Beliefs about 'stroke' and 'its effects': A study of their association with emotional distress

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Declaration

I, Ellen Townend, hereby certify that this thesis

a) has been composed by myself, and
b) that the work contained herein is my own, excepting in those areas where the help of others is acknowledged

Signed .....

Date 10/12/2004.

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Summary

Emotional distress (symptoms of depression and anxiety) and emotional disorders are commonly experienced following stroke and negatively influence recovery and survival rates. Past research suggests that depressive symptoms are not directly related to lesion location and are only weakly related to actual functional and social losses. Patients' own subjective beliefs have been under-researched. This thesis was developed using cognitive theory, past research on emotional adaptation to emotional disability and observations from piloting. The main study aimed to investigate distress and a set of beliefs about 'stroke' and 'its effects', and to longitudinally test associations between specific beliefs and distress, taking into account relevant background variables. Supplementary studies aimed to explore emotional distress and disorder and relevant beliefs.

A consecutive series of 89 patients, without severe cognitive or communication impairment, were interviewed one month (baseline) after admission to a stroke unit and 81 were interviewed again at nine months (follow-up).

In the main study, distress was measured using global Hospital Anxiety and Depression scale scores. Specific beliefs about 'stroke' and 'its effects' investigated were: Attributions (Casual controllability, 'Why me?', 'Found meaning?'); Negative self-evaluations (Acceptance of disability, Negative identity change, Shame); Beliefs in recovery and recurrence (Recovery locus of control, Confidence in recovery, Recurrence fear). Background variables measured were: Demographics, Stroke severity, Disability, Pre-stroke depression, Social support and Life events.

The first supplementary study used the structured clinical interview (SCID) for DSMIV to assess depressive disorder (major or minor) and common anxiety disorders (generalised anxiety disorder, agoraphobia, social phobia, post traumatic stress disorder) and, additionally, as a means for exploring relevant beliefs. The second supplementary study involved further qualitative

interviews with sixty participants at baseline to explore their own experiences and main concerns.

Associations were found between distress and most belief variables at baseline, follow-up and across time. Backward linear regression analyses for distress were used to study belief variables taking background variables into account. At baseline and follow-up these analyses supported the statistical significance of associations between distress and negative self-evaluative beliefs and recurrence fear. Across time, a role for causal controllability and acceptance of disability was supported. However, these results also highlighted the pervasive influence of a pre-stroke history of depression and of initial distress levels across time.

The SCID interview identified that many patients met criteria for depressive disorder (33% at one and 30% at nine months) or anxiety disorder (35% at one and 33% at nine months) but also yielded information regarding specific stroke-related beliefs relevant to distress versus adaptation. The qualitative interviews provided insight into patients' idiosyncratic concerns. This extended the main findings, for example by illustrating the varied nature of recurrence fear beliefs and highlighting individuals' needs to give as well as receive social support.

This study provides qualified support for cognitive theory of distress following stroke by demonstrating associations between distress and beliefs concerning 'stroke' and 'its effects' in the short- and longer-term aftermath of stroke. Over and above measures of disability, a personal sense of being unable to accept reduced capability, which some went so far to describe as 'uselessness', was related to higher levels of distress and disorder. Fear of recurrent stroke was common. Belief in the controllability of risk factors tended to be low; however a greater initial sense of causal controllability appeared protective against distress across time. These results have implications for the development of interventions to address the high prevalence of emotional distress and disorder following stroke.

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Chapter 1

Emotional distress and disorder following stroke

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1.1 Forward

'You can of course treat the medical side of the illness, but if you fail to address the emotional or psychological side, you will never cure more than fifty percent of the afflicted person...'

p.39, McCrum (2000)

Robert McCrum, who is literary editor of the *Observer*, made this statement in a British Medical Journal article. Its' credibility rests with his own personal experience of a severe stroke aged only forty-two years. In this chapter the nature of emotional distress and disorder following stroke will be considered. The importance of addressing the emotional side of stroke, in terms of prevalence and negative impact of emotional disorder will be presented.

Competing theories and evidence for understanding emotional distress and disorder following stroke will be considered. The role of cognition in distress, in particular Beck's cognitive theory, and its applicability to our understanding of emotional distress following stroke will be introduced. Finally, a rationale for an in-depth study of beliefs related to emotional distress following stroke will be presented.

1.2: Stroke

Stroke is a rapid onset of signs of brain disturbance such as loss of bodily function, speech or vision, lasting at least twenty-four hours, caused by blood vessel disease (Samuels, 1994).

Stroke is very common. A new stroke occurs every five minutes in the UK (S.A., 2003). Approximately one in four men and one in five women aged forty-five will have a stroke by eighty-five (Wolfe et al., 1996). Older people are at increased risk. Of 130 000 new individuals who have a stroke in the UK each year, 117 000 are fifty-five years or older (SA, 2003). Current predictions suggest the older population will double in size by 2050 (Katon, 2003). Therefore we can expect the incidence of stroke to multiply.

Stroke is currently the third most common cause of death in Scotland, the UK and the US (SIGN, 2002; Wolfe et al., 1996; American Heart Association, 2002). Approximately one in five strokes result in death within a month (SIGN, 2002) and one in three within a year (Wescott, 2000). Nonetheless, long-term survival rates have significantly improved. A thirty percent decrease in mortality at two years amongst twenty-eight day survivors was reported for 1980 to 1990 (McGovern et al., 1993, in Ebrahim, 1999).

