

UNIVERSITY OF SOUTHAMPTON

New world, new rules: life narratives and changes in
self-concept in the first year after stroke

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ABSTRACT

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NEW WORLD NEW RULES: LIFE NARRATIVES AND CHANGES IN
SELF-CONCEPT IN THE FIRST YEAR AFTER STROKE

Caroline Susan Ellis-Hill

Within rehabilitation research recovery from a stroke has been defined by health professionals as the improvement in the physical ability and task-related skills of an individual. The negative psychological consequences of a stroke for both individuals and their families have been recognised for several years, but are poorly understood. Within this thesis an alternative approach has been used to explore psychological consequences following a stroke. The focus of study has been the change in identity of individuals and their spouses, rather than the ability of an individual to carry out tasks.

Ten consecutive couples were included following one partner's admission to hospital following a stroke. Separate narrative life history interviews were carried out with the stroke respondent and their spouse in hospital, and at six months and at one year after hospital discharge. Data collection and analysis was based on an interpretative phenomenological approach. A second concurrent study was carried out including 38 stroke respondents who were admitted to hospital following a stroke. While in hospital they were asked to complete a questionnaire including indices of physical ability, task-orientated ability, mood and self-concept. The questionnaire was administered again at six months and one year following discharge. Multivariate statistical procedures were carried out to describe the associations between the variables assessed.

All respondents reported that they had experienced a fundamental change in their lives. They continued to report this fundamental change up to the final interview at one year, apart from one couple, where the stroke partner had made a complete physical recovery. The issue which appeared to dominate the stroke respondent's first year post-stroke was a split between their body and their physical and social self. They could not maintain their prior identity within the capabilities of their new body. The spouses reported that they became totally responsible for not only their own lives but also the life of their partner. The issues of body-self split and total responsibility appeared to be hidden from others, making the situation of the respondents more challenging. Younger spouses reported more difficulty than older spouses in integrating the stroke into their life situation. Issues facing the respondents also varied depending on their own life histories and life goals. Within the quantitative analysis the mood of the stroke respondents was not highly correlated with physical ability or task-oriented improvement. Perceived difference between past and present self-concept was correlated to anxiety and depression at all assessment times even when the other indicators were taken into account.

Exploration of identity change appears to be a useful framework for exploring the psychological consequences of a stroke.

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CHAPTER ONE

A pebble in a pond - a metaphor for stroke

1.1 Introduction

When a pebble is thrown into a pond, the ordered surface is broken. The ripples slowly radiate out. This metaphor can be used to describe life following a stroke. The pebble represents the focal area of damage in the brain which occurs in stroke. A permanent interruption of the blood supply to a specific area of the brain damages the cells in that area. Interruption may be caused by one of three events; an embolism or blood clot which breaks off from a damaged blood vessel causing a blockage; atheroma or thrombosis which cause deposits to build up and cause a blockage; or a haemorrhage, when blood leaks into the brain itself (Delaney and Potter 1993; Mayo 1993). The brain cells may be damaged or permanently destroyed.

1.2 Impairment

The ripples in the pond spread outwards. If the area of the brain damaged is large the person may die. About 20% of people admitted to hospital die in the first four weeks following stroke. A further 10% of people can be expected to die within a year of their stroke (Bamford, Sandercock, Dennis et al, 1990). Smaller areas of damage may leave the person incapacitated. Often there is damage in the motor cortex - the brain area responsible for activating movement in the body. Of survivors two-thirds have some degree of permanent disability (Bronstein, 1991). Many of those who survive, experience hemiplegia or paralysis of one side of their body (Hedley, 1994). The initial paralysis usually reduces over time with the highest rate of recovery being within the first three months, continuing for at least a year post stroke (Kinsella and Ford, 1980; Wade and Langton-Hewer, 1987). Researchers from the Frenchay Community stroke project studied a sample of over 190 stroke patients. They found that at one week 76% of people had hemiplegia or hemiparesis and by six months 53% still had some detectable weakness (Wade, Langton-Hewer, Skilbeck et al, 1985).

Language areas may be damaged leaving people with aphasia - a difficulty in understanding and communicating with others. A third of all people who have strokes develop aphasia (Parr, Byng, Gilpin et al, 1997). Often people know what they want to say but cannot find the right words. Wade, Langton-Hewer, David et al (1986) found that 25% of conscious patients had aphasia in the first week post stroke and that 12% of people remained aphasic at six months. Nicholas, Helm-Estabrooks, Ward-Lonergan et al (1993) in a study of 24 people with severe aphasia found that although they improved in the first six months, that recovery slowed and people still experienced severe aphasia at two years.

Damage may leave people with cognitive deficits following a stroke, although the effects may be temporary. People may have a reduced attention span especially in the early stages after stroke (Wade, Langton-Hewer, Skilbeck et al, 1985). Short-term memory may be affected (Wade, Parker and Langton-Hewer, 1986). Perceptual problems are a common feature of stroke (Corbett and Shah, 1996). People may not be able to interpret sensory stimuli - vision, proprioception and touch may be affected (Van Deusen, 1993). Edmans and Lincoln (1989) assessed 150 people following stroke and found that 76% had perceptual problems. Depression is experienced after stroke, affecting between 30 and 40 % of survivors (Ebrahim, Barer and Nouri 1987; Robinson, Starr and Price, 1984). It may be experienced at any stage after stroke although more likely in the first year. It may improve or become worse over time (Robinson, Starr and Price, 1984).

1.3 Tasks in everyday life

The ripples following these impairments spread wider and affect a person's everyday life. This is not just in the short term, the majority of people will have to manage to live with their impairments for a minimum of a year, perhaps for many years. Dobkin (1995) in a study of users of Medicare in America found that hemiplegia or hemiparesis was present in 70% to 85% of stroke patients at two weeks and present in 50% of stroke patients at six months. There are few studies of long-term physical recovery, but Lindmark and Hamrin (1995) found that although there was improvement in the first year, there was a gradual physical decline over the next five

years. They concluded that people found it difficult to maintain physical skills, such as their balance, and walking skills if they did not use them on a daily basis.

Difficulties with cognition and speech (aphasia) may be long-lasting and affect everyday life. If a person continues to have perceptual difficulties one month following their stroke it is likely that the problem will be intractable (Baggerley 1991; Brockmann Rubio and Van Deusen, 1995). Aphasia can improve over time and some language can return in days or months following a stroke. But for many people aphasia does not disappear (Parr, Byng, Gilpin et al, 1997). This has far reaching consequences in a person's life, affecting the whole of their social and emotional worlds (Code and Muller, 1992; Brumfitt, 1993). Even people with seemingly mild aphasia mention communication as a significant loss (Mumma, 1986).

Within two weeks of a stroke no less than 20% and as many as 60% of stroke patients required some assistance with self-care activities and most have some disability when they are discharged from hospital (Dobkin, 1995). Most functional recovery occurs in the first six months but many people will never recover their full range of pre-stroke skills (Andrews, Brocklehurst, Richards et al, 1981). The long-term nature of the problem has been highlighted by Aho, Hamsen, Hatano et al (1980) in a World Health Organisation study of almost 10,000 cases world-wide. They reported that at one year post stroke over 60% of people still had some neurological deficit and 40% of the sample were dependent on others for self-care. A similar picture was discovered by researchers on the Oxfordshire Community Stroke Project relating to first ever stroke, who found that at one year 35% of people were still dependent on others (Bamford, Sandercock, Dennis et al, 1990). Lindmark and Hamrin (1995) in a five year longitudinal study found that most functional improvement occurred in the first three months, and that this was maintained at one year especially if the person carried out the task on a daily basis. However, over the following four years, they found a slight decrease in function which the researchers felt was due to carers taking responsibility for the tasks.

1.4 Relationships with others

The ripples spread wider to include not only the person following a stroke but also family, friends and the community at large. Sjogren and Fugl-Meyer (1982) have reported that intimate social relationships are affected by physical difficulties, changes in body image and reduced self-confidence (see also Vittanen, Fugl-Meyer, Bernspang et al, 1988). Aloni, Ring, Rozenhul, et al (1993) reported from a study of sexual function in male patients and their partners after stroke that two thirds to three-quarters of people experience altered sexual functioning. Finger (1993) also found that as many as three-quarters of stroke survivors experience disruption of sexual functioning, predominately as a result of psychological rather than physiological causes.

Family members and partners may become carers and their lives may change considerably (Labi, Philips and Gresham, 1980; Kettle and Chamberlain, 1989; Evans, Connis, Bishop, et al 1994). Anderson, Linto and Stewart-Wynne (1995) in a study of over 80 caregivers at one year post-stroke found that almost all reported adverse affects on their emotional health, social activities and leisure time. Reduced social life and leisure activities appears to be a problem for both the person following stroke and their partners. It has been found that often social activity is severely limited after a stroke, particularly if it occurs outside the home (Sjogren 1982; Greveson and James 1991; Jongbloed and Morgan 1991; Corr and Bayer 1992). Drummond (1990) found that patients questioned 40-78 weeks after stroke reported a decrease with regard to both the number of activities and the frequency of participation when compared to pre-stroke leisure activity.

Stroke not only has consequences for the individual and their family, but also for wider society. Stroke accounts for 12% of all deaths in the United Kingdom. It is the third most common cause of death in the United Kingdom after myocardial infarction and cancer (OPCS, 1995). The significance of stroke has been recognised in that one of the five main Health of the Nation targets is to reduce the death rate for stroke in people aged 65-74 by at least 40% by the year 2000 (Department of Health, 1991).

Just as a tiny pebble can cause wide ripples in a pond; damage to a small part of the brain, can have a wide effect on the lives of people and those around them.

1.5 Medical intervention

Stroke has been defined as “a clinical syndrome typified by rapidly developing signs of focal or global disturbance of cerebral functions lasting more than 24 hours or leading to death, with no apparent causes other than of vascular origin.” (World Health Organisation, 1973). This is the medical definition used to diagnose a case of stroke. It has a clinical clarity which is hardly reflected in any other aspect of the management, course or prognosis following a stroke.

There are known risk factors for stroke such as hypertension, cigarette smoking, transient ischaemic attacks, diabetes mellitus, a prior stroke and generalised cardiovascular disease (Noll and Roth, 1994). These indicators provide useful information at a population level, but often do not relate directly to an individual's circumstances. This ambiguity about the cause of the stroke is part of the puzzle, part of a continuing uncertainty for a person following a stroke.

A stroke is relatively easy for a doctor to diagnose. With the use of specialised brain scanning equipment an increasingly elaborate typology of strokes is emerging. Despite increasing technological advances and understanding of brain metabolism there is no proven medical treatment for acute stroke which effects a cure (Sandercock and Willems, 1992). Medical intervention is aimed at reducing the risk of a second stroke through the treatment of high blood pressure, via aspirin or anticoagulation therapy. In cases where the carotid artery is partially blocked surgery may be carried out to reduce the risk of further strokes (Gasecksi and Hachinski 1993). Although people are seen and treated by the medical profession and acute intervention may save lives, doctors can do little to aid recovery. This has been reported to cause distress to people who have been admitted to hospital expecting the doctors to cure the stroke (Doolittle, 1991).

Often following a stroke a person is separated from their family, friends and usual surroundings. In an analysis of admission rates from 1970-90 in the UK Blais (1994) found that between 40-78% of people are admitted to hospital following a stroke. The decision to admit patients appeared to be dependent on a number of factors such as the severity of stroke, diagnostic uncertainty, the need for acute medical treatment and the availability of home care and domicilliary rehabilitation services. Although there is a current debate on the necessity for hospital admissions (Lincoln, 1994) about 70% of people are still admitted to hospital following stroke (Young, 1994). People may spend weeks or even months separated from the normal flow of their life.

1.6 Service provision

Stroke contributes a huge burden on service provision, as it is the largest single medical condition causing long-term disability and handicap (Department of Health, 1991). One hundred thousand first-ever strokes occur in Britain each year. A district with a population of 250,000 can expect to see 500 first ever and 100 recurrent stroke cases a year (Bamford, Sandercock, Dennis et al, 1990), contributing to the use of a wide variety of both hospital and community health services. It has been estimated that in 1989/90 stroke attracted about 4% of the total National Health Service expenditure in England excluding Community Health Services (Department of Health, 1991). In hospital, cases of stroke account for 12% of general medical and 25% of geriatric bed days (Young, 1994).

Social Services also carry a large burden. The Office of Population Census and Surveys research suggested that 270,000 people live with a stroke in the community within the UK (Clark and Opit, 1994). A typical district of 250,000 will have around 1500 (0.6%) survivors of stroke living in the community and around 750 (0.3%) will have a significant level of disability, remaining dependent in at least one basic living activity six months after their stroke (Langton-Hewer, 1990).

The incidence of stroke varies markedly with age from 2 per 1,000 between the ages of 55 to 64 to 20 per 1,000 in those over 85 years old (Department of Health, 1994). In all except the young, the risk of stroke is higher in men than women. With the

demographic changes and more elderly people surviving over next twenty years, stroke is becoming an increasing cause of mortality and morbidity placing an increasing strain on health and social service resources. A great deal of money is spent on supporting people following a stroke, but are they getting the kind of support they need ?

CHAPTER TWO

Present rehabilitation research

2.1 Introduction

The focus of this study originated from the author's previous clinical experience. At times during this dissertation the first person rather than the third person will be used, to acknowledge the author as an integral part of the research process and to allow the reader to judge the research within the wider context of the author's professional life. I have had several years experience of working as an occupational therapist with people following a stroke on a medical ward at a general hospital. I was interested to discover why people reacted so differently following a stroke. Some people 'got on with life' despite severe physical difficulties, whereas others who in comparison appeared to have fewer physical problems; were overwhelmed by their situation and could not manage at all. When I turned to the stroke rehabilitation literature to try and understand these differences, I was struck by the limitations of the research.

2.2 Medical domination of research

Following a stroke, rehabilitation may last weeks or months and most direct support is provided by nurses and therapists. As noted in the previous chapter after the acute phase of illness which may last a few days, the medical profession have relatively little to offer people following a stroke. Stroke cannot be cured and the implementation of strategies to reduce the possibility of another stroke is routine and straightforward (Sandercock and Willems, 1992). The relationship between practice and research is incongruous, as although nurses and therapists are more directly involved than doctors in stroke rehabilitation, most research into rehabilitation has been, and still is carried out by the medical profession.

Medical practitioners aim to make a diagnosis, implement a treatment and effect a cure (Armstrong, 1983). The most appropriate approach to take towards knowledge production for the medical profession is one that allows for accurate prediction. Doctors aim for control over disease. With control as a goal, doctors seek research

methods which will generate valid, reliable and generalisable information (Moccia 1988). This approach has been useful in providing information about biological phenomena, such as in understanding how damage to part of the circulatory system within the brain affects the neuromuscular system, affecting an individuals bodily process such as movement and speech. However, this approach could be argued to be of more limited value, when trying to understand the behaviour of people and how best to support them following a stroke. The influence of the epistemological approach used by the medical profession will be described in an analysis of recent articles later in this chapter.

The study of people involves the study of psychological and social, as well as biological phenomena. It has been argued that the epistemological assumptions underlying the study of biological and ‘natural’ phenomena do not hold true for psychological and social phenomena (Helman, 1991). Theorists have put forward the case that they are different phenomena and understanding is limited if differences are not recognised (Howard, 1984). The present medical approach assumes that psychological and social phenomena are linked with biological phenomena and so can be understood in the same way. This assumption cannot be supported as demonstrated in the following example in Table 2.1.

Phenomena		
Biological	Social	Psychological
Woman of 18 stone	18th century Seen as buxom /beautiful Held in high regard	She has high self-esteem
Woman of 18 stone	20th century Seen as obese and ugly Other people scorn and deride her low morals She experiences social isolation	She has low self-esteem

Table 2.1 A comparison of a biological, social and psychological phenomena

Although the biological fact remains the same, the social and historical context influences the psychological phenomena. From an interpretative perspective biological and psychological phenomena cannot be treated in the same way (Moccia, 1988). Biological phenomena have a materiality within the world; they can be

measured directly against some kind of rule, whereas psychological phenomena are often conceptual rather than material in nature. As such they cannot always be observed or measured directly.

It is thought that there are several limitations in using a positivist approach when studying people (Smith, Harre and Langenhove, 1995). These include the dehumanising effect of the approach, and the limitations in understanding complexity in life. When studying natural/biological (material) phenomena it is safe to assume that the presence of the researcher does not pose direct difficulties. As Howard noted, it would not be reasonable:

to think that sodium would become aware that this is an experiment and bond with chlorine at a higher (or lower) temperature deliberately (or inadvertently) because it is being studied. (Howard 1984, p105)

It can be safely assumed that atoms, bones, trees and brain tissue do not have a point of view about the phenomena, so only the reality of researcher needs to be taken into account. Research can be seen as an active process by a researcher on a passive phenomenon. In order to carry out work involving psychological phenomena in a positivist manner it has to be assumed that other humans do not have a point of view or that their views are not important. Bannister (1966) made the point:

I am reminded of a recurrent theme in certain types of science fiction story. The master chemist has finally produced a bubbling green slime in his test tubes, the potential of which is great, but the properties of which are mysterious. He sits alone in the laboratory, test tube in hand brooding about what to do with the bubbling green slime. Then it suddenly dawns on him that the bubbling green slime is sitting alone in the test tube brooding about what to do with him. This special nightmare of the chemist is the permanent work-a-day world of the psychologist, the bubbling green slime is always wondering what to do about you. (Bannister 1966, p22)

By treating people as objects, they become dehumanised. Using a positivist approach researchers stand apart from their own realities and those of others, to observe and study rationally and dispassionately in order to predict with as much certainty as

possible what will happen next. Nagel (1986) described this stance as ‘a view from nowhere’.

The complexity of human life is discounted if there are assumptions that there are universal rules, irrespective of time or place. Using this approach ‘outliers’ are discounted and average responses are obtained. This may be helpful in understanding overall trends in phenomena, but it is limiting when trying to understand individual responses or differences between people. Psychological data are influenced by the social, cultural and historical context in which the knowledge was created. Early researchers trying to explain behaviour in the same way as biological phenomena found such difficulty in prediction that the postulated chains of events were ever more complex. Theories which seriously aimed to produce satisfactory accounts of any but the simplest patterns of behaviour rapidly became full of escape clauses and ad hoc amendments (Gillet, 1994). By discounting any data which cannot be quantified, findings tend to become even more abstract from the everyday life situation.

It is interesting to consider the present medical approach to stroke rehabilitation research within a historical context. In the eighteenth century medical investigators were interested in an integrated conception of the whole person. All aspects of emotional and spiritual life were deemed relevant to the understanding of the functions of the constitutions (Jewson, 1976). As Pound, Bury and Ebrahim (1997) note in an historical study of medical care afforded to people following a stroke, by the beginning of the twentieth century physicians focused on the body rather than the person; and the patient and family became less visible in medical texts. It may be suggested that by using a positivist approach people and individual responses to stroke have disappeared from the dominant medical discourse within stroke rehabilitation research.

2.3 Present definitions of recovery and outcome

A review of recent literature was carried out to explore how recovery and outcome were defined by rehabilitation researchers and to highlight the limitations of this research. The review covered two data-bases, CINAHL, Cumulative Index to Nursing and Allied Health Literature and MEDLINE. These databases were chosen as they are the ones most likely to be accessed by clinicians within stroke rehabilitation and hence frame approaches to clinical practice and policy decision-making. By selecting these data bases it is not possible to claim that all rehabilitation research had been accessed, rather it is a sample taken from 'mainstream' research. The search was limited to articles in the English language and the keywords used were [CVA] and [recovery], and [outcome]; an additional keyword of [rehabilitation] was included in the MEDLINE search to exclude more general medical articles. Two hundred and thirty six references from the past two years (1996,1997) were found. Each article was categorised into one of nine groups depending on the content of the paper. The categories can be seen in Table 2.2.

Category of article	Example	No.	%
A specific aspect of recovery	speech, perception, hand function	56	24%
Functional outcome	activity i.e. washing, driving/ mood	48	20%
Acute/medical care	use of medication, management of acute stroke	39	16%
Neurological studies	brain scan studies, neuromuscular stimulation	29	12%
Validation of measures	mobility, ADL, mood scales	18	8%
Other	cause of CVA, committee reports	17	7%
Service description	cost of technical aids, use of time on a ward	14	6%
Nursing approach	overview from clinical experience	7	3%
Person's perspective	experiences, conceptions of life situation	8	3%
Total		236	100%

Table 2.2 Categories of journal articles related to stroke recovery 1996-7

From Table 2.2 it can be seen that many articles were written about specific aspects of recovery, such as improvements in hand function, perception and speech, acute or medical care and neurological studies. A large proportion of articles were concerned with functional outcome. These will be discussed more fully below. Recovery was

defined by health professionals, only three percent of the articles considered the perspectives of people who had experienced a stroke. Hafsteinsdóttir and Gryphonck (1997) concluded from a review of literature that little attention has been paid to the experience of stroke. They suggested that accounts from people themselves should be studied to redress this balance.

Within the ‘functional outcome’ group of articles, the authors had written in terms of ‘outcome’ and ‘recovery’ and had used measures to define these concepts. In order to explore how recovery was defined, this group of articles was categorised further. For each article the following questions were considered: a) what was outcome/recovery considered to be ? b) when is it considered to have happened ? and c) does it relate to the individual or the family or both? The findings can be seen in Table 2.3.

Definitions of recovery		No. of articles n = 48	%
Recovery defined in terms of	personal daily activities	39	81
	discharge home from hospital	12	25
	length of stay in hospital	9	19
	domestic/social activities	7	14
	mood	6	12
	physical improvement	6	12
	mortality	4	8
	perceptual improvement	2	4
Time of assessment	hospital discharge	22	46
	6 months	8	17
	one year	9	19
	3 years	6	12
	5 years	2	4
	nursing home no specified time	1	2
Outcome related to	person	43	90
	relative/family	1	2
	both	4	8

Table 2.3 Definitions of recovery within the functional outcome category of articles

Recovery was defined by health professionals in terms of physical improvement and self-care skills. Doolittle (1992) in a longitudinal, ethnographic study of 13 individuals following stroke, who were followed up from within 72 hours of their stroke to six months, found that there were differences in outcome as described by the

patient and rehabilitation staff. The rehabilitation staff described recovery in terms of task performance, improved mobility and independence in self-care; whereas patients saw recovery as a return to the existence they lived prior to their stroke. Their point of reference was their pre-stroke life. They saw independence in functional task oriented activity as an improvement in their condition but recovery, for them was a return to previously valued activities in life. They defined recovery in terms of life changes, a much broader concept than physical ability alone. The emphasis on the physical aspects of stroke recovery, limits research into and knowledge about wider life changes experienced by people following a stroke. This gap between professional and personal knowledge was highlighted by Robin Cant (1997), a college lecturer, writing about his experience following a stroke. He noted that he was not a novice in this field, as he had been lecturing on a course entitled 'the social psychology of disability'. He recounted that:

Although I read numerous accounts of the effects of illness and disability, when searching the literature some months after suffering the stroke, I could find very little that seemed to be analysing or describing the experience I had just lived through.

(Cant, 1997, p297)

Within mainstream research there is no framework or theoretical basis to explore life changes following a stroke. There is a gradual realisation by a small number of rehabilitation researchers that the present emphasis on the recovery of physical function has led to neglect of the emotional and social consequences of stroke (Forster and Young 1992; Evans, Griffith, Haselkorn et al, 1992, Hafsteinsdóttir and Grypdonck, 1997). Other researchers have also suggested that the criteria that health care professionals use to record success will not necessarily be those seen as most important or even relevant to patients (Price, 1996).

In a large proportion of the articles, the researchers assessed recovery at hospital discharge; using outcome measures such as length of stay, or place of discharge; highlighting the fact that they were attempting to evaluate hospital service provision. Following a stroke, a person may spend weeks or even months within a hospital setting, but they spend the rest of their lives living with the consequences of a stroke. There is no denying that research is needed both within hospital and within the

community to determine the most efficient and effective way of providing a service. But by emphasising the study of present service provision, insufficient emphasis is placed on research which allows a wider theoretical understanding of the nature of recovery. This is essential if future services are to be developed based on the needs of those using them. There is also the danger that 'recovery' is seen to be complete by six months or one year, allowing policy-makers to conclude that services are no longer needed after that time. Again a small number of rehabilitation researchers acknowledge the need for a longer-term perspective. Young noted that:

the issues high on the research agenda such as CT scans and the optimum preventative doses of aspirin, appear less consequential when viewed from the vantage point of a patient one year after the stroke (Young, 1997, p329)

making the point that although medical practitioners speak of a holistic approach to rehabilitative care, they are still focusing on short-term physical care.

In the majority of research articles, the researchers conceptualised recovery as residing within the individual, as only the person who had experienced the stroke was studied. Occasionally relatives were included, but not in their own right, only in relation to their spouses, as carers. This approach can be understood by referring to the individualistic nature of the medical model (Engel, 1977) and the assumption that biological aspects are closely linked with the psychological and social aspects of life following a stroke. This assumption affects rehabilitation in that although it is stated that relatives are included within a holistic approach, the focus of intervention is the person who has the stroke, and often the needs of relatives are not addressed (Evans, Connis Bishop et al, 1994).

A final limitation of present stroke research can be seen in that knowledge is built up from the study of outcomes at a certain point in time. The majority of studies are cross-sectional. Although there were a few longitudinal studies spanning several years in the review (see [Table 2.3](#)); the basis for analysis was still outcome at a certain point in time. There is little understanding about the psychological and social processes which contribute to these outcomes.

Spencer (1993) described a story which may be seen to reflect stroke recovery research today.

One dark night a student was out walking and at the street corner he came across a rehabilitation researcher and a clinician crawling on their knees and closely examining the ground. The student asked what had happened. The researcher and clinician replied that they had lost some keys and had been looking for some time. The student then asked whether the researcher or clinician had any idea where the keys might be. 'Oh we think they are probably near the centre of the block.' The next question was obvious. 'But why are you looking here at the street corner if you think they keys are at the middle of the block? The reply was 'We are looking here because this is where the light is.' (Spencer 1993, p119)

Researchers appear to be limiting their questions to those it is possible to answer within the epistemological framework they are using, rather than looking for new ways to ask the questions that need to be asked.

2.4 Effects on service provision

Stroke rehabilitation research reflects, and is mirrored by, present service delivery. Pound and Ebrahim (1997) carried out interviews with 64 professionals, within a hospital setting, on their role in the rehabilitation of people following a stroke. The study included doctors, nurses and therapists. The concept of recovery was defined in a different way by different professionals. Nurses considered that a person had made a good recovery if they could return home, perhaps using a walking stick. Physiotherapists defined recovery in terms of functional improvement, with an emphasis on mobility, as observed elsewhere (Kaufman and Becker, 1986). Occupational therapists defined a successful outcome primarily in terms of a good discharge and being able to improve function within the limits of disability. Recovery was not defined in broader terms such as a return to the life experienced before the stroke, the wider definition given by patients themselves (Doolittle, 1992; Cant, 1997). The hospital staff were working with a conceptual framework of task orientated achievement, rather than a return to a normal lifeworld. Price (1996), in a study of people's personal constructs about illness, noted that the impact of chronic illness upon patients and their relative's lives is frequently under-estimated, and often goes

unrecognised by health care professionals, because they gain only a brief and privileged insight into their circumstances.

The discrepancy between professional and personal concepts of recovery leads to perceived inadequacies in service provision. These perceived inadequacies have been defined by professionals as well as people following stroke. Although in Pound and Ebrahim's (1997) study occupational therapists defined a successful outcome primarily in terms of a successful discharge from hospital, they also reported that they had skills and qualities related to wider psychological aspects of rehabilitation which they were not given the opportunity to use. The present rehabilitation literature supports practical, task-oriented aspects of rehabilitation. There is very little literature addressing the psychological needs of individuals following stroke and so this aspect of rehabilitation is under-supported within clinical practice and service provision. Bennett (1996) carried out a study to explore how nurses working on a stroke ward managed depression experienced by patients following a stroke. Nurses reported that they did not feel able to deal with the problem adequately. This was for two main reasons; the first was lack of time, the emphasis in service provision being on physical care; the second was a lack of knowledge about how to provide psychological support, as little training had been given. Physical care was divorced from psychological understanding. Stachura (1994) a physiotherapist highlighted the emphasis of 'hands-on' treatment in stroke rehabilitation and called for wider social and psychological aspects to be taken into account. Hochenstach, Donders, Mulder et al (1996) after a five year follow-up study of 165 patients in the Netherlands concluded that in addition to a motor or function orientated approach, psychosocial treatment programmes are urgently needed.

Therapeutic service provision is short-term. Although a clear picture is difficult to determine it has been estimated that 50-90% of people following stroke are admitted to hospital (Wade, 1994). The estimates vary depending on severity of physical ability, and the ability of the family to cope with their relative at home. Usually within a hospital people have access to a therapeutic team, including nurses, doctors, physiotherapists and speech and language therapists. However after discharge,

although people may receive support from services such as home carers or meals-on-wheels, there is little therapeutic intervention (Hedley, 1994). Often, after rehabilitation within a hospital setting, people and their families are left to cope on their own. Doolittle (1992) found that when people returned home following a stroke they started to experiment; to determine, what they could do, what was possible and what roles they could take within the family. She noted it was just at this period of time that health-care support was withdrawn leaving people feeling abandoned. Lewinter and Mikkelsen (1995) interviewed 19 people at home three months to one year following discharge from a specialised stroke unit in Sweden. Although the people reported positive benefits from being together in a specialist unit and having professional support there; they felt that there should have been more attention to the social and psychological consequences of stroke after discharge. Evidence from these studies shows that there is a great deal of psychological and practical work carried out by people and their families after discharge with which they would like further support. There is a move towards setting up district rehabilitation services to support people in the community (Barnes and Lee, 1995, Utting, 1995, Adams 1997), initiated by an influential consensus statement from the Kings Fund in 1988. It is important that research addresses psychological issues to give guidance to service providers in this new area of work.

The lack of support for people following stroke has had long-term consequences. Emotional and social difficulties have been highlighted for many years (Labi, Philips and Gresham, 1980; Ebrahim, Barer and Nouri 1987; Anderson, Linto and Stewart-Wynne, 1995). Hedley (1994) carried out a survey of over 1000 people who were Stroke Association members. One of the questions related to how they saw themselves and their lives. Only 22% of those canvassed felt confident enough to endorse the statement 'I have got over my stroke and built a new life. For younger people (under 50 years) the figure was only 15%. The majority of people had not reached what they would consider to be 'new' life. Very little is known about how people do build a 'new' life, and how best to support people going through this process.

Within mainstream rehabilitation research there is no theoretical framework to support psychological approaches within hospital and little evidence to support psychological intervention following discharge from hospital. When assessing intervention programmes, outcome measures used by researchers do not appear to be sensitive to changes which are perceived to be beneficial to patients and relatives. Perceptions of stroke respondents have been included in a recently developed activities of daily living scale (Bennekom, Jelles, Lankhorst et al, 1996). Although respondents perceptions of problems are sought these are still related to tasks previously outlined by the researchers rather than aspects of life defined by the respondents themselves. Dennis, O'Rourke, Slattery et al (1997) carried out a randomised controlled trial of the introduction of a stroke family worker who visited people at home. They found no definite beneficial effect when studying the physical, social or psychological quantitative indices of patients or carers. However when patients and relatives were asked they reported great satisfaction with the service provided especially in aspects related to communication and support.

As so little is understood about life following a stroke, development of interventions appear to be based on 'common-sense' rather than theoretical principles. Forster and Young (1996) carried out a randomised controlled trial of five specialist nurses providing support for 240 people following stroke within the community. They provided information and advice over the year following stroke, as previous research had shown this to be an unmet need (Greveson and James, 1991). They found no significant changes in perceived health, social activities or stress among caregivers using quantitative indices. Using this evidence the introduction of this intervention could not be supported. Only after the trial did the researchers try to improve their understanding of the nature of the intervention provided by the specialist nurses. They carried out semi-structured interviews with 30 patients and 15 relatives (Dowswell, Lawler, Young et al 1997). They concluded that the important aspects of the nurses role were coaching, mentoring and motivating and that people appreciated the personalised support. The researchers concluded that although quantitative outcome measures in rehabilitation research could be valid, reliable and easily used tools; they

are insensitive to the complex patterns of patients' experiences, and that further work is needed in this area.

2.5 Development of a new theoretical framework

The aim of the present research is to contribute towards a wider theoretical framework, which will further understanding of the psychological aspects of an individual's life following a stroke. Although focusing on stroke within the present study, it is felt that the theoretical understanding gained may also contribute towards understanding within the wider field of acquired physical disability. The intention is not to replace the present approach into the study of physical and task orientated improvement, but to broaden, complement and enhance the knowledge gained. Evidence from the understanding of psychological phenomena is needed alongside knowledge of physical phenomena to develop a coherent rehabilitation framework. This could then be used to support the development of services which are more likely to meet the needs of those people who use them.

CHAPTER THREE

Development of a wider theoretical approach within stroke rehabilitation research: identity change following stroke

3.1 Introduction

In order to be able to provide services which will be of benefit to people, it is necessary to support those services with research evidence which reflects the concerns of the people receiving support. As noted in the previous chapter present rehabilitation research, although valid in some aspects, is limited by the narrow framework used. A wider framework such as that described in Table 3.1 would be helpful in addressing the concerns and needs of people following a stroke.

	Biomedical perspective	Proposed extended perspective
Period studied	Time in hospital	Time in hospital and over several years at home
Perspective	Defined by professionals	Exploration of the individual's perspective
Focus	The stroke individual	The individual and family
Aim	To study outcome	To explore outcome and process
Range of data	Specific variables	Complex and diverse data
Type of data	Based on group data	Data allowing the exploration of group similarities and individual differences

Table 3.1 Comparison of the biomedical perspective with the approach used in this study

Studies are often used to support the use of present (mainly hospital) services, using specific outcome measures based on group data. Recovery is defined by professionals, focusing on the physical abilities of the stroke individual. Doolittle (1992) found that a group of people who had experienced a stroke defined recovery as a return to a 'normal' life following a stroke, not just an improvement in physical ability. There appears to be more to stroke recovery than physical and self-care improvement alone. A return to a 'normal life' suggests that an analytical view is needed which considers the situation years into the future and the effect not only on the individual in isolation but within their familial, social and cultural context. In order to explore this wider

perspective an approach is needed as described in Table 3.1 which allows the exploration of the subjective experience of individuals over time, highlighting not only group similarities but also individual differences; addressing the complexity of everyday life. In order to explore a wider definition of recovery (i.e. return to normal life) it is necessary to understand three aspects; firstly how people see their lives before stroke and what is seen as 'normal'; secondly how life is seen as abnormal within the present; and thirdly what is seen as movement toward a return to normal in the future. It may be that the concept of recovery is not appropriate, as life never returns to 'normal' following a stroke. There are a small number of studies which consider the experience of stroke respondents; they will be discussed in the first part of this chapter. The following section will discuss research into an alternative approach, which may be used in understanding life and identity. The chapter will conclude followed by describing the methodological considerations of the present study.

3.2 Previous research into the experience of stroke

There is not a large literature regarding the experience of stroke. The focus for a high proportion of studies has been respondents' experiences of service provision. McLean, Roper-Hall, Mayer et al, (1991) carried out semi-structured interviews with 20 carers and 20 stroke survivors who had been discharged from hospital and were attending a day hospital. They investigated people's satisfaction with services and the advice given; how they spent their time; and the effects of the stroke on their relationship and general health. Similar studies were carried out by Greveson and James (1991), and Brandriet, Lyons and Bentley (1994). Respondents were asked how services could be improved and asked to describe their unmet needs. O'Mahony, Rodgers, Thomson et al (1997) carried out a study to explore satisfaction with information and advice stroke patients had received. In all of these studies the structured approach used in data collection, created works which appeared to act as surveys, rather than giving primacy to issues defined by the respondents. Thomas and Parry (1996) explored the views of service providers using in-depth, more loosely structured interviews. These studies have been useful in highlighting the service needs and the practical resources needed by people following a stroke; but the focus of

the research was still the professionals' concerns as service providers. They were asking "Are we doing well enough?" rather than contributing to the theoretical understanding of life following a stroke from the respondents' perspective.

An alternative approach has been used by Pound and her colleagues who analysed the components of care that were valued by people while they were in hospital (Pound Bury, Gompertz et al, 1994 and 1995). They carried out in-depth interviews with 40 people up to ten months after discharge from hospital. Following detailed analysis of respondents accounts, describing what happened when they had their stroke and their experiences in hospital, they concluded that the psychosocial aspects were as important as the practical aspects of care. Respondents spoke of the importance of the professionals taking responsibility for them in a time of crisis, how staff provided re-assurance, and how the feeling of being valued by staff was important. A specific analysis of physiotherapy highlighted that people did not merely value the physical exercise. They reported that they also valued the opportunity to be active and busy within the hospital setting, that treatment provided a structure to the day, and that therapists were seen as not only a source of advice, but also a source of faith and hope. In Denmark, Lewinter and Mikkelsen (1995) carried out in depth interviews with 19 patients, following their discharge from a stroke unit. The patients described the positive effects of being together with others, and the support of professionals experienced in stroke. These studies provide more of an understanding of the factors involved in the practitioner-patient relationship which affects rehabilitation. However the focus is on rehabilitation relationships, rather than how the person sees life following stroke.

Information about personal experience can be found in accounts in books or newspaper articles (Josephs, 1992; McCrum, 1996; O'Kelly, 1996). Although written to inform and inspire other lay readers, they can act as useful reference points for researchers. Articles have also been written in refereed journals. Klein (1996) wrote a critique of present rehabilitation for an audience of occupational therapists following her experience of stroke. Cant (1997) a college lecturer with experience in lecturing in disability and society, who subsequently had a stroke, felt compelled to reflect on his

experience one year following his stroke and tell his story. He described how he wanted to contribute towards a better understanding of the patient's perspective on disability and rehabilitation. Each personal story adds to knowledge about experience following a stroke, but there are limits to reading personal accounts. Often stories are told but are not analysed within a theoretical framework which would provide information about the psychological, social, cultural processes underlying the creation of those stories, and about life following a stroke.

The experience of relatives has also been a focus of research. One of the earliest and most wide-ranging studies was carried out by Anderson (1988). He asked 148 supporters (family members or friends) of people over 60 years of age who had had a stroke, and were identified by GPs within a specific district in London, to complete questionnaires and take part in semi-structured interviews. Interviews were carried out at four weeks, nine months, and eighteen months following stroke. The findings are difficult to interpret fully as the form of the interviews and method of analysis was not described. Anderson reported supporters' descriptions of: how they were coping with caring, how they felt the friend or relative had changed, and how there was a change in how they themselves spent their time, with reduced leisure and social activity.

Some studies have focused on specific needs, such as wives' perceived needs in hospital (Rosenthal, Pituch, Greninger et al, 1993); others have been longer term and more general. Researchers have tended to use semi-structured interviews which focus on limitations in activities or relationships brought about by the stroke. In response, relatives have spoken about specific aspects: such as relationship difficulties, changing roles, and reduced social and leisure activities (Jongbloed, Stanton and Fousek, 1993); the need to practice vigilance and create solutions to problems (Davis and Grant, 1994); and the need to establish a new balance in the relationship considering the practical and emotional issues of caregiving (Robinson-Smith and Mahoney, 1995). The experience of relatives has always been explored within the context of being a carer, in relationship to their family member rather than as an individual in their own right. This narrows understanding of their experience to only one (although possibly

an integral) aspect of their lives. Mumma (1986) studied the perceived losses of stroke respondents and their spouses in a cross-sectional study of sixty couples 3 to 72 months following a stroke using semi-structured interviews. This study provided some useful insights but reinforces the tendency to focus on difficulties and problems rather than the experience of life in general. A wider approach may allow the possibility of a more positive interpretation of life following a stroke.

The present study has been influenced by two ethnographic studies, those by Kaufman (1988a) and Doolittle (1991). Kaufman carried out a study of cultural factors in stroke rehabilitation, aiming to access patient and practitioner perspectives on the stroke rehabilitation process. She focused on patterns of rehabilitation among 102 stroke patients over the course of a year, using participant observation and interviews. As part of a larger study, interviews were carried out with 64 people in their own home, nursing home or rehabilitation facility an average of four times over the following year. Respondents were asked about the stroke occurrence, their responses to hospital treatment, recoveries and losses, their opinions about medical care and social services and their plans for the future. From an analysis of these interviews Kaufman identified three aspects described by the respondents: (a) the discontinuity of life patterns, (b) the failure to return to 'normal' and (c) the management of a re-defined self. From the main study, Kaufman (1988b) described the divergence between practitioner and patient perspectives. She concluded that the practitioners were involved in a 'rehabilitation' process, which included observation and measurement of tasks; whereas patients were involved in a 'recovery' process where recovery was seen as a non specific diffuse goal linked with notions of normality, continuity and identity. Becker (1993) a co-researcher on the same project, discussed: how people reacted to their physical status, how they managed time within the hospital, how they faced the transition of returning home, and how they created a sense of continuity in face of permanent change. She identified stroke as a life-course disruption.

Doolittle (1991 and 1992) carried out an ethnographic study focusing on the bodily experience and practical knowledge gained by the person who has had a stroke. She carried out participant observations on the hospital wards and in therapy sessions;

following up people from 72 hours after their stroke. She carried out 120 interviews with 13 people over a period of six months, covering both the acute and rehabilitation phase. The interviews contained structured and unstructured questions about bodily perceptions, responses to disability and the definition and appraisal of recovery. The analysis is difficult to interpret fully as it is not described in detail, but Doolittle highlighted specific aspects about the experience of recovery of the body which will be discussed alongside the analysis in the present study. Although focusing on bodily recovery, Doolittle moved beyond physical function and highlighted the fact that people spoke about recovery in much wider terms; that is, how their body allowed or did not allow them to lead the lives they wanted. Folden (1994) also provided some useful insights, in her study of the experience of stroke respondents from two weeks following stroke up to four weeks following discharge from hospital. She defined the process experienced by respondents as 'ensuring forward progress' which required: maintaining levels of energy, increasing control over recovery and maintaining hope. Recovery was defined as the accomplishment of personal goals, which were not necessarily the goals set by the rehabilitation teams.

3.3 Research into identity change following an acquired physical disability

In the present research, rather than framing recovery around the physical and practical aspects of life following a stroke; stroke is seen as bringing about a change in the identity of the person and their family. This wider framework has been chosen, as within it, it is possible to study the influence of physical, and social aspects on how a person sees themselves and their lives. With the rise of the field of health psychology and interest in the sociology of health, there is a developing theoretical basis from which one can understand individual responses to permanent health changes. Studies have suggested that individual responses to chronic conditions can be understood by considering three main areas: the meaning that individuals attach to the illness; their views of themselves and their own strengths; and their views of the future (Conrad, 1987).

Researchers in medical sociology have been at the forefront in the theoretical development of the study of identity change in chronic illness. Bury (1982) introduced

the concept of biographical disruption. He studied 30 people with rheumatoid arthritis visiting an outpatients department, to determine how their lives had been affected. Respondents described how they had to adapt to altered ability and accept interaction with the medical profession for the rest of their lives. People also described how they had difficulty in maintaining normal personal and community relationships in the face of their changed biographical experience. Often mundane difficulties affected people's lives and activities which were normally taken for granted required planning and forethought. Often social activities were tiring and frustrating and 'it did not seem worth the effort' so they were reduced. Corbin and Strauss (1987) interviewed 60 people who had a physical disability such as a cardiac problem, cancer, stroke, diabetes and paraplegia. People reported that they felt that their illness separated the person of the present from the person of the past (before illness) and affected images held for the future. They felt that their sense of identity and biography had been disrupted. Corbin and Strauss put forward a model to explain their findings, postulating that biography had three aspects: (a) conception of self (personal identity), (b) biographical time - the person's past, present and future, and (c) the person's body - the medium through which the somebody achieves the tasks that create identity. Corbin and Strauss defined an overall concept, biographical body conception, as a collection of conceptions of self arising directly or indirectly through the body as they evolve over the course of biographical time. They proposed that people did not respond to sickness as described by the medical model but that they responded to body failure and how it affected activities in their lives.

Other researchers have contributed to a small but growing body of knowledge of the effect of chronic illness on identity; including studies involving people with rheumatoid arthritis (Williams and Wood, 1988), multiple sclerosis (Robinson, 1990) and acquired chronic illness in general (Charmaz, 1983; Frank, 1995). Medical anthropologists have contributed to this area by emphasising the distinction between disease and illness experience. They have argued that more attention needs to be given to the treatment of the illness experience and the way in which the disease affects a person's life (Kleinman, 1988, Helman 1991). Physiologically the same

disease can result in a very different illness experience depending on the patients life history and life possibilities.

The present research was influenced also by the work of Tyerman and Humphrey (1984), psychologists who demonstrated the clinical applicability of an approach focusing on identity. They carried out a study of 25 consecutive patients with severe head injury who were attending one of two specialist rehabilitation centres an average time of seven months post injury. They assessed past self-concept (before head injury), present self-concept and future self-concept using the Semantic Differential self-concept scale based on an approach developed by Osgood, Suci and Tannenbaum (1957). They found that people saw themselves more negatively in the present on all aspects assessed as compared to the past. The researchers also found that individuals tended to see themselves returning to their past selves within a year. These were unrealistically high expectations due to the nature of their disabilities. The researchers suggested that it may only be by one year that individuals appreciate that their expectations will not be met.

In a quantitative study of people's self-concept following stroke, also using the Semantic Differential self-concept scale, I found that respondents who were assessed up to two years following their stroke saw themselves differently (Hill, 1992). They saw themselves as more negative in every aspect of self-concept assessed, apart from seeing themselves as more caring. They described themselves as being more bored, dissatisfied, lacking in confidence, inactive, more helpless, incapable and dependent following stroke. They were often housebound, had higher anxiety and depression scores and lower levels of activity than a sex and aged matched control group. These findings were remarkable in that the 26 people who were included could be called the 'successes' of rehabilitation. They had all received in-patient rehabilitation and had managed to return home from hospital. All but one were able to walk and they had no severe communication, cognitive or perceptual problems. Rehabilitation efforts had been directed towards physical improvement, but recovery of a positive identity did not seem to relate to physical disability alone. The person who had the smallest change in overall self-concept and maintained a positive self-concept was the person

who used a wheelchair and was the most physically disabled of the group. She said that she saw her old life as having finished and that she had started a new life.

3.4 New approaches to identity research in psychology

Increased interest in studying identity change associated with chronic illness within health psychology and medical sociology has been paralleled by developments within psychology in the study of self-concept and identity. Self-concept research is framed within a model based on cognitive representations of the self and the world. Shavelson and Bolus (1982) defined self-concept as a person's perceptions of him or herself, which are formed through experience with and interpretation of the environment. They proposed that these interpretations are influenced especially by reinforcements, evaluations by significant others and attributions for one's own behaviour. Self-concept was seen in terms of cognitive representations which were categorical, multifaceted and hierarchical in nature. Cognitive approaches to the study of identity have received criticism from certain areas within psychology (Harre and Gillett, 1994). The idea of a self-concept or a group of self-concept cognitions within the brain, appears to represent an outcome or an endpoint, rather than a process. Researchers such as Markus and Wurf (1987) have tried to introduce dynamism into their models of self concept. They recognised that self-concept can be situation dependent; dependent on different roles, taken at different times, and related to mood. They used the term 'working self-concept' and described the 'peripheral' aspects of self-concept as a continually active shifting array of self-knowledge. Although trying to incorporate dynamism into the model, a cognitive approach provides no clear theoretical basis to understanding possible mechanisms as to how self-processes occur. The focus is on an 'internal' structure private and separate from the world.

Bruner (1990) criticised the cognitive approach as being the study of information processing rather than the construction of meaning. He rejected the move away from everyday life and 'humanness'. In his work he emphasised the study of the symbolic systems individuals use to construct meaning, found in culture and language. The recognition that human activity and social practices have a profound influence on the nature of reality is the basis of what has been termed the discursive approaches

(Yardley, 1997). Qualitative approaches based on everyday life situations have been used for many years in other disciplines such as sociology and anthropology, and have recently been taken up and developed by researchers within psychology (see Bannister, Burman, Parker et al, 1995; Smith, Harre and Langenhove, 1995). Discursive approaches change the focus of study, from a 'reality' out there or representations inside the head defined by psychologists, to the processes by which people create their own realities using symbols and language depending on the sociological and cultural context in which they find themselves. The focus of research is shifted to explore how individual people construct their own perspective of the world and their own sense of self; the focus for study is the everyday world (Smith, Harre and Langenhove, 1995).

3.5 Methodological approach used in the present research

A material-discursive approach was considered to be the most appropriate to use within this research. Using this approach the bodily experience of stroke is recognised to have an inherent reciprocal influence on socio-cultural experience and language. As Yardley (1997) stated:

Using this approach the world is not the fixed objective physical world of the realists, but a world which is simultaneously material and (psycho) social and which is constantly shaped and reshaped by perceptions, intentions and activities of the members of the society. (Yardley 1997, p9)

Bodies are not seen as suitable only for study by biomedicine as neutral physical matter and mechanical processes, but as purposive agents continuously shaped and reshaped by dynamic interaction with the environment. Phenomenology provides a framework for studying the meaning of embodied experience. Merleau-Ponty (1962) put forward the idea that human experience arises from the relationship between the perceiver and the object perceived, through sensation such as sight, smell and touch. These sensations are transformed from neutral data into personally meaningful structures through active (though usually unconscious) interpretation. A sense of reality and the world is created via the senses through body-environment interaction. Merleau-Ponty (1962) highlighted the intrinsically meaningful and intentional nature of embodied 'being in the world'. He challenged the dominant Cartesian idea of a

mind-body dualism, as he suggested that embodied existence is meaningful and purposive, the phenomenological self transcending this split. The body and self are seen to be one. For example, if a person damages their hand, they will say 'I' cannot write or tie up my shoe laces, even though it is only their hand that is damaged. The aim of using a phenomenological approach within the present study is to attempt to capture a sense of 'being in the world'. Using this approach the goal is not to predict or explain. The strength of this approach is in understanding and discovering new meanings that have previously gone unrecognised because of their perceived 'everydayness' (Gullickson, 1993). Also by describing interpretations of subjective experience, readers may be able to appreciate in some sense what it is like to live following a stroke.

Within the present study a complementary theoretical approach, narrative theory, has been used. This approach was felt to be useful as, although phenomenological approaches access ways of 'being in the world', narrative theory highlights how people reflect upon this experience, and understand their worlds within their social-cultural contexts through discursive practices. Ricoeur (1981) challenged Husserl's phenomenological approach by suggesting that it was not possible to have direct apprehension of the self by the self. He proposed that understanding of the world could be conceived as an internal dialogue, a way of explaining life to ourselves. Theorists have suggested that these reflections on life take a particular discursive form - that of narrative (Sarbin, 1986; Ricoeur, 1991; Freeman, 1997). By exploring the structure of narrative, psychological responses to one's sense of self and one's life can be more fully understood.

Definitions of narrative tend to vary from a vague term such as storytelling (Carr, 1986) and life story (Reissman, 1993) to specific definitions applying to rules of grammar (Labov, 1972). My own definition of narrative, used in this research, has been formed from the work of others (Ricoeur, 1984; Kerby, 1991). A narrative is defined as

the re-creation of events and actions in a symbolic structured way so that the motives of the actors and the morality of the situation can be understood by self and others.

(Hill 1997, p 132)

A narrative is a re-creation of events, it is not a repetition of events - as in a list. The teller attends to certain aspects of the events, ignores others, creates actors, sets them on a stage, creates a storyline or plot describing the motives of the actors, which they feel will be of interest and excite the listener. The storyline or plot is the basis of a narrative. Events are linked not because of categorical similarity but because they contribute to a plot (Ricoeur, 1984). Every plot has a beginning, middle and end, and the events included are governed by the resolution or point of the story. Stories are told to convey messages to the listener. Narrative structure communicates moral values between the speakers. Events themselves do not contain valuation properties; whether an event is good or bad depends on the framework which is used for understanding. The potential array of frameworks for rendering events intelligible is infinite (Gergen and Gergen, 1983). In order to appreciate a plot the audience must have shared cultural norms, a common understanding. Sharing of narratives is based on and enhances these cultural norms and expectations. So although every life story is individual and unique there are shared historical and cultural commonalities. Narratives not only re-enact material practice in the telling, but reinforce social and cultural structures of society *through* their telling. These moral and social underpinnings of narrative have been recognised as playing a key part in the interpretation and experience of illness (Radley, 1994).

Narrative structure is thought to contribute to a sense of temporality, identity, and unity (Bruner, 1990; Sarbin, 1986). Although these characteristics have been separated out for discussion, they are interdependent and none can be considered in isolation. Carr (1986) stated that narrative is our primary way of organising our experience of time. It is assumed that people live in the present; but as we move through time, this present state can be seen as a moment which is seen to be passed as soon as it is reached. People do not live in a present where the past cannot be reclaimed and the future cannot be imagined. If we did we would live in a constant state of flux unable to know how to react or respond. Ricoeur (1984) explored the link between narrative and time. He put forward the idea that human experience is not based on linear or clock time, but that events of the past and future are linked to the

present through the use of narrative. Narrative highlights a sense of fluid rather than linear time. The past is not a fixed list of events. Personal reflection is guided by narrative. How somebody sees and interprets their past depends on why they are reflecting on it (i.e. their present state, or ending). Completely different stories may result at different times from the same event, one is no more valid than another and the meanings ensuing from these stories may be different. Just as accounts of the past are not fixed, accounts of the future are not fixed. There are many possibilities for behaviour or response available to people in the future, although it is recognised that options will be limited by personal and societal conditions (Markus and Nurius, 1987; Jansz, 1995).

It is thought that people tend to create stories which reinforce their sense of who they are and so create a sense of personal continuity over time. Aspects of past experience are selected in biography to support present identity. For example, a world famous pianist may recount and remember his first piano lesson in detail, but not his first art class. People tend to create themes and continuities through life by using narrative (Kaufman, 1988a). As one's life story unfolds one may tell the story to oneself and others. This creates a continuous interchange between telling and living the life story. The social psychologists Gergen and Gergen (1983) conclude that present identity:

is not a sudden and mysterious event but a sensible result of a life story

(Gergen and Gergen 1983, p255)

and as such, creation of narrative order is essential in giving one's life a sense of meaning and direction.

When a narrative is told several events are linked to form a complete, whole story. Every story has a beginning, middle and end. The random, chaotic experience of a life is transformed into some semblance of order and unity by a life story. This enables predictions about future relationships to the physical and social world. The process of grouping of significant events into a whole narrative or story was well described by Freeman (1993) when he analysed the novel Nausea by Jean-Paul Sartre. The narrator Roquentin decides to write a diary of his life, keeping a written record of any events whether he feels they are significant or not. He wants to remain as close to the reality

of what happened as he possibly can. He does not reflect on what he has seen as he does not want to contaminate the real data he has collected, he merely notes all his experiences. He finds that his life is given a jerky incoherent aspect. He leads a very solitary existence. He states:

When you live alone, you even forget what it is to tell a story: plausibility disappears at the same time as friends. You let events flow by too: you suddenly see people appear who speak and then go away; you plunge into stories of which you can't make head or tail. (Sartre 1964, p17)

The unity of selfhood can be seen in that the present can be seen to be in a continual and unbroken anticipation of the future and retention of the past. An often cited example is the experience of a melody, its various moments can only be recognised as part of a melody, if the present is not cut off from the immediate past (Kerby, 1991). A sense of continuity and coherence is seen as vital in human experience (Myerhoff and Simic, 1978). It is recognised that continuity is essential for psychological well-being and personal integration and for an individual to experience him or herself as one person, despite change and disruption, throughout the life cycle.

So it can be seen that narrative links conceptions of the past and future to present action. People's stories motivate them as their ongoing action is the continuation of the story they are in. People act with the sense of an ending and because they care about that ending, they try and direct their actions and the actions of other relevant actors in ways that will bring the ending about (Kermode, 1966). Decision making only emerges out of the person's particular appreciation of his or her situation. Stories give decisions and actions, meaning and context. While developing my research approach, I created a pictorial metaphor which I found helpful when thinking about narrative and biography which can be seen in [Figure 3.1](#). A single life is represented as a rope made up of many life threads which have been woven together. The metaphor of a rope represents a sense of passing through time, a sense of selfhood as different from other, a sense of unity and a predictable way of relating to the physical and social world.

