This study suggests that in the context of health, decisions may be made more explicitly than in other areas of life because couples place a high value on health, especially as they get older.

8.5 Communication

It is important to acknowledge that not all thoughts and feeling need to be communicated. Indeed, a balance is needed in terms of communication patterns so that partners can be supportive of one another but still be able to discuss issues at an appropriate time (Rolland 1994). Research examining communication between cancer patients and their families suggests that various factors limit communication within families. For example, couples may feel constrained about discussing the illness because of a perceived lack of knowledge or because they do not wish to upset their partner (Baider, Ever-Hadani, Goldzweig, Wydoda and Peretz 2003).

One cross-sectional study interviewed patients with COPD, cancer or CHF (congestive heart failure) and their carers (Fried, Bradley, O'Leary and Byers 2005) to learn about their communication needs. Using separate interviews these authors found that almost 40% of patients desired more communication with their partner and 37% of carers reported communication was difficult (Fried et al. 2005). They found that although both patients and carers perceive it to be important to communicate, patients tended to desire less communication

compared to their carers. This desire for reduced communication by patients' reflects findings from studies of doctor-patient communication that suggests patients limit information seeking with health professionals to manage their fears and preserve hope (Leydon, Boulton and Moynihan 2000).

Studies have also found that partners can feel socially constrained in what they feel able to discuss and the emotions they feel they can display (Finch 1989; Herzer, Zakowski, Flanigan and Johnson 2006). A prospective study of breast and prostate cancer patients and their partners found that patients feel socially constrained not to discuss their distress because of discrepancies in how partners perceive the level of threat from the cancer (Herzer et al. 2006). The discrepancy literature discussed in chapter two, and results of the study one indicate that stroke patients and carers disagree about aspects of the patient's illness, and although caution must be used in extrapolating from cancer to the context of stroke, these findings reported by Herzer and colleagues suggest that if partners disagree in their interpretation of the illness, that this may affect the level and nature of communication each partner feels comfortable with.

8.6 Secrecy

Studies have found that the communication patterns of patients and carers change during the course of the illness. When the picture is optimistic, family communication is open, but when the prognosis is poorer, family members feel constrained in their communication and adopt "fair weather" communication styles in which stressful topics are avoided (Vess et al. 1988; Nussbaum, Baringer and Dundrat 2003; Zhang and Siminoff 2003). Dealing with serious health issues can also change the boundaries for communication, even within the context of a long term relationship, as disclosing information about their illness may make patients feel embarrassed, uncomfortable or exposed (Petronio 2002).

Carers may also avoid discussing issues which they feel may upset their ill spouse (Edwards and Forster 1999; Edwards and Noller 2002). In a mixed methods study of 53 elderly couples, one of whom had muscular-skeletal or cardio-vascular problems, Edwards and Noller (2002) used questionnaires and observational methods to investigate communication styles. The observational study required each participant to choose topics to discuss with their partner, and then couples were video-recorded discussing these issues. The authors found that carers tended to avoid selecting issues which would upset their partner. Male carers were found to avoid raising either their own or their partners concerns, even those they had previously deemed safe enough to discuss and instead resorted to "chit chat". An examination of the issues which were selected for discussion by partners found that care-receivers reported wanting to make

changes to care routines, their partner's communication style and their partner's activities. Carers reported wanted to increase activities and change their lifestyles. However, some couples failed to raise the issues they had selected to discuss, and instead used chit chat and topic management strategies to avoid discussions. These couples had been married on average 51 years, and well spouses had been caring for their partner for an average of nine years, and so the avoidance of issues is of interest because it suggests that some issues remain unresolved in the long term.

8.7 Communication in the Context of Stroke

As discussed in chapter one, previous research has shown that when one partner has a stroke this presents a significant challenge to pre-existing patterns of relationships, and the family may be faced with restructuring patterns of interaction and communication (Robinson-Smith and Mahoney 1995; Palmer and Glass 2003). A few quantitative studies have examined the interaction styles of patients and carers (Norris, Parris Stephens and Kinney 1990; Parris Stephens and Clark 1997; Cox et al. 1998). The overall conclusion from these studies is that partners use both positive and negative forms of interaction, and although positive patterns dominate, both patients and carers demonstrate forms of communication which can be considered unsupportive and insensitive. These studies have found that in common with other chronic conditions, some couples find it difficult to communicate feelings of distress (Robinson-Smith and Mahoney 1995), and may be unaware of how their partner feels about the stroke (King et al. 1995). This suggests that some couples may struggle to negotiate a shared understanding of the stroke because they find it difficult to share their thoughts and feelings.

Parris Stephens and Clark (1997) examined the interpersonal communication patterns of a sample of 57 older American couples where one partner had experienced a stroke within the past two years. In this quantitative, cross-sectional study, both partners reported using both supportive and unsupportive patterns of communication. Females were more likely to express supportive communications than males, and expressed unsupportive comments less often. However, gender and role were confounded as 80% of carers were female, so it cannot be determined whether they were more supportive because they were carers or because of their gender. The couples in this study were up to two years post stroke, so care needs to be taken extrapolating to couples who have experienced a stroke more recently. High levels of supportive behaviour were reported, but the use of quantitative self-report measures means that these scores may have been affected by socially desirable responding. Participants in this study were also reporting their general "retrospective" behaviour, rather than actual behaviour, a problem which could be overcome by observational or diary methods.

8.8 Aims of the Qualitative Study

Taken together, the literature suggests that there are different patterns or styles of adjustment to chronic illness, and that spouses may not have a shared understanding of the illness or how it should be managed. Therefore, the aim of this qualitative study is to explore the process of adjustment to stroke for patients and carers during the first year after a stroke, and the role that illness perceptions play in the adjustment process. Although the qualitative studies reviewed above suggest that adjustment to stroke is an ongoing, dynamic process which requires negotiation and re-negotiation over time, little is known of the role of partners in this process. The results of the studies reviewed further suggest that at the onset of the illness, patients and carers may struggle to communicate their beliefs and worries, thereby failing to address important issues, and that this style of communication may be maintained over the longer term. There is also evidence to suggest that communication between patients and carers can be constrained, both by the caring role and by emotional distress. It is therefore beneficial to see how this unfolds over time, rather than look retrospectively at this process as this may provide useful evidence to inform interventions to help couples adjust to stroke. It is also likely that some couples will adjust better than others, and exploring their experiences may identify possible factors which contribute to good adjustment.

Exploring this with patients and carers together places adjustment within a social context and is an important step in understanding adjustment as a jointly enacted process, rather than an intra-individual one. The quantitative study found good links between discrepant illness perceptions and concurrent distress, and this qualitative study aims to examine the way in which these beliefs manifest themselves as couples negotiate ways of adjusting to the stroke. This qualitative study therefore asks the following questions:

- How do couples negotiate a way of living with the stroke?
- How do discrepant illness beliefs affect how couples negotiate changes in their lives in response to illness?

9 Qualitative Method

9.1 Rationale for a Qualitative Method

Qualitative research is interested in life as it is lived in real situations, and researchers work to obtain inside knowledge of the social life under investigation. As discussed in the previous chapter, little is known about the process of adjustment to chronic illness in couples, and so this study uses qualitative methods to explore how adjustment to illness is negotiated by couples and the role of discrepant beliefs in this process. This research is largely exploratory, and beyond aiming to understand negotiation in couples coming to terms with a chronic condition in more depth, it was not clear what aspects of the stroke experience would be important in that process. Therefore it was decided to let couples share their own experiences and let this be the starting point for other research.

9.2 The Personal Interview

The focus of this study is on discovering meanings that participants attach to their behaviour, how they interpret situations and their perspectives on the process of adjusting to life after stroke. In general researchers have used semi-structured interviews in order to gain a detailed picture of the respondents' beliefs about, or perceptions of a topic (Smith, Harre and Van Langenhove 1995). During semi-structured interviews the researcher allows his or herself to be guided by an interview schedule rather than dictated by it, and this allows researcher and participant to engage in a dynamic and collaborative dialogue, whilst allowing the participant the freedom to tell their story in their own way. The semi-structured interview format also allows the modification of questions in light of participants' answers, and the researcher is able to probe interesting areas as they arise in the discussion. Semi-structured interviews generally focus on the individual in order to investigate each individual's understanding of the personal context within which the research phenomenon is located (Ritchie and Lewis 2003). In the present study the process of negotiation and adjustment by the couple was the area of interest and so it was decided that conducting joint interviews would provide the best opportunity to observe this process. However it important to consider the implications of interviewing couples together and how this may change the interview dynamic.

9.3 Interviewing Couples Together

Interviewing couples together presents both benefits and challenges, and this section has been informed by a useful account written by Seymour, Dix and Eardley (1995) from their research experience interviewing couples. Although susceptible to possible biases in terms of what couples are willing to discuss in front of their partner, the opportunity to observe the interaction between couples provides insight in a form which is hard to obtain from individual interviews. Allan (1980) goes as far to suggest that interviewing couples together provides richer material, because the picture of the event is balanced by the contributions of both partners. It is the case that when couples are interviewed together partners can provide supplemental information, corroborate the events, and also modify one another's accounts of the events (Seymour, Dix and Eardley 1995). However, in terms of the present study, the strength of the joint interview lies in its ability to allow the couple to interact around the question. It is through the careful observation of these interaction processes, and seeing how the couple support and influence one another, that a better understanding of the ways in which issues are negotiated within couples can be achieved.

Although there are advantages to joint interviews, it has been argued that in some instances the presence of the marital partner may result in participants not revealing their private reflections and thoughts, but instead choosing to present a jointly constructed, socially desirable picture of themselves as couple who are coping well (Seymour et al. 1995). The evidence for this criticism is mixed, with some studies finding interviewees were more forthcoming in the presence of their spouse (Bennett, Wolin and McAvity 1988), and others finding there to be no difference in the data obtained from joint and separate interviews (Collins, 1986, cited in Seymour et al. 1995). However, it is likely that there will be some issues that one or other partner does not wish to raise for discussion, and it will be important to be alert to the issue of topic management within the context of the interview as this may provide valuable insights into what is negotiable within the relationship, and the degree to which the couple are presenting a socially desirable "public story" (Cornwell 1984).

A particular concern for the joint interview is whether one partner will prove more talkative and outspoken than the other partner (Arskey 1996). Again the evidence is mixed, with one study reporting that well partners tend to interrupt and talk for their ill spouse (Shakespeare 1993), and another finding that the patient tended to be the dominant "story teller", with carers deferring to them (Morris 2001). However, whereas Shakespeare was interviewing couples where one partner had dementia, Morris's participants were coping with a

cancer diagnosis, which is likely to account for the differences in these findings. In the present study there are participants who have residual language and cognitive difficulties, and so care will be needed to remain alert to ensuring that one partner does not dominate the discussion. The nature of the topic under discussion in the present study is of course sensitive, and some couples may find it difficult to be open about their feelings, and this is another reason for interviewing couples at two time-points. The second interview is timed such that the couple should have had time to start to come to terms with the events and may be able to look retrospectively at the event, but not so far in the distant past that the events have been told and retold to the extent they have become part of an agreed story of the stroke.

9.4 Devising the Interview Guide

The interview guides for the study were compiled by drawing from the literature and information that was gathered during the focus group sessions described in chapter 3. Questions were also included which addressed the couples' illness perceptions in order to examine how these relate to adjustment. This list was modified during the course of the research in light of emerging themes. The first half of the interview used a topic guide (see appendix 17) rather than structured questions so that the flow of the discussion could be kept conversational (Smith et al. 1995). Given the sensitive nature of the topic, it was particularly important to build rapport with the participants, and the topic guide assisted in this process by providing participants with the greatest freedom to tell their stories, and maintain some ownership over the experience. The second half of the interview introduced the idea of discrepancy and here a more structured approach was taken to questioning. Little is known about how discrepant illness perceptions evolve and are resolved, and this section was designed to explore this area in more detail.

Due to the small sample size available, the use of pilot interviews was not feasible, so after the first three interviews were completed and transcribed, an interim analysis of the data was conducted to ascertain the quality of the responses. Although these interviews went well, the wording of some questions and prompts was changed, and although their use was potentially problematic in terms of leading the respondent, they prompted couples to describe their difficulties and how they affect them in more depth. The structure of the interview was designed to encourage couples to discuss things between them, rather than simply answer my questions. Participants were encouraged to provide more information and to contrast their experiences with that of their partner.

The design of the study incorporated a follow-up interview, scheduled initially for six months after the initial interview, but due to the time taken by respondents to return their completed questionnaires, this interview generally took place seven to eight months after the initial interview. The aim of the second interview was to explore couples' experiences of adaptation retrospectively. A topic guide was constructed which asked couples to reflect back over the recovery period and then allowed for an exploration of the specific difficulties the couple had faced in this process.

9.5 Selecting a Qualitative Analysis Method

Interpretative phenomenological analysis (IPA) (Smith 1995) was selected to analyse the interview transcripts. The aim of IPA is to explore in detail how people make sense of their personal and social world (Smith and Osborn 2003), and is concerned with the participant's personal perceptions of events. This method was considered suitable for this study because the way in which couples negotiate a shared understanding of the stroke will be affected by how they experience, give meaning to, and respond to the stroke, both emotionally and behaviourally. IPA adopts a critical realist epistemology that assumes a connection between the participant's thoughts, feelings and behaviour, but also acknowledges that individuals may struggle to express these thoughts and feelings, and it is therefore incumbent on the researcher to interpret their mental and emotional state from what they say (Smith and Osborn 2003). It uses what Smith and Osborn (2003) describe as a double hermeneutic, that is to say it applies a two stage process of interpretation, with the participant trying to make sense of their world, and the researcher trying to make sense of the participant making sense.

Smith (2004) is cautious about using IPA with groups because of its focus on personal experience. However, phenomenology is the study of meanings as experienced in everyday existence, and it can be argued the way in which married couples make sense of their world is influenced by the beliefs and perceptions of their partner, and indeed this is the theoretical stance taken by other researchers when interviewing couples together (Racher 2003; Mann and Dieppe 2006). Therefore, the concerns noted by Smith (2004) were kept in mind during the interviews to ensure that both partners were given space to discuss their own personal experiences and thoughts in detail, and then again during the analysis to ensure that the voices of both partners could be heard.

IPA sampling tends to take a purposive rather than the theoretical approach to sampling adopted by grounded theory (Willig 2001). Whilst grounded theory seeks to establish claims for

a broader population, IPA is usually more concerned with examining divergence and convergence within smaller, more homogeneous samples (Brocki and Wearden 2006), and therefore tends to make more modest claims about generalisation. However, some studies have adopted other sampling strategies, such as theoretical sampling (Golsworthy and Coyle 2001) and maximum variety sampling (MacLeod, Craufurd and Booth 2002) and argued for the generalisability of their results. Although there is no intention of developing a theoretical model of adjustment to stroke, a theoretical approach to sampling was used in order to learn more about different aspects of adjustment.

9.6 Ethical Considerations

Couples were required to opt into the qualitative study. As discussed in chapter 3, in light of the sensitive nature of the topic careful consideration was given to ensuring that participants were informed about what the interview process would involve. The information sheet highlighted that some couples may find the process of talking about their experiences distressing (see appendices 11 and 14) and may not want to take part in the interview. This was considered a particularly important issue as the timing of the first interview was generally within 12 weeks of the stroke. Those choosing to opt out of the qualitative study were older than those agreeing to take part, but there were no other obvious differences between the couples who agreed to take part and those opting out. It may also be the case that couples who do not generally discuss things together will not be portrayed in this study. Ethical approval was granted by North Cumbria Ethics Committee (see appendices 5 and 6).

9.7 Design

The study used a qualitative longitudinal design to explore how couples negotiate changes in their lives in response to illness during the first year after a first-ever stroke. Couples were interviewed together at two time-points, seven to eight months apart, to examine how they had adapted to the stroke and their negotiation style in relation to the stroke. The second interview explored the changes they had made to their lives in response to the stroke and how the couples felt they had negotiated these changes to their lives.

9.7.1 The Sample

Twenty four pairs recruited to the quantitative study volunteered to take part in the qualitative study, and the sample for interview was selected from this larger sample. The exploratory nature of the study and the focus on the process of adaptation meant that it was appropriate to interview a range of couples who could represent the different levels of disability

within the sample, and to this end a theoretical sampling approach was taken. As discussed earlier, this is not the general approach taken with IPA, but it was decided that, given how little is known about discrepancy and its impact on couples, a theoretical sampling approach would allow these abstract concepts to be examined in more depth. Smith and Osborn (Smith and Osborn 2003) note that “a number of factors determine sample size and that there is no correct sample size” (p. 54). It was decided that between ten and twenty couples would be selected for interview at time one, which would provide an in-depth awareness of the whole picture, with follow-up interviews at time two. Small samples are the norm for IPA, and Smith and Osborn note that larger samples may mean that there is a loss of potential subtle detail in the analysis. However, this had to be balanced both against discovering the breadth of the phenomenon, and also against the possibility that some participants may be lost to the study due to declining health.

9.7.1.1 Saturation

There is a case for interviewing until saturation has been reached (defined as the point at which no new themes emerge) (Brocki and Wearden 2006), although these authors note that there is always the possibility that new themes will emerge in the next interview. In the present study the interview and analysis processes became desynchronised such that a small backlog of unanalysed interviews developed. Before this backlog of four interviews could be transcribed and analysed, it became clear that no new themes were emerging. At this point, ten time one interviews had been analysed, so time one interviewing ceased. However the remaining four completed interviews were transcribed and added to the corpus of data, giving a total of 14 interviews. The study permitted the examination of the experiences of different patient-carer relationships, but only one non-married couple consented to take part in the study, and they were not interviewed due to difficulties arranging the interview, so the sample comprised exclusively white, heterosexual, married couples.

Formal criteria for determining discrepancy proved difficult to develop initially, as no baseline data were available. Therefore, couples were selected on the basis of their IPQ-R scores at time one. After discussions with the supervisory team, criteria were drawn up such that couples were classified as discrepant if they reported any of the following: more than five different symptoms; had a “difference score” (calculated by subtracting the patients’ mean score on a subscale from that obtained by their spouse) of more than one (using a 1-4 scale) on any one IPQ-R scale, or if partners indicated different patterns of causal beliefs. Twelve couples were selected who were discrepant in their illness beliefs on this basis. Six more couples were

selected who had very similar beliefs at time one. Each group included both males and females, but although it would have been desirable to have a balance in terms of gender and levels of disability in each group, the available sample size meant this could not be achieved.

Due to the longitudinal nature of the study, consideration was given as to whether taking part in the interviews would in itself influence how couples' negotiated a way of living with the stroke. The couples in this study did not comprise a clinical sample, and so it was considered feasible that taking part in the interview process might affect their communication about the stroke. Following discussions with an experienced family therapist, it was therefore decided to select four couples (two discrepant, two congruent) who would not be interviewed at time one, but who would be interviewed at time two. A flow diagram of the interview process is presented in. Figure 9-1. With hindsight not interviewing these couples at time one was an unnecessary and unhelpful decision. Two of the couples selected to be seen at time two only declined to be interviewed, and so only two couples were seen at time two only. There was no difference in how these two couples interacted compared to the couples seen at time one, and so the data from these interviews was analysed along with the remaining couples. Six couples were lost to the study by time two, and so the study comprises 14 time one interviews and ten time two interviews.

Of the participants interviewed, six of the patients were female, and ten were male, which broadly reflects the gender balance of the quantitative study. The median age of female patients was 63 years, ranging from 54 to 85 years. The occupational background of female patients was broad, with housewives and professionals represented. The median age for male patients was 60 years, and the age range was much narrower than for females (58 – 67 years). Again, their occupational backgrounds varied, with management, skilled manual and non-skilled workers all represented. Male partners tended to be slightly older than female patients, and female partners were generally younger than male patients. With the exception of one couple, all had been married for over 20 years. A range of different stroke subtypes were represented, with both severely impaired and physically unimpaired patients represented.

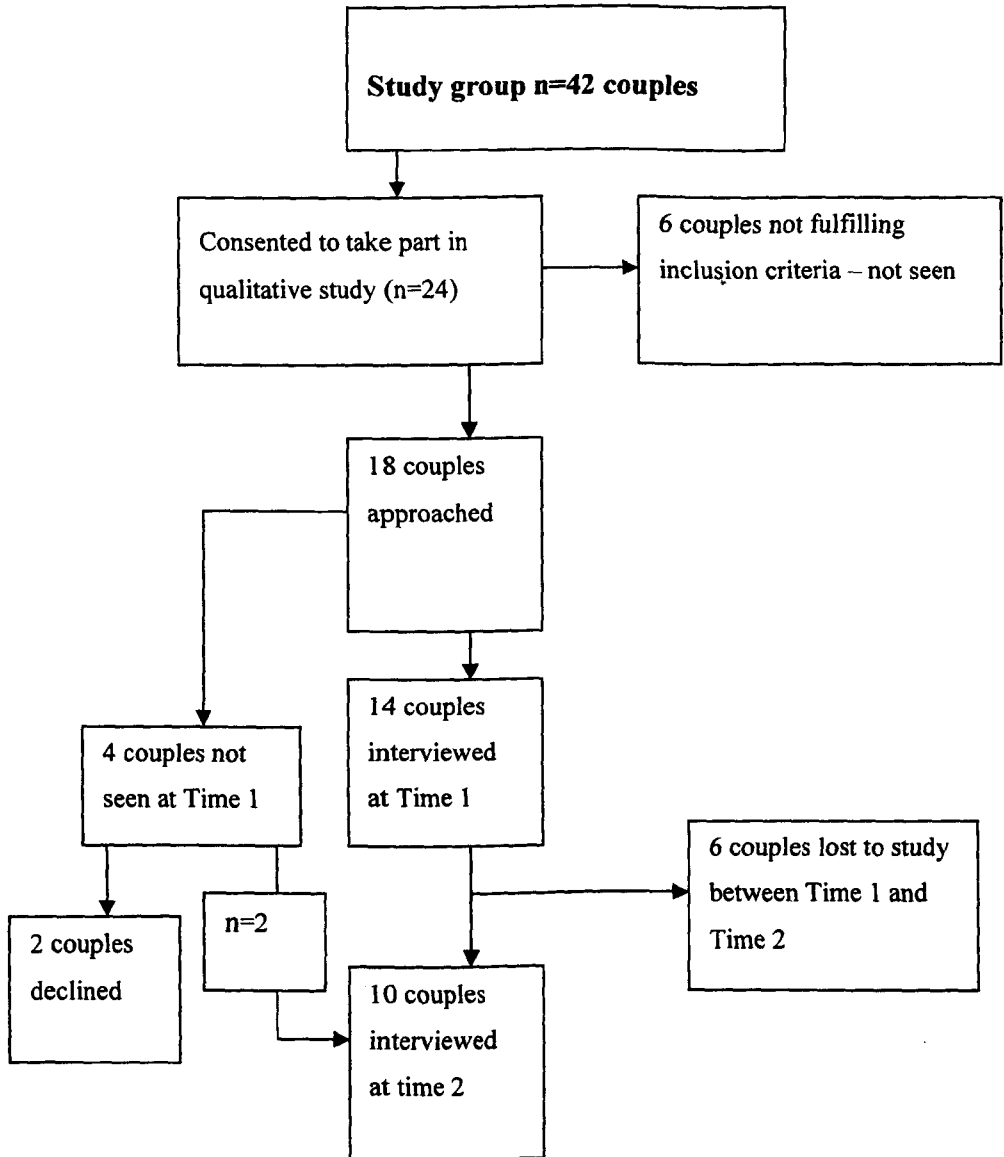


Figure 9-1: Recruitment of Participants to the Qualitative Study

9.8 Procedure

Couples were recruited to the qualitative study at the time of recruitment to the quantitative study (see appendices 11 and 12, and 14 and 15 for information sheets and consent forms). After patients and spouses had completed and returned the first set of quantitative questionnaires and these had been analysed manually, couples who fulfilled the inclusion criteria were contacted by telephone and asked if they were still willing to be interviewed. At this point the nature of the study was explained again and couples were given the opportunity to withdraw from the study. All of the couples selected to be interviewed at time one consented. Two of the four couples selected to take part in the time two interviews withdrew, but no

reasons given. For those consenting to take part, a time and place was arranged for the interview which was convenient for the couple. Where possible interviews were conducted after the patient was discharged home. However, two interviews were conducted at the hospital as the patient was not yet well enough to be discharged. The second interviews all took place in the participant's home.

Semi-structured interviews were conducted with couples to gather a rich account of the couple's perceptions of the effect the stroke had on their lives. Interviews lasted between 60 minutes and 180 minutes. Breaks were built into the interview schedule to allow couples the opportunity to rest, and some couples took this opportunity, whilst other couples chose to continue with the interview. The resulting transcripts were between 22 and 50 pages in length. The time one interviews focus on how the stroke was affecting their lives at the time, and the differences in their approaches to managing the stroke. The time two interviews focus on how things had changed for the couple, and how they saw the process of adjustment. Interviews were tape recorded with the permission of participants and subsequently they were transcribed verbatim. In addition, field notes were made immediately after the interview and these form part of the final analysis. These notes included interactions which were not captured by the tape recording and information about the patient's level of disability and my reflections of the interview.

9.9 Analysis Process

IPA was used to analyse the data. The background to IPA has already been detailed, so this section sets out the analysis process used in the study in order to make this transparent to the reader. Prior to the start of the analysis each transcript was checked against the recording to ensure accuracy. As I had conducted the interviews, transcribed some of them, and checked all of them, I was already familiar with the data. IPA is not a prescriptive methodology (Smith and Osborn 2003), and two main approaches are used for the development of themes from the data. Smith (2004) recommends that a detailed examination is made of the first case and a thematic structure developed for this case before moving on to the second case, and then on through the remaining cases. It is only when the analysis of the individual cases has been achieved that a cross-case analysis of the emerging themes is conducted and a convergence of themes across transcripts examined (Smith 2004). This process is useful when there is a small data set because it allows the researcher to become intimately acquainted with each transcript and allows those themes which are produced by the analysis of later interviews to be given equal emphasis.

However, it is more difficult when the data set comprises more than ten cases, as in the present study (Smith and Osborn 2003).

An alternative strategy is to use the themes that emerge from the first interview to orient the analysis of subsequent cases, adding and elaborating on themes as the analysis progresses. When this approach is taken, it is important to be open to the emergence of themes which are found in later cases. This was of particular importance for the present study as it was likely that themes would be identified in the second interviews which did not emerge at the time of the first interviews. Using either approach, the emergent themes are all treated equally. It was agreed that a hybrid approach would be used whereby the first three time one interviews would be analysed using the former approach, and then this would be used to create a master list of themes with which to continue the analysis of the time one interviews. When the time two interviews took place this process was then repeated to ensure themes which emerged in these later interviews were identified. The next section details that process.

9.9.1 Analysis of the First Interviews

The first stage of the analysis process was familiarisation with the first transcript, which involved reading it a number of times and using the right hand margin to annotate the transcript. I used the tape-recording and field notes to assist in the process of reorientation towards the data. At this point, hand-written notes were made on the transcript including paraphrasing, and summarising of key points. In addition, initial thoughts were noted about the communication style of the couple. This process continued for the whole transcript. An example of the note-taking stage is presented above in figure 9.2. This is from the first interview with Sonya and Peter and shows how the descriptive notes taken during the first readings pick up on what I felt to be important within this transcript. Following the initial read through of the transcript a subsequent reading was used to note the emergent themes which capture the essence of the text. The aim of this analysis is to produce a more abstract and psychologically oriented understanding of the participants' account.

Interview with Sonya (patient) and Peter (spouse) lines 345 - 365		
Peter	But, yeah, what I mean, em our problem is that we're not in a position to look forward. I mean we've talked; we've not sat down and talked, if you like formally. What we used to do, in the past, if we had something to decide, if we had something difficult to discuss we'd go out on the fell for the day and chat it over as we were walking. Er, but we've not sat down and, well the hospital isn't conducive to doing that	<i>Life on hold – limbo</i> <i>We-ness</i> <i>In the past – comparing to past lives</i> <i>Hospital</i>
I	No, it's not. I was going to ask what your normal way of dealing with difficulties is, and for you it's to be out and to talk things over	
Peter	It is, we sit down and talk things over at home	<i>Our style</i>
Sonya	We will talk things over half a dozen hours, won't we, before we come to a conclusion. We usually explore lots of avenues, to off at all sorts of tangents, look at all the possibilities, go down lots of dead ends before we come to a solution. We often think about it and come back to the problem later, don't we?	<i>Joint language – we</i> <i>Negotiation style – equals</i> <i>Present tense</i>
Peter	Yes. The only thing we've got to, the only resolution we've come to and this is informal and ongoing, cos initially I really felt I was treading on egg-shells when talking to Sonya about the future, I know we want to continue as close as we can to the lifestyle we've had, by picking up with things as best we can to what we have. I mean we went to the Shetlands and Orkney and that was the start of a Scottish Islands visitation over the next few years. We've done some of Scotland, but we'd never been to the Islands. Now we'd like top do the Islands, and er, so as far as we're concerned that's still on the cards. And I think that this is where we are so the outlook for the future is <u>very alien</u> to the people here!	<i>Communication as fragile</i> <i>Wishful thinking</i> <i>Hopes and dreams</i> <i>At odds with health profs</i>

Figure 9-2: An extract of a transcript at the stage of making initial notes

An example of some of the themes emerging from Peter and Sonya's interview is presented in figure 9.3. In this extract the themes applied are presented in italics on the left. It was however important to consider not only what each partner was saying but also the dynamics of the couple, such as the emergence of dominant voices or perspectives (Smith 2004). I was therefore alert to the possibility that one partner could dominate the interview and the view of the other partner may be lost, and where this appeared to be the case this was also noted.

Interview with Sonya (patient) and Peter (spouse) lines 335 - 365		
P	<i>Life on hold</i> <i>We-ness</i> <i>Comparison with past selves – like we used to be</i>	But, yeah, what I mean, em our problem is that we're not in a position to look forward. I mean we've talked; we've not sat down and talked, if you like formally. What we used to do, in the past, if we had something to decide, if we had something difficult to discuss we'd go out on the fell for the day and chat it over as we were walking. Er, but we've not sat down and, well the hospital isn't conducive to doing that
I		No, it's not. I was going to ask what your normal way of dealing with difficulties is, and for you it's to be out and to talk things over?
P	<i>Communication style</i>	It is, we sit down and talk things over at home
S	<i>Story of their relationship</i> <i>Selves as successful negotiators</i>	We will talk things over half a dozen hours, won't we, before we come to a conclusion. We usually explore lots of avenues, to off at all sorts of tangents, look at all the possibilities, go down lots of dead ends before we come to a solution. We often think about it and come back to the problem later, don't we?
P	<i>Treading on eggshells – fragile reality</i> <i>Denial of reality of stroke severity</i> <i>Problems relating with health professionals</i>	Yes. The only thing we've got to, the only resolution we've come to and this is informal and ongoing, cos initially I really felt I was treading on egg-shells when talking to Sonya about the future, I know we want to continue as close as we can to the lifestyle we've had, by picking up with things as best we can to what we have. I mean we went to the Shetlands and Orkney and that was the start of a Scottish Islands visitation over the next few years. We've done some of Scotland, but we'd never been to the Islands. Now we'd like top do the Islands, and er, so as far as <u>we're</u> concerned that's still on the cards. And I think that this is where we are so the outlook for the future is <u>very alien</u> to the people here!

Figure 9-3: Extract from interview at the stage of coding to constituent themes

The first transcript was then left and the process was repeated for two further cases, which resulted in a list of constituent themes. The third stage of the analysis involved imposing a structure onto the data. Once the first three transcripts were coded and emergent themes identified, these were listed and connections were made between them. This involves identifying how themes relate to each other or cluster together and how they are different. This process involves a theoretical and analytical ordering (Smith and Osborn 2003). At this stage, master themes were created which connected themes together. In some cases these were hierarchical links, with themes becoming subordinate to higher order (Superordinate) themes, and indeed some themes were subsumed as categories of larger themes. An example of this can be found in Figure 9-4.

Text	Initial notes made at step 1	category	Theme (sub)	Master Superordinate Theme
Mary: I took it to Dr [name] and explained some of my fears and frustrations and how tired I was	Sharing stresses with health professionals	Dealing with it elsewhere	Failing to engage with spouse	negotiation
Barbara: In fact, I was really frightened, I never told anybody other than Sandra,	Sharing fears	Dealing with it elsewhere	Failing to engage with spouse	negotiation
Annie: it was a journal of every day, as my day went, and I wrote down exactly how I was feeling. All the things I couldn't say out loud, that I couldn't tell anybody else.	the journal	Dealing with it elsewhere	Failing to engage with spouse	Negotiation
Peter: I really felt I was treading on eggshells when talking to Sonya about the future.	Treading on eggshells	Keeping thoughts hidden	Failing to engage with spouse	Negotiation
Barbara: He says it is a problem, I don't; think it is (...) I've tried to persuade him...	Persuasion attempts	Impasse	Tried and failed	Negotiation
Veronica: But together we started walking, and we saw this was something we could still do together	Learning together how things are now	Collaborative working	Successful negotiation	Negotiation

Figure 9-4: Example of how master themes and themes are linked

This list of master themes was revisited at the time of the second interviews and new themes were added to ensure that the experiences described in these later interviews were not constrained by the themes emerging in the initial interviews. To do this, the process used at time one was repeated and the first three time two interviews were coded in isolation, and then the new emerging themes were added to the overall master list, and this became the master list for later cases. During this stage of analysis, when the same theme emerged the same theme title was applied to the data. However, I became aware that I was using the same theme title for different ideas, and so at this point a full description of the theme and what it covered was written. This aided later analyses and ensured consistency across the data set.

At this stage Smith and Osborn (2003) recommend checking that the connections between themes “work” and that the connections are grounded in the experience of the participants. At this stage I became aware that some quotes, such as Veronica’s in figure 9.4 did not appear to directly reflect the theme assigned. It became clear from re-reading the coded data that this was the correct code, but the context was lost because, as with many of the participants, the sense of what Veronica was saying was spread over some pages, rather than one concise quote. This led to difficulties when it came to writing up the results because there was often no concise quote to use and so many quotes use (...) to indicate text is missing because the essence of what they were saying was spread across several utterances. Also, as I was interviewing couples it was common for the partner to interrupt, but not necessarily with information that was pertinent to what their partner was saying.

I also became aware that the development of the analysis was driven more by my reading and research questions than by the data, and so some reviewing of the connections I had made between themes was needed. There were also themes which appeared to be separate to those identified, such as dealing with health professionals which appeared to be linked indirectly to a range of themes and so these were retained in the analysis. This master list of themes was however still viewed as tentative and subject to change in the light of later transcripts. At this point the first three transcripts were entered into NVivo using the master list of themes as a guide to the analysis. This also provided the opportunity to review and revise quotes that had been assigned and ensure they were situated appropriately. The analysis of the remaining transcripts was completed using the same process. Although the later transcripts shared much in common with the earlier ones, the time two transcripts resulted in the creation of additional themes, especially in terms of “*getting back to normal*” and “*compromising*”.

9.10 Reliability and Validity

As qualitative research has been more widely accepted and used, there has been considerable debate among qualitative psychologists about how to assess the quality of qualitative research (Smith, 2003). To this end, much has been written about the appropriate criteria to adopt (Henwood and Pigeon 1992; Elliott, Fischer and Rennie 1999; Madill, Jordan and Shirley 2000; Reicher 2000; Yardley 2000), although researchers differ in the degree to which they believe traditional forms of reliability and validity can be applied to qualitative data (Murphy, Dingwall, Greatbatch, Parker and Watson 1998). Some writers have argued that since qualitative research is characterised by such epistemological diversity that different criteria are

needed for their evaluation (Madill et al. 2000; Reicher 2000). As IPA takes what Anna Madill calls a contextual constructionist stance (Madill et al. 2000), the present study adopted the guidelines proposed by Elliott and colleagues (1999) who locate themselves in a phenomenological –hermeneutic tradition (Willig 2001). Elliott and colleagues (1999) identified a set of seven guidelines which identify the importance of situating the sample, owning one’s own perspective, (reflexivity- disclosing one’s own assumptions and values), providing credibility checks in the form of colleagues’ or participants’ interpretations of the data, applying other research analysis methods and coherence (does the analysis make sense). Finally, the material should resonate with the reader, such that they feel they have an understanding of the subject matter.