Stroke survivors outnumber the annual rate of new stroke patients almost five fold (SIGN, 2002). For those who survive, the quality of that survival gains importance. Unfortunately, stroke survivors are not guaranteed a good recovery and approximately half will remain disabled a year later (Wescott; 2000). Stroke is now the most common cause of adult disability in the UK and US (Wolfe et al., 1996; American Heart Association, 2003). This research refers only to basic functional physical disability. Emotional distress is one of the various other unseen difficulties experienced in the aftermath of stroke (Anderson, 1992).

1.3: The constructs of emotional distress and disorder

1.3i: Emotional distress, symptoms and disorder

There are many different shades and hues of emotional distress: worry, fear, anxiety, panic, sadness, hopelessness, and depression. It is commonly accepted that emotional distress exists as a continuum, and terms such as distress, negative affect or neurosis refer in a non-specific way to the high end of the spectrum (Kendler and Jablensky, 2003). Distress may be described in terms of types of symptoms: cognitive (for example, worthlessness), physiological/somatic (for example, fatigue), or behavioural (for example, agitation), symptoms as well as more affective symptoms such as worry or low mood. Distress can also be described categorically in terms of emotional disorders.

Emotional disorders are essentially syndromes defined by number, type and duration of symptoms, and are intended to identify severe cases that warrant clinical attention. Criteria for emotional disorders are described in classification systems such as 'The Diagnostic and Statistical Manual for the American Psychiatric Association' (DSMIV; APA, 1994, that will be referred to as DSMIV from now on). As these systems developed, there was a movement towards the division of symptoms of distress into separate depressive or anxiety disorders (please see Chapter 8, section 8.3 for description of major depression, minor depression, generalised anxiety disorder (GAD) and other more specific anxiety disorders). DSMIV criteria are described as:

> 'current formulations of evolving knowledge…They do not encompass, however, all conditions for which people may be treated or that may be appropriate topics for research efforts.'
>
> p.xi, APA (1994)

There are two ongoing debates fuelled by diverse research with relevance to this thesis. The first questions the splitting between anxiety and depression symptoms as the classification systems of disorders develops. The second questions the different advantages of using the continuum construct or the disorders construct to study emotional distress.

1.3ii: Overlap between depression and anxiety symptoms and disorders

Accumulating research findings question the separation of general anxiety and depression symptoms into distinct disorders. The testing and reformulation of criteria for different disorders has improved the reliability with which they may be diagnosed (Riskind et al., 1987; Brown et al., 1994). However, general anxiety and depressive disorders have much in common: very high rates of co-morbidity, clinical instability between the two states, lack of specific drug responses, even similar genetic profiles (Andrews et al., 1990; Brown et al., 1994; Kendell and Jablensky, 2003; Liebowitz et al., 1990; Riskind et al., 1987; Strarakaki and Vargo, 1986).

Experts and research addressing emotional distress in primary care and general hospitals have particularly questioned the relevance of criteria for specific depressive and anxiety disorders amongst these patients. In reviewing the literature, Mayou and Hawton (1986) suggest that this nomenclature is relevant to an important minority of patients. However, undifferentiated symptoms of distress not captured by anxiety or depressive disorder criteria are commonly found amongst medical patients. These symptoms are often moderate but sometimes are of high severity and associated with social dysfunction (Clark and Streer, 1996; Liebowitz et al., 1990; Mayou and Hawton, 1986; Sensky, 1986; Zinbarg et al., 1994). This understanding is reflected in the manner in which distress tends to be measured as a continuum amongst medical patients to avoid 'floor effects' (Creed, 1988; Herrmann, 1997).

Co-morbidity rates between general anxiety and depression amongst older adults may be particularly high. For example, in the Guys/Age Concern study, ninety-one percent of older participants meeting criteria for GAD had depressive symptoms (Lindesay et al., 1989). It has been suggested that anxiety and depression may particularly blur in elderly patients owing to a general attenuation of symptoms (Roth, 1988, quoted in Kay, 1988). A study of symptoms of distress in older general practice patients supports this idea (Good et al., 1987). They found anxiety explained more of the variance in scores than depression but there was also significant overlap between the two factors. When the data was subjected to cluster

analysis, a large normal cluster was followed by a cluster that the authors described as 'anxious and mildly depressed'.

In contrast to the development of thinking about the apparent overlap between anxiety and depression symptoms and disorders discussed, the bulk of past emotional research in stroke refers only to depression. This term has been used 'rather loosely' to refer to a high level of distress or, more specifically, to depressive disorder (House, 1987).

An exception was a study that explored the severity and type of a range of symptoms amongst three diagnostic groups of stroke patients ('not depressed', 'minor depression' or 'major depression') and in-patients from a psychiatric hospital ward with major depression (Gainotti et al.,1999). They suggest that hallmark depressive symptoms amongst the stroke patients with major or minor depression tended to be less severe than amongst the patients hospitalised for depressive disorder. More anxious symptoms were as severe amongst the stroke patients with minor depression and more severe amongst those with major depression. This study supports a picture of overlapping anxious and depressive symptoms amongst stroke patients who meet criteria for depressive disorder.

The few studies that have assessed generalised anxiety disorder amongst stroke patients have found rates of high co-morbidity with depressive disorder (please see Table 1.1). Fedoroff et al. (1991) found higher levels of general anxiety symptoms among stroke patients with major depression, than among spinal cord injury or myocardial infarction patients with major depression. In contrast, Lipsey et al. (1986) report a 'strikingly similar' profile of depressive symptom type and severity in a study that compared patients with major depression from stroke rehabilitation wards to patients with major depression from a psychiatric hospital ward. However, they did not look at anxiety symptoms.