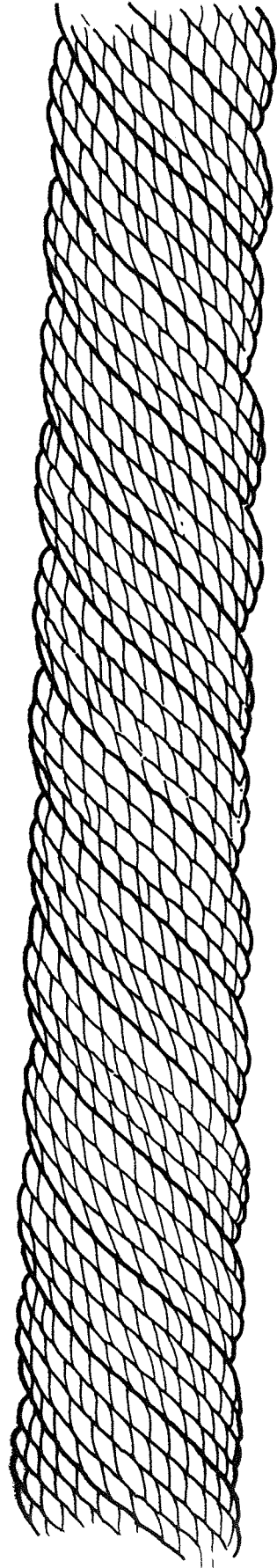


Figure 3.1 Complete life thread

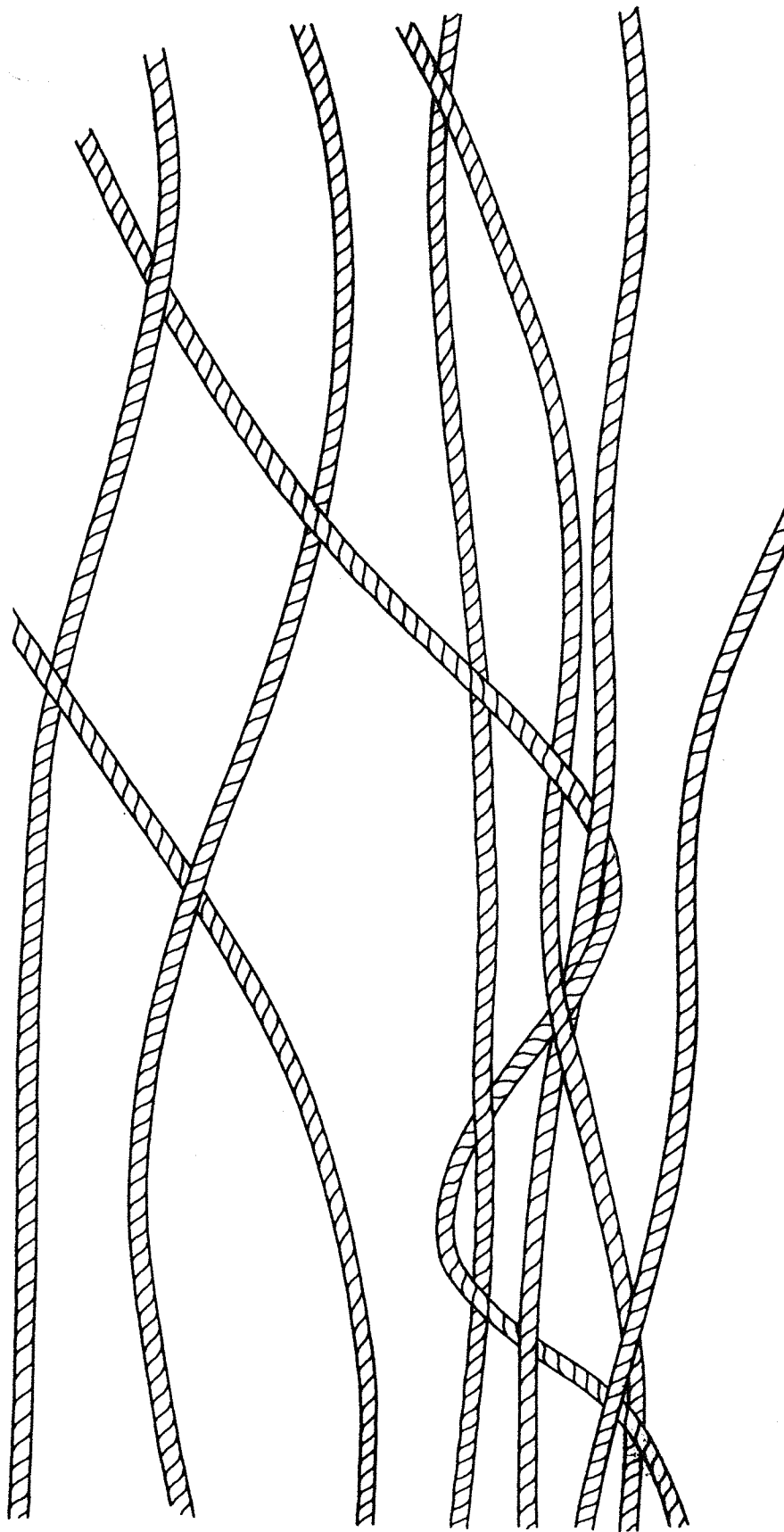


Figure 3.2 Parallel life threads

Within this pictorial metaphor an individual's life is seen as part of a larger picture of life narratives as in [Figure 3.2](#). These other threads weave with an individual's thread and create and limit the possibilities of life narrative. This model highlights the fact that other people's narratives will be affected by an individual's chronic disability. The proximity of the threads represents closeness of relationships. It would be expected that carers who share more extensive joint life narratives with a person (and are represented as having a thread close to the central life thread) would be more affected than say a colleague at work (who could be represented by more distant threads).

People use stories to understand the social world. People try to understand the motives of themselves and others through exchanging stories. For example, if a person known to you, walked past you without saying hello, you recreate the event in your mind and make up a story about it - perhaps she didn't see me? or perhaps she's angry with me for some reason? This emphasises the social nature of behaviour. Bruner (1990) highlighted the fact that narratives are only brought to consciousness when cultural, social or personal situations and meanings cannot be found. He cites the 'situational rule' put forward by Barker (1978). This rule states that people behave in a manner appropriate to the setting in which they find themselves. For example, when people go into the post office they behave 'post-office'. If a person was asked why they are behaving as they do in a post office they would feel they did not need to look for an explanation and reply 'It's what you do in a post office'. If something out of the ordinary happens, it is then that an explanation is sought. For example, if a man rushed into the post office, unfurled a union jack and started waving it about, people would look for explanations. They may say that he was mad, or that perhaps he's an enthusiastic supporter of the queen and it's her birthday. The function of the story is to find an intentional state which mitigates or at least makes comprehensible a deviation from normal everyday expectations. When telling a self-story the narrator describes events moving through time; the actors including the self-actor are purposeful, being part of the plot. When the narrator can create a coherent story, the events have meaning; the narrator can make sense of a situation, they can understand why certain things happened. It is when people cannot create a coherent narrative

from past or future events that the events and therefore life becomes meaningless. Normally a person has a sense of being a particular person whose world is relatively controllable and predictable. They understand what is going on around them and so do not need to be consciously aware of the narrative process. As Bruner (1990) stated, narration only comes to the fore when people try to make comprehensible a deviation from normal everyday expectations. This was well described by Oliver Sacks after a traumatic leg injury:

being full of strength and vigour one moment and virtually helpless the next.. with all ones powers and faculties one moment and without them the next .. such a change, such a suddenness is difficult to comprehend and the mind casts about for explanations.

(Sacks, 1991, p 6)

A phenomenological-narrative approach can be seen to be appropriate within the present research as following a stroke normal everyday explanations have gone, people experience changed relationships with their physical and social environment. There is a challenge to personal assumptions about oneself and the structure of the world one lives in and to the ability to change predict and understand environmental transactions. Links between the bodily lived world, life narrative and sense of identity can be seen in the following two quotes. Federico Fellini when asked about what he missed most following his severe illness replied:

What do I miss? I miss myself. What I used to be

(Guardian, October 20th, 1993 p7)

and Jill Tweedie on being diagnosed with Motor Neurone Disease stated:

I don't want to be uplifted, or uplifting. I just want to go on being me.

(Guardian 2 September 14th 1993, p1)

Personal identity was identified as a fundamental concern following permanent bodily transformation.

Returning to the pictorial rope metaphor, following permanent bodily transformation, the life threads can be seen to become unravelled (see [Figure 3.3](#)). There may be some threads which remain intact, for example a person may still see themselves as a mother, a son, but other threads or roles, such as gardener, painter, provider for the family, may be cut and frayed. Because the life threads/life narratives are broken there is a loss of predictability and stability in life.

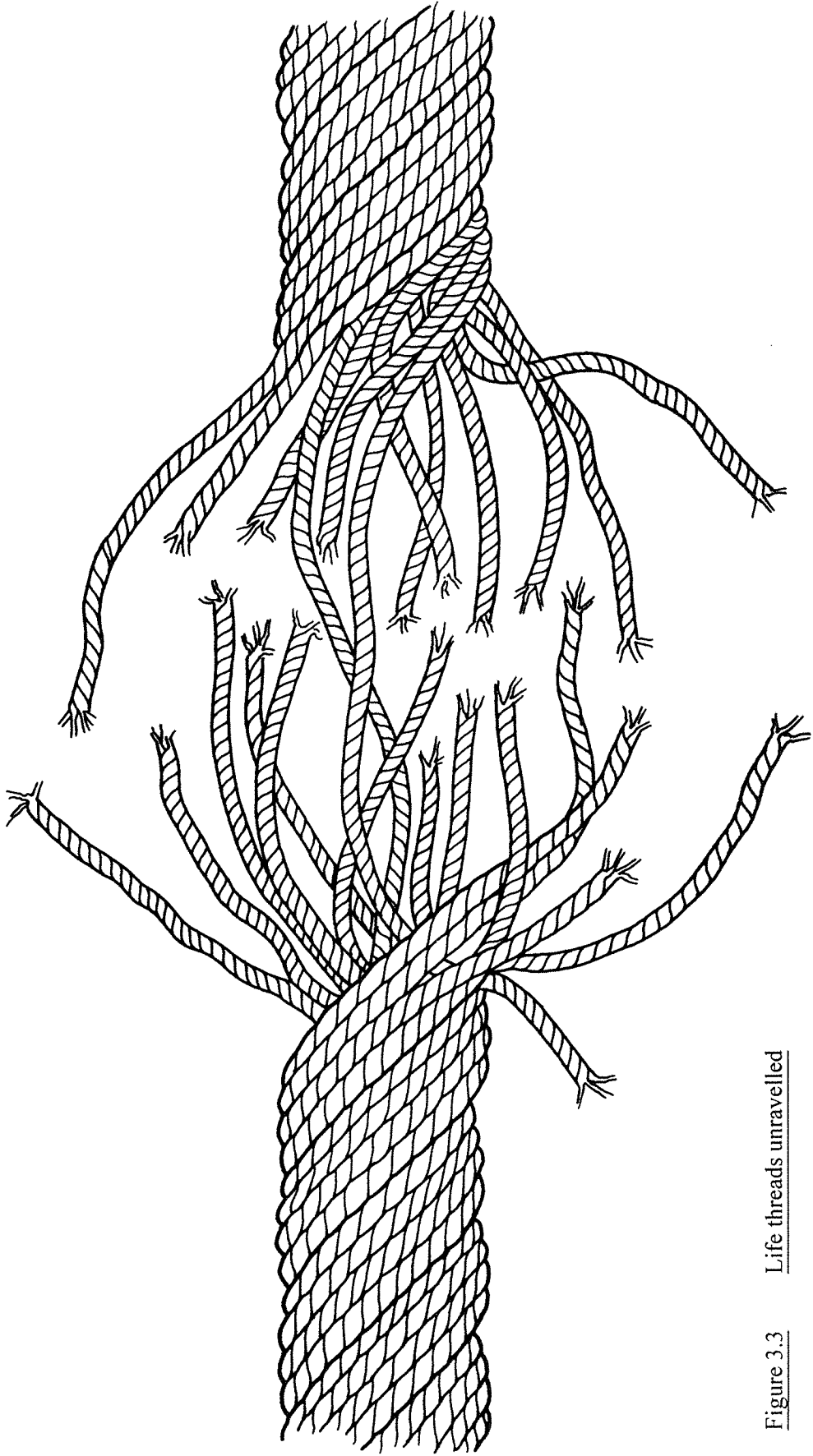


Figure 3.3 Life threads unravelled

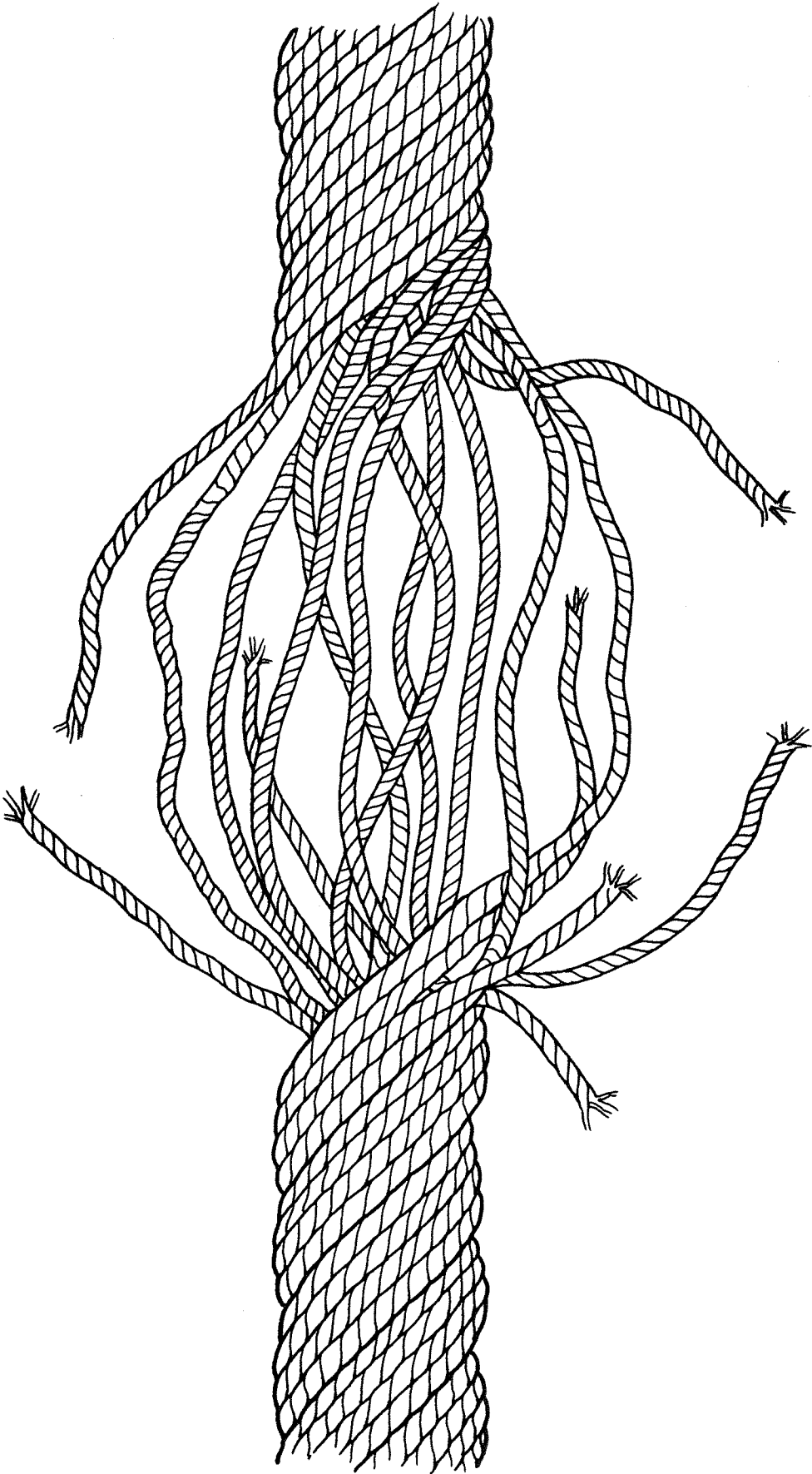


Figure 3.4 Life threads joining up or tied off

Using the rope metaphor, it can be seen that the role of rehabilitation professionals is to help the individual link life threads or tie off ones which cannot be linked (Figure 3.4).

The methodological approach taken in this thesis is similar to that used by Smith (1996) which he describes as interpretative phenomenological analysis (IPA). The aim of IPA is to explore the participant's view of the world and to adopt as far as possible an 'insiders' perspective (Conrad, 1987) of the phenomenon under study. The focus of the present study is not so much an attempt to elucidate the interactive tasks being performed by verbal statements and how these tasks are accomplished, as would be the case in discourse analysis (Potter and Wetherell, 1987); but to create a cognitive and emotional link between the reader and the world as described by respondents and at some level, engagement with and understanding of their situation.

As a clinician I am aware that I would like my work to contribute to clinical practice. As well as considerations on theoretical grounds I recognise that practical considerations have also influenced my choice of methodology. From a practical standpoint the adoption of a unitary framework, i.e. life narrative, as a way of exploring identity following stroke, is an attractive proposition. It provides an overall framework with which clinicians may be able to identify, and which allows specific aspects related to practice to be explored. It has been noted previously that professionals have little understanding of the experience of people with a chronic illness (Price, 1996), and that people following stroke are seen as 'other'. Susko (1994) contrasted 'caseness' and 'narrative' approaches for treating individuals who are psychiatrically labelled. He suggested that 'caseness' as well as supporting objectification of people, created associations with negative connotations. When people are viewed as patients or 'cases' they are associated with passivity and limitation, the focus is on deficit and difference. By using a life narrative approach which highlights the sharing of perspectives between narrator and audience, professionals will not only gain more of an appreciation of a persons life situation but just as importantly, by listening they will share cultural and social norms, and so will be less likely to perceive them as 'other'. Bogdan and Taylor (1989) suggest

acceptance of people with disabilities is connected with a notion of ‘humanness’ that all people contain. As Nochi stated about people following a head injury:

narrative sharing is crucial to understanding people with Head Injury as neighbours to live with and not as patients. (Nochi 1997, p552)

I have made a conscious decision to broaden the field of research to include the views of spouses as well as the person following a stroke. I feel it is important to include them as individuals in their own right rather than existing only in relation to their partners; as carers.

3.6 Aims of the present study

Within this study I have used two very different approaches, with two different but connected aims.

- The first and main aim is to contribute to a theoretical understanding of identity change by people and their relatives following a single stroke.
- The second and supplementary aim is explore a measure which could be used by rehabilitation practitioners, to broaden the range of outcome measures to include assessment of identity change.

CHAPTER FOUR

Method

4.1 Overall design

The research programme encompassed two studies which were carried out concurrently. The main study consisted of narrative life interviews, which were carried out with stroke respondents and their spouses, in order to gain further understanding of identity change following a stroke. In the secondary quantitative study, a larger number of stroke respondents and their spouses (if existing) were asked to complete a questionnaire including a Semantic Differential self-concept scale. This study was included to allow exploration of a scale which could be used by rehabilitation practitioners, to broaden the range of outcome measures to include aspects of identity. The design of the study can be seen in Figure 4.1.

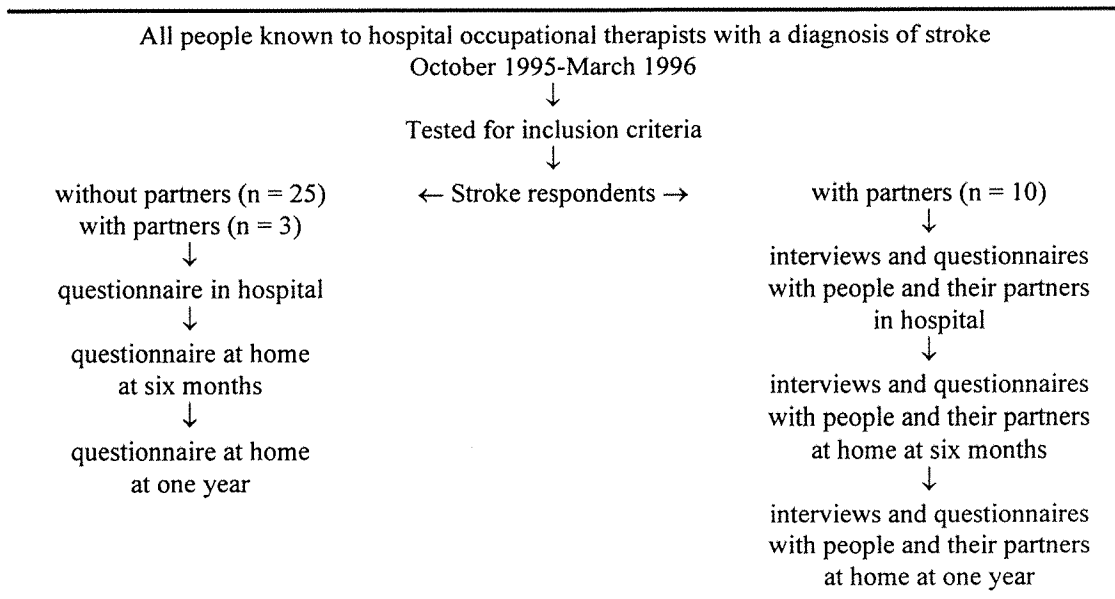


Figure 4.1 Overview of study

The overall study was a prospective longitudinal study of stroke respondents and their spouses up to one year after their hospital discharge. This approach was considered as it was expected that the nature of life narratives would change over time. Separate life narrative interviews were carried out with the stroke respondent and their spouse while

they were in hospital, at six months and at one year post-discharge. The first interview was carried out while they were in hospital. Interviews were conducted within the last two weeks before discharge, when respondents had nearly come to the end of their hospital stay and were preparing to return home. The timing of the follow-up interviews was linked to hospital discharge rather than the stroke event, to reflect the effect of living at home, instead of following a medical time-line. Interviewees were asked to complete an additional questionnaire containing indices of physical and functional ability, mood, and past, present and future self-concept. The questionnaire was also completed by a larger group of stroke respondents and their partners (if they had one) while they were in hospital, at six months and at one year.

The focus of the study was the transition from being able-bodied to living life following a stroke. It was assumed that people who were admitted to hospital following stroke would be those most likely to experience a change in their lives due to physical difficulties. Hospital admission can be seen as a 'typical' trajectory for a person who had experienced a stroke and experiences permanent physical disability, as the majority of people who experience permanent physical disability are admitted to hospital. Young (1994) reported that about 70% of people are still admitted to hospital following stroke. Hedley (1994) in a recent survey found that 84% of respondents canvassed by the Stroke Association in the UK had been admitted to hospital.

The life narratives of spouses as well as those who had experienced a stroke were central in this study. From a life narrative approach one would expect that spouses' future possibilities would be affected, and so an exploration would add to theoretical understanding. Also, spouses are often not directly included in the rehabilitation process and I did not want to reinforce this omission in the present research.

4.2 Ethical approval

Ethical approval was sought and given by the Southampton joint ethics committee in May 1995. Ethical considerations were addressed throughout the study. They were determined by the principle that people's psychological or material conditions should not have worsened through their involvement in the research (British Psychological Society, 1993). These considerations were paramount as the participant group consisted of a potentially vulnerable group of people within a hospital situation, who may be compromised to some degree in their ability to offer willing consent to health care professionals (De Raeve, 1994). Consent was sought and given by the consultants covering every appropriate ward to approach their patients. Each consultant was contacted by letter (see Appendix 1). Each potential participant was approached by the researcher on the ward. The study was explained with the aid of an information leaflet (see Appendix 2) which was left with the person. The leaflet explained why the project was needed, why they in particular had been approached, and who and what was involved. Within the leaflet they were encouraged to discuss their decision with nursing staff, family and friends. Also, the contact number and address of the researcher was included within the leaflet. People were offered two days to consider their involvement in the project. Before taking part in the study each partner within the couple gave written consent (see Appendices 3 and 4).

Throughout the study measures were taken to ensure that anonymity was maintained. Reference codes rather than names were used on any personal material, such as questionnaires or interview tapes. When not being used, this material was stored securely. Names and addresses of participants were stored securely and separately from this material. When names and addresses were used during follow-up visits, paperwork was held securely at all times. The computer data-base could only be accessed by the researcher. A number of the tapes were transcribed by a third party. They were given a code number, and although the transcriber gained personal insights from the tapes, they were not linked to a named person. The transcriber did not talk about the content of the tapes to others. When writing this thesis pseudonyms were used. Difficulties were encountered due to the nature of biographical material. Even though real names were not used, due to the personal nature of the material,

individuals may have been recognised by others. Care was taken within the thesis not to use any material which may have been considered sensitive.

All people taking part in the study were informed that they could withdraw at any time and that withdrawal would not affect their future health treatment in any way. Following the ethics committee request that others were informed of the study, the fact that the stroke respondent had agreed to take part in the study was written in their medical notes. With the patients knowledge, their GP was also informed.

4.3 Pilot studies

During the preparation for the main study, several informal and one formal pilot studies were carried out. Several trial interviews with colleagues were held, in order to practice interview techniques and develop the interview schedule. Although I had previous experience of using the quantitative assessment battery, it was with stroke respondents at home rather than within a hospital situation. Following ethical approval, a pilot study was carried out involving two couples, in order to assess the practicality of approaching people on a hospital ward. Several aspects of the situation were assessed. They included: the response of people on being approached, the acceptability of the patient information leaflet, aspects of privacy when the questionnaire was completed on the ward, the ease of organising a quiet room for the interview, the usefulness of the interview schedule and my self-presentation. Overall, the approach which had been considered appeared to be acceptable and is discussed in detail in following sections. However some changes were made. I discovered that relatives often preferred to be seen in the evenings and the quiet room I had arranged was not suitable, only being available in working hours. An alternative room was arranged within the hospital. Also, I had considered asking stroke respondents to complete the questionnaire in two stages, so that they did not tire. I found that people were happy to complete the questionnaire in one visit, taking about 20 minutes. Following the pilot studies the level and type of transcription was determined from an initial assessment of the interview tapes.

4.4 Recruitment

From my previous study I knew it would be difficult recruiting sufficient numbers of participants. Throughout the preparation for the study a great deal of thought and effort was directed towards building and maintaining relationships with others. The previous research included a similar but not identical sample. Two hundred and eleven people following stroke had been available in total, but following the application of exclusion criteria only thirty-four were available to be contacted. In order to maximise my efforts, links were made with health professionals who could identify potential respondents.

4.4.1 Gaining access to hospital consultants

A meeting was held with the director of stroke services and she advised on further contacts. They included medical and elderly care consultants, clinical nursing managers and ward staff. I agreed to report back to the director at the end of the research. Medical and elderly care consultants covering all local hospitals within Southampton were contacted by letter for permission to approach their patients (see [Appendix 1](#)). All consultants agreed and several asked for information about the findings of the research. I agreed to write in the medical notes that people were taking part in the study.

4.4.2 Gaining access to occupational therapists

As all people admitted to the hospital who had some residual physical disability were routinely seen by an occupational therapist (OT), they were able to identify possible participants. As an OT myself I felt comfortable in approaching the service. Initially, I met the OT service manager, who gave me permission to liaise with her staff, and also to use a quiet room in the OT department for interviews. Having attended a staff meeting where the project was introduced, I gave a more detailed presentation to the Senior OTs. I had individual meetings with the three therapists who agreed to notify me of possible participants. We discussed the research, the entry criteria for the study, the most appropriate way to liaise (which was either by phone or via ward meetings) and the fire and safety procedures within each hospital. I agreed to provide each therapist with a short research report on completion of the study.

4.4.3 Gaining access to nursing staff

Having written to the clinical nurse managers to inform them of my research. I wrote to the key ward sisters to arrange a meeting. At the meetings the project was described and I reassured the sister that I had experience of working within a ward environment. Later in the study, as the recruitment area widened (see [Section 4.4.4](#)) it was not always possible to have individual meetings with the ward sister. Whenever entering a ward I always ensured that the person in charge was informed about the project. Several aspects were considered when working on the wards. They are listed in [Table 4.1](#).

Considerations	Action
Introduction of project to ward staff	Staff were given copies of the patient information leaflet Posters were placed in ward staff rooms
Rapid turnover of staff	I attended 'handover' meetings
On-going communication	I always left a record of appointments in ward communication books
Timing of visits to patients	avoided mealtimes avoided visiting times, unless meeting spouse avoided therapy times avoided early morning patients getting up always checked with staff that no other plans i.e. medical tests
Timing of visits to staff	learnt times of handovers learnt times of staff meetings
Self presentation	smart but casual dress wore name badge -rehabilitation research unit

[Table 4.1](#) [Practical consideration when working on a ward](#)

Although I had joint supervision from the Rehabilitation Research Unit and the Psychology department, both university departments; I used the Rehabilitation Research Unit in preference on my badge as the unit was based within the hospital and known to the staff.

4.4.4 Phases of recruitment

Initially, stroke respondents were recruited within a small geographical area in the hospital, to make the most efficient use of my time. The focus was the medical wards, enabling access to younger patients who were less likely to have secondary problems which would affect inclusion or follow-up. After assessing the recruitment rate, the

area was widened to include other wards, and eventually several local hospitals. Recruitment was influenced by several hospital policy changes which occurred over the six month period. The changes can be seen in Table 4.2, and are described as six phases.

Phase	Recruitment areas
One	One of four medical wards which was a designated stroke unit
Two	The policy of the ward changed and it became a general medical ward, stroke patients were seen on all of the four medical wards, and so they were included.
Three	One elderly care ward was designated as the stroke unit
Four	On assessment I found that only people with very severe strokes were seen on the unit. Others were seen on the other three elderly care wards
Five	I discovered that younger people were more likely to be admitted to another local hospital and then moved to a separate rehabilitation unit
Six	Change in hospital policy - people spent only two weeks on the acute elderly wards before being moved to local longer-term elderly care hospitals

Table 4.2 Phases affecting recruitment

Most of the changes occurred over the first six weeks of the recruitment period. Following up to longer-stay elderly hospitals occurred later in the recruitment period. By phase six, I was working with OTs and ward staff in four local hospitals.

4.5 Selection of possible participants

Having obtained the name and location of a possible participant, ward staff were consulted, and medical records on the ward were checked, to ensure a diagnosis of stroke and for the theoretical and practical exclusion criteria which can be seen in Figure 4.2.

1	No previous disability
2	Discharged to own home
3	No severe cognitive problems
4	No severe communication problems
5	English speaking
6	Medically stable
7	In hospital for 10 days
8	Lived on the mainland within 30 miles of the hospital

Figure 4.2 Exclusion criteria

Potential participants were excluded on either the theoretical or practical grounds which are described in the following sections.

4.5.1 Exclusion criteria based on theoretical considerations

- (i) As the focus of the study was the transition from being able-bodied to life following a stroke, people with a previous stroke or another chronic disabling physical illness, such as rheumatoid arthritis which already affected daily life, were excluded. People suffering from a chronic illness which was controlled by medication, such as diabetes and minor cardiovascular disease were not excluded if their practical daily life was not affected.
- (ii) If the person was likely to be discharged to a nursing home they were excluded. This was for two reasons. Firstly, a move to a nursing home is a major life transition in itself and the theoretical understanding of stroke would be compromised. Secondly, often people and their families were too distressed to take part in interviews. Future studies with this group would provide useful comparisons to the present study.

4.5.2 Exclusion criteria based on practical considerations

Respondents needed to be able to take part in an interview and/or complete a questionnaire.

- (i) Several people could not be included in the study as they had severe cognitive difficulties. Skilful research has been carried out studying the narratives of people with dementia (Cheston, 1996). In the present study it would have been difficult to disentangle the effects of dementia and stroke.
- (ii) People who had expressive communication difficulties but who could make themselves understood through reading or writing were excluded from the interview study but were included in the supplementary questionnaire study.
- (iii) Only English speaking respondents were included as I did not have access to interpreters. This denied access to one Indian and one Chinese participant, but English speaking West Indian and Polish participants were included.
- (iv) Only people who were medically stable were approached to take part in the study. The main reason for this was not to cause distress to people who were feeling unwell. Also, it was recognised that people who were unwell for long periods following their stroke, would be less likely to return home and be able to complete a year long follow-up.
- (v) Only people who were still in hospital ten days after admission were considered for recruitment into the study. This excluded people who died within a few days of admission and those who had a minor stroke who could look after themselves or be looked after at home. This meant that the participants included in the respondent group were those with some physical disability.
- (vi) As I was following up respondents in their own homes, it was only feasible to include those people who lived on the mainland within 30 miles of Southampton.

4.5.3 Sample size

The couples who took part in the interviews were selected on a consecutive basis. A sample size limit was set at ten couples, giving 60 interviews in all. This was thought to be the maximum number of interviews which could be analysed in the necessary depth. Also following selection of the ten couples; variations in age, sex, cultural background, time spent in hospital and degree of physical disability were found in the group.

All respondents were selected for inclusion in the questionnaire study on a consecutive basis. In order to study the relationships between indices of mood and self-concept, physical ability, and daily activity; it was necessary to collect sufficient information for statistical analysis of the data. From previous work (Hill, 1992) I knew that significant clinical changes could be observed using a sample size of 30, and so this was set as the minimum data set size.

Due to the difficulty in recruiting this population, it was expected that the selection method needed would be labour intensive and time consuming and this was found to be the case. But this approach was essential if the rest of the longitudinal study was to be successful. Once a person was considered for inclusion, their medical progress was followed up on a weekly basis by looking at medical notes and from discussions with ward staff. One to two weeks prior to discharge patients were approached on the ward.

4.6 Procedure for gathering data

In this section the overall procedure for data gathering will be described. Specific aspects of the interview and questionnaire design and administration are described in Section 4.7.

4.6.1 Approaching stroke respondents in hospital

Once a person was seen to be suitable for the study the process outlined in Figure 4.3 (page 54) was followed. In order to encourage people to stay in the study I needed to build up a positive relationship with them from the initial contact. From the pilot study it was decided that the best way to approach people on the ward was to introduce myself as a researcher from the university who was interested in peoples experiences after a stroke. I did not introduce myself as a health professional or an occupational therapist, but during the course of the study often people recognised me as a health professional due to my knowledge about stroke. If asked, I would explain my position, in that I was professionally qualified, but that I was not connected with the health services within Southampton and had no influence over care they received.

Following discussion of the research using the leaflet, often people immediately agreed to take part. I was concerned about accepting people at this stage. Patients were used to being approached and agreeing to tests such as blood tests, X-rays and clinical interviews and may have approached the research in the same way. However, on further discussion people said that they were bored sitting on the ward, and would welcome the chance to talk to somebody. People also stated that they wanted to do something to help others as they had received so much help themselves. The best time to visit with the questionnaire was agreed. If the person had a spouse I asked permission to contact them.



Figure 4.3 Flow diagram of procedure for data gathering

4.6.2 Administering the questionnaire

On my second visit the consent form (see [Appendix 3](#)) was read and signed. From the pilot study it was decided that the questionnaire would be completed sitting by participants beds on the ward. Respondents appeared to be quite comfortable completing the form, most of which was written rather than spoken. People had become accustomed to discussing personal issues in the open environment of a ward. At end of the questionnaire participants were thanked for their time. If they had agreed to take part in an interview, a suitable time for them was arranged for a third visit.

4.6.3 Completing the interview

On the third visit the interview was carried out (see [Section 4.7](#) for details). Through completing the questionnaire, a working relationship had been built up and respondents appeared to be more at ease when taking part in the interview.

4.6.4 Follow-up on the ward

Respondents were visited, when I was on their ward, until they were discharged. This was not only to find out when they were discharged, but also to maintain the relationship built up during the study.

4.6.5 Data gathering with the spouse group in hospital

Spouses were contacted either by phone or on the ward. Preference was given to meetings on the ward at visiting time. On the first contact, the nature of the project was explained, and spouses were asked if they would consider taking part. They often mentioned that they were grateful to be included as they had not been given much attention. A suitable time and place was arranged to carry out the interview. A small number of spouses only completed the questionnaire, as ten couples had already been recruited. The meetings with spouses occurred at varying times during the day. They were held either in private in the hospital or at the spouses home.

From the pilot study, I found that spouses were expecting in the interview to talk about their partners rather than themselves. Time was spent before the interview

reiterating that the interview was about them and their lives. They were asked to complete a shortened version of the questionnaire. This was introduced at the end of the interview, so as not to influence the narrative flow. Also, it allowed a build up of rapport before they were asked unusual personal questions, which they would be unaccustomed to answering (unlike the stroke respondents who had been exposed to being asked personal questions during ward life).

4.6.6 Follow-up at six months and one year

Once a participant had been discharged, they were sent a letter thanking them for their time, and a copy of the letter sent to their GP was enclosed, to inform them that their GP was aware of the project. At six months participants were contacted by telephone. If participants did not have a telephone I visited their house when I was in the area and a suitable time for a full visit was arranged.

Before the visit, the previous questionnaire, tape and transcript was studied. During the visits, before the questionnaire was introduced or interview started, time was allowed for general conversation. Originally, I was unsure about the possibility of conducting separate interviews with people in their homes. However, people were quite happy to take part in separate interviews. Spouses either arranged to be out shopping, spent time in the garden or stayed in another room until the interview was over. Only one couple could not agree to separate interviews. They were interviewed together at home, and created a joint narrative which was fitting as they had been known each other from the age of six and were now in their eighties. After the second visit, participants were sent a card thanking them for their help.

The one year visit followed the format of the six month visit. At the six month meeting people were reminded that the one year meeting would be the last. At the last meeting people were informed that they would have the opportunity to have a copy of a short report from the study.

Practical issues were considered when visiting people at home. The name, address telephone number and time of visit was left with colleagues. A record of a local next

of kin and GP was always taken in case there was no answer at the door. With a stroke respondent group this may have meant that the person had fallen or was in difficulty within the house. Twice respondents did not answer; once a relative was able to tell me that the participant had forgotten about my visit and was out visiting a friend, another time the GP informed me that the participant had been admitted to hospital.

4.7 Details of the interview and questionnaire

In this section the design and implementation of the interview and questionnaire are described in detail.

4.7.1 The narrative life history interview

The narrative life history interview will be described under four headings. The ethical and procedural issues will be described, followed by the setting, content and style of the interview itself.

4.7.1.1 Ethical and procedural issues

The difficulties of being a clinician as well as a researcher with the possible blurring of roles were considered before interviews were undertaken. A protocol was drawn up which addressed the following issues.

- (i) I introduced myself as a researcher, rather than an occupational therapist. At the first meeting I mentioned that I could not affect or influence respondents' care. This was re-iterated at times during the study.
- (ii) When asked for advice or information interviewees were directed to contact their GP, hospital OTs, social services or the Stroke Association.
- (iii) Although the interviews involved active listening, which could be construed as counselling and seen as therapeutic, care was taken that a formal counselling relationship was not established. This was only found to be difficult with one respondent who felt a strong need to talk about her experiences. Her husband would not allow her to contact organisations such as the Stroke Association although he was happy for me to visit. A single fourth interview (i.e. at 18 months) was carried out at her request.

- (iv) Aspects of confidentiality were considered. Serious difficulties such as those involving suicide threats were not encountered. One respondent spoke of her abuse as a child fifty years previously, but declined further professional support when this was suggested at the end of the interview.
- (v) A system was put in place to provide personal support as it was expected that I would be exposed to the respondents' personal problems and emotional pain during the interviews (Payne and Westwell, 1994). Although as an occupational therapist I was used to working with people in distressing and emotionally charged situations, further support was set up. This included review by myself, and my supervisor and the possible use of university counselling services if necessary. In the event, additional personal support was not used.

4.7.1.2 Setting

All interviews were carried out in private, either in a quiet room in the hospital, or alone at the respondents home, apart from one couple who chose to be seen together. Disturbances were kept to a minimum in hospital by putting a sign on the door. Time was allowed for informal discussion before the interview took place, to help the interviewees feel more at ease. In the hospital setting, the room was already arranged with the tape recorder in an unobtrusive place, out of the line of sight of the participant. For a short while a mains dependent tape recorder was used, necessitating the location of electric sockets within the home. Extension leads were always carried. The audiotape which had been prepared with a verbal reference number and date was in the machine before meeting the interviewee. All the functions of the tape recorder were familiar following the pilot stage; it was used confidently, transferring confidence to the interviewee. Interviewees appeared to ignore the tape recorder but occasionally said "This is for the tape" or jokingly "You'll have to rub that bit off" demonstrating their awareness.

4.7.1.3 Content

When conducting the first interview, interviewees were thanked for taking part and given a brief introduction. It was explained that:

- (i) The conversation was going to be taped. They had been told this at the previous meeting on the ward.

- (ii) The tape would only be heard by me, my supervisor and an assistant (transcriber).
- (iii) Their name was not on the tape.
- (iv) The tape was switched off and that I would tell them before I switched it on.
- (v) If at any time during the interview they wanted it to be turned off to let me know.
- (vi) The tape lasted 45 minutes on one side and made a clicking sound as it turned over.
- (vii) I expected our conversation would last about 45 minutes but there was no time limit.

The style of the interview was introduced using the following statement:

“In order to put the effect of stroke on your life in context I would like you to tell me your life story, as if you were writing a book. I will leave the beginning of the story and the telling up to you. I will let you speak and will not interrupt you. If you get stuck or ‘dry-up’ during your story, I’ll help you out.”

Interviewees were then asked if they had any questions; the interview began using the following phrase:

“I’m now turning on the tape. Can you tell me what happened from your childhood onwards?”

The schedules for the interviews were developed during the pilot stage. They can be seen in Appendices 7, 8 and 9. They were developed to access narratives of the interviewees’ past, present and future life. In the initial interview the areas covered were: life from childhood onwards, the stroke event, hospital experience and views of the future. From the pilot study it was found that it was helpful to have an identifying time marker with which to start an interview. At six months, interviewees were asked about their hospital experience (creating an overlap with the first interview) and their views of the present and future. At one year areas covered included their experience from first having the stroke, including first being at home, and their views of the present and future. It was felt that by using an approach which encompassed life in general, undue attention would not be focused on problems and difficulties.

Interviewees were asked how they felt about taking part and contributing to a research project. Often they mentioned that they enjoyed the interviews and were happy that somebody was taking a personal interest in them. Occasionally interviewees

mentioned that they felt the interviews to be of benefit to them, allowing them time to reflect on their experience. It has been reported from several narrative studies of trauma in life history that people felt that they had benefited personally from the experience (Reissman, 1993; Hutchinson, Wilson and Wilson, 1994). Most mentioned that they enjoyed feeling useful and helping others. Although it was unlikely within the setting, nobody mentioned that they regretted taking part in the interview and nobody withdrew from the interviews over the year period.

4.7.1.4 Style

Interviewees were encouraged to speak at length by using open rather than closed questions. The 'narrative flow' was disturbed as little as possible. Interviewees were not interrupted or asked to elaborate on a point, using probing questions. I sat, listened and made encouraging sounds such as 'mm' or 'ahah'. Only when an interviewee ran out of things to say was the next area for discussion introduced. When the interviewee was prompted to encourage them to continue, phrases they had used were repeated. The direction of the interview was only altered in one case by the interviewer when a respondent was talking at great length and in great detail about the processes involved in carrying out genealogical research.

Interviewees were allowed to speak for as long as they liked, there was no sense of a time limit. As there was no probing and the five main areas covered were general, it was felt that interviewees only included aspects they felt happy to talk about. Although occasionally interviewees did become tearful, they were not overly distressed. If an interviewee did get tearful, they were given time to compose themselves and if necessary time was spent with them after the interview. A particular difficulty for some members of this group was that due to neurological changes following their stroke, they became emotionally labile and cried easily when discussing or thinking about issues. This was particularly difficult for male respondents. Time was spent during the interview in reassuring them that was not unusual and that the effect would reduce over time. Specialist knowledge of this kind was one of the benefits of having a clinical background when carrying out this research.

4.7.1.5 Field notes

Following the interview, field notes were written describing: the interview situation, previous meetings, how respondents appeared, and how I felt during the interview. Data from the field notes were taken into account when interpreting transcriptions.

4.7.2 The questionnaire

When deciding which measurements to use in this study certain properties of the instruments were sought. As far as possible assessments were used which had demonstrated reliability and validity for the situation in which they were to be used. Measures chosen were those routinely used by stroke rehabilitation researchers. As the battery of assessments was quite large (ten indices); measurements were chosen which were as concise as possible. This enabled the maximum amount of data to be collected from the minimum amount of time and effort on the part of the participant. The data collected from stroke respondents and their spouses in the hospital using the questionnaires can be seen in Tables 4.3 and 4.4 (see Appendices 10 and 11 for complete copies of the assessment forms).

The questionnaire for stroke participants consisted of three main sections: background information, screening tests, and the assessment battery, focusing on physical ability, self-care activity, mood and self-concept. Physical and self-care ability measures were chosen to describe the stroke respondent group and to examine whether physical and task-orientated activity may be related to mood. The Frenchay Activity Index, an assessment of social and domestic activity was introduced at six months as it was not a valid measure to use within a hospital setting.

The self-concept measure was used to determine how perceptions of past self differed from those of the present and of the future. It was also used to examine whether perceived changes in self-concept were related to mood.

Data	Measures	Baseline	6 months	1 year
Background				
<i>Demographic</i>				
Gender		✓		
Age		✓		
Marital status		✓		
<i>Stroke related</i>				
Date of stroke		✓		
Date admitted hospital		✓		
Date discharged hospital		✓		
Side of weakness		✓		
Factors affecting completion of the questionnaire				
Language problems (yes/no)		✓		
If yes	Frenchay Aphasia Screening Test	✓		
Left inattention	Behavioural Inattention Test	✓		
Confusion	Mini-Mental State Examination	✓		
Assessment battery				
Physical ability	Rivermead Motor Assessment	✓	✓	✓
Use of affected arm	Affected arm rating	✓	✓	✓
Self-care activity	Nottingham 10 point ADL scale	✓	✓	✓
Domestic and social activity	Frenchay Activities Index		✓	✓
Mood	Hospital Anxiety and Depression scale	✓	✓	✓
Past self-concept	Semantic Differential self-concept scale	✓	✓	✓
Present self-concept	Semantic Differential self-concept scale	✓	✓	✓
Future self-concept	Semantic Differential self-concept scale	✓	✓	✓

Table 4.3 Data from the stroke respondent questionnaire

Data	Measures	Baseline	6 months	1 year
Background				
Gender		✓		
Age		✓		
Assessment battery				
Mood	Hospital Anxiety and Depression scale	✓	✓	✓
Past self-concept	Semantic Differential self-concept scale	✓	✓	✓
Present self-concept	Semantic Differential self-concept scale	✓	✓	✓
Future self-concept	Semantic Differential self-concept scale	✓	✓	✓

Table 4.4 Data from the spouse questionnaire

The questionnaire was usually completed in 20 to 30 minutes. The screening tests were repeated at six months and one year if the stroke respondent did not reach the maximum score at baseline.

Spouses completed a questionnaire consisting of two sections; background information and assessment of mood and self-concept. It was usually completed in 10-15 minutes.

The individual indices included in the questionnaire are described in detail below.

4.7.2.1 Frenchay Aphasia Screening Test (FAST)

(i) Purpose

This assessment was used only with stroke respondents who demonstrated expressive aphasia (speech difficulties). It was used to identify stroke respondents who although demonstrating expressive aphasia would be able to complete the questionnaire.

(ii) Background

The FAST is a test specifically developed for use by health workers to screen for aphasia among stroke patients (Enderby, Wood, Wade et al 1986). Unless otherwise stated all quoted information is referenced to Enderby, Wood, Wade et al (1986). The test has been designed to cover the four major aspects of language which may be disturbed in the aphasic patient: comprehension, expression, reading and writing.

(iii) Advantages

- a) Designed specifically for use with stroke patients.
- b) Has been developed for use with patients seen within days or weeks of an acute stroke.
- c) Brief and easy to use taking between three to ten minutes to complete.
- d) Designed for use by 'non-specialists' i.e. not speech and language therapists.
- e) Recommended for use on research as a screening test before administering other tests which rely on good linguistic function.
- f) Normative data is available for age groups from 20 to over 80 years.
- g) Validity has been established. The FAST was compared against a qualified speech and language therapist's assessment using a full Functional Communication profile with respondents giving a correlation coefficient

between the scores of 0.87 ($p < 0.001$) for patients a few days after stroke, and 0.96 ($p < 0.001$) 1-3 years after stroke. Subsequently, the assessment has been compared with the Minnesota Test for Differential Diagnosis of Aphasia with 25 dysphasic stroke patients attending a speech therapy department giving a correlation coefficient of 0.91 ($p < 0.001$) (Enderby and Crow, 1996).

- h) Inter-observer-reliability has been established, giving a Kendall coefficient of concordance of 0.97 or better for each section and for the overall score.

(iv) Disadvantages

Specificity of the test is reduced by such factors as hemianopia, illiteracy and confusion, which need to be taken into account when interpreting low scores.

(v) Adaptations for this study

Only two of the sub-tests, assessing comprehension and reading were included in this study. The writing subtest involved the person writing a description of a picture, assessing skill levels which were not considered to be necessary to complete the questionnaire, which involved ticking boxes. The expression sub-test was not included, as it was already known that people tested had expressive difficulties.

(vi) Scoring

The maximum comprehension score is 10, the normal cut off score for this age range (i.e. 60-80 years) is 8. The maximum reading score is 5, which is also the normal cut off score for this group. A high score does not exclude aphasia but does suggest that communication is at least reasonable.

4.7.2.2 Behavioural Inattention Test - Letter cancellation

(i) Purpose

This test is an assessment of a neurological deficit following stroke, visual neglect (i.e. ignoring the left side of the visual field) (Halligan, Marshal and Wade, 1989). It was included to identify stroke respondents who would have difficulty completing the bipolar scales of the semantic differential assessment of self-concept, as the whole width of the page would not be perceived. Letter cancellation, one of the pen-and-paper subtests was used as an indicator of peoples ability to read across a page. If a respondent demonstrated difficulties a note was made and they were

assisted in the completion of the scales by placing the page on the right of the mid-line of their field of vision and physical cueing to the left side of the page.

(ii) Background

The Behavioural Inattention Test was designed by Wilson, Cockburn and Halligan (1987) to measure unilateral visual neglect. The test consists of six conventional 'pen and paper' tests and nine behavioural tests i.e. telephone dialling, menu reading. Halligan, Wilson and Cockburn (1991) found that the letter and star cancellation sub-tests could be used as an adequate test for determining stroke survivors who may benefit from completing the full test i.e. as a screening test.

(iii) Advantages

- a) Developed for use in this country.
- b) Developed for use with stroke patients.
- c) Has norms based on 50 subjects.
- d) Easy to administer.
- e) Acceptable to subjects.
- f) Has operational definitions.
- g) Has standardised instructions and scoring.
- h) Validity and reliability have been established. Wilson, Cockburn and Halligan (1987) demonstrated inter-rater reliability, the correlation between two testers was 0.99 ($p < 0.001$). Test-retest reliability was assessed using ten subjects on two separate occasions over a mean length of time of 15 days (correlation 0.99, $p < 0.001$). Halligan, Marshall and Wade (1989), tested the severity and presence of inattention in 80 unselected stroke patients. They found that the six conventional tests intercorrelated highly and subsequent factor analysis demonstrated that all the tests were loaded significantly for one underlying factor, suggesting high construct validity.

(iv) Disadvantages

Only visual neglect is assessed. This is adequate for completion of the questionnaire, but does not give any information about other areas of neglect or perceptual difficulties which may have been of interest in this study.

(v) Scoring

The scoring was used as specified in the original work (Wilson, Cockburn and Halligan, 1987). For letter cancellation the score range is 0-40. The cut off point is 32.

4.7.2.3 Mini-Mental State Examination

(i) Purpose

As a screening test to detect cognitive difficulties following stroke (Ecgelko, Simon, Riley et al, 1989) which may preclude completion of the questionnaire.

(ii) Background

This test was designed to detect patients with cognitive impairment among a psychiatric population (Folstein, Folstein and McHugh, 1975). It has also been found to be valid and reliable in screening neurological patients (Dick, Guilloff, Stewart et al, 1984).

(iii) Other measures considered

Hodkinson Mental test (Hodkinson, 1972)

Middlesex Assessment of Mental state (Golding, 1988)

(iv) Advantages

- a) Widely used.
- b) Short time to complete.
- c) General measure of cognitive ability.
- d) Easy to administer.
- f) More detailed than Hodkinsons test.
- g) Validated for use in a neurological population (Dick, Guilloff, Stewart et al, 1984).
- h) Reliable on 30 days retest (range 7-70 days) (Dick, Guilloff, Stewart et al, 1984).
- i) Normal values available (Bleeker, Bolla-Wilson, Kawas et al, 1988).

(v) Disadvantages

Has only been validated for use with in-patients.

(vi) Adaptations for this study

- a) The original three stage command 'Take a paper in your right hand, fold in half, and put it on the floor.' This was changed to 'point to the ceiling, give

me the pen and close your eyes.’ Subjects may have had difficulty with the original statement as often they could only use one hand. This statement was derived from a publication by Goodglass and Kaplan (1983) following discussions with a speech therapist.

- b) The original assessment included naming the hospital and ward. This was inappropriate for a community setting. Subjects were asked to name the road and house name or number.
- c) In the original paper there is a choice of serial sevens or spelling WORLD backwards. It was decided that spelling WORLD backwards would be used in this study.

(vii) Scoring

The score range is 0-30. In this study a score greater than 23 was used as a cut-off point. Folstein, Folstein and McHugh (1975) used a score of below 20 to identify patients with dementia. Dick, Guilloff, Stewart et al (1984) found that optimum specificity and sensitivity was achieved by regarding a score of 23 or less as suggestive of cognitive impairment.

4.7.2.4 Rivermead Motor Assessment (Gross motor subscale)

(i) Purpose

To assess level of physical ability.

(ii) Background

This scale was designed by Lincoln and Leadbitter (1979) to provide an assessment of physical recovery from hemiplegia following stroke. The Rivermead Motor Assessment has three subscales, with sections on arm function (15 items), leg and trunk function (10 items) and gross function (13 items).

(iii) Other scales considered

Motor Assessment Scale (Carr, Shepard, Nordholm et al, 1985)

(iv) Advantages

- a) It is a widely used measure of motor function after stroke.
- b) It is quick and easy to use (unlike the Motor Assessment Scale).

- c) The gross function subscale has been shown to be reliable when administered verbally with patients six months after a stroke (unlike Motor assessment scale) (Sackley and Lincoln, 1990).
- d) Inter-rater reliability has been established (Lincoln and Leadbitter, 1979).
- e) Test-retest reliability of the gross motor subscale was established with stroke patients two to six years following stroke (Collen, Wade and Bradshaw, 1990).
- f) The hierarchical nature of the gross motor function subscale, with less severely disabled patients obtaining a higher score, has recently been confirmed (Adams, Pickering, Ashburn et al, 1997).
- g) It has standardised guidelines for administration (see [Appendix 12](#))

(vi) Scoring

The items are followed in order of difficulty. If a person can perform the activity they score 1; if they cannot, they score 0. As there are 13 items, the scores can range from 0 to 13. The test can be stopped after three consecutive failures, due to the hierarchical nature of the test.

4.7.2.5 Affected arm rating

(i) Purpose

This rating was included to give an indication of arm function.

(ii) Other scales considered

Arm subsection of the Rivermead Motor Assessment (Lincoln and Leadbitter, 1979)

Frenchay Arm Test (DeSouza, Langton Hewer and Miller, 1980).

Action Research Arm Test (Carroll, 1965)

(iii) Background

The scales listed above were designed to assess specific changes in arm function. They include from 15 (Arm subsection of RMA) to 20 (Action Research Arm Test) items. The Frenchay Arm Test although including only five items requires (as do the other assessments) observation, a standardised setting and procedure and specific pieces of equipment. These scales were considered to be too lengthy and more specific than needed. An indicator was developed which enabled categorisation of arm function into one of six groups. This can be seen in [Figure 4.4](#).

Figure 4.4 Affected arm rating

1	No movement
2	Movement for stabilising only -no hand movement
3	Movement gross grip only
4	Movement some use of individual fingers
5	Clumsy normal use of hand
6	Normal use of hand

(iv) Advantages

- a) The rating scale was quick and easy to use.
- b) It gives a general indication of arm function.

(v) Disadvantages

- a) The rating has only face validity. Thorough validity testing has not been carried out.
- b) The reliability of the rating has not been tested.
- c) The scores can not be related to other studies. The rating can only be considered as a method of categorising the arm function observed by the researcher during this particular study.

(vi) Scoring

The scores range from 1 (no movement) to 6 (normal movement).

4.7.2.6 Nottingham ten point ADL scale

(i) Purpose

To assess self-care activities, such as washing and dressing.

(ii) Background

This is a ranked activities of daily living (ADL) scale developed for stroke patients Ebrahim, Nouri and Barer (1985).

(iii) Other scales considered

Barthel Index (Mahoney and Barthel, 1965)

Functional Independence Measure (Keith, Granger, Hamilton et al, 1987)

(iv) Advantages

- a) It is a quick, simple scale.
- b) It was developed for use with stroke patients.
- c) As a hierarchical ranked scale it has the advantage that patients with the same scores are able to perform the same activities, so that scores can be directly compared (unlike the Barthel index).
- d) It is widely used.
- e) It can be completed by questionnaire rather than direct observation.
- f) It has scoring guidelines (see Appendix 12)

(v) Scoring

A person is considered to have passed an item if they can carry out the activity independently. Each passed item is given a score of one, giving a total possible score of ten.

4.7.2.7 Frenchay Activity Index

(i) Purpose

To assess individuals domestic, social and leisure activity at home.

(ii) Background

Developed by Holbrook and Skilbeck in 1983 as an objective measure of actual activities undertaken by a person with a stroke in the recent past. Validity and reliability was established by Wade, Legh-Smith and Langton Hewer (1985). Also it has been found to be a valid measure for stroke survivors over 70 years of age (Cockburn, Smith and Wade, 1990). It has recently been used as an outcome assessment for one year survivors of stroke (Dijkerman, Wood and Langton Hewer, 1996).

(iii) Other scales considered

Nottingham Extended A.D.L. Index (Nouri and Lincoln, 1987)

(iv) Advantages

- a) The scale was developed to provide information about the lifestyle of patients living in a community setting who had suffered a stroke.
- b) It was developed using a U.K. population - the activities reflect the cultural norms of the population.

- c) The activities require greater decision making and organisation on the part of the subject than most A.D.L. scales.
- d) The scale has an emphasis on what the person actually does, rather than what they may be capable of doing.
- e) The scale is widely used.
- f) The scale is quick to use.
- g) It has operational definitions (see Appendix 12).
- h) It is possible to assess by questionnaire rather than recording observation.
- i) Recommended by stroke research group (Wade, 1992).
- j) Wade, Legh-Smith and Langton Hewer (1985) have established the content validity of the measure. The degree to which the items are related to a single 'idea'. Factor analysis demonstrated that all of the 15 items had a common underlying construct. Inter-rater reliability was established using a sample of 14 patients. The correlation between the two sets of results was 0.80 ($p = 0.001$).

(v) Disadvantages

- a) The scale is numeric but this does not mean that patients with the same score are able to perform the same activities.
- b) There may be a gender bias in household activities normally carried out.

(vi) Scoring

Range of possible scores is 0-45.

4.7.2.8 Hospital Anxiety and Depression scale

(i) Purpose

To determine the levels of anxiety and depression in the subject and comparison group.

(ii) Background

This scale was designed as a self-assessment scale to detect present levels of anxiety and depression in the setting of a hospital out-patient clinic (Zigmond and Snaith, 1983).

(iii) Other scales considered

General Health Questionnaire (G.H.Q.) (Goldberg and Hillier, 1979; Goldberg and Williams, 1988)

(iv) Advantages

- a) Assesses anxiety as well as depression.
- b) Quick and easy to use.
- c) Completed by the individual, does not depend on professional assessment.
- d) Does not include assessment of physical signs such as sleep disturbance, crying spells, which may be side-effects of a stroke (unlike G.H.Q.).
- e) Acceptable to a general population, does not imply suffering from psychiatric disorder i.e. suicidal preoccupation.
- f) Recommended by the British Stroke Research Group (Wade, 1992).
- g) Has demonstrated reliability and sensitivity (Zigmond and Snaith, 1983).
- h) Normal ranges available.

(v) Disadvantages

- a) Not validated for use in a community setting, although it has been more widely used, including stroke patients (Gibson, MacLennan, Gray et al, 1991).
- b) One question 'I feel slowed down' may be associated with physical disability.
- c) Only validated for people aged 16-65.
- d) The exclusion of somatic items may increase the false negative rate (Hall, Fallowfield and A'Hearn, 1997).

(vi) Scoring

Total score range is 0 to 42. The higher the score the greater the mood disorder. Subscore range for depression and anxiety are both 0 to 21. Zigmond and Snaith used a cut-off score to determine clinical cases. Non-cases had a subscore of seven or below. Score above or equal to eleven were definite cases.

4.7.2.9 Semantic Differential self-concept scale

(i) Purpose

To assess perceived self-concept prior to the stroke, in the present, and six months into the future.

(ii) Background

The semantic differential is a technique for measurement rather than a specific test. It was developed by Osgood, Suci and Tannenbaum (1957) to specify differences between two concepts in terms of meaning. To examine the meaning of a certain concept groups of subjects asked to complete series of graphical rating scales. The ends of the scales are described using polar adjectives taken from a list drawn up by Osgood, Suci and Tannenbaum (1957). Detailed information about the technique may be found in Osgood, Suci and Tannenbaum (1957) and Warr and Knapper (1968). Tyerman and Humphrey (1984) applied the technique and developed a scale assess to self-concept in a rehabilitation setting. Adjectives were chosen that were thought to be most appropriate to an individual following head injury. The scale which was designed has since been used in a study of self-concept in chronic obstructive airways disease (Kersten, 1990) and head injury (McWilliams, 1991).