I have tried to show reflexivity throughout the analysis section. It is worth examining whether characteristics of my personality and experience have affected how I conducted the study and understood the analysis. This approach is consistent with the guidelines of (Elliott et al. 1999) who highlights the importance of “owning one’s own perspective”, and Henwood and Pigeon’s (1992) concept of reflexivity. I was aware, especially during the earliest interviews of not always giving patients the time and space to talk, and allowing well partners, and especially well wives to dominate the discussion. It is possible that my interviewing style meant that some topics were not explored in as much depth as they could have been. I was acutely aware of how difficult some of the themes were to explore for some couples, and encouraged couples to feel relaxed. However, by trying to keep the interview more conversational I did not use as many probes as perhaps I should have, which means there are issues which are described by some couples, but for which there is little emotional content. On analysing the data I was also aware of how I responded to complaints with consolation comments, rather than remaining objective, which may also affect the results. However, there were a lot of discussions and disagreements between couples about how they manage the stroke, which suggests that the balance was appropriate. I spent a substantial amount of time in the field during the data collection process for the study and I believe this has provided me with a richer understanding of the lived experience of these couples. I also kept a reflective diary throughout the process in order to monitor my own subjectivity and I used this throughout the analysis.

It is also possible that my interests affected how I approached the questioning. Having taken a mixed method approach I may have pushed too much to examine disagreements and difficulties, and tried to find these where they did not exist, or over-interpreted that which simply reflects normal differences of opinion. This needs to be considered when reading the results section. I would however argue that couples did indeed disagree, viewed their exchanges

as disagreements and were open about these disagreements, and the difficulties having such different views had on their lives. I have also tried within the results to reflect the experiences of couples who did manage well, and who coped with the transition.

I have tried to provide a clear explanation of the data collection and analysis process to permit others to judge the quality of the resulting report, and also tried to provide sufficient information on the sample to allow other researchers to explore the extent to which the sample in this study is similar or different to their own. I have provided 'thick' descriptions which are grounded in examples, although as discussed earlier, it has proven difficult at times to find concise quotes with which to back up some of these descriptions. One of the disadvantages of interviewing couples was that they interrupted one another and so quotes are rarely concise.

In the results section I have used diagrams and descriptions to map how different themes relate to one another in order to help orientate the reader to the analysis. These links are not intended to be interpreted as a 'theoretical model', and indeed the process of negotiation is much more complex than the basic framework provided in figure 10.1. Whilst 'member checking' is often suggested as an appropriate credibility check the use of colleagues is also appropriate (Elliott et al. 1999). In this instance the use of a non-participant credibility check was considered more appropriate as the reader would be able to consider the analysis more objectively, rather than looking for themselves in the analysis. Therefore the results were shared with two colleagues. The first has a close family member who has experienced a stroke and her feedback indicated that she felt it resonated with her experience of living with stroke as a close family member and reflected the breadth of difficulties her family had faced. The second colleague was an elderly care nurse and she also read through some parts of the transcripts and provided feedback on my analysis. As a final credibility check, the reliability of the material coded to specific themes was tested. A random sample of 15 extracts was presented to three researchers, only one of whom had experience of the subject matter. These researchers were also provided with a list of seven themes (along with descriptions of the theme) and asked to apply these to the data. They were also given the opportunity to code the extract as none, and one of the extracts was not covered by the codes provided. Cohen's kappa coefficient was calculated to assess the level of agreement between the three respondent coders and the researcher. Kappa scores of 0.81, 0.69 and 0.59 were obtained, with the highest kappa score belonging to the person who had knowledge of the analysis. The kappa scores suggest there is moderate to substantial agreement between coders (McGinn, Wyer, Newman, Keitz, Leipzig and Guyatt 2004). Where discrepancies were found, the theme applied was conceptually related to the theme applied in the analysis.

10 Qualitative Results

10.1 Introduction

As described in the previous chapter, this analysis is based on interviews with 16 couples, comprising 14 time one interviews and 10 time two interviews. As referred to in the previous chapter, IPA was used to analyse the data, and categories were developed from the analysis of the transcripts and field notes which were taken following each of the interviews. The categories explore the experience of living with stroke during the six to eight months after discharge and how couples negotiate a way of adapting to the changes brought about by the stroke.

Four main themes were discernable, but, as will be observed, there are strong associations and connections between the different themes presented. As the process of adaptation and negotiation is by definition active, the data represents both stable and dynamic aspects of their experiences. Each theme is described briefly and then presented in more detail and supported by quotations from the transcripts. Table 10.1 provides demographic information on the participants, and pen-portraits are provided in appendix 18. The first three interviews which were used to form the original master theme list from which the analysis was developed are marked with an asterisk. Pseudonyms given to the stroke survivor are in bold, and the table is in alphabetical order by patient pseudonym. Within the results section the participant's name will be used at the end of quote along with a code to indicate whether the speaker is a patient (P) or well spouse (WS), and the interview number (1 or 2). For example, Malcolm, patient, interview 1, will be presented as (**Malcolm P,1**). In the extracts 3 dots (...) indicates text omitted.

Table 10-1: Demographic details of Participants recruited to the Qualitative Study.

Participant names	Age	Occupations	Years married	Stroke subtype	BI	Discrepant at time one	Time and place of 1st interview and transcript length	Time and place of 2nd interview and transcript length	Co-morbid conditions
Bill Mary	69 63	Wood machinist (retired) Secretary (retired)	40+ yrs	Frontal	8	Yes	50 pages 12 weeks home	39 pages 40 weeks home	Pre-existing Emphysema. Post stroke hemiparesis, dysphagia and dysarthria. Carer anxiety (Clinical diagnosis)
Cathleen John	71 C75	Office worker (retired) Mmanager (retired)	47 yrs	TACI	13	Yes	40 pages 12 weeks home	30 pages 38 weeks home	Hemiparesis, mild dysphasia, fatigue. Patient depression
*David Camilla	55 C55	Manager Teacher	27 yrs	MCA	7	Yes	29 pages 16 weeks hospital	Withdrew from study	Hypertension, high cholesterol Significant hemiplegia, fatigue
Dave Barbara	61 60	Driver (retired) Nurse (retired)	38 yrs	TACI	16	Yes	43 pages 18 weeks home	39 pages 45 weeks home	Myeloma, psoriasis, arthritis, mild dysphasia and hemiparesis, fatigue Hypertension hypercholesterolemia

Participant names	Age	Occupations	Years married	Stroke subtype	BI	Discrepant at time one	Time and place of 1st interview and transcript length	Time and place of 2nd interview and transcript length	Co-morbid conditions
Dick Ellie	64 64	Skilled manual (retired) Housewife	38	LACS	16	No	22 pages 6 weeks home	unable to schedule 2nd interview	Mild Hemiparesis, diabetic, hypercholesterolemia, Hypertension
*George Alison	65 62	Retired (self-employed) Administrator	30+ yrs	Not known	19	No	52 pages 14 weeks home	30 pages 42 weeks home	High cholesterol heart disease. Dyscalcula,
Karl Morag	59 65	Driver Health Professional (retired)	28 yrs	LACS	18	Yes	34 pages 7 weeks home	32 pages 40 weeks home	Hypertension, hypercholesterolemia Fatigue
Malcolm Annie	61 62	Skilled technical Administrative	27 yrs	TACI	11	Yes	48 pages 15 weeks home	48 pages 40 weeks home	Hemiparesis, Hypertension hypercholesterolemia
Marjorie Albert	85 C85	Retired teacher Retired Engineer	60+ yrs	PACI	15	No	32 pages 8 weeks home	Not seen – ill	Atrial fibrillation, hypercholesterolemia fatigue
Neville Cilla	56 53	Craftsman Shop worker	32 yrs	Not known	20	yes	42 pages 7 weeks home	Withdrew from study	Diabetic, fatigue, hypertension, hypercholesterolemia Carer anxiety

Participant names	Age	Occupations	Years married	Stroke subtype	BI	Discrepant at time one	Time and place of 1st interview and transcript length	Time and place of 2nd interview and transcript length	Co-morbid conditions
Rebecca	55	Administrator	31 yrs	TACI	14	Yes	21 pages	31 pages	Central pain, fatigue
Andrew	57	Factory worker					16 weeks home	48 weeks home	Hemiparesis, mild dysarthria
Roger	63	Craftsman	27 yrs	Brain stem	19	No	Time 2 interview only	41 pages	Fatigue
Dee	60	Accountant						34 weeks home	
Shirley	74	Housewife	40 +yrs	TACI	16	No	37 pages	Not seen - ill	Hemiplegia, emotionalism & depression
Gordon	79	Farm worker					10 weeks home		Concurrent cancer, arthritis
*Sonya	55	Professional	33 yrs	TACI	6	Yes	47 pages	39 pages	Significant hemiparesis, fatigue, visual neglect
Peter	58	Professional					14 weeks hospital	42 weeks home	Patient depression (clinical diagnosis)
Trevor	56	IT Professional	7 yrs	LACS	20	yes	43 pages	Not seen	Fatigue Hypertension
Veronica	55	Management					6 weeks home		hypercholestrolemia
Yvonne	55	Care Assistant	24 years	PACI	20	Yes	time 2 interview only	60 pages	Dysphasic, Hypertension, Fatigue,
Tom	57	Farmer						30 weeks home	Patient distress

Barthel Index (BI) is a measure of activities of daily living and is scored out of 20, a higher score indicates better functioning. C age = actual age not provided.

10.2 Overview of Themes

Although couples were homogeneous in terms of the cause of their disabilities, all couples were faced with different challenges as they attempted to adapt to the impact of the stroke. The themes described are presented in diagrammatic form in figure 10.1. This is not to be interpreted as a theoretical model of negotiation and adjustment, but is presented to orientate the reader. The themes form an iterative process of negotiation and re-negotiation as couples come to an understanding of the stroke, and manage its impact. This analysis attempts to provide an interpretation of that process, which involves acknowledging the difficulties they face, and trying to come to a solution which will allow them to integrate the event into their lives. During the negotiation process issues are raised and discussed, often over a period of months before a solution is achieved, and even then this solution may only be an interim one. Couples differ in the degree to which they achieve this, with some couples appearing to adapt relatively well, whereas other couples struggle to adapt to the impact of the stroke.

10.2.1 Theme 1: Entering an altered world

This theme is different to those following it because it constitutes where the couple start from in the process of adjustment to stroke. The purpose of this theme is to portray the wide-ranging difficulties faced by the couples in the study. Stroke represents a significant challenge to couples as they cope with the patient's physical, cognitive, behavioural and emotional disabilities. Many couples were faced with trying to negotiate and renegotiate roles and responsibilities and find a new balance in terms of how things are done. As will be seen throughout the analysis, many of the disabilities left by the stroke could themselves constitute a significant barrier in the process of getting back to normal.

10.2.2 Theme 2: Getting back to normal

All of the couples described how they were trying to get back to some sense of normality in their lives after the stroke. For some couples this took the form of them *striving for restoration* of their past lives and goals, whilst others sought to *accommodate* the impact of the stroke into their lives. Initially, the uncertainty engendered by the stroke left couples reeling, and they lived day to day. For most this pattern was not maintained and they began to find ways of adjusting to the stroke. However, partners did not always agree in their conceptualisation of normal, or agreed on some aspects, such as daily care, and not others, such as health behaviour changes, or prognosis for recovery. In a few cases there existed a

discrepancy in the views of partners, with well spouses successfully accommodating the impact of the stroke into their lives, whilst their partner still sought restoration to their old life. However, a small number of couples did not emerge from the crisis phase of the stroke and although their expressed desire was to get back to how they were before the stroke, the impact of the stroke on their lives was so great that for them there was a sense of a *life on hold*.

10.2.3 Theme 3: Striving to reach a shared understanding (the negotiation process)

This theme examines the range of different negotiation strategies used by couples in order to make sense of the stroke and move towards a shared understanding of the stroke and through this, get back to normal. Initially, the distress engendered by the stroke made negotiation difficult. Over time, couples started to re-engage with one another, and the negotiation process began, but partners were often mismatched in their willingness to engage with some subjects and negotiations failed. Over time some made compromises in order to move from the status quo. Although a small minority of couples tended to adopt a narrow range of strategies, most adopted a wider range of strategies depending on the salience of the topic, and the time since stroke. These strategies have been categorised depending on the degree to which they helped the couple come to a shared understanding of how to face these challenges.

10.2.4 Theme 4: Factors affecting the negotiation process

The difficulties faced by couples presented a significant challenge to couples as they attempted to negotiate a way of adapting to the impact of the stroke. Cognitive and behavioural problems made negotiation particularly difficult as well partners struggled to comprehend the extent of the patient's difficulties. In addition, discrepancies in the illness perceptions of partners, their communication style, and emotional distress levels presented further challenges to negotiation. In some couples there were significant tensions because they adopted different coping mechanisms, and this impacted on the degree to which they could successfully negotiate. In extreme cases there was a breakdown of communication between the partners.

• The Process of Negotiation

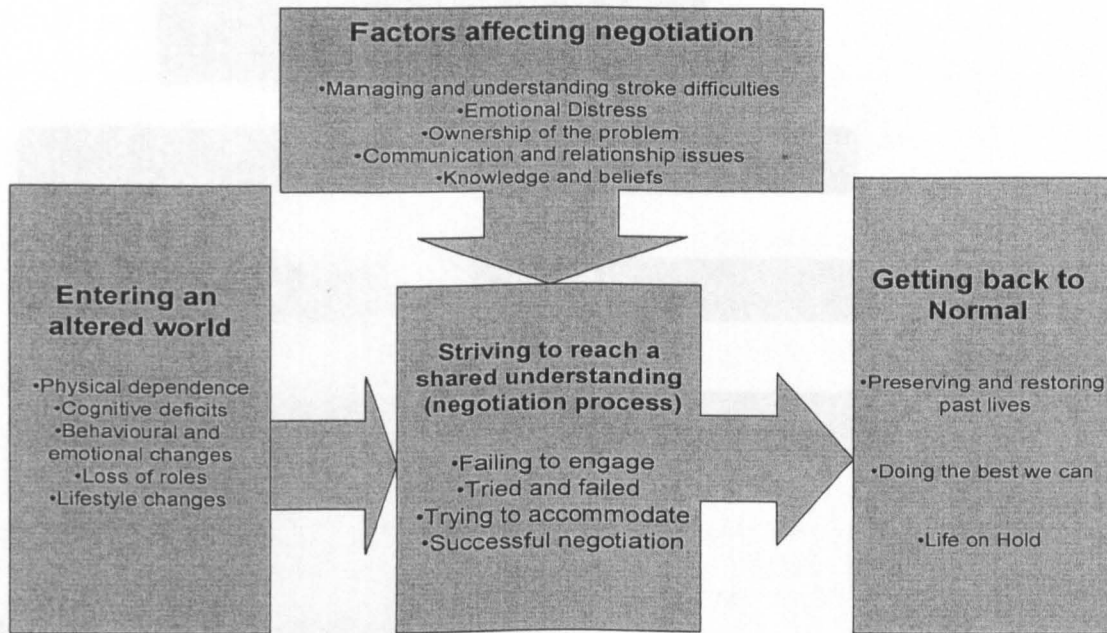


Figure 10-1: Flow diagram showing themes in relation to each other

10.3 Theme 1: Entering an altered world

"It's just a shock to the system as well [coming home], it's not just home, bang, back to normal, although we did know that, you don't realise"(Annie, WS,1)

This theme addresses the difficulties that couples were faced with as they tried to come to terms with the stroke. As discussed in chapter one, the effects of stroke are wide-ranging and it is often only once the patient is discharged home that the reality of these changes becomes clear. Over half of patients were left with moderate to significant disabilities, which resulted in wide-ranging changes to the lives of these couples. Others described themselves as having *"got off lightly"* (Trevor, P, 1). However, those patients who appeared physically unimpaired still found it difficult to come to terms with the stroke. This theme examines issues of physical dependence, cognitive and behavioural changes, dependence and independence and loss of roles and responsibilities (see Figure 10-2 for a graphical representation). All of these issues constituted a problem for at least some couples in terms of negotiation, but the way in which couples dealt with these difficulties determined

how well they adjusted, and the strategies they adopted to manage these difficulties is discussed in theme four.

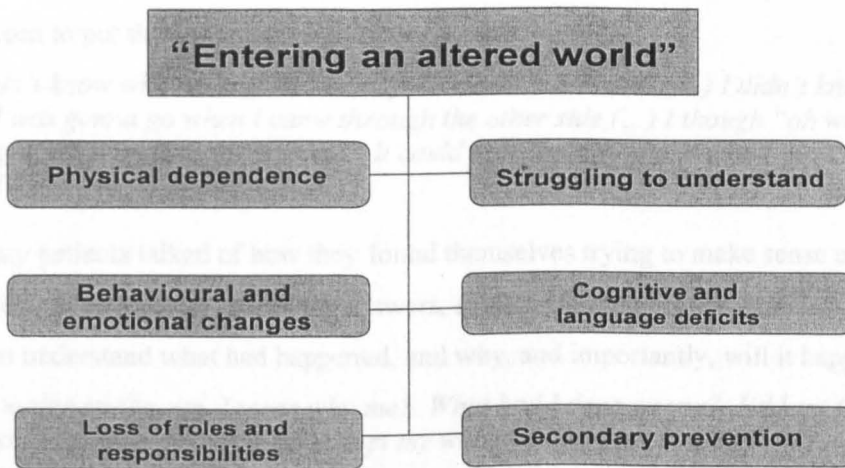


Figure 10-2: Theme 1: Entering an altered world

10.3.1 Subtheme 1: Struggling to Understand

Not all couples described the events surrounding the stroke in great detail, but for those that did, the onset of the stroke was described as unexpected, bewildering and frightening. Some couples talked of the trauma of watching the stroke develop, and living through being told it was a mild stroke to discovering it was much more severe.

“The doctors didn’t seem to be saying there was anything seriously the matter, you know, so that calmed me down (...) next morning the doctor caught me and said things had developed and that it was a stroke (...) but the time I saw him again he was having difficulty speaking and it was obvious this side had gone. I was quite angry they let it happen” (Camilla, WS, 1)

“Well it has frightened me a little bit, that it can happen to any of us, you know (...) it makes you wonder (...) of course I need to keep an eye on him, I don’t want it happening again, do we, because it is possible you can have another after your first” (Ellie, WS, 1)

Progress for some of the most disabled patients was very slow and couples found themselves relying on others to gauge the patient’s progress.

“people come in and say that they’re astounded at the progress you’ve made. I look at it like this, that to Sonya and myself the change and the improvements is like

watching wallpaper get dirty. Until you move the picture you don't see it, so you snatch as every little bit of info" (Peter, WS, 1)

Those who escaped with few disabilities described how grateful they were, and how they were keen to put the experience behind them.

"I didn't know what was at the back of the cloud, you know? (...) I didn't know which way I was gonna go when I came through the other side (...) I thought "oh well, that's all right, what a lucky fellow I am" It could have been worse, it could have been an awful lot worse" (Neville, P, 1)

Many patients talked of how they found themselves trying to make sense of events.

A repeated discourse was the search for answers, as patients and spouses were left struggling to understand what had happened, and why, and importantly, will it happen again.

"A major stroke, em, I mean why me? What had I done wrong? I'd kept fit, I wasn't a smoker or a drinker, I kept my weight down, how could this have happened to me?" (Rebecca, P,1)

"for me it was like she were on sentry duty, absolutely keyed up in case anything happened, when will it happen? You're scared it will happen. I suppose in the back of my mind I was worried too, yes, it stays with you, will it happen again?" (Albert, WS, 1).

Some patients and spouses described how they felt that the world as they knew it has suddenly been brought into question, and this sense of discontinuity in their lives was often described during the first interviews, and was still evident for some in the second interviews. *"I was aware that our whole life, well to me was gone in a second (...) I know it hasn't but at first, even for the first couple of months, you know"* (Annie, WS, 2).

10.3.2 Subtheme 2: Physical Dependence

Physical limitations such as loss of co-ordination, visual problems, loss of mobility and falls were reported by some patients, whilst others focussed on the tasks which had been affected by their physical limitations, such as not being able to drive, or go out alone, and problems with bathing, eating and dressing. Coming to terms with needing assistance in activities of everyday living was difficult, and several patients mentioned how they did not like having to ask their partner to help and were worried about being a burden *"you just don't bloody stop, that's your problem! She's cooking, ironing, cleaning, washing, showering me"* (Malcolm, P, 1). Well partners were often acutely aware that their spouse was reluctant to accept help even when the task is exhausting for them to do alone *"Malcolm's always saying is I'll just have a wash today, because, you know, it saves a lot of work and I say, No!"* (Annie, WS, 1).

Well partners found the first few weeks after discharge particularly stressful as they came to terms with the changes to their lives. Practicalities, such as getting used to the equipment needed to facilitate the care process, setting up and managing care routines, and engaging health professionals were described as particular problems for spouses.

“I had to sort of rearrange me whole life really erm, furniture, bring a bed down in [living]-room have a commode in the hall and all that which were upsetting ... as fast as I’m trying to open things up to give him room to manoeuvre with the zimmer, they’d bring in more equipment” (Mary, WS, 1).

Although the level of care needed by some patients declined over time, for others the problems described at the first interview were still evident six months later *“at the moment, you are pretty well fully dependent aren’t you? There’s not a lot you can do, erm, and that’s still unresolved”* (Peter, WS, 2).

10.3.3 Subtheme 3: Cognitive Deficits

Cognitive changes were common in the sample with over half of patients reporting memory or language problems, such as long and short term memory deficits, dysphasia, and difficulties remembering faces, numbers, and places. Planning and organising everyday life was a challenge for patients, and well spouses tended to shoulder this responsibility and devised strategies to help their spouse. Concrete help such as the use of post-it notes and phone calls to remind them to do things worked to some extent and were well accepted by most patients *“I leave him notes on a night, cos he’s terrible in the morning, he would have forgotten when he comes in at night. He’s in before me on a night, so I will leave him a note to remind him [laughs]”* (Cilla, WS, 1). However, patients talked how they feel they were constantly watched and evaluated by others, and many partners are aware that their constant observation is irritating as this quote illustrates:

“because I know you’re not as able to get things [measuring wood for cutting] accurately the first time I will often say, I mean I try not to, “are you sure that’s the right measurement” or you know... Well it must drive you potty, but on the other hand you could be about to make an expensive mistake [laughs], and I suppose I don’t always make things easier” (Alison, WS, 2)

10.3.4 Subtheme 4: Behavioural, Personality and Emotional Changes

Patients and spouses struggled to understand the behavioural and emotional changes brought about by the stroke, such as irritability, aggression, and tearfulness. Well partners described the patient as changed as a person, and behavioural and emotional changes were

commonly mentioned, although these types of problems were mentioned most often by well wives. One well partner talked of how her husband had changed so much it was like living with a different, albeit nicer person *“that kind of acquiescence would not have happened to the previous man, the man he was before the stroke. He wouldn’t have listened to a word I said”* (Dee, WS, 2). Some patients were also aware that they had changed, and talked about how they struggled to control their feelings *“Sometimes I get aggressive. Usually verbally, (...) it’s not me to do that”* (Neville, P, 1). Others found the unpredictability of their emotional balance, which could leave them in tears at inappropriate times difficult to understand or cope with *“I can burst into tears at the drop of a hat, which I didn’t before, I mean, how can that be?”* (George, P, 1). A few well partners talked about how their spouses was no longer cognisant of the dangers around them *“in Dave’s head he can do anything (...) he has a chain saw, drills and all kinds of electrical equipment in there. I’m a bit frightened in case (...) he decides he can do something and injures himself”* (Barbara, WS, 1). The unpredictability of these changes was a significant challenge for patients and spouses, and this will be explored in the theme “developing strategies”.

10.3.5 Subtheme 5: Loss of Roles and Responsibilities

All patients reported that at least some aspects of their previously held roles and responsibilities were lost or threatened by the stroke. In the acute post stroke period, well partners often had to take over roles and responsibilities which had previously belonged to the patient, and patient’s inability to master simple, taken-for-granted tasks was a source of distress for patients *“I feel so bloody inept, you know? (...) not being able to just go out and do things, you know, well ordinary things, such as that lawnmower (...) rather than seeing two women struggling”* (Malcolm, P, 1). The imbalance of roles between partners was also felt by well spouses who sometimes struggled to cope.

“While I were at work he did the shopping. He used to also go to the bank while I were at work and finance and now [long pause] it’s difficult to keep a balance cos I’ve taken on every role” (Mary, WS, 1).

It was at this point that the imbalance in couples’ relationships, and the true impact of the stroke was felt most keenly by both partners. Although taking over of roles was both functional and necessary, couples were faced with the challenge of accommodating these changes without the patient resenting their well partner’s health, and without the well patients resenting the additional workload. Couples achieved this with differing degrees of success, and patients were often well aware that their well spouse was finding the additional roles difficult to cope with. By the time of the second interview, many, but not all couples

had come to terms with these changes, but this is not to say it did not still impact on their lives.

"The biggest thing to come to terms with is that we have had a lot of workmen having to do jobs that Malcolm has always done, but we've got used to that, and we've got over it, but you've got to pay for it". (Annie, WS, 2).

"I just don't want Bill to think that, em, how can I put it [pause] he does rely on me a lot. I don't want him to think that I'm punishing him by making him feel guilty because of the pressure I'm under because of his illness" (Mary, WS, 1)

However, for over half of couples, there were some roles which were not open for negotiation, even when they created almost insurmountable obstacles, as in the case of George who was left with significant problems recognising numbers as a result of his stroke but refused to relinquish his control over the couple's financial affairs.

10.3.6 Subtheme 6: Secondary Prevention

A major task for couples was the prevention of another stroke. For most patients this meant reducing cholesterol and blood pressure levels, which was generally achieved through prescription medication. Although changes to lifestyle were seen as important, by the second interview few proactive secondary prevention measures had been started, with most patients relying on their medication to reduce their cholesterol and blood pressure. This proved to be a significant source of stress for some couples, with well wives trying to encourage health changes to manage blood pressure and cholesterol pro-actively, whilst patients were happy to rely on medication. When well spouses offered advice to their spouse about changes to health behaviours this was often not taken well. For one couple in particular this presented a persistent challenge and was discussed at some length during both interviews.

Morag: "It isn't just walking, Karl. You're just walking, if I had what you'd had, I've told you this before, I would be down that gym, where you can get personalised trainers".

Karl: "That's no [laughing] you know that I hate the gym and it's a non-starter". (P, 2).

Many patients expressed a desire to get back to their old routines and habits, but in most couples there was evidence of a divergence in their views about how and when this should, or should not happen, which was a significant challenge for couples although this was often taken with good humour: *"as far as DIY and that like is concerned, I think window cleaning is out [laughing], I've been threatened with all-sorts if I dare do the upstairs ones!" (Dick, P, 1).*

However, some couples had serious disagreements about the cause of the stroke and this was a significant cause of strain in their relationship. When there was a serious divergence of views, as was the case of Roger and Dee this took a long time, and many arguments to resolve.

Roger: "I have been a regular user, smoker of cannabis for many years, and I only stopped it because our Doctor, (...) said stop using cannabis, stop smoking."

Dee: "She was adamant! She said to stop immediately."

Roger: "So whether that is a cause or not, when I say I was a regular user of cannabis I would, smoke the leaf, em with nothing else, not with tobacco."

Dee: "She said [Dr] she has experience of people who smoke cannabis; she feels that she has quite wide experience of it and of the affects (...) but she did have to tell him several times not to do it again. I had to get her down here 4 times because every time he just distorted what she had said. So like the first time he said she said I can do it in moderation, and she never did, she said stop it! Don't ever do it again! Second time she came down, he was off trying to do it again, he said, she said I can do it in 6 months. She never did, she said stop it! It took me 4 times getting her down, saying to Roger do not do this again, until he finally got the message."

(Roger, P; 2 Dee, WS, 2)

10.4 Theme 2: Getting "Back to Normal"

It seemed to be important for couples to try to restore a sense of normality in their lives. The onset of the stroke was characterised by uncertainty, both in terms of why it happened to them, and why now. A strong thread throughout the interviews was the drive to get back to normal, and make sense of events, and this was represented by three subthemes shown in figure 10.3. When asked to elaborate on what normality meant to them, there was tremendous diversity in their descriptions, and partners often diverged in their views. Some individuals were driven by a desire to *restore their past lives*. For a small minority the uncertainty overwhelmed them, and this was compounded by the level of disability experienced by the patient, which made it difficult to plan, or even see a future. For these couples there is a sense of *life on hold*. For a small group there was a sense of acceptance and positive reappraisal. Well spouses in particular talked of how they had tried to construct an understanding of the stroke in which they were *doing the best we can*. Some patients also prescribed to this goal, but this did not ameliorate their desire for a restoration of function. As well as wanting to get back to normal there was also a drive to set the stroke into context and some couples did this by *minimising the impact* of the stroke, whilst others talked of re-appraising their lives and *establishing new priorities* in their lives.

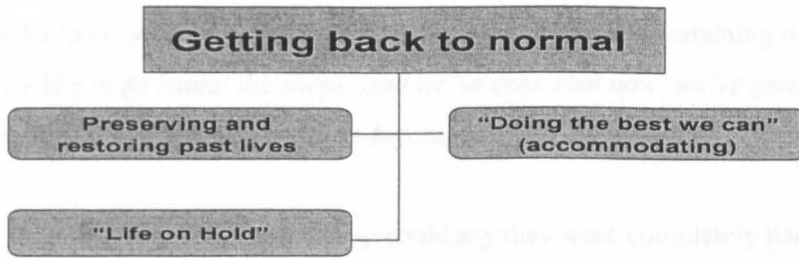


Figure 10-3: Theme 2: Getting back to normal

10.4.1 Subtheme 1: Preserving and Restoring Past Lives

At the time of the first interviews, getting back to normal for many couples centred on issues such as the restoration of lost function, and on regaining the use of limbs which would allow the re-learning of valued skills and roles. This focus on full restoration, especially of physical function was understandable, particularly whilst the patient is still in hospital or only recently discharged and the full effects of the stroke were not known. At this point the focus of hospital attention is itself on the restoration of function.

“he’s [Dr] told me I’m in the top one percent, that I should make a ninety-eight percent recovery, but that’s not good enough for me, ninety-nine point nine percent is just about acceptable” (Rebecca, P, 1).

Rebecca had experienced a serious stroke, and was making a good recovery, but as these quotes illustrate, some couples feel compelled to get back to how they were before and the battle or fight metaphor was one which cropped up several times, especially from well partners *“I just knew Rebecca would fight it, she’s a fighter, (...) she has fought it all the way, cos she’s strong. I never had any doubt she’d make a good recovery.” (Andrew, WS, 1).* This focus on restoration of function was the goal of most couples at time one, and for about half of them it seemed, on the face of it, to be a realistic one. For these couples, the impact of the stroke is minimised and “normal life” is maximised as much as possible. This was true for both patients and spouses. For patients it meant trying to regain lost roles, skills and abilities. For well partners preserving past lives centred on managing things so they could still go out to work *“As it was I was able to go back to work, and know she wasn’t on her own, and that there was someone there for her” (Andrew, WS, 1)* maintaining social

contacts, both within and external to the family, and trying to maintain important aspects of their pre-stroke lives, such as planning and taking holidays, and maintaining pre-stroke activities *“we like to go round the shops, and we’ve done that now, we’ve gone into town, he still looks at the CDs, exactly the same as before, but with a wheelchair”* (Camilla, SW, 1).

By time two, few couples felt they could say they were completely back to normal, because they had still had to live with, and work around the patient’s residual disabilities. Nevertheless, accommodating the stroke was not their goal and instead they focussed on carrying on as normal and trying to re-establish old routines. Some of the couples who were focussed on restoration at time one now diverged in their views of the prognosis and timeline for recovery. Some well partners now tended to talk of living with how their spouse is now, and living within the limitations of their disabilities. However, although patients happily prescribed to the idea of living within their limitations, most still clung to their goal of restoration, and talked of how things will be different when they are better.

Annie: “I would just feel happier if you just voiced an opinion (about care and meals)”. (WS, 2)

Malcolm: “There will be plenty of that when I’m better” (P, 2).

Annie: “You keep saying that, he keeps saying that”. (WS, 2)

For some, back to normal was not an unchanging entity but was subject to reappraisal over time.

“I’m hoping in another year, that me leg and me hand will be as good as it’s gonna get... I would say, cause they say that after 18-24 months that’s about as good as its gonna get anyway, so hopefully, I am planning to do that. I don’t wanna set me sights too high” (Rebecca, P, 2).

Aids and adaptations were the most visible symbol of the patient’s disability, and for a few, abandoning these aids was constructed as a step towards restoration, although the drive for this was most evident in the language of well spouses. For Cathleen, who would have been independent with the use of two sticks, or her wheelchair, this meant not using the wheelchair unless going long distances, and managing with one stick and her husband’s arm, which paradoxically increased her dependence on her husband. However his approach was *“You’re improving all the time, that’s the thing to do, Not get caught up in the idea of being able to sit in a chair, there is no need to do that”* (John, WS, 2).

10.4.2 Subtheme 2: Life on Hold

For some couples, the doubts and uncertainties which made the stroke so difficult to cope with, became a repeating theme and dominated their discussions. For two couples in particular this resulted in a sense of a *life on hold* in which acceptance and adaptation are in hiatus because of a mismatch between reality and their own idealised view of the future. Peter and Sonya struggled to come to terms with what the stroke might mean to their lives. *"It's like being a tourist with no map and no language, we're still lost really"* (Peter, WS, 1). This couple struggled to accept the doctor's prognosis for recovery, and they felt that health professionals were being overly pessimistic, which led them to ignore what they were told because it did not fit their model for recovery *"there is a difficulty in seeing the way forward, and it's not helped by the fact that every time we see and try to talk to people here [staff at the hospital], they, to me, take a very negative stance"* (Peter, WS, 1). Here discrepancy was not between the couple, but very strongly between the couple and the professionals caring for Sonya, and this had a profound impact on how they came to understand the stroke.

Sonya was significantly disabled and the magnitude of what they face is difficult to comprehend. Until they have more concrete answers, and indeed the *right answers*, their uncertainty cannot be resolved. Whilst Sonya says she is ready to face the truth *"It's only when I know how bad it is going to be, that I can face it"* (Sonya, P, 1) when faced with the truth she disengaged from reality and indulged in wishful thinking and day dreaming *"we used to go to Switzerland we used to go walking in the high peaks,.... next time it will be the farm tracks"* (Sonya, P, 1). At the time of their second interview Sonya had been home two months, and Peter was trying to put in place routines to help them, but also struggling to come to terms with the demands of being a full-time carer *"I'm in permanent survival mode and I've finished one thing and getting another one the next"*. He talked of being in a transition period where they still didn't know how mobile Sonya would eventually be, and it was evident that the slow recovery process meant that their lives were largely suspended, because they could not achieve their pre-stroke goals. *"By that time [2 months time] we'll have a better idea of where we're going, of how mobile Sonya is. I think we live on hope to be honest, and we plan to get as far back as we can."*(Peter, WS, 2).

For Bill and Mary there was also a sense of a life on hold. Bill had experienced a stroke which had left him with moderate disabilities, to which he seemed to have adapted

well. However, at the time of the first interview Mary, who was struggling with her own health concerns, was worried whether she could cope with caring for Bill *"I come out of hospital [after pneumonia] and I wasn't well enough myself, then I felt guilty. Then I had all these different emotions, well who's gonna look after him?"* Her feelings of guilt and inadequacy were repeated during both interviews, as she constantly compared herself negatively against others who she perceived were coping better.

"if you go down you feel less of a person cos you think, he's still in a better state of health that what he is or she is ... You can't help it, I still compare how he is to how other people.... and I know we came off light compared to them, so I feel even more guilty for not being able to cope, you know?"(Mary, WS, 1).

By the time of the second interview Bill's health had declined and had suffered several falls, and Mary was frightened to leave him unsupervised, but at the same time resentful about being tied in this way.

"I am looking for what's going to happen next. Like sort of always being prepared and not been able to relax about it. [I think about] what the future will bring and trying to look forward and then see the stepping stones like stumbling blocks" (Mary, WS, 2).

By not coping she felt a failure and this made her reticent to involve health professionals who she saw as the *"powers-that-be"* rather than gatekeepers to help and support *"you're frightened of what you look like, which diminishes a bit of your pride"* (Mary, WS,2). For Mary, her fears meant she struggled to cope without help and as a result she was *"just existing really, day to day"*. In having to live day by day the couple were unable to move forward or negotiate a way of living in the longer term.