Experienced clinical researchers have begun to describe concerning emotional states amongst their stroke patients as typically 'sub-clinical mood states' (Reich, 2002) and well characterised by the concept of 'distress' (Lincoln, 2003). Johnston (1991) has highlighted the neglect of anxiety research following stroke. House (1996) has

criticised the tendency for stroke researchers to refer to 'post-stroke depression, or PSD' as creating an idea of something 'special' about depression following stroke. These criticisms coincide with the preceding discussion that has highlighted the overlapping nature of anxiety and depressive disorder and the prevalence of moderate levels of both anxiety and depression symptoms amongst older adults, primary care patients, general hospital samples and stroke patients.

1.3iii: Different advantages of the continuum and disorders constructs for the study of emotional distress following stroke

The preceding discussion of opinion and evidence converges to suggest that the continuum construct of distress is a conceptually appropriate subject of study amongst stroke patients. By studying a continuum, moderately severe as well as severe symptoms are studied. By investigating both types of symptoms, the past neglect of anxiety symptoms in stroke research can be avoided without rejecting the importance of depression. The continuum of distress also has statistical advantages with relatively small samples (please see Chapter 7 for discussion).

Kendell and Jablensky (2003) have defended the clinical utility of emotional disorders construct. Clinicians seek to divide normal from disordered experience even if it is at the point of an arbitrary boundary. Research that looks at specific disorders can provide information about sub-groups of patients at the high end of the spectrum of the multifaceted continuum of distress. For example, community studies of anxiety amongst older adults have found 'a strikingly rare' prevalence of panic disorder (Kay. 1988) but yet a high prevalence of agoraphobia (without panic) often of late onset (Flint, 1994). Although these reviewers concluded that DSM anxiety disorder criteria did not capture the high prevalence of moderately severe anxious symptoms in this population, these specific findings may still have useful clinical implications.

Ideally, research would utilise both the continuum and disorders constructs. For the reasons described, a continuous measure of distress has been chosen as the main subject of study in this thesis. However, for reasons discussed here, criteria for common emotional disorders were also applied and developed into a supplementary study (please see Chapter 8).

1.4: Prevalence of emotional disorder and distress following stroke and discussion of variation

1.4i: Prevalence of emotional disorder following stroke

A number of reviews have now combined results from the large number of studies of depression prevalence following stroke (Robinson, 2003; Spencer et al., 1997; Whyte and Mulsant, 2002). On balance these studies suggests a high prevalence of depression but a marked variability in results across studies. Whyte and Mulsant considered only results for major depression assessed using DSM criteria (fourteen studies) and found rates to vary between 5% and 37% across studies conducted between two weeks and two years following stroke. Spencer et al. (1997) considered studies that used either cut-off points on rating scales or DSM criteria for minor or major depression with samples of at least fifty patients that accounted for past psychiatric history (nineteen studies). They found a 3% to 68% depression prevalence rate across all studies. The rates for just DSM major depression varied between 3% and 40%, and the rate for just DSM minor depression varied between 10% and 40%.

Robinson's (2003) review is the largest (thirty studies) and includes small studies that have used rating scales or DSM criteria for minor or major depression. Across four community studies, the rate of depression ranged from 23% to 44%, giving an average of 32%. Across eighteen acute or rehabilitation hospital sample studies, the rate of depression ranged from 21% to 72%, giving an average of 36%. Across eight out-patient sample studies, the rate of depression ranged from 16% to 33%, giving an average of 33%. Higher prevalence rates may be expected amongst hospital samples compared to community samples due to higher stroke severity and disability levels. This difference emerged in a comparison of depressive disorder assessed by DSMIII or DSMIII-R criteria. The pooled frequency for hospital sample studies was 19% for major and 19% for minor depression, whereas the pooled frequency for community studies was 14% for major and 9% for minor depression.

Available studies of the prevalence of generalised anxiety disorder have produced mixed results summarised in Table 1.1.

Table 1.1: Prevalence studies of generalised anxiety disorder following stroke

Investigators	Patient population	n	*Criteria*	General anxiety disorder rates in percentages	
				Total %	**% co-morbid with depression [2]**
House et al. (1991)	Community sample (1 month)	89	DSMIII	1% [1]	
	6 month follow-up	119		1% [1]	
	1 year follow-up	112		0% [1]	
Sharpe et al. (1990)	Community sample 3-5 years following stroke	60	DSMIII-R	5%	
Burvill et al. (1995)	Community sample (4 months)	294	DSMIII	2%	2%
Castillo et al. (1995)	Consecutive series of stroke admission without severe comprehension or cognitive difficulties	142	Modified DSMIII-R [3]	27%	22%
	3 month follow-up	78		27%	22%
	6 month follow-up	80		36%	33%
	1 year follow-up	70		17%	14%
	2 year follow-up	66		27%	19%
Astrom (1996)	Consecutive series of stroke admissions who survived without a recurrent stroke who could be assessed	71	Modified DSMIII-R [3]	28%	15%
	3 month follow-up	70		31%	22%
	1 year follow-up	66		25%	14%
	2 year follow-up	57		25%	14%
	3 year follow-up	48		19%	15%
Schramke et al. (1998)	Members of stroke support groups or post rehabilitation patients obtained from telephone lists	44	DSMIII-R	0%	

1: House et al. (1991) used a hierarchical approach (so patients with depression were excluded from the diagnosis of GAD). The other authors used a non-hierarchical approach (so figures in the left column refer to overall percentage of patients meeting criteria for GAD regardless of depression status)

2: Some authors indicated overlap between GAD and depression by reporting percentages of patients who met criteria for both.