(iii) Other scales considered

Tennessee Self-concept Scale (Fitts, 1965)

(iv) Advantages

- a) It allows access to subjective experience.
- b) The scale was developed for use in this country (unlike Tennessee Self-concept Scale).
- c) The scale is short (unlike Tennessee Self-concept Scale).
- d) The scale is acceptable to participants who appear happy to complete it.
- e) The scale has clinical applicability. It is useful in a clinical setting.
- f) It is easy to score.
- g) It is easy to communicate results to others.
- h) It has been used in other recent studies.
- i) The technique is supported by theoretical and empirical research.
- j) It has face validity and has been correlated with the Leeds scale of anxiety in a study of head-injured people [Spearman's $Rho = -0.73$] (A Tyerman, personal communication, 1992).
- k) Internal reliability has been determined; Cronbach's $\alpha = 0.88$ (A Tyerman, personal communication, 1992).

(v) Disadvantages

- a) An individual's description of self-concept is limited to the adjective pairs available.
- b) The scales are not weighted differently according to perceived salience to the subject.
- c) Similar total scores do not necessarily mean two individuals have the same self-concept.
- d) A difficulty of a self-report measure is that the score depends on the participants' interpretation of the scale adjectives. The assessment has been designed to ensure that the meaning of the adjective pairs is unambiguous.

(vi) Adaptations for this study

The scale has been adapted from the original due to my experience in a previous study (Hill, 1992). In the pre-pilot study of my previous research it was found that individuals did not know how to answer as their self-concepts varied depending on the situation. In order to encourage a general idea of self-concept an additional heading 'most of the time' was added to the top of each adjective list. This criticism of the technique was also put forward by Wylie (1970) in her critique of self-concept assessment.

(vi) Scoring

The adjective pairs are at each end of a row of 7 boxes. The score range for each adjective pair is one to seven. There are 20 adjective pairs in the assessment and so the total score range is 20-140.

4.8 Analysis

Both qualitative and quantitative analysis was carried out. Analysis of the interview data and questionnaire data are described in more detail in the following section.

4.8.1 Analysis of interview data

All 60 individual audiotapes were transcribed in detail. The texts were analysed at three levels:

- (i) Each interview was analysed to explore themes relating to a) the stroke and b) personal life history at one point in time.
- (ii) The three interviews given by one individual were compared, to see how the themes changed or remained the same over one year.
- (iii) The similarities and differences between the stroke themes were compared for all the participants.

The levels of analysis can be seen in Figure 4.5

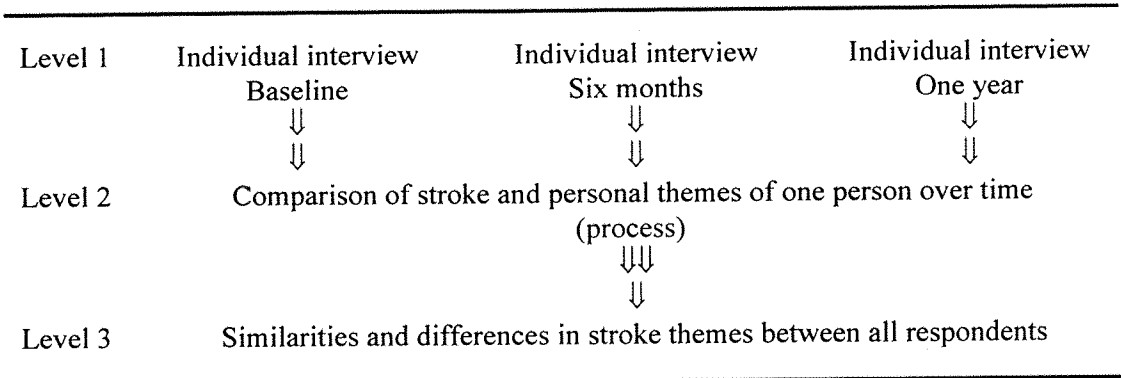


Figure 4.5 Levels of analysis

4.8.1.1 Analysis of an individual interview at one point in time

(i) Transcription

All 60 interviews were transcribed in detail (please see Appendix 15 for an example). Transcription has been included in the analysis section as it is seen as one of the interpretative steps. The transcription included:

- ° The comments of the interviewer as well as interviewee to acknowledge the joint contribution to the creation of the narrative.

- ° Overlapping talk which was marked e.g.

D: it was horrible [at the time]

c: [must have been] horrible

- ° Pauses, hesitations and silences were noted. The length of the silences were indicated by seconds in brackets.
- ° Non-word vocalisations, such as mm, ahahh, laughter were included.
- ° Although detailed punctuation was not included, capital letters were used to denote the starting of a new phrase.
- ° Asterisks (****) were used for parts of the tape which could not be heard clearly. The number of asterisks denoted the number of syllables heard.
- ° The text was parsed into clauses (groups of words containing a single finite verb); lines which could stand alone. This highlighted not only what people said but how they said it. It produced text which appeared poetic in nature. Excerpts of the text will be presented in this form in later chapters because, as also described by Coffey and Atkinson (1996), the quotes appear to have more emotional resonance when presented in this way.
- ° Each line was numbered for future reference.

(ii) Mapping

The text was divided into sections determined by the introduction of new topics.

This gave an overview of the topics discussed in the interview and who introduced the topics and hence controlled the direction of the interview. It was also a way of mapping the transcript for future reference.

(iii) Analysis for themes

The manuscript was read through several times. The text was analysed line by line. Notes were made next to the text of either preliminary personal themes or stroke related themes. When the text was re-read, further instances, which would either confirm or dispute the personal or stroke related themes identified, were sought and highlighted.

(iv) Researchers influence

The influence of the interviewer was taken into account by referring to fieldnotes and the transcripts. Field notes which described the place, person, how they appeared and how I felt were read alongside the transcripts for added context.

(v) Creation of an analysis document

For each transcript an analysis document was drawn up. This included:

- (i) field notes for context
- (ii) quantitative data for context
- (iii) table of interview sections
- (iv) table of personal themes and further analysis
- (v) table themes relating to stroke and further analysis

Tables (iv) and (v) were not final texts, they were a way of organising thoughts and ideas; which in turn generated further thoughts about the person's description of themselves and their relation to their stroke within the interview. (see [Appendix 16](#) for an example of an analysis document).

A small number of transcripts were read by independent assessors and the themes identified were compared. Many similar themes were identified, although often with a different emphasis. Also there were several insights, which had not been considered previously, which were incorporated in the analysis.

4.8.1.2 Analysis of one individual's interviews over time

Once a small number of one year interviews had been analysed, the analysis documents and transcripts for baseline, six months and one year were compared within one individual over time. The personal and stroke themes were compared over the three time periods. The three analysis documents for each person were analysed in sequence, starting with the baseline and ending with the one year document. The original transcripts were consulted when further detail was needed.

The three documents from each stroke respondent and spouse from a couple was analysed in turn. By analysing the documents in turn it was possible to become more familiar with a person's style of speaking and more sensitive to idiosyncratic ways of speech, and phrases, continuities and changes in interpretation over time.

4.8.1.3 Analysis of stroke themes across individuals over time

In order to determine any generality in the way respondents included stroke into their life stories, the stroke themes for all of the participants were compared and similarities and differences noted. After the themes of two couples (and 12 interviews) had been compared, it was found that the wider analysis provided data which were extremely rich and complex. There were many themes relating to stroke which could be followed up. At this stage it may also have been possible to take the analysis to a further level and compare personal and stroke themes within each couple over time, to explore interpersonal relationships in response to stroke. It was decided that as little is known about individual reactions to stroke, this aspect would be an interesting focus for future research.

It was not possible to follow up and explore in detail all the aspects which were identified from the texts. The necessary further narrowing of the focus was guided by my professional experience. I would like to make explicit my reasons for focusing on only three of the five possible aspects identified. The three aspects were: the nature of stroke and recovery, the effect of stroke on identity, and the balance of dependence and independence. As a health professional, I am aware of the professional discourse linked with stroke and recovery. I was interested to explore how people and their relatives view stroke, and how these ideas change over time, i.e. what sort of 'model' people are working to. As the theoretical approach for the study was change in identity, I was interested in exploring how people described ways in which they felt they and their lives had changed. As one of the stated goals of occupational therapy practitioners is to enable a person to be as independent as possible, I was interested to explore how couples created the balance of dependence and independence within the home setting. Research has shown that often people revert to being more dependent than they need to be once they are home (Corr and Bayer, 1992).

The two other themes which were not pursued were; the relationship between health staff and the participants and the effect of differing hospital facilities. These themes warrant further study, with wider social analysis. An ethnographic approach would

provide more in-depth data in these areas. Useful insights will be woven into present analysis where they are pertinent to one of the main themes above.

4.8.2 Analysis of questionnaire data

Responses from the questionnaire were coded and entered into an SPSS database. Descriptive statistics were used to characterise both the stroke participant and spouse groups in terms of demographic details, mood and self-concept. Physical ability and self-care activity levels were also described for the stroke participant group. Inferential statistical tests were applied to assess changes over time. Multivariate statistical procedures were applied to describe the associations between mood and self-concept, physical ability, and self-care activity levels, for the stroke participant group.

CHAPTER FIVE

Similarities in the text: issues facing respondents following a stroke

5.1 Introduction

The following two chapters describe the qualitative analysis of the interview transcripts. The setting and respondent group will be described at the beginning of this chapter. From the analysis it was possible to define specific stroke themes described by respondents over time. These could be divided into two groups. Certain stroke themes were included in all of the accounts, suggesting specific issues facing all of the respondents. These will be described in the present chapter. The differences found in the stroke and personal themes will be described in Chapter Six. These differences suggested that respondents approached their situation differently depending on the context of their own life history. Reflections on the research process will also be included in Chapter Six.

A description was given in Chapter One of a metaphor for stroke, ripples spreading out on a pond. Following a stroke, ripples spread out from one tiny blood vessel in the brain, affecting the use of muscles, speech, memory and concentration. The ripples spread wider to the physical and social roles possible for that person, which in turn affects the lives of those around them. Having worked as an occupational therapist for several years I have met many people following a stroke. The role of an occupational therapist is based on the philosophy of working alongside disabled people to help individuals reach their maximum level of function and independence in all aspects of life (College of Occupational Therapists, 1994). Present research which guides practice is based on objective measures. It has provided health professionals with knowledge about blood vessels, muscles, physical recovery, recovery of self-care skills, -the inner ripples which are created following a stroke. Further knowledge is needed if health professionals such as occupational therapists want to reach the potential of their professions and in reality support people in wider aspects of their life- the wider ripples following a stroke. In the analysis of the life narratives I would

like to explore this aspect of stroke recovery, how life appears to the stroke respondent and their spouse.

5.2 Details of respondents

Ten stroke respondents who had been admitted to hospital following stroke and their spouses were approached to take part in the study, all of them agreed. The group were made up of six male and four female stroke respondents. Their ages ranged from 46 to 82 years. The ages of their spouses ranged from 41 to 82 years. They ranged from social class 1 to 5. Eight were British, one Polish and one West Indian. All had been living within the British Isles for at least 40 years. There was a variation in the severity of the stroke. The least physically affected person had been in hospital for three weeks, experiencing weakness in his arm and leg and had physically recovered at six months. The most physically affected person had been in hospital for four months, was using a wheelchair at six months and was just beginning to walk at one year. Two of the interviewees were the relatives of partners who had suffered expressive dysphasia - difficulty with verbal expression. Before the stroke, all of the people had been fit and well, apart from one man. It had been reported that he had fully recovered from a previous heart attack, but once he was recruited it was discovered that he had already had to make several life changes. While the stroke respondent was admitted, respondents were seen either in a hospital setting or at their home, at six months and one year all respondents were seen at their home. All participants were seen alone, apart from one couple for whom the idea of talking separately did not seem to be an option.

5.3 Researcher as audience

When reading the analysis, my contribution to the production of the stories needs to be taken into account. Respondents were talking to a white, middle class 37 year old woman. I introduced myself as a rehabilitation researcher. People knew I had some links with the hospital as I first met them within a hospital setting. I stressed that I could not influence their care in any way and that nothing would go back to the staff at the hospital. Throughout the interviews I took on many roles such as confidante, advisor, sounding board, ally, conspirator, expert and judge.

The relationships changed over the time of the three interviews. Often by the second meeting contact with the hospital had been lost; people often saw me as some link with the hospital and were glad somebody was taking an interest in them and occasionally asked about other people they knew in hospital. Often people mentioned that the fact that I had 'been there' with them from their time in hospital was important to them. I kept the meetings as informal and relaxed as possible. Interviews were arranged for a time which suited the respondents. I was always punctual and thanked and reminded respondents of the importance of their contribution. All of the people taking part allowed me to visit them three times, apart from one person who at the third meeting was undertaking exams to be able to get back to college and who would not have been able to see me until after my interview period had ended.

5.4 Similarities in identified themes

Five main similarities were identified in the accounts of people, giving some insight into the issues facing people over time following a stroke. The first two themes 'entering a new world' and 'living in the present' were described by both partners. The dominant themes of 'a separate precarious body' and 'responsibility' were described by the stroke respondent and their spouse respectively. Finally, all respondents described being influenced by issues of 'hidden disability'. The issues were described by all people within the interviews to a greater or lesser degree. Occasionally there were exceptions within certain themes and these will be described.

Quotes have been included from specific respondents where they seem to capture the flavour of the overall response. They are referenced *line number/ time of interview*: 1= baseline, 2 = six months, 3= one year i.e. 1364/1. My contributions to the interview section in the quotes have not been included if they were utterances such as 'yeah', 'that's right', 'ahah' as they seemed to distract from the quote. If my contribution was integral to the quote it has been included. All names have been changed throughout the analysis.

5.5 New world, new rules

As had been reported in previous studies into acquired physical disability (Bury, 1982; Corbin and Strauss, 1987) respondents described their lives as having changed. The fundamental nature of this change could best be described as entering a new foreign world. Mr Evans was in his late fifties, fit and active when he had a stroke. He had been in hospital over three months and was about to go home. He said:

*it's a very severe thing to happen to anyone
it's not like getting a -y'know - having a broken arm or something like that
which incapacitates you for a couple of months
put your arm in plaster
and normally just take the plaster off
and you get back to where you were before 1364/1*

*..... you lead a normal life one day
and within a matter of minutes, overnight
it all comes to an end 1387/1*

There was a sense of no return, of not being able to get back to where he was before, his normal life had come to an end. The fundamental nature of the change was well described by Mrs Scott. She had been in hospital ten weeks. In her comments the connection between body and self was apparent. She said that the stroke had shattered her; she described how she felt she would not be able to sew or knit again, how she couldn't even comb her hair:

*it's er you sort of think good Lord
I'm only half a person 448/1*

At six months Mr Evans told of how another person with a stroke had '*hit the nail on the head*' for him. His friend told him a long story about his own father having three heart attacks, appearing to have 'got over' all of them and returning to work as if nothing had happened. He continued:

*But with a stroke
right it doesn't happen like that
nope , no way
It affects, it's hard to describe, how it affects you completely*

*...they [people following heart attack] seem to live quite a normal life
obviously I mean they probably got to cut a few things out
but their life comes back almost back to normal
That doesn't happen to a person with a stroke does it? 294/2*

These descriptions support the work of Becker (1993) who carried out interviews with 100 people up to a year following their stroke and found that the research participants unanimously viewed the stroke as a profound disruption to their lives and destroyed the fabric of predictable everyday life. Nilsson, Jansson and Norberg (1997) in an in-depth study of ten stroke respondents at discharge and after two months at home concluded that the effect of the stroke was more than managing the physical aspects of disability. They described how the stroke appeared to embrace and challenge the whole of the individuals 'being'.

Although previous researchers such as Becker (1993) have focused on the experiences of people following a stroke; from the present study it was found that spouses also experience a similar psychological challenge. They described how they found themselves in what could be considered a foreign land with new rules.

This was well described by one of the spouses Mrs Gunner, as she was reflecting on her experience at six months:

*Nobody knows,
I didn't know that Friday
it was just a perfectly ordinary Friday
.. just the same routine
and it was gone
within seconds it was gone,
your whole life is completely changed within seconds
and that's all it takes with a stroke
is seconds
one thing and your life is completely different
I don't know
It's a strange feeling
it's the most frightening thing 1151/2*

Within this new world, respondents entered a new physical and social reality. Often respondents did not have the words to explain their situation. Mrs Scott a stroke respondent said to me in hospital:

- I put it that it's like having a baby,
until you've had one you really don't know what it's like.*
- c* *Hmm.*
- I* *Hmm, um I really, you don't know,
you can't understand what the predicament is till you, you're in it.
I mean er it feels funny um,
it does feel like pins and needles all the time,
and er it's like when your hand goes to sleep
and it feels all big and that.*
- c* *Right.*
- I* *That's how that,
it feels like that
more or less all the time. 505/1*

Mrs Scott tried to help me understand her situation by focusing on her physical predicament, creating an analogy with 'pins and needles' with which she felt I could identify. But even focusing on her bodily experience she could only describe her arm and hand as being 'all big and that', which did not really appear to capture her experience.

The difference between discourses used by health professionals and by the stroke respondents was highlighted by Anna McKenzie (1996). She wrote of her experience

of being a professional counsellor in a social services setting. She had worked with many people who had an acquired injury, and was considered to be an expert in the field. Following a car crash she said:

I had entered the strange and new experience which I now know as 'disability country.'

Of course it is not a different country but it often felt like it - with different names, expectations, conventions and possibilities. (McKenzie 1996, p42)

Although being an 'expert' she still found herself in a new foreign land, with foreign discourses and narratives. The dominant discourse held by the general public and professionals when considering life following an acquired physical disability is one of deficit and loss (Shakespeare and Watson, 1997). McKenzie (1996) on reflection mentioned that it was too simple to equate her experiences with just loss, as she felt she had gained a lot as well. She described the change as a total transition; because everything she knew was suddenly changed and challenged. The metaphor of entering a new foreign world will be used throughout this thesis, to allow the reader to identify in some way with the respondents. The term transition or transformation will be used to describe this process.

The experience of fundamental change was described by most of the group at all of the baseline, six month and one year interviews. There were two notable exceptions. Mr Finch, who had already experienced disability and Mr Snow who made a complete physical recovery. Their responses will be discussed later in this chapter. The psychological process of change appeared to be a long-term process. This was described by Kaufman (1988b) who carried out open ended interviews with 64 people following stroke over one year. She found that the main theme described by people was the discontinuity of life patterns. When asked 'do you feel your life is back to normal?' Kaufmans respondents said 'No'.

Becker (1993) found that the dominant theme of her study with 36 people 4-16 months post stroke was how lengthy the process of life organisation was: she found that most often life organisation was not complete at the end of the study. All the respondents in the present study mentioned that recovery was much slower, and took much longer than they expected.

As Mrs Robinson said in hospital:

*it happens in a flash
but it takes so long to get over it 340/1*

This experience of slowness was reported by both of the partners. Mrs Evans reflected on her husband's difficulties at six months. She described her unfulfilled expectations after her husband left hospital:

*I think I felt hopeful that things would be just
..that everything was going to get better
.. I don't think I realised how long and slow it was going to be 35/2*

Oliver, Zarb, Silver et al (1988) in a study of people following spinal cord injury, also found that the length of time involved in the process of getting used to having a spinal cord injury was emphasised by many of those interviewed. The overall consensus was that it took from two to six years and as one man said:

then things suddenly do fall into place and life goes on fairly normally.

(Oliver, 1988 p 46)

Carpenter (1994) carried out a study of ten respondents who had a spinal cord injury but described themselves as successfully rehabilitated or 'back on track' three to five years post injury. From the present and previous studies it can be seen that personal upheaval lasts for at least one year and possibly longer.

5.6 Living in the present

Within this new world, time appeared to take on a new meaning. Spouses did not seem to have enough time, stroke respondents had too much time and everything took a long time. All members of the group described how they had a foreshortened sense of time, they tended to live very much in the present. In hospital, both stroke respondents and spouses found it difficult to look into the future. Mrs Scott had been in hospital ten weeks, when she said:

*well I don't think I can look in the future
not as I would like it to be
you've got to wait for developments all the time
.. I would like to think that things could get back to normal
and I hope things will get back to normal
but I can't say that you you
I think they will because I mean I don't kn..
.. Like I say
I can't really look into the future at the moment
I'm very much, very much with the present I think 727/1*

Spouses also felt the same way. While her husband was in hospital Mrs George said when asked about what she sees in the future:

*Future
to me I haven't got any future any more
...I don't know I don't know what the future lie, holds for us
I can see today
but I don't see for tomorrow
so there is no answer for the future 880/1*

This was also found by Nilsson, Jansson and Norberg (1997) who carried out in depth interviews with ten stroke respondents, they found that individuals did not look forward and avoided talking about their future. From a theoretical narrative perspective this could be interpreted as the narrative flow of life having been broken. There was a past and a present, but no sense of a future. People were held in the present. The future usually running out before them had become unknown, uncertain; people were 'waiting to see'.

Occasionally people made tentative plans while in hospital, although they felt that they shouldn't really do so. As Mr Evans said:

*hopefully perhaps six months or whatever,
I shouldn't set dates
I'm not going to set dates
But I hope in the near future
to go back to work 964/1*

Although 'knowing' they shouldn't set dates, in hospital respondents still appeared to be using an acute model of illness. This was noted by Charmaz (1991) who worked with a respondents group with differing chronic illnesses. She found that initially they interpreted illness as an interruption, something which was temporary, which had a predictable recovery. The respondents expected to get better. Nilsson, Jansson and Norberg (1997) also found a change over time. At discharge their respondents were hopeful of a full physical recovery, reinforced by training and improvements in the first few weeks. At the follow-up visit two months after being at home, respondents found that they had not regained full physical recovery and their sense of hope, although still present had weakened. By six months Mr Evans had a different view of the future. As he said:

*... because you haven't experienced it before
you've got notions of what you are going to achieve
and what you're going to do
but it doesn't happen 53/2*

It was not until respondents had been at home for a few months that they recognised that life was never going to return to the one that they had lived prior to the stroke. Cant (1997) reported how it took at least eight or nine months for the full implications of his stroke to sink in completely. He said only after this time did:

the after effects of the stroke became less of a novelty and more of a reality to be lived with (Cant 1997, p298).

Future narratives could not be based on the rules of the old 'normal' world people had inhabited. Mr Evans had tried to do this and found that things just 'don't happen' as they used to. The future narratives and possibilities had to be created in a new world with new physical and social rules which had to be learnt. Following hospital admission people not only had to contend with relating to a new body but also learn about a new and novel environment. Cant (1997) while describing his hospital stay

following his stroke, reported how he did not know how to behave in hospital. As he said:

you actively seek clues as to what is appropriate behaviour, how to respond to situations, what is expected of you, what is right (Cant 1997, p 298).

So initially people learn the physical and social rules of their new world which was in a hospital setting. As noted by Carpenter (1994) these rules did not necessarily help when respondents returned to the 'real' world as the physical and social rules were different again.

Living in the present continued to be described by people at six months and one year, again supporting the work of Becker and Kaufman (1995). The main reason people gave for their experience was that they could not rely on their health, or have confidence in their future abilities and so did not want to plan things which then had to be cancelled or changed. Both partners' possible future narratives were dominated by uncertainty about the stroke respondent's new post-stroke body. It appeared that bodily dysfunction not only affected the stroke respondent, but also had a direct affect on the identity and future possibilities of their spouse.

It appeared that stroke respondents and their spouses were living in a new world, with unknown rules, affecting every aspect of their lives. The old rules of the old world i.e. 'the past' could not be used to help people move forward in their lives, as they did not apply in this world. They had to learn everything anew, manage the present moment as it arrived, and tentatively explore more of their new world. This was not a short lived experience - it lasted for at least a year, the time scale of the study. Respondents had made a transition from expecting to return to their previous life, to learning about how to live the rest of their lives with a new body. Roberta Pierce (1996) a speech and language therapist who experienced a stroke leaving her with memory difficulties, described this sense of exploration two years following her stroke:

Every time I enter into a new situation I do not know how my brain is going to react. I am still getting used to this new brain that I have, this new person that I am. I know how I used to react to situations, but I cannot count on how I am going to react in any given situation. (Pierce 1996, p57)

In order to live their lives following stroke the respondents had to constantly explore and discover the new physical and social rules of their new world.

Robinson (1988) described a similar but not identical process experienced by people with multiple sclerosis. He described how order and a sense of normality had to be continually re-created in the face of changing symptoms. The people with multiple sclerosis were facing a trajectory of deterioration; people were slowly moving from a 'normal world' into a new foreign one - they were on shifting sand. The trajectory in the present study was different; people had been dropped 'in seconds' into this new world - the initial change and shock was much more dramatic. Suddenly all points of reference in the world had changed. However, there was always a hope and expectation that things would improve and that 'things would get back to normal'. Only one person described a differing view. Mr Finch, who had suffered a previous heart attack, described how he had lost the security of a predictable future. He said at one year:

*I just don't know what the futures going to be
I don't bank on anything or plan
just hope for the best sort of thing that's all
cause you don't know what's round
This taught me a lesson
not to think, to take things for granted
because you never know (continued)
I've learnt that now
well I've accepted it
what's going to be
going to be you know 430/3*

Mr Finch had had to make major life changes after a previous heart attack three years previously. Having re-organised his life, he had his stroke which threw him into a new world - with more new rules to learn. The second major disruption of his life narrative made him appreciate the unpredictability of life; he was not expecting to get back to 'normal'.

Only one couple, Mr and Mrs Snow, said that they could look into the future. By six months, Mr Snow who had suffered a mild stroke, had physically recovered and was back to his usual routine again. His relationship with his body had been restored - he

was capable of carrying out his usual activities. The couple's routines and lives continued as expected. They had returned to their familiar world. For them, things were back to 'normal', the stroke was a thing of the past and their time horizon had expanded again. Johnson and Morse (1990) in a study of people following a heart attack described this process as 'refocusing'; the heart attack was no longer considered to be of primary concern, and as physical limitations diminished, the environmental, social and temporal worlds of informants expanded.

Although both the stroke respondent and their spouse entered new worlds following a stroke, from an analysis of the data they appeared to enter worlds with a different emphasis, with different pressures and issues. The next two sections will be used to describe the main issue for the stroke respondents which was their new precarious body and the main issue facing spouses - which was responsibility. These separate issues appeared to be unique to each of the partners within the couple.

5.7 The dominant theme described by the stroke respondents

Stroke respondents discussed many aspects of their life in the interviews, but the dominant issue with which they were faced appeared to be the relationship between themselves and their body.

5.7.1 Separate precarious body

The stroke respondents described changes in their relationship with their bodies. Talking of their lives before the stroke, people described tasks and goals they had reached, taking their body for granted. Following their stroke, people said that however much effort they made, they could no longer move their limbs and body to achieve their goals - they described a loss of bodily determination. This was described by Mr Finch looking back at six months:

*Well I was very upset
like I say it's the first time I've ever been in hospital for so long
except when I had the heart attack
which was only three or four days
but I knew I'd be all right all right then
but when you're lying there
and you can't do nothing
and always been able to do those things
it's worrying 6/2*

There was a sudden fundamental separation of self and body, Mr Finch could still move his limbs after his heart attack. As Mr Finch described, he felt his situation was worse than when he had another life threatening condition as he '*knew [he] would be all right then*'. Doolittle (1991) noted the shock of sudden immobility and paralysis described by the respondents following stroke. She saw them as being 'suspended in a passive objectified body' (p237). She found that respondents described this experience from immediately following the stroke for up to about three weeks. Within this present study people described how their bodies had become unreliable, had let them down and put them in vulnerable and precarious situations.

Mr Evans described during his hospital stay:

*all the time I was in that [acute] ward
which is the worst really
because the first couple of weeks
or the first eight days anyway
I was completely useless
used to have to get carried out to the toilet
used to leave me out in the toilet
plonk me on the toilet
and Um I used to have to get turned in bed
couldn't do anything myself 573/1*

For Mr Evans in particular who suffered numerous set-backs with a viral infection, bowel problems and was experiencing toothache at the time of the interview, his body had become something which was puzzling and perplexing, the workings of which were rather precarious and fraught with danger.

There is a growing literature about the experience of the body in chronic illness which can provide some clues to understanding this experience (Williams, 1996). Merleau-Ponty (1962) working from a phenomenological perspective put forward the concept of corporeality challenging the idea of a separation of the cognisant subject on the one hand and the world of objects on the other. From a phenomenological perspective, body and self are inseparable, the self in relation to the world can only be known through the body. Normally, the relationship between self and body remains largely unproblematic, giving people freedom to act in the material and social world (Leder, 1990). Bleeker and Mulderij (1992) suggest that normally the body has a 'silence' as we are unaware of it. They suggest that the body is the 'silent taken for granted base from which we act on and learn about the world' (p2). Gadow (1982) put forward a useful theoretical framework for exploring the change in body-self relationship following a stroke. She described the usual relationship of self and body as primary immediacy: the body is not seen as an instrument with which the person acts, it is their acting. She suggested that normally this unity of the self-body creates a separation from the world on which it acts.

Gadow suggested that this relationship changed when a person's body does not act under the will of the self. She described this changed relationship as disrupted

immediacy. The body and self are seen as separate. They are experienced as acting upon one another just as the lived body and the world interacted in primary immediacy. In this state the body takes on the nature of an object. Gadow suggested that this 'object body' is sensed as much as a part of the world and its objects as it is a part of the self. The body loses its sense of purpose. Doolittle (1991) found that all thirteen of the stroke respondents spoke of the affected limbs in a passive, objective manner; they described the involved limbs as 'it' or 'they'. This sense of objectification can be seen in the way Mrs Scott talks about her affected arm while in hospital. She cannot move her arm voluntarily although she practices moving it with her unaffected arm. She said:

*I can move it about a bit you know
I keep lifting it up
do my bit of exercises
I let go and it drops (laughs)
you know you think oh lovely, it's up there
and that's it,.. er like I say 485/1*

Even although she knows she has lifted it with her other arm she still feels 'oh lovely it's up there' - like a normal arm, but as soon as she lets go 'it drops' (as any other object would do if it were dropped). It appears that following a stroke the inner self is felt to be the same, but the body does not allow expression of this self. The body becomes an object like others in the environment which have to be acted upon. Cant (1997) describing his hospital stay reported that it was a strange feeling to be confined in a body which no longer functioned as it had functioned for the previous 50 years.

Not only does the body appear to become objectified, but Charmaz (1991) has described how it becomes the focus of attention. As the body is no longer 'silent', it is brought into conscious awareness. People develop a heightened awareness of their body. They judge it, test it and look for signs of potential crisis. The body becomes perplexing and people try to understand it. When admitted to hospital the respondents looked toward doctors, judged to be the 'experts' in bodily matters, to help them to understand what had happened to them - to solve the puzzle of their body. Several respondents reported their frustration and fear at how the medical profession, expected to understand the workings of the body, were powerless to do anything about the

condition. There was a sense of discrepancy between the situation in which the stroke respondents found themselves and their expectations of medical knowledge and support. The frustration with the impotence of the new technological health service was apparent in a quote from Mrs Snow, while her husband was in hospital:

*why can't they stop it [raise in blood pressure] from happening
when they're supposed to be able to do marvellous things 955/1*

'Blood pressure' was seen as a simple ordinary everyday condition making the inability of the new hi-tech medical profession to manage it even more frustrating. There were few answers to respondents' questions. Mrs Scott talking in hospital mentioned that:

*Unfortunately they can't say
yes you'll be all right
because I mean they don't know
how long the muscles are going to take to react 495/1*

This sense of frustration with physicians was reported to Becker and Kaufman (1995) by their 36 interviewees when they found that doctors could not give them any answers following their stroke.

Trying to understand their bodies' inability was made even more difficult to comprehend because often the respondents felt healthy and all their clinical signs demonstrated that there was nothing wrong. This was described by Mr Finch while he was in hospital:

*I'm mad because I feel fit
and I just can't use my arm or leg
they keep taking different readings and tests
I'm OK
I'm normal blood pressure temperature 'n all of that
all normal
.. had some students here today, yesterday
and they took my blood pressure
and I had nearly the same reading as a youngster there 1191/1*

There was an incongruity between their own situation and the medical evidence and support. As Mr Evans said:

*I kept on asking the consultant and the doctors
every time they came in
why did I have this stroke?
what have I done wrong ?
and nobody could answer the question 1015/1*

The moral imperative which has been linked with many chronic conditions which cannot be treated by doctors is apparent in this quote (Robinson, 1988; Benner, Janson-Bjerklie, Ferketich et al, 1994; Pound, Bury and Ebrahim, 1997) in Mr Evans asking ‘*what have I done wrong*’. Often respondents were aware of the risk factors described by doctors, but they did not seem to be related to their own lives. Mr Evans described how he had spoken to several doctors and how the only thing the doctor could find was slightly raised blood pressure and so they put him on tablets. As he said:

*so I can't ask the question anymore,
though yet I still wonder 1069/1*

This inability to understand what had happened, and to be able to identify a cause, led to a long-lasting fear of recurrence reported by both stroke respondents and their partners.

Following the stroke the respondents had suddenly found that the body through which they had known the world was not the responsive medium it had been for perhaps the previous 60 years. Body and self had become separated. This appeared to be a frightening and frustrating experience. In order to gain some control, respondents had to focus on their perplexing bodies and work out how to relate through them with the physical and social environment. Within this strange world respondents often felt let down by doctors who could not give them any clues with which they could plan their future. They did not know why the stroke had happened, none of the tests ‘showed’ anything, it could not be cured and so the possibility of recurrence was ever present. Over the year following stroke talk of recurrence although present, was less frequent.

Respondents appeared to build up a level of confidence from their own everyday experience that their condition was not critical.

5.7.2 Unreliable body

Over time, all of the stroke respondents could do more for themselves, but even by one year all but one of the group still perceived their bodies to be precarious and fragile. At six months Mrs Scott described how her 'head lets her down' while she was talking about problems she was having with falls. As she said:

*I've always tried to be careful
but I mean if your balance goes
or my head lets me down
there's nothing there you can grab hold of
you just go
I'm very careful now
hang onto the furniture
then you don't go anywhere where there's nothing
you know will save me 656/2*

So six months after leaving hospital she still has to be 'saved' by external objects as she could not rely on her own body. By one year most people had reached a stage where although they could do more for themselves they still felt vulnerable and expected their bodies to let them down at an inopportune moment. Mr Evans described the improvement in his walking but felt he had to add:

*As I say I could fall over when I go,
when you go out now
and um end up on the bed for the next whatever 1098/3*

Because people were physically fitter they expected to be able to achieve more but often were frustrated to find that their bodies still let them down. One year after leaving hospital Mr Finch told a story about how he was working under the sink, expecting to be able to unblock the drainpipe. He was well into the job, but came to a halt when he didn't have the strength to undo part of the pipe work.

His frustrations are apparent in his comment:

*I'll have a go if it's reasonable
But even though I know in my mind
I can probably do it
me body says
No you can't
Lets me down
I can't do it
And that makes me mad still you know 781/3*

Respondents appeared to be experiencing what Bleeker and Mulderij (1992) described as a rebellious body. The body protested, was uncooperative and did not do what the person wanted to do; or only did it very slowly, or with effort. The split between body and self was still evident. Because the body was unreliable it was still the focus of attention, rather than allowing the person to attend to what it is that they wanted to achieve. Bleeker and Mulderij (1992) suggested that with a rebellious body, the person has to concentrate on each movement in order to achieve their goals. This was well described by Mr Evans at one year:

*cause the big, the big day I want
is to be able to get up
and not even think about doing it
you know what I mean
I think that might happen one day
you know
I'll just get up like you do
without thinking about walking
I've still got to get up there
and stand up
and get my leg
just one leg out ready to take
and move forward
you know push my leg through
all this sort of thing
all these motions
I've still got to think about it 1037/3*

As the body dominated existence so much it appeared to be difficult to focus on the activity, the purpose of the movement. Doolittle (1992) found that, at the end of six months, all 13 participants continued to experience a very objectified body and there was there was little evidence of pre-stroke automaticity and smoothness of movement. In the present study even at one year people had still not reached a stage described by

Gadow (1982) as 'cultivated immediacy', the reunion of self and body - where the body and self are still experienced as distinct, but are no longer opposed, and there is free and unconstrained movement.

During the year following discharge from hospital it appeared that stroke respondents had built a new relationship with their body, but even by one year all but one felt that it could let them down at any moment. Often they had to concentrate on movements in order to achieve their goals. This disrupted relationship affected both physical and social activity. Often the meaning of an activity changed. Johnson and Morse (1990) described how following a heart attack, each new activity such as having sex, bowling, vacuuming was approached with a sense of trepidation. What were considered normal routines were now viewed as challenges. This was also described by Nijhof (1996) who studied the life stories of 25 respondents with Parkinson's disease, a progressive neurological condition, in order to explore their sense of uncertainty. Many of the informants spoke of a lack of trust in their bodies and the sense that the world in which they once felt familiar had become a different one. What used to be a natural world was seen as a source of concern. Respondents had to 'dare' to act in the world.

Within the present study it appeared that the body-self relationship was not static or gradually improving but dynamic and situation dependent. There appeared to be a different relationship in different environments. By one year, members of the group described certain moments when their body was 'silent' physically and socially. Mrs Robinson spoke of her daily routine and mentioned how she was quite happy to sit in her chair and read while her husband was out in garden. As she said *'but sitting here like this I feel just as I used to, but it's when I get up to walk.. 789/2*, suggesting that as soon as she got up and walked around the house, of which she was quite capable, her body came into her awareness again.

Within the home, the body came into awareness physically, but often respondents felt quite comfortable socially. Family and visiting friends were accustomed to their new situation and the body was not a social focus. This changed as soon as the respondent left the house. The body became the focus of the social gaze and lost its 'silence'. In

Western culture when adults lose control of their bodies they are expected to attempt to regain it if possible and if not then at least to conceal the loss as effectively as possible (Frank, 1995). When away from home, respondents felt more precarious and uncertain, as the environment often made movement more difficult. They became tired, often there were not 'things to get hold of' and people walking past put them off their balance. The body gained not only heightened physical awareness because respondents had to concentrate more in the unfamiliar environment but also heightened social awareness as the need to control movement and appearance was paramount. This created the uncomfortable experience of a heightened disparity between body and self, which often limited activity outside the home. This was described by Nijhof (1995) in the study of people with Parkinson's disease; respondents made a division between the inside world (home) and the outside world. The inside world was relatively safe and predictable whereas respondents described the outside world as the place where things could go wrong. The respondents in Nijhof's study described that as their illness progressed they often found it easier to withdraw from the outside world to protect their sense of self. Nijhof reported how their physical difficulties were interpreted by others and themselves with a sense of shame and embarrassment. Williams and Wood (1988) in a study including people with rheumatoid arthritis found that although families were accustomed to the changes taking place, in the outside world respondents constantly felt the need to explain and justify a piece of behaviour to a real or imaginary uncomprehending stranger. In the present study lack of knowledge by others of the new physical and social rules with which respondents were living often led to social misunderstandings. These will be discussed in a later section.

At one year respondents were still working to get a sort of negotiated settlement - a realignment between body, self and society (Williams, 1993). Robert McCrum (1996) a journalist wrote about his experience of his recent stroke at 42. The inherent link between physical and social performance and a sense of identity can be seen from his writings. He described how he was puzzled and curious with his body that let him down so badly; how he found himself in a new country with no name. Immediately

following his stroke it dawned on him that he was not the same person he had been 24 hours previously. Even when writing the article several months later he noted:

I still wonder if the “I” who is typing this with my ‘good’ right hand is the same “I” who used to peck away two handed at 50 words a minute. (McCrum 1996, p29)

The only respondent in the present study who did not express these concerns was Mr Snow who had full physical recovery by six months.

While the stroke respondent was concerned with trying to re-establish a sense of unity between self and body, their spouses appeared to have their own issues to confront.

5.8 The dominant theme described by spouses

After their partners were admitted to hospital there was a physical separation of the stroke respondents and their spouses. It could be expected that the circumstances of this separation would alter their relationship to a certain extent. From the analysis, it was found that there was a fundamental change in the relationship which could not be understood by physical separation alone. From the time the stroke respondent was admitted to hospital spouses described taking full responsibility for managing the couple's life.

5.8.1 Responsibility in hospital

While the person was in hospital the responsibility for care was shared with hospital staff. Relatives still had to fulfil time-consuming responsibilities such as visiting and providing clean laundry. This was at a time when they were still shocked and frightened for their partners. Spouses tried to understand what had happened by talking with staff and as Mrs Evans said:

*there were many times
when they said little things
which made me really worried 502/ 2*

Staff would mention something which to them was apparent from their experience, but which came to spouses as a shock. When asked to describe these 'little things' Mrs Evans continued:

*Well it was just just little things
like when A said that you know
he'll probably never go back to work
and you could have another stroke
.. I was grateful that he did give it to us straight
but at the same time I was petrified that this was going to happen
and could happen quite quickly you know 513/1*

Spouses entered a new world and did not know what to expect. Rosenthal, Pituch Greninger et al (1993) explored the needs of 14 wives, while their husbands were hospitalised following a stroke, using a list of 27 perceived needs rated by the respondents. They concluded that within the hospital setting the most important need was for information. Wives wanted to know: what they could do to assist care, to be involved in discharge planning, to know their husband was well cared for and to know

what their husband would be able to do in the future. Wives needed to have practical information about the new world in which they found themselves. The researchers found that wives gave low priority to their own feelings. It appeared that in hospital, wives were not ready or did not have time to reflect on their own needs. This pattern was found throughout the present study in spouses of both genders. The needs of the stroke respondent were the spouses first priority, the focus was on them. Anderson (1992) in a survey of 176 stroke respondents and 148 supporters found that one month after the stroke the majority of supporters expressed worries about the future and about how they were going to cope; whereas the majority of stroke respondents reported no major worries about the future, they seemed to be more concerned with the present. It appeared that relatives had taken responsibility from an early stage.

For many spouses in the present study the hospital was seen to be a place of sanctuary and hope; they often felt safe and secure when visiting but worried when they returned home. Mrs Gunner looking back at six months said:

*while I was in hospital
I coped
and I could do anything for Bob
and I would do anything to help him
As soon as I was away from the hospital
I went to pieces
.. it was when I was away from him
that I couldn't cope you know,
you find your fears when you're away 436/2*

Other spouses who lived alone mentioned the loneliness of returning to an empty house and also the fear of being alone overnight.

Mrs Curtis highlighted the value and support provided by the rehabilitation ward environment.

*well VH was wonderful
I described it like going into a church
You know when you go into a church
there is this wonderful feeling of peace and tranquillity
an aura when you go into VH
there is an aura of positiveness
of enthusiasm
it's a bit like a womb
didn't matter how depressed I was feeling
I'd go there
and I would enjoy my time there 417/1*

During the time their partner was in hospital, life was totally given over to them. This time was a very emotionally draining time for spouses as described by Mrs Curtis reflecting at six months.

*there was that dread earlier on
I don't know a numbness
I just felt void of any feeling really
I can't remember
other than that it was just a case
of going through the motions
from day to day
just get through each day 26/2*

The wives studied by Rosenthal, Pituch, Greninger et al (1993), during their husbands' admission following a stroke reported similar experiences. All of the fourteen wives indicated that they experienced heightened feelings while their husbands were in hospital. They described a variety of feelings including: feeling that they were on a roller coaster, feeling their lives were being turned upside down, feeling emotionally drained when confronting the unknown outcomes of the stroke, having difficulty concentrating and experiencing a state of shock. Spouses experienced a fundamental change in their present and future lives. Responsibility for caring for their spouses was their main concern. From the present study it appeared that while visiting the stroke respondents in hospital, responsibility was shared with hospital staff, spouses often gaining relief within the hospital situation. The emotional difficulties they faced were in trying to maintain an 'ordinary' life outside the hospital, when they found

themselves in an extra-ordinary situation, with an uncertain present and an unknown future.

5.8.2 Responsibility at home

Once home the spouses appeared to take on total responsibility for their partner. There were three exceptions, Mr Court a stroke respondent and his wife who was disabled looked out for, and after, each other as they had always done; Mr Snow who had few residual physical difficulties and was ‘back to normal’ by six months; and Mr Wren who had made a relatively good physical recovery by one year. The responsibilities assumed by the spouses were wide and varied. They consisted of their own and their spouses’ usual responsibilities and those imposed by the stroke. Table 5.1 shows the type and range of responsibilities described.

Responsibilities	Examples
Own usual responsibilities	which may include household/ maintenance /family/ finances/ future
Spouses’ responsibilities	which may include household/maintenance /family/ finances/ future
Imposed by stroke	Partner’s health Potential problems Constant requests Rehabilitation programme Occupation/’being there’

Table 5.1 Responsibilities of spouses

5.8.2.1 Usual responsibilities of both partners

As well as having to be available for their partner, spouses found that they were responsible for household management including daily domestic work, such as cooking, shopping and cleaning. Spouses also took on broader household responsibilities such as paying the bills and sorting out financial arrangements.

Mrs Curtis said at six months:

*my in-tray was tottering
all these things like my car insurance was overdue you know
never get done
and you know it definitely needed sorting
when it starts to spill out all over the kitchen
I think it's time
and of course I do it all now
everything
S and mine
and everything he used to sort out
so it's a time consuming job, running a family 240/2*

Enterlente and Kern (1995) carried out a pilot study using a marital roles questionnaire with ten wives within two weeks of their husbands' discharge from hospital following a stroke. They found that the wives' role responsibilities in the family had increased. Wives reported fixing things round the house and handling financial matters which were new experiences for them. This was also found in a study by Robinson-Smith and Mahoney (1995). They interviewed 73 elderly stroke couples 6-12 months post stroke and found that spouses mentioned an increase in household work. Spouses not only had to manage their own usual responsibilities but also those usually undertaken by their partner such as maintenance of car, garden and house. Often they were aware of the frustration of stroke respondent in not being able to continue as they had done previously. As well as having to manage the practical aspects of life, spouses were also had to manage the emotional consequences. Spouses had to either take on the tasks themselves or arrange for others to assist them. Where finances did not allow a person to be employed, family members had to be asked, which was seen as an added difficulty. At one year Mrs Gunner described how although her husband said they could sort things out, he could not physically cope.

*and he gets upset
because he's never had to be dependent on other people
he's always put right what went wrong
and Like when the heater went wrong
I was in a hell of a state
my son in law came over
but I can't depend on him every time 657/3*

New types of relationship had to be developed with wider family members. What used to be controlled within the family unit now involved other family members.

As well as present concerns, spouses also appeared to be responsible for the couple's future. Within the interviews they often spoke of their worries about the future including: how to organise holidays, whether to move or not, or how the stroke respondent would manage, if they became ill themselves. The stroke respondents tended to speak in the context of the present situation in which they found themselves. It appeared that the responsibility of the stroke respondent was to get better, and the responsibility of the spouse was to look after everything else. When the couple had a dependent family additional responsibilities were encountered which will be discussed in the following chapter.

5.8.2.2 Responsibilities imposed by the stroke

As well as family and domestic responsibilities, spouses appeared to have additional responsibilities related directly to the stroke. All of the spouses described how they were acutely aware of their partner's physical condition and felt responsible for their health - they were constantly looking out for signs of recurrence. They often hid their fear and anxiety from their partner as they did not want to upset or frighten them. Spouses had to decide when to call for medical support. Because the original stroke was so unexpected, all signs were often considered to have possible life or death consequences. At six months Mrs Evans described this dilemma:

*but I mean there were days when he did look really poorly
and I was sort of really worried
but (4) there was nothing positive that you could say,
right we'll get the doctor you know
so it was sort of having to make these decisions
Do I give
gosh, If I don't get the doctor
is he going to be all right 150/2*

At the same time, spouses described how they did not feel equipped to deal with possible problems. At one year, Mr Robinson described an incident when his wife lost her speech. He called an ambulance, and by the time they had arrived her speech had returned.

But as he said:

*I don't know what it was
you don't know about medicine
well you don't know do you
I wouldn't know right from wrong you know 78/3*

Spouses spoke of being always aware of possible dangers or problems which their partner might encounter. At six months Mrs Gunner described how she saw her husband as being more vulnerable:

*I do find sometimes I get a bit nervous here
I think if anything happened you know
I wouldn't be able to get B out of the house quick
that type of thing makes you very aware
you look you check things double
to make sure everything's switched off you know,
you see danger 813/2*

At one year Mr Robinson described how he still had to 'look out' for his wife.

*I mean I've seen her do things
I think Christ don't you do that again
.. I can foresee problems now
.. I'm always looking to see if there's a problem ahead
that she might run into 1320/3*

Davis and Grant (1994) in a study exploring the management strategies of carers used within the first few weeks home from hospital following a stroke described how carers practiced vigilance. Respondents described how they monitored and evaluated their relatives condition over time, for example watching to see how they were managing on the stairs or how they were coping with being with other people. Parker (1993) interviewed 21 couples under 65 years of age where one partner had become disabled since marriage. Carers reported the constant watching that they undertook. This ranged from making sure things were not left on the floor to trip over, medical decision making and being around in case anything went wrong.

Spouses described how they had to respond to constant requests. Because their partner often found it difficult to move around the house and get things for themselves they were reliant on people fetching and bringing things for them. When people were

first home from hospital, relatives took on this 'nursing' role but found it very frustrating when it continued over a long period of time.

As Mrs Evans said at six months:

*the minute I sit down and pick up knitting or a book
he'll want something
um he does try hard
not to impose on me too much
but he still finds something
can't help himself* 978/2

This behaviour was occasionally recognised by the stroke respondent themselves. At one year Mrs Robinson described this difficulty and how the couple managed it.

*G gets up before me
because I like him to have his breakfast on his own
so I don't, cause as soon as he starts doing something
I start - just do this for me, just do so and so, you know what I mean
whether it's automatic or what it is
he's only got to start something
and I want something done
so he, he likes to get on and have his breakfast in peace* 278/3

Because of the constant requests from their partner, however much the spouses planned their day it was often disrupted. The emotional difficulty between the couples induced by this new position was highlighted by Hasselkus (1988) who studied the informal learning processes of family caregivers of 15 frail community dwelling elderly people. She found that expectations of attentiveness were seen as unreasonable by some of the caregivers when their relatives found it difficult to wait for help. The strain on his marital relationship was described by Robert Murphy (1987) who had a benign spinal cord tumour which caused paralysis of his arms and legs. He reported how he generally hesitated to ask his wife for things, feeling guilty about bothering her. As he wrote

I am especially sensitive to the tone of her response..... Does that slight inflection say
'What the hell does he want from me now?.' (Murphy 1987, p214)

In managing this new situation, new forms of communication and new strategies were needed to achieve a delicate balance acceptable to both partners.

Spouses described how they were involved in their partners rehabilitation programme.

They all described that they needed to give time and effort to support and encourage their partner, not only practically but emotionally as described by Mr Hyland at six months:

*I want, my main aim
is to get her out
to get her active enough and meet people
and not to do it all on the stroke
and say I've got this stroke
and I'll never get better
I want her to get it into her head
that she will get better
and she wont be completely 100%
but if she is 90% better that will do me 391/2*

Some people took on personal responsibility for the rehabilitation programme, and the results obtained. At one year Mr Robinson said:

*the thing that as I say gets me
is I can't seem to make much progress with her arm
I does her exercises every night
... and er we do that
and I think to myself well I'm doing this every night
and I'm dammed if I'm not getting anywhere
you know 1426/3*

As part of rehabilitation, spouses had to let their partners struggle to do things for themselves. At the same time relatives described how they had to manage their own feelings of hurt and loss. As Mr Robinson said at one year:

*and I feel sorry for her really
I do really feel sorry for her and all
and it upsets me sometimes to see her
incapable as she is
to what she used to be 1506/3*

Anderson (1988) interviewed 148 supporters up to eighteen months following a stroke. Many of the supporters described how it was distressing to see their relatives dependent and restricted. Parker (1993) highlighted the intensity of feeling when the cared-for was a spouse. She suggested when spouses act as carers they are not only caring *for* their partner but also caring *about* them in an intimate way. The nature of the relationship makes it difficult if not impossible to distance themselves from the

experience. Again, this highlights the emotional as well as practical situation in which spouses find themselves.

Spouses spoke about how they felt responsible for how their partners spent the day. They did not feel that they could get on with their own work if their partner was not occupied. At six months Mrs Gunner said:

*the one thing I do find
is that I've got to keep
I wish he would think of things to do for himself
rather than me saying to him oh Bob
why don't you do so and so you know
I wish he would just think
oh I think I'll do so and so today
you know like he used to 526/2*

Spouses described how they had to 'be there' for their partners. Mr Robinson described how, although he was working in his garden shed and keeping contact via an intercom:

*I don't leave her too long on her own see
.. if I'm in about half an hour
I'm bound to sit down and have a chat
and then she don't get sort of bored
and feel too much on her own see 367/2*

The intercom was still important at one year, as Mr Robinson described:

*if she can't [communicate with me]
she gets worried
if she knows in her mind that I'm just a shout away
she's not too worried then
but if I'm disappeared
and she can't get hold of me
that's a different thing altogether 1091/3*

If partners did have ideas for what they wanted to do, occasionally spouses felt they had to sacrifice their own routines to help the person fulfil them.

At six months Mrs Evans said:

*but lately it's um, Are you going to take me out today?
Right where shall we go
and that's it
Oh dear I was going to do this
or I was going to do that 654/2*

Responding to the requests of partners often made the spouses feel that they were not able to keep up with their other domestic responsibilities. Even after hospital discharge a sense of responsibility could be shared with health professionals. Outpatient rehabilitation was often seen as a time when responsibility was shared. Mrs Curtis' husband had good physical recovery but severe speech problems. At six months she said:

*he has such an empty life
and he does get bored
but I don't know what to do to make his life fuller
cause he's got to do it for himself to a certain extent
you can't do everything for him
and I'm really worried about when he stops going into hospital 343/2*

Outpatient rehabilitation was seen as a way of structuring her husband's week, having some activity that was his own, for which she was not responsible.

The responsibilities taken on by the spouses had emotional as well as practical implications within their lives. Anderson (1988) highlighted that although some stroke supporters found physical tasks difficult and tiring, generally these were not seen as serious difficulties. The feeling of being tied, of being constantly available rather than the tasks involved was a source of difficulty for many carers. Respondents felt that they were 'on call' all the time. This sense of being responsible all of the time created a fundamental change in the spouses' lives.

5.8.3 Fundamental sense of responsibility

The fundamental feeling of responsibility was well described by Mrs George at six months when describing how she was explaining their changed relationship to her husband.

*I have to depend on you for something
and something you have to depend on me
because at the moment
I am your hand,
I am your foot
I am everything 142/2*

It can also be seen when Mrs Evans described her response on returning home from church on a Sunday:

*when I came back
[a visitor] was peeling potatoes for me
which was nice
It's just little things like that, you know
that can make a difference 266/3*

Spouses found that they had little time for themselves and often could not understand why they were so stressed because they did not seem to be 'doing' very much. As Mrs Evans said at one year:

*nothing gets done out there[garden] any more
it's silly, because I'm inactive
and yet I've got no time
it's a contradiction
you know, I'm aware of it
and I just can't understand it
I seem to be at everybody's beck and call
but I don't achieve anything
and I don't feel as if I'm doing anything
it feels as if anything's just gone by the board 292/3*

From the descriptions given by the spouses it appeared that their whole life was fundamentally affected. At one year a comment made by Mr Robinson highlights this experience.

When asked what advice he would give to others he suggested that people should take up a shared interest with their partner.

*you don't forget your problems do you,
um it tends to take the weight off
if you've got some other,
something [else] you can sort of discuss
.. it takes your mind off it really
because sometimes we'll sit talking here
about what you're going to do [planning the garden]
and you think to yourself
Christ it's almost the same as we used to be 1063/3*

The pervasive nature of the stroke within the practical and discursive lives of the couple can be seen in how exceptional it felt to be able to sit and discuss 'ordinary' future plans.

The influence of a chronic illness on the identity of the spouse was highlighted by Pinder (1988) in a study including people with Parkinson's disease. One spouse commented:

well we're both disabled aren't we.
I can't do what I'd like to do.
I can't just go swanning off can I ?
I'm tied up.
My first priority is him (Pinder 1988, p78)

The sense of responsibility appeared within the hospital setting. Spouses put the needs of their partners before their own. Their focus was their partner. This pattern, once set up in hospital, was described by the spouses over the whole time period, up to one year. It appeared that the person with the stroke was responsible for his/her own physical recovery but that the spouse assumed responsibility for everything else. This was also found by Nilsson, Jansson and Norberg (1997) during an in-depth study of ten people following stroke. They reported that stroke respondents became self-centred, as their personal treatment of the situation required all their mental energy. The effect of the healthcare system in reinforcing this position will be discussed in the final chapter.

5.8.4 Responsibility versus caring

It is helpful to focus on the concept of responsibility rather than the concept of caring. When looking for comparative research, I was struck in the same way as Nolan, Grant and Keady (1996), in that current conceptualisations of caring are essentially task-based. Nolan and Grant (1989) in a study of 726 National Association carers described how the objective circumstances of caring contributed only a small part to carer stress and that emotional elements appeared to be more significant. From Section 5.7 it can be seen that there is a large emotional element in the situation in which spouses find themselves.

Mrs Evans highlighted the difficulty of the fundamental change at one year.

*As far as coping [physically] with [husband]
really I mean that's been quite straight forward.
It's it's difficult
but it's coping with the change in life
total change in our lives together
cause you suddenly come to an abrupt halt you know
everything's just switched off
and changed 1089/3*

In order to understand the spouses' situation, wider psychological aspects need to be addressed.

There have been developments within the caring literature, which go some way to addressing these issues. Bowers (1987) suggested a model of family care based on her work with couples in which one partner has dementia. She suggested that much of caregiving is invisible as it does not include overt behaviour. She described five aspects of care: anticipatory, preventative, supervisory, instrumental, and preservative care. Anticipatory care involves making long-term plans for the future, preventative care involves monitoring at a distance, such as checking a person's medication and diet, supervisory care involves direct monitoring, instrumental care involves practical tasks and preservative care involves maintaining the self-esteem of the cared-for person. This model was helpful in that it moved consideration beyond instrumental care alone and highlighted the 'invisible work' of carers, reflecting that carers have a sense of responsibility for their relatives' life.

Nolan, Keady and Grant (1995) who have carried out extensive research into caring developed Bowers typology, which was seen to be most appropriate for families with dementia, into one more appropriate for any chronic illness. Overall they kept a similar typology but incorporated two new aspects of care, reconstructive care and reciprocal care. Reconstructive care involves developing new roles and encouraging change. Reciprocal care highlights the reciprocity in care relationships which are not based on the exchange of instrumental care given, but on financial, material and psychological reciprocity (Grant, 1990). With this new model there is a move towards an active rather than a passive role for the cared-for, and through their work the researchers have contributed to the possibility of increased sensitivity when statutory care is provided. I find this model conceptually inadequate as relatives, friends and spouses are still categorised in terms of being a carer. They only exist in the literature due to their relationship with the cared-for, who is still the focus of attention. A discourse confined to caregiver-receiver issues inherently reinforces only one type of relationship which is often one based on an unequal balance of control and responsibility between partners.