10.4.3 Subtheme 3: "Doing the best we can"

Even at time one there was evidence that a few couples had adapted well to the impact of the stroke. This was reflected most in the accounts of two older husbands who were caring for their ill wives. For these husbands, who had a meagre repertoire of domestic skills, this meant working under her guidance *"she's a good director"* (Gordon, WS, 1). These couples demonstrated a collaborative attitude to coping with the stroke and when asked whether they had sat down and talked about it, Gordon admitted it was trial and error.

"I've learned more of what needs done, so I do it now, and that's easier on both of us. There are a lot of things I hadn't really done much before, so what we do now, if I never did it before, she just directs the action, so to speak. It was trial and error, you know, just taking things as they come" (Gordon, WS, 1).

For these couples the stroke was not constructed as a crisis, but something that happens at their time of life, and not of great importance *"In the scheme of things, well it's nothing, not at our time of life"* (Albert, WS, 1). By the second interview, more couples were starting to talk about how they tried not to allow the stroke to dominate their lives and how they were striving for a "new normal" in which we can *"get on with our life to the best we can with what we have got now"* (Barbara, WS, 2). This position was most strongly represented by well wives who talked about how they tried to establish routines that meant they could go out and do things together. Another important mechanism for accommodating the stroke was the development of a shared understanding which was achieved through improved communication with their partner.

"We've always been able to go out for a meal and sit and chat, but now we really say what's on our minds in a way we never did before. We always talked, now we communicate" (Annie, WS, 2).

Accepting a *new normal* did not mean that these wives did not want their spouse to achieve further recovery. Instead, it reflected an unwillingness to wait for some future recovery, and accepting what they had, and living in today. They and their ill spouses still hoped for further recovery, but that this was their normal now.

"I would like to think there will still be improvements with things like vision or memory whatever but I'm quite happy to accept this is the normal and I can live with it and I think you can live with it." (George, P, 2).

By constructing it in this way, restoration and new normal are not viewed as opposing options. For these couples, aids and adaptations were also viewed differently too. One patient described how it was a way of doing the things they always did before, and for Malcolm it was a compromise that allowed them the freedom to do things together.

"I've got an electric scooter now, so, often if we go down into town we'll take the scooter down, which means we can get round town better, cos I do walk slow, so that makes a difference, cos the alternative is her pushing me and I'm not having that.. if you'd asked me what I thought about a scooter before I got one I'd have said I'd never been seen dead on one, but it's made such a difference to us, and what I can do". (Malcolm, P, 2)

For well partners, a new normal meant accepting new limitations on their freedom and lifestyle, and accommodating to these changes. *"We tend, if we go out together, we go out in the morning when he's fresh, before, you know, the day wears him out"* (Barbara, WS, 1). Accommodating the stroke also meant making allowances for the changes in their partner's moods and allows things to slide rather than make an issue out of them.

"that is slightly irritating (...) I've been away all day and the washing up is still on the draining board (...) I don't say anything much do I?" (Alison, WS, 2)

Doing the best we can often meant involving family members so that the well spouse could have some time alone and maintain some separateness and independence.

"[daughter] lives so close (...) so she pops in, and maybe if Malcolm is having a rest, I'll pop down to town, which is nice" (Annie, WS, 1).

As their partner's health improved some well spouses were also able to regain some of their independence and were more willing to leave their ill partner alone and go and see friends, or in some cases return to work.

"Malcolm has always been the same, and quite likes his own company, he's always been a bit of a loner (...) I need company more than he does (...) so going back to work, for me, well that's something I need, and I miss my friends at work" (Annie, WS, 1).

For all but one of these couples physical intimacy had been lost, either because of the stroke, or prior to the stroke, but emotional closeness and being able to spend time together were valued by well spouses *"it's nice that we do more things together because that was always a bit of a beef of mine that we didn't do enough together"* (Alison, WS, 2).

These couples were also the ones most likely to make downward social comparisons and positively reappraise their situation. Couples often deliberately played down the impact of the stroke by comparing themselves against others they felt to be more disabled *"I think I've been very fortunate, you know. When I look at other people (...) there were so many who couldn't walk"* (Marjorie, P, 1). Even when patients were living with significant other health problems they still compared themselves positively against others, *"I think I am quite a lucky bloke anyway health wise. I know I've got this lot and I've got all this cupboard full of tablets through there, but I think, you know there are a lot of people (...) they're not as lucky as me"* (Neville, P, 1). A few patients compared their circumstances to those of people in the public eye. One patient compared his stroke to that of Ariel Sharron and said *"I'm glad I'm not in his shoes! Didn't I get off light"* (George, P, 1).

Over time, these couples started to focus on what had been spared rather than what had been lost, and a few talked about what they had learned from their experiences. Others used the stroke as an opportunity to reflect on their lives and decide what was important to them, and what their priorities were.

"I can empathise [crying] I know what it's like to be disabled, not to be able to do things, to lose confidence, and it's not a nice feeling. (...) I used to work with people who had physical disabilities, (...) I never really understood before [weepy] how they felt, and I think that now, if I was well enough to go back to it, you know in the future, that I'd be better equipped to work with them and understand their needs better, and that's a good thing, you know, a good thing to learn" (Rebecca, P, 1)

"we have talked a lot about reviewing our lifestyle since the stroke, because suddenly you know, you plan everything, for, oh one day we'll do this and this (...) suddenly you get a glimpse that suddenly one day might not be there, so it makes you question what you're doing, and why you're doing it" (Dee, WS, 2).

Couples who were already retired talked about wanting to spend more time with each other, or with their families, and especially grandchildren, or achieving goals and dreams they had talked about, but prevaricated over *"A positive thing has come out of it, I think. If I want something, I don't mean things, not objects, but if I want to do something, I'll do it (...) I won't prevaricate and put things off"* (Karl, P, 2).

10.5 Theme 3: Negotiation: Striving to reach a "Shared Understanding"

Adjusting to stroke was a psychosocial transition which required couples to negotiate a shared understanding of the stroke. Some couples were faced with making often quite significant changes to their lives, and negotiation was found to play a pivotal role in this process. This theme comprised four subthemes which are represented graphically in Figure 10-4. These subthemes reflect the degree to which the couples attempted to negotiate their problems. These divisions are somewhat arbitrary and encapsulate a range of communication strategies. Although presented separately, there is overlap between aspects of each stage. Furthermore, each partner may be at a different stage in terms of willingness to negotiate, and this may mean that couples have to revisit the problem again at a later date. In addition, couples may be willing to negotiate some issues and not others. As the process of recovery unfolds the negotiation process changes as couples become more aware of the difficulties the patient has, and attempt to find new ways of relating which allow them to adjust to the stroke.

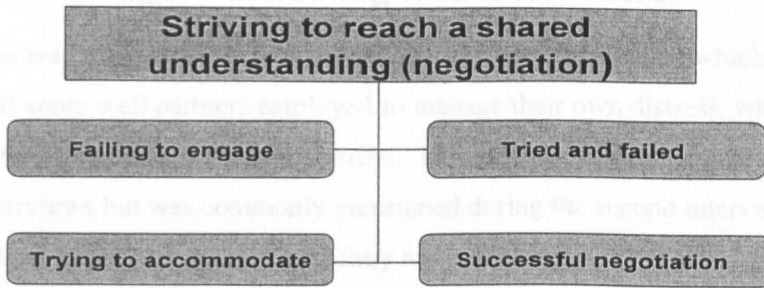


Figure 10-4: Theme 3: Striving to reach a "Shared Understanding"

10.5.1 Subtheme 1: Failing to Engage

This subtheme covers four strategies which are characterised by a lack of discussion: keeping thoughts and feelings hidden, dealing with it elsewhere, social constraints and non-negotiated decisions.

10.5.1.1 Category 1: Keeping Thoughts and Negative Feelings Hidden

There were issues relating to the stroke, about which couples avoided talking, and which they did not talk to others about. In the early days there were some things which were simply not discussed and well partners talked about how it was like "treading on eggshells" (Peter, WS, 1) and how they were "wary about saying anything" (Tom, WS, 2) around their ill partner, especially if they thought this would upset them. This was most common whilst the health threat was current, and receded over time. At time two, couples talked retrospectively about how they had actively avoided talking about the consequences of the stroke, and the prognosis and timeline for recovery, with more than two-thirds of well spouses, and half of patients mentioning how these were issues they had found too difficult to raise with their partner.

"But then you didn't just come to me and say by the way I'm going to be in for so long! The only thing I kept from Malcolm ... the only thing I kept from Malcolm was the length of time [he would be in hospital], not the severity of it [the stroke]" (Annie, WS, 1)

10.5.1.2 Category 2: Dealing with it elsewhere

One way of managing distress was *dealing with it elsewhere* which refers to the strategy that some well partners employed to manage their own distress, whilst avoiding burdening their ill spouse with their worries. This strategy was mentioned only once during the first interviews but was commonly mentioned during the second interviews when well partners talked in retrospect about how they had coped with their distress, during the weeks after the stroke. Well partners talked about how they had found people outside the marital relationship such as family members and friends with whom they shared their worries instead. Annie talked of how she had used a journal as a way of venting her emotions, without feeling that she was burdening her family at a time she felt they were ill-equipped to cope.

"It was a journal of every day ... I wrote down exactly how I was feeling. All the things I couldn't say out loud, that I couldn't tell anybody else. I knew that [daughter] would read it, but so much of it was something I couldn't say to her, so it was a way of sharing without saying it. I mean ... you know you've got your family, and you love them but there's things that you can't say, because you love them, you don't want to put pressure on them because they're going through enough." (Annie, WS, 1)

In contrast, few patients in the study talked about sharing their feelings in this way. A number mentioned how difficult it was having any sort of meaningful conversation in hospital because of a lack of privacy "*there's nowhere private, you know, to talk, on the ward anyone can listen*" (David, P, 1), but few patients looked beyond their spouse for emotional support, and only one described sharing feelings with friends rather than their spouse.

10.5.1.3 Category 3: Watchful Waiting

A common form of avoidance of negotiation during the early weeks was a desire to *wait and see* what happens. The weeks following the stroke were filled with uncertainty regarding prognosis and recovery and many couples felt unable to make informed choices about what action to take and so gathered information and deferred any decisions.

David: "It's [transferring to a hospital closer to home] an option that obviously we have to cover, and at the end of the day it might be the best, but we don't know yet. We probably won't know until we do something, but it is certainly worth considering, we have to weigh things up."

Camilla: "It would be as step nearer, wouldn't it, really. And you wouldn't have to stay all the time in the hospital, cos we are just down the road. I could easily get him into the chair and take him back home again. But we wouldn't like to compromise the really good physio here, we will really be guided by the doctors."

David: "Yes, at the moment it's very much suck it and see, but at the minute we know we will be here til Christmas, and so we will make that decision later on, (...) The more other information we can gather..."

(David, P, Camilla, WS, 1)

Information and knowledge were commonly mentioned by patients and carers as pre-requisites for moving forward in any meaningful way. Yet most couples felt they had insufficient information or knowledge about *their* stroke to make any decisions. Without this certainty couples felt helpless to move forward, and their plans were held in abeyance.

Peter: "The next move is, if we can get her into it [camper van], once you get there, can you use the facilities? Now, I can't move on that until we get some idea of where we're going. And this is the frustrating part as far as I'm concerned, cos I just, so far they [doctors] are being evasive."

Interviewer: "You feel that the doctors are not sharing the real trajectory for recovery with you?"

Sonya: "Yes, it's not about determination [to get better] I've got that"

Peter: "Yeah, it's not that, what we're saying is, it's not even about time-scales. People would say well, well, em, the problem we've got now is that people say, "Well if I say something, you might come back and sue me because what I've said isn't happening?" We cannot get it through their heads, that, Look give me an idea -"

Sonya: "That we can work towards-"

Peter: "That may change, but at least I've got something to work on. At the moment I feel I'm batting completely in the dark, and I find it, I just get so angry about this, it's just so frustrating,"

(Sonya, P, Peter, WS, 1)

10.5.1.4 Category 4: Social Constraints

Although the majority of well spouses talked of how they had shared their worries with family and friends, for others, family members actively constrained the voicing of concerns. One reason for this may be a desire for the family to stay strong and remain positive. In these instances, admitting concerns may break an implicit agreement which exists within the family to remain positive and hopeful, and indeed many well spouses talked of how they, as a family were trying to stay positive. The use of social constraints was not common, but was explicitly mentioned by two couples who said that worries and concerns were not shared with others because family members inhibited the expression of fears.

"The girls were marvellous, but they didn't want to see me upset, they didn't want to see that in me, so I, in a way I had to hold back with them. ... they [daughters] were looking at me to see if I was alright, because as soon as I wasn't seeming to be alright, they would say "we can't cope with Dad being ill and we can't cope if you get ill as well, so you're going to have to stay alright" (Camilla, WS,1)

Whilst remaining positive can be viewed as beneficial to the patient, closing down discussions within family members may leave well spouses without support. Such overt collusion within the family was rarely mentioned, but this does not of course mean it did not occur. Unfortunately this couple declined to be interviewed at time two, and the other couple did not report this at the second interview so it cannot be determined what the longer term effect of this form of interaction may have on negotiation.

10.5.1.5 Category 5: Non-Negotiated Decisions

Some decisions were taken by one party without recourse to discussion with the other partner. This was particularly prevalent in the early post stroke phase when the ill spouse was unable to actively participate in decisions making, and decisions were made by the well spouse on their behalf. At this point, this behaviour was not constructed as problematic, indeed most patients talked of how their spouse had made good decisions in difficult circumstances “*they asked the best person (...) I trust Camilla’s decision, always implicitly*” (David, P, 1).

However, a few patients felt that decisions were taken by their well spouse that should have been discussed more, and patients felt that they weren’t making joint decisions, as they had done prior to the stroke.

Sonya: We talked about it [moving hospitals] a bit and then you came with a letter to Dr [name] saying this is what our decision is. And they signed that. (P, 2)

Peter: Yes, I thought we had agreed on that, maybe I, maybe we hadn’t agreed as much I had thought. (WS, 2)

10.5.2 Subtheme 2: Tried and Failed

This subtheme was found most often during the second interviews when couples talked about difficulties they had faced during the previous months and how they had attempted to resolve problems. This subtheme reflects the interaction between couples as one partner tries to approach the difficulty by raising it for discussion, whilst the other partner is not yet willing to engage with the issue and avoids negotiation. Two categories of distancing behaviour were described which closed down discussions before any resolution could be reached, or at least before a resolution acceptable to the partner opening the discussion could be found. Negotiation attempts involve active engagement with the conflict topic by one or both partners. When one partner attempts to open a dialogue on a topic that the other partner does not wish to discuss then it can be closed down through the use of topic management strategies.

10.5.2.1 Category 1: Topic Management

During the interview process couples occasionally used topic management strategies to avoid talking about an issue which their partner had raised for discussion. This generally took the form of not responding or offering non-committal remarks which neither confirmed nor denied the difficulty, such as *"I mean, don't try to ask me to comment"* (Roger, P 2, in response to being asked about his behaviour towards other people), or false reassurances which stopped the discussion *"it's happened and there's nowt we can do about it."* (Peter, WS 1, reassuring his wife that her disabilities do not worry him). A few participants used negative or critical comments such as *"subject closed"* (Mary, WS, 2) to close down discussions, but this strategy was rare. A consequence of topic management is that conflict issues are avoided and not available for resolution, and this difficulty was just as common during the follow-up interviews. Well wives complained most about it, and described how their attempts to engage their partner in discussions about their health or feelings had failed *"It's still a bone of contention.....I don't want to push him about exercising, because he gets so angry when I do, you know"* (Morag, WS, 2).

10.5.2.2 Category 2: Impasse

The second form of resolution failure centres on difficulties which couples have raised and discussed, but failed to resolve. This emerged from the descriptions couples provided of past experiences when they had failed to resolve an issue. Most of the problems described as being difficult to negotiate were issues such as the giving and receiving of care and re-establishing activities. In these interactions, the issue was raised and both partners justified their own positions, but neither partner was open to persuasion by the other, and the discussion ends without resolution.

Barbara: "he won't go in the [wheel] chair if he can help it, so we go where he can walk. I mean we have only been out twice in the wheelchair, haven't you? He doesn't like it" (WS,1).

Dave: "What I have been thinking about is getting one of those motorised things, a scooter, you know, I mean, I could go with the wife like and she's not having to push me,..... she doesn't mind one little bit, but she has problems of her own let alone pushing a big lump like me about you know. So it's, that's what it goes back to."

Barbara: Well as you see, he says it is a problem but I don't think it is. I've tried to persuade him that it is alright, but we never get round this one" (P,1)

In some cases, such as this example, the impasse was constructed by the couple as agreeing to disagree and although the patient to some extent wins this argument, neither is happy, nor anything resolved. Both partners viewed the interaction positively because it

meant they had said their piece, but this situation could just as easily become a stand-off in which one partner uses their power to enforce a detrimental resolution on the other partner. However, not all failed negotiations are viewed as a step forward, and for one couple in particular this pattern of behaviour became a common theme.

Bill: "I'd like to think we could go on a holiday for at least 3-4 days which I know we can! But Mary is reluctant –"(P, 2)

Mary: "No, it's not a case of I'm reluctant, it's the safe circumstances to get him there ... and when he's there ...!" (WS, 2)

Bill: "See what I mean ...you're always sticking things up! Always saying you've got to take account of how I am now, always making excuses." (P, 2)

Here it is clearly difficult for the patient to negotiate control over this aspect of his life, but there is also significant conflict between the ill person's need for normality, which is represented by the holiday and the well partner's anxiety about how this might be achieved. This couple struggled to negotiate on a range of issues, but as Mary's view of the stroke was so much more negative than Bill's these rarely succeeded.

10.5.3 Subtheme 3: Trying to Accommodate

Compromising or yielding to the desire of one partner emerged as one of the most common ways of solving difficulties. Compromising involved admitting differences of opinion and finding a working solution albeit a sometimes unequal solution. It was described more commonly at time two, when more than half of the well partners talked of how some decisions had been a compromise on their part, with the majority being female partners of male patients. These compromises were almost exclusively about helping the patient return to normal activities. In the weeks and months after the stroke, patients pushed themselves to regain lost activities, but couples often disagreed about how quickly the patient should wait before trying to do things. By the time of the second interviews there was evidence that some well partners compromised in order to restore some control to their ill partner. Withdrawing their veto over valued activities was one way of doing this and allowed the patient greater independence *"For me, I suppose it has been about learning to compromise, he won't regain anything, you know any of the things he was able to do if I don't let him try"* (Barbara, WS, 2).

Over time, changes were needed to the coping strategies put in place during the crisis, and compromises were made over a range of topics. One area for negotiation centred on issues of secondary prevention because many couples differed in their beliefs about how

a second stroke could be avoided. Many of these negotiations failed, but Roger made a significant compromise by agreeing to stop smoking cannabis against his own beliefs, because his partner and GP believe it has caused the stroke, thus privileging their concerns over his own views.

"I am erring on the side of caution because I think that it's like this, it's worth giving up something which I enjoyed before, which I didn't feel, which I was convinced actually wasn't doing me any undue harm. But it was worth giving that up for them" (Roger, P, 2).

There was also evidence that in some instances, well partners would simply yield to the patient for a quiet life. This differs from compromising because it simply allows one partner to win the argument for the sake of peace and quiet. This behaviour was not commonly reported, but in all cases it was the well partner yielding to the ill partner.

"That is one of the biggest problems. He is still like a naughty child. If he wants something it has to be done now! He might as well be a seven year old and stamp his feet! (...) well I don't know what he was doing with the fire but he couldn't get it to light, (...) I said "you're turning it the wrong way", so, he said "you will have to take all the coals... I did say to ya "Are you cold?" You said "no", well I said "can you wait ten minutes till I have had me tea?", "Aye! Well go on then" but then he is on his knees taking the fire to bits. I said "FOR GODS SAKE DAVE!", so in the end he said" DON'T YOU SHOUT AT ME", and I said "Don't you shout at me", so in the end of course we had to do the fire first, cause there was no way he would sit back and let me have me tea." (Barbara, WS, 2).

10.5.4 Subtheme 4: Successful Negotiation

Gaining a shared understanding of the stroke was achieved through two processes. Firstly it involved *open discussion*, which was how couples came to a shared understanding. The other form of negotiation was more implicit. Here, agreement had come about through trial and error, and this was characterised by *collaborative working*. Using this approach the couple did not necessarily come to a shared set of beliefs about the stroke, but they nevertheless came to a way of living with it.

10.5.4.1 Category 1: Open Discussion

Successful negotiation resulted in a solution which both parties felt to be satisfactory. From the analysis of unsuccessful negotiation attempts it became clear that successful negotiation required the ability and a willingness to express one's feelings and thoughts on the conflict issue, and the wherewithal to talk things through. In this sample, evidence of successful negotiation was found during the second interviews when couples talked retrospectively about how they had come to a negotiated solution over a particular difficulty. However, this outcome was found less often than compromising, and only half of

couples were able to relate an issue which they had successfully negotiated. The outcome of many of these negotiations were not material benefits, but involved changes to the *status quo*, such as increased independence for the patient or spouse, greater bonding between the couple or reduction of stress for one or both partners. Mary described how she had encouraged Bill to start doing the banking again, a role which had previously been his. Bill was initially reticent and Mary had to offer verbal encouragement for him to persist. For Bill and Mary, this level of collaboration was rare and much of their talk was characterised by conflict, but this division of labour was seen by both of them as doing something for each other, and, importantly handing back some independence and control to Bill.

Interviewer: "you've managed to get back to doing the banking; you've managed to do that on your own. Can you tell me how that happened?"

Bill: "Oh er, first time, well Mary had to talk me into it really, I didn't want to, didn't feel I could do it yet. I felt clumsy. I looked clumsy... so I couldn't do it ...the first time."

Interviewer: "It didn't put you off?"

Bill: "Aye it didn't put me off, well it did but I still felt I had to give it another go. It got easier each time, but I still need to take a taxi and what have you, I can't walk there or owt.""

Mary: I used to say to you, thanks Bill, it saved me a job and he'd be right pleased and next time it weren't as bad, was it?... But it also means he's got something back, you know?" (Interview 2)

10.5.4.2 Category 2: Collaborative Working

In contrast to successful negotiation which contains a verbal element, collaborative working does not involve sitting down and talking, and there was good evidence some changes were brought about through a process of learning how to do things in new ways. Working collaboratively was characterised by the phrase "*we muddle on together, don't we?*" (Albert, WS, 1) which described the way many couples worked together to achieve everyday goals.

"we've had to work a different way round somehow, to make it the easiest way of working. She can't do lots of things she did, and I didn't know how, so she directed operations and taught me how to do. Now, I can just get on with some things, and she keeps me company or tells me where I'm going wrong. (Gordon, WS, 1).

Over half of couples talked about how they have established routines which meant they could do things together. Couples talked about how they tried out different care patterns until they found one which worked for them, but when asked if they had talked about this it became clear that this was a more experiential way of coping, with most talking about how things came about through trial and error. As the quote above illustrates, couples

work together jointly to achieve a division of labour which is flexible and accommodates the stroke. Sometimes this means that roles are reversed, as in the case of Gordon and Shirley, in other cases they do things together so the patient can take responsibility for an aspect of their lives.

“That is one thing that Malcolm can do, and it’s so important that he can feel to be in charge of some things, you know, cos there are so many things we’ve had to accept that he can’t do now. One thing we started to do was internet shopping. It was his suggestion and we gave it a go. We started this when I hurt my shoulder and couldn’t drive. Now, I’m rubbish on the computer, so Malcolm does it, he’s really good with the internet” (Annie, WS, 2).

10.6 Theme 4: Factors Affecting the Negotiation Process

This theme addresses the issues that emerged during the interviews which act as barriers or enablers to the negotiation process. These are factors which were introduced in the previous theme, such as cognitive and behavioural deficits, and the illness perceptions of participants, whilst others relate to relationship issues. These themes are presented graphically in Figure 10-5. This theme addresses how these issues are understood by patients and spouse and largely reflects my interpretation of how these factors may operate, but are supported by participant descriptions. The purpose of this theme is to try to provide a clearer picture of how these factors manifest in the negotiation process and the roles they play, so they are separated into five subthemes focussing on the patient’s level of physical, cognitive, behavioural and psychological functioning, patient and carer distress, ownership of the problem, pre-stroke relationship issues, and knowledge and beliefs.

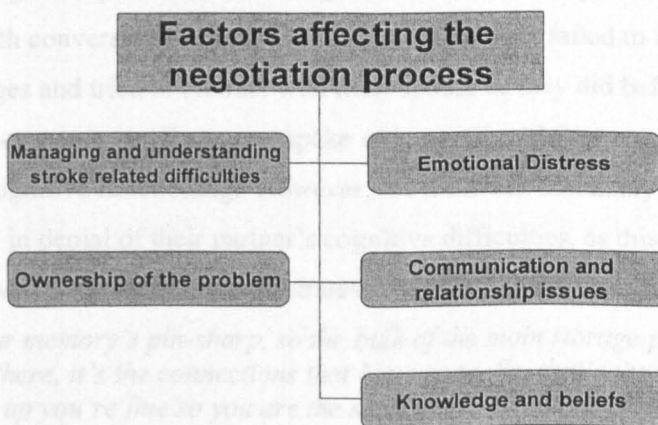


Figure 10-5: Theme 4: Factors affecting the negotiation process

10.6.1 Subtheme 1: Managing and Understanding Stroke Related Deficits

This subtheme comprises three categories: cognitive problems, language problems, and behavioural and personality difficulties. The topics consider the way in which stroke-related changes were understood and acted upon by participants, and how the constructions created by well partners were accepted or resisted by patients.

10.6.1.1 Category 1: Managing Cognitive Dysfunction

In the early weeks after the stroke a significant proportion of patients experienced some degree of cognitive dysfunction. These deficits fluctuated and were influenced by fatigue leading to confusion and frustration for both partners as they struggled to understand their effects. Whilst some patients were aware of their difficulties and talked openly about the changes to their mental faculties, others were largely unaware of the level or impact of their memory losses.

Dee: "he sometimes has no recollection of me telling him anything, even though I have just told him it. So it is an immediate memory thing. I think that it does depend on how hard you concentrate and listen."

Roger: "Yeah, it doesn't seem to happen very often though does it?"

Dee: "Well I think it does!"

Roger: "You do! Oh right-"

(Dee, WS; Roger, P, 2)

In this instance the well partner was well aware of her husband's memory problems, however as this quote illustrates she constructs a view of his difficulties as within his control. Cognitive problems were a significant barrier to negotiation as patients struggled to keep up with conversations. In many cases well partners failed to understand the nature of these changes and tried to interact with their spouse as they did before the stroke. During the first interviews many well spouses spoke of how relieved they were that the patient had not lost their cognitive functioning. However, the truth was that many spouses were simply unaware or in denial of their partner's cognitive difficulties, as this quote from the first interview with Peter and Sonya illustrates.

"Your memory's pin-sharp, so the bulk of the main storage part, the CPU if you like is still there, it's the connections that have gone. So, that's the way I look at it. From the neck up you're fine so you are the same person, the rest is mechanics" (Peter, WS, 1).

By the time of the second interview, Sonya's cognitive problems were more obvious but Peter was still struggling to understand and adapt his communication strategies to accommodate her cognitive problems:

Peter: "we'd talked about going to Whitby (...) and it was a case of whether you fancy going and what there is to do, and I thought that I'd put the logic forward"

Sonya: "You had, then suddenly it was really, "well we'll go to Whitby for four nights or nothing at all!""

Peter: "Well, I didn't feel. (Pause) Well ok, if it was put as that much then that's my fault for putting it in that way. Yeah, I get from what you're saying the logic of it was fairly straightforward to me but I hadn't made allowances that it wasn't so clear to you, and I think that's probably a result of the stroke."

Interviewer: "Yes?"

Peter: "And that's one thing I hadn't appreciated, I'm still treating you as though I would've done before you had the stroke and that is unfair on you, I'm not giving you enough time to do anything, but that's, yeh, fair comment."

Failure by the well spouse to incorporate the patient's cognitive deficits into their interactions resulted in frustration for both partners. Over time, some spouses came to understand the patient's difficulties and adapted their way of negotiating to accommodate these deficits. However, others, like Peter, struggled to do so, and so decisions were made, to which the patient did not feel they had agreed. The non-integration of cognitive problems into how the well spouse understood the patient also impacted on the couple's relationship, as partners came to feel that the balance of their relationship was skewed, and this was seen most clearly in the interview with Sonya and Peter.

Sonya, "Peter makes the decisions now"

Peter: "but I try not to, I don't want to do that, I try to talk to and do both so that we come to a consensus so it's not my decision it's our decision. It's not very easy to do that" (Sonya, (P), Peter (WS), 2)

Not fully understanding the patient's cognitive disabilities, and not integrating this into their understanding of how the patient is now was also a source of distress for well spouses:

"I know, [voice rising] but it's hard, but I'm realising. It still gets to me, but it doesn't last. I'll think, so our plans weren't important enough to commit to memory! You know, but I'm coming to realise that it's not that, it's simply that you can't remember, you know." (Alison, WS, 2)

10.6.1.2 Category 2: Language Problems

Language problems were a significant barrier to negotiation during the early post-stroke period for some couples. Some patients experienced dysphasia or dysphonia during the early months, and even at the time of their first interview, some had difficulty finding words or making themselves heard or understood. Although well spouses tried to give them

time to speak during the interviews, patients were often reluctant to talk for long, and on reviewing these transcripts it is apparent that at times, neither I, nor the well partner had done enough to facilitate this. Language problems proved to be a barrier in terms of aiding the couple towards a shared understanding of the stroke because well partners were often not present when doctors talked to patients, and patients were then unable to retell the story:

“... she couldn't talk to me, so I'd ask the nurses, and they say “Yes, doctor's been round today and he's examined your wife and had a look at her and he's told her everything you see at great length”. What did he tell her then? “Well you'll have to ask your wife”. I can't ask my wife can I because she can't talk to me! So what did the doctor say? “Oh, we don't know” (Tom, WS, 1)

By the time of the second interview it became clear that for this sample language problems were not a long term barrier to negotiation, but created a hiatus in the process. Language problems were still in evidence, but had improved, lessening communication difficulties.

10.6.1.3 Category 3: Managing Behavioural and Personality Changes

Behavioural changes were reported most often by well wives about their ill husbands, and these were a particular challenge to the negotiation process and were commonly responded to in one of two ways. Some well partners tried to relate to their ill spouse as they were before the stroke, and thereby privileged old understandings. Others perceived the patient to have changed in themselves, and treated them as a child. Both of these ways of relating were challenges to the negotiation process. When faced with challenging behaviour which was incongruent with how the patient was before the stroke, some well partners constructed an understanding of their partner's behaviour by comparing them to how they were before the stroke, with wives talking about how *“it isn't him”* (Cilla, WS, 1), *“he's not normally like that”* (Mary, WS, 1). It was also evident that patients themselves did not recognise their current behaviour as *them* and sought to distance themselves from these outbursts.

“Sometimes I get aggressive. Usually verbally, yunno, with the short temper I suppose, just the same. But it comes on that quick that I can't stop it. So that's one that really annoys me. Saying that, it's not me to do that, Yunno” (Neville, P, 1).

Privileging these old understandings made it difficult for partners to accommodate these behavioural changes, and also impacted badly on negotiations, as patients were unable to control their outbursts of temper, resulting in well partners feeling upset or frustrated.

"[I] just walk away and think "get on with it then". I do, I tend to just walk away and do something else if he is not in one of those" I'm gonna listen to you moods". If he's in one of them "I'm gonna do whatever anyways" Just let him do it. It's easier" (Cilla, WS, 1).

Other well wives constructed an identity for their ill partner by using phrases like "childlike" (Cilla, WS, 1) or "naughty", (Annie, WS, 1) and talked of how he was "like a seven year old" (Barbara, WS1). Wives described how their spouse did things like leaving kettles on, or taps running which lead them to be vigilant to dangers on their behalf, but more importantly they worried about their ill partner doing things which they were no longer competent of doing, such as driving.

"I took the dog for a walk. But when I got back, the car was moved. He thought I hadn't noticed, but I was really annoyed about it. He said it was a private road, but I said it didn't matter ... he's agreed not to drive, he's not on the insurance... So I said to him I'm going to have to hide the keys in the future" (Barbara, WS, 1).

For Barbara, Alison and Cilla, this vigilance also extended to worrying that their ill spouse would say something which would be interpreted by others as inappropriate.

"what bothers me is, if he is like this and he is a bit inclined to be like this with anybody else, You know? If they don't realise what has happened to him they are going to think, well he is a very intolerant and very ignorant man. Dave wouldn't normally be like that. It is other peoples' perceptions of him that bothers me". (Barbara, WS, 2)

An important way in which these well wives managed the impact of these changes was to infantilise their partner and to engage in control behaviours which limit the patient's activities. This included vetoing re-engagement with valued roles and activities, such as driving and DIY, and was managed by repeatedly asking the patient not to engage with the activity, which was interpreted as nagging, or by physical control. As the above quote illustrates, for Barbara management meant actually hiding the car keys.

10.6.1.4 Category 4: Resisting Spousal Control

Initially, most, but not all ill husbands accepted spousal controls, albeit reluctantly. However, they did form of a type of resistance which involved constructing an identity for their wife as over-controlling or over-protective.

*Malcolm: "I couldn't be left could I? [Sarcastically]" (P, 1),
Annie: "he couldn't be trusted at the moment." (WS, 1).*

Over time, male patients came to resent their wives' attempts to restrain their behaviour. This resistance took the form of ignoring requests not to engage in the behaviour,

which created significant tensions, or lead to arguments. In some cases patients simply ignored the appeals of their well partner from the outset and continued with their pre-stroke activities, usually invoking a rejection of illness and a desire to carry on as normal as their justification.

"I've been living with disability all my life, I'm not going to let it take over my life, I live with it, it's there, in the background, but that's it" (Neville, P, 1).

"I knew I couldn't but I felt I had to find a way of coping, because the last thing I wanted was, and I was very, very conscious of this, and I know we have joked about it from time to time, was getting into a "does he take sugar syndrome". I was absolutely determined" (George, P, 1)

Over time there was also a handing back of some roles and responsibilities from well wives to their ill husband. However, it was well wives who described these events, and was not spontaneously mentioned by any ill partner. Well spouses seemed to rationalise their behaviour by constructing stories of how they had encouraged re-engagement as *they* felt the patient was able to cope. However, they also made it clear that this re-engagement was on their terms, and they retained control in the relationship.

"I still don't always trust him for some things. I am honest too. But he wanted to stay at the caravan a couple of days while I had to come home to baby sit, and I said no I don't trust you for that yet. One, for his pills, and em. As I say I don't always, but I am honest and I tell you that don't I. So I said we will work towards that then if you want to stay overnight one night I will come home and leave you. - It will give him confidence. Then he will know that I will probably trust him a bit more. I feel I have to be honest and say when I don't really trust him, and try and give the reasons why" (Barbara, WS, 2)

10.6.2 Subtheme 2: Emotional Distress

The stroke resulted in an imbalance in the emotional equilibrium of both partners, and high distress was a significant problem for the negotiation process. The onset of the stroke triggered an awareness of the vulnerability of their lives and the world as they knew it. A few patients talked about the fear and panic engendered by the diagnosis and the symptoms they were left with. One male patient talked candidly about how, since the stroke, he had begun to experience feelings of fear and worry. Whilst the patient was at pains to minimise the potential importance of these feelings by attributing them to his medication, they were nevertheless a significant concern for him.

"I wouldn't call them panic attacks, but I do get worried and frightened about it now, and when I came out of hospital and I felt alright, and alright I was tired, but nothing like this, I didn't have this feeling that I have got now, it is something that's developed in the last week" (Trevor, P, 1)

Others found talking about their stroke to be distressing. One younger female patient talked of the shock of being told she had had a stroke *"when I heard the words 'major stroke' that nearly finished me off [crying]. Sorry, even when I say the word it still makes me cry (...) I mean, why me, what had I done wrong?"* (Rebecca, P, 1). Some talked of how they struggled not to be overwhelmed by their emotions *"It's really hard sometimes, I do get tearful about it"* (Shirley, P, 1). Another patient admitted to being depressed, but did not feel it was something that needed treatment *"he [husband] tells the doctor that I am depressed, I am a bit depressed (...) but I don't really want them to know what I'm like, how I'm feeling, I think it's just part and parcel of the stroke"* (Cathleen, P, 1). Cathleen did not want to go on anti-depressants, and when her husband raised the issue with the doctor it upset her greatly *"I don't like being talked over like that!"*

Well spouses talked vividly about their fears and sense of shock when it happened, and how they felt they needed to keep strong for their partner even though they were falling apart.