3: The DSMIII-R criteria that specifies a 6-month duration of uncontrollable worry for GAD was discounted. They assumed that the DSMIII-R criteria of a further six of eighteen anxiety symptoms could be equated to three out of nine anxiety symptoms identified by the present state exam (PSE; Wing et al., 1974) structured interview schedule they used.

Community studies appear to have found low rates of GAD, whereas high rates are reported by hospital sample studies. Comorbidity between GAD and depression is high, which will have reduced rates in studies using the hierarchical diagnostic approach. Also, studies reporting higher rates have used more lenient criteria. House et al. (1991) actually found that worry was commonly reported and Sharpe et al. (1991) found similar levels of anxiety and depression symptoms. In addition, Gillespie (1997) found high levels of anxious symptoms amongst one in four discharged stroke patients.

A fairly consistent pattern of high rates of agoraphobia but very low rates of panic disorder or other specific phobias tends to be reported by the few relevant studies available. Burvill et al. (1995) report that seventeen percent of their community sample met DSMIII-R criteria for agoraphobia at four months. House et al. (1991) found symptoms of situational anxiety were common during the first year following stroke. They report only a 2% to 3% rate of agoraphobia, but point out a higher rate would have been found if a non-hierarchical diagnostic approach had been used. Astrom (1996) reports that fears of going out alone were common but states that 'these fears were often realistic' and decided not to regard them as phobic. In contrast, Burvill et al. (1995) suggest their agoraphobic patients' fears were 'invariably...out of proportion' to what may be expected in view of their disability levels.

Recently (for example, Shalev et al., 1993), there has been a growth of interest in post traumatic stress disorder (PTSD) amongst medical patients. A third of subarachnoid haemorrhage patients referred to clinical neuropsychology for anxiety problems were found to meet DSMIII-R criteria for PTSD (Berry,1998). More relevant to this thesis, Sembi et al. (1998) report that ten percent of a mixed group of stroke in-patients and out-patients met criteria for PTSD according to criteria developed by Blake et al. (1992). However, Sampson et al. (2003) recently compared PTSD symptoms amongst hospitalised stroke and non-stroke patients (many of whom had been admitted for a fall) using two different scales. They found no statistically significant differences in PTSD symptoms between stroke patients, non-stroke patients who had fallen and other non-stroke patients.

Longitudinal studies suggest that the prevalence of depression may decrease to about twenty percent, from between three to seven years follow-up (Astrom et al., 1993; Dam et al., 2001; Sharpe et al., 1990). Results so far suggest the prevalence of general anxiety disorder may decrease but remains fairly high in the long term (please see Table 1.1). Burvill et al. (1995) found agoraphobia to resolve in half of patients after the first year. This is consistent with Sharpe et al. (1990) who found an 8% rate of agoraphobia in a community sample three to five years following stroke.

Small studies (Dam, 2001; Folstein, 1977; Sampson et al., 2003) and epidemiological studies (Burvill et al., 1995; Wells et al., 1988; Penninx et al., 2003) that have attempted to assess the prevalence of depression amongst stroke patients relative to other populations, such as healthy older adults or those with other disabling conditions, have produced mixed results, and mixed conclusions by reviewers. For example, Robinson (2003) suggests that depression appears to be far commoner amongst stroke patients than amongst the general population. Burvill et al. (1995) conclude that high rates of depression tend to be found amongst disabled populations in general, not just stroke patients. There are many methodological issues concerning comparison across depression studies that will be discussed in section 1.4ii, and also issues with the definition and measurement of disability (Bond et al., 1998) that confound the appraisal of the prevalence of emotional disorder following stroke relative to other populations.

1.4ii: Variation in prevalence estimates of emotional distress and disorder following stroke

The variation in prevalence rates for emotional disorders following stroke may be partly attributable to differences across samples regarding factors commonly associated with emotional disorder (please see section 1.6iii). Spencer et al. (1997) have drawn attention to the inconsistent assessment and reporting of potentially confounding patient attributes, in particular a past history of an emotional disorder.

It is possible that somatic symptoms of distress may be confounded with stroke itself, and their inclusion in emotional distress and disorder assessments may

account for some variability in prevalence rates (Hibbard et al., 1993; Spencer et al., 1997). The use of somatic symptoms to assess distress in medical patients has been much questioned with mixed research findings (see for example, Clark et al., 1983, 1989). Self-report and clinician rated somatic symptoms were less associated with depression diagnosis than non-somatic items in one stroke study (Stein et al., 1996). However, Fedoroff et al. (1997) found that the exclusion of DSMIV somatic items in the diagnostic process only produced minor differences in the number of hospital stroke patients found to met criteria for depressive disorder.

Compared to other medical populations, the assessment of emotional symptoms in stroke patients can be complicated by aphasia (impairment in the comprehension and expression of language) amongst approximately a third of patients (SIGN, 2002; Spencer et al., 1997) or by cognitive impairment in approximately one third of stroke patients (Tatemichi et al., 1994) ranging from memory, perception and attention deficits to executive functions (BPS, 2003). Sometimes it is unclear whether patients with aphasia have been excluded from studies (Carson et al., 2000) or what severity of aphasia or cognitive impairment merited exclusion (Spencer et al., 1997). Methods such as clinicians' observation of behaviour or visual analogue scales have been used as alternatives to language based enquiry into patients' experience of symptoms in some studies, but these appear to perform poorly in practice (House et al., 1989). The inconsistent exclusion or inclusion of patients with severe language or cognitive impairment across studies, and the problematic assessment of symptoms in these patients may account for some of the variability in current prevalence estimates. Unfortunately, the inconsistent reporting of patient attributes on these dimensions makes this possibility difficult to assess.