In moving away from a caring model, I am influenced by the work of Zola (1991) who demonstrated how the use of words constrain possibilities. The aim of the present research has been to focus on spouses in their own right with their own lives and biographies (and so worthy of their own exploration) not as part of a wider homogeneous concept called a carer. This approach makes it possible to explore different ways of relating without taking the unequal balance of responsibility within the couples' relationship for granted. A similar approach was used by Grant and Davis (1997) who asked ten respondents who were spouses, parents or children of a person following stroke about perceived self-losses. The researchers described losses in four areas: loss of a familiar self (due to having to take on new responsibilities), loss of an autonomous self (through not feeling able to leave the spouse for periods of time), loss of an affiliative self (changes in relationships with other family members), and loss of a knowing self (being unsure about how to manage the condition). By highlighting the self, the researchers focused on the relatives rather than the person

with the stroke. However, the focus on loss did not allow positive changes in the self to be described, so reinforcing a negative image of disability.

Rolland (1994) has written extensively on the impact of chronic illness on couples' relationships. I feel that exploring relationships per se rather than focusing on a specific relationship (i.e. caregiver-receiver) is a more helpful and liberating approach. The basis of Rolland's thesis is that chronic illness affects intimacy within a relationship. Wynne and Wynne (1986) consider intimacy within a marriage to be a set of processes through which both partners expose themselves in verbal and non-verbal ways, trusting that the other person will be understanding and will not betray trust. Bowen (1987) and Lerner (1989) suggest that intimacy requires that each partner be able to maintain autonomy with clear boundaries and expectations. Weingarten (1991) has noted that each partner needs to be able to enter temporarily into areas of concern or interest of the other and participate in creating meanings together. Using this approach, life following stroke can be seen in terms of relationships, autonomy, boundaries and expectations. These concepts may be applied to the marital relationship but I feel they are also useful concepts to explore in all social relationships and wider material-discursive practice. I would like to suggest that autonomy or control is the essential aspect which is lost in life following a stroke and that this loss can be maintained by material and discursive practices. I would also like to suggest that it is only when control is regained by both partners that 'things can get back to normal'. Rolland highlights the need for clear boundaries and expectations. As was noted at the beginning of this chapter following a stroke respondents are 'dropped' into a new world with new physical and social rules. New boundaries and expectations need to be built which allow each partner to have a fair measure of control over their life and future. I would suggest that although a large proportion of respondents within this study received rehabilitation, this realignment of relationships has not happened. The implications of a broader view of the role of professionals within rehabilitation will be discussed in the final chapter.

From the previous two sections it can be seen that both the stroke respondents and their spouses had fundamental life changes to manage following the stroke. This work was

long-term and continued throughout the time of the project - that is at least up to one year after leaving hospital, (apart from Mr Snow). From the work of others (Oliver, 1988; Corbin and Strauss, 1987) it may be expected that this process would last several years. These processes appeared to be influenced by another aspect described by both of the partners; hidden disability.

5.9 Hidden disability

All of the interviewees described how the fundamental changes in their lives were more difficult to manage because their difficulties were not apparent to others. In hospital Mr Evans described how he used to have lots of visitors. He described how they expected him to be wired up or covered in tubes and how they were quite surprised to see him sitting in his chair. As he said:

*They don't realise you can look quite well
but that doesn't mean you are well
you know what I mean 1571/1*

At six months hidden disability was still an issue for Mr Evans. He described his visits to the outpatients for treatment:

*I mean it's happened to me several times,
I go over in the chair and I wait outside
...And somebody comes up and says,
'Hello, what er, what are you over here for?'
I say, 'Oh, I'm waiting for treatment'.
'What's wrong with you then? ',
I sit there like this,
..they say 'Well, there's nothing, what's wrong with you?'
'Well, I've had, you know, a bit of a stroke, I can't walk'
'You can't walk?' he says.
Cause, they look at me, they see me sitting in this [wheelchair] or if they see
me on a chair, they,
it looks as though there is nothing wrong with me, you know what I mean.
But there sure enough is
So looks can be deceiving can't they 378/2*

The experiences of the stroke respondents were not validated by others; it appeared that they could not appreciate their situation, the fundamental change in their present and future life was not socially acknowledged. Respondents appeared to find it difficult to explain their experiences to themselves let alone to try and describe them to others. Mr Evans while describing his difficulties with walking said:

*that's one of the hardest things for people to realise
... it's as if you've forgotten how to walk
How could you forget how to walk? 1074/3*

As there was no shared discourse it was difficult for others to imagine what it must be like to live following a stroke.

Hidden disability was still an issue for all but one of the stroke respondents at one year. Mrs Robinson usually a quite accepting person said:

*what annoys me is when I meet people
'oh don't you look well'
I said I don't know, I wish I was
...well I'm not ill as such but I'm just not very swift 606/3*

Again she did not have the words to explain her situation. Others were seen as being dismissive as her difficulties appeared to be invisible to them.

Not only was their new life-world not appreciated, social misunderstandings often reinforced a sense of a discredited social self. At one year Mr Finch described a recent event for him when out with his wife, lifting heavy shopping.

*well she went to pick it up
and she found it a bit awkward
well another woman was walking by pushing the trolley
she went over and helped her to get it out of the trolley
and I was just standing there
and I thought, well what the, you know
I had to say to her
I've only got one good arm
I can't you know, couldn't help
I felt self conscious over it you know
.. that's when it hurts your pride 817/3*

He went on to describe other times when people were passing and he did not have the opportunity to explain 'the new rules' of his world. He was upset that people would misunderstand his behaviour. Williams and Wood (1988) described how the people with the rheumatoid arthritis in their study found that in the outside world they were continually feeling the need to explain and justify their behaviour to uncomprehending strangers. Bury (1991) suggested that following the diagnosis of a chronic condition people find themselves in a situation of "meanings at risk". The risks arise because individuals cannot be sure that their own developing perceptions and definitions of the situation are shared by others. People misunderstand behaviour and as mentioned previously loss of control is socially unacceptable and people run the risk of being discredited. Robinson (1988) found that people with multiple sclerosis reported the risk of symptoms being misunderstood as mental illness, malingering or even drunkenness.

Spouses described how their experiences and needs were not recognised, even by health professionals. Mrs Curtis reflected on the time when her husband was in hospital:

*everyone is Steven, Steven, Steven, Steven, Steven
the hospital is Steven Steven Steven Steven Steven
there's very very very little concern for the carer
No-one I mean I had to volunteer everything I said
Nobody sat me down and said now what are your circumstances
what are your conditions
I told people, because I needed help
and so I volunteered the information
nobody ever takes you by the hand
and say's how are you ? 606/1*

At six months Mrs Gunner described how she did not feel able to talk to others as they did not seem to appreciate her experience. She compared the experience of two of her friends whose husbands had heart attacks which although requiring operations allowed them to get back to work.

*Bob had one stroke
and they can't do anything to put him right
And yet when you say heart attack
people automatically think - waah, terrible
And it is terrible
But they can mend that
And yet they can't mend a stroke
And yet people dismiss strokes,
as though it's er not so serious
That's what amazes me
That, that's the thing that really,
and, and I find myself,
because I think where people don't understand it,
they're inclined to think that,
what's all this fuss about,
why are you still backwards and forwards to the hospital
And you think, well you just don't understand 429/2*

Even at one year the invisibility of her responsibility and the invisibility of her husband's difficulties were highlighted by Mrs Gunner:

*erm it's a 24 hour a day job really you know
I don't think people realise they don't,
they look at somebody
unless they're sat there all twisted up
and his face all distorted like it was in the beginning
then they could see that there was something
Looking at Bob now when he's sat in his wheelchair
you think what the hells he doing in the wheelchair 121/3*

Not only did respondents have the difficulties of entering a new world and trying to learn the new rules, they also had a sense of isolation as they could not share their experiences with their usual peers.

5.10 Conclusion

From an analysis of the accounts it appears that following a stroke the respondents entered a new foreign world. There was a fundamental sense that they and their lives had permanently changed. The stroke respondents described a split between body and self, the medium through which they had known about the world for perhaps 50 years. They described a greater disparity between their selves and their physical bodies when confronted with situations in which they could not achieve their desired, expected goals. The body lost its physical 'silence'. The stroke respondents described a greater disparity between their selves and their social bodies in situations where they were felt to be judged by others. In these situations the body lost its social 'silence'. All of the respondents (bar one who had physically recovered) were exploring their new worlds and were confronting and challenging these new situations on a daily basis at least up to one year following their stroke.

Their spouses entered a new world where they described being responsible for both of the partner's lives. They entered this world within the hospital situation and shared responsibility with hospital staff. Once home their sense of responsibility appeared to dominate their daily life and conceptions of their future. The 'invisibility' of their sense of responsibility often made it difficult for others or they themselves to understand the challenges they were facing within their lives.

CHAPTER SIX

Differences in the text: individual responses to stroke

6.1 Introduction

From the previous chapter it can be seen that the ‘unreliable body’ described by people following stroke, not only has a great effect on their lives, but also on the lives of their spouses. Respondents described specific issues which they had to face directly relating to the stroke. The strength of a qualitative approach is that it is possible to highlight individual differences as well as similarities. From the analysis of the transcripts, although there were similarities, it was found that participants appeared to respond to issues in different ways. The differences described were related to their own lives, one at a social level linked with age related lifestyles and a second at a personal level linked with the meaning of stroke within the individual’s biography. A brief overview of these differences for each couple can be seen in Appendix 26. These two issues will be discussed in turn.

6.2 Age related lifestyles

Although, from analysing the transcripts, and assessing the quantitative data, there did not appear to be great differences in the level of anxiety expressed by the stroke respondents; there appeared to be a difference in levels of anxiety expressed by the spouses, depending on their age. Younger spouses appeared to express greater anxiety than older spouses. In order to describe the differences in the reaction of the spouses, two participant couples will be compared. The particular couples have been chosen not as typical examples of younger and older people, but in order to highlight salient aspects of their lives and lifestyles. Because respondents have spoken in detail about their lives it would be quite easy for them to identify themselves and others if all aspects of the transcripts were discussed in full. Only aspects which appear to be directly pertinent to the comparison of age specific lifestyles will be discussed in order to maintain a degree of anonymity. All names have been changed throughout the analysis. Although the description will be based on the interviews with the two

couples, quotes from other participants will be included where they are thought to be illuminating.

6.2.1 Comparative case study

Mr Evans was 56 years of age when he suffered a stroke. He worked in the docks. He had several children most of whom had grown up but still lived locally; one child still lived at home. His wife worked part-time from home and was very active helping others in her spare time. Mrs Robinson was 61 years of age when she had her stroke. She had retired about two years previously and was enjoying her time with her husband, who had retired a few years before. From Table 6.1 it can be seen that Mr Evans and Mrs Robinson reported similar levels of physical and self-care ability when assessed using quantitative indices. Both participants were of a similar age. Although Mrs Robinson had a slower physical recovery, by one year both were able to walk short distances indoors and to pick up objects from the floor. Both could use their hand for stabilisation only. They were both self caring, they could make themselves a drink, but needed supervision with bathing. They reported a similar level of social activity, although both were severely reduced (the maximum score being 45).

		Mr Evans	Mrs Robinson	Maximum score
Age (years)		56	61	
Motor abilities	hospital	9	2	13 = most able
Rivermead Motor Assessment	six months	9	9	
	one year	11	9	
Affected arm rating	hospital	1	1	6 = most use
	six months	2	1	
	one year	2	1	
Self-care	hospital	9	3	10 = most able
Nottingham 10 point ADL scale	six months	9	8	
	one year	9	9	
Social Activity	six months	14	20	45 = most able
Frenchay Activity Index	one year	13	16	
Anxiety	hospital	7	11	21 = most anxious
Hospital Anxiety and Depression subscale	six months	5	11	
	one year	3	6	
Depression	hospital	6	11	21 = most depressed
Hospital Anxiety and Depression subscale	six months	6	10	
	one year	6	7	

Table 6.1 Physical of and self-care skills of Mr Evans and Mrs Robinson over time

Although Mrs Robinson was anxious at first, Mr Evans’ and Mrs Robinson’s scores reduced to non clinical levels of anxiety and depression by one year. Although the participants appeared to have similar physical and self-care difficulties, their relatives had scores indicating differing levels of stress. These can be seen in Table 6.2.

		Mrs Evans	Mr Robinson
Age (years)		52	69
Anxiety	hospital	12	9
Hospital Anxiety and Depression subscale	six months	15	7
	one year	16	4
Depression	hospital	10	9
Hospital Anxiety and Depression subscale	six months	11	1
	one year	17	1

Table 6.2 Age and Hospital Anxiety and Depression scores of spouses

Both couples started with a high level of anxiety, which may be expected as their partners were in hospital. Over time, Mr Robinson’s level of stress decreased markedly, whereas Mrs Evans’ level of stress rose even higher. It is difficult to understand these findings by looking at the indicators of physical ability and self-care used above.

An alternative approach to understanding the difference in reported levels of stress is to take account of the age related life-style of the couple when the stroke occurred. From Table 6.2 it can be seen that Mrs Evans was in her early fifties and that Mr Robinson was in his late sixties. Mrs Evans was living the lifestyle of a younger middle-aged person. Her husband was out at work and she was responsible for her children’s welfare, even although only one child still lived at home. Mr Robinson had been retired for five years, and spent his time at home with his wife who was also retired.

People with differing lifestyles may be able to incorporate the effect of stroke more or less easily into their lives. Within this study stroke respondents and their relatives described three main ways in which the nature of their lives had changed following the stroke: life became focused within the home, more routine, and the pace of life slowed

down. These changes will be discussed in turn in order to understand their possible effect in the age related difference. The influences were complex and although they have been separated for ease of presentation, it is recognised that they were often closely inter-related.

6.2.2 Life is focused within the home

All of the stroke respondents with the exception of Mr Snow described spending many hours sitting in one place at home. At six months Mrs Scott described her experience when first home:

*to sort of sit here
and not be asked to do something
.. usually when they come they find me in the kitchen talking away
where I would normally been in there with them and you,
now I sit there
I mean that was I found that very hard you know
not to be able to get up
and go in there
so I think I felt that more than anything really
Finding that I've got to sit here
and just wait you know 58/2*

This comment not only highlighted the practical inconvenience of not being able to move about, but also demonstrated the disparity between the self and the social body. A great deal of time was spent in the home. Mr Finch spoke about his plans to drive his car:

*which will make me happier
because I'm upset and miserable indoors,
sitting around you know
I always like to go out when I feel like it
which I haven't been since last year (now March) 69/2*

As mentioned in the previous chapter spouses often felt that they could not leave their partners on their own. Parker (1993) described how the spouses in her study of 21 couples felt that they could only leave their disabled partner on their own for short periods. Anderson, Linto, Stewart-Wynne et al (1995) found that more than half of the 84 caregivers one year after stroke said they felt anxious about leaving their relative unattended for all or part of the day because of fear that they may fall or

experience another stroke. Due to these factors couples spent a great deal of time in the home together.

For Mr and Mrs Robinson spending a lot of time in and around the home was not too difficult. They had both retired several years previously. Mrs Robinson's main hobby was gardening and Mr Robinson spent a great deal of time working on gadgets in his garage. They described themselves as 'home birds'. They enjoyed pottering about and spending time together. They had organised their living space. Mrs Robinson's space was the house and garden; Mr Robinson's space was his garage shed and the garden. When asked in hospital about what she had been doing since retirement Mrs Robinson replied:

*I've just been pottering around at home,
you know housework, garden,
we used to go out Wednesday shopping
apart from that we never went out much
Never wanted to
I was quite happy to be home
I always have been a home bird 179/1*

At six months Mrs Robinson re-iterated her views about home life:

*we never have been ones to go out much
we've never liked company
we always like being on our own 52/2*

By six months, Mr Robinson felt he was able to continue his 'normal' activities such as going out in his garage (keeping in touch with his wife via an intercom), cutting the grass, and undertaking maintenance jobs around the house.

Mr and Mrs Evans were facing differing issues. Prior to his stroke, while Mr Evans was out at work, Mrs Evans was at home with her own hobbies, and friends, children and grandchildren visiting - an open house. On weekend visits home following his stroke Mr Evans recognised that he was going to have difficulty, as he found he became agitated by the noise of the children. Mrs Evans found she had to re-arrange the house space in order to keep a distance between her husband and visitors and maintain respect for both. At one year she was finding this difficult and would occasionally curtail her plans to have her grandchildren to visit. Prior to his stroke Mr

Evans' main responsibility within the home was repairs and upkeep. When describing his first visits home, he described them as enjoyable, but mentioned that while sitting in his wheelchair, he found he would start noticing the jobs that had to be tackled around the house. He described how he felt depressed that he would not be able to sort them out. This aspect was a source of stress for Mrs Evans at one year. As she said:

*it's difficult when I see things deteriorating around the house
.. now he sees them
and he's throwing them up at me
.. he's never worried much about things in the past anyway
It's only now that he can sit and look at it
He's got nothing else to do
and he sees it 83/3*

It appeared that spouses felt under extra scrutiny from their inactive partners within the house. At one year Mrs Gunner described how her husband would notice small things like a white thread on her skirt:

*and I get annoyed
because I think
I says to Bob it's not important
I said all you've got to do all day
is to sit there and pick fault with everything that's gone
I said I'm too busy
to think about menial things like that
you know 1108/3*

From this group of participants it is difficult to tease out whether difficulties at being at home were due mainly to age specific lifestyles or gender; as in this sample, all of the young relatives were wives. In this generation men and women tended to have their defined spaces within the home environment; mens' spaces tended to be the garage, shed or garden, whereas womens' space tended to be within the house itself. Often the male spouses described how they could still spend some time in their own space such as the garden shed even though it was limited, whereas the younger wives described their space as being invaded.

This was well described by Mrs Curtis;

*He's at home most of the time
I never get the house to myself
I like my own company
I just like being at home on my own
and I find it difficult having him here all the time
.. I think it's just the fact he is here
and there's no choice about it 168/2*

Miller (1987) explored the experiences of nine female caregivers who had been full-time home makers. They described their loss of control over the home environment; they perceived that their husbands were intruding into their personal space. DesRosier, Catanzaro and Piller (1992) explored how nine wives, aged 41 to 58, of husbands homebound with multiple sclerosis managed their lives. The respondents described how the need for space became a dominating issue in their daily experience. They felt upset by the constant presence of another individual within the confines of their home, in which many of them had had a solitary homemaking role. They described how they often needed to create personal space within the home, where they could be alone at times during the day.

Although within the present study there were no younger husbands, it was possible to compare younger and older wives. It appeared that the older wives had already worked out issues of their own space within the home after their husbands had retired and they did not bring space up as an issue in the interviews. Parker (1993) in a study of 21 couples under 65 years described how many of the carers strongly believed that people were not meant to spend all their time with one another. This was regardless of gender. It appeared that for younger spouses spending so much time together was more difficult as it was unexpected for their age group. The respondents in Parker's study also described the difficulty of finding something to talk about, as the couples were used to coming home from work and talking about their day. This conversational practice would have changed and been developed by older couples following retirement.

6.2.3 Life becomes routine

Following the stroke, life often took on a routine nature which was essential if all the practicalities of daily life and the spouses responsibilities were to be met. As Mr Robinson commented at six months, the only way to manage all his responsibilities was to be quite systematic:

*well I've slowly got a time,
a loose time programme
that's the only way we're going to get by
is to be fairly systematic
and fairly, reasonably well organised 762/2*

At six months Mrs Robinson said when asked about first being at home described the development of the couples routine in life:

*it was quite hard,
quite hard getting used to a different routine
and sort of getting yourself into a routine
I mean really and truly it's only just recently,
these last few weeks
that we've got into a routine
I mean it might seem a long time to you
but you suddenly realise that if you did this before you did that
you'd be better off you know what I mean
so we've sort of got it worked out now
where we know what we are doing each day 88/2*

Mr and Mrs Robinson were well suited to a routine way of life. Having been retired for several years they found they had needed to create their own sense of routine, as described by Mrs Robinson when asked in hospital about her life before the stroke.

*we try and keep regular hours
like we stop for dinner
might have a sandwich or something for dinner
.. we come in in time to cook the tea
and have it watch the six o'clock news
-that's about it 206/1*

The day no longer revolved around the working day and so they organised it around mealtimes. At one year Mrs Robinson spoke of her daily routine again, repeating it almost word-for-word.

Mr Robinson mentioned that his previous lifestyle had stood him in good stead:

*yeah we've always been fairly well organised
.. so it don't come strange
to try and have some kind of organisation
some kind of plan
and that's why I think we've coped reasonably well 818/3*

The sense of routine which was so important to Mr and Mrs Robinson was a complete anathema to Mrs Evans. At six months she said:

*I found we were just breakfast
um breakfast coffee, dinner, afternoon tea, evening meal you know
-It's just a long line of meals now
whereas before I would eat when I was hungry,
and the evening meal would be the main meal of the day,
the kids would come in perhaps in the morning
and we'd have a coffee in the morning, mid morning
and if we were hungry
we'd sort of have a sandwich or something at lunchtime
but it seems to become a ritual
with all these meals all of a sudden you know
cor life's so boring
there's so much more to life
than just sitting around doing meals
or hanging around making meals
and sitting around eating 436/2*

The flexibility of her previous lifestyle was seen as something which had been lost.

Mrs Gunner also described how she felt a loss of flexibility:

*I hate being tied
I'm a very impulsive person
I can say oh no I'm not going out
I'll stay in
and the next minute I think
I'm going to do so and so
and I'm up and gone
and if I haven't got that freedom
then I, I find myself trapped 550/2*

The previous lifestyle of the younger spouses appeared to be of a more dynamic nature, plans could be made on the spur of the moment. Mrs Gunner described later in the interview how the sense of being able to predict exactly where she would be and what she would be doing weeks into the future was a frightening and limiting experience. The self-imposed routine created by the older retired couples and seen by

them as a liberating structure, was seen as a limitation and constraint by younger spouses.

6.2.4 Lived at a slower pace

As everything took so long to organise, the pace of life slowed down for the stroke respondents, which in turn affected the pace of life possible for relatives. As noted by Ross (1990) in later life most people are released from the obligatory demands of work and family, and they experience greater discretion over their use of time than at any other point in their adult lives. Mr and Mrs Robinson had the opportunity to adjust together to the new pace of life. Mr Robinson spoke about how he spent time helping his wife regain some of her housework skills:

*still I've got all the time to do it
I'm here seven days a week
I'm not on night shift anymore now
Well If I was working it would be difficult
because I used to work fortnightly nights and days
but now I'm here everyday 491/2*

At one year Mr Robinson spoke of how being retired made it easier to manage his extra responsibilities as he was no longer working at the factory and had more free time.

When asked if there were any improvements since her husband had left hospital Mrs Evans said:

*No, No
He went downhill fast when he came home
and everything came to, as I said, a grinding halt,
... I just felt as if my whole life had slowed right down
and I just felt totally out of gear
I don't know how else to describe it really 944/2*

Life was still at a slow speed at one year as Mrs Evans said:

*-it's been a case of getting used to a different way of life,
different pace of life 199/3*

Although the pace of life had slowed down, it was not always possible to slow down when spouses had other commitments.

Mrs Curtis described her experience as a fracturing between her children and her husband:

*It's a horrible situation
to see someone, seeing it happen to someone
but life is busy and we get on
I never find there's enough hours in the day
so we do sort of rush on without him
he just comes along 735/2*

As in this case, slowing down was not necessarily related to physical problems as Mr Curtis was physically able, but had speech and cognitive problems. Often younger spouses found that they did not have the opportunity to adjust to their partners pace of life, creating additional difficulties which had to be faced.

As well as the three aspects above described by all of the participants, other factors were described by the younger spouses which did not appear to be issues for older spouses. These included responsibility for children, future hopes and dreams, and a sense of premature ageing.

6.2.5 Responsibility for children

Younger spouses often had to commit time and energy to their children. Spouses described how they had to keep two lives going. Mrs Curtis at six months described her experience while her husband was in hospital as:

*just being carried along on this roller coaster
trying to keep positive
trying to look forward I suppose
and just make the best of it
and keep things going for the kids
try and keep life going for the kids
without it totally breaking down 22/2*

It appeared that younger wives not only felt that they had their natural children to manage, but that their spouses, rather than being their partner and sharing family responsibilities, had become like another child within their family setting.

Mrs Curtis spoke of having to prepare for her husband's discharge:

*as someone said it's like being a one parent family
except you've still got a husband
but he's just like another ch..
but really at the moment he's just like another child
you have to take
or I find I have to take everything very slowly
to cope 538/1*

This was also described by Mrs Gunner:

*I wish he would just think
oh I think I'll do so and so today
you know like he used to
but I suppose that will come in time
It's tiring for yourself to have to keep on
because you're thinking of going
It's not like looking after a baby
of course he's not a baby
It's looking after another child put it that way
and you're out of practice doing that
because you've done it before
you've been through all that bringing your children up
and you think oh I'm too old to do this again 530 /2*

Again it is difficult to separate out the effects of age related differences in lifestyle and of gender in these examples. Miller (1987) carried out interviews with six husbands and nine wives of spouses with memory loss. The wives described their husband's changes in behaviour in terms of relationships, using childcare as an analogy. The husbands described their wives' behaviour change in terms of a specific disease process and dysfunction of the mind. They described their role as being more like that of a teacher rather than a parent. It appeared that the husbands were more likely to see the relationship in terms of a job, whereas the wives saw it in terms of the family. Again with the group of respondents in the present study it is difficult to explore these issues further as there were no younger husbands.

For the older couples, rather than being an additional responsibility, children were often, but not necessarily, seen as a source of both practical and emotional support. For a particular respondent his family was crucial in how he saw his future. Throughout his interviews, Mr Hyland, an older spouse described the stroke as very

much a family affair. When talking about the future he said he had fewer worries as his wife had the family to stand by her.

6.2.6 Expectations of the future

Older and younger spouses had different expectations of the future. Often older couples described how they had achieved all they had expected in life; their main aim was to continue their lives in a similar way and to be able to spend time with their spouses. In hospital Mrs Robinson said:

*that's what I want to do
when I get back as well,
I don't want to do anything
I just want to potter
.. well it's only now that I've been able to do it you know
now that we've got time kind of thing
My husband is retired as well
so we're home together all day every day
just nice to be home and please yourself 192/1*

Mr Scott an older relative captured the sentiment when he was asked about his future. He said:

*well as long as we can go on
and live as long as we can I suppose
don't want to climb Mount Everest or anything like that
as long as we can be reasonably happy
and carry on as long as we can 468/2*

They had reached a stage in life when they had achieved or resigned themselves to their achievements and were resolved to make the most of the time left to them.

Periard and Ames (1993) interviewed 20 caregivers of relatives following stroke. They found that the younger respondents nearer the study inclusion age of 55 years reported higher levels of strain than the older respondents. Respondents over 70 years commented that things were not too bad and that they just did the best that they could. They appeared to have reached a more settled stage of life. It is useful to consult the theoretical model put forward by Erikson (Erikson, 1963; Erikson, Erikson and Kivnick, 1986) to describe life stages and ego development when considering the older respondents' position. Erikson suggested that in old age, people are in the

eighth and final life stage; and the main psychological issue for people is the balance between integrity and despair. Integrity is achieved by being able to accept one's life as lived, to share interest and concern in the wider world of others and to be able to accept impending death. There is a sense that life has been lived and aspects of life have to be put in order, so that the final transition, death can be faced. There is a recognition that there are not decades of years in the future to plan for and so people make the most of the present, by reconciling themselves to their past.

For the younger spouses there was a sense that their life had been snatched away from them. Mrs Evans spoke about her feelings after her husband's stroke.

*It was the feeling of
my life is finished
I just couldn't see beyond,
well even now I can't look into the future
I can't see how things are going to turn out 108/2*

Younger spouses felt that their hopes and dreams had been dashed. As Mrs Evans said:

*Oh there's so much in life that one could do
You know you have plans and dreams don't you
and you always think that there's tomorrow to do them
and there just isn't 1061/3*

and Mrs Gunner:

*I don't, I cannot see any future
I can't, 48 years old and I just feel that it's gone
I feel cheated 545/3*

Younger spouses still had many expectations for their future. They had many plans; life projects to be completed and life goals to be achieved. Erikson (1963) suggested that the main psychological issue at mid life is generativity or stagnation. Generativity involves establishing and guiding the next generation, either in the form of children, or knowledge. Erikson suggested that this time is characterised by productivity and creativity, suggesting considerable practical work. Skaff and Pearlin (1992) in a study of caregivers of relatives with Alzheimer's disease found that younger caregivers compared to older caregivers reported a greater loss of self. They suggested that this was due to competing priorities and a conflict between what they

felt they should be doing at this life stage and what they were able to do. There was a lack of congruence between their expectations and their opportunities for generativity.

The younger spouses not only experienced the loss of an imagined future but had a future of many years to think about and plan. The prospect was often very frightening. Mrs Gunner said at six months:

*I sometimes not so much now
It's few and far between like I told you
I sometimes sit and think what's it all about
where are we going to be in ten years time
what are we going to do
and then I panic
so I don't think like that anymore
I think tomorrow
I'll face tomorrow when it comes
I don't look to the future,
I just take each day as it comes 1087/2*

The future rather than being seen as a time for short-term goals or a time for reconciliation with the past as for the older spouses or a time for potentialities like peers, was seen by younger spouses as a time of challenges and limitations. Following the stroke, future life plans were lost and at the time of the interviews could not be re-created. From a narrative life history approach where the self is inherently tied to narrative, the inability to create a coherent narrative challenges the very notion of the existence of self in the future decades to come.

6.2.7 A sense of premature ageing /death

For the younger spouses the change in their partner and in their lives was seen to have an un-natural timing in their lives. There was a sense of premature ageing.

Mrs Gunner said at one year:

*I don't know how I'm going to look after him
when I'm old
what happens to us?
when I was younger
I nursed my gran
and you never think of things like that
because you think I've got years
before I get old like this 520/3*

Parker (1993) found a difference in the reactions of older and younger carers although they were all under 65 years. She suggested that the older spouses could share their experiences with some of their contemporaries as they were of an age when others were beginning to become more physically frail. There were shared narratives and understandings. Younger spouses saw themselves and their lifestyle to be very different from their peers. They did not have the shared narratives or understanding. They found that they had more in common with an older age group not usually seen as their contemporaries. Singer (1974) described the experience of people with Parkinson's disease as premature social ageing. She compared the social and economic functioning of a sample of people with Parkinson's disease with a sample of comparably aged people in the general population. By analysing respondents attitudes towards themselves and their outlook on life she found that the effects of illness impinged disproportionately on those contracting Parkinson's disease atypically early in life.

Occasionally younger spouses described the loss of their future in terms of death. As noted in Section 6.2.5 Mrs Curtis described herself as being a one parent family, her partner although still physically present was lost to her future narrative.

Mrs Evans captured the fundamental sense of loss in her future life when she spoke about seeing others sequence dancing.

*We would have loved to have done that together
under normal circumstances you know
and er I just think it's the living dead
It's an awful way to think 756/3*

Speaking of present life in terms of death highlights the intensity of the emotional issues facing the younger spouses. It appears that they were facing issues which would normally be associated with Eriksons' last life stage.

From the analysis it appeared that it was more difficult for the younger spouses to fit the experience of stroke into their lives on a practical level. Their pace of life was still fast, they were not used to spending many hours together with their partner in the home, they did not have a routine life and they had other commitments to their children. Nolan, Grant and Keady (1996) highlighted the need to consider time in life when trying to understand the course of a persons disability or chronic illness. They suggested that the course should be considered in relation to a schema for charting family stages, as periods of family formation, child rearing, children leaving home, middle and later years tend to be associated with discernible family challenges (Aldous, 1994) and these can be as demanding, constraining or liberating as caring itself.

From this analysis it can be seen that it was not only the practical daily considerations which were found to be distressing by the younger relatives. By exploring their experience within a life narrative perspective, it is possible to recognise their difficulties inherent in the loss of their future, the un-naturalness of their situation in being unable to share narratives with their peers and the resulting fundamental impact on their sense of identity.

6.3 Individual differences

From the analysis, there appeared to be differences at an individual as well as a social level. These differences related to how individuals interpreted the event and the effect on their lives within the structure of their own biographies. Although standard prompts were used within the interviews such as What was it like for you in hospital?, How do you see the future?, respondents spoke of issues which were individual to them and not shared by others. These issues were often linked with aspects of their biographies. Often aspects and issues described in the interviews in hospital were mentioned after six months and one year. The themes continued despite the six month gap between each meeting and interview. Different respondents had different issues to address, related to the meaning of the stroke within their lives. This was as true for the spouses as it was for the stroke respondents.

The analysis of the nature of these aspects and issues will be described by highlighting a single case study. Because the themes were analysed across the interviews of one respondent rather than between respondents, the analysis takes the form of narrative analysis where the style as well as the content used by the respondent is paramount. This particular example was chosen to compare the usefulness of traditional and biographical analysis in understanding mental health following a stroke. The wide variation between people will be described towards the end of this chapter.

6.3.1 Case study: Mr Finch

Mr Finch was a 63 year old man with a wife and four children. He had suffered a heart attack two years previously. The medical notes stated that he had fully recovered and so he was included in the study. It was only after discussions with him that it became clear that the previous illness had made an impact on him. Although Mr Finch's life had been affected by previous disability, he was not excluded from the study as he was very insightful and was able to describe his experience in detail. His progress following his stroke can be described using traditional physical and self care measures. At the time of the first meeting, Mr Finch had been on the ward for five weeks following his stroke. He could move himself from bed to chair but could not walk, he had no movement in his arm and he needed help with self care. His scores on

the Hospital Anxiety and Depression scale (anxiety score = 11, depression score = 9) indicated that Mr Finch was a borderline clinical case.

At six months he had improved physically. He could walk around the house, he could walk a short distance up to the shops, he could use his affected hand although it was clumsy and he was self-caring, apart from help from his wife when using the shower. His scores on the Hospital Anxiety and Depression scale (anxiety score = 9, depression score = 7) suggested that his mood had improved slightly.

At one year, his physical abilities and self care skills as assessed by the traditional assessments appeared to be the same. His scores on the Hospital Anxiety and Depression scale (anxiety score = 12, depression score = 8) suggested that his mood had deteriorated slightly again. Using traditional approaches there is an assumption that if a person improves their physical and self care skills, their mental health will also improve. This does not seem to have been the case for Mr Finch. It may be possible to get more insight into the complexity of factors affecting mental health by looking at Mr Finch's biography, his evaluation of what happened to him and his ideas about his future.

Table 6.3 (page 143) is a representation of the themes which were drawn from the interviews with Mr Finch. There are three main reasons for creating this diagram. The first is to highlight the activities which are and have been important in his life - his themes, his life threads, the way in which he defined his life and himself within the interviews. The second is to highlight the issues which appear to be important to Mr Finch at the times of the interviews. The third aim is to show how the themes often remain present over the year time period. Often, the issues also remain, although this is not always the case. The diagram also shows how Mr Finch creates linkages between the threads or themes within his life, the numbers or letters on the lines, corresponding with the numbered activities or lettered issues.

Activity	Life line		youth	married life	heart attack	stroke	six months	one year
	childhood							
1 army /navy good life			a, 2, 4	2,		2,		a
2 drinking			*1	*a, 1		*1		*
3 minor disagreements-wife				*2			b	b, b
4 driving work		1		2,				a, 5
5 driving social				7		*	*	*, * 8
6 camping/holidays								*, e
7 maintenance job				8				
8 dogs				*	7		*, *	a, 5,
9 reading				*		c	*, *	
10 shed/greenhouse				*			a, *	a,
Issues								
a) weather		1, 2,			d,		10,	*, 10
b) difficult asking for help				*	*		3, 3, *	3, 3, *
c) adaptation		1,	2,	*	*9			*, 6, *
d) life is over/death possibility					1, a, *		*, *	

Table 6.3 Life threads described by Mr Finch

Key active major theme non-active but enduring themes * mentioned -not linked
 reduced or minor theme current issue 1, a linked to themes/issues 1, a

In order to see how the diagram was created, the analysis for this diagram will be discussed in detail. The activities and issues represented in the diagram will be described in turn.

6.3.1.1 Army/navy-was a good life

In the first interview in a private room in the hospital Mr Finch told of his wild youth. He joined the army where he:

*had a good time really,
I was a bit of a wild boy 14/1*

*I was always getting into trouble for something or other
I would not take anyone bossing me about
that was me trouble 19/1*

At this time Mr Finch was strong, fit, his own boss. Later he joined the merchant navy with many of his friends.

*I had a good life, enjoyed myself,
done a lot of daft things,
but I enjoyed myself 107/1*

*When I was at sea
to me any port in a storm
.. you never have time to go hunting around
to get a steady girlfriend
..and I had a good life
and I done all, sowed all me wild oats 162/1*

Mr Finch portrays this part of his life as an adventurous time, when he packed a lot into his life, did many things and saw many things. When he 'settled down' later in his life he still kept that part of his life alive by meeting up with his brother-in-law and drinking and talking about old times.

*my brother in law we get together
-he's ex seaman
I sailed with him a few times,
we talk about the people we know what we done,
we'll sit there for hours talking and drinking yeah 1138/1*

The mystique and adventurous nature of this life was still important to Mr Finch as he went on to tell me:

*well we've seen some things in life y'know
in different countries
well I can talk to him [brother -in -law]
cos he understands what I'm on about
or if he talks to me I understands what he's on about
he mentions places and names and I know
y'see that's it
(2) but your average person
you mention something
they look at you they disbelieve you 1153/1*

Mr Finch did not mention his sea faring days at six months, but at one year, when talking about how he found it difficult to cope with cold weather he said:

*when it's nice and warm
then I'm all right
but then I always thirst for the hot weather
so I mean, I always worked in engine rooms
and things like that where it's warm
so I'm quite happy there 61/3*

Also, at one year after the tape recorder was switched off Mr Finch started chatting about his sea faring days and the 'daft things' he did on ship while on the cargo boats. Through these stories he maintained his identity as an adventurous, hard working able seaman, the hero of many a story.

6.3.1.2 Drinking

In hospital Mr Finch told how he used to drink a lot.

*I used to drink heavy at one time
but I only drink weekends
Friday night till Sunday dinner time [when driving] 358/1*

Drinking was often related back to his time in the navy.

*I do like brandy
because more or less
it goes back to me navy days 386/1*

Even drinking the amounts of water expected of hospital in-patients was related back to his sea-faring days.

*I used to work in temperatures of 100 or more
.. you have to drink something to keep liquid in your body
.. that's why now I drink all day
-It's just a matter of habit 395/1*

Mr Finch was talking about how things had changed, how now in pubs people tend to buy their own drinks.

*but when I was at sea of course
you used to go in and throw a fiver on the table each
and we'd just leave it there
and drink up that's gone ah,
people don't do that nowadays
(cseh: no they don't)
No
(cseh: no)
but still, it's changed
passed by now
I've, we got to adapt to another sort of life 441/1*

In the hospital interview, one of Mr Finch's strong issues at the time, was adapting to changes in his life. This emerged from his description of the old days and drinking.

Mr Finch referred to drinking when he spoke about his heart attack. He mentioned how friends took him to a party in their car so he could have a drink. His feeling ill was described in terms of the amount he was able to drink.

He said he felt so tired that all he did was sit in a chair and:

*I had two glasses of wine
that's all I had,
normally I'll have a lot more,
but two glasses of wine
And then most people were saying
"Oh you look ill" y'know "you're white"
"n" I said "no, I'm alright" 666/1*

He also mentioned drink in his stroke story. Again the serious nature of his symptoms was described in terms of drinking. He described being sick and said:

*I couldn't help it
I mean I haven't been as sick as that
even with a hangover you know
too much drink
but I haven't been as bad as that 754/1*

Although no longer a heavy drinker, in the hospital Mr Finch still used drinking to define, describe and present himself within the interview. Mr Finch did not talk in terms of drinking or socialising at six months, but at one year mentioned how he became tired during the day.

*up to now I ain't been out to any parties
and things like that in the evenings
I know I could go there at six or seven o'clock
but probably by eight o'clock
I'd feel really bad
and want to come home 384/3*

By one year, although social drinking was still a theme, it was associated with negative rather than positive connotations. Although Mr Finch was a party-goer and mentions party going as an activity, he felt he could no longer express this aspect of his identity - his tiredness would overcome him.

6.3.1.3 Minor disagreements with his wife

In hospital when Mr Finch mentioned his wife he always said that they had had a good time but always mentioned that they haven't always seen eye to eye. When he spoke about meeting his wife and getting married he said:

*and we had a good time
we've had our ups and downs
I mean our arguments have been over money or the children
nothing else serious like 147/1*

By six months when talking about his wife he spoke more in terms of how having the stroke has brought them together. He said:

*my wife helped me more
which never before
because I never needed help
and it seemed to bring us closer together 95/2*

He described how she was more willing to help him do odd jobs like hammering in nails and putting pictures up.

*I mean she got to do a lot of things
she's never done before
I've got to show her,
tell her how to do it
she don't go up in the air
like she used to at one time
when I used to say things 510/2*

This theme continued at one year. As Mr Finch said:

*me and the wife are a lot happier together at the moment
It's brought us closer together again 42/3*

He described how they work better as a couple.

*one time I couldn't tell her how to do anything
.. she wouldn't like being told when and how to do it
.. she wouldn't listen to me at all
of course now we laugh over it
before we really used to argue
I just laughs at her now
we works well together now
we both, laughing instead of arguing
.. yeah I think we've got better in some ways like that you know 185/3*

Later talking about his wife he said:

*we're enjoying ourselves
and having a laugh now and again
plus a few moans and all that
but still that's it 510/3*

Life appeared to be improving for Mr Finch and his wife.

6.3.1.4 Driving - work

6.3.1.5 Driving - social

As these two issues are closely related they will be discussed together.

In hospital, Mr Finch told how driving had always been an important aspect of his life.

He described how he wanted to drive for a timber firm on leaving the army:

*I went driving
cos I was a driver in the army
and I could drive a vehicle when I was about 12 years old
cos I used to go with me father he drove an artic
.. when we'd get to the timber yard
he used to say 'oh take the thing up there and change the trailers
and I used to do it
anyhow I was only 12 at the time when I started doing it
so when I went in the army it was easy to drive 65/1*

He had driven from childhood and so a career in driving was a natural choice. Mr Finch described himself as something of a free spirit and how moving from one place to another was important to him. He described how after twelve years in the navy, he went back to driving again:

*I was all right
because I was going somewhere
and I was just going anywhere
I didn't care where I was going
I always want, have been best when I'm going somewhere
even like on a ship
I know your workplace is there
you're living on a ship
but at least you're going somewhere
you've got something to look forward to 118/1*

When talking about his heart attack two years before his stroke he talked about how he first noticed difficulties when he was driving delivering parcels. He found he was getting very tired delivering parcels, going up steps etc., but that when he was back in the cab again he was all right. When asked about the consequences of the heart attack the first thing he mentioned was that he had had to give up his heavy goods vehicle licence and how subsequently he was put on long-term sick. He had not worked since. Although this must have been a huge blow for Mr Finch, he interpreted the event as one he had now adapted to, and so he would be able to adapt to new changes following the stroke. Adaptation was a strong theme in Mr Finch's hospital interview.

Social driving was a current issue for Mr Finch, while he was in hospital he was already planning a possible future.

*I'll have to sell my car
cos I haven't got power steering
.. so I wouldn't be able to manage with one hand,
annoying isn't it
but one of my daughters
said she's got an automatic and it got power steering
so if I can drive later on
might go in and have that
.. I'll have that,
I only want something just locally that's all
so it might be all right in the future
it depends how it goes 323/1*

As Mr Finch recognised, driving was very important to him. He might be all right in the future, but it still depended on fate. At six months driving was still an issue for him.

*but I am getting bored again stuck indoors
.. if I get a car and that I'll be able to go out
so I won't be stuck in here so much 210/2*

He described his difficulty on relying on other people -not being able to do what he wanted when he wanted. He had lost his sense of freedom.

*I'd go and visit people
which I can't do at the moment
cause I don't like going with someone
cause you've got to go in with their time
.. if I go somewhere
if I'm fed up with it in an hour
I'll go
but if I like it
I like to stay there for two hours
.. I will hopeful like I say be independent again
in about a months time 232/2*

At the one year interview one of the first things Mr Finch mentioned was:

*I got a car now
I can get about,
I'm a lot happier 17/3*

Later Mr Finch talked about the importance of having a car again.

*I've got the car since the last few months ago
and I got mobile
and I'm out running around
which made me a lot happier
I don't have to rely on people
they're more or less back to relying on me
to fill in for them
like I used to
... it makes me feel a bit useful again
whereas before I didn't feel anything useful at all 241/3*

Mr Finch maintained his links with being a professional driver. He spoke about how he didn't drive more than an hour at a stretch without a break to make sure he didn't get stressed or tired.

*the driving to me, it was me livelihood
It's relaxation now,
I'm enjoying it a bit now,
before I was driving from A to B
as quick as possible
because I've always been on piece work
.. but now it's more relaxing to me
like it used to be years ago
I can enjoy it a bit better
so therefore I'm a bit happier in myself
and there's no, driving no strain on me 293/3*

Links with being a professional driver are also maintained when he discussed the issue of the weather.

*well it never used to bother me too much
cos at one time I was driving
I was running to Scotland all year round
I've spent time stuck in snowdrifts and things like that
..never bothered me
so long as I keep warm you know had the clothes on and that
.. but now I'm not active
and me bloods really thin
I feel it, the cold much easier
I mean I've gone out when it's been as cold as last month
and I really wanted a pair of gloves on
where me hands is freezing 70/3*

Links with the past were both positive and negative. Driving was more relaxing now, but Mr Finch found he was not as strong and invincible as he had been in the past.

6.3.1.6 Camping/holidays

In hospital Mr Finch spoke of the time when he was settled in work and family life.

*I had a long weekend with the children and we went camping
..I've had caravanettes, caravan, tents, trailer tents
you name it we've had it
we used to get real happy times
family and that
It's only a few years ago
I got rid of the caravan gear
I've got another tent now
S the little one
I puts it up for the youngsters play in it at the back 206/1*

At the six month interview Mr Finch spoke about how he had arranged to go on holiday with a couple he had known for 25 years because the two families camped together.

A few years previously they had bought a boat, and Mr Finch felt that he was now well enough to go for a holiday on it.

*they didn't have it when I was all right
.. they've been going every year
since cause I been bad ain't I
I can't go you know,
but now I'm improving 447/2*

He appeared to be quite positive about his abilities and the meaning of the holiday. At one year Mr Finch briefly mentioned that he had been on holiday and said:

*on the boat there
which I never thought I would get again
cause the wife don't like the water
when she said we'll go
but then I suppose she thought
that I'd never have another chance-227/3*

After a short silence he went on to talk about how he was pleased that he was driving again. Aspects of his own mortality, a strong theme for Mr Finch at one year, dominated any ideas of future holiday plans. Talking about his wife he said:

*she'd like to make some plans for next year
.. It's no good saying oh we'll go on holiday
book it up and things like that
and finding out
I'm bedridden or something like that 495/3*

So although Mr Finch still went on holidays, the pleasure of anticipation was overshadowed by a feeling that it might not happen.

6.3.1.7 Maintenance job

This was the shortest theme. In hospital Mr Finch described how he had a maintenance job at a kennels at the weekends even having worked all week. Following his heart attack he had to give it up, as he said:

*my maintaining job went through the shoot
I couldn't go out there and do that 538/1*

6.3.1.8 Dogs

There was a link with the kennels where he carried out maintenance. As the owner gave him two dogs after his own dog had died.

*cos I was upset and she could see it
so she gave me these two dogs
and then I could carry on 279/1*

Later when he was talking about his life after his heart attack Mr Finch mentions his dogs again.

*I ain't got a hobby, except me,
I wouldn't say me dogs are a hobby
yeah I'm quite happy playing with them
on me lap,
going out for walks 555/1*

At six months the dogs were still a background thread to his life. Being with them represented a return to the normal routine of his life.

*I do take my dogs up the shop
get a paper in the morning
walk up there and back
-the normal sort of thing 125/2*

The dogs were linked with driving, one of the first things Mr Finch was planning to do when he got his car was:

*if it's nice like it is today
like this afternoon,
I've nothing on
probably take the dogs out to the forest
for an hour or two let them have a run around
I'll sit out there things like that
I used to do before 218/2*

At one year Mr Finch described how he had achieved his vision, but that his activity depended on the weather which was another strong theme for him.

*sometimes when the weather was good
I used to take the dogs out forest and that
for an hour or two
and get back for dinner time 362/3*

6.3.1.9 Reading

Reading was an important aspect for Mr Finch - it was a current issue for him while he was in hospital.

*I'm a heavy reader
but at the moment I can't handle the big books with one hand,
It's very awkward
It's tiring
before, I had two hands it stayed open 565/1*

In hospital, reading was a way Mr Finch proposed he could manage his worse case scenario - if he had to use a wheelchair long term (see Section 6.3.1.13, page 158)

At six months when Mr Finch spoke about how he spent his leisure time, reading followed on closely after describing his dogs. He said:

*you know I'm quite happy in my own company
because I can get away in a book
and I just go away
if it's really interesting
or something I really enjoy
I just go on for hours 623/2*

6.3.1.10 Shed/greenhouse

In hospital Mr Finch mentioned that following his heart attack being able to potter in the shed and greenhouse was important to him.

*well I was sitting around a lot
and just doing small jobs
I might go out in the shed or the greenhouse
and muck about
or a bit of paint in the house doors and that 504/1*

At the six months interview in June Mr Finch spoke of how he had been getting bored being indoors during the winter.

*but now I've spent time out in my shed,
my greenhouse things like that
I spends an hour out there every day 117/2*

At the year interview in November he voiced his frustrations.

*I can't work out in the shed
because it's too cold now at the moment 136/3*

Issues

6.3.1.11 Weather

The weather was a constant background thread to Mr Finch's story. Although many people mentioned the weather as affecting the activities which could be carried out, Mr Finch's relationship with the weather seems to go back a long way. He mentioned that when he was in the navy:

*I was away at sea for nearly 12 years,
never home specially in the winter
I used to come home for one/two week a year
and that was it 99/1*

Later in the interview Mr Finch repeated the importance of being able to follow the sun.

*I've been in the merchant navy
always followed the sun,
never home wintertime,
I had one Christmas at home from the time I was 18 to 32 877/1*

At six months he described being stuck indoors in the previous winter. This view was often shared by others:

*when the bad weather was here
I couldn't go out or anything because of the cold
and then I had to sit indoors all the time
well you get bored don't you? 109/2*

By the one year interview in November the weather was causing him particular difficulties.

*I hoped to be more mobile
when the winter's gone to summer
as the cold weather affects me
makes me breathe heavy quicker and that and tiring 51/3*

His new experience was compared back to his professional driving days:

*whereas one time, in midwinter,
anytime driving
I never drive with gloves
I'll put gloves on for the first ten minutes
while I cleans the ice and that off the windscreen
but once the motor got warm I took them off
but now I I'm feeling I want to wear gloves and things like that
all the time now
when the cold weather comes now 101/3*

Before, he was immune to the weather, he could carry on rain, shine, heat, or cold; but now the weather pierced his body, his self. He was now a victim of the weather, constrained by it's activities.

6.3.1.12 Difficulty with asking for help

In hospital Mr Finch described how he was frustrated when people helped with DIY jobs. He described how his son helped him in the house:

*well that grieved me
because people never seem to do it
the way I want
or fast enough 521/1*

Talking about how he was planning to adapt in the future he said:

*cos I hate having things done for me
I'd rather do it myself 1247/1*

At six months when asked how services could be improved, he mentioned that the services had been good and that he has had a lot of help from people. As he said:

*and I don't like that
for people to do things for me
but the situation of last year
I just had to 572/2*

At one year needing help was still an issue for Mr Finch. When talking about how he was happier now that he could get out in his car he felt he had to qualify the statement:

*not as happy as I would be
if I could do a lot of things you know
which I can't do now I used to do
I can still get upset or mad
when I ask someone to do something for me
and I can see her not doing it wrong,
right in my eyes you know
then they say well you know you're telling us what to do
but then I ask them to do it
and I want them to do it my way
but they can't see that sometimes 22/3*

Mr Finch described how he became breathless, clumsy and his legs ached, and how he had 'an attack' later if he did too much DIY. He described the new role he had with his wife:

*well at first I didn't like having to ask
now I do it so often
well not so often
but I ain't worried
I don't like asking her
but I've accepted the fact that I have got to
and she's accepted the fact that she's got to do these things
and that's it 162/3*

The importance of this issue to Mr Finch can be seen in the following statements.

*but I'm saying it's stopped me doing
what I want to do
that's the main thing 215/3*

*I only gets mad now and again
when I find I can't do things
I I got to ask people to do it
that's me main thing you know
cause I never asked people to do anything
one time I would get on and do it myself
or have a go at it 764/3*

6.3.1.13 Adaptation

Adaptation was a strong theme for Mr Finch in hospital, he described how due to his previous experience of disability he felt he could adapt again to his changed

circumstances and continue a basically happy life. While talking about life at home he said:

*and we've been happy
I mean I can't do the things I used to [after the heart attack]
now after the stroke I can't do a lot more can I
but I expect we'll adapt to it after a while
we generally do 284/1*

He makes links with his past life to show how he is an adaptable person.

*I mean I adapted in married life
two years ago I adapted [following heart attack]
I couldn't do a lot
I couldn't do things
I had to get people to do lifting and things
which I daren't try
but at one time I wouldn't ask
I'd just do it
I adapted to that
so I'll probably adapt to this as time goes by 453/1*

He linked adaptation to his life at sea.

*So I'll be all right with that like
I generally adapt to my surroundings
I mean you go from ship to ship
never ones the same
you've got to adapt to what that is
and what life is 595/1*

In his stroke story Mr Finch described how he was brought into hospital, thought he was going to improve and suddenly became worse again on the ward. He finished his story by saying:

*so I've started to have to adapt again
I sort of [2] I will, I'll get round it somehow or other 865/1*

In hospital even if his worst fears were realised, Mr Finch still felt he could adapt to it.

*If I'm stuck in a wheelchair like
and I can't do nothing
then I shall be fairly miserable I tell you
but then I've got a lot of books
I could learn to adapt to it
and be happy 1237/1*

This theme was not maintained at six months or one year, a less hopeful theme came to the fore.

6.3.1.14 Lived a full life/death a possibility

In hospital following his stroke story and how he had to adapt again to a new way of life, Mr Finch speaks of his life as if he is weighing it up as a full one, so that he can accept it may almost be over.

*That's about it
I've done most things in my life like,
or a lot of scrapes and things
(cseh: it sounds very adventurous)
I've been mostly everywhere 871/1*

Mr Finch had achieved most of the things he had wanted, he goes on to say how he always managed to follow the sun.

In hospital Mr Finch was unusual in that he spoke directly about death. Towards the end of interview having mentioned that he could not see his future and that it was probably a good thing that people don't know their futures, he said:

*Tell you one thing
If I do go
I wanna go quick
I don't want to hang around that's all (2)
cos. if I stop and think about it
I'll get morbid
(cseh: I don't think you need to worry about that)
I hope not
I've got another ten years at least
I'd really like to live to 200 no hope of that
(cseh: no)
still hang on as long as possible
when it do happen
I hope it'll be quick
none of this laying around 1442/1*

At six months, when talking about his planned holiday thoughts of mortality are still evident.

*things ain't too bad
I'd say I'm thankful I'm still around you know
but er I say like everybody thinks
things could be better 490/2*

When he was asked about the future he said:

*well sometimes I sits and worries
not worries,
just thinks how much future have I got
I know I can't plan years and years ahead so
and this goes on
hope it will improve
and get a bit better
-enjoy myself a bit 497/2*

At one year when talking about how his condition prevents him from doing his DIY he said:

*and as I say
so long as I'm here
I'm still here
I'll say I'm glad of that 218/3*

Towards the end of the interview he expands on his thoughts:

*I don't bank on anything or plan
just hope for the best sort of thing
that's all
cause you don't know what's round,
this taught me a lesson
not to think to take things for granted
because you never know 432/3*

and

*you might say I used to worry
well about going to sleep at night
and I thought well I wouldn't wake up in the morning
especially when I felt bad
but now I says to her well,
we've got to accept it
if I go to sleep and don't wake up
that's it
you know things like that
I've accepted it 445/3*

and

*Well at one time like everybody I suppose
you always thought well it won't happen to me
but it do
It's the only sure thing you've got in life isn't it dying ..
you've got to accept it
and I'm just about ready to accept it
sometimes I think about it
not as much as I used to
.. I talk about it and joke about it
and cause the wife don't like me saying things like that
if I brings something up like that
I says to her well I don't think,
I might not be here next year
and she goes, don't talk like that
well it's a fact
you don't know 462/3*

6.3.2 The complexity of life

The complex web of contradictory aspects of Mr Finch's life can be seen from this analysis. The strength of a narrative approach is the ability to highlight ambivalence. Over the year following his stroke Mr Finch manages to maintain his identity as a seaman and a long distance lorry driver, often referring back to those past times. He is able to continue some of the 'normal' activities of his life, taking his dogs for a walk, driving his car, pottering around in his shed. His relationship with his wife has improved - they have a laugh together and he enjoys life. There are many positive things in his life.

But his activity is restricted by the precarious nature of his body, he gets tired easily, he cannot do his DIY jobs, he has to ask for help, he can only drive for short periods,

he can't socialise as he used to. Many of his life themes are curtailed or reduced. Although able to maintain his identity as a seaman and as strong and resilient, through the stories he tells, he also expresses his present vulnerability by describing the penetrating force of the weather to which he was impervious before.

In the hospital the strongest theme was adaptation. Mr Finch had adapted in the past and so felt he would be able to do in the future. By one year he describes how he was living a more precarious existence, he cannot fully control his body, he needs to rest more than he was used to, he is constrained by the weather and he had accepted that he might die at any moment.

The complexity of aspects of his life affecting his mental health is captured in Mr Finch's statement:

*so in some ways things have improved for me
in other ways it's deteriorated
but it's the way you look at it I suppose
you've got to be thankful for what you've got really 269/3*

6.3.3 Conclusions

From this case study it can be seen that by exploring a person's experience through their biographical account, and how they see their lives, it is possible to gain more insight into aspects which may influence mental health which are not apparent from external assessments of how people appear to be managing in life. The life narrative interview appears to be a very informative technique when trying to explore aspects of mental health.

From Mr Finch's narrative, it can be seen that recovery is spoken about in terms of life goals such as driving the car, walking the dogs and going to parties rather than in terms of daily tasks defined by health professionals such as being able to wash, dress or go shopping. By exploring life narratives it is possible not only to discover the existence of life goals, but also to understand their importance and relevance to the person concerned.

6.4 Variability of individuals’ life themes

All of the transcripts were analysed to the same level of detail as that of Mr Finch’s. From the analysis unique issues and aspects were revealed for each person, running through all three interviews. These issues, aspects, ways of speaking, acted almost like ‘fingerprints’; the three interviews could be picked out from the group and matched on content and style alone, even when the participant was anonymous. Individuals had their own aspects and issues which were important to them over the time of the three interviews. The variety of these aspects for the stroke respondents can be seen in Table 6.4. The aspects are anonymous due to the personal nature of the information. The table contains up to three of the themes expressed by respondents to show the variation in issues for people following the stroke.