"You didn't allow your self that privilege [to fall apart] when it happens, when it happened to him, you know. But I really felt completely pole-axed you know!" (Morag, WS, 1).

During the second interviews most well spouses talked in retrospect about their own worry and distress, although few mentioned this during the first interview. Worries were triggered by fears for the future, slowed recovery, or fears about leaving the patient alone for fear of them falling, or doing something dangerous. For Mary this fear became so acute that she struggled to allow Bill any independence.

"Sometimes I don't know whether it's misguided but I smother you, erm maybe it's just become, the thing is it's foreign to me I have to deal with it as I see fit, I sometimes think am I over protective? If he's going to have the falls he'll have them! Whereas I worry about them, but Bill won't" (Mary, WS, 2).

In addition to feelings of anxiety and worry, some well partners reported feeling intensely conflicting emotions, with anger and frustration reported, especially by well partners who felt that the stroke could have been avoided if the patient had taken better care of their health.

"Sometimes it just wells up in me the fact that all this could have been avoided if he'd had his blood pressure done. And I get really, I know it's unreasonable, but I do, I get really, frustrated, I think "Oh!" You know? And he wouldn't have all this upset if he didn't have to do that" (Morag, WS, 1).

A few well spouses also talked of feeling guilty about how they were with their partner, and how their distress affected the care they provided for them.

“it’s so frustrating you know. I mean I’m guilty of the fact that because of the circumstances it’s affecting me bad, I’m in the home at times when I don’t need to be, and that’s sort of come about since the stroke. That was forced on me and now I’m finding it difficult to get out of” (Mary, WS, 2).

10.6.3 Subtheme 3: Ownership of the Problem

Partners differed in the extent to which they viewed the stroke as a conjoint problem, and determining whether the problem belonged to the patient, partner or the couple was crucial in deciding whether it was “open” for negotiation, or indeed needed negotiating. Most of the couples in the study were explicit about confronting the problems associated with the stroke together, as a team, and described it as a shared difficulty “*we’ll cope together*” (Annie, WS, 1). One couple, who framed the management of the stroke as *belonging* to the ill partner, still talked of the stroke and the recovery process as a joint venture, but the well wife showed respect for her husband, and placed control over his treatment in his hands. She did not initiate any actions which would invoke any conflict with him, and by providing support in this way Camilla empowered David and provided him with a sense of self-efficacy and agency in the process. It also clear however from this quote that this reflects the pre-stroke power balance within their relationship.

“Its slowly turning back to what it was now, to how we were, he doesn’t want me talking [for him]. We sit there, when we’re both at these meetings [progress meetings in hospital] and he taken back that role now. He’s kind of looking at me as if to say, back to where you were, “I can manage” and he can” (Camilla, WS, 1)

Other couples did not agree on ownership of the problem, but in all cases this was associated with well spouses feeling that it was a joint problem, and the ill partner viewing it as belonging to them as this quote from a well wife illustrates “*we are talking about it [the stroke], it’s mainly him saying one thing and me another, and then I start getting really stropky and start saying, look it’s not happening to you, it’s happening to us!*” (Veronica, WS, 1). When such disagreements emerged they were associated with increased distress and negotiation difficulties. In most cases these conflicts arose during discussions about sharing feelings, returning to work, health behaviours, such as smoking or diet and re-establishing pre-stroke routines as this quote from a well spouse illustrates:

“it was a case of her saying “I’m going to go back to the nursing home I worked at, and that’s what I’m going to do”, and me saying not this year you’re not!” (Tom, WS, 2).

10.6.4 Subtheme 4: Communication and Relationship Issues

Couples varied in the degree to which they communicated with each other about the stroke and their feelings, and some acknowledged that the stroke had affected the way they were with each other. However, patients in particular talked of how supportive and caring their spouse had been towards them during the crisis and recovery period.

"You are my wife she's my rock, she's been there for me through this, she's my rock."
(Bill, P, 1)

"I want to say that I wouldn't be here at all if it weren't for Camilla, my children and my sister. They all helped, came to see me, to feed me, you know when I was bad and down, it's for their support that I'm here." (David, P, 1)

Most couples explicitly characterised their pre-stroke relationship as close, and talked about how they had always *"talked things through"* (Annie, WS, 1). It is perhaps not unsurprising that couples who have come through a trauma such as a stroke describe their relationship in positive terms, especially as each partner has a renewed feeling of needing and being needed. During the time one interviews, couples frequently reassured each other about the future, and about their capacity to deal with anything that they had to face. Often, these comments related to the prognosis for recovery, and represented deliberate optimism.

"we've talked right from the beginning that whatever happens it will be all right, and we've talked about, we can't even imagine what it's going to be like, because there's no point going there (...) we'll take it as it comes" (Camilla, WS, 1).

Some couples talked about how the stroke had brought them closer together and made them realise how much they meant to each other and a few couples talked about how much closer they felt to each other *"There is something settled about us now that there never was before"* (Annie, WS, 2).

However, a few participants described how they had closer relationships with people outside their marriage. Bill talked about how he found it difficult to share his feelings, but when he did it tended to be with his daughter, not his wife *"really, if I'm honest, I can talk to her [daughter] more than anyone. We always have really, cos we're the same, you know, personality-wise, like"* (Bill, P, 1). One female patient talked of how she shared concerns with girl-friends rather than her husband because she found him unsympathetic *"I don't really talk to you, [laughs] I don't think you understand. Andrew is not a very understanding sort of person"* (Rebecca, P, 1). Although said with humour, this couple were the most independent of the couples in the study, and this did reflect other comments they made about their relationship.

For a small number of couples the stroke challenged their pre-existing relationship and communication style. For two couples in particular the stroke badly affected the quality of their relationship, and previous levels of intimacy were lost, which was a source of distress. For one couple, the ill partner's disability meant that physical intimacy was difficult and this had been lost from their relationship *"you keep saying, are you going to come in and join me and have a cuddle, and I'm saying well, a) it isn't all that possible and b) I'm so knackered out [laughs]"* (Peter, WS, 2). The couple also described how they felt that the stroke had resulted in an imbalance in their relationship such a that it was more of a patient-carer relationship in which Sonya felt that spent her time asking for things and she felt her disability was turning her into a nag *"nagging, that's how I feel, that's all I do"* (Sonya, P, 2).

Other couples talked of how they had managed to maintain the communication between them and how this had not changed. It was also evident however that many couples had to learn how to 'communicate' to each other, and move from a state whereby they just kept conversations to safe topics. Some couples differed in their views of their relationship style. Although Trevor he felt his relationship with his wife had not changed *"the nature of our relationship does mean that we have really never stopped talking about it, have we?"* (Trevor, P, 1), his wife Veronica nevertheless complained about feeling shut out by him because he would closed down emotionally. Indeed, most of the male patients seemed to withdraw emotionally from their spouse at some point. For many men, and some women, this pattern of not talking about intimate feelings was one which was described as a life-long pattern, and wives especially described their husbands as always being reserved about their feelings *"Dave can keep things to himself; I've always had to prise it out of him. (...) and sometimes he won't tell me anyhow"* (Barbara, WS, 2). Some patients talked of how this behaviour reflected a desire not to dwell on the stroke *"I just keep it to myself and get on with it, you know, I'm not one to whinge"* (Dave, P, 1). However, when asked whether withdrawing was useful for them, one male patient said it was just what he did *"I never really thought about it before"* (Malcolm, P, 1). It was well wives who resented this lack of communication and connection and saw it as a problem. Nevertheless it significantly impacted on patients' abilities to discuss their concerns, and therefore negotiate a way of living with the stroke.

Humour was a thread that was woven through the interviews, and partners laughed as they described events, but humour also played a more important role, both in relationship maintenance and as a coping mechanism. The frustration of coping with the stroke could be unbearable for couples, and so seeing humour in events was a way of diffusing this tension.

"I don't mean we don't laugh anymore cos we do, don't we? Something will hit us, something silly and he'll start grinning at me, and I'll start grinning at him, so it's there, that closeness (...) but the frustration sometimes is unbearable" (Mary, WS, 1)

However, some attempts at humour were not well met by others. One patient's attempts at flippancy about his stroke were not well met by his daughter who was very distressed.

"When we came to the hospital he was just waving his legs around and being really silly and joking. [daughter] said to him "No Dad, this is serious, you nearly died" and you went "oh cool", and she said "Dad that is not cool" (Dee, WS, 2)

Although conflict interactions were not the dominant style for most couples in this study, it emerged at some point in almost all interviews, usually when they were talking about an issue upon which they disagreed. This usually took the form of complaining and criticism aimed at the target behaviour.

Karl : "Well, I tend to walk quite a lot".

Morag: " No, you saunter!"

Karl: "Alright, I saunter, but I can go miles sauntering."

Morag: "No, walking! No Karl, we used to walk right through [name] park, walk right round and come right back (3-4 miles) and we used to do it regularly. You know, fast walking, speed walking. I keep on telling him, but I nag him, I tell him he should walk until he feels breathless, until he feels tired, not just sauntering!"

(Karl, (P) and Morag, (WS), 1)

10.6.5 Subtheme 5: Knowledge and Beliefs

It seemed important to couples to develop a cognitive framework within which to understand the stroke and past experience, stroke information, health professionals and illness beliefs all came into play as the couple tried to understand the stroke and how to manage its impact.

10.6.5.1 Category 1: Past Experience

Most participants knew someone who had experienced a stroke, with parents, siblings, relatives and friends all mentioned. However, over half of participants felt they knew little about it before it happened to them *"It's just not something you think about, unless someone close has it, you know, and you have experience of it. Till then, a stroke is a stroke"* (Albert, WS, 1). A few of the women mentioned that they had some contact with

stroke patients, either currently or in the past, through their work, and overall, three quarters of couples had at least one partner who had experience of stroke within some context. Most did not feel this affected how they approached their present situation because the present situation was very different to their past experience, but a few found their past experiences made them think about the stroke differently.

"I didn't discuss it with Roger, it really spooked me, because I am a very superstitious person and I thought, right there's one stroke, he's recovered,(...) his best friend, it happened at the same age, I was just waiting for the second big one to come and finish him off. So I was really quite traumatised by that previous experience". (Dee, WS, 2)

For these well spouses the trauma of their past experience made them fearful for their ill partner, and for the future, and this had a significant impact on how they approached the management of the stroke.

10.6.5.2 Category 2: Stroke Information

The confirmation of the stroke initially shocked couples into immobility, but over time there was a flurry of activity around gathering information. The internet was a commonly cited source, and well spouses mentioned specifically the Stroke Association website as a source of information.

"Peter went on the internet and got an excellent book from the Stroke Association, which he has read and told me about. I still find reading hard work, so he reads things and gives me the edited highlights, so to speak." (Sonya, P, 1).

Other sources of information included leaflets picked up on the hospital ward, the discharge pack given to patients, and talking to other people, including others who had experience of stroke.

"It it really is a nightmare trying to get..um ... and I found out more about what's likely to happen from asking people on my round who are nurses and I know, or people on the round that've experienced strokes in the past. And those're the people who we've got a lot of information from isn't it?" (Tom, WS, 2)

Gathering information seemed important to well spouses, as they felt it aided them in preparing for what lay ahead. However, although information was helpful and necessary, it could also be overwhelming, and over half of patients described how they had given their discharge information packs provided by the hospital to their well spouse. This behaviour was particularly common in male patients, who generally relied on their wives to read the information and pass it on to them.

"Yes, it's quite good, it covers everything. We sat down together and took a look at the big booklet [hospital discharge booklet], but I have to be honest and tell you that Ellie's been the one to take a good look at it all." (Dick, P, 1).

Three patients had significant problems reading as a result of their stroke and they talked of how they had given the pack to their well spouse to read, which highlights the difficulties patients face trying to learn about their stroke, and how misconceptions and misunderstandings can develop or be perpetuated.

Barbara: "To be fair, Dave has only just taken up reading again. He did pick them up in hospital but the words, how did you describe them again?"

Dave: "They just go over your head."

Barbara: "He read the words but they couldn't sink in. They weren't registering; he is just starting to read now, cos SALT gave him a speech therapy book on Strokes. A very good simplistic book, I read it and it was very informative for relatives. And he couldn't read that either". (Barbara, WS, 1)

10.6.5.3 Category 3: Contact with Health Professionals

Relationships with health professionals emerged as an important factor in how couples came to understand the stroke, and the illness perceptions they generated. Although patients and spouses gathered information from other sources, health professionals were portrayed as gatekeepers to knowledge about *their* stroke and so were viewed as particularly powerful in terms of understanding what had happened. Significant variation existed in the degree to which couples felt they could engage with health professionals, and the time they felt doctors had to give to them. Some felt that the consultant had been willing to spend time with them and could give them the answers they needed.

George: "We knew that he was strapped for time, but he didn't give us the impression that he didn't have the time to talk to us"

Alison: "No he didn't, quite the reverse ... the whole appointment was a good positive experience, even though we sat and waited for such a long time"

(George, (P) and Alison (WS), 1)

Others felt they had not got the answers they needed, and two spouses in particular talked about how health professionals had used language they didn't understand *"he said it was a mild stroke, but he came out with all these fancy words, so we asked him to translate"* (Annie, WS, 1). For some couples there was also a significant mismatch between what they believed they needed in terms of support and the level of support they felt they received. A third of participants felt they had insufficient contact with their doctor, and many complained that they either did not get to see the consultant, or were unable to get the answers they felt they needed.

Annie and Malcolm's daughter: "I don't think Dr [name] has spent any quality time with Dad"

Annie: "No, not once. Nothing good to say about him [dr]. We stopped him in the corridor the day, the second day, because he'd been round to see Malcolm and I wanted to know exactly what was happening. So, we stopped him and asked. And granted he came back and got Malcolm's notes and that, but I've never spoken to him since that day" (Annie, WS, 1)

10.6.5.4 Category 4: Illness Perceptions

The couples in this study not only had to deal with their own illness beliefs but they also had to deal with what their partner felt about the stroke. For many, this was a difficult challenge to negotiate. One of the most common areas of disagreement for couples was the cause of the stroke, with over two thirds of patients providing different explanations to those offered by their well spouse. Although many patients had significant risk factors for stroke, few felt they were the cause of *their* stroke. Instead, most patients provided attributions towards chance factors and stress *"I really don't agree that it's all around the work, I think it's just down to bad luck"* (Neville, P, 1). Only one patient attributed their stroke to their increased risk *"it were my leukaemia that did it, that's it"* (Dave, P, 1). In contrast, their well spouses commonly attributed the stroke to behavioural factors *"overwork, she always did too much, she never stopped, that was her problem"* (Andrew, WS, 1), *"his blood pressure (...).that's what's caused it in the first place"* (Morag, WS, 1), *"We think he hasn't been looking after his diet properly. He had a sweet tooth, let's put it that way."* (Ellie, WS, 1).

Discrepant causal beliefs had a significant impact on how each partner believed the stroke should be managed in terms of secondary prevention and this caused significant and ongoing difficulties for couples *"it's still a bone of contention; I can't get him to exercise right! I mean I give up"* (Morag, WS, 2). Few couples successfully negotiated changes in the patient's health behaviours, and indeed, most patients made few health related changes. Only one patient reported changing their behaviour against their own beliefs *"[I] have stopped it, [smoking cannabis], but I am still not necessarily convinced"* (Roger, P, 2). This was the only patient to actively privilege their partner's views over their own, and for most other couples, negotiations met with little success. The timeline for recovery was another significant source of discrepancy and well spouses tended to perceive the recovery timeline to be longer, and the prognosis less optimistic than the patient. Two couples in particular disagreed strongly about the potential for recovery, and in each case the well spouse was

perceived by the ill partner to be unsupportive or too pessimistic. Well spouses responded by talking of how they felt they had to temper their ill partner's over-optimism.

"I like that he is hopeful, but I don't want him to be hurt. I don't want him to build his hopes for recovery too high and be disappointed. Whether me being more negative is a preparation for that, I don't know, but if I keep saying it, then it won't hit him like a ton of bricks if somebody else says it. I think he'll be more happier when he comes to terms with it. I see my role as being the balance, I have to counter balance his over-optimism, that's the only way I can explain it, I don't want him to be gutted [pause], not that I'm saying that he will be, but if things don't work out, I don't want it to be a shock to him"(Annie, WS, 2).

For some couples discrepancy in partners' illness perceptions about the prognosis and timeline for recovery were due, at least in part, to differences in what they had been told by the doctor.

Andrew: "Dr [name], he took me to one side was because everybody, all the friends and me included, we were all, everybody was saying it's just a mild one. He actually got me to the side and he said "I have got to tell you now, I have listened to you all round the bedside talking, talking, talking, it's not a minor one", then he explained it that it was a major one... that's what he said."

Rebecca: "Did you think that maybe somebody would have told me?"

Andrew: "I did yeah! If I'm honest, I thought maybe it would have just come out."

Rebecca: "No, I never...I got a shock actually"

Andrew: "Maybe it was better waiting till later, and that's why Dr [name] told you months and months later."

(Rebecca, P, Andrew, WS, 2)

The timeline for recovery proved particularly important in terms of handing back activities to the patient, with those well partners who had a longer recovery timeline tending to be slower in this process. Couples also disagreed about whether or not the patient actually understood the nature and severity of the stroke itself. This was common when the patient displayed evidence of cognitive or behavioural problems after the stroke, and as discussed earlier, when well partners perceived the patient to be changed this impacted on spousal control behaviour. This was also associated with a belief that the patient did not understand the extent of their difficulties. This became a significant source of ongoing tension for couples because it led to well spouses controlling their ill partner's behaviour.

There was also wide variation in how patients and well spouses understood notions of health and illness. Patients in particular tended to try to minimise the impact of the stroke. Active denial of post stroke difficulties by patients were associated with a minimisation of the symptoms they associated with the stroke, a desire to hold on, or return to valued roles and responsibilities, and a psychological distancing between their behaviour

and the cause of their stroke. Patients were keen to avoid being perceived as the sort of person who “deserved” to have a stroke. Indeed, most patients went to pains to describe how good their pre-stroke health had been. *“I was super-fit, that’s what I used to call myself, you know. I may have been wrong, but I thought I was super-fit, didn’t I?”* (Malcolm, P, 1). Even when patients had pre-existing conditions such as hypertension they still described what they had done in the past to protect their health, thereby distancing themselves from blame *“I’ve diet and exercise at the right level”* (Bill, P, 1). Others, including well partners, believed that stroke was not like other illnesses and that you could not protect yourself against it.

“don’t tell me that not smoking and exercising prevents you having strokes, because the chap in the bed next to Karl cycled about 30 miles a day, never smoked in his life, never drank, never did anything, and bang it was a big one! I mean he was virtually paralysed, a left hand one with, you know he was incontinent, although I couldn’t see that part, dribbling, he couldn’t speak and he was so upset.” (Morag, WS, 1)

Although patients often constructed an identity for themselves as fit, healthy, and health-conscious, their partner did not always agree and described how the patient had not taken sufficient care of their health. This was particularly true of well wives and ill husbands.

“I was always aware of telling Malcolm he should have a check-up, and er, it started when he was forty, and I actually forced him to go to the well-main clinic (...) and that would be the last time Malcolm, it’s well over ten years ago. I know he’s never been an ill person, but that’s no excuse for not having a check-up”. (Annie, WS, 1)

A few male patients went so far as to blame their doctor for not diagnosing their high blood pressure, and therefore prevent their stroke.

Malcolm: “I’m not a believer in the blame culture, I think you have to take responsibility for your own health, but if I’d been told then that I had high blood pressure I would have done something about it, and I wouldn’t be sitting here the way I am now. I think you know he gets paid for looking after me as well and so he is partly responsible for how I am now”

Annie: “But doctors haven’t got radar Malcolm”

Malcolm: “But it’s their job to look after me.”

Annie: “Yes, if you go.”

Malcolm: “And I went and they didn’t give me tablets.”

Annie: “No, because it sorted itself out then, so it was up to you to keep going and getting it monitored.”

Responsibility for one’s own health was perceived as important, and patients talked of how they felt they had done all they could to protect themselves, and therefore could not be blamed for what had happened. Some patients, including a few who were quite disabled by their stroke sought to distance themselves from their own visions of stroke “victims”, with

one patient describing them as “those poor souls” (Marjorie, P,1). During the first interview a rejection of illness and a drive for restoration to full pre-stroke functioning was common in this sample of patients and the different ways in which patients and spouses constructed health and illness played a role in the adjustment process, with a strong rejection of illness being associated with a desire for restoration to past lives at time two.

11 Qualitative Discussion

The aim of this study was to explore the process of adjustment in a sample of first-ever stroke patients and carers. The interlaced and overlapping themes derived from the analysis suggest that couples engage in an active process of negotiation and re-negotiation over time, as the recovery process unfolds. Initially couples were shattered by the experience and struggled to come to terms with what had happened and what it meant to their lives. Over time most started the slow process of making sense of the stroke and began to adjust, but even when couples adjusted well to some aspects of the stroke, they still struggled to come to terms with other changes it had brought. For a few couples the stroke presented such overwhelming challenges that moving forward proved almost impossible.

Four themes were derived from the analysis *entering into an altered world* which described the impact of the stroke on their lives and *getting back to normal* which describes their adjustment goals. These two themes were connected by two further themes, one of which encompasses the strategies used by couples to achieve a shared understanding (*the negotiation process*) and the other reflects the factors which acted as *barriers or enablers* to the negotiation process. The issues couples had to face were negotiated and renegotiated as circumstances changed. The conclusions drawn from the analysis suggested that negotiation existed at different levels, were embedded in everyday actions and activities, and differed both within and between couples. The study found adjustment to be an interactive process, which participants experienced as a couple, and the views of one partner had an impact on the other. It has been argued that the literature has lost sight of the social context within which patients and carers function, and this analysis is an attempt to re-situate the patient and spouse within their social context (Stainton-Rogers 1991).

11.1 Entering an Altered World

Other studies have found that during the first weeks after a stroke the patient experiences feelings of unreality and a growing awareness of the changes brought by the stroke (Backe, Larsson and Fridlund 1996), and this closely resembles the descriptions provided by patients in the present study, although the present study found that this sense of unreality was shared to a great extent by their well partners. Previous studies have noted the

heterogeneous nature of stroke (Pound et al. 1998b; Dowswell et al. 2000), and the findings of this study support this conclusion. Most of the patients in the present study had been fit and healthy prior to their stroke, and there was often a stark dichotomy between their pre-stroke and post-stroke abilities. This may go some way to understanding the overwhelming focus on its physical effects, with patients talking about the difficulties associated with loss of physical functioning, and valued roles and responsibilities, although this is consistent with the findings of other studies (Anderson 1992; Pound et al. 1998b; Clark 2000).

Quantitative studies (Knapp and Hewison 1999; Visser-Keizer et al. 2002; Tooth et al. 2003a, b; Hochstenbach et al. 2005) have previously found that patients and carers disagree in their perceptions of the stroke, and indeed this is the conclusion of study one. However, the findings of this analysis suggests that not only do couples diverge in their views of the stroke, but that these discrepancies manifest in their approaches to recovery, secondary prevention, restarting activities, and at a more fundamental level in how partners understand concepts of health and illness.

11.2 Coming to Understand the Impact of the Stroke

A major difficulty for couples centred round the behavioural and cognitive changes resulting from the stroke. Many patients and their spouses talked of how the patient had changed as a person. Although most patients were aware of these changes to their cognitive functioning and behaviour, one patient was unaware or in denial of these changes. Previous research has considered the impact of identity changes resulting from a stroke from the perspective of the patient (Grant 1996; Dowswell et al. 2000; Ellis-Hill and Horn 2000), but this study found that both patients and their families struggled to know how to understand and cope with these changes.

An important finding of this study relates to how well partners come to understand these physical, cognitive and behavioural changes, and the discrepancy in patient and spousal perceptions of these deficits. Well wives in particular were found to formulate an understanding of their ill partner as child-like, changed, or simply too ill to manage the roles and responsibilities that the patient had used to define themselves prior to the stroke. Well spouses were trying to cope with seemingly inexplicable changes in their spouse and one plausible explanation of their response is that observing their ill partner having to relearn basic developmental activities such as walking, speaking and eating, provided them with a

developmental model of recovery. Indeed well spouses were often involved in working with their partner as they re-learned these activities in hospital, thereby reinforcing this model of their spouse as child-like and vulnerable.

In an attempt to protect their ill spouse, well wives became vigilant to potential dangers posed by the patient's former roles, which culminated in well wives stopping patients engaging in former activities, such as driving, going out alone, or doing jobs around the home (DIY) which well spouses thought were now too much for them. This behaviour was not negotiated and control was enacted through psychological and in some cases physical control and highlights the lack of negotiation between many couples during the first months after the stroke, but especially between well wives and their ill husbands. The provision of too much care has been termed "*compulsive caregiving*" (Kunce and Shaver 1994), and the actions of these well wives appear to accord with this model.

In the present study ill partners came to resent the protective actions of their well partner. This way of understanding the patient has been well documented in the stroke literature and is usually conceptualised as "over-protective care" (Thompson and Pitts 1992; Thompson and Sobolew-Shubin 1993a; Cox et al. 1998; Thompson, Galbraith, Thomas, Swan and Vrungos 2002) and has been shown to be associated with higher carer distress (Thompson, Medvene and Freeman 1995), and negative consequences for the patient (Baltes 1996; Edwards and Noller 1998). The term "over protection" refers to "*a perception on the part of the ill adult that he/she is overhelped, induced to be dependent, shielded from stress, and in general not treated as an adult (p.87)*" (Thompson and Sobolew-Shubin 1993b). The results of this study suggest that over-protective behaviours can develop quickly after the stroke and this merits further research. Earlier studies have examined the issue of over-protection where the carer has been in the caregiving role for over two years (Thompson and Sobolew-Shubin 1993b), but the present study suggests it may develop quite early. However it was also much less common by the second interview, it is therefore pertinent to follow patients and carers for 2-3 years to discover more about the development and trajectory of over-protection.

In most couples this over-protective caring was short-lived, and although well wives attributed their controlling actions to concerns over the safety of their spouse, they also acknowledged the role of their own feelings of worry and distress in this process. Well

spouses tended to interpret their control behaviours as protective, but acknowledged that they could promote passivity and dependence in their ill spouse. By the second interview, some well spouses had begun to hand back some roles and responsibilities to their ill partner. In many cases the handing back of old roles was not possible, but a few well wives worked with their spouse to develop new skills and roles. The handing back of responsibilities to well patients was described by well partners as a collaborative venture, whereby they engaged with patients to enable them to gradually move towards increased independence.

This behaviour resembles Vygotsky's notion of a zone of proximal development, with well wives providing scaffolding for their spouse within which they could develop their confidence (Gross 1996). Over-protection was most strongly maintained by one well spouse who also expressed feelings of guilt and resentment about her caring role, as well as high levels of negative affect. The pattern of behaviour described by this well spouse and her husband strongly resembles what Thompson and colleagues called the resentment model of over-protection (Thompson et al. 2002), and suggests this pattern of interacting can develop early in the caregiving cycle, if the well partner feels overwhelmed by the caring role and has little external support.

Even in the face of spousal control, some patients ignored the complaints of their well spouse and engaged in behaviours that were interpreted by well partners as too much for them. This reflects the fundamental differences in how patients and well partners perceived what constitutes *correct* or *normal* behaviour after a stroke. However, such risk taking by patients may be a way of them actively managing their own recovery. Patients often pushed themselves harder than their well spouse would like them to do, and other researchers note that voluntary risk taking, as well as being pleasurable, gives the patient the chance to prove what they can do (Lupton 2002; Alaszewski, Alaszewski and Potter 2006). The mismatch in the couple's illness perceptions was at its most apparent in the context of restarting activities. Patients invariably came to the point where they wished to restart old activities earlier than spouses thought it was safe to do so, and this was a source of significant tension for couples, and not one which all couples negotiated successfully.

11.3 Coping with Cognitive and Behavioural Deficits

Some patients and spouses struggled to acknowledge the presence or severity of the patient's cognitive or behavioural deficits. Analysis of the data revealed that this was more common in well partners than in patients. The non-integration of these problems into how well spouses related to their partner had significant implications for the negotiation process as well partners attempt to relate to their ill spouse as they did before the stroke. In some cases well spouses acknowledged these changes at a behavioural level by using notes and reminders to help their partner, or by going round and apologising for their ill partner's behaviour. However, at a psychological level there was unwillingness on the part of well spouses to accept these changes, and especially to accept the likely permanence of the changes. This behavioural acceptance, but psychological rejection of their partner's cognitive deficits seems irrational, but can be understood if one thinks of it as a protective mechanism to protect the spouse against psychological distress.

Many people choose their life-partner often because of the intellectual and emotional fit between them (Rolland 1994). Within this context, changes to the cognitive or behavioural functioning of the patient can be understood as particularly distressing for the well spouses. However, the non-integration of these changes into how the well spouse understands their ill partner had negative implications both for their relationship and for their subsequent adjustment to the stroke, especially if the couple's pre-stroke relationship had been characterised by shared decision-making. The impact this had on the couple merits further investigation because how the couple understood the patient's disabilities had significant implications for the negotiation process and for the couple's psychosocial adjustment.

11.4 Negotiation

Negotiation played a key role in the couple's adjustment to the stroke. Although it is well known that the marital relationship is an important source of support for patients during their adjustment to stroke (Knapp and Hewison 1998) and that spousal support is not always viewed positively (Clark and Stephens 1996; Thompson et al. 2002) little is known about how the couple negotiate the stresses associated with the stroke. The analysis explored the differing degrees of interaction within couples, and found couples differed

significantly in terms of what they felt able to negotiate with their partner, and when it was appropriate to do so.

11.4.1 Avoidance of Discussions

The avoidance of discussions was common in this sample, especially during the early weeks and months after the stroke, and it was still evident at the time of the second interviews. Active avoidance of discussions is well reported in the literature, especially within the serious or chronic illness literature (Vess et al. 1988; Edwards and Noller 1998; Edwards and Forster 1999; Edwards and Noller 2002; Zhang and Siminoff 2003). The active avoidance of discussions reported by participants does however provide a plausible explanation for the initial discrepancies in the illness beliefs of couples found in the quantitative study. In the present study, dealing with worries by talking to others outside the marital relationship was described by well spouses, and in particular well wives, as a strategy they had actively adopted in order to manage their own distress without burdening their partner. This is consistent with the findings of Coyne and Smith (1991) who found that the well wives of myocardial infarction patients adopted a form of relationship-focussed coping which involved hiding concerns, denying worries and avoiding disagreements in order to protect the ill partner.

In contrast, keeping feelings hidden, and not sharing them with others, was most commonly reported by male patients. In the present study, men generally minimised the impact of the stroke when discussing their experiences. Not acknowledging distress or vulnerability are aspects of 'traditional' masculinity which have often been described in the literature (Doyle 1995; Kaplan and Marks 1995), and few of the men in the study openly acknowledged their feelings. However, some did admit that they did feel distressed and worried at times, but the concept of 'self-control' and "*not wanting to whinge*" (Dave, P, 1) dominated most men's talk. Those who did acknowledge feelings of anxiety or worry did so by using this masculine/feminine dichotomy, acknowledging they were "*in touch with my feminine side*" (Trevor, P 1), thereby still drawing on the shared notions of what defines hegemonic masculinity (Connell 1995; Wetherell 1996).

Another commonly used strategy was *watchful waiting* whereby decisions and negotiations were deferred until a later date, when the couple had gathered more information upon which to make meaningful decisions. Previous studies have found that patients and carers often feel they lack information (Wellwood et al. 1994; McKenzie et al. 2007), and

participants in the present study found it difficult to make decisions because they felt too much was “unknown”, especially in terms of the prognosis for recovery and the causes of the stroke. These results suggest that this perceived lack of information stalls the couple’s decision making capabilities. Some well partners also described how they found it difficult to find people with whom they could share their concerns because family members closed down conversations which would have allowed the well partner to give voice to worries and concerns. This highlights the importance of social support for well partners, but also the problems that may occur if there is a mismatch between the needs of the well partner for support and the ability of the wider family to offer support. Although not commonly reported, this is worthy of further study as well partners could be left without support.

Not talking about contentious issues during the first weeks after the stroke can be considered adaptive (Rose et al. 2002), as it means that couples can avoid placing additional stress and tension on their relationship at a time when the couple are particularly vulnerable. As discussed in chapter 7 (quantitative discussion) one way of understanding the desire to avoid discussions comes from the coping literature. Lazarus and Folkman’s model (1984) suggests that one way in which individuals cope is by avoidance; and hiding feelings, dealing with it elsewhere and watchful waiting all constitute ways of avoiding disclosing one’s thoughts and feelings to one’s marital partner. An alternative view of this form of avoidance is that it is unhealthy because topics cannot be resolved until they are raised (Rolof and Cloven 1990; Guerrero and Floyd 2006). This may be especially true if the issue is an ongoing cause of conflict because one partner has indicated that they want to discuss the topic. In this case, avoidance by the other partner may engender feelings of resentment in the partner wishing to resolve the issue. This may also become a self fulfilling cycle of avoidance and negative affect if maintained over time (Edwards and Forster 1999; Guerrero and Floyd 2006).

11.4.2 Topic Management

In the present study, one of the most common negotiation strategies identified in the first interviews constituted those where one partner had tried and failed to engage the other in negotiations. Two different patterns were identified: topic management and impasse. Wanting to change some aspect of their partner’s behaviour was commonly reported, and has been reported elsewhere (Padula 1996; Edwards and Noller 1998; Edwards and Noller 2002). In the present study these attempts were generally responded to by the application of topic management strategies that diverted or closed down the discussion. Well partners in

particular complained about how their attempts to change aspects of their ill partner's behaviour met with failure. Whilst well intentioned, these negotiation attempts almost always failed because they did not meet the needs or beliefs of the patient, especially within the context of secondary behaviour change, and patients responded with criticisms, denials or non-committal remarks which closed down the discussion without resolution. Avoidance of discussions in this way has been found in both the quantitative and qualitative literature, and highlights the intention-impact discrepancy in couples' communications (Norris et al. 1990; Parris Stephens and Clark 1997; Cox et al. 1998; Pistrang and Barker 2005). At least two partners admitted that they generally avoided dealing with issues, and openly admitted that their general pattern was to procrastinate, suggesting that this pursuer -distancer pattern of interacting (Scheinkman 2008) may, at least in some cases, predate the stroke. However, there was also good evidence from the present study that the perceptions of partners were ill-matched and so discussions often failed because their differing perceptions of the problem.

The second form of failed negotiation identified was the *impasse* position whereby partners tried to find a solution but neither partner was open to persuasion by the other. This form of communication was common during both interviews. In this pattern, both partners feel the need to assert themselves in deciding how issues are resolved, and both have a need to be heard, but this need to be heard often dissolved into a stalemate whereby neither will give any ground. Impasse, as identified by this study may over time become what earlier studies have termed "old ground", which are unresolved issues which are no longer raised because they have been discussed many times in the past and without resolution (Edwards and Noller 2002). Illness perceptions were strongly implicated in these latter two forms of failed negotiation, and in particular the discrepancy between the views of patients and well spouses. As discussed in chapter two, previous research and the findings of the quantitative study have found discrepant illness perceptions to be associated with higher patient and carer distress. The findings of this study add to this discussion because discrepant beliefs were also implicated in less successful negotiations and thereby hinder the adjustment process. In some cases partners made assumptions about a shared understanding, but failed to elicit their partner's views. In other cases partners would use attacking language "*you don't bloody stop, that's your problem*" (Malcolm, P, 1), or focus on the other person's behaviour, rather than expressing their feelings about the behaviour. In each case the use of non-productive communication patterns and discrepancies in their underlying beliefs about

the stroke meant that the problem was not resolved, and this is an area worthy of further examination.

11.4.3 Approaching the Problem

Four forms of approach behaviour were identified in the present study: *compromising*, *yielding*, *open discussion* and *collaborative working*. Compromising involves meeting one's partner half way in an effort to resolve difficulties (Guerrero and Floyd 2006), but leaves some needs and goals unmet and neither party is a clear winner. In the present study, most well partners described how they had compromised to allow their ill partner greater freedom and independence. This behaviour was closely linked to changes in how the well spouse perceived the patient's level of functioning, and as discussed earlier, compromises were often reached over a period of time, and involved negotiation and re-negotiation as the patient regained physical and cognitive abilities.