Other possible sequelae of stroke: emotionalism (loss of emotional control often with increased frequency of crying or even laughing) aprosody (deficits in the rhythm or tone of emotional expression) emotional agnosognosia (lack of awareness of emotional states) may mask or mimic the symptoms of distress (House et al., 1989; Spencer et al., 1996). It has been suggested that these issues may confound the assessment of emotional distress and disorder in stroke patients and account for

some variability in prevalence estimates (Black, 1993; Spencer et al., 1997; Gordon et al; 1997; Hibbard et al., 1993).

Various authors have highlighted that continuous measures of distress are designed to measure the severity of disorder, not the disorder itself. A cut-off point on a questionnaire should not be seen as interchangeable with a diagnosis made by structured interviews and diagnostic criteria (Fechner-Bates et al., 1994; House et al., 1989; Schramke et al.,1998; Spencer et al., 1997). Studies that have compared scores on continuous measures to diagnoses of emotional disorder assessed by structured interview and diagnostic criteria report different rates of sensitivity and specificity between scales, and with different cut-off points (House et al., 1991; O'Rourke et al., 1998; Schramke et al., 1998; Schubert et al., 1992). This may well partially explain the variation in prevalence estimates (23% to 48%) across studies that have used a cut-off point on a scale as an indication of depression (Robinson, 2003). However, a similar level of variation in depressive disorder prevalence rates (23% to 47%) across studies that have used DSMII or DSMIII-R criteria and the PSE structured interview is apparent in the same review (Robinson, 2003).

Appreciation of the discussed methodological issues contributed to the development of inclusion/exclusion criteria (please see Chapter 5, section 5.4) the choice of measures (please see Chapter 6, section 6.3 and Chapter 8, section 8.3) and issues explored within the structured clinical interview study (please see Chapter 8, section 8.2).

Some of the variability in prevalence estimates of emotional distress and disorder in stroke studies may reflect real differences rather than methodological limitations. Lower rates of distress and disorder amongst community as opposed to hospital samples, and amongst long-term as opposed to acute stage survivors, may be meaningfully expected because of lower levels of disability (please see section 1.6iii) and the discussed results tend to support this pattern. Also, prevalence studies have been conducted across different countries with different health care systems. Patients treated in specialist stroke units rather than general medical wards in the UK have better functional outcomes (Langhorne et al., 1997) and the possibility that this

may associate with distress is plausible (please see section 1.5). A trial of ongoing rehabilitation support in the year following discharge in Sweden actually found statistically significant lower levels of depressive symptoms amongst those receiving additional rehabilitation therapy (Kotial et al., 1999).

On balance, depressive symptoms and disorder appears to be often encountered following stroke. Preliminary evidence suggests that similarly high levels of anxiety symptoms and disorders may be experienced. Given the high prevalence of stroke itself, it is important to consider the impact of emotional distress and disorder on subsequent outcomes.

1.5: The impact of emotional disorders and distress following stroke

Often studies have found a positive association between depression or anxiety and functional disability (please see section 1.6iii). More relevant to this discussion, statistically significantly less functional improvement at both one and two year follow-ups was found amongst initially depressed patients despite controlling for initial disability levels (Parikh et al., 1990). Subsequent studies have replicated, or partially replicated these findings (Gillen et al., 2001; Herrmann, 1998; Kotila, 1999; Morris et al., 1992; Pohjasvaara et al., 2001; Shimoda and Robinson, 1998) although there have been exceptions (van de Weg et al., 1999). Also, a failure to recover may exacerbate depression making the relationship reciprocal (Astrom et al., 1993; Kotila et al., 1999; Pohjasvaara et al., 2001). On balance, an initially depressed reaction seems to negatively impact stroke patients' prospects of long-term functional and social recovery.

Preliminary evidence suggests that negative emotional reactions to stroke may even influence patients' long-term survival. After adjusting for social and physical factors, minor or major depressive disorder in the acute aftermath of stroke was found to increase mortality rates by seven-fold at fifteen months and by three-fold at ten years (Morris et al., 1993). In a larger study, self-reported distress, but not major depression, assessed at one month, independently associated with one and two year

mortality rates (House et al., 2001). Self-reported distress assessed at six months did not predict mortality at three years in a similarly designed study. However, self-reported hopeless and fatalistic attitudes did (Lewis et al., 2001). On balance, there does seem to be a relationship between poor emotional health and mortality following stroke although the exact nature of the relationship is unclear. (please see House et al., 2001 and Lewis et al., 2001 for further discussion and theories regarding the mechanisms involved).

The affects of negative emotional reactions to stroke are likely to extend beyond the lives of patients. Plausibly patients who are depressed or anxious will be stressful to care for and there is some evidence that patients' and carers' emotional states are related (Wade et al., 1986). Depression following stroke may also engender greater costs to society mediated by increased needs for care (Kotila et al., 1999). For example, depression has been associated with length of hospital stays even when functional recovery was controlled for (Ebrahim et al., 1987).

Emotional well-being in itself is essential to overall quality of life. Mood has been identified as a dominant theme within qualitative studies that have sought to understand stroke patients' own perspectives (Murray et al., 2003). Health status utilities research also suggests that stroke patients themselves rate their emotional health highly (Bosworth et al., 2000). Even with adjustments for physical and social factors, depressed patients were found to be more willing to trade statistically significantly more hypothetical years of life to gain an improved state of health for the rest of their lives, than non-depressed patients.

In conclusion, these findings suggest that emotional distress impacts negatively on stroke patients and their families' lives. The discussed findings underlie the importance of seeking greater understanding of the origins of emotional distress and disorder associated with stroke.