Respondent	Theme 1	Theme 2	Theme 3
A	relationships	determination	being active
B	homebird	friendship	gardening
C	friends-pass time away	close to death	improvement
D	lucky	mother-daughter relationships	youth/appearance important
E	local girl	friends vs. family	daughter father relationship
F	smart active person	humour	being content
G	being active	airforce	being positive
H	control	management skills	money
I	shared life	self-reliance	good old days
J	army/navy-good life	drinking	driving

Table 6.4 Variation in the personal themes of individuals

Further details of the couples, and the personal themes described by the stroke respondents can be seen in Appendix 26. For two of the couples the variety of personal themes is demonstrated by describing the personal themes of the spouses, as their partners had speech difficulties which precluded them from taking part in the full interview.

The interviews lasted on average about 45 minutes; the same duration as an initial interview by a therapist. By allowing the person to tell their story, rather than respond to predetermined questions, the interviewer not only gained a sense of the issues particular to the person within their own biographical context, but also by listening, built up a relationship based on acceptance and trust. These aspects were highlighted by Gearing and Coleman (1996) who assessed the use of biographical interviewing by elderly care co-ordinators. They found that the health professionals gained a greater understanding and respect for the older individual, built a sense of trust security and acceptance, and were able to design packages of care which were particularly suited to their needs.

Within the present research, the interviews were taped, transcribed and analysed in detail to demonstrate the usefulness of this approach. This took a length of time which would not normally be available to clinicians. Within a therapeutic encounter, clinicians would not need to analyse the interview to the same degree of detail. The benefits of a biographical approach could probably be gained from written notes made at the time of the interview. The present study supports the work of Clark (1996) who criticised problem-based health care in which problems are defined and solutions found by health care professionals. He stressed the benefits of a goal-orientated model of healthcare which was seen as a collaborative process in which the values of individuals embodied in their life stories and life goals were brought into the therapeutic encounter.

6.5 Reflections on the research process

It is helpful to put the qualitative analysis within the context of the research process. The descriptions and interpretations given have been influenced in several ways; by the members of the participant group, by the research method adopted, the type of analysis used and the relationships built up with respondents.

6.5.1 Participant group

The participant group was selected from within a hospital environment. Their discourses may well have been influenced by that environment. Further research is needed including participants who have and have not been admitted to hospital following stroke. This would provide a broader understanding of the material and social processes affecting available discourses. Stroke respondents with severe speech problems were not included within the present study due to my lack of expertise in communication skills and the inability to provide sufficient time for interviews. From the work of Parr, Byng, Gilpin et al (1997) there is recognition that respondents with communication problems experience even greater challenges to their identity. Potential stroke respondents who either had minor physical problems and returned home within ten days, or who were finally admitted into a nursing home were not included in this study. Further exploration is needed with people who are discharged quickly following stroke. Little is known about their experience or service needs. The challenge of entering a nursing home environment following stroke would also be an area for further exploration. Due to the time limitations of the study, respondents were followed for one year following discharge. From the analysis it appeared that they still had specific issues related to the stroke which dominated their lives. Further research is needed over a longer period of time in order to explore the development of the processes described.

Because of my interest in spouses as well as stroke respondents, the present study highlights the issues described by couples following stroke. Respondents living alone, may well have differing issues to confront following stroke. During the interviews I also became aware of the impact of stroke on children within the family, especially dependent children of the younger spouses. Issues faced by this group have not been

addressed. As well as focusing on certain social groups, the present study has focused on a specific cultural group. Although two of the ten respondents had Polish and West Indian cultural origins, they had both lived for many years in England and specific cultural differences were not apparent from their interviews. Wider cultural and racial differences in stroke experience and the meaning of stroke need to be explored.

6.5.2 Process

Unlike many qualitative studies a theoretical framework, that of identity change, was used to structure and guide the research process before data collection. I feel that this approach did not limit the analysis by imposing preconceived ideas but acted as a perspective through which the responses of the participants could be interpreted in a new way. The framework was helpful in guiding the approach and structure of interviews, the analysis and the relationships with the participants.

6.5.2.1 Interview

By deciding to use interviews to collect data, it was recognised that it was not possible to access behaviour and the interpersonal relationships which could contribute to a wider understanding of the creation of respondents meanings. These aspects could be studied using an observational or ethnographic approach. Within the present study the wider social discourses which inform the narratives were not studied in detail. They could be indicated from the life narratives, but a detailed exploration would involve the study of other texts such as the perceptions of others, books, leaflets or health professionals records. This was not thought to be appropriate within the present research as the focus of this study was how the individual creates a life narrative rather than the social processes and discourses themselves, but it is a useful area for future research.

I was aware of my role as a clinician as well as researcher. Within the interviews there was a recognition that the interviewees presented themselves in a certain way. They were trying to accomplish a specific purpose, related to how they saw me, in what capacity they saw themselves and what seems relevant in the particular circumstances of time and situation. As Radley and Billig (1996) suggested the words within an

interview should be understood in terms of what they are rhetorically accomplishing. I think I was seen as a knowledgeable, but powerless health professional. Although I presented myself as a researcher I feel I was seen as a health professional as I met respondents first within a hospital setting. Respondents soon found out that I was knowledgeable about stroke in the way I spoke with them and shared their stories. At the six month interviews respondents had reduced contact with health professionals. At times I felt respondents used me to assess whether their experiences were normal. I sensed that occasionally when they told me things they were looking at my response as a cue to decide whether further action was needed. Occasionally respondents would ask me direct questions. In reply I would say 'I don't know' which was often the case when discussing medication and I would suggest that they contact their GP. With wider issues I would suggest that they contact the appropriate person, such as either their hospital therapist, their GP, the Day Hospital or the Stroke Association. I feel that my clinical background was helpful in that respondents felt reassured that they were talking to somebody who 'knew about' stroke. Also following several years of talking with people within their own homes as part of my clinical work; the environment was familiar and I felt comfortable within it. This helped to put respondents at their ease. There were potential disadvantages linked with my clinical background. People may have decided to take part because I was a health professional linked with the hospital which had helped them and to which they may have felt indebted. All of the respondents had the opportunity to withdraw before every interview. None of interview respondents and only two of the questionnaire respondents withdrew after the first interview, suggesting that this was not an issue.

The responses were affected by the nature of the interview. Within the interview I encouraged respondents to talk and share their narratives without interruption. I did not respond with undue emphasis or surprise. Although respondents became emotional at times, they only spoke about issues which they felt they could manage, as within the interview there were no probing questions. I would like to think that by using a biographical, narrative approach, people were allowed to talk in their own way, and by being non-intrusive respondents felt able to talk about things which were important to them. The longitudinal aspect of the research was helpful. Respondents

often mentioned that they appreciated the fact that I had 'been there' from the hospital onwards. Also due to the nature of the situation in which respondents found themselves where others did not appear to understand, respondents often welcomed the opportunity to talk about themselves and their situation.

Radley and Billig (1996) highlighted the discursive challenges that sick interviewees faced when interviewed by young, healthy interviewers. They suggested that respondents may feel that their personal worth is challenged and that even with a sympathetic listener the sick are encouraged by the healthy to redefine their misfortune in positive ways thus avoiding embarrassment for the healthy. They suggest interviewees tell stories of 'being strong' and 'bearing-up'. There were respondents who presented themselves in this way to some extent but respondents also shared their fears, disappointments, frustrations and failures, presenting themselves in ways which demonstrated that they were not managing. This response may have been enhanced because respondents knew that I would not act on their stories. Voysey (1975) proposed that only by appearing normal and not distressed could families protect themselves from the intrusions of experts or others who might otherwise inquire into their life. Radley and Billig (1996) suggested that giving private accounts might allow insight into one's life situation, but this might well be at the price of risking intervention which may be unwelcome.

Because of my approach I felt I obtained private rather than public accounts. Cornwell (1984) described public accounts as representations of the social world, was used to make the speaker acceptable in the eyes of a knowledgeable or influential stranger. By contrast I felt that people were giving more private accounts - stories about their own life circumstances. Throughout the analysis it should be noted that respondents were talking to a 37 year old white, female, middle class researcher. The accounts given to a younger or older male researcher of a different ethnic background or social class, would not be expected to be exactly the same, as respondents would build differing relationships and want to present themselves in different ways. Research into accounts shared between stroke respondents themselves would contribute further to an understanding of the discourses surrounding stroke.

6.5.2.2 Tape recording/ transcription

It is recognised that several aspects of the interview situation which could contribute to understanding meaning were lost because the interviews were recorded on tape and transcribed. These include non-verbal gestures, the actual pronunciation of speech, accents, and the inflections and rhythms of speech and the emphasis or intonation within a word. On repeated listening of the tapes it was noted that the interviews were often more light-hearted than they appeared from reading the transcripts. It is also recognised that the analysis although based on the transcriptions and must have been influenced in some way by my experience of meeting with and getting to know the couples over the year period.

6.5.3 Feedback to/from participants

The research would have been strengthened by feedback about the analysis from the participants. This would not be to validate a 'true' reflection of their experience as within the epistemological approach I am using the meaning of personal reality is mediated through discourse which would be expected to change with different temporal perspectives. Taking the analysis back to the respondents would have given them the opportunity to see if they could recognise the issues described as important to them. Zola (1991) stressed that the people who are studied should be able to recognise essential parts of themselves in the researchers descriptions. Reissman (1993) suggested that correspondence is achieved if the account is recognised as an adequate representation by the participants.

I would have welcomed feedback about the interviews and my interpretations of participants' narratives. This was difficult within the structure of this study. I was interested to see how people perceived their life at the three time points, so that temporal comparisons could be made. I did not want to influence my relationship with the participants, or how people reflected upon the six month and one year life narratives, by directing people to consider my interpretations on their life stories, during the course of the study. I had considered feeding back at each meeting, but I felt it would influence further narrative telling. I had considered sending

interpretations via post to people for their comments and feedback, but as the couples lived at the same address I did not want to risk breaching personal confidentiality. Unfortunately there was insufficient time for further visits at the end of the interview period. A future study is planned which will involve visiting each of the respondents at home and completing ratings of agreement on a short questionnaire which highlights the overall interpretations from the study. The questionnaire will also contain open ended questions allowing further discussion. The complete meeting will be taped and transcribed. Issues raised by the respondents will be identified and analysed to guide further research.

CHAPTER SEVEN

An exploration of self-concept following stroke

7.1 Introduction

Having discussed the qualitative analysis in the previous two chapters I now turn to the quantitative part of the research. This study was carried out to explore self-concept following stroke using a measure which could be used by rehabilitation practitioners. By exploring a self-concept measure it was hoped that it would be possible to encourage researchers and practitioners familiar with quantitative outcome measures to consider assessment of identity change.

The questionnaire study was carried out concurrently with the interviews in order to fulfil the following aims:

- to determine whether aspects of self-concept change following stroke
- to determine if mood is associated with self-concept, activity levels or physical ability
- to provide evidence of the usefulness of the Semantic Differential self-concept scale for clinical use or in large scale research.

The chapter will be presented in six sections.

Section 7.2 Description of the sample

Including baseline demographic information, and results from the screening tests

Section 7.3 Physical and task orientated changes in the stroke respondent group

Descriptive statistics were used to provide information about the physical and task-orientated changes of the stroke respondent group. Inferential statistics were used to explore the degree to which physical and task oriented skills changed over time.

The following null hypotheses were tested:

1. There is no change in gross physical ability over time.
2. There is no change in arm function over time
3. There is no change in self-care activity over time.
4. There is no change in domestic and social activity over time.

Section 7.4 Mood change following stroke

Descriptive statistics were used to provide information about the levels of anxiety and depression reported by the stroke respondent and spouse groups. Inferential statistics were used to determine whether mood levels changed over time, and to compare the

mood levels of the stroke respondent and spouse groups. The following null hypotheses were tested:

5. (a and b) There is no change in anxiety level reported by the stroke respondents and spouses over time.
6. (a and b) There is no change in the depression levels reported by the stroke respondents and spouses over time.
7. There is no difference in the mood levels reported by the stroke respondents and spouses.

Section 7.5 Self-concept following stroke

Descriptive statistics were used to provide information about perceived changes in the past, present and future self-concept of the stroke respondent and spouse groups over time. Inferential statistics were used to test the following null hypotheses:

8. There is no difference between past and present self-concept following a stroke.
9. There is no difference between perceived present and future self-concept following a stroke.

Section 7.6 Associations between mood and activity levels, physical ability and self-concept

Inferential statistics were used to test the degree to which mood is associated with physical ability, self-care skills and difference in past-present self-concept. The following null hypotheses were tested:

10. There is no association between mood and physical ability.
11. There is no association between mood and activity levels.
12. There is no association between mood and difference in past-present self-concept.

Multiple regression analysis was carried out to determine the contribution of physical and task orientated ability and the difference in past-present self-concept scores to estimations of mood.

Section 7.7 Discussion

Although it is unusual, a discussion of the findings will also be combined in this chapter. This approach has been taken to allow comparison of the quantitative data obtained in the present study with previous quantitative research. In the following chapter evidence from both the quantitative and qualitative aspects of the study will be compared and discussed within a wider context of stroke research.

7.2 Description of the sample

The stroke respondent and spouse groups were described using statistics which could be compared with the general stroke population, previous studies of recovery, and provide a profile of the abilities of the respondents within the sample.

7.2.1 Inclusion rate

One hundred and sixty-two people were ascertained, of whom 38 fulfilled eligibility criteria shown in [Table 7.1](#).

	Number included	Number excluded	No originally identified
Number of people considered for inclusion from studying medical notes	162		162
People died		40	
Previous residual physical disability		25	
In hospital for less than 10 days		14	
Discharged to nursing home		16	
Receptive dysphasia		10	
Confusion		5	
Lived out of area		3	
Did not speak English		2	
Too ill to be seen		5	
Cumulative total	42	120	162
Number of people approached at baseline	42		
Person declined		1	
Screened out as too confused		3	
Cumulative total	38	124	162
Number of respondents at baseline	38		
Number of respondents approached at six months	38		
Person declined		1	
Person died- did not visit spouse		1	
Not available for six month interview		1	
Lost contact		3	
Cumulative total	32	130	162
Number of respondents at six months	32		
Number of respondents approached at one year	32		
Person declined		1	
Not available		1	
Confused		1	
Now available for one year interview (see 6months)		+1	
Cumulative total	30	132	162
Number of respondents at one year	30		

[Table 7.1](#) [Eligibility for stroke respondent sample](#)

Of the 42 people approached, one declined and three people did not reach the cut-off point for the cognitive screening test, giving an inclusion of 38 stroke respondents. The attrition rate from identification in hospital records to being approached on the ward was 74%. The attrition rates at baseline, six months and one year were 9%, 16% and 6% respectively. Seventeen of the respondents were married. Three spouses were known to have cognitive problems and so could not be included, leaving 14 spouses who all agreed to take part. Inclusion of the spouses can be seen in [Table 7.2](#). By six months, three people could not be traced, one person declined and one person had died and so their spouse was also excluded. One person found it difficult to arrange a time for a visit and the next visit was nearer a one year visit, so the six month data were lost.

	Number excluded	Number included	Total
Number of married stroke respondents			17
Confused spouses	3		
Cumulative total	3	14	17
Number of spouses at baseline		14	
Spouse widowed	1		
Cumulative total	4	13	17
Number of spouses at six months		13	
Number of spouses at one year		13	

[Table 7.2](#) [Spouse sample selection](#)

At one year, one stroke respondent declined, the date of one person’s one year follow-up visit fell after the end of the data collection period, and one person was experiencing increasing cognitive problems and was excluded.

7.2.2 Baseline demographic information

7.2.2.1 Stroke group

The profile of the stroke respondent group over time can be seen in [Table 7.3](#). The age of the participants ranged from 46-88 years, the median ages were 74, 76 and 74 years at baseline, six months and one year respectively. There were slightly more

female participants in the baseline group {female 20 (53%); male 18 (47%)}. This changed by one year following exclusions when there were slightly more male than female respondents {female 4 (47%); male 16 (53%)}. The exclusions, caused by being unable to trace respondents, a spouse dying, withdrawal from the study and cognitive difficulties did not appear to be directly related to gender. Inferential statistical analysis was carried out on the baseline composition of each of the time groups i.e. baseline, six months and one year to determine whether changes in physical and mood and self-concept outcomes, could have been influenced by changes in the composition of the group over time. Although, there were six exclusions at six months and eight exclusions at one year, when the variation between the groups was tested using a Kruskal Wallis one way Anova and chi-squared test respectively there were no statistically significant differences found in the baseline age ($\chi^2 = 0.23$, df 2, $p = 0.89$) or the baseline gender ($\chi^2 = 0.32$, df 2, $p = 0.85$).

		Baseline	Sample Six months	One year
Gender	female	20 (53%)	15 (47%)	14 (47%)
	male	18 (47%)	17 (53%)	16 (53%)
Age (years)	mean	72	72	72
	median	74	76	74
	range	46-88	46-88	46-88
Marital Status	single	3 (8%)	3 (9%)	3 (10%)
	married	17 (44%)	14 (44%)	14 (47%)
	widowed	15 (40%)	14 (44%)	12 (40%)
	divorced	3 (8%)	1 (3%)	1 (3%)
Attrition			6	8
Number in Group		38	32	30
Baseline group		38	38	38

Table 7.3 Baseline age and gender - Profile of stroke respondents at baseline, six months and one year samples

From Table 7.3 it can be seen that the majority of the group, at the three sample times were either married or widowed. The stroke related profile of the group can be seen in Table 7.4. It can be seen that a higher percentage of respondents had left-sided weakness, probably because severe language problems, usually associated with right weakness, were excluded from this study. When tested using a chi squared test there was no statistical difference in the percentage of respondents with left weakness over time ($\chi^2 = 0.05$, df 2, $p = 0.977$). The stroke respondents demonstrated a wide range of

motor ability, scores ranging from 1 to 11 out of a possible total of 13. The median scores for all three time groups was 5 at baseline, meaning that 50% of the group could transfer to and from a chair, but could not walk ten metres. When a Kruskal Wallis one way Anova was used to compare the variation between the groups no statistically significant difference was found in the baseline motor scores ($\chi^2 = 0.03$, df 2, $p = 0.986$). There was wide variation in respondents ability to use their affected arm at baseline ranging from those who could use their hands normally to those who had no movement. When a Kruskal Wallis one way Anova was used to compare the variation between the groups no statistically significant difference was found in the baseline arm function scores ($\chi^2 = 0.20$, df 2, $p = 0.897$).

		Baseline	Sample Six months	One year
Weakness	Left	23 (60 %)	20 (62%)	18 (60%)
	Right	15 (40%)	12 (38%)	12 (40%)
Motor ability	mean	5.5	5.6	5.7
Rivermead Motor Assessment (0-13)	median	5	5	5
	range	(1-11)	(1-11)	(1-11)
Affected arm	no movement	12 (32%)	12 (37%)	12 (40%)
	for stabilising only	7 (18%)	5 (16%)	3 (10%)
	gross grip	3 (8%)	2 (6%)	2 (7%)
	indiv. movt. fingers	4 (10%)	4 (13%)	4 (13%)
	clumsy use hand	9 (24%)	7 (22%)	7 (23%)
	normal use of hand	3 (8%)	2 (6%)	2 (7%)
Communication problems	yes	5 (13%)	5 (16%)	5 (17%)
	no	33 (87%)	27 (84%)	25 (83%)
Time in hospital (weeks)	mean	9	9	9
	median	6	7	7
	range	(2-30)	(2-30)	(2-30)
Number in group		38	32	30
Attrition			6	8
Baseline group		38	38	38

Table 7.4 Baseline stroke related measures - Profile of stroke group at baseline, six months and one year

There was wide variation in the length of the respondents hospital stay (2-30 weeks). When a Kruskal Wallis one way Anova was used to compare the variation between the stroke group composition at baseline, six months and one year, no statistically significant difference was found in the time spent in hospital ($\chi^2 = 0.02$, df 2, $p = 0.990$).

7.2.2.2 Spouse group

The age and gender profile of the spouse group was similar at baseline, six months and one year (see Table 7.5). The majority of spouses were women.

		Baseline	Sample Six months	One year
Gender	female	11 (79%)	10 (77%)	10 (77%)
	male	3 (21%)	3 (23%)	3 (23%)
Age (years)	mean (SD)	64 (12.5)	63.7 (13.0)	63.7 (13.0)
	median (range)	65 (41-82)	65 (41-82)	65 (41-82)
Number in group		14	13	13
Baseline group		14	14	14

Table 7.5 Age and gender profile of spouse group at baseline, six months and one year

The higher percentage of female spouses reflects the fact that more of the women with strokes had previously lost their spouses or were unmarried.

7.2.3 Screening tests

7.2.3.1 Communication

This assessment was included to determine the respondents’ ability to complete a written questionnaire. At baseline, five respondents demonstrated expressive speech problems. All were included in the study. Two had completed the baseline assessment before a more systematic indicator of communication was used. Of the remaining three respondents, two scored the maximum of 15 in the reading and comprehension subtests of the Frenchay Aphasia Screening Test. One person scored 14 out of a possible 15, failing in the comprehension of the name of one shape - a semicircle. The respondent was not excluded as he was able to understand other complex verbal and written commands.

7.2.3.2 Cognitive ability

This assessment was included to determine that respondents had the cognitive ability necessary to complete the questionnaire. Mini-Mental State Examination (MMSE) scores are shown in Table 7.6. At one year one stroke respondent was excluded from the study as he scored below the 24/30 cut off point as he had become increasingly confused over the previous three months.

		Baseline	Six months	One year
MMSE score (0-30)	mean	28.7	28.6	28.9
	median	29	30	30
	range	21-30	24-30	26-30
Number completing MMSE		34	29	27
Number not completing MMSE		4	3	3
Number in participant group		38	32	30

Table 7.6 Mini-Mental State Examination scores

Four respondents could not be assessed using MMSE. One person had tunnel vision and so could not see the paper which was necessary for some of the tasks. Three respondents could not answer the verbal questions due to expressive dysphasia and an inability to respond in writing. There was no evidence from the way the participants completed the rest of the questionnaire that they had a cognitive deficit which affected their responses and so they were not excluded. At six months one of the respondents with expressive dysphasia improved so much that he was able to make himself understood and was able to complete the cognition test, scoring well above cut-off.

7.2.3.3 Left visual inattention

This assessment was included to highlight respondents who may have had difficulty viewing the full width of the page when scoring the semantic differential self-concept scale due to perceptual difficulties brought on by the stroke. One person was unable to complete the test due to tunnel vision.

		Baseline	Six months	One year
Letter cancellation score (range = 0-40)	mean (SD)	33.6	36.9	37.4
	median (range)	36 (13-40)	39 (27-40)	39 (26-40)
Number below cut off		12 (32%)	4 (13%)	2 (7%)
Number not completing test		1	1	1
Number in participant group		38	32	30

Table 7.7 Letter cancellation scores

The cut off point is 32 (Wilson, Cockburn and Halligan, 1987). From Table 7.7 it can be seen that at baseline 32% of respondents were below cut off in this task. All respondents below cut off on this subtest were helped to complete the semantic differential self-concept scale by placing the page on the right of the mid-line of their

field of vision and physical cueing to the left side of the page. In two severe cases the scale was completed by the researcher with the close collaboration of the respondent.

When the improvement in the inattention scores is considered over time it can be seen that by six months only 13% and by one year only 7% of respondents were below cut off. When the variability of the inattention scores of the 30 respondents at one year were compared within the groups using a Friedmans two-way Anova a significant difference was found ($\chi^2 = 11.3$, df 2, $p = 0.003$). The improvement in scores occurred within the first six months, the difference in baseline and six months giving a z score of - 2.98 ($p = 0.003$) and that for six months and one year being $z = -0.79$ ($p = 0.426$) when tested using a Wilcoxon signed ranks test. Previous studies have demonstrated that visual inattention improves early after stroke (Friedman and Leong, 1992; Fanthome, Lincoln, Drummond et al 1995).

7.3 Physical and task-orientated changes in the stroke respondent group

7.3.1 Physical ability

Overall there was a gradual improvement in physical abilities over the year following discharge from hospital. Figure 7.1 (page 182) presents the scores of the gross motor subscale of the Rivermead motor assessment at baseline, six months and one year. As this is a hierarchical score, abilities are represented by achievement scores. A respondent who is able to sit unsupported, but not able to sit from lying would score 1. A respondent who is able to complete all the tasks described in the scale would score 13. When interpreting the figure it should be noted that the raw scores of the respondents from each assessment time have been used, and so the groups compared have differing numbers of respondents (baseline 38, six months 32, one year 30). The raw scores of respondents in each category were used in preference to percentage frequency scores, as a comparison of percentages gives the false impression that some respondents had deteriorated over time.

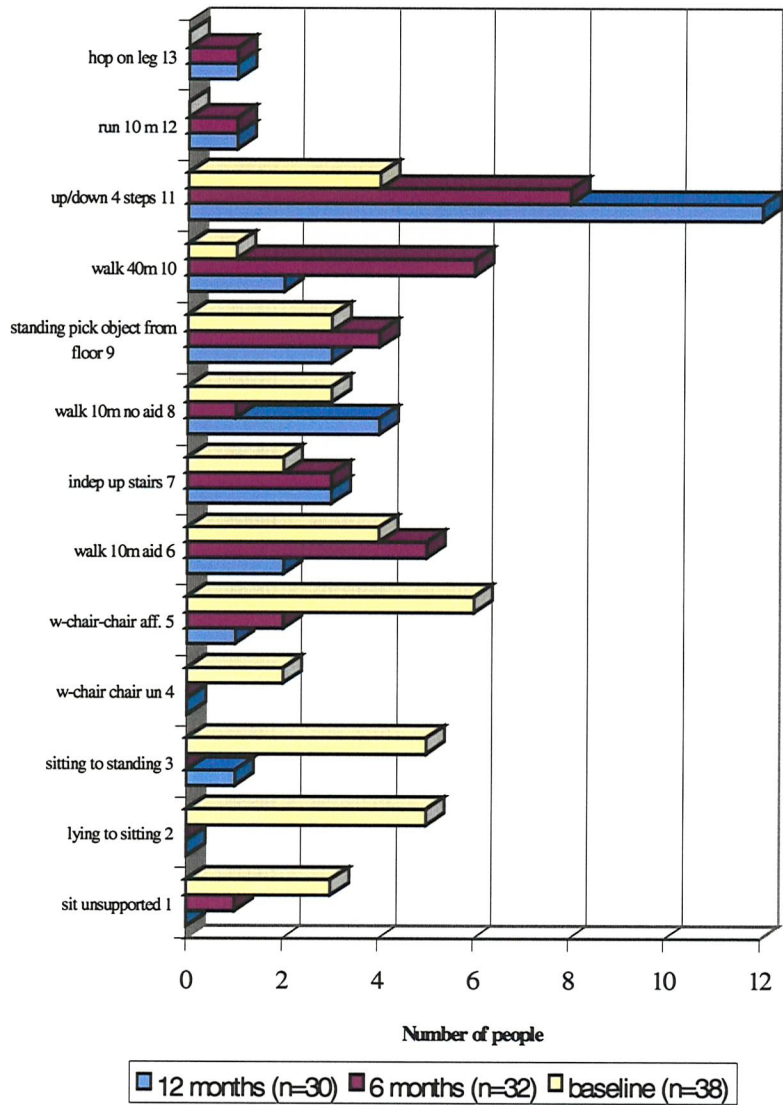
At baseline, the stroke respondents had limited physical abilities. Many spent most of their time sitting during the day and could only walk a short distance. Although the physical ability of the group improved over the following year (the median scores

rising from 5 to 10 out of a maximum possible score of 13), physical difficulties were still apparent. By one year eight respondents still could not stand unsupported and only two respondents were able to run ten meters and only one hop on one leg.

The null hypothesis (no.1), that there is no change in physical status over time, could not be supported as the change in physical ability of the 30 respondents from baseline to one year was statistically significant when tested using a Wilcoxon signed ranks test ($z = -4.1$, $p = 0.000$). Further analysis between the groups using a Wilcoxon signed ranks test showed that the improvement occurred within the first six months, there was a significant difference between the baseline and six months scores ($z = -3.89$, $p = 0.0001$) but not the six month and one year scores ($z = -0.93$, $p = 0.3536$).

Figure 7.1 Rivermead Motor Assessment (gross motor subscale)

Maximum Achievement



		Baseline	Six months	One year
Score (0-13)	mean (SD)	5.5 (3.1)	8.7 (2.6)	9.2 (2.3)
	median (range)	5 (1-11)	9.5 (1-13)	10 (3-13)

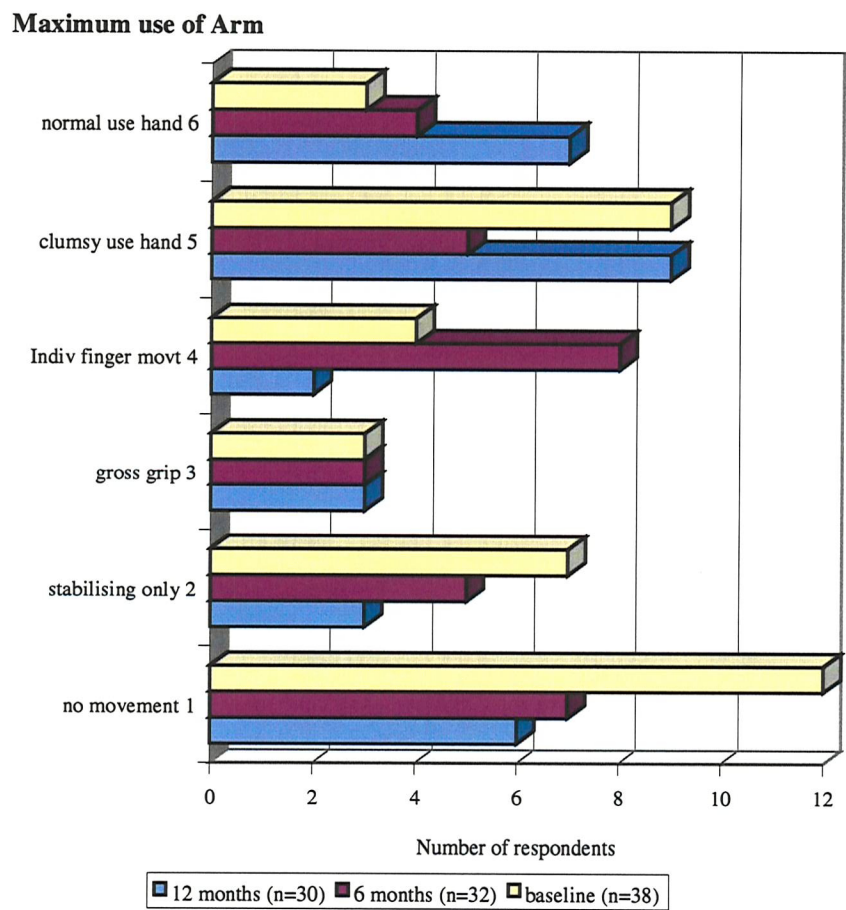
Table 7.8 Rivermead motor assessment (gross motor subscale)

7.3.2 Affected arm

From Figure 7.2 it can be seen that there was a gradual improvement in arm function. Using Wilcoxon sign ranks test the difference between the arm function rating at one year was found to be statistically different from the baseline scores

($z = -3.38$, $p = 0.0007$), and so the null hypothesis (no.2) could not be supported. Further analysis within the groups using a Wilcoxon signed ranks test showed that the improvement occurred over the year; there was a significant difference between the baseline and six months scores ($z = -2.35$, $p = 0.0186$) and from six months to one year ($z = -2.72$, $p = 0.0064$).

Figure 7.2 Affected Arm rating



		Baseline	Six months	One year
Score (1-6)	median	2.5	4	5
	range	(1-6)	(1-6)	(1-6)

Table 7.9 Affected Arm rating

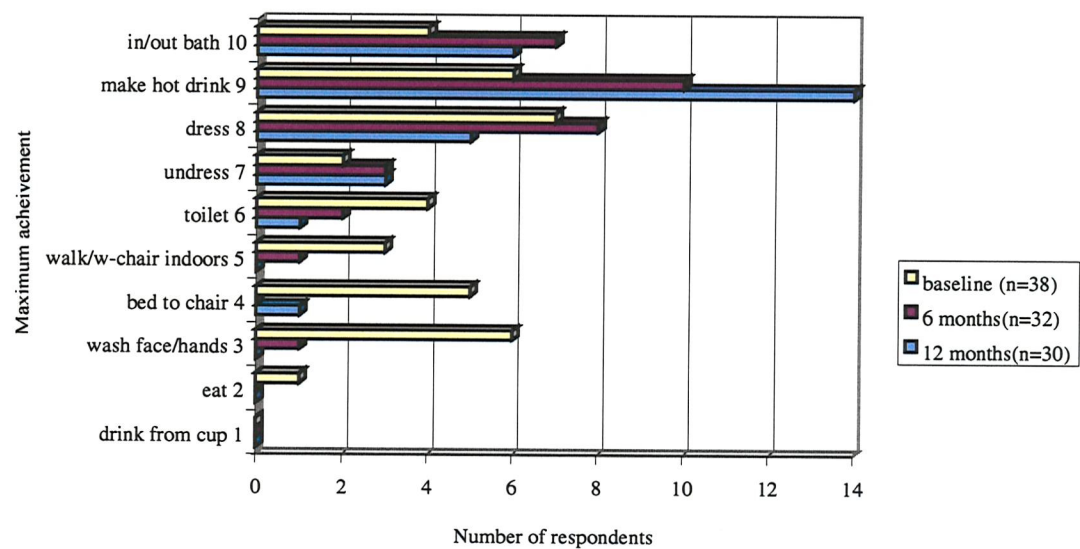
Again raw scores of the respondents from each assessment time were used, and so the groups compared have differing numbers of respondents (baseline 38, six months 32, one year 30). The raw scores of respondents in each category were used in preference to percentage frequency scores, as a comparison of percentages gives the false

impression that some respondents had deteriorated over time. After one year six stroke respondents still did not have any movement in their arm, although four regained the normal use of their hand over time.

7.3.3 Self-care abilities

As the Nottingham 10 point ADL scale is hierarchical, abilities are represented by achievement scores. A respondent who is able to drink from a cup but not feed themselves would score 1. A respondent who is able to complete all the tasks described in the scale would score 10. Raw scores of the respondents from each assessment time were used, and so the groups compared have differing numbers of respondents (baseline 38, six months 32, one year 30). The raw scores of respondents in each category were used in preference to percentage frequency scores, as a comparison of percentages gives the false impression that some respondents had deteriorated over time.

Figure 7.3 Nottingham 10 point ADL scale



		Baseline	Six months	One year
Score (0-10)	mean (SD)	6.4	8.3	8.6
	median (range)	6 (2-10)	9 (3-10)	9 (4-10)

Table 7.10 Nottingham 10 point ADL scale

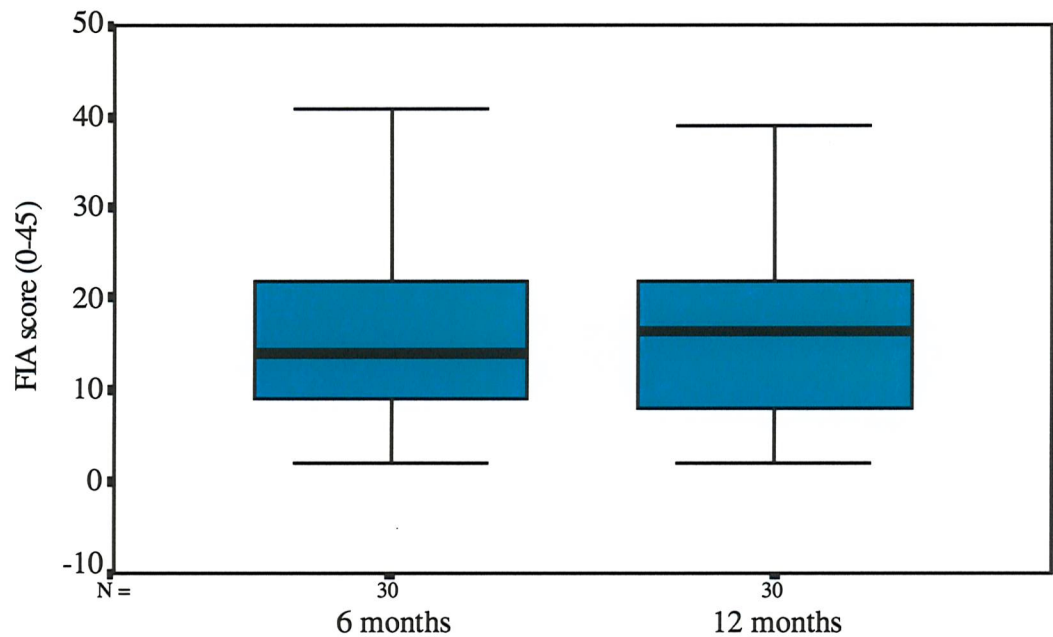
At baseline, there were a wide variety of abilities in self-care; one respondent could only feed themselves whereas four respondents could complete all the tasks including getting themselves in and out of the bath (see [Figure 7.3](#)).

By one year following discharge 20 (67%) of respondents could wash and dress themselves, and make a hot drink, although only 6 (20%) could bath themselves without supervision. The null hypothesis (no.3), that there was no change in self-care abilities, could not be supported as the change in self care abilities of the 30 one year respondents from baseline was found to be statistically significant when a Wilcoxon signed ranks test was applied ($z = -3.54$, $p = 0.0004$). As with physical ability, the improvement occurred in the first six months. The difference between the baseline and six month groups was statistically significant ($z = -3.54$, $p = 0.0004$), whereas no statistically significant difference was found between the six month and one year groups ($z = -0.45$, $p = 0.649$) using a Wilcoxon signed ranks test.

7.3.4 Domestic and social activity

The Frenchay Activities index is an indicator of domestic and social activity over the previous six months. As the stroke respondent may have been in hospital for several weeks it would not have been valid to complete the index at baseline and so data were collected at six months and one year. [Figure 7.4](#) is a boxplot comparing data from six months and one year. At six months the median score was low (15 out of a possible maximum score of 45) demonstrating that the group had a low level of social and domestic activity.

Figure 7.4 Boxplot of Frenchay Activity Index



		Baseline	Six months	One year
Score (0-45)	median(range)	n/a	14 (2-42)	16 (2-39)
	mean(SD)		17 (11.2)	16.4 (10.7)
			n = 30	n = 30

Table 7.11 Frenchay Activity Index of stroke respondent group

There was a wide variation in activity, with scores ranging from 2 to 42 out of a possible 45. By one year there was a slight increase in the level of activity (median score was 16). The null hypothesis (no.4), that there was no change in domestic and social activity over time, was supported as level of activity was not found to be statistically significantly different when a Wilcoxon signed ranks test was applied ($z = -0.25$, $p = 0.798$). The low mean score demonstrates that the stroke respondent group maintained a low level of domestic and social activity. The range of the scores was narrower at one year as one respondent who had been carrying out his own housework had employed a house-cleaner.

7.4 Mood change following stroke

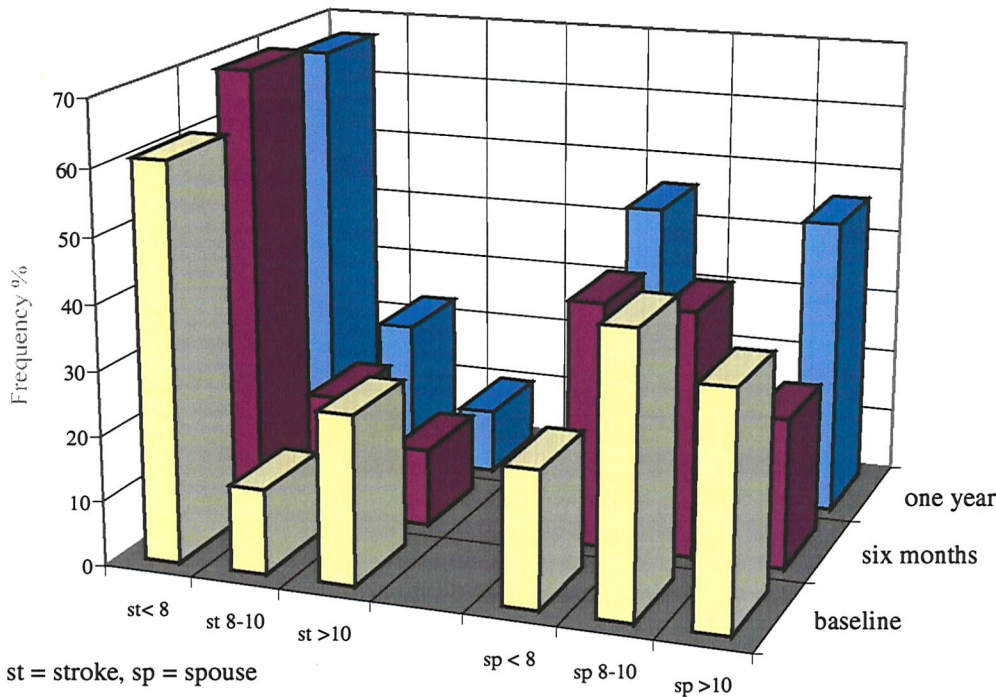
Changes in the Hospital Anxiety and Depression subscores over time will be presented in two ways. The first describes the ‘caseness’ of the stroke respondent and spouse groups, the second describes the central tendency and dispersion of the two groups. The ‘caseness’ of the respondents is presented in [Figure 7.5](#) and [Figure 7.6](#).

Table 7.12 and Table 7.13 highlight the percentage of respondents who suffer from psychological distress following stroke. The tables have been constructed using the scoring system of Zigmond and Snaith (1983). Respondents scoring seven or below were classified as definitely not showing signs of anxiety or depression or ‘non-cases’; respondents scoring eight to ten were classified as borderline cases; and respondents scoring equal to or above eleven were classified as ‘possible’ cases.

7.4.1 Anxiety

From Figure 7.5 and Table 7.12 it can be seen that at baseline 15 stroke respondents (39%) could be classed as borderline or possible cases of clinical anxiety.

Figure 7.5 HAD anxiety scores



			Baseline	Six months	One year
Anxiety	stroke	non case 0-7	23 (61%)	22 (69%)	20 (67%)
		borderline 8-10	5 (13%)	6 (19%)	7 (23%)
		possible 11-21	10 (26%)	4 (12%)	3 (10%)
		<i>n</i>	38	32	30
	spouses	non case 0-7	3 (21%)	5 (38.5%)	6 (46%)
		borderline 8-10	6 (43%)	5 (38.5%)	1 (8%)
		possible 11-21	5 (36%)	3 (23%)	6 (46%)
		<i>n</i>	14	13	13

Table 7.12 HAD Anxiety scores - frequency of ‘cases’

Over time there was a gradual decrease in the percentage of stroke respondents who could be classed as borderline or possible cases. By one year there were still 10 respondents (33%) who could be classed as borderline or possible cases. However, the null hypothesis (no.5a), that there is no change in anxiety levels over time, was supported as there were no statistically significant changes in the levels of anxiety of the 30 one year respondents at each assessment time when tested using a Friedmans two-way Anova.

The data from the spouses group needs to be interpreted with care due to the small sample size. Spouses experienced high levels of anxiety at baseline while their partners were in hospital; 11 spouses (79%) could be classed as borderline or possible cases. The levels of anxiety gradually reduced over time. At one year seven spouses (54%) could still be identified as borderline or possible cases. The null hypothesis (no.5b), that there is no change in levels of anxiety over time, was supported as there were no statistically significant changes in the levels of anxiety of the 13 one year respondents over time when tested using a Friedmans two-way Anova.

The distribution of the anxiety scores for the stroke respondent and spouse groups is shown in Table 7.13.

			Baseline	Six months	One year
Anxiety	stroke	mean (SD)	6.6 (4.5)	5.9 (4.1)	5.9 (4.3)
		median (range)	6 (0-16)	6 (0-15)	6 (0-17)
		<i>n</i>	38	32	30
	spouses	mean (SD)	10 (3.5)	8.2 (4.0)	8.9 (4.6)
		median (range)	10 (3-17)	9 (3-15)	8 (2-16)
		<i>n</i>	14	13	13

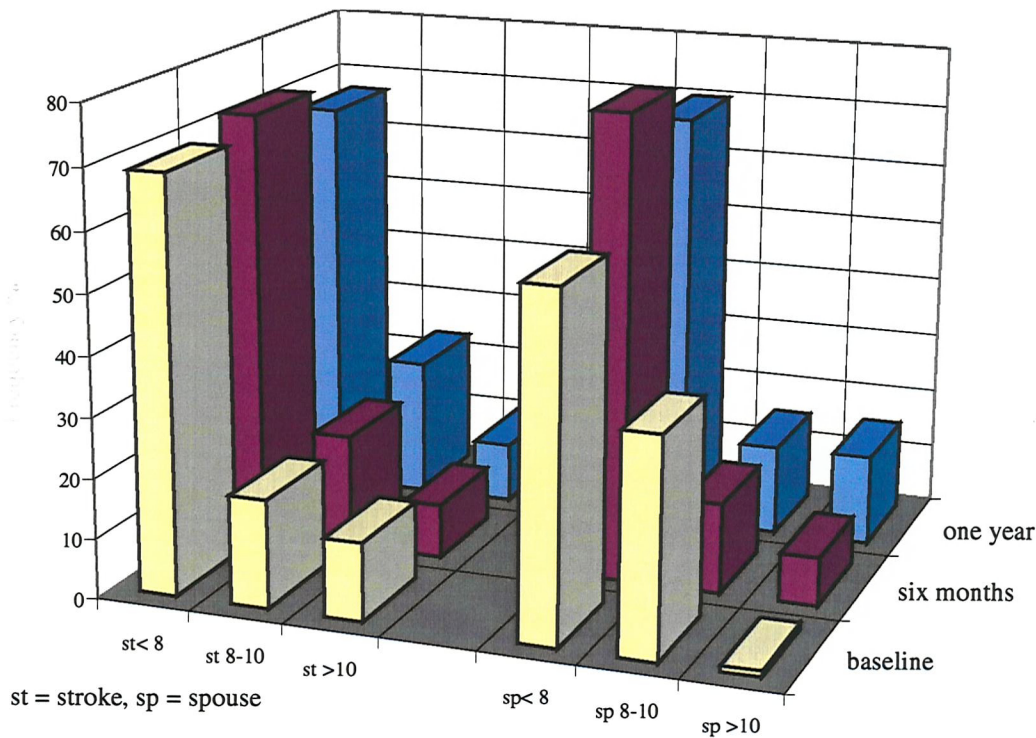
Table 7.13 Central tendency and dispersion of HAD Anxiety scores

The null hypothesis (no.7), that there is no difference in the mood levels reported by the stroke respondents and spouses, could not be supported, as the spouse group were statistically significantly more anxious than the stroke respondent group at baseline ($z = -2.41, p = 0.016$) when tested using a Mann Whitney U test. No other statistically significant differences were found between the stroke respondent and spouse groups but this may have been due to low numbers in the spouse group.

7.4.2 Depression

At baseline 12 stroke respondents (31%) could be classed as ‘borderline’ or ‘possible’ cases of clinical depression (see [Figure 7.6](#) and [Table 7.14](#)). The level of depression remained constant over the year follow-up. At one year 10 respondents (33%) could be classed as borderline or possible cases. The null hypothesis (no.6a), that there is no change in depression levels over time, was supported, as there were no statistically significant changes in the levels of depression of the 30 respondents at one year in each group when tested using a Friedmans two way Anova.

Figure 7.6 HAD depression scores



			Baseline	Six months	One year
Depression	stroke	non-case 0-7	26 (69%)	23 (72%)	20 (67%)
		borderline 8-10	7 (18%)	6 (19%)	7 (23%)
		possible 11-21	5 (13%)	3 (9%)	3 (10%)
		<i>n</i>	38	32	30
	spouse	non-case 0-7	8 (57%)	10 (77%)	9 (70%)
		borderline 8-10	5 (36%)	2 (15%)	2 (15%)
		possible 11-21	1 (7%)	1 (8%)	2 (15%)
		<i>n</i>	14	13	13

Table 7.14 HAD Depression scores - frequency of ‘cases’

Again the spouses data need to be interpreted with caution due to the small sample size. At baseline six spouses (43%) could be classed as borderline or possible. From Table 7.14 there appears to be reduction in depression levels over time. At one year four spouses (30%) could still be classed as borderline or possible cases of clinical depression. The null hypothesis (no.6b), that there is no change in depression levels over time, was supported, as there were no statistically significant changes in the levels of depression between the spouse groups when tested using a Friedmans two way Anova.

The central tendency and dispersion of the depression scores for the group as a whole can be seen in Table 7.15.

			Baseline	Six months	One year
Depression	stroke	mean (SD)	6.4 (4.2)	5.6 (3.8)	5.9 (3.4)
		median (range)	6 (1-17)	6 (0-16)	6 (0-14)
		<i>n</i>	38	32	30
	spouses	mean (SD)	6.2 (2.9)	4.6 (3.2)	5.8 (4.8)
		median (range)	5.5 (1-11)	4 (1-11)	6 (0-17)
		<i>n</i>	14	13	13

Table 7.15 Central tendency and dispersion of HAD Depression scores

There were no statistical differences in the depression levels of the stroke respondents and the spouses when each assessment time was compared using a Mann-Whitney U test. The range of depression scores for the spouses increased from 1-11 at baseline to 1-17 at one year suggesting that certain individuals became more depressed over time. The lack of statistical significance found when depression scores were compared over time may be due to the small sample size of the spouse group.

7.5 Self-concept following stroke

7.5.1 Stroke group

Data from the self-concept scales of the stroke respondents were analysed to test two null hypotheses:

- (8) there is no difference between past and present self-concept scores
- (9) there is no difference between present and future self-concept scores.

This was to determine whether perceptions of self differ following a stroke. The data were analysed using a Wilcoxon signed ranks test as the data were ordinal, within subjects and were not normally distributed. Due to the number of tests, in order to avoid a Type I error the probability level was set at $p \leq 0.001$.

From Table 7.16 it can be seen that there is a statistically significant difference between the total past and present self-concept scores at baseline ($z = -4.2, p \leq 0.001$), six months ($z = -4.4, p \leq 0.001$) and one year ($z = -4.4, p \leq 0.001$), and so it is possible to reject the first null hypothesis and state that there is a difference between past and present self-concept scores.

It can also be seen that there is a statistically significant difference between the total present and future self-concept scores at baseline ($z = -4.9, p \leq 0.001$), six months ($z = -4.5, p \leq 0.001$), and one year ($z = -4.1, p \leq 0.001$), and so it is possible to reject the second null hypothesis and state that there is a difference between present and future self-concept scores. This difference was found up to one year following discharge from hospital.

Comparison of the profiles from each time period provide evidence of which aspects of self-concept assessed were perceived to have changed. The baseline, six months and one year semantic differential scores can be seen in Figure 7.7, Figure 7.8, and Figure 7.9 and respectively. The construct pairs are presented in the order that they appear in the questionnaire, but unlike the questionnaire all of the positive adjectives have been shown on the right to clarify presentation. The median score was used to express central tendency as the data were skewed to the right. Throughout this section measures of central tendency and dispersion will be described by the median and range in the following format (median, range).

Wilcoxon signed-rank test of self-concept scores

	Hospital				Six months				One year			
	Past-present		Present-future		Past-present		Present-future		Past-present		Present-future	
	z score	p value (2 tail)	z score	p value(2tail)	z score	p value(2 tail)	z score	pvalue(2tail)	z score	pvalue(2tail)	z score	pvalue(2tail)
Bored-interested	-4.381	0.0000**	-4.087	0.0000**	-3.482	0.0005**	-3.823	0.0001**	-3.506	0.0005**	-2.689	0.0072*
Unhappy-happy	-3.988	0.0001**	-3.893	0.0001**	-3.571	0.0004**	-3.045	0.0023*	-3.516	0.0004**	-2.691	0.0071*
Helpless-in control	-4.153	0.0000**	-3.047	0.0023*	-3.680	0.0002**	-2.352	0.0187*	-4.014	0.0001**	-2.277	0.0228*
Worried-relaxed	-3.508	0.0005**	-4.249	0.0000**	-1.668	0.0952	-2.938	0.0033*	-2.538	0.0111*	-1.603	0.1089
Dissatisfied- satisfied.	-3.211	0.0013	-1.957	0.0503	-3.733	0.0002**	-2.657	0.0079*	-3.211	0.0013*	-2.958	0.0031*
Unattractive-attractive	-3.500	0.0005**	-3.111	0.0019*	-2.166	0.0303*	-1.258	0.2084	-2.534	0.0113*	-2.865	0.0042*
Despondent -hopeful	-0.827	0.4080	-1.820	0.0687	-2.223	0.0262*	-2.196	0.0281*	-2.785	0.0054*	-0.533	0.5940
Lacking conf.-self confid.	-3.486	0.0005**	-3.528	0.0004**	-3.139	0.0017*	-2.716	0.0066*	-3.667	0.0002**	-2.925	0.0034*
Unstable- stable	-3.198	0.0014	-3.048	0.0023*	-2.699	0.0069*	-1.765	0.0776	-3.621	0.0003**	-2.756	0.0058*
Worthless-of value	-3.406.	0.0007**	-3.513	0.0004**	-3.229	0.0012*	-2.352	0.0187*	-2.515	0.0119*	-1.680	0.0929
Aggressive - unaggressive	-0.824	0.4101	-0.353	0.7241	-0.949	0.3433	-0.459	0.6465	-1.098	0.2719	-0.157	0.8753
Irritable-calm	-2.499	0.0124	-3.078	0.0021*	-2.385	0.0171*	-1.852	0.0640	-2.746	0.0060*	-1.444	0.1488
Unfeeling-caring	-1.502	0.1330	-1.260	0.2076	-1.733	0.0831	-0.700	0.4838	-2.666	0.0077*	-1.599	0.1097
Incapable -capable	-4.285	0.0000**	-3.597	0.0003**	-3.2227	0.0013*	-2.700	0.0069*	-3.873	0.0002**	-3.179	0.0015*
Dependent-indep.	-4.546	0.0000**	-4.156	0.0000**	-3.9844	0.0001**	-2.157	0.0310*	-4.136	0.0000**	-3.419	0.0006**
Inactive-active	-4.708	0.0000**	-4.541	0.0000**	-3.5800	0.0003**	-2.938	0.0033*	-3.815	0.0001**	-3.051	0.0023*
Unco-op- co-operative	-1.244	0.2132	-0.414	0.6784	-2.551	0.0107*	-1.956	0.0505	-2.667	0.0076*	-1.412	0.1579
Withdrawn-talkative	-2.485	0.0129*	-1.655	0.0980	-0.734	0.4631	-0.917	0.3590	-3.219	0.0013*	-2.551	0.0107*
Unfriendly-friendly	-1.944	0.0519	-1.050	0.2936	-0.9683	0.3329	-0.944	0.3452	-2.202	0.0277*	-1.521	0.1282
Impatient-patient	-3.005	0.0027*	-2.790	0.0051*	-1.959	0.0501	-2.079	0.0376*	-1.664	0.0962	-2.393	0.0167*
Total score	-4.220	0.0000**	-4.972	0.0000**	-4.409	0.0000**	-4.474	0.0000**	-4.432	0.0000**	-4.076	0.0000**

KEY * p ≤ 0.05 ** p ≤ 0.001

Table 7.16 Differences in past-present and present - future self-concept scores of stroke respondents

7.5.1.1 Baseline

From Figure 7.7 it can be seen that at baseline, the stroke respondent group saw themselves more negatively in every aspect of self-concept assessed apart from seeing themselves as just as attractive (4,1-7), hopeful (7,1-7), unaggressive (7,1-7), caring (7,1-7), co-operative (7,3-7) and friendly (7,2-7). From Table 7.16 it can be seen that the negative changes were statistically significant. From Figure 7.7 it can be seen that respondents reported that they expected to 'return to normal' again (i.e. regain their pre-stroke scores) in the future. Again these perceived changes were statistically significant (see Table 7.16).

7.5.1.2 Six months

From Figure 7.8 it can be seen that at six months there was a similar profile in that median scores of present self were lower than both past and future self. The median score for future self on the dependent-independent scale was 5 (range 1-7). It appeared that at least 50% of the stroke respondent group did not expect to 'return to normal' in this aspect. Again the social aspect of self-concept was not perceived as having changed, there were no statistically significant changes in the six subscales; the stroke respondents reported that they were just as relaxed, unaggressive, caring, talkative, friendly and patient as they had been before the stroke.

7.5.1.3 One year

From Figure 7.9 it can be seen that at one year the profile was similar, except that the stroke respondent group rated their present selves as more helpless (4,1-7) incapable (4, 1-7) and lacking in confidence (4,1-7) than they had at baseline or six months. These changes were not found to be statistically significant when pairs of scores over time was tested using a Wilcoxon signed ranks test. There were only two present self-concept scales on which the stroke respondent group had a median score of 7. The group reported that they saw themselves as still as caring (7,2-7) and friendly (7,3-7) as they were before the stroke. From Table 7.16 the only two present self-concept scales which did not show a significant difference from the past self-concept were aggression and patience.