Couples' research has traditionally focussed on conflict interactions (Bradbury, Fincham and Beach 2000) and much less is known about supportive interactions (Pistrang and Barker 2005). In the present study, successful negotiation appeared to involve couples identifying what the problem was and *talking it through* so that each partner gains an understanding of the other person's perspective. Indeed, talking things through was perceived by participants as an important factor in the adjustment process. As already discussed, negotiations often failed because of differences in the beliefs and knowledge of partners and an inability to communicate these beliefs. Other factors implicated in successful negotiations were the absence of cognitive deficits, an acknowledgement by the well spouse of the patient's returning capacity (physical, emotional or cognitive), a sense of mutual trust and care between them which allowed the patient to have "their say" in the discussion, and a willingness by both parties to express their needs. By the time of the second interviews, few couples achieved a negotiated settlement in more than one or two areas. Many did however demonstrate ways of communicating which were supportive and facilitating, and the importance of open communication was valued by couples. However, even those couples who said they thought it was important admitted they had avoided discussions about the stroke. This has been reported elsewhere in the literature (Fried et al. 2005), and suggests that communication may be a difficulty for many couples.

Successful negotiation required the couple to construct a new, 'shared' understanding of the problem and for partners to help each other change the way they

thought about the difficulty and promote change. Therefore, negotiation between the couple shared many similarities with therapeutic approaches to change within the context of formal therapy and counselling (Pistrang and Barker 2005; Scheinkman 2008) such as establishing a working alliance, making meaning and promoting change and this also resembles what Stanton (2000) referred to as a “facilitating relationship”. Successful negotiation was often a culmination of previous failed attempts, and thereby constitutes an ongoing process. Indeed, one of the most important factors in the negotiation process appeared to be the passage of time, and the re-visiting of earlier failed discussions.

In the present study there was also a strong emphasis on “collaborative working” which describes how couples worked together to put in place routines which allowed them to manage the impact of the stroke on a day-to-day basis. Collaboration in the present study was much more common than open negotiation, especially during the first interviews, and was characterised by *muddling through*, whereby the couple renegotiated the division of tasks based on what each partner was able to do. This often meant making compromises, or accepting lower standards and expectations, as was the case when male spouses took on housework and cooking duties. This was a particularly interesting way of getting things done because partners were largely unable to describe how these decisions had been made and therefore closely resembles Finch’s (1989) implicit negotiation style. The result of collaborative working was the active involvement of the ill spouse in everyday activities. However, although the outcome of muddling through was collaborative working, and this was achieved in such a way that the ill partner was still actively involved, what is missing from the picture is the open discussion which Corbin and Strauss (1984, 1988) posited to be necessary to ensure that there is effective collaborative working. It could be posited that although on the surface *muddling through* seemed to be working, at least in the short-term, it may actually reflect an inability to *talk and listen*. In this pattern of interacting, things just seemed to happen, and it may be that partners do not have the language to communicate their wishes or reveal their feelings and distress. An alternative explanation is that the underlying tradition of the couple was to ‘do what was necessary’ and this guided them to finding new ways of dealing with things. The couples were faced with an urgent necessity of re-delegating many roles and responsibilities, and therefore an equally plausible explanation is that the schema which drives their moral beliefs about how things should be done may have been triggered. In contrast, open discussion and negotiated ways of doing

things emerged over time, and may reflect longer-term patterns of working, and thereby resembles Corbin and Strauss's (1984) notion of collaborative working.

Concepts such as successful negotiation and shared agreement suggest an ongoing negotiation in which the stroke survivor is an active participant. However, the presence of cognitive dysfunction presents certain challenges to this process, and these were not challenges that the couples in the present study were able to easily overcome. Several writers in the context of dementia have also stressed the importance of partners coming to a shared view of the world (Whitlach 2001; Pearce, Clare and Pistrang 2002) and argue that the way in which couples relate determines the 'dynamics of dementia' and thereby how well the couple cope (Keady and Nolan 2003).

Overall, negotiating a way of living with the stroke was complex and made all the more so by differences in how partners perceived the changes that were needed. It is oversimplistic to assume that adjustment to stroke is a straightforward process. Partners have very different adjustments to make, and may have different indicators of what adjustment means to them. In their study, Dowsell and colleagues (2000) note "*adjustment was not merely an adjustment to impairment and disability, it was also an adjustment to an unspecified prognosis (...) bedevilled by constant reference back, not to milestones of recovery, but to life before stroke*" (pg. 514). In the present study, patients did indeed refer back to their past life, but so did well partners, and adjustment constituted an ongoing 'dance' to try to accommodate the differing needs of partners, as well as their shared dreams and goals.

11.4.4 Adjustment to Stroke (getting back to normal)

Adjustment to stroke for this sample of patients and spouses was characterised by three subthemes *restoring past lives*, *doing the best we can* and *life on hold*. Most of the patients in the sample were in their fifties, sixties and seventies, and had been fit and active prior to the stroke, although a few were already living with life limiting conditions including cancer or debilitating conditions such as arthritis and heart disease. Nevertheless, the first weeks and months after the stroke were characterised by a drive to regain their pre-stroke lives and so focussed largely on the *restoration* of lost function and the preservation of pre-stroke dreams and goals. It was also apparent that recovery and adjustment were also measured in terms of very personal goals which were driven largely by the patient's pre-

stroke lives and abilities, and, in common with other studies it was these goals that patients used as a yardstick by which to measure their progress (Dowswell et al. 2000).

Consistent with other studies, some patients and spouses could find no space for a future which included the possibility of long term disability, and instead focussed their attention on the restoration of physical function and through this a return to their past lives (Radley 1989; Alaszewski et al. 2006). Many patients actively resisted their disabilities by trying to participate in normal life as much as possible, and this was especially true for male patients. In keeping with the findings of other studies (Radley and Green 1985; Radley 1989; Gray et al. 2000), men in the present study were more likely than women to maintain a focus on restoration. This held true for both patients and male spouses. In contrast, when the patient was male, the patient tended to retain their focus on restoration, whilst their wives tended to move towards a strategy which accommodated the stroke, and this caused tension for couples. Radley (1988) found that accommodation was made more readily by middle-class couples whilst working class patients tended to adopt the active-denial (restoration) style of adjustment or became resigned to it. In the present study there was no evidence of this trend. This may reflect the passage of time, or simply be because of the small sample in the present study.

One way in which some couples justified the maintenance of a restoration goal was through the use of upward social comparisons, citing individuals who had experienced a worse stroke than them, but had made a better recovery. Ultimately, the ambiguous and uncertain trajectory of stroke recovery, and the seemingly contradictory messages provided by health professionals and their hospital experiences feed the restoration goal. On the one hand patients are informed by their doctor that their disabilities may not resolve, but on the other the focus on physiotherapy and occupational therapy are seen as ways of regaining function. For some couples there is also the likelihood that their perceptions are influenced by what they want to hear, rather than what they are told, and this was certainly the case for the most disabled patients in the present study. For some couples the goal of restoration is realistic, for others it is not, and I would contend that those who were the least well adjusted were those who had the strongest, but most unrealistic goals for restoration. For these few couples the restoration goal transformed over time into a life on hold, because they were unable to accept the reality of the recovery trajectory.

For two couples in particular, the uncertainty engendered by the stroke resulted in a *life on hold*. For both of these couples the results of the stroke were perceived to be severe and negative, and its impact dominated their lives. The findings show that for these couples there was an apparent discontinuity between their pre and post-stroke lives, and their experiences resembled those described in other studies (Mumma 1986; Anderson 1992; Folden 1994; Dowswell et al. 2000; Ellis-Hill and Horn 2000), but it was on this idealised, pre-stroke life that the couples fixated. Both of the well spouses and one of the patients remained focussed on the goal of restoration and did not express any acceptance of the permanence of their situation. Although this only reflects the experiences of two of the couples interviewed, it does suggest some cognitive disengagement by these participants. Indeed, there was a sense that they needed to grieve for the loss of the life they had before the stroke, but well spouses in particular were unwilling to accept living with the threat of the loss of their partner and so could not engage in the process of grieving.

Although these couples differed in many respects, they were similar in terms of the strength of their future plans, and neither couple was able to come to terms with the changes in their retirement plans. Having worked hard all their lives, these couples deeply resented the stroke and its impact, but they seemed unable to reclaim their lives. Corbin and Strauss (1984) note that when illness strikes, hopes and dreams are often shattered or greatly changed, and that the individual or the couple must come to terms with these losses. In these two couples, at least one partner failed to do this. These couples demonstrated significant communication difficulties, and struggled to engage with one another in any meaningful level, which lends support to Corbin and Strauss's assertion that "*without talk a couple may have difficulty arriving at shared trajectory and biographical projections*" (p. 113, Corbin and Strauss, 1984).

In the present study these couples became locked into an unsatisfying pattern of relating in which ill partners felt smothered and over-protected, a finding well reported in the literature (Thompson and Sobolew-Shubin 1993b, a). At the same time a blurring of the boundaries was evident, as couples moved from a spousal relationship to one which was characterised by well partners as patient-carer relationship. Boss's research (Boss and Greenberg 1984; Boss, Caron, Horbal and Mortimer 1990) in the context of dementia found that well partners experienced relief when this blurring of boundaries is clarified as the dementia progresses. However, in the context of stroke which does not have the downward

trajectory of dementia, it is unclear how this might be achieved. Instead these well partners became locked into this circumscribed relationship with the patient, whereby they spent most of their time in the caring role, at the cost of their marital relationship. For these couples, the primary relationship was that of patient and carer but both couples rejected external help, tying them even more closely into this relationship. Neither carer had a realistic sense of the stamina needed to provide 24 hour care, but each chose to provide this without substantial support.

For one couple, one-to-one care was their chosen model because this would allow them the freedom to travel, and thereby fulfil one of their pre-stroke goals. However, the reality was that one-to-one care meant exhaustion and fatigue for the well spouse. For the other carer, external help was rejected because she struggled to engage with “the powers that be” that could help her. Finally, these well spouses felt guilty if they did anything which could be construed as being ‘for them’. One carer in particular voiced the need to talk to others in the same situation, but also retreated from this as she feared others would be managing better. Inherent in this was the need for validation of her feelings and experiences, but her fear of being perceived by others as not coping made her reject the support which could help them move forward. These well partners were least able to accept the realities of the stroke or acknowledge the changes in their partner, and this resulted in damaged communication, a lack of shared decision making, over-protective care and an ongoing pattern of distress.

In comparison, couples who took a collaborative *doing the best we can* approach sought to accommodate the effect of the stroke. Radley (1989) described couples who were accommodating as “... *husbands and wives for whom a recovery of health meant, not a return to the days prior to the illness, but an exploitation of the alternative ways of living produced out of their discourse on how they might cope*” (pg 246). In the present study some couples came to accommodate the stroke over time, and others came to a partial accommodation whereby they agreed about some aspects of the stroke. For example in some cases the patient presented behaviour which was consistent with accommodation (e.g. taking up new roles) and with emotional adjustment (e.g. not emotionally distressed), but the patient was unable to cognitively disengage from the goal of restoration of physical function. This form of adjustment has also been found in the context of adjustment to end-stage renal failure (Wright and Kirby 1999). These authors found that patients’ cognitive,

behavioural and emotional adjustment to end-stage renal failure was often desynchronised such that patients could behave as if they had adapted but not accept their illness at an emotional level. This clearly warrants further research.

Accommodating the stroke meant that couples changed their routines but accepted these changes as part of their lives. They adapted their ways of doing things such that they could spend time together enjoying valued activities, but they also tried to allow one another space and independence. Accommodation emerged over time as couples found new ways of relating, and this sometimes meant allowing other family members into the relationship so that well spouses could have time for themselves. Well spouses described how, during the initial post stroke phase they had severely limited their own activities to cope with the needs of their spouse. However, finding ways of accommodating the stroke generally resulted in some improvement in this situation such that they had agreed with their partner ways of working that allowed them some independence.

Well partners also encouraged and coached their ill partner to learn and take on new roles; a form of interaction which highlights the importance of the partner in the adjustment process, and one which has been reported elsewhere (Stanton 2000). The well spouses who found ways of accommodating the stroke also described how they enjoyed, and found meaning in their caring role, a finding which has been noted elsewhere (Davis and Grant 1994; Morrison 1999). This process of readjustment from a restoration goal to a way of living which accommodated the stroke was facilitated by an ongoing discourse in which couples engaged with one another and negotiated a shared view of the stroke. Positive appraisal of the events surrounding the stroke was one important aspect of this process during which the couple's goals were redrawn.

11.5 Variability in Adjustment

An important finding of the study was the variability in participants' adjustment to stroke over time. Some studies have found patients adjustment well to stroke over time (Pound et al. 1998b, a), whereas others find patients struggle to adjust (Dowswell et al. 2000). The present study finds some support for both viewpoints, but also makes an important contribution by highlighting that patients' and carers' perceptions of their situation can change dramatically over the space of six months, and these changes are a

result of how the individuals perceive the stroke, their own abilities to cope, the patient's disabilities and their ongoing relationship.

The illness perceptions of patients and spouses and concepts such as congruence and divergence of beliefs were found to play an important role in the adjustment process. However, also implicated in the adjustment process were a set of much more fundamental beliefs about the meaning of health and illness, and how these beliefs are negotiated by the couple had consequences for the adjustment process. A key finding of the study was that adjustment was not understood or constructed by couples as an individual phenomenon but rather couples construct the concept of adjustment as something they do together, and which is jointly constructed over time, in an ongoing, dynamic fashion. Indeed, when one partner struggles to adjust, this was found to have major implications for the other partner.

In the present study, a handful of couples found it difficult to disengage from the goal of restoration whilst others were able to move towards a model of adjustment which accommodated the stroke, and they accepted that these changes constituted a 'new normal'. Most couples fell between these two positions, and in many cases partners came to a view of what getting back to normal meant them at different times, and at the time of the second interview a few couples still diverged in what 'back to normal' meant, or indeed whether it was possible to achieve. There seems to be a pressing need to move away from the internal, person-centred approach to recovery and adjustment to chronic illness which still dominates the care pathway for stroke (e.g. National Guidelines for Stroke, ICWP, 2004, 2008) to one in which adjustment is conceived as a social phenomenon. This does not mean that patients and carers should not be treated as the individuals they are, but that significantly greater emphasis should be placed on the dyadic relationship and the joint nature of the recovery, rehabilitation and adjustment process.

11.6 Strengths and Limitations of the Study

To date, very little attention has been given to the relationship between patients and carers beyond the role of social support in the recovery and adjustment process of patients. This study adds to the discussion of the role of the family in the adjustment process by providing evidence of a multi-dimensional, dynamic relationship between spouses. This study is the first to use joint interviews to shed light on the processes associated with

successful and unsuccessful negotiation attempts and explore with couples the communication strategies they use as they try to negotiate a way of coping with the stroke.

Whilst standard instruments can uncover information on outcomes of the adjustment process, such as depression, quality of life etc., the qualitative methods adopted by this study allowed some insight into the circumstances surrounding the process of adjustment and the role of illness beliefs and communication in this process. The presence of both partners provided insights into the differences and similarities in the couples' understandings of the illness and highlighted the negotiated reality of adjustment to stroke. The study should therefore be viewed as an attempt to shed light on the experiences of couples as they come to terms with stroke.

11.6.1 The Sample

The sample for the study is large in qualitative terms, and the longitudinal nature of the design meant that changes in how couples negotiated over time could be observed. However, the sample was limited in terms of demographic variables, and this should be considered when reading the results and the conclusions drawn from the analysis. The participants were drawn from one NHS Trust in semi-rural northern England, and all the couples in the study were white, spousal couples, and with the exception of one couple they had all been married for over 20 years. Participants were aged between 53 and 85 years and so the experiences of younger stroke survivors are missing from this analysis. Also the focus on spousal couples clearly does not cover the range of caring relationships in which stroke is experienced. However, the use of theoretical sampling meant that both mildly impaired patients, as well as those with complex and multiple disabilities were included in the sample. The intention of an interpretative phenomenological analysis is not to make general claims, but to provide some theoretical insights into the process of adjustment, and it is up to the reader to determine whether this has been achieved. Due to the lack of diversity in the age and ethnicity of the sample it is likely that other negotiation and adjustment patterns exist, and indeed the present study did not find any patient who fell into Radley's (1989) 'secondary gain' pattern of adjustment.

11.6.2 Recruitment

Maintaining recruitment to a longitudinal study proved challenging, and recruiting both patients and spouses was a factor that limited participation in the study. The decision to interview partners together, rather than offer separate interviews was taken for both

pragmatic and theoretical reasons. Nevertheless, it may have put off some couples from volunteering to take part.

11.6.3 Interviewing Couples

Conducting joint interviews offered a different perspective to that provided by individual interviews, and it became clear that most, but not all of the couples constructed the stroke as a joint event. In her experience of interviewing patients and carers in the context of cancer, Morris (2001) found that patients tended to be the 'storyteller'. In contrast, the present study found that the patient was not always the main storyteller. Some patients in the present study had residual language problems, and so well partners often provided the bulk of the story, and asked their partner to provide additional information and asked if they agreed with their rendition of events. In other cases, well partners did take a back seat and allowed the patient to take control of the story and be central to the event, but this was not the case when the patient was more disabled. By having the well partner tell the bulk of the story, this potentially privileged the account of the spouse over that of the patient, but the interactions between partners strongly suggests that the couple were 'jointly remembering' (Edwards and Middleton 1986) and contradicted and filled in the details for one another.

Cornwell (1984) made the distinction between private and public accounts of health. Cornwell argued that the accounts patients give of their health would differ depending on how they perceived the audience. A public account was that which would be given when the speaker was concerned how others will view it, whilst a private account would be given to those they perceived to be like themselves, and that the nature of the account depended on how they perceived the relationship between themselves and the interviewer. She argued that when the exchange is situated with the interviewer being perceived as an expert questioning the patient, then a public account will be rendered, but when the patient felt they were being asked to tell their story, this resulted in a private account. Others argue that a private account will be provided when trust has been built up (Radley and Billig 1996). In the present study significant effort was put into trying to build rapport and trust with patients and carers, and also in allowing them the space to tell "their story", and I would argue that, given the nature of what patients and carers divulged of themselves, a private account was rendered by participants in this study. However, it should be acknowledged that there will be information which participants will have chosen to keep secret, and there was some

evidence that some male patients in particular used topic management strategies to divert discussions from topics which they did not wish to discuss.

Some researchers (Dowswell et al. 2000; Stanton 2000; Fried et al. 2005) have used separate interviews in a bid to get around the difficulty of participants having things they do not wish to discuss with their partner present, and it is likely that this would have provided a different perspective onto the negotiation process. Other studies have suggested that the gold standard is to conduct both joint and separate interviews with couples (Seymour et al. 1995). However, as a sole researcher this was not feasible. In order to avoid couples having the chance to discuss the issues raised during the individual interviews, it would have been necessary to conduct all three interviews on the same day, which would have proven too exhausting for patients, (and the researcher). Also, in many of the homes I went to, this would have meant one partner sitting either in the kitchen or bedroom whilst the individual interviews were conducted, which would not have been appropriate.

I would contend that significant benefits were derived from interviewing couples together. Couples in this study went through a process of joint remembering as they told the story of the stroke, and were able to corroborate events and provide supplemental information. They also argued, disagreed, contradicted one another, and laughed and joked, and this provided rich information about their interaction style and how each partner perceived the events they were describing. The quality of the data was constrained by couples' ability to discuss and verbalise their feelings and the difficulties they were facing, and often by interviewing the couple together thoughts and feelings emerged as they described to one another how they felt about things. Significant benefits were derived from creating the opportunity for couples to have a dialogue about the stroke and its impact on their lives. Several couples commented that they had learned something from listening to their partner's perspective on events, and that for some, this was the first time they had discussed the events surrounding the stroke.

The decision to interview couples whilst the events were unfolding, rather than waiting until after the process of adjustment had been completed, may have constrained what couples were willing to talk about. However, what emerged from the interviews, and especially at time two, was that they portrayed events that were unfolding at the time, or were still salient because the events were very recent. However, this means that many

couples did not feel they had 'adjusted' or were 'back to normal', and indeed this accords with the findings of Stanton (2000) who found adjustment to an ongoing process, and that couples were only just adapting 2 years post stroke. There is therefore a need for longer-term studies which can examine the process of adjustment over the first 2-3 years. Finally, choosing not to interview all couples at time one was, with hindsight, an unhelpful decision as it was not possible to observe the 'process' of adjustment in these couples. Nevertheless, these couples did provide rich, thick descriptions of the difficulties they had faced, although it is possible that allowing them to talk in hindsight about the events produced a different account to that which they would have produced at the time of the events.

11.7 Methodological Issues

The data produced from the IPA analysis was diverse and extensive and, as can be seen from the analysis, the themes overlap and are dependent on one another. This makes it problematic to represent accurately some of the associations between the different themes within the results section. The study provided extensive data on patient and spouse accounts of the process of making sense of the stroke and the interaction between partners.

Included in the title of this thesis are the terms 'negotiation' and 'shared understandings'. However, before the study began, and indeed during data collection, the term 'shared understanding' was a rather ill-defined construct. The research question emerged out of considering the impact that discrepant illness beliefs may have on patient and carer adjustment. It is therefore possible that I have privileged considerations of a 'shared understanding' within the analysis to the detriment of other ways of adjusting. However, until the analysis of the data, the importance of psychological and behavioural factors in the adjustment process and how these influenced the way couples came to terms with the stroke was not one I had considered, and I believe that this shows I have been open in the way in which I have approached the analysis.

To try to address the potential for these biases in my reading of the data, I have tried to show reflexivity throughout the analysis section and as I have already discussed, I have tried to be transparent in coming to my conclusions, although this is obviously only one interpretation and one way of presenting the analysis. I have provided demographic information about the couples so that other researchers can compare my findings against theirs, and used quotes throughout the results section in order to ground the findings in the

experiences of the couples represented here. I have also tried to ensure that the voices of both parties can be heard and represented in the account presented.

As a relatively inexperienced qualitative researcher, the guidelines created for conducting IPA were used to help with the process of analysis, but I did find these sometimes constrained rather than aided the analysis, and I resorted to the use of memos and diagrams to aid the analysis, thus drawing from elements of grounded theory, which helped in clarifying in my mind the relationships between some of the themes identified by the analysis. It was never the intention of this analysis to create a theoretical model of the process of negotiation, and the diagram presented at the beginning of the analysis should not be interpreted as such. It is however a tentative first step towards an understanding of the process, but does not represent the complexity of this process. During the analysis, it became clear that different themes could 'work' in different ways, and it proved a challenge to present the data such that it the reader could understand the complexity of the adjustment process. For example, cognitive dysfunction is a deficit resulting from the stroke, but acts as a barrier to successful adjustment because it hinders the negotiation process. Ultimately this was resolved by going back to the transcripts and separating out the experience of the deficit from the impact that this has on negotiation and adjustment.

11.7.1 The Role of the Researcher

I have given the role of self in the analysis considerable attention in the methods section, and it is not my intention to repeat here what has already been said. As a relatively inexperienced researcher my interview technique will certainly have influenced the interview process, and the way in which the interviews were conducted certainly changed over the data collection period as I gained confidence and experience, and so it should be kept in mind that some of the differences in the open-ness of participants from interview one to interview two is likely to be a combination of both improvements in my interview style and in their confidence in me as the interviewer. Despite the limitations set out above, the research presented in this study was conducted in accordance with guidelines of good qualitative research (Elliott et al. 1999). A full account of the interview and data analysis process has been provided in order for the process to be rendered transparent, as advocated by Yardley (2000) and Elliott et al. (1999). The analysis and the themes presented were discussed with a researcher with experience of living with the impact of stroke, and with a nurse who had extensive experience of caring for stroke patients, and both found the accounts made sense in the light of their experiences.

11.8 Clinical Implications

Although there has been a move to involve carers in the stroke pathway (Royal College of Physicians 2008) the guidelines for stroke care still present a *person-centred*, rather than a couple or family-centred approach. Indeed, although 'informal carers' qualify for a full page in the recommendations of the new edition of the National Clinical Guidelines for Stroke (Royal College of Physicians 2008) their voice is otherwise largely missing from this document. The findings of the present research whilst limited to spousal couples, present a challenge to this person-centred approach and have implications for the management of stroke, service planning and delivery.

11.8.1 A Couple-based Approach

These findings suggest that when considering patient recovery and adjustment to stroke, health professionals need to consider the patient's wider social world, and the role of the spouse in particular. It is important to acknowledge that health professionals were not interviewed and no data was provided regarding communication between the health professionals and families, apart from what was provided by the couples, and this is a limitation of the study.

It is important to acknowledge that not all patients have spousal carers, but this study suggests that for married couples, the dominant model for recovery from stroke was 'couple-centred'. Specifically, in this study, couples were engaged in an ongoing negotiation and re-negotiation of the stroke and what it meant to their lives. The analysis revealed that almost all couples made sense of the events as a couple, and the findings illustrate the interdependence of couples during the recovery and adjustment process.

11.8.2 Illness Perceptions

In the quantitative study, patients and carers reported similar levels of emotional distress and previous research indicates that both patients and carers are at considerable risk of extended distress. The results of the qualitative study clearly suggest that patients and carers diverged in their beliefs about the stroke, and in their fundamental beliefs about health and illness, and that this has implications for distress levels. A number of difficulties were of particular interest, and all have serious implications for service planning and provision and patient care.

Couples initially constructed different recovery trajectories, with well partners being far more cautious in their recovery beliefs than patients, and more wary about the risk for the patient in re-engaging with old activities. The study therefore highlights the need for a more proactive couples-based approach to patient rehabilitation which engages with well partners to help them address their concerns. Well partners may also benefit from professional input to help them devise strategies to assist in the management of risks, which would enable spouses to be more supportive of patient attempts to re-engage with activities. However, it is also important to be sensitive to the carers needs and not over-burden them with additional tasks which well partners do not feel able to refuse, but which add to the burden of caring.

Many patients struggled to accept care from their well partner, and this became a source of distress for both partners. Although there is a culturally held expectation for wives to care for their ill spouses, few well wives described receiving much external support. In contrast, all husbands caring for ill wives were offered support, even though some declined it. On the whole, well partners are happy to care for their spouse, and indeed some gain satisfaction from the role. However, the implicit expectation that caring responsibilities will be handed to well wives may mean that questions are not asked about the carers' ability to cope, or their need for additional support, and well partners are left to feel they are failing if they cannot cope alone. The findings of this study suggest there is a pressing need for a reassessment of this assumption for the benefit of both partners. In this study, some patients struggled to accept care from their wives because they feared becoming a burden on them. Providing practical assistance and respite early in the discharge process, and ensuring that carers know it is still available even if they choose not to take it initially may help alleviate this distress. Finally, couples differed significantly in their perceptions of the causes of the stroke, and this had significant implications in terms of secondary prevention measures. This was compounded by a perceived lack of clear guidance on health behaviour changes which left patients and spouses unsure of how to proceed or how to reduce their risks.

Taken together, the results indicate that both partners may benefit from the opportunity to discuss their worries and thoughts about the stroke with a trained counsellor or nurse, both separately and together. The study also found that some couples struggled to address conflicts and used avoidance strategies, and a few fell into a cycle of avoidance of

discussions. There is evidence to suggest that this pattern of behaviour is detrimental (Rolof and Cloven 1990) and the results of the present study support that assertion. Therefore both partners could benefit from guidance and assistance in problem solving and conflict resolution strategies. This could take the form of a targeted psychosocial education package to address the specific needs of the couple. Stroke education and information programmes are not new, and a 2001 Cochrane review concluded that their effectiveness remains to be established (Smith, Forster and et al. 2001). A more recent review concluded that there is some tentative evidence to suggest that counselling interventions have some potential (Visser-Meily, Van Heugten, Post, Schepers and Lindeman 2005), with three out of four studies reviewed showing a positive overall effect. However, none of the interventions reported in the literature specifically addressed the illness beliefs of patients and carers. Therefore a programme to address partners' discrepant illness representations and communication skills may prove beneficial, although further research is needed to determine the timing of such an intervention.

11.8.3 Social Work

This study found that the couples who were at the greatest need were often the ones who were least likely to ask for support, and were also the ones where the carer demonstrated the highest distress and burden. This may appear paradoxical, but this finding has been reported elsewhere in the context of stroke (Pound et al. 1998a). In her study, Pound described how patients were in great need but did not want to make a fuss. As inpatient times decrease and patients are discharged home even more rapidly, carers will need increasing levels of support to help them adjust to their caring role, and there may be an increasing need for community based systems of support that can step-in at short notice, and can help in practical ways, not just offering advice or providing basic personal care for the patient. For example, in the present study well partners reported high levels of distress during the first weeks because promised care was not in place. There is a legal duty of care for this to be in place before discharge, but the experiences of these participants suggest this is often not the case. The pressure to discharge quickly and a lack of communication between relevant bodies mean that things do not happen. Patients do not feel they want to make a fuss, but there was an underlying fear from some that to do so may mean the withdrawal of such services, by 'the powers that be'. At the same time, these well spouses are left struggling to cope with equipment in their homes, additional workload, and faced with considerable bureaucracy to apply for benefits and assistance. Providing flexible, sensitive support at this time may reduce carer distress, and aid adjustment.

There is also a clear need for social support for both partners. In this study, three patients were assigned social workers to help with the discharge process, to ensure that the needs of the patient were assessed. However, in some cases the needs of the well partners did not appear to be assessed at the same time, and in two cases these well partners had their own healthcare needs and social worker, but in neither case was the same person assigned to attend to the needs of both partners. This meant that decisions were taken to the benefit of one partner, but on occasion this was detrimental to the other partner. There is an obvious need for 'joined-up care' which fulfils the needs of the individual, but also considers the context of the couples.

11.8.4 Timing of Support

There is a difficulty in the timing of any package of support for couples as the process of adjustment differed across couples. Although there is an obvious need for targeted input whilst the patient is in hospital to address the most urgent adjustment challenges, the results of the analysis indicate that couples may not be ready to discuss some issues until some time after the stroke. To date, most interventions have provided short programmes during the first weeks and months after the stroke, but the results of the present study indicates that a flexible couples-based approach may be needed. Indeed, there may be a role, not just for the NHS, but for the voluntary sector such as Age Concern and the Stroke Association to provide such support. However, in the present study only two interviews provided any support to suggest that patients or carers had been guided to other sources of advice or support.

11.9 Research Implications

The current study has explored the process of adjustment to stroke by spousal couples. Whilst the study contributes to our understanding of this process, and expands the concept of adjustment from the individual to the couple, the study also raises questions for further research. There is an obvious need to examine the negotiation and adjustment process within other dyads to determine whether the observed interdependence between marital partners is present in other dyads. There is also a need to examine the process of adjustment in couples who are younger and perhaps have dependent children, to examine whether adjustment is still a couple-based or perhaps a family-based process.

Couples in this study were followed for only 6-7 months, and most couples did not feel they had adjusted by the time of the second interview, and so there is a need to examine the process of adjustment over a longer period. Stanton (2000) examined the process of adjustment over 2 years but did not interview couples together, and so more research is needed to explore this in greater depth. By the time of the second interview, couples diverged in their adjustment patterns and it may be enlightening to examine individual factors that contribute to the different adjustment patterns. The evidence from the present study suggests that overly optimistic illness beliefs, poor communication style, and carer distress are implicated in the least successful adjustment trajectory (life on hold), whilst open communication, realistic illness beliefs and a collaborative approach to working together are implicated in an ability to accommodate the illness. However, little is known of the personal attributes which may contribute to this process. Over time there may be increasing variability in the adjustment patterns of couples, and the use of in-depth qualitative methods over a number of years may enhance our understanding of the adjustment process, and lead to a theoretical model of adjustment.

More needs to be known about what predisposes couples to adopt particular coping and negotiation approaches. For example, in this study all couples where the patient was infantilised by the well spouse constituted ill husbands, which suggest that there may be sex differences in the approaches of male and female partners. Although three female patients demonstrated similar behaviour difficulties to those described by well wives, well husbands minimised the impact this had on their lives. As this behaviour was also closely linked to feelings of over-protection by the ill partner, this is an area in need of further research.

11.10 Conclusion

In summary, the study explored the experiences of patients and spouses over the first months following a first-ever stroke. The majority of research examining the concept of adjustment to stroke has taken a quantitative approach, and focussed on discrete psychosocial outcomes, such as anxiety and depression. Only a few studies have considered the process of adjustment, and the majority of these have been cross-sectional studies, so the *process* of adjustment has not been adequately tapped. Only two longitudinal studies have sought the views of patients and carers (Dowswell et al. 2000; Stanton 2000), and neither of these studies has examined adjustment as a socially negotiated process. Consistent with

previous research, well partners were strongly implicated in the adjustment process. Furthermore, most couples conceptualised adjustment as a 'joint process'.

In the first year the process of adjustment centred on the phenomenon of 'getting back to normal'. In the early post-stroke period, couples wished to reassure each other and avoided talking about contentious issues. Over time, couples were faced with trying to negotiate a way of living with the stroke and it was at this point that the discrepancies in the illness beliefs of patients and spouses, their communication skills, and their fundamental beliefs about health and illness emerged as important to the way in which the couple negotiated a way of living with the stroke. Couples differed in terms of what back to normal meant to them, and by the second interview few couples felt they were back to normal.

The value of the analysis has been to open up the discussion on the issue of adjustment to stroke beyond considering it either as a discrete outcome or an intra-individual process, to considering it as a socially constructed and negotiated phenomenon. In doing so, it has placed the couple at the centre of the recovery and adjustment process, and sets the scene for more research to consider how to help couples manage the impact of stroke and minimise its intrusion into their lives.

12 Final Discussion

The research reported in this thesis has been guided by Leventhal's self regulatory model of illness (Leventhal, 1980, 1984), which proposes that, when faced with a health threat, individuals formulate a cognitive representation of the threat which guides their coping behaviour. Previous research has found illness perceptions to be important predictors of patient outcomes (Hagger and Orbell 2003). However, as discussed in chapter two, despite the fact that stroke is one of the most common chronic conditions affecting older people, surprisingly little research has been conducted into the illness perceptions of stroke patients, and most of the existing research has focussed on the role of personal control beliefs as predictors of physical recovery or patient distress (Johnston et al. 1999; Morrison et al. 2000; Johnston et al. 2004; Morrison et al. 2005).

Although Leventhal's model (1980, 1984) highlights the role of significant others, most early studies considered the illness experience within a social vacuum (Morrison 2001), and if the role of significant others was considered at all, it took the form of examining the nature of social support provided to the patient, rather than considering the nature of the illness perceptions of both patient and carer on the outcomes of both partners. As discussed in chapter two, researchers have begun to become increasingly cognisant of the impact that other people's beliefs have on how patients come to understand and to cope with chronic illness (e.g. Heijmans, 1999). However, no studies were found that included stroke patients and carers within their sample. Well spouses, as well as other family members, are profoundly affected by, and in turn contribute to the patient's experience of coming to terms with their stroke, and so the lack of research into this area is surprising. To date, research has primarily emphasised the individual responses of patients and carers to stroke, and little attention has been paid to the experiences of the couple or dyad. Within the context of stroke, research has tended to consider adjustment as an outcome which can be measured quantitatively, and studies have tended to focus on a discrete range of psychosocial outcomes, such as quality of life, and emotional distress. However, adjustment to stroke can also be considered in terms of an inter-personal, psychosocial process, and almost nothing is known about the process of adjustment or how couples negotiate a shared

understanding of how to live with, and accommodate its impact. The research presented in this thesis has begun to fill in some of these gaps.

The quantitative study (study one) was a longitudinal cohort study that considered the illness representations of patients and carers. No previous study had attempted to examine the illness perceptions of this group. This was the first study to examine the nature of the illness perceptions of couples, the ways in which the discrepancy between the perceptions of patients and carers could be assessed, and the relation between discrepancy and patients' and carers' psychological adjustment. The second study considered the process of adjustment to stroke. Although several studies have examined the process of adjustment in stroke patients and carers, no previous study was found that articulated the involvement of carers in the adjustment process. This qualitative study recruited patients and carers from study one in order to examine the ways in which couples come to terms with the impact of the stroke and negotiate ways of living with its impact.

The aim of this final chapter is to discuss the main findings of the two studies with reference to the research questions set out in chapter two. In doing so, it will use firstly what Mason (2006) refers to as a 'rhetorical logic' (p. 4) to expand on the quantitative results of study one. In particular the discussion will focus on discrepancy in the illness perceptions of patients and carers and how this has been assessed, and the utility of the IPQ-R as a measure of discrepancy between couples.