1.6: Competing theories and evidence for emotional distress and disorder following stroke

1.6i: Commonsense understanding of emotional distress following stroke

There is a commonly held assumption that, as a natural 'understandable' reaction to the physical losses involved with stroke, emotional distress is inevitable and untreatable (Robinson and Chait, 1985). Authors of varied persuasions have chosen to question this commonsense position. Reich (1996) suggests 'ageist stereotypes' may operate in such assumptions. Laidlaw et al. (2003) highlight the 'understandability phenomenon'. Distressed reactions can be too easily accepted as inevitable amongst the elderly or those with acquired disability simply because they seem intuitively reasonable.

Depression is not absolutely always a consequence of stroke (Laidlaw et al., 2003; Kneebone and Dunmore, 2000). The ability of many people to elude emotional disorder following stroke contradicts commonsense assumptions. This opens the field up to the study of individual differences in emotional response to stroke.

1.6ii: The lesion location hypothesis for depression following stroke

In complete contrast to the commonsense view that emotional distress is a natural psychological reaction to stroke, Robinson, and colleagues (Parikh et al., 1990; Robinson et al., 1984, 2000) suggested a direct biological aetiology. Having observed lateralised behavioural disturbances in experimentally brain injured rats (Robinson, 1979; Robinson and Coyle, 1980) stroke lesions located in the left hemisphere of the human brain were hypothesised to directly cause the specific syndrome of depression.

A large number of studies have tested this hypothesis. A recent systematic literature review identified 117, although many included duplicate data (Carson et al., 2000). Their meta-analysis of thirty-five suitable studies found that results supporting an association between depression and right hemisphere stroke lesions were actually as common as studies supporting an association with left hemisphere lesions. Other studies reported no association between side of brain damage and depression.

Reviewers have highlighted methodological limitations within the body of lesion location research, including duplicate publications and small unrepresentative samples (Carson et al., 2000; Bhogul et al., 2004; Singh et al., 1998; House, 1996). In addition, they have questioned the theoretical meaningfulness of these studies in terms of human brain structure and function vis-à-vis the brains of rats and affordances of scanning analyses (Carson, 2003; Johnston, 1991; Singh et al., 1998).

House (1996) has criticised the use of the term 'post-stroke depression' (PSD) for giving some kind of credence to the idea of a special type of depression in stroke. He points out that depression amongst other medically ill populations has been viewed as reactive. Whyte and Mulsant (2002) have pointed out that DSMIV has even condoned the lesion location hypothesis with specific reference to it as a 'plausible etiological factor' (page 167, APA, 1994).

The lesion location hypothesis for depression following stroke is not supported by the world literature (Carson et al., 2000). It does actually reflect only one current biological theory that may inform understanding of the phenomenon of emotional disorder following stroke (Whyte and Mulsant, 2002). With hindsight, a disproportionate amount of attention has been given to the lesion location hypothesis for depression (Spencer et al., 1995) which has helped create the 'overemphasis' on depression in stroke research (Anderson, 1991). He has also voiced concern that other aetiological factors (disability, lesion size, cognitive impairment and social functioning) have been paid relatively less attention.

1.6iii: Disability, background and social factors and associations with depression and anxiety following stroke

As discussed previously (please see section 1.5) associations between depression and disability have often been studied and these variables may be reciprocally related across time. Whyte and Mulsant (2002) have recently reviewed cross-sectional and follow-up studies together, and found that only a slim majority (ten out of sixteen) report a statistically significant association between depression and functional disability. The findings of two studies of GAD conflict: statistically significant associations with disability were found at regular intervals between three

months and three years by Astrom et al. (1993) but not at regular intervals between three months and two years by Castillo et al. (1993, 1995). Restriction in the range of disability levels likely to be found in small samples of hospitalised patients may explain the lack of association with emotional distress in many stroke studies (Johnston, 1991).

It is widely acknowledged that emotional disorder tends to associate with certain 'background' variables: age (please see section 1.3) gender (Bebbington, 1999) economic status (Stansfeld, 2003) life events (for example, Brugha et al., 1985) and previous history of emotional disorder (Coyne et al., 1999). Dennis et al. (2000) have reviewed relatively large cohort stroke studies that have included demographic variables. All eight of these studies tested associations between higher levels of depressive symptoms and increasing age, and three actually found this relationship was statistically significant in multivariate analyses. Female gender was statistically significantly associated with higher levels of depression symptoms in four of eight studies, but this relationship was only maintained in two multivariate analyses. Only two studies identified by Dennis et al. (2000) tested association between social economic status and depression: a statistically significant association between lower status and depression was found by Andersen et al. (1995) but not by Burvill et al. (1995).

I have only been able to identify three studies of pre-stroke life events. House et al., 1990) alone used a well-recognised approach for assessing life events, but did not report association with emotional outcome. Both Andersen et al. (1995) and Bush (1999) report a statistically significant univariate association between life events reported for the six month pre-stroke period and depression at one year and six month follow-up respectively. Eleven studies have been found that have addressed pre-stroke history of emotional disorder or specifically of depressive disorder. At face value, a slim majority of studies (six) report a statistically significant association between pre-stroke history of depression or any emotional disorder and depression following stroke (Andersen et al., 1995; Eastwood et al., 1989; Herrman et al., 1998; Kotila et al., 1999; Morris et al., 1992; Schwartz et al., 1993). However five studies do not (Astrom et al., 1993; Dam et al., 1989; Fedoroff et al., 1991;

Sharpe et al., 1994; Starkstein et al., 1989). Some of the inconsistency in these results may be accounted for by inconsistency with which pre-stroke history of emotional disorder has been defined and assessed (Spencer et al., 1997).