Figure 7.7 Stroke group -median self-concept scores at baseline

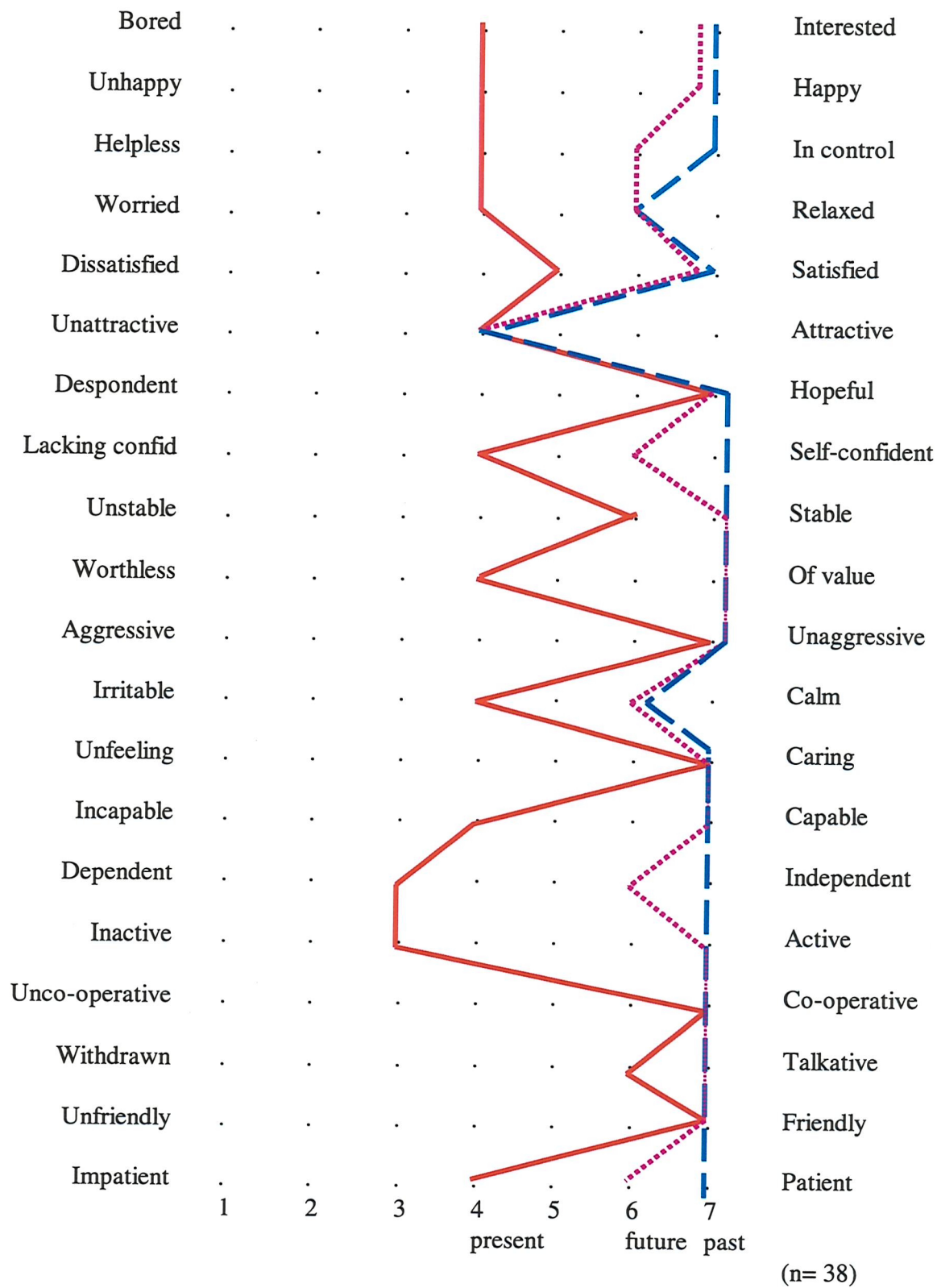


Figure 7.8

Stroke group -median self-concept scores at six months

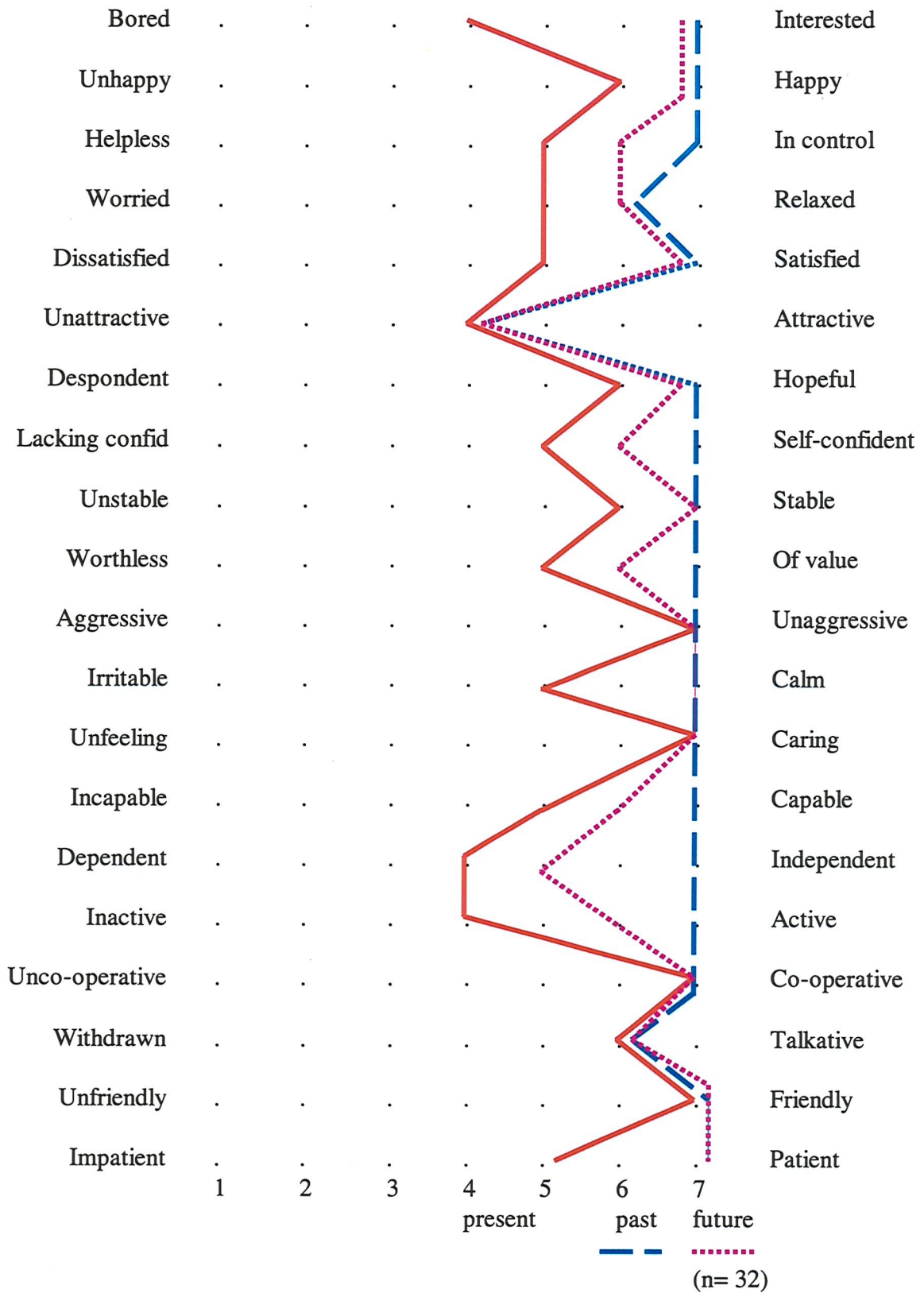
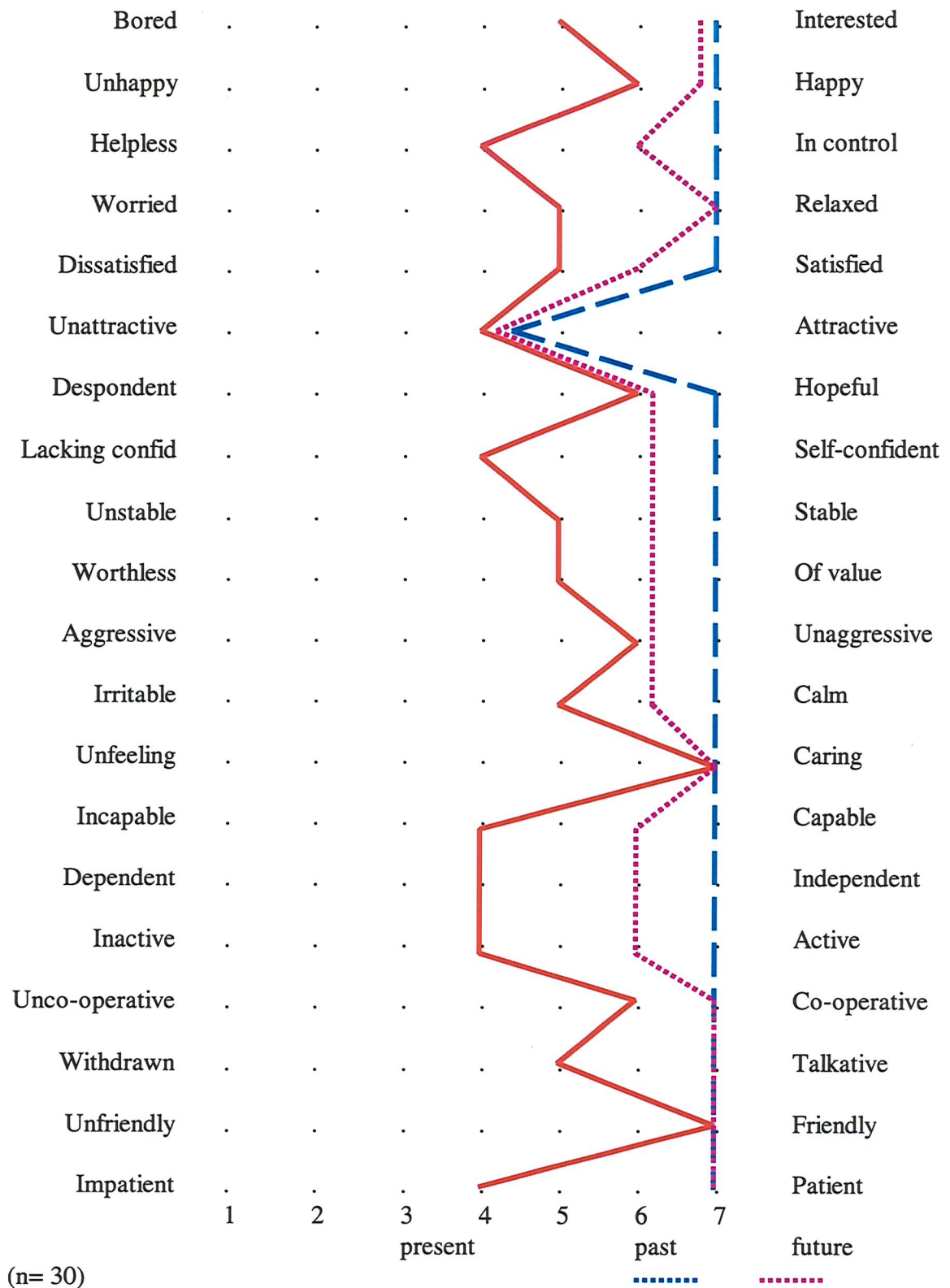


Figure 7.9

Stroke group -median self-concept scores at one year



From [Figure 7.9](#) it can be seen that when respondents described their future self, they scored 12 of the 20 scales giving median scores of 6 or below, compared to 9 of the 20 at six months and 7 of the 20 at baseline suggesting a lowering of expectations in the future. The stroke respondent group reported that they expected to remain as worried, hopeful, worthless, irritable caring, co-operative and friendly in the future (see [Table 7.16](#)).

7.5.2 Spouse group

The baseline, six months and one year semantic differential profiles for the spouse group can be seen in [Appendices 17, 18 and 19](#) respectively. Median scores were used to express central tendency as the data were skewed to the right. It can be seen that using this assessment spouses reported very little change in perceived self-concept. This will be discussed in [Section 7.8](#).

7.5.2.1 Baseline

There was little change in the past, present and future median scores of the spouses, apart from a reduction in the present worried scale (see [Appendix 17](#)). The change from the past score was found to be statistically significant when a Wilcoxon signed rank test was applied ($z = -2.80$, $p = 0.0051$).

7.5.2.2 Six months

Two statistically significant changes were found using a Wilcoxon signed rank test; spouses described themselves as more bored and more unhappy (for both $z = -2.20$, $p = 0.0277$) than before the stroke. At six months there was no statistically significant difference between past and present worry ($z = -1.61$, $p = 0.1073$). From [Appendix 18](#) it can be seen that this was because spouses saw themselves as worried in the past (5, 4-7) and expected to be worried (4,1-7) in the future.

7.5.2.3 One year

At one year the spouse group reported that they were still significantly more bored post stroke ($z = -2.17$, $p = 0.0300$) and described themselves as more unco-operative ($z = -2.02$, $p = 0.0431$) than before the stroke. Again they saw themselves as worried

in the past (5, 2-7) and in the future (5, 1-7) see [Appendix 19](#). It should be noted that the statistical significance of changes in median scores on each scale may have been low due to the small sample size.

7.5.3 Individual variation in self-concept change

For some individuals there was a marked difference between their past and present self-concept scores whereas for others there was little change.

Figure 7.10 Individual variation in perceived past-present self-difference

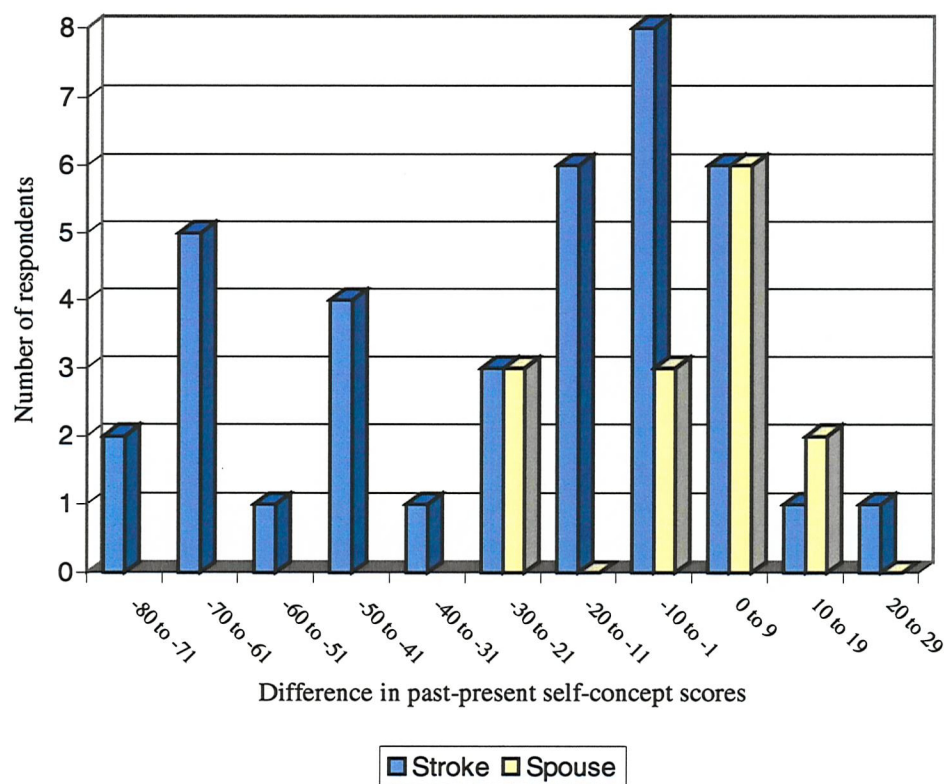
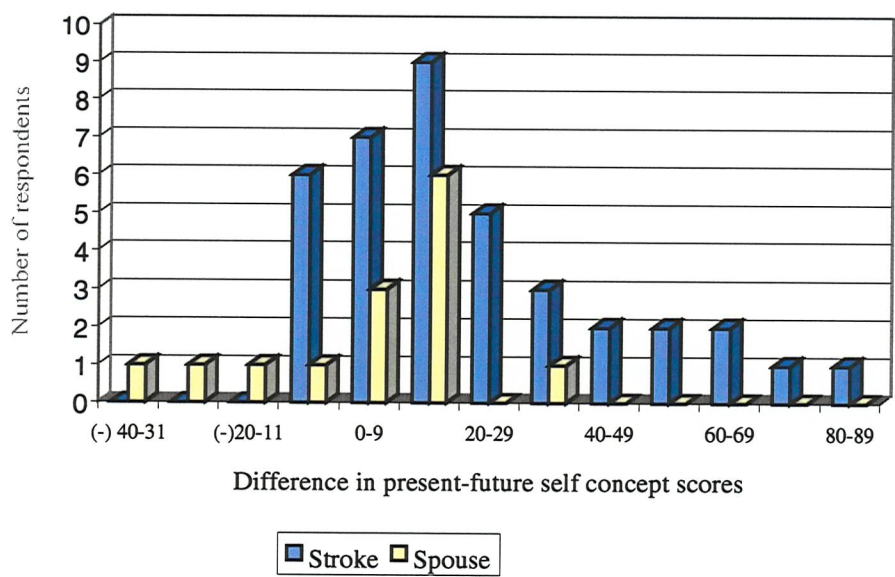


Figure 7.10 shows the difference in past and present total self-concept scores at baseline for both the stroke respondent and spouse group. As there were 20 scales with a possible score of 1 to 7, the minimum total score was 20 (20x1) and the maximum total score was 140 (20x7) for each respondent. As expected, the majority of differences were negative, (the present scores were lower than the past scores). The negative scores ranged from 0 to (-) 74, demonstrating the wide variation in response.

In a previous study, using an age and sex matched comparison group a variation of +10/-10 around zero (i.e. no change) was found on the scale (Hill, 1992). Taking this

into account only two spouses and two stroke respondents reported that they saw themselves more positively than they had done in the past. One of the stroke respondents had been finding it difficult to manage alone at home and felt that coming into hospital had improved her situation, the second stroke respondent had a high present self-concept score and no major physical problems, but the reasons for the improvement in perceived self-concept were not clear. One of the spouses had a high present self-concept score, and had scored 6 rather than 7 on several past-self-concept scores. He spoke of the difficulties his wife had experienced with angina, which was now controlled by medication. The second spouse also spoke of the difficulties she had been experiencing with her husbands diabetes which was now under control.

Figure 7.11 Individual variation in perceived present-future self-difference



From [Figure 7.11](#) it can be seen that respondents saw themselves more positively in the future. At baseline three spouses saw themselves less positively in future. They remarked that they did not know what the future held for them and tended to mark the future self-concept scales at midpoint.

The wide variation in responses was also found at six months and one year. The pattern of responses can be seen in [Table 7.17](#). This highlights not only the wide range of the responses but also the sensitivity of the self-concept scale in being able to reflect these changes.

		Baseline	6 months	12 months
stroke	past-present	(-) 74 to (+) 20	(-) 71 to (+) 6	(-) 84 to (+) 7
	present-future	(-) 6 to (+) 84	(-) 7 to (+) 69	(-) 11 to (+) 67
spouse	past-present	(-) 30 to (+) 15	(-) 30 to (+) 5	(-) 45 to (+) 16
	present-future	(-) 34 to (+) 37	(-) 18 to (+) 12	(-) 37 to (+) 12

Table 7.17 Range of perceived self-difference scores

From this analysis it can be seen that there is a wide variation in the degree to which respondents feel they have changed following a stroke. Theoretically it may be expected that the greater the change, the greater the anxiety experienced. This aspect will be discussed in the following section.

7.6 Association between mood and activity level, physical ability and self-concept

As noted in Chapter Two psychological response following stroke is poorly understood, but thought to be related in some degree to physical disability. An analysis was carried out to examine the degree to which physical ability, self-care ability and difference in past and present self-concept (perceived self-difference) contribute to psychological state following stroke. Perceived past-present self-difference was chosen to indicate how much the respondent felt that they had changed following the stroke. The analysis was based on data from the stroke respondent group as the spouse group did not experience changes in physical ability affecting self-care, the self-concept scale used was not sensitive to their particular self changes and the sample size was small.

7.6.1 Examination using scattergrams

The association between mood, and activity, physical improvement and perceived self-difference (i.e. difference in total past-self and total present-self scores) was examined by plotting, for each of the assessment times (i.e. baseline, six months, one year) scattergrams of:

- ° Anxiety against each of the variables, physical ability, activity levels and perceived self difference.
- ° Depression and each of the variables, physical ability, activity levels and perceived self-difference.

The scattergrams can be seen in Appendices 20 to 25.

7.6.2 Correlation coefficients

Spearman rank correlation coefficients (r) were calculated for each assessment time, to summarise the strength of the linear relationship between each pair of variables. This test was used as not all of the variables were normally distributed. The hypothesis that the population correlation coefficient was zero, was tested to determine whether the apparent association between the variables could have arisen by chance.

7.6.2.1 Baseline

The results of the analysis of the variables at baseline can be seen in [Table 7.18](#). Due to the number of correlations the probability level was set at $p \leq 0.001$.

n = 38	Anxiety (HAD)	Depression (HAD)	Physical ability (RMA)	Self-care (N10pt ADL)	Perceived self-difference (SD-SC scale)
Anxiety	1.000				
Depression	0.74 (p = .000)	1.000			
Physical ability	-0.19 (p = .261)	-0.35 (p = .028)	1.000		
Self-care	-0.253 (p = .137)	-0.545 (p = .000)	0.84 (p = .000)	1.000	
Perceived self-difference (SD-SC scale)	0.51 (p = .001)	0.61 (p = .000)	-0.56 (p = .000)	-0.54 (p = .000)	1.000

Key HAD = Hospital Anxiety and Depression scale
 RMA = Rivermead Motor Assessment
 N10pt ADL = Nottingham 10 point ADL scale
 SD-SC scale = Semantic Differential self-concept scale

[Table 7.18](#) [Spearman rank correlation coefficients for variables at baseline](#)

From [Table 7.18](#) is possible to see that as may be expected the depression score had a relatively strong relationship to the anxiety score ($r = 0.74$; $p \leq 0.001$). The perceived self-difference scores were related to both anxiety ($r = 0.51$; $p \leq 0.001$) and depression ($r = 0.61$; $p \leq 0.001$) scores. It was negatively related to the physical ability ($r = -0.56$; $p \leq 0.001$) and self-care ($r = -0.54$; $p \leq 0.001$) scores. The self-care score had a negative relationship with the depression score ($r = -0.55$; $p \leq 0.001$). Self-care was relatively strongly associated with physical ability ($r = 0.84$; $p \leq 0.001$).

7.6.2.2 Six months

The results of the analysis of the variables at six months can be seen in Table 7.19. The relationship between the depression and anxiety scores was still strong ($r = 0.83$; $p \leq 0.001$). The perceived self-difference score was also still relatively strongly related to both the anxiety ($r = 0.74$; $p \leq 0.001$) and depression ($r = 0.72$; $p \leq 0.001$) scores. It was also negatively related to physical ability score ($r = -0.58$; $p \leq 0.001$). The self-care score was still associated with the physical ability score ($r = -0.64$; $p \leq 0.001$). The social/domestic activity score was associated with both the physical ability ($r = 0.66$; $p \leq 0.001$) and self-care ($r = 0.74$; $p \leq 0.001$) scores.

n = 32	Anxiety (HAD)	Depressio n (HAD)	Physical ability (RMA)	Self-care (N10pt ADL)	Social domestic (FAI)	Perceived self-differenc e (SD-SC scale)
Anxiety	1.000					
Depression	0.83 (p = .000)	1.000				
Physical ability	-0.40 (p = .022)	-0.31 (p = .083)	1.000			
Self-care	-0.46 (p = .008)	-0.44 (p = .012)	0.63 (p = .000)	1.000		
Social/domestic *(n= 31)	-0.31 p = .086	-0.26 (p = 0.16)	0.72 (p = .000)	0.75 (p = .000)	1.000	
Perceived self-difference (SD-SC scale)	0.74 (p = .000)	0.72 (p = .000)	-0.58 (p = .000)	-0.49 (p = .004)	-0.48 (p = .006)	1.000

Key HAD = Hospital Anxiety and Depression scale
 RMA = Rivermead Motor Assessment
 N10pt ADL = Nottingham 10 point ADL scale
 FAI = Frenchay Activities Index
 SD-SC scale = Semantic Differential self-concept scale

Table 7.19 Correlation coefficients for variables at six months

7.6.2.3 One year

The results of the analysis of the variables at one year can be seen in [Table 7.20](#).

n = 30	Anxiety (HAD)	Depression (HAD)	Physical ability (RMA)	Self-care (N10pt ADL)	Social domestic (FAI)	Perceived self-difference (SD-SC scale)
Anxiety	1.000					
Depression	0.59 (p = .001)	1.000				
Physical ability	-0.42 (p = .021)	-0.34 (p = .069)	1.000			
Self-care	-0.34 (p = .068)	-0.43 (p = .018)	0.64 (p = .000)	1.000		
Social/domestic *(n= 31)	-0.07 (p = .694)	-0.26 (p = 0.163)	0.66 (p = .000)	0.74 (p = .000)	1.000	
Perceived self-difference (SD-SC scale)	0.64 (p = .000)	0.80 (p = .000)	-0.54 (p = .002)	-0.63 (p = .000)	-0.43 (p = .019)	1.000

Key HAD = Hospital Anxiety and Depression scale FAI = Frenchay Activities Index
 RMA = Rivermead Motor Assessment SD-SC scale = Semantic Differential self- concept
 N10pt ADL = Nottingham 10 point ADL scale

Table 7.20 **Correlation coefficients for variables at one year (n=30)**

From [Table 7.20](#) it appears that at one year the relationship between the depression and anxiety scores had weakened ($r = 0.59$; $p \leq 0.001$). The difference in past-present self-concept score was not as strongly related to anxiety ($r = 0.64$; $p \leq 0.001$), although was increasingly strongly related to the depression score ($r = 0.80$; $p \leq 0.001$). Although no longer related to the physical ability score, it was negatively related to the self-care score ($r = -0.63$; $p \leq 0.001$). The self-care score itself was still associated with the physical ability score ($r = 0.64$; $p \leq 0.001$), but was no longer related to the depression score. The social/domestic activity score was still associated with both the physical ability ($r = 0.65$; $p \leq 0.001$) and self-care ($r = 0.64$; $p \leq 0.001$) scores.

At each assessment time, the association between mood and physical ability did not reach significance and so the null hypothesis (no.10), that there is no association between mood and physical ability, could be supported. The association between mood and self-care activity only reached significance at baseline and so the null

hypothesis (no.11), that there is no association between mood and activity levels, could only be rejected at baseline. The association between perceived difference in self-concept and mood reached significance at all assessment times and so the null hypothesis (no.12), that there is no association between mood and perceived difference in self-concept, could be rejected.

7.6.3 Multiple regression analysis

Within rehabilitation research mood change following stroke is understood in terms of physical limitation affecting everyday activities. Within this thesis a different conceptual starting point has been proposed; which is that mood is related to the degree to which a person perceives their self-concept and identity to have changed. In order to compare these two starting points a multiple regression analysis was carried out to assess the degree to which perceived change in self-concept could predict mood scores, taking physical and task oriented indices into account.

For the analysis, the dependent variable was taken to be either anxiety or depression and the independent variables considered for the equation were the assessments of physical ability, self-care, social and domestic activity, and perceived self-difference. The independent variables were added into the regression equation in two stages or blocks, as shown in Table 7.21.

Block	Variables	Aim
1	Rivermead Motor Assessment Nottingham 10 point ADL scale Frenchay Activities Index	To assess the ability of the physical task oriented variables alone to predict either the anxiety or depression scores
2	Perceived self-difference Semantic Differential self-concept scale	To assess how perceived changes in self-concept are related to either of the anxiety or depression scores, taking the physical and task oriented scores into account.

Table 7.21 Blocks of variables added into the regression equation

When the first block is added, the equation to describe the ‘best-fit’ linear relationship between these variables and mood is estimated. When the second block is introduced,

it is added into the final equation produced by analysis of the previous block, to see if this estimation can be improved.

At baseline the analysis was carried out using either depression or anxiety as the dependent variable. The analyses were repeated for the six month and one year assessments. The results can be seen in [Table 7.22](#) and [Table 7.23](#).

Assessment	Dependent variable	Independent variables	R ²	F	df	p
Baseline	Anxiety	RMA + NADL	0.05	1.00	2,35	0.376
		RMA + NADL + Dpast-pres. SC	0.29	4.68	3,34	0.007
	Depression	RMA + NADL	0.31	7.94	2,35	0.001
		RMA + NADL + Dpast-pres. SC	0.56	14.5	3,34	0.000
Six months	Anxiety	RMA + NADL + FAI	0.28	3.45	3,27	0.030
		RMA + NADL + FAI+ Dpast-pres. SC	0.64	11.6	4,26	0.000
	Depression	RMA + NADL + FAI	0.32	4.2	3,27	0.014
		RMA + NADL + FAI+ Dpast-pres. SC	0.58	9.2	4,26	0.0001
One year	Anxiety	RMA + NADL + FAI	0.15	1.48	3,26	0.241
		RMA + NADL + FAI+ Dpast-pres. SC	0.46	5.39	4,25	0.029
	Depression	RMA + NADL + FAI	0.10	0.98	3,26	0.417
		RMA + NADL + FAI+ Dpast-pres. SC	0.65	11.8	4,25	0.000
Key	RMA =	Rivermead Motor Assessment				
	NADL =	Nottingham 10 point ADL scale				
	FAI =	Frenchay Activities Index				
	Dpast-pres.SC =	perceived self-difference on the Semantic differential self-concept scale				

[Table 7.22](#) Coefficient of determination (R²) of the physical/activity indices and difference in self-concept score with mood indices

The level of significance was set at 0.0025 (0.05²) as two analysis had been carried out on the same data. From [Table 7.22](#) it can be seen that at baseline the combination of the self-care (NADL) and physical (RMA) scores was a poor predictor of the variability in the anxiety score. It was a better predictor of the depression score being able to account for 31% of the variation in this score (F = 7.94, df 2,35, p = 0.001). When the social and domestic score (FAI) was added into the equation at six months and one year, the ability to predict either of the mood scores was still low and did not reach significance. When the perceived self-difference score was added in the second

step it accounted for a further percentage of the variability in the anxiety or depression scores in all cases apart from anxiety at baseline when the test of variance did not reach significance.

The parameters of the second (and final) equations are shown in Table 7.23.

Assessment	Dependent variable	Independent variable	B	SE	t	p
Baseline (n= 38)	Anxiety	RMA	0.25	0.36	0.70	0.488
		NADL	-0.07	0.46	-0.16	.0.872
		Dpast-pres.SC	0.09	0.03	-3.84	0.001
	Depression	RMA	0.39	0.27	1.46	0.152
		NADL	-0.74	0.33	-2.20	0.034
		Dpast-pres.SC	0.09	0.02	-4.40	0.0001
Six months (n= 32)	Anxiety	RMA	-0.14	0.29	-0.46	0.647
		NADL	-0.55	0.46	-1.19	0.245
		FAI	0.08	.0.07	1.21	0.236
		Dpast-pres.SC	0.15	0.03	-5.13	0.0000
	Depression	RMA	0.66	0.30	0.22	0.829
		NADL	-1.07	0.48	-2.25	0.0329
		FAI	0.08	0.07	1.22	0.234
		Dpast-pres.SC	0.12	0.03	-4.09	0.0004
One year (n= 30)	Anxiety	RMA	-0.22	0.42	-0.51	0.617
		NADL	0.18	0.72	0.25	0.802
		FAI	0.12	0.09	1.42	0.167
		Dpast-pres.SC	0.12	0.03	-3.84	0.0007
	Depression	RMA	0.33	0.27	1.21	0.236
		NADL	0.40	0.46	0.88	0.389
		FAI	-0.02	0.05	-0.40	0.6890
		Dpast-pres.SC	0.13	0.02	-6.316	0.0000

Key	RMA = Rivermead Motor Assessment
	B = Regression coefficient
	NADL = Nottingham 10 point ADL scale
	SE = standard error
	FAI = Frenchay Activities Index
	Dpast-pres.SC = perceived self-difference on Semantic Differential self-concept scale

Table 7.23 Regression analysis of physical/activity indices and perceived self-difference score on mood indices.

From Table 7.23 it can be seen that the perceived self-difference score was related to both the anxiety and depression scores at baseline, six months and one year even when the other physical, task orientated variables are taken into account.

7.7 Discussion

7.7.1 Description of the sample

The respondents could be considered to be at the more 'able' end of the spectrum of those who are discharged from hospital following a stroke, due to the nature of the exclusion criteria. None of the respondents had a previous disability or severe communication, perceptual or cognitive problems and they all returned to their own home. The mean number of weeks spent in hospital was nine weeks, although there was a wide individual variation (range 2-30 weeks). At baseline 53% of the group were female, the percentage not changing significantly over the time of the study. This reflects the trends in incidence rates reported in the literature (Wolf, 1990; Hedley, 1994). The group had a mean age of 72 years (range 46-88 years). Again this is representative of the prevalent age range of people following stroke (Dale, 1988). Stroke affects an older population and it would be expected that only around 10% of the stroke population to be aged 50 or under (Hedley, 1994).

7.7.2 Physical and task-orientated changes in the stroke respondent group

The respondents in the stroke group showed wide variation in physical ability at baseline, from those who could only sit when supported to those who could walk easily. There was significant improvement in physical ability during the study, the majority of improvement occurring in the first six months. This early improvement has been described in previous studies. Wade and Langton Hewer (1987) following up 976 people from a population based register found that only 27% of the patients could walk within one week of stroke, but at six months 85% were independent, although only 25% regained normal speed ambulation. Lindmark and Hamrin (1995) in a five year follow up study of a hospital based group found that the physical abilities of the 177 stroke survivor group improved significantly in the first year. These abilities were maintained, but with a slight decrease over time.

The self-care ability of the stroke respondent group also improved over time but seemed to have stabilised by six months. By this time at least half of the respondents were completely self-caring apart from being able to use the bath independently. This was found by Wilkinson, Wolfe, Warburton et al (1996) in a five year follow-up

community sample of residents in SE London below 75 years of age who had had their first ever stroke. Of those that needed help, the activity of daily living that most people (49%) reported needing help with was bathing. Improvement in self-care skills has been reported in previous studies. Wade and Langton Hewer (1987) found that total dependence in self-care decreased from 58% in the first week to 9% at six months post stroke. As in the present study most improvement is found to have occurred within the first few months of stroke. Lindmark and Hamrin (1995) found that most improvement occurred in the first three months and was then maintained for up to a year after the stroke. Visser-Meily, De Witte, Geerts et al (1994) studying a hospital population of 63 patients living at home, found no significant differences between six months and one year in physical ability and self-care skills, and concluded that no functional recovery occurs after six months.

One limitation in the present and the previous studies is that the self-care assessments may have a ceiling effect and so once the majority of respondents reach a maximum score, no change is noted. Also, the assessment may not be sensitive enough to detect subtle improvement in physical ability or self-care skills. Keeping these issues in mind, it can still be seen that the present and previous studies show that most gross motor ability and basic self-care ability improvement occurs within the first few months of stroke.

Although there was improvement in self-care, the overall social and domestic activity levels of the group were low, as has been reported in previous studies (Sjogren 1982; Greveson and James 1991; Jongbloed and Morgan 1991; Corr and Bayer 1992, Young and Forster 1996). Although within the present study there was wide variation in the levels of activity no respondent achieved a maximum score on the Frenchay Activity Index. The levels of activity did not appear to improve from six months to one year. Greveson, Gray, French et al (1991) studying 82 stroke survivors for up to three years, 62 of whom lived at home, found that restriction of activity was common and only 42% of those at home regularly went out of the house.

7.7.3 Mood change following stroke

At baseline, 39% and 31% of the stroke respondents could be classified as borderline or possible cases of anxiety and depression respectively. The mood levels did not change significantly over time. These results support previous research which suggests that a small but significant number of people experience psychological difficulties following a stroke. Although depression is a widely researched area in stroke rehabilitation there is considerable variance in reported rates of depression from 5-11% (House, Dennis, Mogridge et al, 1991) to 50% (Starkstein and Robinson, 1989). These differences are due to different definitions of depression, measuring instruments, populations sampled and time of assessment. The findings from the present study support two recent studies. Wilkinson, Wolfe, Warburton et al (1996) in their five year follow-up of a community sample found that of the 96 stroke respondents who completed the Hospital Anxiety and Depression scale 32% and 37% and had scores classifying them as borderline or possible cases of anxiety and depression respectively. Similar mood disorder levels were found by Dijkerman, Wood and Langton Hewer (1996) who carried out a cross-sectional study of 57 stroke respondents who had been discharged from a rehabilitation unit one to two years previously. They found that 37% and 40% of respondents had scores classifying them as borderline or possible cases of anxiety and depression respectively. The slightly more negative mood levels found in this study may be explained by the higher number of severely disabled people within the group.

At baseline 79% and 42% of spouses could be classified as borderline or possible cases of anxiety and depression respectively. Although this decreased to 54% and 30% by one year, there was no statistically significant difference over time. The lack of statistical significance may have been due to the small sample size. The wide variation in anxiety scores at baseline (range 3-17) and one year (range 2-16) demonstrate the wide individual variation in psychological distress reported by spouses, and suggests that certain spouses are deeply affected at baseline and still distressed at one year.

The emotional and social difficulties experienced by relatives have been reported for many years (Labi, Philips and Gresham, 1980; Kettle and Chamberlain, 1989; Greveson, Gray, French et al, 1991; Evans, Conies, Bishop, et al 1994). Anderson, Linto and Stewart-Wynne (1995) in a study of 84 caregivers, including mainly spouses and but also children found that the most frequent changes reported were emotional ill health (79%), disruption in social activities (79%) and leisure time (44%). They found that 44% and 30% of the relatives could be classified as experiencing borderline or possible cases of anxiety and depression respectively. Wilkinson, Wolfe Warburton et al (1996) in their five year study found that of the 37 caregivers (spouses and children) who completed the Hospital Anxiety and Depression scale, 32% and 16% of the relatives could be classified as experiencing borderline or possible cases of anxiety and depression respectively. From the present and previous studies it can be concluded that high levels of anxiety and depression can be found in a small but significant number of spouses following stroke.

7.7.4 Self-concept following stroke

The stroke respondents perceived that their identity had changed following their stroke. At baseline there was a significant difference between past-self and present-self scores, and also present-self and future-self scores. The respondents rated present constructs of self more negatively in the present and expected them to improve again over the following six months. This pattern was maintained at six months and one year. There has been little research using the Semantic Differential self-concept scale and so only limited comparisons can be made. The findings of the present study support those of a previous study (Hill, 1992) which was a cross-sectional study of 26 people with stroke up to two years following their stroke. There were significant differences between past-self and present-self scores and respondents saw their present-self in a more negative way in all but one of the constructs. Future-self scores were not obtained.

Researchers working with respondents following head injury, a similar although not necessarily directly comparable client group, have found a similar pattern (Tyerman and Humphrey, 1984; Wright and Telford, 1996). This client group is similar in that

onset is sudden, and people often experience physical disability, but different in that there is a higher incidence of cognitive difficulties affecting emotion, memory and the control of behaviour. Tyerman and Humphrey (1984) studied 25 young adults who were attending two medical rehabilitation centres an average of seven months (range 2-15 months) following a severe head injury. As in the present study they found that the respondents rated their present self as more negative than their past self. The differences were found to be significant on all but three of the 20 adjective pairs. As in the present study the ratings of future self relative to present self revealed that significant positive change was anticipated over the next year for all but two constructs; having confidence and being friendly. This pattern was also found by Wright and Telford (1996) who administered the SD self-concept scale to 36 head injured people who had been admitted to hospital; six months after their injury. They found a significant difference in the construct ratings of past and present self and present and future self. Again respondents rated present constructs of self-concept more negatively in the present and expected them to improve again in the future. No significant difference were found in a comparison group of 36 people matched for age sex and history of mental health problems.

In the present study there were no significant differences between past-self and future-self ratings at each of the time ratings, suggesting that respondents expected to regain aspects of past-self. This pattern was also found by Tyerman and Humphrey (1984) and Wright and Telford (1996). In the present study this pattern was found at baseline, six months and one year, suggesting the long-term existence of this psychological state. Although the sample size was small, this finding was supported by the work of Wright and Telford (1996) who followed up their respondents for three years and found that a similar pattern was reported by the remaining 15 respondents.

A study of the profile of the SD self-concept scale as well as the total score was carried out. In a previous study of 26 people up to two years following a stroke (Hill, 1992) respondents appeared to describe how although their 'active' self was greatly affected their 'social' self was intact. They still described themselves as friendly, caring and co-operative; their 'personable self' appeared to be the same. Their 'active

self' appeared to be affected. Most people saw themselves as more bored, inactive, dissatisfied, helpless and dependent than prior to their stroke. A similar profile was obtained in the present study. Tyerman and Humphrey (1984) found following head injury that the only constructs which did not change were those which could be described as part of a 'personable self' being caring, talkative and friendly. It may be suggested that respondents felt that they could only present themselves as sociable within the interview situation, but within the present study certain individuals did rate themselves at the negative end of these scales, and so this cannot necessarily account for the findings. In the present study at one year respondents 'social selves' still appeared to remain intact, whereas their 'active self' was still an issue, respondents describing themselves as inactive and dependent. Although respondents had improved physically over time, and their 'social self' appeared to be intact, it appeared that issues related with their 'active self' prevented them from not being able to make the most of these attributes as shown by their low scores on the social and domestic activity scale, the Frenchay Activity Index.

Using the SD self-concept scale spouses reported very little change in perceived self-concept. They reported that they perceived themselves to be as social and as active as they were before the stroke. Three main differences were found. At baseline spouses described themselves as more worried; this trend continued up to one year post discharge. By one year spouses also described themselves as more worried in the past and future. Worry appeared to be engulfing them. At six months spouses reported that they perceived themselves to be more bored and unhappy following their spouses stroke. By one year spouses still reported that they were bored and were also described themselves as more unco-operative. The use of the SD self-concept scale with this group is discussed further in [Section 7.8](#).

7.7.5 Associations between mood and activity levels, physical ability and self-concept

There was wide individual variation in perceived self-difference (difference between past-self and present-self) scores. It is interesting to consider how perceived self-difference may be related to mood scores. It may be expected that the greater the

perceived self-difference, the greater the anxiety or depression. Comparisons were made between baseline mood, physical, self-care ability and perceived self-difference scores. It was found that self-care was associated with anxiety, depression and physical ability. Within a hospital situation the correlations between these variables may be expected as it may be assumed that the people who were less able to care for themselves would be more anxious or depressed. Parikh, Lipsey, Robinson et al (1987) studying 86 inpatients following stroke also found that severe impairment in functional physical activity was associated with severe depression. In hospital, perceived self-difference was associated with anxiety and depression, physical ability and self-care.

By six months only the perceived self-difference score was correlated with either of the mood scores. The self-care score was linked with the physical ability and social and domestic score but was not related to mood. It appeared that there was a 'separation' of physical ability and mood. The relationship between mood and physical ability has received considerable attention from rehabilitation researchers and a clear consensus still has not been reached. Feibel and Springer (1982) in a study of 91 patients up to six months post stroke found that 26% were depressed and that there was no relationship with activities of daily living ability. Completely physically independent patients were depressed as frequently as physically dependent patients. Robinson and Price (1982) found that there was no correlation between depression and activities of daily living in 30 patients who were randomly selected for in-depth assessment from a group of 103 patients who were attending clinic, from 6 months to 15 years following stroke. Hochstenbach, Donders, Mulder et al (1996) studied 165 respondents who had been admitted to hospital following stroke within the previous five years. They found that there were significant differences in physical functioning but not psychosocial functioning when they compared those who had returned home directly and those who attended for further rehabilitation before going home. They concluded that functional recovery measures which are limited to physical function per se are not accurate predictors of psychosocial functioning after stroke.

Other studies have reported a significant relationship between depression and activity of daily living (Starkstein, Cohen, Fedoroff et al, 1990), however they reported that the clinical strength of the relationship between the two variables was low. Parikh, Lipsey, Robinson et al (1987) found a significant association between depression and impairment in ADL which peaked at 6 months and thereafter fell, but remained significant at 1 and 2 years post stroke. They suggested, based on a previous study looking at acute onset to delayed onset depression (Robinson, Lipsey, Rao et al 1986), that impairment did not provoke reactive psychological depression but that severe depression affected rehabilitation and sustained severe impairment. The complexity of the relationship can be seen by these results, which varied in the indices used, patient groups and times of assessment. It may be that there are different types of relationships between mood and ability in different groups, such as those who have no physical or cognitive disability, those with either some physical and cognitive disability and those who have severe physical or cognitive difficulties. By studying all these groups as if they were homogeneous the picture appears to remain unclear.

In the present study at one year only the perceived self-difference score was correlated with either of the mood scores. As there was little change in physical or self-care activity after six months similar correlations with mood may have been expected. Wright and Telford (1996) found a significant correlation between perceived self-change and mood as assessed using GHQ-12 scores at one year. They found that increased distress was associated with greater discrepancy between past self and present self. This was not found to be the case for a control group matched for age, sex, history of mental health problems.

From the literature it appears that physical and self care ability as assessed by present indicators are not good predictors of mood. Perceived difference in self-concept appears to be more closely related to mood. This was also found in the present study. From the regression analysis it was found that perceived self-difference was a good predictor of both anxiety and depression scores at all assessment times even when the physical and self-care scores were taken into account.

7.8 Assessment of the usefulness of the Semantic Differential self-concept scale

During this study the practicality of using the SD self-concept scale as a tool for clinicians or researchers in large scale research was assessed. Formal assessment of validity or reliability was not attempted.

The scale appeared to be suitable for use as it was completed within three minutes, and the respondents were happy and able to complete it. The scale could be used as a basis for discussion during clinical work. It appeared to be sensitive indicated by the wide variation in individual scores. There was a wide range of scores for all of the adjective pairs in the stroke respondent group. All of the scales were marked along their length (i.e. 1-7) apart from one - attractive-unattractive; respondents remarked that they did not know where to place their mark and tended to mark it in the middle (i.e. 4). Tyerman and Humphrey (1984) did not find this when working with respondents following a Head Injury, suggesting that it was a more useful construct for that group. The scale provides ordinal data allowing statistical analysis and data from scales can be demonstrated clearly giving greater impact with others not familiar with research i.e. some clinicians, patients and families.

Spouses were asked to complete the self-concept scale to test its face validity. It did not appear to be sensitive to their life changes. The only change that was noted was that they were more bored and worried. This scale was designed for use by respondents following a physical trauma and did not appear to discriminate between the differing aspects of change which were important for relatives following a stroke such as being responsible and being impulsive, which have been identified in previous chapters. In order to be of use with spouses the scale needs further development with larger sample sizes including constructs which are more sensitive to changes in spouses lives.

7.9 Conclusion

The present study group could be considered to be the successes of rehabilitation, they had no severe communication, cognitive or medical problems and they all returned home. Although they experienced most of their physical and self-care improvement

within the first six months, there was no change in their levels of anxiety and depression over the length of the study. The group reported that they saw themselves differently following their stroke. They saw themselves in a more negative light in the present when compared to their past self, prior to the stroke, but expected to improve in the future. This pattern in past, present and future self-concept was found at all of the three assessment times. One year following their stroke, respondents still felt a deep dissociation with their past but were expecting to regain aspects of past self in the future. The psychological processes related to stroke appear to be long-term and continuing at least up to one year following stroke.

In this study mood was strongly related to perceived self-difference even when physical and self-care activity scores were taken into account. It appears that change in identity and self-concept is a more adequate conceptual model than looking at physical and task oriented ability when trying to understand mood change following stroke. Bronstein (1991) in a review of depression, physical ability and psychosocial adaptation, noted

the dichotomy that exists between physical recovery and resumption of previous lifestyles is puzzling. Many stroke victims can carry out the tasks and functions necessary to resume activities and roles they previously enjoyed, but are not doing so (Bronstein 1991, p1011).

The study of identity and self, encompassing the meaning of stroke in bodily and social terms within the persons life course may give further clues to solve this puzzle.

7.10 Critical evaluation of the method used

Due to theoretical interest in focusing on 'first time' strokes, a specific sample from the stroke population was chosen. This resulted in findings that were not generalisable to the total stroke population. By focusing on a hospital rather than a community population certain people were excluded. There is a small but significant number of people who are not admitted to hospital, such as those with minor physical difficulties and those which their family feel they could manage at home. These people may experience perceptual or communication problems. Theoretically it may be expected that these groups would also experience changes in identity (Rice, 1992). Also due to

the nature of the research stroke respondents with severe communication problems were not included. Future studies including respondents who have little physical disability, or groups with aphasia and difficulty in communication would contribute to a wider understanding of identity change following stroke. Parr, Byng Gilin et al (1997) speech and language therapists, have carried out work with a small group of respondents with aphasia, who are able to communicate about their life following stroke, and their work suggested that identity change was an issue for their respondents.

The findings are only relevant to understanding identity change up to one year following discharge from hospital. It would be expected that life changes may well occur beyond one year following discharge (Hochstenbach, Donders, Mulder et al, 1996). It would have been beneficial to have followed up for a longer period but this was not possible within the time restrictions of the study.

Ideally, a comparison group would have been included to determine whether self-concept varied over time regardless of experience of stroke. Research suggests that self-concept is relatively stable over time (Marsh, 1990). In a previous study using an age and sex matched comparison group, Hill (1992) suggested that this was the case when using the SD self-concept scale and so a comparison group was not considered to be essential. This view was supported by the work of Wright and Telford (1996) who studied self-concept following minor head injury. They used a control group of 36 people matched for age, sex, marital status, socio-economic group and mental health history and found that there were no statistically significant changes in the past present and future self-concept profiles assessed using the SD self-concept scale.

The strength of the design in being prospective and longitudinal brought methodological disadvantages. The difficulty in recruiting from a clinical stroke population resulted in a small sample size. The longitudinal nature of the study also meant that difficulties with attrition were a possibility, although the attrition rates were only 16% and 6% at six months and one year respectively. The sample size affected

the possible statistical analysis. Due to the small sample size of the spouse group, only descriptive statistics could be used with confidence, as inferential statistics would have been affected by the size of the group. Both descriptive and inferential statistics could be used with the stroke respondent group, but due to the low numbers the possibility of one individual score affecting results was increased. This led to the possibility of sampling errors, such as Type II errors where the null hypothesis that there was no change was accepted even when change did exist.

The design also made it difficult to decide on the most appropriate inferential statistical test to apply. When comparing changes over time the size of the stroke respondent groups was reduced from 38 to 30. It was decided that it would be more appropriate to use a matched rather than unmatched statistical test, but this meant that the analysis was limited to 30 individuals within the sample and not all the available data was used.

CHAPTER EIGHT

Discussion

8.1 Introduction

Within this thesis two discursive approaches to life following a stroke have been compared. A narrative life history approach has been explored in order to challenge and develop what could be termed the ‘traditional’ rehabilitative approach. In comparing these two approaches it should be noted that discourses not only ‘tell a story’, but reinforce social norms and impose a moral framework which is used to guide action.

Traditional approaches focus on the material aspect of stroke. The focus is an individual’s body and rehabilitation practice is linked to the performance of that body. By using a life narrative approach the perspective is broadened; discursive as well as material practice are considered not only as an appropriate focus for the rehabilitation researcher but also for the clinician. Approaching rehabilitation in terms of life narratives, gives the opportunity to understand the respondent’s life situation in different ways, allowing different and potentially more creative clinical responses.

Within this study respondents were encouraged to talk about their lives, and the place of the stroke within it. The perspective of respondents has been privileged over that of health professionals. This gave access to discourses about practical and psychological issues not usually available to researchers using traditional approaches. The details of these issues have been described in previous chapters, allowing the opportunity to discuss wider issues within the present chapter. By comparing the ‘traditional’ rehabilitation discourse with descriptions given by respondents in this study, it is possible to highlight differences between the discourses. These suggest new avenues of research and highlight opportunities for rehabilitation professionals to work differently in the future. A theme which appears to run through the comparison is one of autonomy. Brisenden (1986) described how the aim for people with chronic disability is to regain autonomy and the ability to control their own life. This appears

to be a fundamental issue within stroke rehabilitation research. This chapter will be divided into four sections for discussion; these are: the theoretical implications of the research, potential avenues of research, possible practical implications within rehabilitation practice, and a final summary.

8.2 Theoretical implications of the research

Several aspects of rehabilitation discourse supported by ‘traditional’ research, were challenged by evidence from the present study. These aspects included discourses about the body, spouses, the individual, and disability. Each of these aspects will be discussed in turn. Although each aspect is discussed separately for ease of presentation; it is recognised that the discourses are closely linked.

8.2.1 Discourse about the body following stroke

Within the present research the physical and task oriented skills as measured by the standardised assessments did not improve after six months, supporting the work of traditional researchers (Wade and Langton Hewer, 1987; Lindmark and Hamrin, 1995). Using the ‘traditional’ approach which focuses on the gross aspects of bodily improvement, recovery is seen to be reached by six months. However, in the present research, stroke respondents described a fundamental change in identity, and a split between self and their physical and social body at least up to one year following stroke. ‘Recovery’ or change was still occurring at least up to one year post-stroke, it was not complete at six months. Using a life narrative approach, the complex process of ‘recovery’ can be seen as one which has a long time span, perhaps lasting for several years.

By exploring the body in discursive as well as material terms, psychological aspects of recovery come to the fore. ‘Traditional’ approaches, by focusing on the material bodily abilities of their respondents, do not support a framework for understanding the psychological impact of acquired chronic disability. In the present research, psychological aspects were highlighted; for example stroke respondents described their self-body split, and both stroke respondents and spouses described their anxiety at not being able to create a coherent future. A life narrative approach provides a

framework within which psychological aspects of acquired chronic disability can begin to be researched. It opens up the opportunity for further research to answer such questions as: how long do respondents experience this split?, does self-body integration ever occur? and if so how is it achieved? The work of Carpenter (1994), who interviewed ten subjects three to five years post spinal cord injury who described their lives as 'back on track'; gives some insight into possible fields of inquiry. Respondents described the importance of regaining a coherent sense of self. They spoke of the confusion resulting from the perceived lack of connection between their internal self, the person they knew themselves to be from their accumulated life history and experience; and their external self. They described that an important part of their recovery was to be able to 'tune into' or re-establish a language with their physical body, and to redefine 'disability' which helped them to re-establish links with their social body. Redefining 'disability' will be discussed in [Section 8.2.4](#). Links between anxiety and individual life goals will be discussed in [Section 8.2.3](#)

Using the 'traditional' approach improvement is context free, it is a characteristic of the person and can be measured on a universal scale. From the present research it can be seen that the split between self and physical social body was situation dependent; ability was often determined by social norms expected within differing environments. Often respondents could manage within their own home, but found it difficult to act within the wider community. This experience was highlighted by Cant (1997) when describing his loss of confidence when considering his return to work following a stroke.

I had not been conscious of losing it [confidence], but in the period since my stroke it 'leaked away'. I had become very well adapted to living in an institutional environment and had not experienced many of those small day to day cues that keep you informed that you are an okay 'normal' person. Now my unconscious was dominated by a 'disability outlook' and a fear of failure in the 'real' world. This was nobodies fault. Merely an inevitable consequence of institutionalisation. (Cant 1997, p303)

This challenges the notion that ability can be seen in terms of an existential absolute. As highlighted by Williams and Wood (1988), ability is not an attribute of the individual person, but based on detailed self-interpretations built out of multiple social

relationships and negotiations within different environments. Using a life narrative approach, attention is directed towards the material and discursive relationships experienced by individuals rather than their individual physical abilities.

‘Traditional’ rehabilitation research is carried out by professionals who define recovery; the views of respondents are rarely considered. Using the traditional approach professionals are defined as the ‘experts’ and so control the rehabilitation process. From the present study, it can be seen that the respondents described how they had entered a new world, with new rules, which they needed to learn in order to manage the rest of their lives. Several of the respondents in the present study reported how once they were home and not receiving daily rehabilitation they did not know how best to proceed because they did not know what the ‘next stage’ was. They were waiting to be told by their therapist. It appeared that the respondents in some sense had become passive recipients dependent on rehabilitation care rather than building their own expertise in learning how to manage their new life. Doolittle (1992) highlighted the pervasive nature of the ‘traditional’ rehabilitation discourse; once rehabilitation services were withdrawn several of her respondents reported that they believed they had ‘come as far as they could’ and that further improvement in their life was not possible.

Within the ‘traditional’ rehabilitation discourse; as the focus is the body which is not going to change a great deal after six months; views of possibilities in the future often appear to be limited. This was described by a respondent following a car accident (Rolland, 1994).

I fought it like hell for a while, but I just couldn’t make my body do what I wanted it to do. When I finally let go, I became a different person I noticed possibilities I was blind to before. It may sound odd, but I feel healthier now than I did before my accident.

(Rolland 1994, p 329)

By diverting his attention from his material body the respondent was able to consider wider possibilities for his future. From the present research it appeared that the focus of respondents’ recovery was the achievement of life goals, rather than bodily improvement alone. Respondents spoke of being able to walk their dogs, drive their

cars, go on holiday, or return to a hobby such as fishing. Several researchers have highlighted how respondents had different goals from, and higher aspirations than, rehabilitation practitioners (Carpenter, 1994; Doolittle 1992; Folden, 1994 Klein 1996). In those studies respondents described how they had 'proved them [professionals] wrong' in achieving their own personal goals.

By focusing on present bodily ability, 'traditional' rehabilitation researchers appear to be defining recovery in a limited way. From a life narrative perspective, recovery is defined in terms of the achievement of life goals, brought about by the re-unity of self and the physical and social body.

8.2.2 Discourse about spouses following stroke

Within the 'traditional' rehabilitation discourse, the focus is the body and hence the individual with stroke. Within this discourse if other people exist, they only exist in relation to that individual. Using the traditional approach spouses are seen as carers, and are not considered in their own right, as individuals.

Traditional research defines spouses' situations in terms of the physical and emotional limitations placed on them by physically caring for their partner. From the present research it can be seen that spouses had many changes in their lives, which had an impact on their psychological state and mental health which were not necessarily related to the physical care of their partner. An all-pervasive sense of responsibility seemed to be the dominating feature in spouses' lives irrespective of the amount of physical care given. The limitations of 'traditional' research can be seen in that, as the focus is on physical caring, spouses are only researched once their partner had been at home and been 'cared-for' for a period of time. In the present study it can be seen that spouses took responsibility for their partners lives from the time they were admitted to hospital and still being 'cared-for' by hospital staff. Although spouses were worried and were planning for the future, they did not get any formal support from rehabilitation staff. Nolan, Keady and Grant (1995) highlighted the role of anticipatory care; and the need for information so that speculation could become informed anticipation.

From a life narrative perspective, spouses' situations are seen in terms of being able to achieve their own life goals. By taking a life span perspective, the psychological impact linked with age-related lifestyles becomes clearer. In the present study younger spouses had few peers with which to share narratives of disability and at the same time had a future of many years ahead of them with no clear life goals. The psychological impact of loss of life goals is discussed further in [Section 8.2.3](#). Also using this approach it is possible to see that life changes following stroke are not always negative, as several spouses reported being able to return to their usual routines in time.

The present research highlighted how stroke respondents and their spouses appeared to be entering different worlds and focusing on different issues. Stroke respondents appeared to be responsible for the improvement in their bodies, and their spouses appeared to be responsible for everything else. It could be argued that this position is supported by the centrality of the individual and their body within 'traditional' rehabilitative discourse. Rolland (1994) suggested that defining 'the problem' as the exclusive domain of the patient, skewed couples' relationships, causing a fundamental split. He suggested that introducing the concept of 'our' problem, provided:

an opportunity for couples to explore cultural and multigenerational beliefs about the rights and privileges of ill and well partners (Rolland 1994, p331).

In 'traditional' rehabilitation research spouses are not considered as equal partners within the rehabilitation process; they do not get equal attention. When spouses are defined in terms of 'carers'; the inherent imbalance in responsibility between the couple is reinforced. From a life narrative perspective both partners enter a new world with new rules which have to be learned, both have life goals to be achieved. Research is needed which explores how both partners within a couple work towards achieving their life goals. Rolland (1994) began to explore this area; and suggested that it is only possible to maintain a balanced mutual relationship, and establish clear illness boundaries, if the couple undertake certain tasks. These include understanding the illness and its psychosocial demands over time, exploring beliefs about the cause

of the disorder and what can affect its course, exploring how to live with threatened loss, and recognition of the personal and relationship priorities of each partner.