12.1 The Quantitative Study

The first study, the results of which are reported in chapters 5 and 6, examined the nature of illness representations in first-ever stroke patients and carers. This longitudinal cohort study recruited 42 first-ever stroke patients and their carers and, using self-report measures, assessed their illness perceptions, social support, relationship satisfaction and emotional distress levels at approximately 3, 6 and 9 months post stroke. This study had three aims; firstly to **examine the nature of illness representations in the sample**; secondly to **determine the extent of discrepant illness perceptions in the sample**, and thirdly to **explore the relations between discrepant perceptions, distress, relationship satisfaction and social support**.

The results of correlational analyses indicated that patients had a coherent model in terms of the more negative aspects of the stroke, with strong positive correlations between negative consequences, a longer timeline for recovery, lower personal control and lower illness coherence. Carers reported similarly negative perceptions of the stroke. Although both patients and carers believed that the patient had good control over their recovery, and reported a strong belief in the role of treatment in the recovery process, these beliefs were largely independent of other beliefs about the stroke. The lack of association between control beliefs and other aspects of participants' illness representation was unexpected, and suggests that the generic nature of the IPQ-R may not be flexible enough to assess control beliefs in conditions such as stroke. With the exception of beliefs about personal control and treatment control, which became significantly more pessimistic over time, patients' and carers' perceptions appeared to change little between the three assessment times. Declining recovery confidence has implications for rehabilitation and treatment as this may manifest as poorer commitment to rehabilitation. Other studies have found that carer perceptions can negatively affect patients' commitment to rehabilitation (Maclean, Pound, Wolfe and Rudd 2000), and so this is an area in need to further research.

The second aim of the study was to determine the extent of discrepancy within the sample. Few studies have reported how common discrepancy is within their sample (see Figuerias and Weinman 2003 for an exception), and this constituted an attempt to map out areas of difference within couples. Patients and carers were found to diverge on the illness identity, consequences, personal control and causal attributions subscales. Discrepancy reduced over time, but was still common in the causal attributions subscale at time three. The study also aimed to quantify the level of discrepancy within the sample. At time one, only 30% of couples were classified as congruent in all illness representation domains, and by time three, discrepancy was much less common, although almost a quarter of couples still disagreed about the causes of the stroke, and almost half still disagreed in at least one illness representation domain. The final question asked to what extent is the maintenance of discrepancy associated with socio-demographic variables. Although studies have examined the relation between discrepancy and outcomes, only one previous study has attempted to examine possible causes of the discrepancy (Visser-Keizer et al. 2002). In this cross-sectional study, Visser-Keizer and colleagues found that discrepancy was associated with carer distress. In the present study, the only variable associated with the maintenance of discrepancy was carer distress, with higher distress at time one associated with a lack of

convergence in couple's illness perceptions over time. Taken together these results suggest that carer distress may be an important variable, and this warrants further research.

The third aim of the quantitative study was to explore relations between discrepant illness perceptions, distress, relationship satisfaction and social support. It was anticipated that this would provide information on the causal relations between discrepancy and distress. However, the small sample size means the results should be viewed as provisional. The results from this analysis are presented in chapter 6. Strong positive correlations were found between patients' and carers' predictor and outcome variables, indicating that the data was non-independent. Therefore the Actor-Partner Interdependence Model (APIM) was used to analyse the data. The results of the cross-sectional and longitudinal analyses indicate that patients' and carers' distress levels are associated with their own illness representations. However, few consistent effects were found, and few longitudinal effects were found. Both patients and carers were found to influence their spouse's later distress, with stronger effects found from carers to patients, suggesting that carer beliefs may be important contributors to the maintenance of patient distress.

The study also found that discrepancy was associated with patient and carer distress, but the only consistent finding was for the role of discrepant illness coherence beliefs. Specifically, discrepancy over how well partners felt the patient understood their stroke was associated with higher carer distress at time one and time three, and higher patient distress at time two. Discrepancy was found to be associated with carer distress even though the carer's own illness perceptions were not significantly associated with their distress levels. This finding needs to be replicated, especially given the small sample size, but does suggest that when partners disagree this can have an independent impact on distress, and is an area worthy of further research.

12.2 The Qualitative Study

The second study, the results of which are reported in chapter 10, was a qualitative study which sought to explore the process of adjustment to stroke and the role of discrepant beliefs in this process. In this study 16 couples who had been recruited to the quantitative study were selected for interview, to explore the role that discrepant illness perceptions and negotiation play in the adjustment process. Couples were interviewed on two occasions, 6-7 months apart to examine how the process of adjustment unfolds over time.

The key findings from this study relate to the way partners come to understand the changes in the patient's physical, emotional and cognitive functioning. Individuals varied in their understandings of the stroke, the deficits it brought and the possible permanence of its effects. As couples struggled to make sense of the events and 'get back to normal' their conflicting views of its causes, consequences and ongoing management manifested in the way they talked about the stroke. The negotiation process was complex, and the ways in which negotiation was enacted within couples changed over time. Couples varied in terms of when they felt it appropriate to open discussions on important topics. Initially most couples actively avoided contentious discussions about the stroke and what it might mean to their lives, and focussed on staying positive, and their goal was to get back to normal. Early negotiations often failed, either because one partner was not ready to discuss the issue or because the couple struggled to find common ground upon which to negotiate, each bringing with them their own perceptions of the problem, what it meant, and how it should be addressed. Time was a critical factor in the negotiation process. It was only with time that couples started jointly to try to make sense of what had happened to them, and it was through a process of negotiation and re-negotiation that they worked and reworked their adjustment goals. However, this meant that couples were faced with the problem of trying to integrate their sometimes conflicting views of how the stroke should be managed and what it meant to their lives. Nevertheless, most couples constructed adjustment as something they were doing together, and when one partner struggled to adjust the other partner struggled also.

The third key finding was the variation in couples' adjustment goals. For some couples the goal was the restoration of past lives and dreams, which meant minimising the impact of the stroke, and taking an approach which involved an active-denial of its impact and a focus on trying to get back to how they were prior to the stroke. For some, this goal was realistic, but for a few couples the focus on restoration was deeply unrealistic and constituted a serious problem in terms of their adjustment. Other couples sought to accommodate the stroke and its effects into their lives and find a way of living that constituted a new normal.

The findings from the two studies will now be discussed more generally, considering their implications for how discrepancy is considered.

12.3 Illness Beliefs

Leventhal's self-regulatory model of illness posits that the cognitive model an individual constructs about his or her illness guides their coping behaviour (Leventhal et al. 1980; Leventhal et al. 1984). Although the model does suggest that these cognitive models are influenced by external pressures, the results of the present study raise a number of issues about the person-focussed approach to illness representations as represented by Leventhal's model, and argues for a more socially constructed understanding of illness perceptions.

12.3.1 Personal Control and Treatment Control

The quantitative study revealed interesting results about the personal and treatment control beliefs of patients and carers. The illness perceptions of patients and carers were found to be initially positive, but became more pessimistic over time. The views of partners were found not to covary, which meant that although patients and carers held similar views at a group level, this did not necessarily translate as both partners within the dyad holding similar views. Rehabilitation professionals commonly believe that patient 'motivation' plays an important role in determining outcome (Kaufman and Becker 1986), with internal, social and clinical factors all implicated in patient motivation (Clark and Smith 1999b; Maclean and Pound 2000). In the present study the confidence of patients and carers regarding control over recovery and the role of treatment declined over time. The qualitative study was able to expand on these results, and found that patients and carers often had different beliefs about the recovery trajectory, the potential for recovery and indeed how recovery might be best achieved. Although many well spouses had attended physiotherapy and occupational therapy sessions, there was often confusion about the purpose of such therapy and its outcome goals. Indeed, on some occasions there was little evidence that patients knew what their recovery goals were, beyond a more general goal of 'getting back to normal' or 'get walking properly'. The findings of these studies therefore contribute to the argument that patient motivation for recovery is influenced by more than internal, personality factors (Maclean and Pound 2000).

Once the patient was home, the differences in patient and carer understandings of the recovery process emerged. Importantly, although well spouses worked with patients on their physiotherapy and occupational therapy tasks, this behaviour was not generalised by well spouses to other areas. Indeed, well spouses often encouraged over-dependence by controlling the patient's activities, rather than promoting independence in daily activities.

Some well spouses failed to understand the purpose of aids and adaptations that had been provided for the patient and these were often consigned to the garage by well spouses, with them arguing that reliance on these was detrimental to patient recovery, highlighting a fundamental difference in the beliefs of spouses and health professionals.

12.3.2 Causal Beliefs

In the present study an attempt was made to examine the relation between causal beliefs and patient and carer distress. No previous study has examined this relationship in the context of stroke, and so there are no findings with which the present results may be directly compared. Indeed most previous research which examined the impact of causal beliefs tended to focus on behaviour changes (Petrie and Weinman 1997). To reduce the causal attributions down to manageable variables, the data in the present study were subjected to a factor analytic approach, which resulted in two factors reflecting a belief in the role of behavioural and psychological causes. Statistical analyses revealed that the beliefs of patients and carers were positively and significantly correlated at each assessment point, suggesting some similarity in their views. The regression analyses found that behavioural causes were unrelated to distress, but did find that a belief in a psychological cause was related to patient distress, especially during the early months after the stroke.

However, the results of the qualitative study revealed that patients and carers often had very specific causal beliefs about the stroke, although these often differed. Although patients acknowledged the role of hypertension and hypercholesterolemia because these were evidenced by the patient now being on relevant medication, most patients focussed on causes such as chance factors and stress. A qualitative study by French et al. (2005) (French, Marteau, Senior and Weinman 2005) found that myocardial infarction patients made similar specific single cause attributions, and these writers posited that a stress attribution provided a plausible and acceptable explanation because it was construed both as an uncontrollable demand, but also subsequently avoidable, thus avoiding the need to blame either oneself or others. Stress reflects the 'public' understanding (Radley and Billig 1996) of stroke and myocardial infarction, and some well partners made similar 'safe' attributions. However, other well spouses made attributions based on the biomedical model, and these attributions related to a belief in the role of poor diet and lack of exercise, thus implicating the patient.

These differences in causal attributions can be explained in terms of the actor-observer bias (Jones and Nisbett 1972). However, such discrepancies in the causal beliefs of patients and carers were an important source of tension between partners, especially within the context of secondary prevention. This relationship is not one which can be tapped by the quantitative methods used in the present study. However, the interviews revealed that the difficulties experienced by couples were not always related to differences in their attributions for the cause, but frequently related to how partners felt they should manage the risks associated with the perceived cause. The interview data revealed that patients varied in their views of the information provided regarding secondary prevention. Some complained of being given little advice, whilst others felt that the information was insufficiently tailored to their needs. Indeed, although there was a general awareness that changes should be made to their behaviour to reduce their risks, few made many changes beyond changing their diet, and many, although not all, were content to manage their risk factors through the use of medication. The National Clinical Guidelines for Stroke (Royal College of Physicians 2004, 2008) make explicit that patients should be provided with information about secondary prevention measures. When asked, many patients recalled being told of these recommendations. However patients still struggled to start making changes, or to adhere to changes they instigated. Other qualitative studies have reported similar findings (Gregory, Bostock and Backett-Milburn 2005), suggesting that secondary prevention in chronic illness is an ongoing and potentially widespread difficulty.

In contrast, some well spouses often had their own views about how these risks should be managed, and these rarely coincided with the views of the patient, since they usually involved the patient taking a proactive approach to secondary prevention. However, this left some well spouses caught in a contradictory bind. On the one hand they wanted to encourage their ill partner to do more exercise to reduce their cholesterol and blood pressure, but on the other hand they did not want them 'overdoing it'. Secondary prevention was seen as important by both partners, but they rarely agreed about the best way of achieving this. Couples were also faced with the contradiction of trying to understand and follow the advice given by health professionals, family members, health information leaflets etc. about the changes they 'should' make on the one hand, and trying to 'get back to normal' which couples interpreted as being able to put the stroke behind them on the other hand. Changing health behaviours is notoriously difficult. For example, interventions put in place to promote changes in exercise, diet and smoking following myocardial infarction

have shown poor long term adherence (Wiles 1998; Jolly, Bradley, Sharp, Smith, Thompson and Kinmonth 1999; Redfern, McKeivitt, Dundas, Rudd and Wolfe 2000). There seems therefore to be a need for longer term support, and specific advice and support for couples, both to address their own beliefs about secondary prevention and to create sustainable joint goals.

12.3.3 Discrepancy and Cognitive Dissonance

As already discussed, patients and carers diverged in their beliefs about the stroke at time one, with less than a third of couples classified as congruent in their illness representations. Over time, the number of couples thus classified declined, and the quantitative discussion (chapter 7) posited a number of possible explanations, but could not provide any support for these hypotheses. The results of the qualitative study will therefore be discussed within the context of these quantitative results.

The results of the qualitative analysis revealed that patients and carers knew relatively little about stroke, misconceptions were common, and carers often struggle to gather relevant information. These findings accord well with the conclusions of earlier studies, (Wellwood et al. 1994; McKenzie et al. 2007). Although provided with information leaflets, many patients were either unable to read them or struggled to understand their contents, and most passed them, often unread, to their well spouse. Therefore, what emerged from the qualitative interviews was that patients rely on their well spouse for information, and well spouses are therefore in a position of informational power. Once the initial shock of the stroke was over, well spouses started to actively seek out information about the stroke. In common with other studies, this often proved difficult (McKenzie et al. 2007) and well partners complained about a lack of information specific to their circumstances.

The information-avoidant behaviour of patients and information-seeking behaviour of carers led to disparity in terms of what each partner understood about the stroke. This initial discrepancy in the knowledge levels of patients and carers has been well documented (Wellwood et al. 1994; Clark 2000), and these results provide a plausible explanation for the level of discrepancy in this sample of patients and carers at time one. The interviews revealed that couples initially avoided discussions about contentious or difficult subjects. Patients often actively avoided asking health professionals about their stroke. This information-avoidant behaviour has been reported in the context of other chronic conditions (Leydon et al. 2000; Schattner and Tal 2002) and may be a way of patients trying to manage

their distress following the shock of the stroke. At the same time, well spouses gather information about the stroke, but often took a conscious decision to keep family discussions positive, which accords well with the findings of earlier studies (e.g. Zhang and Siminoff 2003). It therefore seems likely that the high levels of discrepancy shown at time one reflected their different informational levels, and a lack of communication about the stroke at this time. Communication was also limited by the patient's physical presence but emotional or cognitive absence during the first weeks and months after the stroke. In this sample, mild cognitive problems and serious language problems were common, and these problems certainly affected communication at time one, and also contributed to discrepancy.

The quantitative results showed that fewer couples were classified as divergent in each of the illness perception dimensions by time three. One hypothesis posited for this finding was that the convergence of patient's and carer's beliefs was due to the influence of cognitive dissonance (Festinger 1957). Cognitive dissonance theory posits that "*the open expression of disagreement in a group leads to the existence of cognitive dissonance in the members. The knowledge that some other person, generally like one's self holds one opinion is dissonant with holding a contrary opinion*" (Festinger, 1957 p. 261-262). Social influence perspectives posit that individuals are driven to agree with others for informational reasons (Kelley 1952) normative reasons, persuasion or dominance (Cialdini and Trost 1998; Wood 2000). However, the central tenet of dissonance theory is that there is an 'open expression' of disagreement, and the quantitative results could not confirm that patients and carers discussed their views about the stroke, and therefore whether patients and carers were open to these influences. The result of the qualitative study is therefore able to shed some light on the cognitive dissonance hypothesis.

As discussed above, couples described how they initially avoided contentious discussions, and only came to talk openly about the stroke over time. The qualitative data clearly indicates that by the end of the study, most couples were openly expressing their views about the stroke, and therefore convergence in their beliefs may indeed be due to social influence between partners. Informational influence pressures originate in "*peoples' desire to have a valid understanding of reality and thereby to effectively negotiate their world*" (Matz & Wood 2005 p. 23). An important finding of the qualitative study was that patients and carers are desperately trying to make sense of the changes brought by the stroke, and so the findings accord well with the notion of informational pressure, but do not

indicate the direction of this pressure. Patients did invest their partner with informational power by handing over control of the stroke-related information provided to them by the hospital, and this suggests that the direction of influence may be from carers to patients. However, there is still much to learn about these processes, and these conclusions must remain tentative and an important caveat placed on these conclusions. The qualitative data is limited by its recruitment of spousal couples, and therefore it remains to be seen whether other patient-carer dyads communicate in this way.

The qualitative study therefore enriches the results of the quantitative study, and provides some support to cognitive dissonance theory (Festinger 1957) but the direction of any influence remains untested, and indeed there are other theories of attitude change, such as the elaboration likelihood model (Petty and Cacioppo 1986), which provide alternative explanations about the process of attitude change. Indeed a key question in the resolution of discrepancy relates to the direction of influence and the nature of these influences. The qualitative results do tentatively suggest some influence from carers towards patients, and the nature of these influences appear to be cognitive, in the form of well partners having access to stroke knowledge and information, and certainly some well spouses used their increased knowledge in their negotiations with patients. However, well spouses also changed their views about the stroke over time as their understanding of the stroke changed. Therefore although taking a mixed methods approach provided an added dimension to the quantitative results more work is needed to explore the process of belief change over time.

The conclusions and recommendations presented in this thesis are based on the data collected as part of this PhD research in conjunction with other published literature and existing theoretical understandings of chronic illness. The methodological issues pertaining to each of the studies have already been discussed. Whilst the findings of the studies are considered generally robust, a consideration of the methods used and the limitations of the studies are now discussed.

12.4 Limitations of the Research

A critique of the methods used in the quantitative study was presented in chapter 4, and the issues raised there will not be discussed again. However, issues arising out of the decision to focus on primary rather than secondary (coping) appraisals, and how illness perceptions were measured in this study will be discussed in brief. This will be followed by

short examination of the adoption of the APIM for the analysis of the data, and the impact that this had on the results of this study will be discussed.

The study chose to modify the IPQ-R for stroke. This decision was taken in conjunction with a group of stroke survivors who acted in an advisory capacity during the initial work for the project. The measure was modified in light of the findings of a review of the literature, advice from health professionals working in the field, and following focus group discussions with stroke survivors. However, modifying the measure in this way means that the results of the study may not be directly comparable to the findings of the two other studies examining the illness perceptions of patients (Joice et al. 2003; Ford 2007). Although inter-item reliability and test-retest reliability was conducted on the modified measure, insufficient questionnaires were returned in the initial reliability study for a principal component analysis to be conducted, and therefore the factorial structure of the resulting measure has not been adequately tested (Kline 2000). It was also decided to use a four-point rather than the traditional five-point response scale, and this may have affected the responses as participants were not provided with a 'don't know' option, although this four-point format is recommended by Rust and Golombok (1999).

12.4.1 Actor-Partner Interdependence Model

Actor-Partner Interdependence Model The small sample size in the present study meant that the results of multivariate analyses in particular must be treated with caution as the regression analyses may be less stable than desired. However, advice was sought about the use of the APIM (William Cook, personal communication), and the analysis proceeded on that basis. To improve the predictor to participant ratio (Tabachnick and Fidell 1989) separate APIM analyses were conducted. This means that the unique contribution of each IPQ-R predictor was examined, but possible shared variance between variables cannot be observed (Tabachnick and Fidell 1989).

An important limitation in this analysis is the interrelated problem of type I and type II errors. Limiting the number of predictors included in each analysis provided the necessary power to detect real effects, thus reducing the risk of type II errors. However, as the number of independent variables examined in this study is large, and a decision was taken to examine all the IPQ-R variables as possible predictors of patient and carer distress, this capitalises on chance and increases the risk of spurious findings. One solution would

have been to use Bonferroni corrections, but these run the risk of increasing type II errors in small samples. Therefore, a decision was taken not to set the type I error at a low level to accommodate the increased number of analyses because this would have increased the level of type II errors. However, failing to control for multiple comparisons inflated the chances of false-positive results and this must be considered when examining the results.

The use of the APIM provided a novel way of assessing the impact of discrepancy, whilst allowing the inclusion of both the patient's and the carer's own scores in the regression model. This is an improvement on the traditional method which examines the effect of discrepancy alone (Benyamini et al. 2007), but the modest sample size in the present study means that there are increased risks of both type I and type II errors. It is therefore important to replicate this study with a larger sample to test the stability of these findings.

12.4.2 Reactivity between Study One and Study Two

A decision was taken to 'nest' study two within study one, such that the same participant pool would be available for both studies and data collected in study one (quantitative study) would be used to identify couples who fulfilled the inclusion criteria for study two, and the findings of study two could be compared with those of study one. However, in doing this there is the potential for reactivity between studies one and two, both for participants and the researcher.

Specifically, for participants, having completed the time one interviews in which couples were asked about living with the impact of the stroke, and which provided the couple with the opportunity to hear their partner's perceptions of the stroke, participants were then sent the second set of questionnaires some four to six weeks later. It is possible that participants may have changed their perceptions of the stroke because of taking part in the interviews and hearing their partner's views and thereby affected participants' responses. This possible reactivity between study one and study two may account for the reduction in the number of couples classified as discrepant over time.

For the researcher, collecting and analysing the questionnaire data from couples to determine whether they were classified as congruent or discrepancy may have affected my interview style and approach for these couples. Furthermore, knowing that couples were classified as 'discrepant' may have made me more sensitive to observing discrepancy within

these couples, and interpreting 'normal' differences as discrepancy, and this should be borne in mind when considering the results.

12.4.3 Appraisal, Coping and Adjustment

Leventhal's self-regulatory model (Leventhal 1980, 1984) is a mediation model in which coping strategies are hypothesised to mediate the primary appraisal (illness cognition) outcome relationship. Coping refers to the gap between how the individual appraises the demands of the situation and the resources available to them, and coping strategies are aimed at either modifying the demands of the situation (problem-focussed) or how one feels about the situation (emotion-focussed) (Leventhal et al. 1984). The way the health threat is perceived is posited to guide the selection of coping strategies, and the outcomes of these actions are then appraised in terms of how they control or manage the illness. Leventhal's model is however an iterative one, and so the effectiveness of coping strategies are posited to lead to changes in the illness representations of the individual (Cameron and Moss-Morris 2004). At the beginning of the study in 2004, no published research was found examining the illness perceptions of stroke patients and carers, and relatively little was known about the impact of discrepancy on patient and carer distress. As this was a relatively new area it was decided to focus on the primary appraisal processes of stroke patients and carers by assessing couples' illness representations and how differences in partners' representations of the health threat affected psychosocial adjustment. However, the results of the qualitative study highlighted that discrepancy existed not only in couples' illness perceptions, but also in the coping strategies they adopted to cope with the emotional impact of the stroke, and it is therefore pertinent to consider the issue of coping strategies.

A significant body of literature examining how patients cope with chronic illness already exists (Boynton and De Sepulveda 1994; Kaptein et al. 2003). One influential model of coping is Lazarus and Folkman's (1984) transactional model of stress which conceptualises coping as an 'effort to manage' the demands of the illness using the resources available to the person (Jones and Bright 2001). Illness cognitions thus set the scene for coping (Leventhal et al. 2003) and guide coping strategies to manage the illness. The results of the quantitative study found that although couples' illness perceptions and discrepancy were associated with patient and carer distress, these relationships were generally modest, and although fewer couples were classified as discrepant by time three, distress levels did not decline during the study period. This suggests that other variables have a role to play in the maintenance of patient and carer distress, and the results of the

qualitative study suggest that coping strategies are one plausible explanation for the maintenance of distress. This warrants further research.

Traditionally, coping research has examined how individuals adjust to chronic illness by considering the adaptability of coping strategies adopted by each partner (Lazarus and Folkman 1984; Carver, Scheier and Weintraub 1989). However, the results of the quantitative study concerning illness representations indicate that patients and carers appraise the situation differently, and others have hypothesised that this may give rise to different configurations of coping strategies (Berg and Upchurch 2007). Certainly the evidence from the present qualitative study suggests that a mismatch between the appraisal and coping strategies of partners was particularly problematic for the adjustment process of patients and spouses. Taken together these findings suggest a model of dyadic coping. This is a relatively new, but growing area of research (Revenson 2003; Revenson, Kayser and Bodenmann 2005). A recent review by Berg and colleagues (2007) culminated in a proposed model of dyadic adjustment in which coping with chronic illness is conceptualised as a process whereby patients and carers are situated in a context in which their appraisal, coping and adjustment efforts exist in relation to each other. Although Berg's (2007) model was published after the studies upon which this PhD thesis is based were completed, and did not influence the aims of this thesis, the findings of the present thesis broadly support the framework developed by these authors, and suggest that more research is needed that considers dyadic appraisal and coping within the context of couple.

12.4.4 Qualitative Methods

The second study took a qualitative approach to expand on the notion of adjustment from being an outcome, to considering it as a socially constructed and negotiated process. A key finding of the qualitative study is the importance of other people in the adjustment process and the inherently relational aspects of adjustment. A critique of the literature pertaining to conducting interviews with couples was presented in chapters 9 and 11, and will not be revisited here. However, the decision to use Interpretative Phenomenological Analysis (IPA) to analyse the results of the qualitative study will be discussed along with a short critique of other qualitative approaches that could have been used.

The decision to use IPA rather than other qualitative analytic tools, such as grounded theory (Glaser and Strauss 1967; Charmaz 1990), or discourse analysis (Potter and Wetherell 1987; Potter 1998) was determined by the nature of the research question. IPA is

an exploratory tool rather than one designed to generate theories (Shaw 2001). Although it would have been tempting to use a method such as grounded theory (Glaser and Strauss 1967) to try to create a theoretical model of negotiation within the context of chronic illness, this was not the intention of this study. It was decided to use the qualitative study as a scoping exercise during which more could be learned about what constitutes a largely novel research domain. Little is known about the communication and negotiation processes of couples who constitute non-clinical samples as they come to terms with the effects of chronic illness, and it was decided that this would be an exploratory study upon which later research can begin. IPA emphasises the contextual factors that are at work within the individual's life which "*may directly or indirectly play a part in the meaning-making process*" (Shaw 2001 p. 50), and it was just this 'meaning making' (Bruner 1990) process that was of interest in this study.

IPA reflects both the shared and unshared aspects of participants' experiences, making it ideal for examining differences and similarities (Brocki and Wearden 2006). This made it particularly relevant to this research question. Little is known about the adjustment process within couples as they come to terms with chronic illness, and so being able to explore both similarities and differences between couples was important. Smith (2004) has cautioned against the use of IPA with groups and so it was important to remain vigilant during the interviews and analysis to ensure that the thoughts and feelings of both partners were given the opportunity to be heard. In the event, IPA proved flexible enough for the voices of both partners to be seen as distinct entities, but also to map the interactions between parties. Although a decision was taken that the study would not be used to create a model of negotiation, grounded theory was considered because it can be used to develop typologies of relevant phenomena and can be used to identify patterns in behaviour (Potter 1998), and to some extent it could be argued that this is what has happened in the present study. Nevertheless, aspects of the grounded theory method made its use problematic. An important aspect of the qualitative study was to try to capture the essence of the negotiation process. However, the use of line-by line coding means that the essence of interpersonal communication and negotiation between the couple which is encompassed within the broader textual narrative can be lost (Potter 1998). However, some aspects of grounded theory, such as the use of memos, were adopted for use in the present study as they provided a valuable method of tracing the development of thoughts about the negotiation process.

An alternative approach that could have been taken to the analysis was through discourse analytic or discursive psychology (Edwards and Potter 1992). In direct contrast to IPA and grounded theory, in which by talk is considered a 'route to cognition' (Willig 2003), discourse analysts take a radical constructionist perspective (Madill et al. 2000) and focus on the use of language. Discourse analysis has been widely used within the context of clinical research (Potter 1998), and its focus is the social context of the conversation. The discursive approach explores what the participants are attempting to achieve through discourse, and examines the context, variability and construction of the account (Willig 2003). A discourse approach would therefore have provided a very different account of the process of negotiation between couples. In discourse analysis, talk is viewed as a tool which is used by the speaker to actively manage their interactions and pursue their goals. However, this method of analysis is not well suited to the research question posed by this thesis, in which the focus is on what participants feel and think about the events facing them and how people 'make sense' of their changed world (Bruner 1990). Discourse analysis is also better suited to natural conversations than to semi-structured interviews, although it has been used with interview data (Willig 2003). Finally, as well as being demanding to conduct, discourse analysis takes a great deal of time to learn, and certainly more than the researcher had available.

12.5 Clinical Implications

The findings of this thesis have implications for clinical practice. In terms of patient rehabilitation, the results provide compelling evidence to suggest that couples quickly become disillusioned by the slow-down in their recovery trajectory, and their beliefs about the patient's self-efficacy and the ability of treatment to aid the recovery process become more pessimistic. The results also suggest that couples are involved in an ongoing negotiation process as they try to adjust to the impact of the stroke, and often have different adjustment goals and different beliefs about the nature of recovery, what can reasonably be expected and how this is best achieved.

The National Clinical Guidelines for Stroke (Royal College of Physicians 2004, 2008) recommend that carers should be involved in the management process and be given accurate information about the stroke and the prognosis for recovery. However, the results of the qualitative study suggest that there needs to be a move away from focussing on the 'patient' and 'carer', and a move towards a more holistic approach in which the 'couple' or

the 'family' are included placed at the centre of the recovery process. The evidence presented suggests that opportunities for open discussion about the stroke are often missed, and misconceptions about the recovery prognosis are promulgated and maintained. The involvement of the family does have significant implications for patient-doctor communication. The National Clinical Guidelines for Stroke (Royal College of Physicians 2008) highlight the need to seek the views of the patient on their recovery goals, and recommends that "*the patient's views on the involvement of their family and other carers should be sought to establish if possible the extent to which the patient wants family members involved.*" (p. 110). However, the evidence presented in this thesis suggest that if the patient is to be cared for within the family home, not involving family members fully in discussions may be counter-productive for the rehabilitation and recovery of the patient. There are obvious ethical implications for involving the family against the will of the patient, but I would contend that, wherever possible, health professionals should involve the couple in joint discussions rather than talking to partners separately.

The results suggest a need for an interpersonal couples-based approach to try to improve the mood of both partners. The strong positive correlation between patient and carer mood, and the predictive relationship between carer mood and later patient distress means there is a pressing need to consider carer distress when trying to manage patient distress and this makes a promising target for an intervention. A question remains whether reducing the discrepancy between partners would result in a reduction in patient and carer distress. Certainly the results of the quantitative analysis suggest that when couples are discrepant in their illness perceptions, this is associated with higher distress, and this finding was supported by the results of the qualitative study which showed that when couples disagree about aspects of the stroke this tends to result in interpersonal tensions within the couple. It is therefore plausible that a tailored intervention which challenged the illness perceptions of partners and reduced discrepancy may also result in lower patient and carer distress and ultimately better adjustment.

12.6 Research implications

The studies described in this thesis constitute a first attempt to examine the illness perceptions of stroke patients and carers, as well as the impact of discrepancy on psychosocial outcomes. However, although the study has shown that the use of the APIM is a useful way of examining the impact of discrepant illness perceptions, the sample size in

the present study limits the conclusions that can be drawn from the study. Therefore the results of this study need to be replicated with a larger sample size and with a sample of patients and carers where the patient is living with other chronic conditions. The usefulness of the model needs to be tested in other patient-carer dyads to examine the stability of these effects, and to determine whether this approach could be usefully applied to other settings.

The lack of predictive power in the IPQ-R study needs to be examined in more detail. Larger samples need to be recruited to determine whether the lack of predictive power was an artefact of the low power of the multivariate analyses. However, it is also plausible that the lack of predictive power was due to measurement issues. In the present study absolute difference scores were used as a measure of discrepancy, and it needs to be determined whether this had an effect on the results. Earlier studies have used the mean difference score (Heijmans et al. 1999) or have used a discrete groups approach (Figueiras and Weinman 2003). Furthermore, although the APIM offered a novel approach, the results of this study are not directly comparable to the findings of these earlier studies. It therefore would be worth further examination of these data to determine whether the direction of difference matters.

There are also broader measurement issues that need consideration. In the present study couples were selected for the qualitative study on the basis of their IPQ-R scores, and couples with small and large discrepancy scores were selected. However, the interviews revealed that even when couples were identified as having similar beliefs on the IPQ-R they still disagreed on important aspects such as the management of the stroke, secondary prevention, and the prognosis for recovery. Indeed, the illness beliefs of patients and carers were found to be both complex and contradictory and this may not be adequately tapped by using a numeric score on an assessment tool such as the IPQ-R. This raises the question of whether the IPQ-R is sensitive enough to tap the nuances of discrepancy. The literature has to date focussed largely, though not exclusively, on using the IPQ (Weinman et al. 1996) and IPQ-R (Moss-Morris et al. 2002) to assess discrepancy between the primary illness appraisals of patients and carers. The measure is a well designed generic tool, but was designed to assess the illness perceptions of patients, and the validity and reliability of the carer version has not been adequately tested, although it has been widely used. It was also not designed as a measure of discrepancy. It is therefore worth considering whether other measurement tools might prove useful at assessing discrepancy between partners.

Therefore, given the clinical implications highlighted by this study, more work needs to be done to develop methods of assessing discrepant illness perceptions in couples.

The quantitative study suggested that discrepancy in the illness representations of patients and carers was associated with distress. However, the qualitative study suggests that discrepancy between partners encompasses more than their beliefs about illness, but also encompassed discrepancy in their coping strategies and mechanisms and their beliefs about health and illness. Therefore, further research is needed to identify other measures which could be used to examine differences between partners.

12.7 Conclusion

Overall this research has shown that there is frequently discrepancy in the illness beliefs and representations of stroke patients and their carers. Whilst this discrepancy has been found to have limited use as a predictor of future psychosocial health status, it has nonetheless been shown to affect the relationship between patient and carers, and particularly to affect the way that, as a dyad, they negotiate a way of dealing with the stroke once the immediate acute phase is past.

The focus of medical and other health professionals at presentation and during the acute phase is of necessity the patient. However, this research strongly suggests that thereafter, although 'patient' and 'carer' may be thought of as playing different roles in the recovery and rehabilitation process, and although both patient and carer do need to be treated as the individuals they are, there needs to be a significantly greater emphasis placed on the dyad and the role of the dyadic relationship in that recovery and rehabilitation process than has hitherto been the case

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Search strategy to identify literature pertaining to discrepant illness perceptions in patients and carers.

1. Exp cerebrovascular disorders/
2. stroke.tw
3. (infarct\$ or isch?emic\$ or thrombo\$ or emboli\$).tw
4. 1 or 2 or 3
5. common-sense.tw
6. Self-regulation.tw
7. lay belief\$.tw
8. causal explanation\$.tw
9. subjective perception\$.tw
10. (illness adj representation\$).tw
11. (illness adj perception\$).tw
12. (illness adj cognition\$).tw
13. 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12
14. (divergen\$ or incongruen\$ or discrepan\$ or dissimilar\$ or dissimilar).tw
15. (congruen\$ or similar\$ or share\$).tw
16. 13 and 14
17. 13 and 15
18. 4 and 16
19. 4 and 17
20. Weinman J.au
21. Petrie K.au
22. Johnson M.au
23. Morrison V.au
24. Heijmans M.au
25. De Ridder .au

Modification of the IPQ-R for Stroke: Identification of new items from the literature

Symptoms

Main Theme	Specific symptoms (*- indicates item maps to existing IPQ-R item)	New item
Cognitive problems	Concentration (Pound, 1998; Bendz, 2000) Confusion (time/place) (Cox, 1998; Backe 1996) Memory problems generally inc forgetfulness (McPherson, 2004) Losing track of conversation (Pound, 1998b)	Forgetfulness
Communication problems	Aphasia/dysphasia (eg Burton, 2000; McPherson, 2004) Cognitive problems resulting in communication difficulties (eg Pound 1998a) Slurred speech (Murray & Harrison, 2004; Pound 1998a)	Difficulty reading, seeing, speaking or writing
Physiological Problems (Physical disability)	Clumsiness / loss of co-ordination (Cox, 1998) Dysphagia (Burton, 2000) Incontinence (Burton, 2000, Kvinge, 2003) Weakness* (Bendz, 2002; Burton, 2000) Falls (Dowswell, 2000; Jorgensen, 2002) Walking problems (Pound, 1998a) Tiredness/fatigue* encompassing: Lack of stamina (Dowswell, 2000)	Clumsiness Tingling/numbness Weakness or paralysis <i>Items also generated by the focus groups: tingling and numbness</i>
Psychological consequences	Emotionally labile (Kvinge, 200) Murray & Harrison, 2004) Anxiety (see Murray et al., 2003b for review) Stroke as a challenge to identity (Secretst & Thomas, 1999; McPherson, 2004; Burton, 2000) Personality changes (Dowswell, 2000: Ellis-Hill, 2000)	What I'm like as a person has changed. Getting upset or weepy <i>Items also generated by the focus groups: anger, frustration, resentful, mood swings,</i>

Modification of the IPQ-R for Stroke: Timeline Acute/Chronic

IPQ item	Maps to literature	New item
IP1 my illness will last a short time	Stroke as an acute illness (Bendz, 2003) Returning to normal (Faircloth, 2004)	No
IP2 My illness is likely to be permanent rather than temporary	Wiles (2002) the possibility that the patient will not recovery is a view that is rejected by most in the early post stroke phase when recovery beliefs strongest, but develops over time.	No
IP3 My illness will last for a long time	This view reflects those of longer-term stroke survivors, who are living with effects of stroke (eg Pound, 1998a) Some patients cannot envisage recovery (Bendz, 2000).	No
IP4 this illness will pass quickly	Bendz, (2003)- see IP1	No
IP5 I expect to have this illness for the rest of my life	More negative timeline for stroke is associated with patient depression (Burton, 2000 and carer distress (McClenahan & Weinman 1998).	No
IP18 my illness will improve in time	Belief that recovery takes time vs belief that recovery is time-limited. Dowswell (2000) found stroke patients and their carers often harboured hopes for a full recovery	No
Myths about its timeline	"if recovery is going to happen it is immediate" (Smith et al., 2004)	

Timeline Cyclical

IPQ item	Maps to	New item
IP29 The symptoms of my illness change a great deal from day to day	This is likely, especially in acute phase (Burton, 2000).	
IP 30 My symptoms come and go in cycles	Reflects plateau period (Burton, 2000, Doolittle, 1991)	
IP31 my illness is very unpredictable	Cox, (1998) fear of 2 nd stroke – patients avoid activities in fear of bringing on 2 nd stroke	New item There is a lot/nothing I can do to prevent another stroke
IP32 I go through cycles in which my illness gets better or worse.	Doolittle (1991) found survivors described plateau & going downhill.	