The World Health Organisation (WHO, 1980, 2001) highlights the importance of social participation and integration as well as functional disability as an aim of rehabilitation. Twelve relevant studies of social integration have been identified, and mixed results have been found. Simply living alone rather than with someone does not appear strongly related to depression. It was found to have statistically significant association with depression in two studies (Astrom et al., 1993; Anderson et al., 1995) but not in five others (Dennis et al., 2000; Ebrahim et al., 1987; Feibel and Springer,1982; Kotila et al., 1998; Robinson and Price,1982). Decreased contact with wider social groups (friends, neighbours, friends) may be more relevant. It was found to statistically significantly associate with major depression and GAD (Astrom et al., 1993, 1996) at various intervals over three years, and with depression and anxiety symptoms at six months (Bond et al., 1998). However, Costillo et al. (1993, 1995) did not find an association between a combined measure of social ties and social functioning and GAD.

A more subjective perspective on social support has rarely been addressed. However, lacking a 'confiding relationship' was found to statistically significantly associate with depressive disorder in a univariate but not a multivariate analysis at long-term follow-up (Sharpe et al., 1994). Friedland and McColl (1987) found statistically significant associations between eight types of perceived social support and symptoms of depression. However, the size of these associations tended to be small.

Eight studies that have addressed social participation in some way have been identified. Statistically significant univariate associations between social activity and depressive disorder or symptoms have been reported (Andersen et al., 1995; Angeleri et al., 1993; Burvill et al., 1995; Feibel and Springer, 1982; House et al., 2001; O'Rourke, 1996; Sharpe et al., 1994; Wade et al., 1987). However, the relative importance of this relationship appears unclear. Feibel and Springer (1982)

and Wade et al. (1987) report results that support a stronger relationship between depression and social activities rather than functional disability, however House et al. (2001) and Sharpe et al. (1994) found the reverse. O'Rourke (1996) highlights that the 'social' content of measures of activities that have been used (for example, housework, shopping, gardening) are often of doubtful face validity. She actually found a larger association between emotional distress and a measure of social adjustment, and suggests this may be because it captures a subjective perspective of patients' social needs.

The evidence reviewed here suggests that depression and, to a lesser extent, anxiety amongst stroke survivors may be partially understood in terms of background and social factors as well as functional disability following stroke. However, Wade et al. (1987) concluded that none of these factors 'account for much of the depression seen'. House (1996) suggests that relationships between emotion and 'social' factors have often been assumed as 'self-evidently understandable' in stroke research. The importance of theory in the dialectic of science has been reiterated with particular reference to psychological variables (NIMH, 2003; MRC, 2000) and as an essential pre-requisite to the development of psychological interventions (Salkovkis, 2002). The use of psychological cognitive theory may further our understanding of the experience of stroke survivors. Research relevant to this perspective in stroke will be reviewed in Chapter 2. The next section will introduce the development and applicability of cognitive theory.

1.7: Cognitive theory of emotional distress and its applicability to stroke

The Stoics believed:

'Men are disturbed not by things but by the views they take of them'
(Epictetus, p.16 in Blackburn et al., 1990)

Kant further emphasised subjective experience. He proposed that things-in-themselves cannot be known but are interpreted through prior knowledge. These philosophies reflect the essence of cognitive theories (Blackburn et al., 1990) now considered to 'vanguard' psychological approaches to emotion (Dobson and Segal, 1992).

The cognitive paradigm has become dominant through converging influences (Blackburn et al., 1990). This represents a major shift from radical behaviourism in academia and from psychoanalytic clinical practice (Shaw and Segal, 1988). Developmental psychology, notably Piaget's theory, used mental processing and mental structures (schemata) to explain the growth of intellectual ability through childhood. Paradoxically, computing science helped influence the study of human perception and memory as active information-seeking processes and cognitive science emerged (Weishaar, 1993). Eventually, cognitive reformulations were added to behaviourist theory to explain individual differences, for example emotional response to non-contingency (Abrahmson et al.,1978). Pioneers of social-cognitive-behavioural science, most notably Bandura (1969) for example, through modelling experiments and therapeutic techniques, helped develop cognitive academic-clinical alliances (Blackburn and Davidson, 1990; Mahoney and Gabriel, 1987; Dobson and Segal, 1992).

There is now not so much a cognitive theory as many different cognitive theories and therapies for emotion (please see Mahoney and Tyler, 1987). The preceding philosophy, influences and aspects of many other theories (examples being Arnold, 1960; Ellis, 1962; Freud, 1939; Horney, 1950; Lazarus, 1984; Miechenbaum, 1977; Mahoney, 1974, all quoted in Beck, 1976 or Beck, 1987) are acknowledged and incorporated into Beck's (1976, 1987) cognitive theory of emotion (Beck, 1988;

Weishaar, 1993). A clinician and also a collaborative researcher, Beck has done much to forward his conviction that cognition should be assigned primacy in our understanding of emotional disorders (Weishaar;1993).

Beck's theory is currently the most well-recognised approach to understanding relationships between subjective beliefs and emotional distress. Also, cognitive therapy is the most dominant and empirically supported psychological therapy (Salkovskis, 1996). Cognitive therapy involves active, collaborative, directive behavioural and cognitive techniques: formulation, pleasant event scheduling, Socratic questioning, dysfunctional belief monitoring, challenging and reformulation (JS Beck, 1995). Its plausibility in facilitating emotional adjustment to stroke inspired the original application for my studentship. Beck's theory will be briefly introduced as a popular example of the cognitive model.