8.2.3 Discourse about the individual following stroke

In the ‘traditional’ rehabilitation discourse individuals do not exist, as evidence for intervention is based on group data. From the present study, it can be seen that each person not only has shared issues to face following stroke, but also has individual issues related to the meaning of stroke within their life and their own life goals.

In sharing their narratives, the respondents control their self-presentation to a greater degree than is possible when relying on their ‘broken’ bodies. Oberg (1996) highlighted that, by using biographical narratives, it is possible for an audience to look beyond the present physical body and for the person to have control over how they present themselves. This may allow the narrator to maintain valued aspects of their identity. For example in the case study, Mr Finch was able to portray himself as an adventurous sea-farer, and man of the open-road in his trucks, even though at the time he could barely stand unaided. By focusing on biography rather than the present physical body, the life narrative approach brings ‘the person’ back into rehabilitation research.

Psychosocial difficulties have long been recognised within stroke research (Ebrahim, Barer and Nouri 1987; Anderson, Linto and Stewart-Wynne, 1995). Researchers using the traditional approach have no clear theoretical approach which links the body with psychological changes following stroke. A life narrative approach gives a useful framework which could be used to explore the psychological impact of a stroke. As discussed in Chapter Three coherent life stories create a sense of purpose and meaning. Battista and Almond (1973) concluded that when individuals state that their lives are meaningful this implies that (a) they have a framework from which they can see their life within some perspective or context and have derived a set of life goals, and (b) they see themselves as having fulfilled or as being in the process of fulfilling their framework or life goals. People have a purpose when they can incorporate their actions moving towards a goal in their life story. From the quantitative study it could

be seen that the levels of anxiety and depression reported by the stroke respondents were associated with the degree to which they felt that their present self was different from their previous self, irrespective of physical or self-care ability. Anxiety and depression appeared to be related to disruption of self and hence their life story (as following a life narrative perspective, self is defined by life story). It appeared that some respondents had lost their normal framework for viewing their life and they were frustrated in trying to achieve their life goals.

8.2.4 Discourse about disability following stroke

Using the 'traditional' discourse where the focus is the body and disability is defined by tasks an individual can no longer perform; disability is seen in terms of deficit and loss. Disability is linked with limitations, problems and difficulties experienced by a particular person which are not usually experienced by an able-bodied person. This supports the negative view that disabled people are in some way 'less than' or different from other people.

The inherently negative view of disability can be challenged when disability is seen in the context of life narratives. In the present research, Mr Finch described changes in his life following his stroke in both a positive and negative way. Although he tired easily, could not do his DIY jobs, and could only drive for short periods; he was able to continue some of the 'normal' activities of his life, such as taking his dogs for a walk, and pottering around in his shed. His relationship with his wife had improved and they had a laugh together, and he enjoyed life. The stroke was not necessarily a purely negative event.

Carpenter (1994) described how long-term survivors of spinal cord injury did not categorise the event as positive or negative but emphasised the change from an existing steady state, interpreting the event within the context of their own lives. For these respondents part of their recovery was to re-define disability. It was not defined as a personal trait, but as a set of physical characteristics that influenced function. This meant that the respondents just had to do things differently in order to achieve their goals. Researchers described how respondents gradually saw themselves as

‘experts’ and re-created their own definitions of disability moving away from inadequacy or limitation, and began to understand themselves in terms of their possibilities instead of their deficits (Doolittle, 1994; Carpenter, 1994).

Within the ‘traditional’ rehabilitative discourse, people following stroke are observed and labelled. They are seen as specific sorts of people with specific problems, linked very closely with their medical condition. This separates patients from rehabilitation professionals and they are seen as ‘other’ (Susko, 1994). When narratives are shared, the story invites the audience to enter into the lived world of the ‘other’, and to identify with the narrator. This invites the audience to participate in the narrator’s world and challenges them to consider “how would I have behaved?” or “what would I have done?”. By approaching the world of the narrator through life narratives, their situation is seen as one of a shared human experience. They are seen as an ordinary person within an extra-ordinary situation, rather than being seen as ‘other’. This creates the opportunity for further understanding and a more creative response focused within the narrator’s life context.

Within the present study several respondents described how they felt isolated from their peers, and how they found it beneficial to talk with other disabled people, ‘further down the line’, who helped them redefine their disability. Bonnie Klein (1996) spoke of her experience following her stroke:

I did not know how to live in a world which is not disability friendly. I had no role models or friends with disabilities and the rehabilitation professionals had not exposed me to any disability organisations I had the feeling I was the first person in the world to be going through what I was going through. The turning point for my acceptance of my disability was finding peers and role models, getting to know people who shared my problems and who were going ahead and making their life with their disability. (Klein 1996, p 24)

From a life narrative perspective people enter new worlds with new rules. The experts about those rules are those who have experienced and overcome them in order to achieve their life goals i.e. other disabled people. People following stroke can, not only learn a great deal about their new world, but also build a more positive sense of

future possibilities and their own identity, by sharing the social norms and values inherent in the narratives of these experts.

8.3 Further research

The use of a life narrative framework opens up many avenues for further research as very little is known in this area. The respondents in this study described their experiences, but these may not be shared with others with different social or cultural backgrounds. Further research is needed into cultural differences, and groups, such as those who are already disabled prior to their stroke, those with minimal physical disabilities, or those with severe physical disabilities which necessitate nursing home care. Two of the younger spouses independently suggested that I should speak with their dependent children, as they felt that their lives had also changed following the stroke. The effect of acquired physical disability on the identities of children needs further consideration within rehabilitation research.

Research is needed into individuals' experiences, to explore how respondents resolve the self-body split, and how some respondents make the transition into their new world, with little apparent psychological distress. Further research is needed with those respondents who do not experience mood changes to try and understand how they create a new useful framework for their lives, and how they re-create life goals. Research is needed into the experience of spouses and how couples re-negotiate their relationships in order to achieve their life goals. Longer term research is needed to explore psychological processes beyond the year following hospital discharge.

Studies are needed to understand the social, material and discursive practices which influence the experience of disability following stroke. Areas of research could be factors which influence the self-body split, the position of spouses, and the role of rehabilitation practitioners.

Finally, but by no means least, it is necessary to study the practicality of introducing this alternative approach within the healthcare system. A development of a spouse self-concept indicator could be the first step in this direction.

8.4 Implications for stroke rehabilitation practice

Often rehabilitation services are withdrawn within a few months of hospital discharge as evidence from the 'traditional' approach, which focuses on bodily improvement, suggests that recovery is complete by this time (Doolittle, 1992; Hedley, 1994). From the present study it can be seen that 'recovery' or change was still occurring at least up to one year post-stroke. This suggests that rehabilitative monitoring should be extended for at least one year following stroke, possibly longer, even though input does not necessarily need to be intensive.

Using the 'traditional' approach improvement is context free. As the focus is the body, the person can learn new skills and new movements in an environment separate from their everyday life. This supports the work of rehabilitation professionals who work with individuals in hospital departments as outpatients. From the present study it could be seen that ability was context specific, suggesting that there is a need to consider social issues within rehabilitation programmes. Programmes could include the exploration of many different physical and social environments and the focus for intervention could be the meaning of physical and social relationships, rather than the physical ability of the individual.

Using the 'traditional' approach spouses only exist as carers. As they do not exist in their own right, it appears that it is only valid to spend time with the spouse if the intervention is focused on the partner's body and abilities. Carers may be shown how to care for their partner such as how to lift, dress or feed them or counselled as to how to fit caring into their usual routine. Using a life narrative approach which recognises that spouses also have their own life goals to achieve, attention can be focused equally on both partners within the couple. Spouses could be supported and helped to explore their new worlds, by being encouraged to seek information, and being allowed to focus on their own as well as their partner's situation. By working with the couple rather than the stroke respondent in isolation, the couple can be encouraged to approach the tasks necessary in order to maintain a balanced mutual relationship.

The information gained in this study was based on three 45 minute interviews. Within this short time period it was possible to understand the complexity of the respondents personal life situation. This is not necessarily a time consuming or complex approach. New roles for rehabilitation professionals could be developed where life goals, rather than just bodily improvement and tasks, are the focus of rehabilitation. By sharing life stories, it is possible to identify life goals which could be the basis for intervention. The use of life narratives gives rehabilitation professionals an opportunity to act discursively as well as materially. Gergen (1996) described how the definition of a problem can be altered by exploring and creating alternative life narratives. Although a person may be physically static, the number of possible ways of acting and responding can be increased by exploring the meaning of the stroke for the person and exploring different options for future life.

Rather than focusing on teaching specific context free skills, rehabilitation professionals could support people as they explore their new world and the new rules of the physical and social world, focusing on the meaning of stroke within the person's own life story and their life goals. There may be opportunities to work in different ways, in new environments, discursively as well as materially, working alongside other disabled experts, when helping people to build up their own expertise in their new world so that they can achieve their life goals.

The aim of rehabilitation could be to help people learn the skills of exploration, so that they build the confidence to play, experiment in and explore their new world. Kirmayer (1992) discussed how the use of metaphor can unpack new meanings and open up a situation. From the present research, I would like to suggest a new metaphor for the rehabilitation professional; that of a sherpa; as they know the territory, having met many people following stroke, and can act as a guide. This leaves the people themselves to be the adventurers, or explorers.

8.5 Summary

When people have an acute illness, they turn to the medical profession, who focus on the body of their patient and through treatment, cure them. During this treatment phase life is 'put on hold' until things are back to normal again. When people have a chronic illness, they turn to health professionals, but by definition they cannot be cured. In this case, life cannot be 'put on hold' until they get back to normal, because it never will. In chronic illness, the focus of intervention has to move away from the body and towards life goals. This was eloquently put by Cassell (1992) when describing a case study of a patient with cancer:

For her doctors and herself her survival, thwarting the cancer will become the major focus of treatment and every day, every goal will be in relation to cancer rather than her own life purposes. If on the other hand, the treatment of her cancer is in the service of her purposes, then her aims and not the cancer become the primary object of treatment.disease and death are not the enemy, the true enemy is the loss of central purpose (Cassell 1992, p246).

The present study has focused on life following a stroke, but I feel that the life narrative perspective could be applied to a wider clinical group - those experiencing an acquired chronic physical disability. By focusing on life goals rather than present bodily ability, a theoretical framework is created which brings 'the person' back into the centre of rehabilitation research. By defining recovery in terms of life goals, ideas about recovery are expanded, and become more wide ranging and creative. The process becomes longer-term, it can be seen in a more positive light as a transformation rather than a loss, and others, whose life goals have been affected (such as spouses), can be included as a legitimate focus of research.

Most importantly, this framework highlights the psychological implications of acquired chronic physical disability. Where the self and identity are the focus of research, acquired chronic physical disability is seen as a fundamental challenge to an individual's future existence.

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Rehabilitation Research unit address

Stroke / life history study

Dear Dr,

I am a research occupational therapist undertaking a PhD funded by the Department of Health studentship scheme. I am carrying out a study to explore the experiences of patients and their close relatives following stroke. Great emphasis is placed on physical and self-care aspects of recovery in stroke research and although these aspects are important, I am focusing on peoples' experience and recent life history as psychological experience following stroke is poorly understood.

I aim to carry out an in-depth study of twenty people and their relatives who have been admitted to hospital following stroke. My research will involve carrying out interviews with both partners. These interviews will be carried out in a private place in hospital and follow up interviews will take place at home at six months and one year. I am an experienced occupational therapist and used to carrying out interviews and working within a ward environment. Please see the abbreviated research proposal overleaf for further details.

I hope to interview people admitted to the wards at Southampton General Hospital from July 1995. I have approval from the Southampton Ethics Committee. I would be very grateful if you would consent to your patients taking part in this study. Please return the tear-off slip below. If you would like to meet to discuss the study further or have any queries please do not hesitate to contact me either at the Rehabilitation Research Unit or the Psychology Department, Southampton University.

Thank-you for your help.

Yours sincerely,

Caroline Hill
Research occupational therapist

Stroke / Life history study

[] I **Agree** to my patients being considered for the stroke study

[] I **do not** agree to my patients being considered for the stroke study.

Signature Name (block capitals)

Please return to: Caroline Hill, Rehabilitation Research Unit, Level C, West Wing,
Southampton General Hospital

An exploration of the narrative life histories of people and relatives following stroke

Caroline Hill M.Sc. Research Occupational Therapist
Rehabilitation Research Unit /Psychology Dept
University of Southampton

Aim

The aim of this study is to explore the processes involved in stroke recovery as defined by the person following stroke and a close relative in the context of their life histories. This approach will be used to broaden the view of recovery from the present focus where it tends to be defined by professionals using objective measures such as physical improvement and self care processes alone. Data will be collected which can provide further insight into psychological experience following stroke and this study will provide evidence for the usefulness of a narrative life history approach in future therapeutic interventions.

Method

Process

Twenty people following stroke who have been admitted to hospital and their close relative will be asked to take part in a prospective longitudinal study of recovery. Both partners of ten couples will be asked to take part in separate in-depth taped interviews describing their recent life histories and views of the future. These interviews will be carried out in a hospital setting following stroke and at home at six months and one year. They will be carried out in private and last no longer than 30 minutes.

All twenty couples will be asked to complete a set of measures including physical and activity indices, a mood and a self-concept scale; again within the hospital setting, at six months and one year. The measures will take no longer than 30 minutes.

Inclusion criteria

Only people who a) have a relative living at home, b) are at least one week following stroke, c) who are medically stable, d) with no severe cognitive or communication problems will be approached and asked to take part in the study.

Ethical considerations

Both patient's and relatives permission will be sought before entry into the study. Their rights of confidentiality and withdrawal at any time will be made clear throughout the study. People will not be approached until ethical approval is granted by the Southampton Ethics Committee and their consultant has given their permission.

Analysis

The interviews will be taped, transcribed and analysed using narrative analysis techniques to determine recovery as viewed by the person and to discover which aspects of peoples lives are important in stroke recovery. Data from the narrative analysis, the standardised measures, mood and self-concept scores will be compared to determine the relationship between these aspects.

Supervisors Dr Sheila Payne, Psychology Department, University of Southampton
 Professor CD Ward, Rehabilitation Research Unit, Univ. of Nottingham
Advisor Professor L McLellan, Rehabilitation Research Unit, Univ. Southampton

For further information contact at:

Rehabilitation Research Unit, Level C West Wing, Southampton General Hospital Tremona Rd
or Psychology Department, University of Southampton Highfield, Southampton
Tel: 01703- 702084 (messages), E-mail: csh@soton.ac.uk

Personal experience of stroke

A research project by

Caroline Hill M.Sc.
Research fellow
Rehabilitation Research Unit
Southampton General Hospital
Tel 01722-744608
or 01703- 796466

Why is this project needed?

Hospital staff are very experienced at treating people following stroke. Their training is based on the work of many professionals before them and services are guided by this work.

However, little is known about stroke from a personal perspective. It would be of great benefit to know how people feel following stroke, so that future services can be structured to meet individuals' needs.

Why am I being asked about this project?

All people who have been admitted to the wards at Southampton General Hospital and the Royal Southants Hospital following a stroke and who are able to take part in an interview are being invited to take part in this project.

Who is involved ?

All the research will be carried out by Caroline Hill who has three years research experience. She will carry out all the interviews .

What is involved ?

Caroline Hill will visit you and your close relative separately while you are in hospital. The visit will be at your convenience and should last no longer than one hour. This will be reduced

if you are feeling tired.

The visit will be carried out in private and all information will be kept by the researcher in the strictest confidence. Any information will be used for this project only and will not affect your care in any way.

Most of the visit will consist of an interview about your life and how it has been affected by stroke. You will be asked to complete a short questionnaire. Your relative will also be asked to have an interview. Previous participants have found the interviews quite beneficial

You will be able to withdraw from the study at any time. Withdrawal will not affect future treatment in any way.

What do I do now ?

Discuss the project with any of the staff on the ward, family or friends. Make a note of any questions you may have overleaf.

Caroline will visit again in the next couple of days to see if you would like to become involved in the project.

Thank-you for your time

Rehabilitation Research unit address

Stroke / Life history study
CONSENT FORM

Dear Mr ,

I am a research fellow in the rehabilitation research unit, Southampton General Hospital. I am carrying out a study into peoples' experiences following a stroke. At present little is known about this subject from a personal perspective. It would be of great benefit to know how people feel, so that services can be structured to meet individuals' needs.

All people who have been have been admitted to the medical wards at Southampton General Hospital or the Royal Southants Hospital following a stroke and who are able to take part in an interview are being approached to take part in this study. You are invited to take part in the study that will involve me visiting you and your close relative while you are in hospital. I will visit you

- 1) On the ward to carry out simple screening tests and a short questionnaires on how you are feeling and how you see yourself . This should take about 20 minutes.
- 2) In a private quiet room to carry out an interview. I am interested in your life story and how it has been affected by your stroke. The interview will be taped which is usual practice to allow further analysis. The tapes will be completely confidential and anonymous. They will be stored in a safe secure place and used for this project only. At the completion of the project they will be erased. Previous participants have found these sort of interviews quite beneficial. The interview will take about 45 minutes.
- 3) At home at six months and one year, where the questionnaire and interview will be repeated.

All information will be kept in the strictest confidence and measures taken to ensure that your anonymity is maintained. All information will be used for this study only. You may withdraw from the study at any time. Withdrawal will not affect future treatment in any way.

I agree to undertake the interview as outlined above and explained to me by the research worker.

signed _____ (subject) Date _____

Name (in capitals) _____

I confirm that I have explained the nature of the study to the subject.

signed _____ (researcher) Date _____

Rehabilitation Research unit address

Stroke / Life history study
CONSENT FORM

Dear Mrs,

I am a research fellow in the rehabilitation research unit, Southampton General Hospital. I am carrying out a study into peoples' experiences following a stroke. At present little is known about this subject from a personal perspective. It would be of great benefit to know how people feel, so that services can be structured to meet individuals' needs.

All people who have been admitted to the medical wards at Southampton General Hospital or the Royal Southants Hospital following a stroke and who are able to take part in an interview are being approached to take part in this study. You are invited to take part in the study that will involve me visiting you while you are in hospital. I will visit you on the ward to carry out simple screening tests and a short questionnaire on how you are feeling and how you see yourself. This should take no longer than 30 minutes. Also, I would like to visit you at home at six months and one year, when we will repeat the questionnaire.

All information will be kept in the strictest confidence and measures taken to ensure that your anonymity is maintained. All information will be used for this study only. You may withdraw from the study at any time. Withdrawal will not affect future treatment in any way.

I agree to undertake the interview as outlined above and explained to me by the research worker.

signed _____ (subject) Date _____

Name (in capitals) _____

I confirm that I have explained the nature of the study to the subject.

signed _____ Date _____

Rehabilitation Research unit address

Stroke / Life history study

CONSENT FORM

Dear Mrs,

I am a research fellow in the rehabilitation research unit, Southampton General Hospital. I am carrying out a study into peoples' experiences following a stroke. At present little is known about this subject from a personal perspective and even less is known about relatives' experiences following stroke. It would be of great benefit to know how people feel, so that services can be structured to meet individuals' needs.

All people who have been have been admitted to the medical wards at Southampton General Hospital and the Royal Southants Hospital following a stroke and who are able to take part in an interview are being approached to take part in this study. You are invited to take part in the study that will involve me visiting you and your relative in hospital after six months at home and one year at home.

The visits will be at your convenience and should last no longer than one hour. Most of the visit will consist of an interview about your life and how this has been affected by your relative's stroke. The interviews will be taped which is normal practice to allow further analysis. The tapes will be completely confidential and anonymous. They will be stored in a secure place and used for this project only . At the completion of the project they will be erased. The visit will end with a short questionnaire on how you are feeling and how you see yourself.

All information will be kept in the strictest confidence and measures taken to ensure that your anonymity is maintained. All information will be used for this study only. You may withdraw from the study at any time. Withdrawal will not affect future treatment in any way.

I agree to undertake the interview as outlined above and explained to me by the research worker.

signed _____ (subject) Date _____

Name (in capitals) _____

I confirm that I have explained the nature of the study to the subject.

signed _____ (research worker) Date _____

Rehabilitation Research unit address

Stroke / Life history study

CONSENT FORM

Dear Mrs,

I am a research fellow in the rehabilitation research unit, Southampton General Hospital. I am carrying out a study into peoples' experiences following a stroke. At present little is known about this subject from a personal perspective and even less is known about relatives' experiences following stroke. It would be of great benefit to know how people feel, so that services can be structured to meet individuals' needs.

All people who have been have been admitted to the medical wards at Southampton General Hospital or Royal Southants Hospital following a stroke and who are able to take part in an interview are being approached to take part in this study. You are invited to take part in the study that will involve me visiting you and your relative in hospital after six months at home and one year at home.

The visits will be at your convenience and should last no longer than half an hour. The interview will consist of completing a short questionnaire on how you are feeling and how you see yourself.

All information will be kept in the strictest confidence and measures taken to ensure that your anonymity is maintained. All information will be used for this study only. You may withdraw from the study at any time. Withdrawal will not affect future treatment in any way.

I agree to undertake the interview as outlined above and explained to me by the research worker.

signed _____ (subject) Date _____

Name (in capitals) _____

I confirm that I have explained the nature of the study to the subject.

signed _____ (research worker) Date _____

Questions asked, (not necessarily in this order)

- Can you tell me about your life from childhood onwards (family, work, leisure)?
- Can you tell me what happened when you (your partner) had the stroke ?
- What is it like for you (while your partner is) in hospital?
- Have you noticed any improvements in your situation since the stroke ?
- How do you see the future ?
- Is there anything else which you feel is important which we haven't discussed yet?

Questions asked, (not necessarily in this order)

- What was it like for you (while your partner was) in hospital?
- What was it like when you (your partner) first came home from hospital?
- What is a typical day for you ?
- Have you noticed any improvements in your situation since the stroke?
- How do you see the future ?
- Is there anything else which you feel is important which we haven't discussed yet?

Questions asked, (not necessarily in this order)

- Can you tell me whats been happening to you since you (your partner) first had the stroke
- What was it like when you (your partner) first came home from hospital?
- What is a typical day for you ?
- Have you noticed any improvements in your situation since the stroke ?
- How do you see the future ?
- Is there anything else which you feel is important which we haven't discussed yet?

Stroke and Life History Research.

Personal details

Reference Number _____ Date of meeting _____

Group [] patient [] relative

Demographic information

Sex [] Male [] Female

DOB _____ Age _____ years

Relationship to relative _____

Own ethnic description _____

Last employment _____

Accommodation/ownership _____

Stroke related information

Date of stroke _____

Date admitted hospital _____

Date discharged hospital _____

Weakness [] Left [] Right [] N/A

Left Inattention score _____

MMTS score _____

Communication problems [] Yes [] No

Frenchay Aphasia score _____

Addn info

Other chronic medical conditions [] Yes [] No

If yes, please give details _____

Appendix 10 (continued)
Stroke respondent questionnaire

Frenchay Aphasia Screening Test score sheet

to be used if respondent has been previously noted to be aphasic

Number _____

Date _____

Comprehension

a) River scene

- 1 [] Point to a boat
- 2 [] Point to the tallest tree
- 3 [] Point to the man and point to the dog
- 4 [] Point to the mans' left leg and then to the canoe
- 5 [] Before pointing to a duck near the bridge show me the middle hill

b) Shapes

- 1 [] Point to the square
- 2 [] Point to the cone
- 3 [] Point to the oblong and the square
- 4 [] Point to the square, the cone and the semicircle
- 5 [] Point to the one that looks like a pyramid and the one that looks like a segment of orange

Reading

- 1 [] Point to the dog
- 2 [] Show me the bridge
- 3 [] Point to the man standing in the barge
- 4 [] Touch the bottom of the paper and then the top of it
- 5 [] Touch the left hand corner of the paper

AEIKNRUNPOEFBDHRSCOXRPGEAEIKNRUNPB
BDHEUWSTRFHEAFRTOLRJEMOEBDHEUWSTRT
NOSRVXTPEBDHPTSIJFLRFENONOSRVXTPE
GLPTYTRIBEDMRGKEDLPQFZRXLGLPTYTRIBS
HMEBGRDEINRSVLERFGOSEHCBRRHMEBGRDEI

E & R

Appendix 10 (continued)

Stroke respondent questionnaire Letter cancellation test (from Wilson, Cockburn and Halligan, 1987)

Appendix 10 (continued)
Stroke respondent questionnaire

Mini-Mental State Examination

Cognitive assessment

- | Reference number | | Date |
|------------------|---|---|
| 1. | What is the | <input type="checkbox"/> year <input type="checkbox"/> season
<input type="checkbox"/> date <input type="checkbox"/> day
<input type="checkbox"/> month |
| 2. | Where are we | <input type="checkbox"/> country <input type="checkbox"/> county
<input type="checkbox"/> town/city <input type="checkbox"/> road
<input type="checkbox"/> house number |
| 3. | Name three objects: Ball, Flag and Tree, taking one second to say each. then ask the patient to name all three after you have said them.
<input type="checkbox"/> Give one point for each correct answer

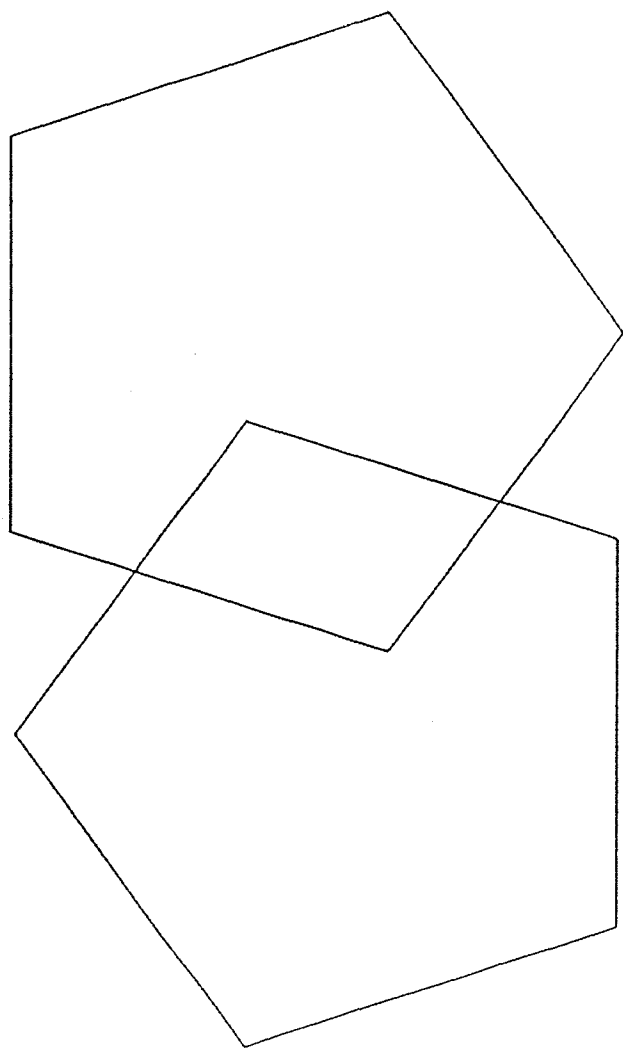
Repeat the answers until the patient learns all three
<input type="checkbox"/> Number of attempts | |
| 4. | <input type="checkbox"/> Spell WORLD backwards | |
| 5. | <input type="checkbox"/> Ask for the names of the three objects learned in question 3
Give one point for each correct answer | |
| 6. | Point to a pencil and a watch.
<input type="checkbox"/> Have the patient name them as you point | |
| 7. | <input type="checkbox"/> Have the patient repeat "No ifs, ands or butts." | |
| 8. | Have the patient follow a three stage command
<input type="checkbox"/> "Take the paper in your right hand. Fold the paper in half. Put the paper on the floor." | |
| 9. | <input type="checkbox"/> Have the patient read and obey the following CLOSE YOUR EYES | |
| 10. | <input type="checkbox"/> Have the patient write a sentence of his own choice. (the sentence should have a subject, object and makes sense. (Ignore spelling when scoring) | |
| 11. | <input type="checkbox"/> Enlarge the design printed to 5cm per side and have the patient copy it .
(Give one point if all sides and angles are preserved and if the intersecting sides form a quadrangle.) | |

CLOSE YOUR EYES

Appendix 10 (continued)
Stroke respondent questionnaire Mini-Mental State Examination (continued)

Appendix 10 (continued)
Stroke respondent questionnaire

Mini-Mental State Examination (continued)



Appendix 10 (continued)
Stroke respondent questionnaire

Rivermead Motor Assessment (Gross motor subscale)

	Yes	No
Sit unsupported		
Lying to sitting on side of bed		
Sitting to standing		
Transfer from wheelchair to chair towards unaffected side		
Transfer from wheelchair to chair towards affected side		
Walk 10m indoors with an aid		
Climb stairs independently		
Walk 10m indoors without an aid		
Walk 10m pick up beanbag from floor, turn and carry back		
Walk outside 40m		
Walk up and down 4 steps		
Run 10 m		
Hop on affected leg 5 times on the spot		
Total score		

Affected arm rating

	Yes	No
No movement		
Movement -for stabilising only - no hand movement		
Movement - gross grip only		
Movement -some use individual fingers		
Clumsy normal use of hand		
Normal use of hand		

Nottingham 10 Point Scale of Activities of Daily Living

	Yes	No
Can the person carry out independently		
Drink from a cup		
Eat		
Wash face and hands		
Transfer from bed to chair		
Walk or use wheelchair indoors		
Toilet		
Undress		
Dress		
Make a hot drink		
Get in and out of bath		
Total score		

Reference no. _____

Date _____

Appendix 10 (continued)

Stroke respondent questionnaire

THE FRENCHAY ACTIVITIES INDEX

Reference number _____

Date _____

In the last three months

Code

☐ Preparing main meals

0 = Never

☐ Washing up

1 = Less than 1/week

2 = 1-2 times a week

3 = Most days

☐ Washing clothes

0 = Never

☐ Light housework(dusting)

1 = 1-2 times over last 3 months

2 = 3-12 times over last 3 months

3 = At least once a week

☐ Heavy housework(making beds)

☐ Local shopping

☐ Social outings

☐ Walking outside > 15 mins

☐ Actively pursuing hobby(knitting,sport)

☐ Driving a car/bus travel

In the last six months

☐ Outings/car rides (pleasure)

0 = Never

1 = 1-2 times in 3 months

2 = 3-12 times in 3 months

3 = At least weekly

☐ Gardening

0 = Never

☐ Household/car maintenance

1 = Light(weeding/small repairs)

2 = Moderate(pruning/upkeep)

3 = All necessary

☐ Reading books(not magazines/papers)

0 = None

1 = 1 in 6 months

2 = Less than 1 a fortnight

3 = Over 1 a fortnight

☐ Gainful work (paid)

0 = None

1 = Up to 10 hours/week

2 = 10-30 hours/week

3 = Over 30 hours/week

From Holbrook and Skilbeck, 1983

Appendix 10 (continued)

Stroke respondent questionnaire

Hospital Anxiety and Depression Scale

This questionnaire is designed to help the researcher understand how you feel. Read each item and place a firm tick in the box which comes opposite the reply which comes closest to how you have been feeling over the past week. Do not take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought out response.

Reference Number _____

Date _____

I feel tense or 'wound up'

- ☐ Most of the time
- ☐ A lot of the time
- ☐ Time to time
- ☐ Not at all

I still enjoy the things I used to enjoy

- ☐ Definitely as much
- ☐ Not quite so much
- ☐ Only a little
- ☐ Hardly at all

I get a sort of feeling as if something awful is about to happen

- ☐ Very definitely / quite badly
- ☐ Yes, but not too badly
- ☐ A little but it doesn't worry me
- ☐ Not at all

I can laugh and see the funny side of things

- ☐ As much as I always could
- ☐ Not so much now
- ☐ Definitely not so much now
- ☐ Not at all

Worrying thoughts go through my mind

- ☐ A great deal of the time
- ☐ A lot of the time
- ☐ From time to time/not too often
- ☐ Only occasionally

I feel cheerful

- ☐ Not at all
- ☐ Not often
- ☐ Sometimes
- ☐ Most of the time

I can sit at ease and feel relaxed

- ☐ Definitely
- ☐ Usually
- ☐ Not often
- ☐ Not at all

I feel as if I am slowed down

- ☐ Nearly all the time
- ☐ Very often
- ☐ Sometimes
- ☐ Not at all

I get a sort of frightened feeling like butterflies in the stomach

- ☐ Not at all
- ☐ Occasionally
- ☐ Quite often
- ☐ Very often

I have lost interest in my appearance

- ☐ Definitely
- ☐ I don't take as much care as I should
- ☐ I may not take quite as much care
- ☐ I take just as much care as ever

I feel restless as if I have to be on the move

- ☐ Very much indeed
- ☐ Quite a lot
- ☐ Not very much
- ☐ Not at all

I look forward with enjoyment to things

- ☐ As much as I ever did
- ☐ Rather less than I used to
- ☐ Definitely less than I used to
- ☐ Hardly at all

I get sudden feelings of panic

- ☐ Very often indeed
- ☐ Quite often
- ☐ Not very often
- ☐ Not at all

I can enjoy a good book or radio or TV programme

- ☐ Often
- ☐ Sometimes
- ☐ Not often
- ☐ Very seldom

From: Zigmond and Snaith, 1983 *(font reduced to fit page)

Appendix 10 (continued)
Stroke respondent questionnaire

Past self-concept

Semantic Differential Scale

Reference no. _____ [☒] Before stroke
 [☐] Present
 Date _____ [☐] Future

Most of time	Most of time
Bored [] [] [] [] [] [] []	Interested
Unhappy [] [] [] [] [] [] []	Happy
In control [] [] [] [] [] [] []	Helpless
Worried [] [] [] [] [] [] []	Relaxed
Satisfied [] [] [] [] [] [] []	Dissatisfied
Attractive [] [] [] [] [] [] []	Unattractive
Despondent [] [] [] [] [] [] []	Hopeful
Self-confident [] [] [] [] [] [] []	Lacks confid.
Unstable [] [] [] [] [] [] []	Stable
Of value [] [] [] [] [] [] []	Worthless
Aggressive [] [] [] [] [] [] []	Unaggressive
Calm [] [] [] [] [] [] []	Irritable
Caring [] [] [] [] [] [] []	Unfeeling
Capable [] [] [] [] [] [] []	Incapable
Dependent [] [] [] [] [] [] []	Independent
Inactive [] [] [] [] [] [] []	Active
Co-operative [] [] [] [] [] [] []	Unco-operative
Withdrawn [] [] [] [] [] [] []	Talkative
Friendly [] [] [] [] [] [] []	Unfriendly
Impatient [] [] [] [] [] [] []	Patient

from Tyerman and Humphrey 1984 revised A Tyerman 16.8.91)
 (font reduced to fit page)

Appendix 10 (continued)
Stroke respondent questionnaire

Present self-concept

Semantic Differential Scale

Reference no. _____ [☐] Before stroke
[☒] Present
Date _____ [☐] Future

Most of time	Most of time
Bored [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _]	Interested
Unhappy [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _]	Happy
In control [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _]	Helpless
Worried [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _]	Relaxed
Satisfied [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _]	Dissatisfied
Attractive [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _]	Unattractive
Despondent [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _]	Hopeful
Self-confident [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _]	Lacks confid.
Unstable [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _]	Stable
Of value [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _]	Worthless
Aggressive [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _]	Unaggressive
Calm [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _]	Irritable
Caring [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _]	Unfeeling
Capable [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _]	Incapable
Dependent [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _]	Independent
Inactive [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _]	Active
Co-operative [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _]	Unco-operative
Withdrawn [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _]	Talkative
Friendly [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _]	Unfriendly
Impatient [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _]	Patient

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Appendix 10 (continued)
Stroke respondent questionnaire

Future self-concept

Semantic Differential Scale

Reference no. _____ ☐ Before stroke
☐ Present
Date _____ ☒ Future

Most of time	Most of time
Bored [] [] [] [] [] [] []	Interested
Unhappy [] [] [] [] [] [] []	Happy
In control [] [] [] [] [] [] []	Helpless
Worried [] [] [] [] [] [] []	Relaxed
Satisfied [] [] [] [] [] [] []	Dissatisfied
Attractive [] [] [] [] [] [] []	Unattractive
Despondent [] [] [] [] [] [] []	Hopeful
Self-confident [] [] [] [] [] [] []	Lacks confid.
Unstable [] [] [] [] [] [] []	Stable
Of value [] [] [] [] [] [] []	Worthless
Aggressive [] [] [] [] [] [] []	Unaggressive
Calm [] [] [] [] [] [] []	Irritable
Caring [] [] [] [] [] [] []	Unfeeling
Capable [] [] [] [] [] [] []	Incapable
Dependent [] [] [] [] [] [] []	Independent
Inactive [] [] [] [] [] [] []	Active
Co-operative [] [] [] [] [] [] []	Unco-operative
Withdrawn [] [] [] [] [] [] []	Talkative
Friendly [] [] [] [] [] [] []	Unfriendly
Impatient [] [] [] [] [] [] []	Patient

from Tyerman and Humphrey 1984 revised A Tyerman 16.8.91) (font reduced to fit on page)

Appendix 11 Spouse questionnaire

Stroke and Life history Research.

Personal details

Reference Number _____ Date of meeting _____

Group [] patient [] relative

Demographic information

Sex [] Male [] Female

DOB _____ Age _____ years

Relationship to relative _____

Own ethnic description _____

Last employment _____

Accommodation/ownership _____

Stroke related information

Date of stroke _____ N/A

Date admitted hospital _____ N/A

Date discharged hospital _____ N/A

Weakness [] Left [] Right [✓] N/A

Left Inattention score _____ N/A

MMTS score _____ N/A

Communication problems [] Yes [] No

Frenchay Aphasia score _____ N/A

Addn info

Other chronic medical conditions [] Yes [] No

If yes, please give details _____ N/A

Appendix 11 (continued)
Spouse questionnaire

Hospital Anxiety and Depression Scale

This questionnaire is designed to help the researcher understand how you feel. Read each item and place a firm tick in the box which comes opposite the reply which comes closest to how you have been feeling over the past week. Do not take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought out response.

Reference Number _____

Date _____

I feel tense or 'wound up'

- ☐ Most of the time
- ☐ A lot of the time
- ☐ Time to time
- ☐ Not at all

I still enjoy the things I used to enjoy

- ☐ Definitely as much
- ☐ Not quite so much
- ☐ Only a little
- ☐ Hardly at all

I get a sort of feeling as if something awful is about to happen

- ☐ Very definitely / quite badly
- ☐ Yes, but not too badly
- ☐ A little but it doesn't worry me
- ☐ Not at all

I can laugh and see the funny side of things

- ☐ As much as I always could
- ☐ Not so much now
- ☐ Definitely not so much now
- ☐ Not at all

Worrying thoughts go through my mind

- ☐ A great deal of the time
- ☐ A lot of the time
- ☐ From time to time/not too often
- ☐ Only occasionally

I feel cheerful

- ☐ Not at all
- ☐ Not often
- ☐ Sometimes
- ☐ Most of the time

I can sit at ease and feel relaxed

- ☐ Definitely
- ☐ Usually
- ☐ Not often
- ☐ Not at all

I feel as if I am slowed down

- ☐ Nearly all the time
- ☐ Very often
- ☐ Sometimes
- ☐ Not at all

I get a sort of frightened feeling like butterflies in the stomach

- ☐ Not at all
- ☐ Occasionally
- ☐ Quite often
- ☐ Very often

I have lost interest in my appearance

- ☐ Definitely
- ☐ I don't take as much care as I should
- ☐ I may not take quite as much care
- ☐ I take just as much care as ever

I feel restless as if I have to be on the move

- ☐ Very much indeed
- ☐ Quite a lot
- ☐ Not very much
- ☐ Not at all

I look forward with enjoyment to things

- ☐ As much as I ever did
- ☐ Rather less than I used to
- ☐ Definitely less than I used to
- ☐ Hardly at all

I get sudden feelings of panic

- ☐ Very often indeed
- ☐ Quite often
- ☐ Not very often
- ☐ Not at all

I can enjoy a good book or radio or TV programme

- ☐ Often
- ☐ Sometimes
- ☐ Not often
- ☐ Very seldom

From: Zigmond and Snaith, 1983 *(font reduced to fit page)

Appendix 11 (continued)

Spouse questionnaire

Past self-concept

Semantic Differential Scale

Reference no. _____ [☒] Before stroke
[☐] Present
Date _____ [☐] Future

Most of time		Most of time
Bored [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _]		Interested
Unhappy [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _]		Happy
In control [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _]		Helpless
Worried [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _]		Relaxed
Satisfied [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _]		Dissatisfied
Attractive [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _]		Unattractive
Despondent [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _]		Hopeful
Self-confident [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _]		Lacks confid.
Unstable [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _]		Stable
Of value [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _]		Worthless
Aggressive [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _]		Unaggressive
Calm [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _]		Irritable
Caring [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _]		Unfeeling
Capable [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _]		Incapable
Dependent [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _]		Independent
Inactive [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _]		Active
Co-operative [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _]		Unco-operative
Withdrawn [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _]		Talkative
Friendly [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _]		Unfriendly
Impatient [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _] [_ _ _]		Patient

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Appendix 11 (continued)

Spouse questionnaire

Present self-concept

Semantic Differential Scale

Reference no. _____ [☐] Before stroke
[☒] Present
Date _____ [☐] Future

Most of time		Most of time
Bored	[____] [____] [____] [____] [____] [____] [____]	Interested
Unhappy	[____] [____] [____] [____] [____] [____] [____]	Happy
In control	[____] [____] [____] [____] [____] [____] [____]	Helpless
Worried	[____] [____] [____] [____] [____] [____] [____]	Relaxed
Satisfied	[____] [____] [____] [____] [____] [____] [____]	Dissatisfied
Attractive	[____] [____] [____] [____] [____] [____] [____]	Unattractive
Despondent	[____] [____] [____] [____] [____] [____] [____]	Hopeful
Self-confident	[____] [____] [____] [____] [____] [____] [____]	Lacks confid.
Unstable	[____] [____] [____] [____] [____] [____] [____]	Stable
Of value	[____] [____] [____] [____] [____] [____] [____]	Worthless
Aggressive	[____] [____] [____] [____] [____] [____] [____]	Unaggressive
Calm	[____] [____] [____] [____] [____] [____] [____]	Irritable
Caring	[____] [____] [____] [____] [____] [____] [____]	Unfeeling
Capable	[____] [____] [____] [____] [____] [____] [____]	Incapable
Dependent	[____] [____] [____] [____] [____] [____] [____]	Independent
Inactive	[____] [____] [____] [____] [____] [____] [____]	Active
Co-operative	[____] [____] [____] [____] [____] [____] [____]	Unco-operative
Withdrawn	[____] [____] [____] [____] [____] [____] [____]	Talkative
Friendly	[____] [____] [____] [____] [____] [____] [____]	Unfriendly
Impatient	[____] [____] [____] [____] [____] [____] [____]	Patient

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Appendix 11 (continued)

Spouse questionnaire

Future self-concept

Semantic Differential Scale

Reference no. _____ [☐] Before stroke
[☐] Present
Date _____ [☒] Future

Most of time		Most of time
Bored	[____] [____] [____] [____] [____] [____] [____]	Interested
Unhappy	[____] [____] [____] [____] [____] [____] [____]	Happy
In control	[____] [____] [____] [____] [____] [____] [____]	Helpless
Worried	[____] [____] [____] [____] [____] [____] [____]	Relaxed
Satisfied	[____] [____] [____] [____] [____] [____] [____]	Dissatisfied
Attractive	[____] [____] [____] [____] [____] [____] [____]	Unattractive
Despondent	[____] [____] [____] [____] [____] [____] [____]	Hopeful
Self-confident	[____] [____] [____] [____] [____] [____] [____]	Lacks confid.
Unstable	[____] [____] [____] [____] [____] [____] [____]	Stable
Of value	[____] [____] [____] [____] [____] [____] [____]	Worthless
Aggressive	[____] [____] [____] [____] [____] [____] [____]	Unaggressive
Calm	[____] [____] [____] [____] [____] [____] [____]	Irritable
Caring	[____] [____] [____] [____] [____] [____] [____]	Unfeeling
Capable	[____] [____] [____] [____] [____] [____] [____]	Incapable
Dependent	[____] [____] [____] [____] [____] [____] [____]	Independent
Inactive	[____] [____] [____] [____] [____] [____] [____]	Active
Co-operative	[____] [____] [____] [____] [____] [____] [____]	Unco-operative
Withdrawn	[____] [____] [____] [____] [____] [____] [____]	Talkative
Friendly	[____] [____] [____] [____] [____] [____] [____]	Unfriendly
Impatient	[____] [____] [____] [____] [____] [____] [____]	Patient

from Tyerman and Humphrey 1984 revised A Tyerman 16.8.91) (font reduced to fit page)

12(a) Rivermead Motor Assessment - Gross Function Subscale

- 1) Sit unsupported.
- without holding on, on edge of bed, feet unsupported.
- 2) Lying to sitting on side of bed.
- using any method.
- 3) Sitting to standing.
-may use hands to push up. Must stand up in 15 seconds and stand for 15 seconds, with an aid if necessary.
- 4) Transfer from wheelchair to chair towards unaffected side.
-may use hands.
- 5) Transfer from wheelchair to chair towards affected side.
-may use hands.
- 6) Walk 10 m indoors with an aid.
- any walking aid, No standby help.
- 7) Climb stairs independently.
-any method. May use banister and aid. Must be a full flight of stairs.
- 8) Walk 10m indoors without an aid.
-no standby help, no calliper, splint or walking aid.
- 9) Walk 10 m, pick up beanbag from floor, turn and carry back.
-bend down any way, may use aid to walk if necessary. No standby help. May use either hand to pick up beanbag.
- 10) Walk outside 40 m
-may use walking aid, calliper, or splint. No standby help.
- 11) Walk up and down four steps.
-patient may use an aid if he/she would normally use one, but may not hold onto rail. This is included to test ability to negotiate kerbs or stairs without a rail.
- 12) Run 10 m.
-must be symmetrical.
- 13) Hop on affected leg five times on the spot.
-must hop on ball of foot without stopping to gain balance. No help with arms.

Appendix 12 (continued)
Guidelines for physical and ADL assessments

12(b) Nottingham 10 point ADL scale

- | | |
|-----------------------|---|
| 1) Drink | Ability to drink a hot drink from an ordinary cup without spilling more than an eighth of contents. |
| 2) Eat | Ability to eat a simple meal using any necessary aids. |
| 3) Wash face | Ability to wash face and hands thoroughly at bowl or sink including drying themselves. |
| 4) Transfer bed/chair | Transfer onto a chair with arms from lying on bed. |
| 5) Walk inside | Ability to walk (with/without aids) or propel wheelchair independently on carpeted surface. |
| 6) Toilet | Ability to transport selves to toilet or commode (5+m).
Must include transfers, managing clothes, cleaning themselves and flushing toilet. |
| 7) Undress | Removing day or night clothes Must include socks and shoes. |
| 8) Dress | Ability to put on day clothes, when placed close by. Patient to do all necessary fastenings. |
| 9) Hot drink | Ability to fill and lift kettle, set out cup, prepare and pour out drink and clear up afterwards. |
| 10) In/out bath | Ability to get in and out of a dry bath with or without the use of aids. |

Appendix 12 (continued)

Guidelines for physical and ADL assessments

12(c) Frenchay Activity Index

General

The aim is to record activities that require some initiative from the respondents. It is important to concentrate on the actual frequency of activity, not past performance, potential capacity or future intentions. Any one activity should only be included in one item i.e. gardening cannot score in both item 9 hobbies and item 12 gardening.

Specific items

1. **Preparing a meal** Needs to play a substantial part in any of: organisation and/or preparation and/or cooking of main meal. Not just cooking snacks unless this constitutes a main meal. May include cooking of pre-packed prepared meals.
2. **Washing up** Must do it or share equally e.g. washing, or wiping and putting away; or filling and emptying machine. Not just rinsing an occasional item.
3. **Washing clothes** Organisation and/or doing of washing and/or drying of clothes, whether by washing machine, by hand or at launderette. Not just 'small's'.
4. **Light housework** Dusting, polishing, tidying small objects, tidying duvet on bed, vacuum cleaning exposed areas. Anything heavier requiring strength is included in 5
5. **Heavy housework** All heavier housework, including making beds (changing sheets etc.) cleaning fires and floors, moving chairs etc.
6. **Local shopping** Playing a substantial role in organising and buying shopping, whether small or large amounts. Must go to shops (i.e. not telephone ordering). Not just to push trolley. If regular visit must be to buy three or more items (i.e. not just to collect daily paper).
7. **Social outings** Going out to clubs, church activities, cinema, theatre, drinking, to dinner with friends etc. May be transported there, provided he/she takes an active part once arrived. The common factor is initiative and activity, not travel itself. Includes lunch with relatives.
8. **Walking outdoors** Sustained walking for at least 15 minutes (allowed stops for breath). About one mile. Can include walking to shops if far enough.
9. **Hobbies** Must require some active participation and thought, for example, propagating plants in the house, knitting, painting, games, sport, not just watching games or sport on television.
10. **Car/bus travel** Needs to drive a car (not just be a passenger), or to get to a bus, coach or train and travel on it.
11. **Outings** Coach or rail trips, or car rides to some place outside the immediate locality for pleasure. Not for routine 'social outing' (e.g. going shopping, visiting friends). Must involve some organisation and decision making by the respondent. Excludes trips organised by others (e.g. the hospital) unless respondent can chose whether or not to go. The common factor is travel for pleasure.
12. **Gardening** Gardening outside: light - occasional weeding; moderate - regular weeding, pruning mowing the lawn; heavy - heavy digging and other heavy activities.
13. **Household/car maintenance** Light - repairing small items e.g. china, wiper blade; moderate - some painting decorating, routine car maintenance; heavy - most necessary household /car maintenance /repairs.
14. **Reading books** Must be full length books, not magazines, periodicals or papers.
15. **Gainful work** Work for which respondent is paid; not voluntary work.

Rehabilitation Research Unit address

Dear Mr (and Mrs),

I am writing to thank-you for your help in the stroke /life history project while you were at [X] Hospital and over the recent weeks. Your continuing help with the project is greatly appreciated. I'm sure a great deal of valuable information will emerge from the analysis of all of the sets of data collected so far.

I will visit you (both) again in [month] when we can talk about how things have been going.

As part of the regulations of research I have written to your (Mr X's) GP to let him/her know that you will be taking part in the study over the next year. This is purely a formality and a copy of the letter is enclosed. When you next see Dr [X] he/she may mention that they have received a letter from me.

Again many thanks for your help and I look forward to seeing you both in [month]. If you have any queries or concerns about the project please do not hesitate to contact me on [tel number].

Best wishes,

Caroline Hill
Rehabilitation researcher

Rehabilitation Research Unit address

Stroke\ life history study

Dear Dr ,

I am a rehabilitation researcher undertaking a PhD funded by the Department of Health studentship scheme. I am carrying out a study to explore the experiences of patients and their close relatives following stroke. Great emphasis is placed on physical and self-care aspects of recovery in stroke research and although these aspects are important, I am focusing on peoples' experience and recent life history as psychological experience following stroke is poorly understood.

I am undertaking an in-depth study of twenty people and their relatives who have been admitted to hospital following stroke. My research involves carrying out interviews and/or questionnaires with both partners. These interviews will be carried out in a private place in hospital and follow up interviews/questionnaires will take place at home at six months and one year.

Following approval from the Southampton Ethics committee, permission from their hospital consultant and their consent **Mr and Mrs X, of [home address]** have been admitted into the study. I will be visiting them at home in [month] 1996 and [month] 1997.

If you would like further information about the project or have any comments or queries please do not hesitate to contact me at the address above.

Yours sincerely,

Caroline Hill M.Sc.
Rehabilitation researcher

Transcription 1006 - one year 13th January 1997

C Ok, now this is going to be the last time that I come and see you,
I Yeah.
C so it's really helpful to have an overview
 of um how you got to where you are today.
I Yeah.
C So it's really helpful
 if you can tell me what's been happening to you
 since you first had your stroke
 and went into hospital.
I Yeah.
 Well, since I first had the stroke er
 I was unconscious
C Uh huh.
I and when I come to meself
 and find that I was in hospital
C Hmm.
I I was worried.
C Yeah.
I Because I was helpless
C Uh huh.
I and er the months I was worried
C Right.
I about me health
C Yeah.
I because I never used to be like that.
C Right.
I And bit by bit I'm recovering
C Uh huh.
I because everyday, every night I went to bed
 I used to worry
C Right.
I when am I going to feel better
 and eventually,
 bit by bit
 I'm, I prove that I'm getting a little bit better
C Uh huh.
I because I'd depend on my wife
C Right.
I if I goes out,
C Hmm.
I when I come and want help me undress
C Right.
I and now I'm trying my best.
C Uh huh.

Appendix 15 (continued)

Example of transcription

I I can take me clothes off
C Right.
I put my sleeping clothes on
C Yeah.
I and er (2) I must say it's a big change
from my, when I was, when I just took sick
C Uh huh.
I until now.
C Right.
I I improve a lot.
And er if the feelings continue to be the same
C Uh huh.
I by the end of the year
C Yeap.
I I promise I can walk
and I hope to walk.
C Yeap.
I I'll be better every day,
so er I must say it's a great, great improvement.
C Uh huh.
I Yeah.
C So what was it like when you first came home hospital.
I When I first came home from hospital
I was coward to do anything
C Uh huh.
I because once I fell over
C Oh right.
I and I got a job to get up
C Get your confidence.
I once.
? Once or twice.
C Hmm.
I Bit by bit
I'm getting me confidence back
C Uh huh.
I and when I first left the hospital,
I did know the days different
C (Oh right) yeah.
I because I spent so long in the hospital
that I lost
C (You lost track of things).
I track of the outside world.
C Yes.
I Yes, so it's improving slowly.
C Uh huh.