Consequences

IPQ-R Item	Areas raised by literature	New IPQ-R item?
IP6: my illness is a serious condition	Fear of 2 nd stroke leads to avoidance of activities (Dowswell, 2000). Fear of falling, resulting in avoidance of activities (Dowswell, 2000; Murray & Harrison, 2004)	
IL7 my illness has major consequences on my life	Consequences of loss of function (Cox, 1998, Bendz, 2000, Dowswell, 2000)) Loss of confidence regarding both the body and mind (Murray & Harrison, 2004). Consequences often initially determined only in terms of physical problems (Clark, 2000) Role changes/ loss of roles (Burton, 2000; Dowswell, 2000; Robinson-Smith & Mahoney, 1995)	
IL8 my illness does not have much effect on my life	Minimization of its effects, especially in older respondents who have other comorbid disorders "it doesn't have much affect on me" (Pound 1998a, 1998b). Comparisons with others (Pound, 1998a)	
IL9 my illness strongly affects the way others see me	Shame stigma (Bendz, 2000; Cox, 1998; Dowswell, 2000; Kvinger, 2003; McKeivitt 2004) Loneliness commonly reported, as former friends drift away (Pound, 1998; Burton, 2000)	
IL10 My illness has serious financial consequences	Rarely discussed by any respondents.	
IL11 My illness causes difficulties for those who are close to me	Consequences for family- the burden is both emotional & physical (Hunt & Smith, 2003) Restriction on family caused by caring duties (Hunt & Smith, 2003; Robinson-Smith, 1995) Personal and social losses for carer /family members (Cox, 1998)	
Dependence independence – not tapped by IPQ-R	Fear of becoming a burden on others (Cox 1998) Loss of physical independence results in increased dependency on others (Doolittle, 1991) Role loss(Cox, 1998; Doolittle, 1991) Perceived control over life (Secrest & Thomas, 1999) Mismatch between patient and carer perceptions of the patient's abilities (Pound 1998a)	Yes "Since my stroke I fear becoming a burden on others".
Family relationship problems Not tapped by IL11	Changes in family functioning: some report being closer (Pound 1998b), others more distanced from family (Clark 1998; Holbrook, 1982) Anger directed at family members (Murray & Harrison, 2004) Communication with family strained, (Cox, 1998)	Yes My stroke has badly affected my relationship with my family

Consequences cont...

Sexual dysfunction – not tapped by IPQ-R	Problems resuming intimate relationships (Korpelainen, 1999)	No – better tapped in interview if appropriate.
Memory problems – not tapped by IPQ-R	Use of memory aids (to-do lists) – others unaware or unsympathetic to problems (Secrest & Thomas, 1999) The loss of shared memories breaks the connection with those the patient was close to (Secrest & Thomas, 1999)	Yes. Memory problems since my stroke are affecting my life
Emotional problems – not tapped by IPQ-R	Emotionalism (Secrest & Thomas, 1999). Stroke as challenge to self-identity (Murray & Harrison, 2004; Pound, 1998b; Secrest & Thomas, 1999)	Emotional problems since my stroke are affecting my life

Personal Control

IPQ item	Evidence from the literature which maps onto the IPQR item	New item required?
IP12 There is a lot which I can do to control my symptoms	Recovery beliefs literature suggests patients perceive self as in control eg Johnston et al., (1999, 2005) Morrison et al., (2000)	No
IP13 what I do can determine whether my illness gets better or worse	Patients thought that squeezing a ball would get their hand working again. (Rodgers (1999) Commitment to rehabilitation (Maclean, 2000)	No
IP14 The course of my illness depends on me	For many patients commitment to the rehabilitation process is viewed as their route to normality (Dowswell, 2000, Bendz, 2003)	No
IP15 Nothing I do will affect my stroke	Smith, (2004) found 65% of patients thought that most recovery took place in first few weeks. Common myth about regarding recovery. “recovery is immediate”	No
IP16 I have the power to influence my illness	Influence recovery through commitment to rehabilitation (eg Maclean, 2000). Internal control beliefs associated with better recovery Johnston et al., (1999, 2005) Morrison et al., (2000)	No
IP17 My actions will have no affect on the outcome of my illness	The body perceived as unreliable/unpredictable, by not being able to exert control over one’s limbs leads to feelings of helplessness and loss of control (Kvinge, 2003)	No
	Theme: lack of control Whilst some feel in control of their recovery, evidence also suggests some feel that recovery is outside their control (Maclean, 2000, Bendz, 2000)	

Treatment Control

IPQ item	Literature	New item
IP19 There is very little that can be done to improve my illness	Reflects low motivation for rehab (Maclean, 2000). Literature suggests that patients in the acute post stroke phase believe that much can be done to return them to their pre-stroke functioning, but that this changes significantly over time (Bendz, 2003)	No
IP20 My treatment will be effective in curing my illness	Physiotherapy as a route to normality (Dowswell, 2000, Pound, 1998, Bendz, 2000, Wiles 2002)). Patients fail to understand role of rehabilitation. (Clark, 2000)	Need to reword this item for use with stroke patients.
IP21 The negative effects of my illness can be prevented by my treatment	Negative effect of stroke is physical disability. Rehabilitation is perceived by patients as a method of avoiding the negative consequences of stroke (Bendz, 2003; Dowswell, 2000)	
IP22 My treatment can control my illness	Little discussion in the literature about the impact of other treatments, such as drug treatments in protecting against further strokes.	
IP23 There is nothing which can help my condition	Smith (2004) patients in the acute post-stroke phase do not understand role of rehabilitation in recovery process.	
	Theme: hopes for full recovery Expectations of a full recovery are commonly cited, and patients and carers are often at a loss to understand why physiotherapy is withdrawn before "full recovery" is made. Physiotherapy is perceived to be "treatment".	

Illness Coherence

IPQ-R item	Findings from literature mapping onto this	New item?
IP 24 the symptoms of my condition are puzzling to me	Body goes through changes which are difficult to understand (Hunt & Smith 2003). The range of symptoms often difficult to understand (Hunt & Smith, 2003) The progressive paralysis as symptoms get worse are difficult to understand (Doolittle, 1991)	No
IP25 my illness is a mystery to me	The sudden onset of stroke, especially in those with no obvious risk factors makes it puzzling to patients and families alike (Hunt & Smith, 2003).	No
IP26 I don't understand my illness	Maps to IP27	No
IP27 My illness doesn't make any sense to me	Hanger (1998) found that up to 2 years later patients were still trying to make sense of their symptoms.	No
IP28 I have a clear picture or understanding of my condition.	Hanger, 1998 found patients had a poor understanding of their condition up to 2 years post-stroke.(info provision lit)	No

Emotional Responses to Stroke

IPQ-R item	Maps to in literature	New item
IP33 I get depressed when I think about my illness	Literature supports relationship between depression and stroke (Young, 2003; Murray 2003a, 2003b).	No
IP34 When I think about my illness I get upset	Good evidence that patients find stroke upsetting (eg Dowswell, et al., 2000)	No
IP35 my illness makes me feel angry	Anger over the loss of control over the body (Burton, 2000) Anger directed at other (Cox, 1998)	No
IP36 my illness does not worry me	This may reflect denial or minimization (see Pound, 1998a)	No
IP37 Having this illness makes me feel anxious	Anxiety common after stroke for both patient and carer (Murray et al., 2003a)	No
IP38 My illness makes me feel afraid.	Fear of 2 nd stroke often voiced (Benz, 2003) Fear of the future & consequences of stroke (Hart, 1998; King et al., 1995) Fear of losing independence (eg Cox, 1998)	No
	Theme: Shame Kvinge (2003) ashamed of body and inability to control it (mobility/continence). Ashamed of how one looks. Ashamed at not being understood – language deficits	I get embarrassed by the disabilities caused by my stroke.
	Theme: Uncertainty for carers Uncertainty, anxiety and distress also common in carers. The IPQ-R does not tap these. There is evidence that P & C may appraise future differently.	My stroke is very worrying for those closest to me.

Ethical Approval for Focus Groups

Ethics Form for Research with Human Participants*Ethics Committee, Institute of Psychological Sciences, University of Leeds***Project title**

Beliefs about stroke: how do people negotiate shared understandings?

Investigator(s)

Maureen Twiddy

Supervisor (undergraduates and postgraduates only)

Fiona Jones, Allan House, Michael Barkham

Project Summary for Psychology Level 3 Projects ONLY

Please be as explicit as possible about methods to be used, including details about participant tasks – especially if these tasks could invoke ethical issues.

The present study is designed to generate preliminary data for a later (main) research project which is an investigation into beliefs about stroke. (The main project will recruit NHS patients and COREC approval is being sought).

The participants in this preliminary study will be a volunteer sample recruited solely via the Stroke Association and Different Strokes (two survivor lead stroke groups). No current NHS patients will be recruited and thus this study does not require COREC approval.

The main project will use the IPQ-R (Illness Perception Questionnaire – Revised) to gather data regarding the beliefs stroke patients and their carers have about stroke. However, the questionnaire requires adapting in order to make it more applicable to stroke patients and their carers. To this end, the current preliminary study has two aims. First of all, to generate items that can be incorporated into the adapted IPQ-R. Secondly, to pilot the revised questionnaire.

In order to generate items for the revised questionnaire, two or three focus groups are envisaged each of 4-5 participants (a mix of stroke survivors and carer/partners). The purpose of the focus groups is to generate additional items to allow the revision of the IPQ-R (Illness Perception Questionnaire- Revised). Focus groups will discuss participants' beliefs regarding the causes and symptoms of stroke and their beliefs regarding recovery. The data generated will be used, along with data gathered from research literature, to revise the IPQ-R. The revised measure will then be reviewed by experts and stroke survivors to ensure face and content validity.

The final questionnaire will then be piloted with N=10 couples to test its reliability over time and its acceptability to stroke survivors and carers. This will involve 10 "couples" (patient and carer/ partner) completing the revised measure on two occasions, 3 weeks apart. Feedback will also be sought concerning the time taken to complete the measure, to ensure patients in the main study are not overburdened by the measures to be used in the study.



Ethical Approval for Focus Groups

Confirmation of Ethical Safeguards**Undergraduate and postgraduate research projects**

The project supervisor has read this form and affirms that appropriate ethical safeguards are in place:

Signature Fiona Jones Date 8/3/05
Project Supervisor

Block Capitals FIONA JONES

Postgraduate, research and academic staff research projects

The postgraduate/researcher/academic who is conducting this research has read this form and affirms that appropriate ethical safeguards are in place:

Signature Maureen Twiddy Date 8/3/2005
Postgraduate/Researcher/Academic

Block Capitals MAUREEN TWIDDY.

Authorisation of Ethics Form**Institute of Psychological Ethics Committee**

The Institute Ethics Committee, or Chair of the Departmental Ethics Committee as representative of the Ethics Committee, has read this form and affirms that appropriate ethical safeguards are in place:

Signature B. Gough Date 15/03/05
Chair (or representative) of the
 Institute of Psychological Sciences Ethics Committee

Block Capitals B Gough

Additional Feedback (if applicable)

Amendments made to the IPQ-R

New items/wording in italics. Original wording and deleted items in brackets.
Items marked with * indicate that they were included in the IPQ-R measure but excluded at the data analysis stage to increase the internal reliability of the scale

Symptoms

Pain	Sore throat
Feeling sick (nausea)	Breathless
Weight loss	Fatigue
Stiff joints	Sore eyes
Wheeziness	Headaches
Upset stomach	Sleep difficulties
Loss of strength	Dizziness
<i>Feeling forgetful</i>	<i>What I'm like as a person has changed</i>
<i>Clumsiness</i>	<i>Difficulty writing</i>
<i>Getting upset or weepy</i>	<i>Difficulty speaking</i>
<i>Tingling or numbness</i>	<i>Weakness or paralysis in arm or leg</i>
<i>Difficulty seeing things/</i>	<i>Difficulty reading</i>

Cause items

Stress or worry	Heredity
A germ or virus	Diet or eating habits
Chance or bad luck	Poor medical care in my past
Pollution in the environment	My own behaviour
My mental attitude	Family problems or worries caused my stroke
Overwork	My emotional state eg feeling down, lonely, anxious, empty
Ageing	Alcohol
Smoking	Accident or injury
My personality	Altered immunity
<i>High cholesterol</i>	<i>Blood pressure (Hypertension)</i>
<i>Diabetes</i>	<i>Heart disease</i>
<i>Not taking enough exercise</i>	<i>Sudden emotional shocks</i>
<i>Cold</i>	<i>Liver disease</i>
<i>Heat exposure</i>	<i>Seizures</i>
<i>Getting worked up emotionally</i>	

Timeline Acute/Chronic (high score denotes chronic timeline).

The effects of my stroke (illness) will last a short time (r)
My stroke (illness) is likely to be permanent rather than temporary
The effects of my stroke (illness) will last for a long time.
My stroke (This illness) will pass quickly (r)
 I expect to have *these symptoms (illness)* for the rest of my life
My stroke (illness) will improve in time.

Timeline cyclical (high score denotes cyclical timeline)

The symptoms of my *condition (illness)* change a great deal from day to day.
 My symptoms come and go in cycles.
 My *condition (illness)* is very unpredictable.
 I go through cycles in which my *condition (illness)* gets better and worse.

Consequences (high score denotes a perception of a high level of negative consequences)

My illness is a serious condition.

My *stroke* (illness) has major consequences on my life.

My *stroke* (illness) does not have much effect on my life. (r)

My *stroke* (illness) strongly affects the way others see me.

My *stroke* (illness) has had serious financial consequences.

My *stroke* (illness) causes difficulties for those who are close to me.

Since my stroke I fear becoming a burden on others.

My stroke has badly affected my relationship with my family.

My stroke has strongly affected how I see myself.

Emotional problems since my stroke are affecting my life.

Memory problems since my stroke are affecting my life.

Personal control (high score denotes a perception of high levels of control over condition)

There is a lot which I can do to control my symptoms.

What I do can determine whether my *stroke* (illness) gets better or worse.

The course of my *recovery* (illness) depends on me.

Nothing I do will affect my condition (illness). (r)

(I have the power to influence my illness).

My actions will have no effect on the outcome of my *stroke* (illness).(r)

There is nothing I can do to prevent another stroke occurring. (r)

I need to avoid doing too much as this may cause another stroke. (r)

Treatment control (high score reflects belief that treatment will be helpful).

There is very little that can be done to improve my *stroke* (illness) (r)

My treatment will (be effective in curing my illness) *help me to recover.*

(The negative effects of my illness can be prevented (avoided) by my treatment)

(My treatment can control my illness)

There is nothing which can help my condition (r)

Illness coherence (low score denotes a sense of not having a good understanding of their stroke).

The symptoms of my condition are puzzling to me.(r)

My *stroke* (illness) is a mystery to me. (r)

I don't understand my *stroke* (illness). (r)

My condition (illness) doesn't make any sense to me. (r)

I have a clear picture or understanding of my condition.

Emotional Representation(a high score denotes a stronger negative emotional response to the stroke).

I get depressed when I think about my illness

When I think about my illness I get upset

My illness makes me feel angry

My illness does not worry me (r)

Having this illness makes me feel anxious

My illness makes me feel afraid.

I get embarrassed by the way I am since my stroke.

My stroke is very worrying for those closest to me.

Those closest to me get very distressed about my stroke.

COREC Approval



Cumbria and Lancashire A
Lancashire & South Cumbria Agency
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28 December 2005

Maureen Twiddy
PhD Research Student
School of Medicine
University of Leeds
15 Hyde Terrace
LEEDS LS2 9LT

Dear Ms Twiddy

Study title: **Beliefs about Stroke: How do couples negotiate a shared understanding?**
REC reference: 05/Q1303/1

Amendment number: version 3
Amendment date: 14 November 2005

The above amendment was reviewed at the meeting of the Sub-Committee of the Research Ethics Committee held on 12 December 2005.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

- notice of substantial amendment form dated 14 November 2005
- protocol revised version dated November 2005
- patient information sheet version 4 dated October 2005
- patient consent form version 3 dated November 2005

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Research governance approval

COREC Approval for extension to study

14 Favourable opinion following consideration of further information
 sion 2, October 2004



North Cumbria Local Research Ethics Committee

Lancashire & South Cumbria Agency
 3 Caxton Road
 Fulwood
 Preston
 Lancashire
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11 April 2005

Mrs Maureen Twiddy
 PhD Research student
 University of Leeds
 Academic Unit of Psychiatry and Behavioural Sciences
 University of Leeds
 15 Hyde Terrace, Leeds
 LS2 9JT

Dear Mrs Twiddy

Full title of study: *Beliefs about stroke: How do couples negotiate a shared understanding?*
REC reference number: 05/Q1303/1
Protocol number:

Thank you for your letter of 23 March 2005, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document Type:	Version:	Dated:	Date Received:
Application	4.0	27/01/2005	02/02/2005
Investigator CV		07/01/2005	02/02/2005

GENERAL HEALTH QUESTIONNAIRE (GHQ28)

Id No _____ Time _____

date: _____

Please read this carefully. We should like to know if you have had any medical complaints and how your health has been in general over the *last few weeks*. Please answer ALL the questions on the following pages simply by circling the answer which you think most nearly applies to you.

Remember that we want to know about present and recent complaints, not those that you had in the past.

We need to ask everyone the same questions, so you may feel that some of the questions do not apply to you, but I would ask you to try to answer all the questions. The questionnaire is split into four sections, giving a total of 28-questions.

Thank you very much for your time and co-operation.

Have you recently...

A1	... been feeling perfectly well and in good health?	Better than usual	Same as usual	Worse than usual	Much worse than usual
A2	..been feeling in need of a good tonic?	Not at all	No more than usual	Rather more than usual	Much more than usual
A3	... been feeling run down and out of sorts?	Not at all	No more than usual	Rather more than usual	Much more than usual
A4	... felt that you are ill?	Not at all	No more than usual	Rather more than usual	Much more than usual
A5	... been getting any aches and pains in your head?	Not at all	No more than usual	Rather more than usual	Much more than usual
A6	... been getting a feeling of tightness or pressure in your head?	Not at all	No more than usual	Rather more than usual	Much more than usual
A7	... been having hot or cold spells?	Not at all	No more than usual	Rather more than usual	Much more than usual
B1	... lost much sleep over worry?	Not at all	No more than usual	Rather more than usual	Much more than usual
B2	... had difficulty in staying asleep once you are off?	Not at all	No more than usual	Rather more than usual	Much more than usual
B3	... felt constantly under strain?	Not at all	No more than usual	Rather more than usual	Much more than usual
B4	.. been getting edgy and bad tempered?	Not at all	No more than usual	Rather more than usual	Much more than usual
B5	... been getting scared or panicky for no good reason?	Not at all	No more than usual	Rather more than usual	Much more than usual

Have you recently.....

B6	... found everything getting on top of you?	Not at all	No more than usual	Rather more than usual	Much more than usual
B7	... been feeling nervous and strung-up all the time?	Not at all	No more than usual	Rather more than usual	Much more than usual
C1	... been managing to keep yourself busy and occupied?	More so than usual	Same as usual	Rather less than usual	Much less than usual
C2	.. been taking longer over the things you do?	Quicker than usual	Same as usual	Longer than usual	Much longer than usual
C3	... felt on the whole you were doing things well?	Better than usual	About the same	Less well than usual	Much less well
C4	... been satisfied with the way you've carried out your task?	More satisfied	About same as usual	Less satisfied than usual	Much less satisfied
C5	... felt that you are playing a useful part in things?	More so than usual	Same as usual	Less useful than usual	Much less useful
C6	... felt capable of making decisions about things?	More so than usual	Same as usual	Less so than usual	Much less capable
C7	... been able to enjoy your normal day-to-day activities	More so than usual	Same as usual	Less so than usual	Much less than usual
D1	... been thinking of yourself as a worthless person?	Not at all	No more than usual	Rather more than usual	Much more than usual
D2	... felt that life is entirely hopeless?	Not at all	No more than usual	Rather more than usual	Much more than usual
D3	... felt that life isn't worth living?	Not at all	No more than usual	Rather more than usual	Much more than usual
D4	... thought of the possibility that you might make away with yourself?	Definitely not	I don't think so	Has crossed my mind	Definitely have
D5	... found at times you couldn't do anything because your nerves were too bad?	Not at all	No more than usual	Rather more than usual	Much more than usual
D6	... found yourself wishing you were dead and away from it all?	Not at all	No more than usual	Rather more than usual	Much more than usual
D7	... found that the idea of taking your own life kept coming into your mind?	Definitely not	I don't think so	Has crossed my mind	Definitely has



Medical Outcomes Study (MOS) Family Relationships

Participant No _____ **Date:** _____

The following statements are about your relationship with your spouse or partner. How TRUE or FALSE has each been for you during the **past four weeks**? If you do not have a spouse or partner, please answer these about the person you feel closest to.

Please circle one number on each line.

	Definitely True	Mostly True	Don't know	Mostly False	Definitely False
1. We said anything we wanted to say to each other.	1	2	3	4	5
2. We often had trouble sharing our personal feelings .	1	2	3	4	5
3. It was hard to blow off steam with each other.	1	2	3	4	5
4. I felt close to my spouse or partner.	1	2	3	4	5
5. My spouse or partner was supportive of me.	1	2	3	4	5
6. We tended to rely on other people for help rather than on each other.	1	2	3	4	5

SIGNIFICANT OTHERS SCALE (B)

Participant Number _____ Date: _____ Assessment No: _____

INSTRUCTIONS : Please list below up to three people who may be important in your life. This can be your partner, spouse, sibling, close friends or others who are important in your life. For each person please circle a number from 1 to 7, to show how well he or she provides the type of help that is listed. The second part of each question asks you to rate how you would like things to be if they were exactly as you would hope for. As before, please put a circle around one number between 1 and 7 to show what the rating is.

Person 1 is

		Never			Sometimes		Always
1a	Can you trust, talk frankly and share your feelings with this person?	1	2	3	4	5	6 7
1b	What rating would your ideal be?	1	2	3	4	5	6 7
2a	Can you lean on and turn to this person in times of difficulty?	1	2	3	4	5	6 7
2b	What rating would your ideal be?	1	2	3	4	5	6 7
3a	Does he/ she give you practical help?	1	2	3	4	5	6 7
3b	What rating would your ideal be?	1	2	3	4	5	6 7
4a	Can you spend time with him/her socially?	1	2	3	4	5	6 7
4b	What rating would your ideal be?	1	2	3	4	5	6 7

Person 2 is

1a	Can you trust, talk frankly and share your feelings with this person?	1	2	3	4	5	6 7
1b	What rating would your ideal be?	1	2	3	4	5	6 7
2a	Can you lean on and turn to this person in times of difficulty?	1	2	3	4	5	6 7
2b	What rating would your ideal be?	1	2	3	4	5	6 7
3a	Does he/ she give you practical help?	1	2	3	4	5	6 7
3b	What rating would your ideal be?	1	2	3	4	5	6 7
4a	Can you spend time with him/her socially?	1	2	3	4	5	6 7
4b	What rating would your ideal be?	1	2	3	4	5	6 7

Person 3 is		Never		Sometimes			Always	
1a	Can you trust, talk frankly and share your feelings with this person?	1	2	3	4	5	6	7
1a	What rating would your ideal be?	1	2	3	4	5	6	7
2a	Can you lean on and turn to this person in times of difficulty?	1	2	3	4	5	6	7
2b	What rating would your ideal be?	1	2	3	4	5	6	7
3a	Does he/ she give you practical help?	1	2	3	4	5	6	7
3b	What rating would your ideal be?	1	2	3	4	5	6	7
4a	Can you spend time with him/her socially?	1	2	3	4	5	6	7
4b	What rating would your ideal be?	1	2	3	4	5	6	7

Participant No: _____ date: _____

BARTHEL INDEX (Mahoney et al., 1965)

Activity	Scoring	Time 1 (pre)	Time 1 (post)	Time 2 7mths
Bowel control	2= continent 1= occasional accident 0=incontinent			
Bladder control	2=continent 1= occasional accident 0=incontinent/catheterized and unable to manage			
Personal Toilet (wash face, comb hair, shave, clean teeth)	1= independent 0= Needs help			
Feeding	2=independent 1= needs some help (cutting up food, spreading butter etc.) 0=dependent			
Toilet (getting on/off, handling clothes, wipe, flush)	2= independent 1= needs some help 0= dependent			
Walking on a level surface	3= independent (may use an aid) 2= walks with help of person (physical/verbal) 1= independent (in wheelchair) 0= unable			
Transfer (chair to bed and vice versa)	3= independent 2= minimal help (verbal/physical) 1= can sit, major help 0=unable			
Dressing (all fasteners etc.)	2= independent (including zips, buttons etc) 1= needs help but does at least half 0=dependent			
Stairs	2=independent 1=needs help (verbal/physical) 0=unable			
Bathing	1=independent 0=dependent			
TOTAL (score out of 20)				

PATIENT INFORMATION SHEET

(on headed paper)

Stroke: Negotiating shared understandings

I would like to invite you to take part in a research project. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask me if you would like any further information, or anything is not clear. I am studying what patients and their carers think about the causes and effects of stroke. Having a stroke can leave people with a sense of loss about their past life, especially when the stroke results in a loss of good health. I am interested in finding out whether what you think change over time, and whether this affects how you both cope with stroke.

I am asking everyone at the <hospital name> who has been admitted to hospital following a stroke if they would be interested in being involved in the study. It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and you will be asked to sign a consent form. If you decide not to take part, or decide to withdraw at any time, it will not affect your care in any way.

If you decide you want to take part I will ask you for your permission to contact your partner or carer. This need not be a relative, but must be someone involved in your care. If they are willing to take part in the study you will both be asked to complete four questionnaires. These will ask you for your thoughts about your stroke, how you are feeling emotionally, the state of your health and about your relationship with your partner or carer. You will then be asked to complete the same questionnaires again in 3 and 6 months time. If in the meantime, you are discharged from hospital, the second set of questionnaires will be sent to you through the post. You will be asked to complete them and post them back to me.

I would also like to interview some patients with their partner or carer to talk to you together about how you both feel about your stroke, how it has affected both of your lives and about your thoughts about the future. These interviews would take place one and six months following your stroke. The interviews would last about an hour and will take place somewhere convenient for you. I would need to tape record the

interview with you and your partner or carer so that I can use what I learn from our discussion in my research. There are no risks involved in taking part in this study and your involvement in the study would be no more than completing three set of questionnaires and taking part in two interviews. If you would like to be involved in the project, but do not feel you want to take part in the interviews, you can consent to only completing the questionnaires.

Before deciding to take part in the interviews, you may wish to consider how you and your partner or carer feels about discussing the effect that your stroke has had on your lives. If you believe you would find the discussion distressing you may prefer not to take part in the interviews. If you decide to take part in the study, you are still free to withdraw at any time. If you are unhappy with the way you are treated by the researcher and wish to complain the normal National Health Service complaints mechanism will be available to you.

If you decide to participate in the study, all the information which is collected about you will be kept strictly confidential. It will be stored on a computer but will be coded so that it will not be possible to identify you in any way. The interviews will be audio-taped and what is discussed will be typed up so that I can analyse it. You can have a typed copy of what was discussed, and you can also ask for sections of the interview not to be used. Your names and any information which could be used to identify you or your partner or carer will not be included. The tapes will be destroyed after a period of five years, and during that time they will be kept in a locked filing cabinet. We expect to publish the results of this research in scientific journals, and I will be using the results to obtain a degree (PhD) at the University of Leeds. You will not be identified in any report or publication. At the end of the study you will be sent a summary of the findings and given details of any report that is to be published as a result of this study. If you have any questions about the study, please contact:

Maureen Twiddy, School of Medicine
The University of Leeds, 15 Hyde Terrace, Leeds
LS2 9LT Telephone: 0113 343 1898

Thank you for taking the time to read this information sheet.

Please keep this sheet in a safe place. You may need it to contact me.

Patient identification number:

PATIENT CONSENT FORM

Title of Project: Stroke: Negotiating shared understandings

Name of Researcher: Maureen Twiddy

(Please tick the boxes)

Have you read the Patient Information Sheet dated
December 2004 (version 2)?

YES NO

Have you had the opportunity to ask questions and discuss
the studies?

Have you received satisfactory answers to all of your questions?

Have you received enough information about the study?

Whom have you spoken to? Dr/ Mr/Ms _____

Do you understand that you are free to withdraw from the study at any
time, without having to give a reason, and without it affecting your
medical care?

I agree to my carer/partner being approached to request their participation
in the study.

I agree to my medical records being looked at by the researcher solely
for the purpose of the study.

I agree to take part in the questionnaire study.

I agree to being interviewed with my partner or carer on two
occasions over the next 6 months.

I agree to my GP being informed of my involvement in the study.

Name of Patient Date

Signature

Researcher

Date

Signature

1 for patient; 1 for researcher, 1 to be kept with hospital notes.

Letter of Invitation to patients not seen whilst they were in hospital, or seen via
Neurovascular Clinic
(on headed paper)

Date

Dear

Stroke Research

Your name has been passed to me by Dr <name> following your recent attendance at the Neurovascular Clinic at the <hospital>.

I am interested in finding out more about what patients and their families think about the causes and effect of their stroke, and I would very much like to hear your views. I am therefore writing to give you some information about the research project and to invite you and a family member to take part in the study.

Enclosed with this letter is an information sheet which I would be obliged if you could take the time to read through. When you have read the information sheet, I would be grateful if you would let me know whether or not you are interested in finding out more about this project. To do this, please complete the tear off slip at the bottom of this letter and return to me in the freepost envelope provided.

Thank you for your time.

Yours sincerely

Maureen Twiddy (MSc)
PhD Research Student

Stroke Research

I am/ am not interested in taking part in the above project _____

I would like to find out more about the above project _____

From

PARTNER/CARER INFORMATION SHEET

(On headed paper)

Stroke: Negotiating shared understandings

As the partner or carer of someone who has recently had a stroke, I would like to invite you to take part in a research project. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and feel free to ask me if you would like any further information, or anything is not clear. I am studying what patients and their carers think about the causes and effects of stroke. Having a stroke can leave patients and their loved ones with a sense of loss about their past life, especially when the stroke results in the loss of good health for the patient. I am interested in finding out whether what you think about stroke change over time, and whether this affects how you both cope with stroke.

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and you will be asked to sign a consent form. If you decide to take part in the study, you are free to withdraw from the study at any time, without giving any reason, and your withdrawal will not affect the patient's care in any way. If you are willing to take part in the study you will be asked to complete four questionnaires. These will ask you for your thoughts about the patient's stroke, how you are feeling emotionally, and about your relationship with the patient. You will then be asked to complete the same questionnaires again in 3 and 6 months time. The questionnaires will be posted to you to complete at home. With them will be a reply-paid envelope so you can post them back to me.

I would also like to conduct some joint interviews with patients and their partner or carer to talk to you together about how you both feel about the patient's stroke, how it has affected both of your lives and about your thoughts about the future. These interviews would take place one and six months following the patient's stroke. The interviews would last about an hour and will take place somewhere convenient for you. There are no risks involved in taking part in this study and your involvement in the study would be no more than completing three set of questionnaires and taking part in two interviews.

Before deciding to take part in this study, you may wish to consider how you feel about discussing the effect that stroke has had on your lives. If you believe you would find the discussion distressing, you may prefer to only complete the questionnaires, or not take part in the research. If you decide to take part in the study, you are still free to withdraw at any time. If you are unhappy with the way you are treated by the researcher and wish to complain the normal National Health Service complaints mechanism will be available to you.

If you decide to participate in the study, all the information which is collected about you will be kept strictly confidential. It will be stored on a computer but will be coded so that it will not be possible to identify you in any way. The interviews will be audio-taped and what is discussed will be typed up so that I can analyse it. You can have a typed copy of what was discussed, and you can also ask for sections of the interview not to be used.

However, your names and any information which could be used to identify you or the patient will not be included. The tapes will be destroyed after a period of five years, and during tht time they will be kept in a locked filing cabinet. We expect to publish the results of this research in scientific journals, and I will be using the result to obtain a degree (PhD) at the University of Leeds. You will not be identified in any report or publication. At the end of the study you will be sent a summary of the findings and given details of any report that is to be published as a result of this study.

If you have any questions about the study, please contact:

Maureen Twiddy
School of Medicine
The University of Leeds
15 Hyde Terrace
Leeds
LS2 9LT
Telephone: 0113 343 1898

Thank you for taking the time to read this information sheet.
Please keep this sheet in a safe place. You may need it to contact me.

PARTNER/CARER CONSENT FORM

Title of Project: Stroke: Negotiating shared understandings

Name of Researcher: Maureen Twiddy

Carer Identification Number: _____

(Please tick the boxes)
YES NO

Have you read the Carer Information Sheet dated December 2004? (version 1) YES NO

Have you had the opportunity to ask questions and discuss the study? YES NO

Have you received satisfactory answers to all of your questions? YES NO

Have you received enough information about the study? YES NO

Whom have you spoken to? Dr/ Mr/Ms _____

Do you understand that you are free to withdraw from the study at any time without having to give a reason, YES NO

I agree to take part in the study. YES NO

I agree to being jointly interviewed on two occasions with the patient. YES NO

_____	_____	_____	_____
Name	Relationship to patient	Date	Signature

_____	_____	_____
Researcher	Date	Signature

1 for carer; 1 for researcher, 1 to be kept with hospital notes

Correlation of patients' and carers' illness representations at Time 2 (n=29 couples)

	Carers	1 Id	2 TLA	3 TLC	4 Cons	5 TC	6 PC	7 Coh	8 ER	9 Beh	10 Psyc
Patients 1. Identity (Id)		.86 (<0.001)	.3 (0.1)	.7 (<0.001)	.73 (<0.001)	-.18 (0.33)	-.05 (0.78)	.44 (0.01)	.8 (<0.001)	-.36 (0.05)	.27 (0.13)
2. Timeline acute (TLA)		.28 (0.12)	.3 (0.1)	.42 (0.02)	.51 (0.003)	-.02 (0.92)	-.08 (0.67)	-.28 (0.12)	.33 (0.07)	.15 (0.42)	-.12 (0.53)
3. Timeline cyclical (TLC)		.57 (<0.001)	.42 (0.02)	.5 (0.003)	.66 (<0.001)	-.22 (0.22)	.05 (0.8)	.33 (0.07)	.67 (<0.001)	.48 (0.006)	.39 (0.03)
4. Consequences (Cons)		.82 (<0.001)	.4 (0.03)	.73 (<0.001)	.62 (<0.001)	-.08 (0.65)	-.05 (0.8)	.14 (0.43)	.81 (<0.001)	-.34 (0.06)	.15 (0.4)
5. Treatment control (TC)		.26 (0.15)	0.41 (0.02)	0.32 (0.08)	0.27 (0.13)	.4 (0.02)	.32 (0.07)	-.03 (0.85)	-.16 (0.38)	.26 (0.15)	-.03 (0.88)
6. Personal control (PC)		.12 (0.5)	.55 (<0.001)	.42 (0.02)	.28 (0.12)	.62 (<0.001)	.29 (0.1)	.19 (0.31)	-.11 (0.54)	.27 (0.14)	.16 (0.38)
7. Coherence (Coh)		.02 (0.92)	.11 (0.54)	.11 (0.56)	.16 (0.36)	-.01 (0.96)	.06 (0.73)	.53 (0.002)	.47 (0.007)	-.18 (0.32)	.48 (0.006)
8. Emotional representation (ER)		.81 (<0.001)	.34 (0.06)	.48 (0.005)	.83 (<0.001)	.39 (0.03)	.24 (0.18)	.14 (0.46)	.68 (<0.001)	-.34 (0.06)	.53 (0.002)
9. Cause: Behaviour (Beh)		.01 (0.96)	-.09 (0.62)	.01 (0.95)	-.007 (0.97)	.01 (0.94)	-.03 (0.87)	-.19 (0.3)	-.15 (0.4)	.68 (<0.001)	-.22 (0.23)
10. Cause: Psychological (Psyc)		.48 (0.006)	.06 (0.75)	.33 (0.06)	.54 (<0.001)	.05 (0.8)	.07 (0.7)	.21 (0.26)	.43 (0.02)	.06 (0.73)	.62 (<0.001)

Patient correlations presented in lower diagonal; carer's correlations presented in upper diagonal. Figures in grey boxes represent correlations

Correlation of patients' and carers' illness representations at Time 3											
	Patients	1	2	3	4	5	6	7	8	9	10
		Id	TLA	TLC	Cons	TC	PC	Coh	ER	Beh	Psyc
Carers											
1. Identity (Id)		.78 (<0.001)	.54 (<0.001)	.53 (0.002)	.69 (<0.001)	.13 (0.49)	.14 (0.46)	.07 (0.68)	.73 (<0.001)	-.08 (0.66)	.23 (0.21)
2. Timeline acute (TLA)		.33 (0.07)	.41 (0.02)	.47 (0.007)	.59 (<0.001)	.5 (0.003)	.29 (0.11)	.06 (0.77)	.51 (0.003)	-.07 (0.7)	-.11 (0.57)
3. Timeline cyclical (TLC)		.37 (0.04)	.59 (<0.001)	.46 (0.008)	.57 (0.001)	.06 (0.76)	-.02 (0.9)	.25 (0.17)	.48 (0.006)	-.18 (0.33)	.26 (0.16)
4. Consequences (Cons)		.62 (<0.001)	.53 (0.002)	.6 (<0.001)	.7 (<0.001)	.39 (0.03)	.3 (0.1)	.06 (0.75)	.83 (<0.001)	-.04 (0.83)	.39 (0.03)
5. Treatment control (TC)		-.07 (0.71)	.48 (0.006)	.1 (0.59)	.33 (0.07)	.12 (0.51)	.55 (0.001)	.18 (0.32)	.3 (0.1)	.12 (0.5)	.09 (0.63)
6. Personal control (PC)		.007 (0.97)	.65 (<0.001)	.2 (0.28)	.11 (0.56)	.66 (<0.001)	-.08 (0.67)	.26 (0.15)	.31 (0.08)	.07 (0.7)	.11 (0.56)
7. Coherence (Coh)		-.17 (0.35)	.22 (0.23)	.17 (0.36)	.01 (0.96)	.53 (0.002)	.49 (0.004)	.43 (0.01)	.06 (0.73)	-.02 (0.93)	.34 (0.06)
8. Emotional representation (ER)		.62 (<0.001)	.57 (0.001)	.7 (<0.001)	.87 (<0.001)	.35 (0.05)	.17 (0.35)	.16 (0.4)	.68 (<0.001)	-.13 (0.46)	.56 (0.001)
9. Cause: Behaviour (Beh)		.005 (0.98)	.05 (0.77)	-.23 (0.22)	.14 (0.44)	.25 (0.17)	.27 (0.14)	-.22 (0.23)	-.14 (0.45)	.62 (<0.001)	-.08 (0.65)
10. Cause: Psychological (Psyc)		.17 (0.36)	-.17 (0.37)	.38 (0.03)	.29 (0.11)	-.21 (0.26)	-.16 (0.38)	-.22 (0.23)	.33 (0.06)	.04 (0.82)	.47 (0.007)

Patient correlations presented in lower diagonal; carer's correlations presented in upper diagonal. Figures in grey boxes represent correlations between patient and carer

TOPIC GUIDE [INTERVIEW 1]

Life history: Tell me a little about life before [patients] stroke?

brief working history / lifestyle
 Social life [hobbies/activities] Can you give me an example?
 how long been together/ family
 general health

Stroke: Could you both talk me through what happened when you had your stroke?

- *When* did it happen? *What* doing?
 - [partner] any things you would like to add?
 Acute hospital period experiences and differences?
 Information provided? Who? When?

Thinking back, before [patient's] stroke, what did you know about stroke?

- **GENERAL** Knowledge / Experience [egg family/ friends]
- **SPECIFIC** – own stroke – how does it compare to expectations?

Can you tell me about how it's affected/changed your life?

Roles lifestyle, work, domestic life, finance, family [can you give me an example?]
 - What/how do you feel about this?
 How do you feel it affected you [carer experiences]?

How have you coped with the changes? Strategies to cope with changes

who has helped [friends/ social services] [examples]
 what roles have they played [examples]
 What differences has their help made? -/+ why?
 Are there any differences in the approach you each take to dealing with
 problems/disabilities?
 Are there any changes in how you feel about yourself?
 (Egg self confidence/ tearful, and down, or worried about future)
 What ways?

Talk about Recovery so far early days compared to now [describe/contrast]

What has helped recovery? Hindered recovery?
 How do you see living with the residual disability you have now?
 Problems/ difficulties?
 Lifestyle changes
 Can you tell me about any changes the doctor has recommended for you?
 Do you think you will be able to make these changes, or not?
 Do you anticipate any difficulties, or not?
 Spouse – how do you see your role in this?

Section 2:

Differences and similarities in ideas about stroke and how to cope with it. "During the interview it has become clear that you have quite similar ideas about [a lot of things/ some things...list areas of agreement] and different ideas about others [list discrepant views]. Research has told us that it is common for patients and carers to have different ideas about the causes and effects of stroke, I would like, if you don't mind, to talk to you about some of the areas where you appear to have different views & those where you have similar views."**[verbatim]**

One area you seem to have different ideas about is [area]. Is this something you have talked about? [REPEAT]

- Is it something you have tried to talk about, **or not**?

Have you talked/tried to talk to anybody else about it or not?

Do you see the doctor together/HP together? Why/why not?

Have your experiences lead you to think differently?

Can you tell me how it makes you feel?

How does having different exp affect how you cope with things? [use examples from above]

Do you think having different views affects how you approach [it] is it a problem?

Closing Questions: Are there any things about [patient's] stroke that you feel you disagree about, or have different views about that you would like to discuss?

Alternative question [if couple largely agree]: Unlike many couples, you appear to have very similar views about stroke. Can you tell me about how it is that you have come to such a shared understanding?

When you [patient] see the doctor do you see him/her together?

Did you start off having different views about things?

Did something happen t bring your ideas closer together?

Do you see having similar views as being important to [patients] recovery?

Is there anything we haven't covered that you feel is important in your experience?

TOPIC GUIDE: INTERVIEW 2

Question: Can you tell me what things have been like for you both since we last met?

specific questions based on last interview- focussing on issues which were outstanding then]

Question: What have been the main changes to your lives?

How have these been achieved? (negotiated/decided)
 Could you tell me more about these? [examples]
 How well do you feel you have coped with these changes?
 How were these decided?

Question: Overall, how do you feel you've adapted to life after stroke?

[probes to Social life, Hobbies/lifestyle, Roles, work, making plans for future.]
 Would you say there have been any barriers to resuming ... (item)?

Question: We talked in [month] about the lifestyle changes you were trying to make [diet/exercise/smoking] change. Can you tell me about how this has gone?

What changes have you made?
 What did the family think about this?
 What help have you had (in trying to achieve this)?[eg. doctor/ family/ friends]
 how have you achieved?"
 Is this an area you have tackled together?
 [Prompt to carer] Can you give any examples of the sort of things you did to help [patient]?).

Prompt when changes not made: "What do you feel is stopping you making these changes?"

[carer] what do you think has stopped them?

Question: How do you feel it has changed your relationship (if at all)?

Examples? Can you tell me how? What ways?

Question: Living with stroke can be very frustrating at times. Who can you talk to about how you feel?

Do you talk to each other about how you feel about the stroke?
 Do you talk to friends/other family members about it?

If I can just take a moment, and summarise what we have talked about up to now. It is clear that you have quite similar beliefs/expectations about [list areas], but different views about [list areas].

Question: One area you seem to have different ideas about is [area]

Question: Why do you think your ideas/ approach is so different?

Question: Why do you think you haven't come to the same view?

Is it something you have tried to talk about?

Is it something you have talked to others about? Eg Doctor/friends
Have you tried talking to the doctor/health worker/GP?

Do you think it matters that you have different views? Is it helpful to see things differently, or does it cause problems?

Alternative question: Can you tell me about how it is that you have come to such a shared understanding?

[Prompts] Have you discussed it? Do you attend doctor's appointments together?
Does (the carer) stay when the Health Professional visits [patient]?

Thank you for talking to me today. Is there anything you would like to add before we finish? [opportunity for patient and carer to raise issues].

Pen Portraits of Participants

Bill and Mary

Bill and Mary are both in their sixties and have been married for forty years. Bill has had a number of jobs over the years, most of which are skilled or semi-skilled manual jobs. As a result of working in smoky and dusty environments for many years he suffers from serious breathing problems, and has circulation problems in his legs. Mary worked as a secretary when she was younger, but prior to her retirement was a hospital ward housekeeper. The couple have one daughter who lives locally. Although the couple describe their relationship as close, Mary says that they struggle to talk about things and that Bill's unwillingness to talk about his feelings has long been a source of tension. Bill experienced a frontal lobe stroke which has left him with moderate cognitive, physical and emotional difficulties. He also suffers from mild dysphasia, swallowing problems (dysphagia) and has had a number of falls. He was offered a PEG (stomach feeding tube) to manage his dysphagia, but declined the operation despite his swallowing difficulties causing choking fits which result in him collapsing. Despite his disabilities Bill appears to have adapted well to the changes to his health status.

Bill's wife Mary is a slightly built woman who is in poor physical health. A month after Bill was discharged from hospital Mary was herself admitted. Since coming home Mary has struggled to cope with caring for Bill. During the first weeks after discharge Bill and Mary were given a lot of support, but this since stopped, and Mary has been struggling to look after him. Mary is a highly anxious woman who makes repeated references to how she worried she is about not coping, but she is also unwilling to solicit help from either the hospital or social services as she fears being perceived as 'unable to cope'. Both interviews took place at their home, with the first taking place two weeks after Bill was discharged from hospital.

The couple live in a small, rather over-furnished terraced house. This makes it difficult for Bill to get around their home with his zimmer frame. They also have no downstairs toilet and as Bill cannot use the stairs, a commode was put in the hallway and a hospital bed put into the living room. By the time of the second interview Bill's health had deteriorated significantly. During both interviews Mary made repeated references to how she feels Bill is overly dependent on her to do things for him, and there was evidence during the interviews that he would ask her to do things which he was capable of doing for himself. However, Mary also restricted what she would allow Bill to do, thus catching herself in a double bind- she wants him to do things, but is highly anxious when he does, leading Bill to become more, not less, dependent on her.

Cathleen and John

Cathleen and John are in their seventies. They live in a comfortable home in a small commuter village. Prior to their retirement, Cathleen was an administrator and John was a manager. The couple have been married for 47 years and have two children, but none of their family live close

by. Cathleen's stroke left her with right sided weakness, difficulty speaking (dysarthria and dysphasia), fatigue and depression.

Photographs of Cathleen from before her stroke show her to be a very attractive, smartly dressed woman, who took a great deal of care over her appearance. However, the stroke has left her significantly disabled down one side and she is unable to wear most of her wardrobe, including her dresses and high heels. She also struggles to style her hair or apply her make-up, which has affected her self-confidence. The first interview took place two weeks after Cathleen's discharge from hospital, the second nine months post stroke. At both interviews she was wearing a jogging suit and slippers and apologised several times for her appearance as she was unable to do her hair as she could not lift her arms up.

Since Cathleen's stroke John has taken over most of the domestic duties, including cooking, cleaning and shopping. Whilst Cathleen accepts that she is not able to do any of these things herself, not having the housework 'up to scratch' is source of distress for Cathleen and not being able to be involved in what she perceives to be 'her domain' has left her feeling redundant. On the face of it John copes well with the changes in their circumstances, but despite being highly educated he struggles to manage the 'mountains of bureaucracy' involved in applying for attendance allowance and other assistance for Cathleen. At the time of the first interview Cathleen would not visit friends, or allow them to visit her. She would not use the telephone and was unable to write as the stroke had affected her right hand, thus leaving her unable to maintain communications with her family or friends. By the time of the second interview Cathleen was using the phone and writing short letters to friends, but would not visit or allow them to visit her. John drives so they can get out and about but it took some time for Cathleen to regain her confidence, although by the time of the second interview they were trying to go out of the house most days, although these trips were restricted to walks around the local shopping centre (they are limited to walking where the surfaces are flat and there are disabled toilets).

David and Camilla

David is a 55 year old married man, with two grown-up daughters. Prior to his stroke he worked as a project manager for a major company. He experienced a major stroke and his family were advised that he might not survive. The stroke has left him with significant physical disabilities. At the time of the first interview he was still in hospital and was largely paralysed down his left side and had no proximal movement in his left arm. He was having daily physiotherapy and was able to walk with the assistance of three people. The stroke left him with left field visual neglect and so he struggled to learn how to manoeuvre his electric wheelchair safely. Cognitive tests revealed significant executive functioning deficits and although able to converse and follow conversations his attention span is short. Following his stroke he was prescribed anti-depressants, and at the time of the interview, he was emotionally labile which irritated him a great deal.

His wife Camilla works as a part-time lecturer and has been able to structure her day to allow her to visit the hospital daily and is generally present for most of David's physiotherapy sessions. During the weeks prior to the interview I gained a picture of them as a very close couple and this is how they came across during the interview. Camilla's attendance at most of the physiotherapy sessions initially caused some consternation amongst some of the health professionals, but during the interview she described how she felt it was her job to ensure he got the therapy they feel he needs. Involvement in the project was instigated by David, and Camilla made it clear during a conversation we had in David's absence that she was more reticent about discussing their relationship than David, and that she would not say anything which would upset him or challenge his beliefs about his recovery. The couple dropped out of the study after the second quantitative data collection point and did not wish to be interviewed again.

Dave and Barbara

Dave and Barbara are both in their sixties and have been semi-retired for some years as Dave has been in declining health, initially following an accident and more recently as he struggles to live with myeloma and the repeated chemotherapy treatments used to stabilise his cancer. Barbara is an ex-nurse and her nursing experience is much in evidence in the way in which she looks after Dave, especially making sure he is comfortable and ensuring he is included in the interview.

The stroke left Dave with physical, behavioural and emotional disabilities which changed little over the time of the study. A major difficulty for the couple is that they differ in their perceptions of the severity and importance of Dave's stroke deficits with Dave tending to under-estimate these difficulties compared to Barbara. Although Barbara talks of his difficulties with humour and tries to make light of them during the interviews they are a theme that is repeated in both interviews and posed a significant challenge. After his stroke Dave was unable to read, and Barbara talked a great deal of how they have worked together to enable him to re-learn this skill. He was also mildly dysphasic and dysarthric. This made him reticent to talk, especially during the first interview, and Barbara spoke much more than Dave. However, Barbara repeatedly asked Dave's opinion on her rendering of events, and he did contradict her view of events on occasion.

The couple live in a small village and have family living close with whom they are very close. Barbara in particular relies on them to sit with Dave so that she can go shopping or into town as she is reluctant to leave him alone. Dave and Barbara regularly baby-sit their grandchildren, although this had to stop for a while after Dave had his stroke. The couple spend most of their weekends at their caravan in the Lake District which allows them to get away but means that Dave is still close to the hospital in case his health deteriorates.

Dick and Ellie

Dick and Ellie are both in their sixties, and have been married for 38 years. Dick suffered a lacunar stroke which left him with significant weakness down his left arm and leg, although by the time

of the first interview, some 6 weeks after his stroke, most of his physical disabilities had resolved. He has some residual memory problems, but these appear to cause him few problems. Prior to his early retirement last year, Dick is very proud of having taken little time off sick during his working life. The couple have three children and three grandchildren, and their social lives revolve around their family. The couple described how they enjoy spending time together and how the two of them spend most of their weekends at their caravan, although they had not been out to the caravan since Dick's stroke because he has not been allowed to drive.

Ellie is a quiet, friendly lady, whose life revolved around her family. She takes an active role in looking after their grandchildren and they take up a good deal of her free time. At the time of the first interview Ellie was much more concerned than Dick about what *might have* happened, in terms of the disabilities resulting from the stroke, whilst Dick very much wanted to play down the effects of the stroke. This had an impact on their secondary prevention measures because whilst Dick wants to 'get back to normal' and forget the stroke, Ellie worried that if Dick did too much that this might bring on another stroke. By the time the second interview was due it proved difficult to find a convenient time to interview the couple because they were away caravanning and so no second interview conducted.

George and Alison

George and Alison are in their mid-sixties and have been married for over 40 years. They have two children and four grandchildren. Before his stroke George was self-employed but had been winding down his business in preparation to retire. Alison works part time as an administrator. The couple describe themselves as 'chalk and cheese' and admit that theirs is a volatile relationship, and that they have 'regularly kept the neighbours amused'. Since his stroke George has given up work, but Alison still works part-time.

George experienced his stroke following surgery, but none of the hospital staff initially admitted that he had had a stroke and so he was not assessed whilst in hospital. The true extent of his disabilities was only obvious once he was discharged home and he was then picked up by the stroke team as an out-patient. The stroke has left him physically unimpaired, but he has significant visual processing difficulties. He is unable to process faces, so he no longer recognises friends and family. He has significant visual field problems which mean he does not automatically see the left hand side of the page, making reading difficult. He has problems with word and number recognition so he struggles to cope with managing their finances, although he refuses to give up this responsibility. At the time of the first interview, although George played down his disabilities, apart from not being able to drive which annoyed him, Alison was struggling to come to terms with his memory problems and his unwillingness to acknowledge the impact of some of his problems. The stroke did however leave George dependent on Alison and he found it difficult to come to terms with this. By the time of the second interview little had changed in terms of George's level of disability but the couple found ways in which to accommodate George's disabilities, although George still found his level of dependence on Alison difficult to manage.

Karl and Morag

Karl is in his late fifties and had been planning to retire prior to his stroke. He trained as an engineer, but hasn't worked in this field since he was made redundant 20 years earlier. Since then he has had a number of jobs, and prior to his stroke he had been working night shifts as a driver. Karl came across as a very quiet man and he said that except for his model railway and walking his dogs he has few hobbies. Karl's stroke initially left him with weakness down his left side and at the time of the first interview he was walking with a stick, although by the time of the second interview he no longer needed the walking stick. He was also left with some minor cognitive problems, and had problems remembering words, although this did not appear to pose a significant problem. At the time of the first interview Karl was experiencing high levels of fatigue and this did not change over time.

His wife Morag worked as a pharmacist until she retired. The couple have no close family. Her hobbies include attending the theatre and doing cryptic crosswords. She is also a keen musician. Morag has personal experience of stroke as her mother suffered a series of strokes when Morag was in her thirties and she cared for her mother until she died. This profoundly affected her perceptions of stroke and its impact, and Karl's stroke made her particularly angry because she felt it could have been avoided. During the interviews it became apparent that each partner wanted to tell the story of how the stroke had affected them but they had very different views of *what* this story was. Morag tended to dominate the discussion and so I had to direct questions to Karl to ensure his participation and his story being heard. During the interviews Morag spent a lot of the time complaining about Karl, and seemed to use her medical background as a resource to support her view of events. There was also a sense that this is their normal pattern of interaction in as much as Karl hardly reacted to Morag's complaints. However, when Karl did respond to her criticisms, Morag's likely reaction was to talk over his response, or to ignore it.

Malcolm and Annie

Malcolm and Annie are in their early 60s. A few years ago they both took early retirement in order to spend time together, although both have part-time jobs. Annie is a care worker, and prior to his stroke Malcolm had a part-time driving job. Malcolm experienced a serious and debilitating stroke from which he made a good recovery. Initially the stroke left him unable to speak, and largely paralysed down his left hand side. Malcolm and Annie live in a bungalow in a pleasant residential estate. Their home is comfortably furnished and the lounge is full of pictures of the family. Living in the bungalow means that movement around the house is not difficult for Malcolm. The first interview took place a week after Malcolm had been discharged from hospital, although he had spent the previous three weekends at home in preparation for his discharge. At this time Annie had taken compassionate leave from work because she did not feel he was well enough to be left alone all day. The interview took place 15 weeks after his stroke, and by this time Malcolm could speak well and walk (with the use of a crutch), although he had no movement in his hand. The second interview took place ten months after Malcolm's stroke. Malcolm was recovering well, but still had no use of his hand. Annie had gone back to work. The couple had decided to pay for additional private

physiotherapy sessions to try to improve the functioning in his hand, but at the time of the second interview there was no obvious improvement in functioning. Just prior to the stroke, their daughter had given birth to their second grandchild. The birth of their first grandchild coincided with Malcolm's retirement and as a result, Malcolm looked after the baby when his daughter went back to work. Spending this time with his grandson was very important to Malcolm, and in his words, they have a very close bond. In contrast, he feels he has only a weak bond with his new granddaughter because he has been in hospital for most of her life so far, and, because of his damaged arm, he does not have the confidence to hold her or interact with her in the same way he did with his grandson.

Marjorie and Albert

Marjorie and Albert are both in their mid-eighties and have been married for about 60 years. They have one daughter who does not live locally. Before his retirement Albert worked as a design engineer and Marjorie was a housewife and then later a teacher until she retired. Because of his job the couple spent most of their married life travelling around the UK and abroad. This meant that they never put down firm roots until their retirement when they retired to Marjorie's home town.

Marjorie and Albert describe themselves as fit and active for their age and they are both keen walkers and gardeners. They live independently in a bungalow and have an active social life, with Marjorie being part of the local painting group, WI and bridge club. They describe themselves as being like chalk and cheese, but the humour and banter in their interactions speaks of a long and happy relationship. They often have differences of opinion, but believe in never going to bed on an argument. The friction between them feels to be constructive and positive, each might try to influence the other, but they both have strong characters.

Marjorie suffered a lacuna stroke which initially affected her speech, swallowing and movement in her left hand. By the time of the interview most of her symptoms had disappeared but she was still having problems sleeping, leaving her fatigued during the day. Her speech was slurred, especially when tired, and she described herself as feeling rather irritable since the stroke. The interview took place two weeks after Marjorie had been discharged from hospital, and at that time her sister was staying with them to help Albert look after Marjorie. At the time Albert was managing most of the household tasks, with the assistance of his sister-in-law, and with the guidance of his wife, he appeared to be managing well. The second interview could not be arranged because Marjorie's health had deteriorated.

Neville and Cilla

Neville and Cilla are in their mid-fifties, and have been married for over 30 years. They have two adult children. They describe their relationship as close, although prior to Neville's stroke they got to spend little time together because Neville was a self-employed joiner and often worked evenings and weekends. Neither of them likes going out to pubs or restaurants, so what little time they have together tends to be spent with their family.

Prior to the stroke, Neville was already living with significant disabilities, including diabetes, arthritis, and a diagnosis of cancer. Following his stroke, Neville was treated as an outpatient through the neurovascular clinic and the stroke has left him with no physical disabilities. However, returning to work after the stroke has proved to be very difficult for Neville, and he has had to struggle with both the fatigue and memory problems, but he feels that taking early retirement or disability is not an option. The stroke also resulted in profound changes to his personality, and his family describe him as being a different person. His wife describes how he has gone from being a quiet, laid-back person, to one who is irritable towards people, including Cilla and the rest of the family. At the time of the first interview Neville had not yet returned to work full-time although he was going to his workshop a couple of days a week and was beginning to accept new work.

Cilla works full-time at a local shop and is the main carer for her elderly father, and mother-in-law, both of whom live independently in pensioners' bungalows nearby. She comes across as a quiet, rather anxious person, and the change in Neville's personality has been very difficult for her to cope with, especially given her other work and caring responsibilities. During the interview the Cilla was very frank about the difficulties that they faced in coming to terms with the stroke, and the strain it had put onto their relationship. Cilla openly discussed her anxiety about what she perceived to be the causes of the stroke and Neville's refusal to modify his behaviour to reduce the risk of a subsequent stroke. However, Neville tended to avoid commenting on her concerns and reverted to using flippant remarks and changing the topic to manage the discussion. The couple subsequently withdrew from the study.

Rebecca and Andrew

Rebecca and Andrew have been married for over 30 years. They have two adult children, one of whom was living with the couple when Rebecca experienced her stroke. The first interview took place five months after her stroke. Rebecca's stroke has left her with some physical disabilities, memory problems, depression, emotionalism and central pain. However given the severity of the stroke she has recovered well, although not as well as she would like, or as quickly.

Prior to her stroke, Rebecca worked as an administrator. By the time of the second interview, some 11 months post stroke, she was back at work on a stepped return programme. Although she described her job as stressful, she enjoyed it and worked with people she liked, and whom she thought of as friends as well as colleagues. Her husband works shifts at a local factory, and so she has always relied on her friends for company as she often sees little of her husband. She told me that before the stroke she was physically very active, and attended classes at her local gym every week. Her stroke left her unable to drive, so she is reliant on friends to take her to the gym, which forms an important part of her social life.

When the couple described their holidays it became clear that even these were shared with friends or family, and they rarely spent time together as a couple. On meeting them together there was a sense of them being very independent, and leading largely separate lives. Despite this apparent 'separateness' in their lives they were otherwise a very traditional couple, with Rebecca managing both to go out to work full time and manage the bulk of the housework. The couple rarely used the pronoun 'we' when talking of either the stroke or their lives. During both of the interviews Rebecca dominated the conversations, and although Andrew expressed support and admiration for his wife, this was not often reciprocated, or responded to by Rebecca. Andrew tried to add to the discussion, and responded to questions directed at him, however, Rebecca rarely asked his opinion.

At the time of the first interview Rebecca was very emotionally labile, and found some topics difficult to discuss, a problem which was still present by the second interview. At the time of the first interview she had been diagnosed with depression and was experiencing high levels of pain and fatigue, which she found frustrating and significantly limited her activities. She felt that the central pain and fatigue also added to her depression because it limited her ability to get out of the house, and thereby limited her social activities. By the time of the second interview her pain had diminished somewhat, but the fatigue was still a major difficulty for her and this was causing problems because even on a stepped-return to work, she was often coming home and having to go to bed for the rest of the day.

Roger and Dee

Roger and Dee have been together for over 27 years and have three adult children, one of whom still lives at home. The couple were interviewed eight months after Roger's stroke. The interview was disrupted several times by phone calls and visitors.

The couple spent a great deal of time talking about how much of a shock the stroke was for them both as neither of them thought Roger was a candidate for a stroke. Roger suffered a brain stem stroke which left him in a coma and doctors warned Dee that he could be left in a vegetative state, and organ donation was discussed. However, he made a remarkable recovery and was left with no physical disabilities, although he had significant short-term memory problems and fatigue. His family also describe his personality as being profoundly changed. Dee described how before his stroke he was easily irritated and often bad tempered and that this had caused difficulties throughout their time together. In contrast, since the stroke she found him calmer and an easier person to live with, although some of his family felt aspects of his former personality were re-emerging. During the interview they talked of their relationship in very positive terms, and described how they had a varied social life with many friends. Previously a professional musician, Roger now works for himself. Prior to, and indeed since his stroke, Roger was a very active person, and his hobbies reflect this. He plays table tennis, chess and snooker. He is a keen gardener and cyclist. The couple are both vegetarians, non-smokers and they drink little alcohol. Roger did however regularly smoke cannabis, a habit that he has been forced to give up since the stroke.

Dee works from home as a freelance accountant as well as working for their business. As they both work from home they are used to spending a good deal of time together. Dee described how, in addition to coping with the impact of Roger's stroke she also cares for her elderly mother who lives in a flat attached to the house and her sister, who has health problems. During the interview their language moved between 'I' and 'we/us' depending on topic. When the couple agreed about events or were describing events from the past they generally use "we", but when they talked about Roger's cannabis use, and especially about his attempts to restart smoking this after his stroke, and the difficulties Dee had in making him give it up their language changed to *I/he/you*, reflecting the significant tensions this had caused in their relationship.

Shirley and Gordon

Shirley and Gordon are both in their sixties, and live in a small, rural village with very poor transport links. They live in a semi-detached house, where they have spent all their married life. Their family are grown-up and provide help and support to the couple. Before the stroke, they were both keen walkers. Shirley experienced a major stroke which left her with significant left sided weakness, minor cognitive problems and depression. At the time of the interview Shirley had been out of hospital three weeks and she was able to get around downstairs with a walking stick and holding on to furniture. However, their home has no downstairs toilet and the bathroom is upstairs which has caused significant problems for Shirley as this means she has to negotiate the stairs several times a day and will only attempt this if Gordon goes up stairs behind her. At the time of the first interview Shirley was unable to use her right hand and it was encased in a cast to support it.

Gordon is a quiet man who spoke little during the interviews apart from to add to Shirley's story or in response to questions directed at him. He was a farm worker until his retirement and the couple still live in a farming community. Since the stroke Gordon has been providing care for Shirley including helping her with her personal care. As she is unable to get up out of the bath because of the weakness in her leg and arm, this means that he has to get into the bath with her to help her out and is unable to leave her alone in the house for more than short periods. Gordon has also taken over most of the cooking duties, with help from their family. At the time of the first interview this arrangement appeared to be working well. A second interview could not be arranged.

Sonya and Peter

Sonya and Peter are in their late fifties and have been married for over thirty years. They have no children. They took early retirement a few years ago so that they could spend time travelling the world. Sonya was a teacher for many years, and then worked with Peter when he set up his own company. Prior to the stroke they were both keen walkers, and had a very active social life, which revolved mostly around their membership of local clubs and societies. They both spoke in positive terms about their relationship prior to the accident, and they described how they enjoyed spending time together.

Sonya suffered a major stroke which left her with wide ranging difficulties. Her memory and executive planning skills have been significantly affected. She also has left visual neglect making reading difficult. At the time of first interview, some 14 weeks post stroke she was incontinent, unable to stand or walk without substantial assistance, and was unable to move one hand. She described her mood as low and was subsequently diagnosed with depression for which she was treated with anti-depressants, and was eventually referred to a clinical psychologist. She also suffered from significant fatigue, which has limited her recovery rate.

At the time of the first interview Sonya was still in hospital and the dominant theme of this interview was Sonya's possible recovery trajectory, and the couple's unwillingness to accept the possible permanence of Sonya's disabilities. At this time-point the couple were resolute in their determination that she would make a full recovery and were reluctant to accept any alternative scenario. This stance was also observable in their discussions with health professionals whom they felt were over pessimistic about her chances of making a full recovery, and in their reluctance to start adapting their home for Sonya's discharge home. The second interview took place a few weeks after Sonya's discharge home. By the time she was discharged Sonya was able to transfer from bed to chair with one helper, but was not walking or standing independently. The couple live in a small cottage and its layout made it impossible for her to access more than two rooms of the house. They had converted the lounge into a bedroom for Sonya and this was fitted out with a hospital bed and a shower/toilet. Under the hospital bed was a small pull out bed in which Peter sleeps.

Although the couple had carers coming in twice a day to help care for Sonya, Peter took on the bulk of the caring responsibilities himself and their stated goal was to achieve full-time one-to-one care which would allow them the freedom to resume their goal of travelling the world. However, trying to manage this alone, as well as look after the house and spend time with Sonya proved to be exhausting for Peter, who admitted that he was struggling to cope.

During this second interview it was difficult at times to get Sonya to participate fully. She seemed to have withdrawn into herself much more than when she was in hospital. She also seemed more depressed, which was confirmed during our discussions when Peter mentioned how their GP had increased Sonya's anti-depressant medication. It was also clear by the second interview that the balance of their relationship had changed significantly over time and Peter described it as a patient-carer relationship rather than a husband and wife relationship. The couple seemed to struggle to share their feelings, and Sonya complained that Peter was making decisions without her agreement, which was at odds with their pre-stroke relationship style. Although this may be as a result of her memory problems, it was apparent during the interview that Peter does not always listen to what Sonya is saying.

Trevor and Veronica

Trevor and Veronica are both in their mid-fifties and have been together seven years. The interview took place some 6 weeks after Trevor's stroke, at the home they were in the process of renovating. For each of them this is their second marriage and both have grown-up children from previous relationships. Unlike most of the couples in the study they had not been married long, and felt that they had learned from the mistakes they made in their first marriages in terms of doing things together and discussing their worries. This couple were not seen for a second interview due to time constraints.

Although his stroke had left him with no physical disabilities, Trevor experienced what he described as panic/anxiety attacks which left him feeling dizzy and with numbness in his arms and hands. He believed his symptoms were made worse because of a lack of information about his stroke. When Trevor tried to see his GP to discuss his concerns he had to see a locum who Trevor felt was dismissive of his concerns, and his symptoms. Trevor also experienced significant fatigue which left him struggling to manage at work and at home. At the time of the interview Trevor was on a stepped return to work but was struggling to manage his fatigue. Before the stroke Trevor thought nothing of working until 11pm on their house after a day at work, and since the stroke he had struggled to "take it easy" and admitted to over-doing things which caused arguments with Veronica, and made his day-time fatigue worse. The house was bought as a long-term renovation project, and Trevor had intended doing all the work himself, and he found it difficult to come to terms with the fact that this may no longer be possible.

Although Trevor has family living locally, he is not close to them and described relationships as 'strained' and indeed at the time of the interview none of his family had visited. As the couple have only recently moved into the area and had yet to make many friends, this left them isolated in terms of social support. Coming from a close family, Veronica found it difficult not having her family around her. Although Veronica said that Trevor discussed his worries with her, he seemed unable to cut back on his activities and reduce his work-load, which at the time of the interview was causing a strain on their relationship.

Yvonne and Tom

Yvonne and Tom are both in their mid-fifties and have no children. The couple live on an isolated farm which requires both of them to work on it to make it viable. The interview took place seven months after Yvonne had experienced a major stroke which left her initially unable to speak, with significant short-term memory problems and with significant weakness in her right arm and leg. Although she had significant therapy whilst as an in-patient, once discharged she had little support from physiotherapy or speech and language services because of her rural location, and she felt her recovery slowed as a consequence.

Tom, as well as being a farmer also works part-time to provide them with a regular income. After her stroke, Yvonne was unable to communicate and Tom described how he had struggled to get information about her prognosis or sources of support and guidance.

When she came out of hospital Yvonne suffered from depression and she struggled to find the motivation to try to do anything around the home or farm. This was compounded by her disabilities which made doing things physically challenging; but this lack of motivation was out of character for Yvonne, and this change in Yvonne was of particular concern for Tom because the survival of the farm relies on them both being able to contribute to its management. At the time of the interview it was not clear whether Yvonne would recover enough to resume working on the farm. As the couple live in a rural part of the county the stroke has left Yvonne physically isolated from all forms of social support apart from her husband. She had lost confidence and would not answer the phone which limited social contact. She could no longer drive which meant that she had to rely on Tom to take her to hospital appointments, shopping or to see friends. As he worked long hours and also did all the work on the farm, this meant that Yvonne spent most of her time alone.

During the interview Tom spoke more than Yvonne because she still had some residual language difficulties. During the interview Tom was very supportive of Yvonne and used a lot of positive language, regularly reassuring her of his support. However, he also described how, since the stroke, they had struggled to re-establish any physical intimacy as Yvonne found it difficult to sleep and was sleeping in another bedroom, although Tom hoped this would be a temporary arrangement.