Analysis of interview**5002 Mr X spouse baseline interview in hospital****Notes**

1) Topics introduced by csh 4 times and Mr X 21 times

From fieldnotes

September Met Mr X in physio at [hospital], waited for room to be ready, went round and started chatting. Mr X quietly spoken. Mr X appeared happy to talk, gave eye contact, but did have arms crossed and legs crossed, but did put hands behind head at one point. Appeared to relax after a while, appeared not used to talking with strangers (health professionals) but seemed very willing to talk. When filling in forms attractive-unattractive didn't know where to put self often when filling in form talked in terms of we rather than I (i.e. interest in appearance it was important to look good for Mrs X so she doesn't worry re me. Talked about how filling in forms made him think about things not really think about a lot. Mentioned that 'don't know if it is going to happen again, they [Drs] can't tell you

Overview of interview

Section	Line no.	Section	Intro by
1	4-52	army	Mr X
2	53-84	work	Mr X
3	85-108	retirement	Mr X
4	108-148	motorbikes	Mr X
5	149-167	retirement	Mr X
6	168-191	motorbikes	Mr X
7	192-265	life document folder	Mr X
8	266-311	model making	Mr X
9	312-382	army	Mr X
10	383-469	being demobbed	Mr X
11	470-519	married life	csh
12	520-542	toolkit	Mr X
13	543-679	stroke story	csh
14	680-710	loss confidence driving	Mr X
15	711-765	time hospital	Mr X
16	766-952	recovery	csh
17	953-1204	future household management	Mr X
18	1205-1271	work	Mr X
19	1272-1296	married life	Mr X
20	1297-1307	garden	Mr X
21	1308-1390	support	Mr X
22	1391-	young outlook	Mr X
23	1555	helping wife back on feet	Mr X
24	1659	important for professionals to know	csh
25	1671	forward planning-layout/access	Mr X

Appendix 16 (continued)
Analysis document
Table 1 General themes for Mr X

Themes	Line no.
<i>army</i>	
well I didn't join the army the army joined me	20
I think the best thing in my life was the day I was called up	26
actually	
army enjoyed it -lots of mechanical things	312
allowed to develop skills	348
see parts world not see otherwise	367
hospital nurses different from ones in the army-innoculations	738
used to iron own shirts in the army	975
 <i>transport/mechanical</i>	
from school to apprentice mechanic	17
motorbike company	39
transport NCO	41
transport engineer looking after all the vehicles	43
worked in motorbike shop for a bit	59
ended up making aeroplanes for vickers	61
cars at ford motor company	68
in retirement makes model motorcycles	
miss my motorcycles-rode up to just after I retired	110
we used to go miles and miles	114
now we use a motor car	120
motorcycle in east africa	139
miss motorbike	175
army teach blokes how to strip down and re-assemble engines	330
not so good after war - cars rationed	425
met wife through somebody met who was also motorbike enthusiast	471
couldn't drive the first month- put me right off	690
must get behind the wheel of a car-turning into an old man or something	698
when I came off my motorbike he [gp] sorted me out then	1124
younger days used to ride fast on big bike	1158
enjoys working in ford's factory- because motor vehicles have	1210
mainly been my life you see one way cars motorbikes or whatever	
aircraft we used to run our engines over eastleigh aerodrome	1247
talk to nieces son in law re motor cars	1446
 enjoys company	
army-all the different people you meet	352
different characters of people	

Appendix 16 (continued)
Analysis document

sorry left army-you miss the people	435
niece- great girl	696
family -three sisters and a brother	464
 <i>active/interested</i>	
we've had quite a lively retirement	105
put all my life in folder -had it all photocopied and pt in order	194
?cos no children?	
had an interesting kind of life	224
collection of motorbike books	254
it gives you an interest , cos if you retire and tyouve got no iterests	266
you'd just shrivel up	
Ive got numerous interests in workshop	270
this keeps me happy	
you've got to interest yourself in whatever you're doing	334
army good see parts world not see otherwise	367
saw things probably wouldnt have seen -nmade your life a bit	375
more interesting	
completely lost when demobbed cos everyone else at wotk	453
a lot of people in those factories.. they turn their brains off wheb	1216
they clock in abnd they turns it on again when they go home	
you've got to raise a certain amount of interest no matter what the	1224
job is	
if youve got anything between your ears you'l interest yourself in	1262
whatever jobs going on	
I couldnt go in a facotry and tun me brain off	1266
I could do that to dsave me life	
wife used to aske waht funny story heard today-chat re work-take	1273
an interest	
we've always interested outrselves in each others jobs	1292
my brother in law he neve rused to tell my sisiter anything	1277
 <i>active/working</i>	
the retired or idle I dont know which	89
dont watch the clock any more	
 <i>good partnership wife</i>	
married 38 years	502
quite a happy marriage	504
we dont fall out	506
whatever she wants-if it possible i'll do itfor her	514
sharing	
wife takes interest in what I do	101
so we work those two things together	103

Appendix 16 (continued)
Analysis document

we've always interested ourselves in one anothers jobs- ...more like a partnership active in helping wife/thinking of wife I often ask her her telephone numer and postcode	1292 775
today I sort f got the fingers on her bad hand movong I think she misses home thats the troble-she gets fed up here all ive got to do is to help her and do whatever I can whateber she wants you know- i'll just lookafter her until shes really on her feet I mean thats all I, yhats what we're married for make sure that you know, make sure she does progress writes all little messages on pad to relate to her when visits - I dont know I might be wrong -but I think if I do that it keeps her mind working broufght in rose bud from teds rose.. I brought it in I thought its a connection goes into physio with wife- it gives her a certain amount of encouragement my big job now is to help [wife] bck on gher feet [sor tout problems] and hopeful [wife] will have a happy life	857 891 959 1062 1071 1315 1343 1378 1558 1928
<i>handyman</i> used to make dolls houses, cots, wardrobes for nieces when children they still keep them I dont know why Ive got all sorts of things to do when she comes out if I cant manufacture it it'll be hard going I've got nearly fifty years of tools so I'll have some equipment to play with when we do things at home I was recycling things long before people started recycling in this world rebuilding greenhouse sat with clipboard and pencil tried to work out what I could do to ease the way of life organising shower organising sliding door in kitchen	276 280 521 524 539 1451 1602 1666 1703 1856
<i>problem solver</i> I can just sit down , find out the problems, and sit down and think how we're going to get over it and er that's the way I'm going to do it	1922

Appendix 16 (continued)
Analysis document

death a possibility

I dont think Ive got many more years on the planet-so Ive got to make the best of what Ive got 1394

young at heart

nieces husband comes and talks re bikes 249
nieces son engineer in Saudi Arabia structural engineer-so we can discuss things together when we get together 308
I dont think you ever grow old 1400
nieces son in law- I can talk to him you know 1418
in Fords happier working with the younger men than men my age 1475
they didn't moan-they saw the lighter side of life 1483
I cant turn myself into a teenager obviously-but part of their lifestyle rubs off on you 1497
D -he's 30 and I get on with him quite easy 1510
brother in law typical Victorians 1520
they live in the dark distant past
they dont understand the things that happen in the world today 1527
if you're going to keep abreast -you got to try and understand it 1538
-got an idea about how computers work cos. I can find out one way or another you've
whatever is invented is going to affect all our lives so you've got to take a certain amount of interest in what it is or why it is 1544
..[sister and husband] they think I'm a bit weird

I suppose people thinks we muddles along.. peoples opinions dont worry me 517

recovery

memory better 800
going up steps 8008

hospital good

took wife back to old ward-they were very kind to her 726
puzzled -they dont loose their tempers or get upset 729
very nice here, very kind 765
I think people have been very good-she's got confidence in the people that's doing the job 855
[GP] they know what they're doing if you go to the doctor you trust him dont you 1113

Appendix 16 (continued)
Analysis document

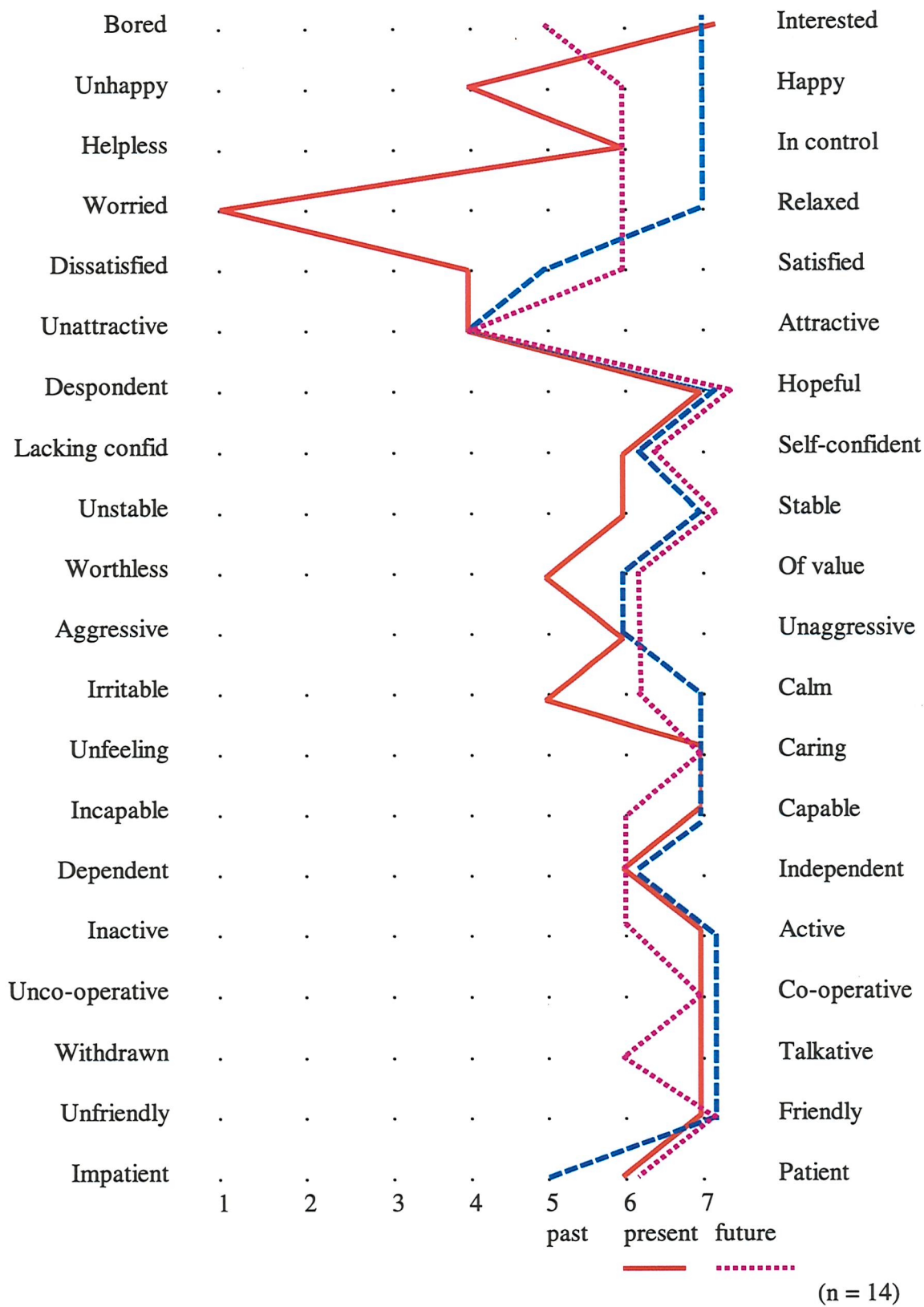
garden

she likes the garden
both enjoy pottering around in the garden
got to try and get the nuts sorted out in the garden-vs. squirrel 1298
brought tin rose bud-well its from the garden 1345

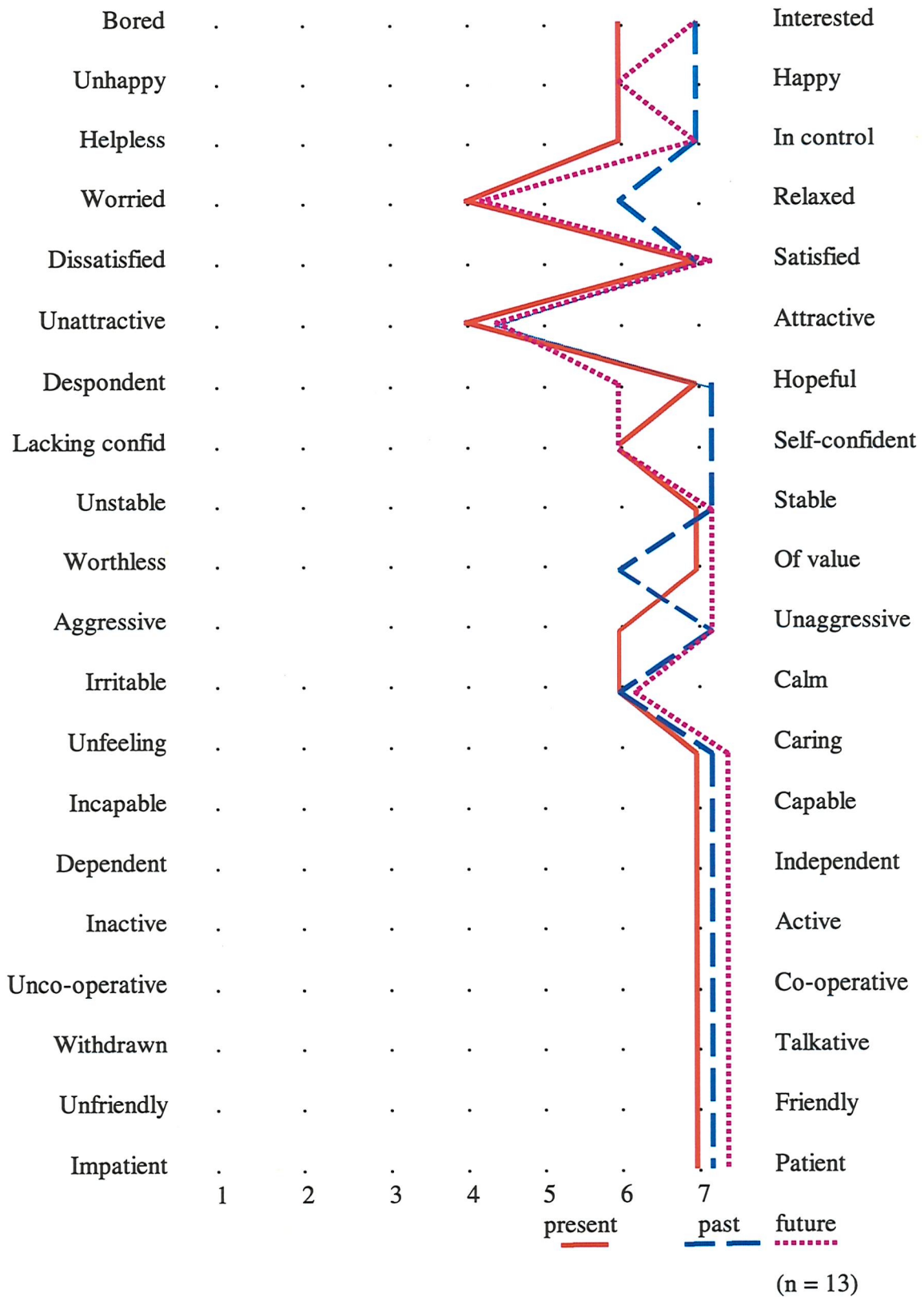
taking/finding advice

talked to fitter that came not going to produce twin tub any more 992
so went for washer/drier
couldn't see how to get the heat range- went down to where bought 1030
it-they put me wise
they were pretty good with the information.. so they gave her the 1678
number of the red d cross for commode
Ive got me leaflet son disabled things-very interesting because 1726
there are things I didn't know

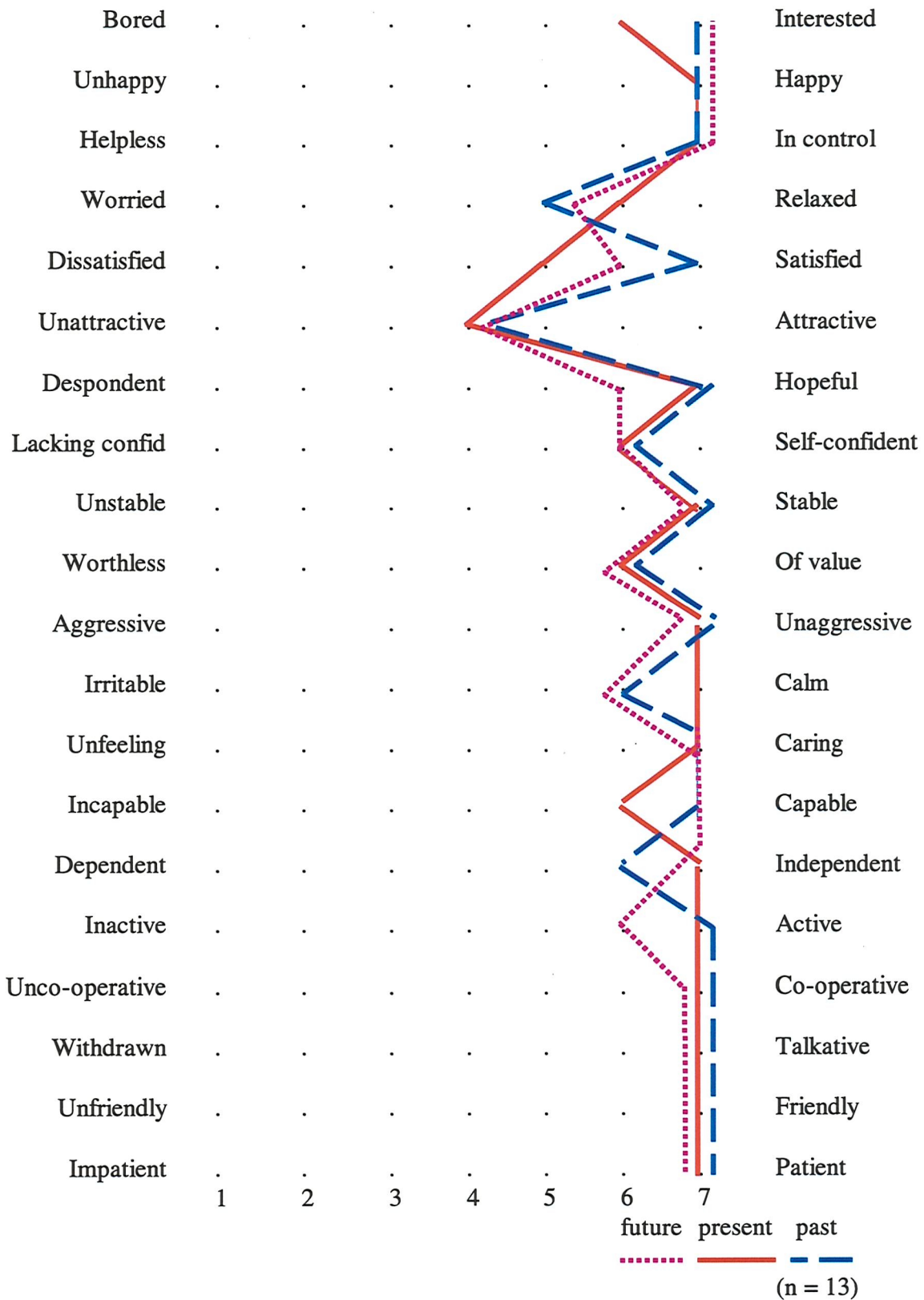
Appendix 17 Spouse group - median self-concept scores at baseline



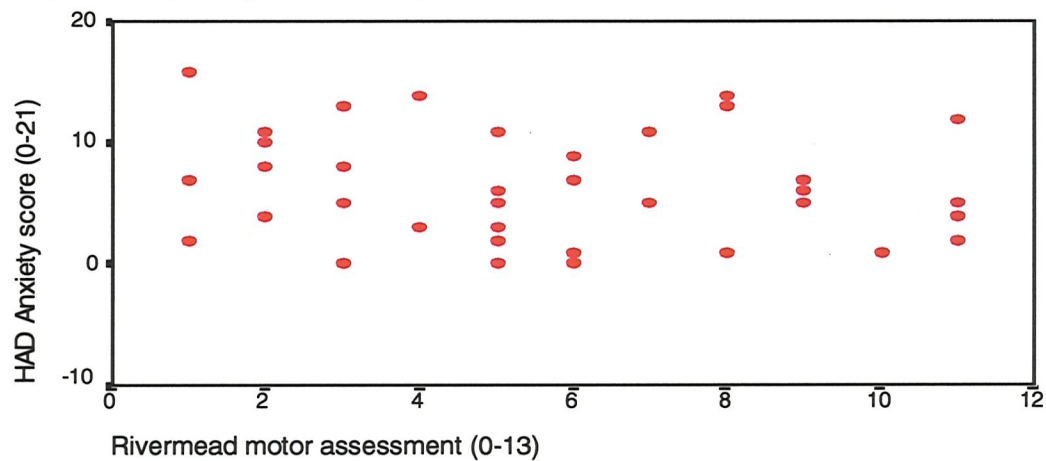
Appendix 18 Spouse group - median self-concept scores at six months



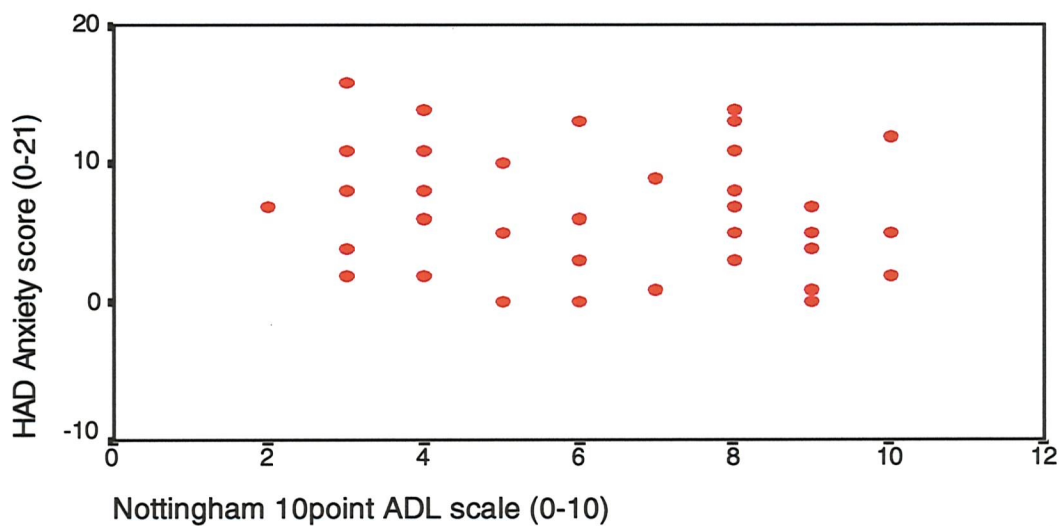
Appendix 19 Spouse group - median self-concept scores at one year



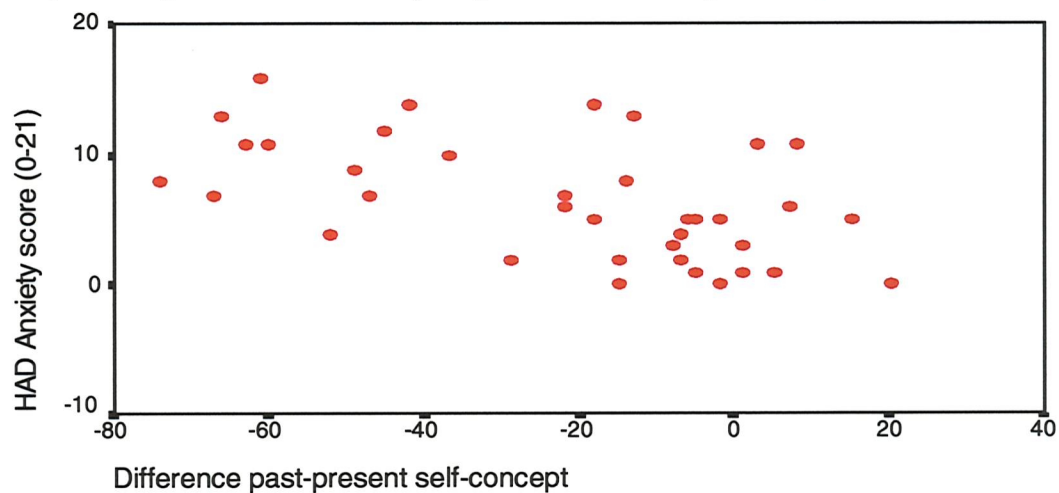
Anxiety score against physical ability score (n = 38)



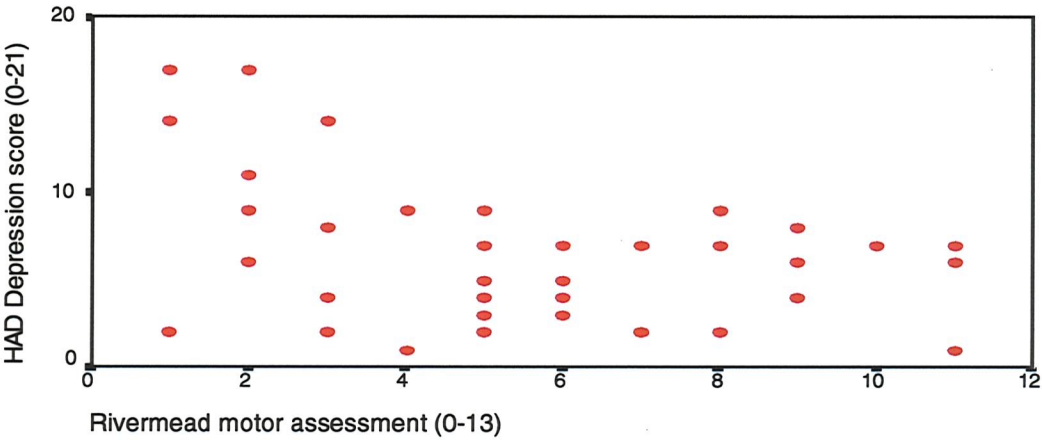
Anxiety score against Activities of Daily Living score (n = 38)



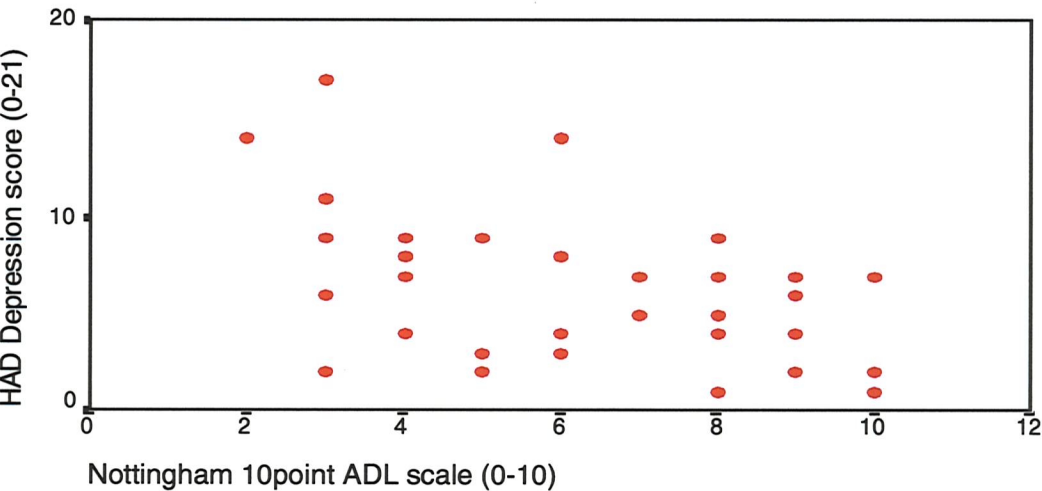
Anxiety score against difference in past-present self-concept score (n = 38)



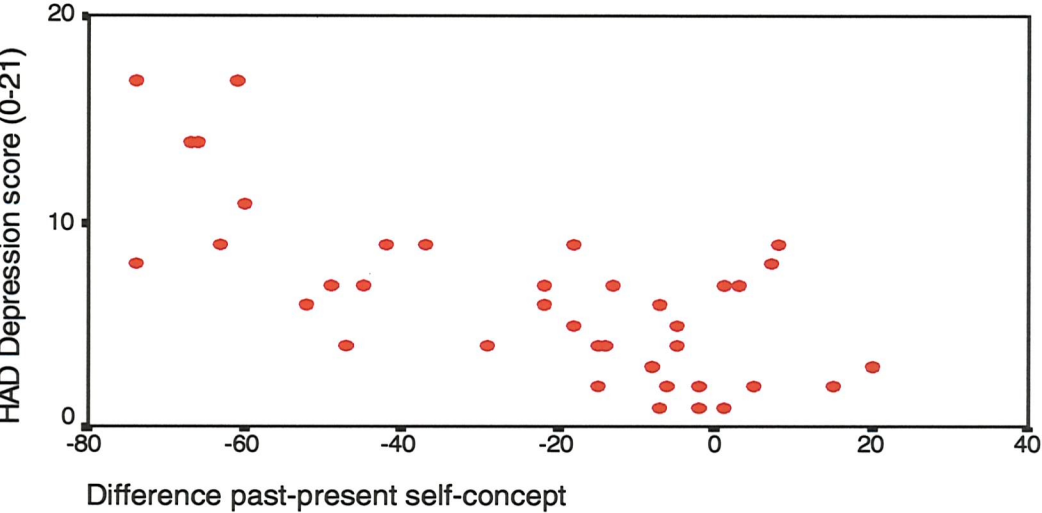
Depression score against physical ability score (n = 38)



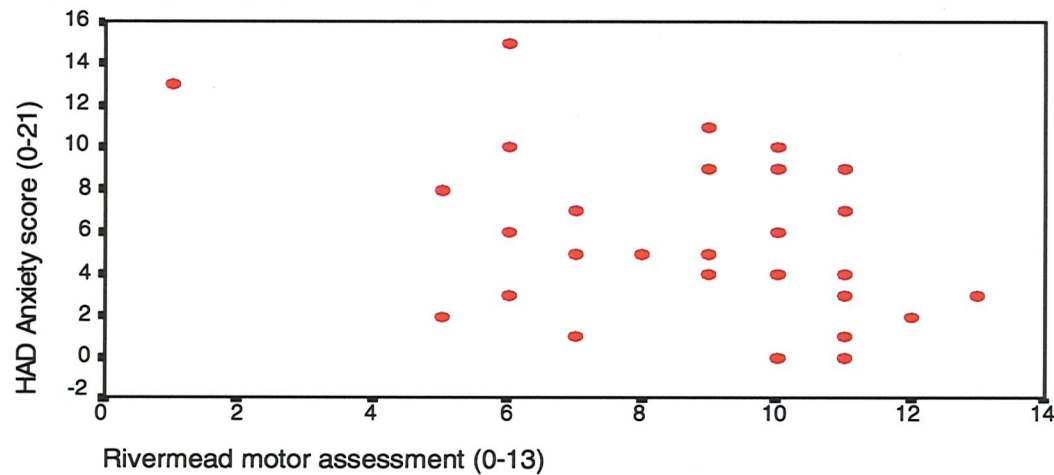
Depression score against Activities of Daily Living score (n = 38)



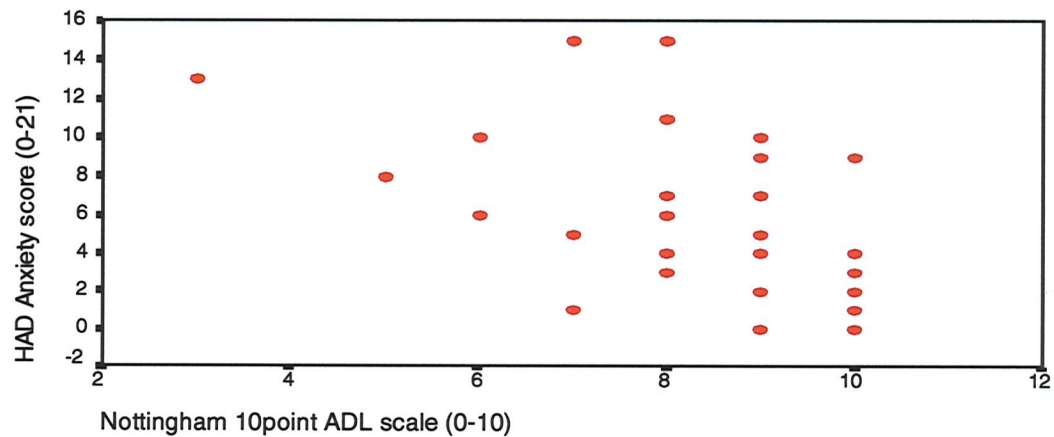
Depression score against difference in past-present self-concept score (n = 38)



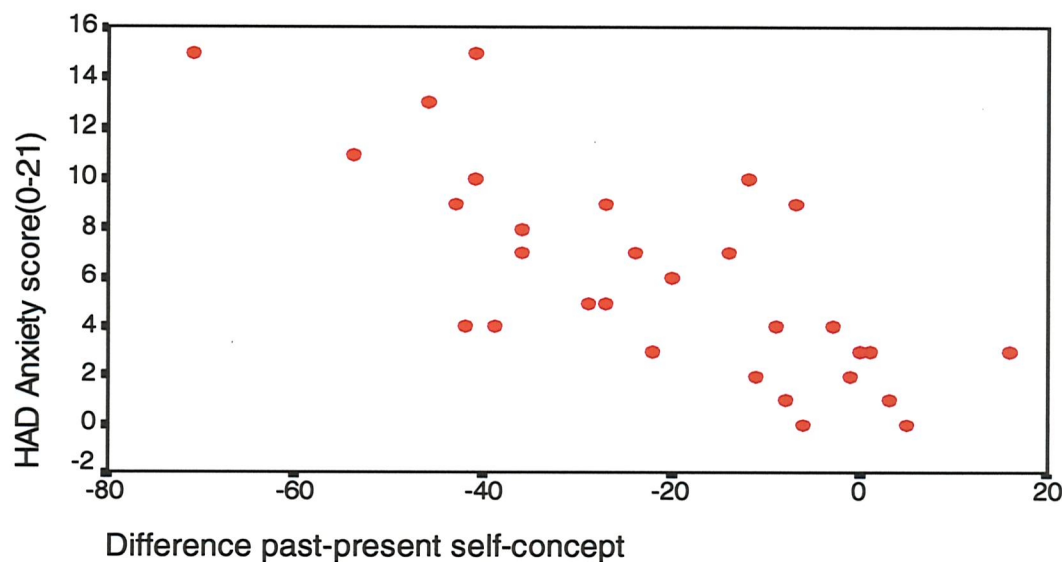
Anxiety score against physical ability score (n =32)



Anxiety score against Activities of Daily Living score (n=32)

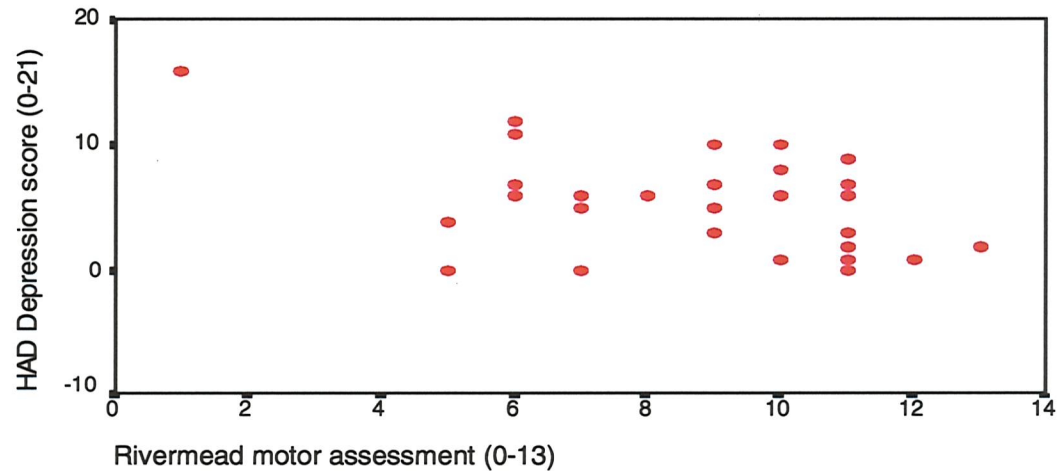


Anxiety score against difference in past-present self-concept score (n=32)

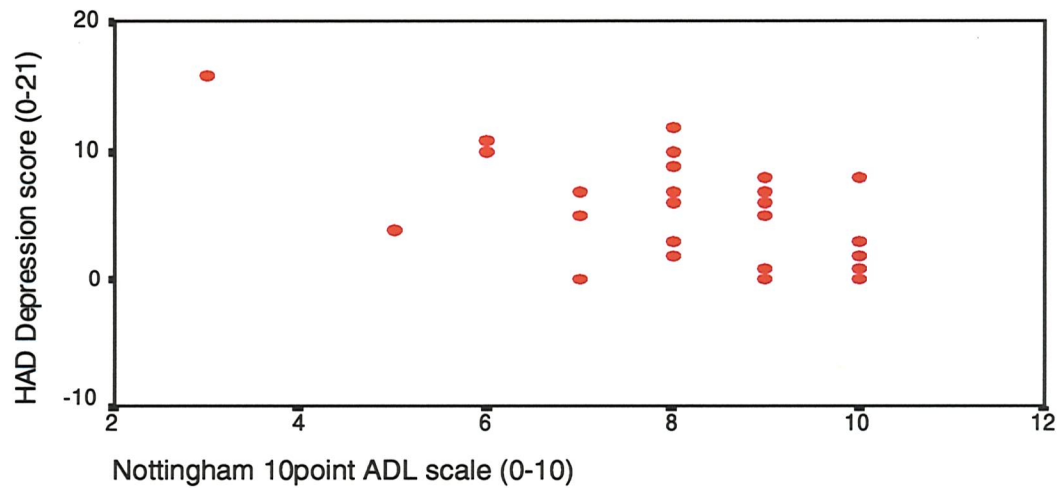


Appendix 23 Six month Depression scattergrams

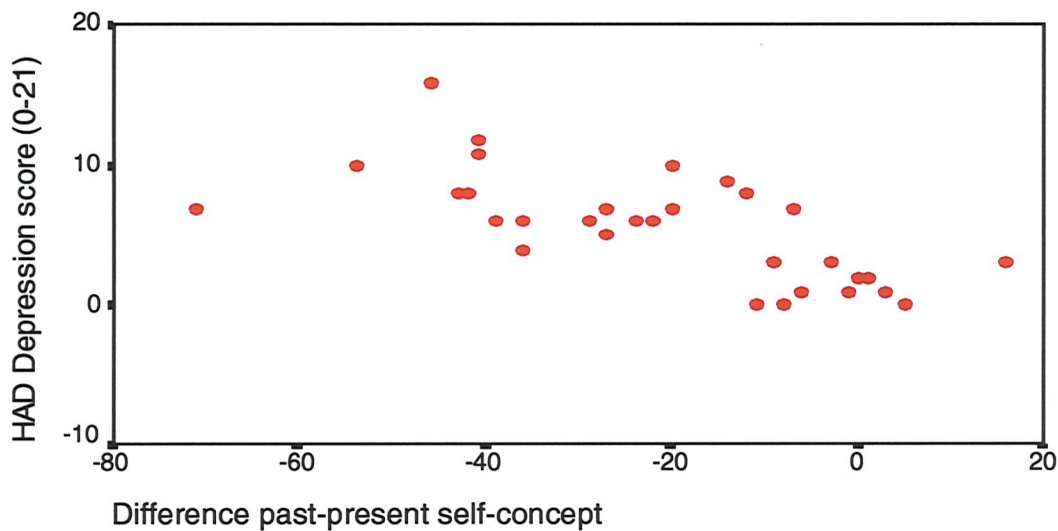
Depression score against physical ability score (n =32)



Depression score against Activities of Daily Living score (n=32)

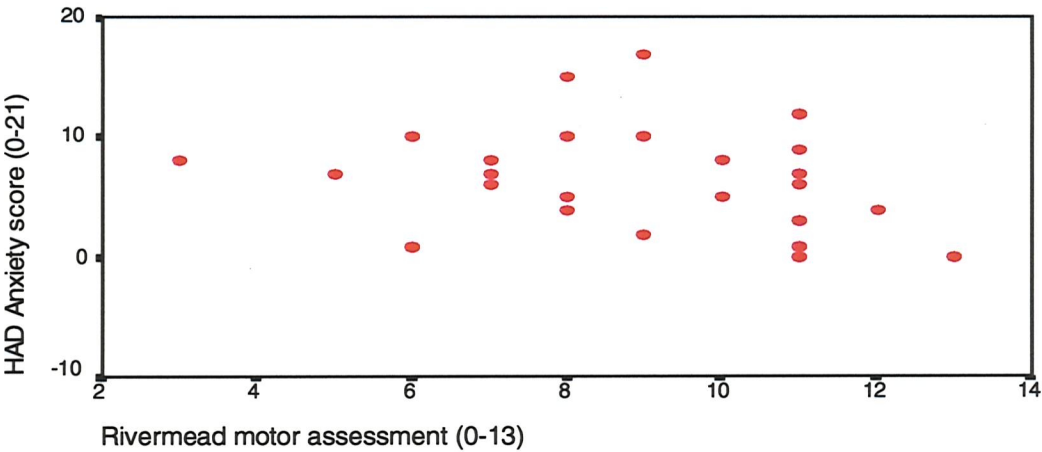


Depression score against difference in past-present self-concept score (n=32)

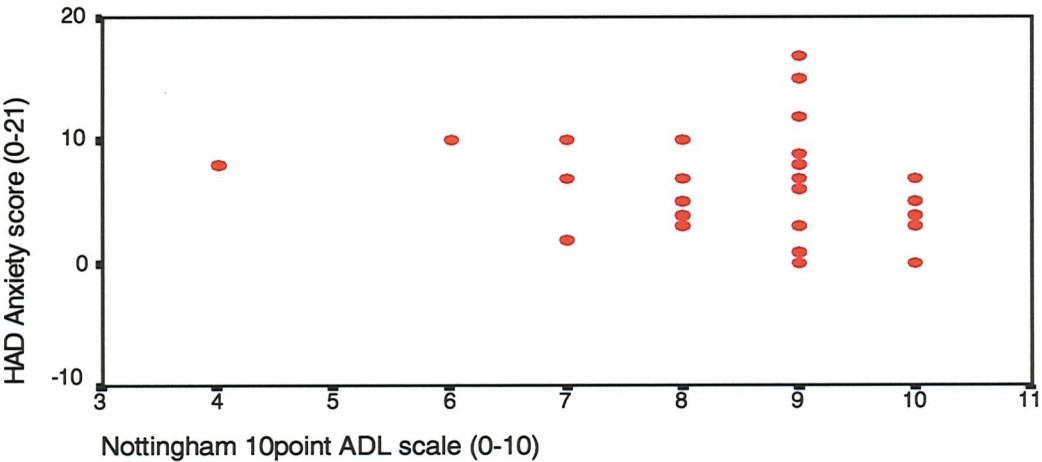


Appendix 24 One year Anxiety scattergrams

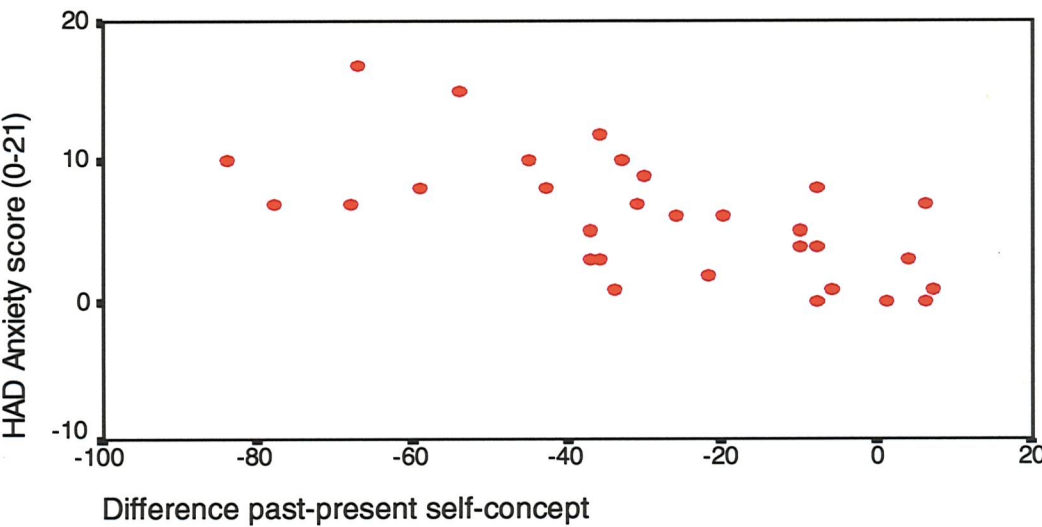
Anxiety score against physical ability score (n=30)



Anxiety score against Activities of Daily Living score (n=30)

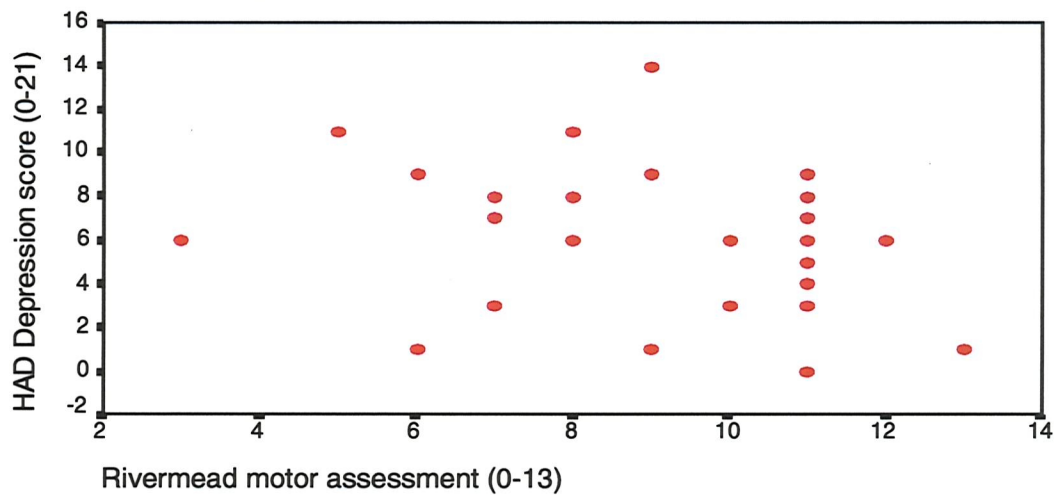


Anxiety score against difference in past-present self-concept score (n=30)

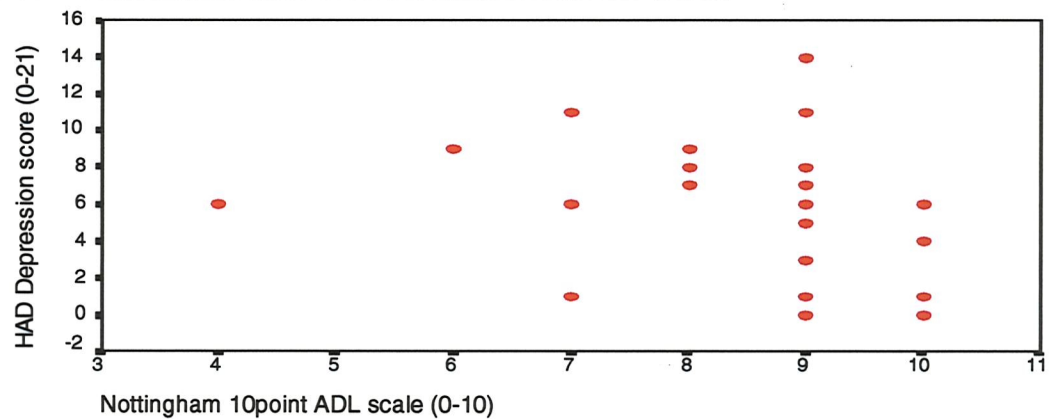


Appendix 25 One year scattergrams

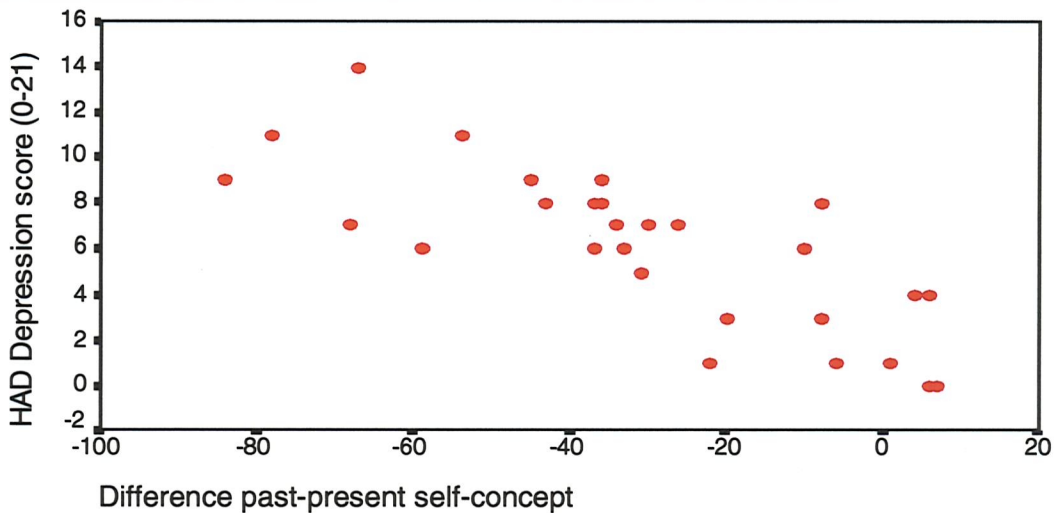
Depression score against physical ability score (n=30)



Depression score against Activities of Daily Living score (n=30)



Depression score against difference in past-present self-concept score (n=30)



Appendix 26 Life Themes

This appendix describes a brief case study of each of the couples who carried out life narrative interviews. The main life themes of the stroke respondents identified from the interview are described in more detail. This appendix provides further details to support the themes described in Table 6.4.

Within this appendix, a balance has been sought which allows me to provide evidence to support Table 6.4, without compromising the anonymity of the participant couples. Each short case study consists of a brief background describing the couples' situation and an overview of the main three themes of the stroke respondents.

As Mr Finches themes (Respondent J) are described in great detail in the text they will not be described again.

Couple A

Couple A were in their mid-fifties. They lived in their own large house with several children who were both their own and adopted. Before his stroke Mr A was working full time and Mrs A was responsible for looking after the children and the daily running of the house.

Following his stroke Mr A was left with a severe left weakness. He was in hospital for nearly three months, before returning home. By six months he was able to stand unassisted, but still used the wheelchair within the house. By one year he could walk within the house and short distances outside using a stick. Mr A was not able to return to work as a supervisor in the docks and was beginning computer classes at the local college at one year.

Mr A's main personal themes

a) determination

When Mr A was describing his early life, he told the story of his determination to marry his wife, even although they couple were geographically far apart for a while and her parents were against the marriage. Reflecting back on his hospital stay Mr A spoke of how the nurses and therapists were quite impressed by his determined attitude. By one year Mr A spoke of how he was determined to walk unaided outside rather than relying on his wheelchair.

b) relationships

Family relationships were important to Mr A. He had a large family of his own and adopted, children. He framed his past history by the birth of different children, which was unusual for the male respondents who mainly spoke in terms of work commitments. When speaking about the possibility of losing his job, he spoke about how the company were looking after him and had always supported him like a family. Throughout the interviews Mr A spoke of the importance of the support gained from fellow stroke patients in the hospital and the importance of meeting others following stroke to give guidance and support.

c) activity

Although in his mid-fifties Mr A described himself as a very active man who before his stroke would almost jog rather than walk anywhere. He spoke of how he maintained his links with his hobbies including the local drama club, and took up local education classes to keep himself busy and active and was planning to improve physically at one year.

Couple B

Couple B were in their late fifties and mid seventies. They had both retired and lived in their own three bedroom bungalow which was backed by a large garden. They have always lived in the area and had lived in their present house since their marriage over 40 years previously. Mr B had worked in different areas of engineering all his life and was a very practical man. Mrs B had worked in accounting and was very good at figures. They had one daughter who lived abroad and they kept in close contact with their nieces and nephews.

Following her stroke Mrs B, was left with a dense left weakness, poor short-term memory and slurred speech. She was in hospital for over two months and still used a wheelchair in the house on her return. Over the year her memory improved, she was able to walk independently, although it was slow and she still became tired when walking outside.

Mrs B's personal themes

a) homebird

When Mrs B described her early life she spoke of how she had always lived in the area, how when she met her husband the furthest she would go on trips was to Devon or Aldershot. In hospital she was extremely anxious to return home, she felt once she had returned home she would 'get on much better'. Over the year Mrs B described how she was quite happy sitting at home and 'pottering' and that she may go out for short trips for the afternoon but was always glad to return home. This theme was closely linked to another theme *gardening*.

b) friendship

Mrs B often spoke of events in terms of the relationships forged. She spoke of how the people who helped her immediately after her stroke kept in contact throughout her hospital stay, how she visited 'old friends' on previous hospital wards after she left, and the importance of a constant stream of friends who used to visit her or keep telephone contact after she had returned home.

c) garden

Mrs B's garden was extremely important to her. During her hospital stay she would fret about what was happening to it, and Mr B spoke of how he brought her in a bloom from her favourite rose to give her some connection with her garden. Over the year Mrs B's spoke of her mood in terms of the garden and how when the spring warmed up all the plants she also felt that things would be all right.

Couple C

Mr and Mrs C were both born in the West Indies and travelled to England in their early twenties. They were both now in their early sixties and had retired from work. They had a son who lived locally and daughter who lived away. They lived in a small terraced house in the heart of the city. Their house appeared to be an open house with many different visitors arriving and departing during my own visits.

Mr C suffered a stroke following an operation to remove atheroma in his carotid artery. He was left with a right weakness, slurred speech, concentration and short term-memory problems. Over the year he improved physically and could walk unaided, but slowly. His speech, concentration and memory improved over the year, but he was still affected by tiredness.

Mr C's personal themes

a) friends pass the time away

Mr C spoke in hospital of how previously he used to spend time with his friends, talking and drinking, playing cards and how sad he felt in hospital because he couldn't summon up the interest to meet his friends. Once home Mr C returned to speaking of how he enjoyed his friends visits, chatting, talking about 'back home' and 'passing the time'

b) close to death

Mr C was a religious man and described how after coming round from the operation he felt that he had been very close to death. He wanted to make the most of his remaining time. Over the year he continued to speak about how he had been close to death and how he was not sure how many years he had left and that he had to take things 'step by step'. This theme was closely linked with the following theme improvement

c) improvement

Although in hospital Mr C spoke mainly about how he was glad to be alive, over time he re-created his sense of improvement and described how he was coming back 'bit-by-bit' and how his walking and memory was getting better 'day-by-day' phrases he used at six months and one year, highlighting that although recovery was happening he was waiting for it and was getting impatient.

Couple D

Mr and Mrs D lived in a comfortable bungalow on the outskirts of the city. They had two daughters who both lived locally. Both had been married previously, but had lost their partners through illness earlier in their lives. The couple were in their seventies and were retired. Mrs D had been a full-time home-maker and Mr D had worked in engineering.

Following her stroke Mrs D was left with a right sided weakness and speech difficulties. She was in hospital for over two months. Over time her speech improved and she could be heard clearly, but not to Mrs D's satisfaction. She improved physically and could walk unaided, although still feeling unsteady at times.

Mrs D's personal themes

a) lucky

Mrs D spoke of her luck in life in having met her present husband after she had brought up her daughter alone after her previous husband had died. While in the hospital, she spoke of how lucky she was to be receiving care from a particular therapist who was very important to her. When at home although feeling lucky about life in general this theme was tinged with a sense of being unlucky at times when her body let her down.

b) mother-daughter relationships

Mrs D spoke in great depth of her own relationship with her mother and the importance of her relationship with her own and adopted daughters. She described herself as 'only an ordinary housewife' but went on to describe the fundamental pleasure the relationships brought. In hospital and at home often when aspects of her life were described her daughters opinions would also be included. Mrs D described how it was very difficult to be dependent on her daughters who she had looked after for so many years.

c) youth/appearance important

Mrs D looked 20 years younger than her real age. Her appearance was very important to her. In hospital she described her horror at being presented with a wheelchair to use. When home she described how she did not want to go out where people may know her, as she did not want to 'let the side down' and upset her friends. She also described how she could not bring herself to put her rings, or make-up on again as she felt she was 'a freak'.

Couple E

Mr and Mrs E who were in their late forties and early fifties lived in a small house which they were buying from the council. Mr E worked full-time as a driver and Mrs E worked part-time. They had two married daughters who lived in two houses opposite their own.

Following his stroke Mr E was left with severe speech problems and right-sided weakness. Mr E could understand what was said to him, but initially could not speak at all. By one year he could speak in halting sentences. When he first returned home Mr E used a wheelchair, but over time he could walk independently and only used the wheelchair for long-distances outside. He did not regain any movement in his right arm. Mrs E's themes will be described, as Mr E was unable to take part in a narrative interview.

Mrs E's personal themes

a) local girl

Mrs E described how generations of her family had always lived locally and how she still regularly walks past the house where her mother and grandmother lived. She described how she met her husband at a local school and how their group of very close friends was formed at school over 30 years previously. This theme was closely linked with the next theme.

b) friends vs. family

A strong theme for Mrs E was how she felt a lack from her own family. She described how she was much younger than her siblings and was brought up almost as an only child. Relationships with her siblings were not good although over the years she had managed to create links with a local sibling. She described how she still felt the loss of a family with her close friends. She described how following her husband's stroke she was not able to keep links with her brother, and not able to share her experiences with friends, which was leaving her increasingly isolated.

c) daughter-father relationship

Mrs E spoke in each interview about how one of her daughters was very dependent on her husband who would always do things for her and watched out for her. Mrs E felt that her daughter felt guilty for her father having the stroke and described how she had to support her daughter as well as her husband as he could no longer be the 'strong', practical father he had been in the past.

Couple F

Mr and Mrs F were in their late sixties and were both retired. They lived in a council house; and their two daughters and son and their own families lived nearby. Both Mr and Mrs F were born in Scotland and moved to the South in mid-life. Mr F was a factory worker and Mrs F worked in the canteen of a local college after her family had grown up.

Mrs F suffered a stroke following an operation to remove an atheroma in her carotid artery. She experienced tunnel vision which was more disabling for her than her right weakness. Over the year following her stroke, Mrs F could walk unaided but was still struggling with her tunnel vision which was found to be permanent.

Mrs F's personal themes

a) smart active person

In all three interviews Mrs F spoke of how she used to be a smart active person. She described how she used to love wearing make-up and shoes with high heels and how she could no longer do this due to the difficulties caused by her affected vision and balance. Mrs F described how one of her favourite past-times was window shopping in town. In the final interview she described how even although her daughter had taken her into town and shopping was no longer an enjoyable activity.

b) humour

Mrs F had a strong sense of humour. In hospital although she was tired from her stroke and isolated due to her tunnel vision she still managed to make jokes about her husband having to 'feed her up' on her first day visit home. Once home Mrs F was still making jokes at her expense and telling stories involving her care-attendants and people at the day centre. Humour was an important part of the couples' family life.

c) being content

Mrs F was an extremely patient lady and despite all her difficulties in hospital she described how she 'just contented' herself and waited for things to improve. She spoke of 'contenting' herself in all of the interviews over the year following her stroke. She spoke of how she was helped to be so accepting of her situation by the support of her husband and family.

Couple G

Mr and Mrs G were in their early eighties and late seventies respectively and were both retired. They had recently moved from their own house to a private warden assisted flat. Mr G was Polish and met his English wife after the second world war. They had a son who lived abroad and a daughter who lived nearby. Before retiring Mr G worked had worked in telecommunications as a supervisor and Mrs G worked in the canteen of a local college. Mr G still had a part-time morning job at a local printing firm.

Mr G had few physical difficulties after his stroke. He experienced weakness for a few days and was in hospital for only three weeks. On his return home he found that he became very tired; but gradually he was able to return to driving and his part-time job. He described how 'things were back to normal' by six months.

Mr G's personal themes

a) being active

Mr G spoke of his good health, prior to his stroke and how he only experienced the usual coughs and colds. He linked his good health with keeping fit and active. He described how he went on annual trips to Poland with his wife, had only given up skiing three years previously, and still managed to get a part-time job at 79 years of age. He described how he 'couldn't just sit on his bottom, [he] had to be active'.

b) airforce school

Mr G described how during the war he was recruited and trained within the Polish airforce. Through all of the interviews Mr G described the annual re-unions which had been held for Polish airman in this country over the last 53 years. He spoke of how the association members kept in touch during the year and compared their health and lives at each re-union. The airforce school training was also linked with the next theme 'being positive'.

c) being positive

Mr G described how during his airforce training, he had to learn discipline in the face of adversity. He described that this was a skill which he felt he had used all his life. He spoke of how having survived the war, he no longer worried about himself, just his wife and daughter. He described how he did not dwell on the stroke and felt that 'the less you worry about it, the sooner you will get better'.

Couple H

Mr and Mrs H were in their late forties. Mr H ran his own consultancy business and Mrs H worked as a secretary and looked after their two teenage children. They lived in their own large house in the New Forest.

Following his stroke Mr H was left with a right weakness and severe aphasia (loss of speech). At first Mr H could not understand others, but gradually over time his ability to communicate improved. By one year Mr H had improved physically although his right arm was still weak; but he could only speak a few words and could not always make himself understood. As Mr H could not take part in the interview Mrs H's themes will be described.

Mrs H's personal themes

a) self-reliance/control

Mrs H spoke of being a very independent child following her own mothers illness. Over the years she had worked around her husbands business and put her own ambitions on hold. She spoke of how her own self-reliance was helping her through this extremely difficult part of her life. Mrs H described how she had never been good at coping with sickness and disability and felt that it was very important for her to create her own life. At the same time she expressed feelings of guilt as that now she had to be in control, she was able to consider her own ambitions, perhaps returning to full-time education.

b) money

Mrs H often spoke in financial terms when discussing aspects of her life. She described how financial pressures had put a strain on the family and felt that they had contributed to her husbands stroke. She spoke of her main concern in becoming a breadwinner to support her family and keep her house. She spoke of the emotional and financial hardships she felt her children had experienced. When speaking about her husbands hospital treatment she mentioned that she was grateful for the amount of money spent in providing services for him.

c) family management

Mrs H spoke in depth about the effect of the stroke on her two children and how she had to balance their, her husbands and her own needs. She discussed the management of many different situations ranging from hospital discharge, the family holiday, practically supporting her children's interests, being aware of their emotional needs, and trying to act as a bridge between her husband and her children.

Couple I

Mr and Mrs I were in their early eighties. They lived in their own bungalow and their daughter lived nearby. Mr I had worked as a building worker and Mrs I had looked after the family. She had suffered from a heart complaint since childhood and had always been looked after by Mr I. She had regular hospital visits and checks and could walk unaided but tired quickly when she was out.

Following his stroke Mr I had a left weakness and was in hospital for over six weeks. In the year following the stroke Mr I's walking improved, although he was not always steady on his feet. Mr I's hand improved but he still tended to be clumsy when using it. He was generally more tired and needed to rest in the afternoon. Mr and Mrs I would not contemplate separate interviews and so the couples two main themes will be presented here. The main respondent was Mr I, but he was actively supported by Mrs I.

Mr & Mrs I's personal themes

a) shared life

The couple spoke about how they had known each other since the age of seven. All of their stories were shared stories, or ones which they had discussed together at length. Often during the interview they would both speak at the same time, cut across each other and hold their own discussions and arguments. They often finished each others sentences.

b) being rebellious

When talking about his childhood, Mr I spoke of getting into as many fights as possible, how he had to fight and look after himself; Mrs I recounted how they used to sneak past the doorman at the cinema without paying. The couple described how they were antagonistic towards any form of authority, although they had great respect for their own GP. Mr I told of how he enjoyed 'telling the doctors off' at the hospital and had always been getting into trouble with the nurses for walking around when he had been told to stay by his bed. As he said 'Sometimes I cross swords with them just to upset them'. Since returning home the couple recounted stories of battles with the milkman and with people parking in their road.

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