Beck's theory can be understood by consideration of meaning, structure and process. He conceptualises anxious beliefs as representing meanings of threat, and anxiety disorders as dominated by fearful beliefs. Depressive beliefs involve meanings of loss relating predominantly to the self, and to self-in-relation to one's view of the world and future ('The cognitive triad'). Empirically support has been found for:

'...the claim that depressed people rate *themselves*, *their* prospects for the future, and *their* fitness for meeting life's demands more negatively...'

Haaga et al. (1991).

Structurally, beliefs are organised into levels of increasing stability, increasing depth of consciousness and decreasing accessibility. Superficial voluntary thoughts are easily accessible, but more important to distress are what Beck termed 'Negative automatic thoughts'. These thoughts are often repetitive, usually out of awareness, but accessible when affect is high. They can then be difficult to suppress; for example, a physically dependent stroke patient may think 'He shouldn't have to do this for me'. Deeper still is the intermediary level of a persons assumptions and values. These may be accessed through therapy, when affect is very high, and may reveal themselves as conditional beliefs ('If...then' statements). For example, a stroke patient may think 'If I don't improve, I'll be a burden'. Negative schemas or

networks of stable, rigid 'core beliefs' are considered to exist deep in consciousness; they may be regarded as a potently distilled version of early negative self-evaluations. These require the most affect for access, but may be inferred through dominant themes amongst other beliefs, or through therapeutic techniques (Laidlaw et al., 2003). For example, a stroke patient may have the core belief 'I am a burden'.

Beck's theory is dynamic in that deeper beliefs 'drive' the more surface level beliefs through negative thinking processes. Anxiety involves catastrophising or overestimating probability and severity of threat, and underestimating resources to deal with it. (Beck and Clark, 1988). Thinking biased towards depression involves negative generalisations, selective abstraction of negative information, arbitrary interference, dichotomous thinking and 'should' imperatives (Beck, 1976; 1987; J.S. Beck, 1995).

In earlier accounts negative thinking processes were described as erroneous, primitive or unrealistic (Beck, 1976). There has been a lot of philosophical controversy and research about whether distressed individuals' thinking is unrealistic (Alloy and Abramson, 1979; Coyne and Gotlib, 1983; Mahoney and Gabriel, 1987) and/or the perspective that depressed people actually do face more negative circumstances (Brown and Harris, 1978; Oatley and Bolton, 1983; Power, 1987). This issue is particularly relevant to those facing the negative circumstances of chronic medical illness (Moorey, 1996). It therefore seems more appropriate to simply consider a continuum of negative through to positive thinking. This acknowledges and accepts negative circumstances as having relevance but also highlights the manner in which negative thinking can produce a further bias towards negative belief.

Many cognitive theories imply a causal pathway between cognition and emotion (Dobson and Segal, 1992). However, Beck (1987) specifically does <u>not</u> argue that negative beliefs <u>cause</u> the onset of emotional disorder. The theory has been developed to incorporate reciprocal interactions between biological, environmental and behavioural systems. For example, an environmental event, or a biological

stressor or vulnerability may trigger a disorder. Beck does suggest that activated negative schemas are believed to contribute to the maintenance and build-up of a depressive episode. The primacy of cognition and yet the non-causal nature of Beck's theory makes it accommodating to exploratory pioneering investigation. This is ideal for this early stage of research into cognition in distress following stroke.

Cognitive theory is flexible and so considered broadly applicable to the circumstances of distressed stroke patients. Recently, Laidlaw et al. (2003) have developed the applicability of the cognitive model to older populations and stroke patients using the current International Classification of Functioning model (WHO, 2001). 'Excess disability' is a key concept in this formulation, and captures the way in which negatively biased thinking and beliefs may engender decreased participation in addition to physical impairment. Research from other cognitive perspectives that specifically addresses emotional adjustment to illness, disability and ageing is also considered relevant. Therefore this will be considered in combination with the central meanings outlined by Beck in the development of hypotheses (please see Chapter 2).

It is relevant to consider boundaries for what, as a relatively pioneering piece of research, this thesis could aim to address. I decided that it was important to consider possible negative thinking processes further in the development of the hypotheses because of their theoretical importance and as reference for interpretation of the results (please see Chapter 2, particularly section 2.3ii). However, due to practical constraints (for example a lack of relevant measures) I decided not to try explicitly to measure negative thinking processes. Some authors propose that qualitative interviews capture 'process' in individuals' experience (Bendz, 2000; Clarke, 2003; Hafsteindottir and Grypdonck, 1997; Hilton, 2002). However, I did not expect the qualitative strand of this study to fully explore the range of thinking biases proposed by cognitive theory (please see Chapter 8). However, this aspect of the study allowed for the possibility that some insights regarding negative thinking processes as well as negative meanings may be gained.

As outlined in more detail later (please see chapter 3), the aim of this thesis will be to measure and explore negative subjective meanings of stroke and its effects, and to test their associations with distress. As regards the depth and structure of cognition, clinical opinion is that numerous sessions are required to gain access to many clients' underlying assumptions, values and eventually core beliefs (J.S. Beck, 1995). The low accessibility of deeper cognitive structures suggests that they will not be amenable to measurement using conventional questionnaire techniques, which will form the main part of this work (please see chapters 4-9). However, the central meanings, or depressed and anxious themes of Beck's theory do seem to be captured using questionnaires (Clark and Steer, 1996). It is probably right to regard bodies of survey research, for example self-esteem studies (please see section 2.3i), as tapping more surface level voluntary and automatic cognitions (Dobson and Segal, 1992). This position will be reflected by use of the term 'beliefs' in this thesis.

1.8: Summary and rationale for the present study of beliefs related to emotional distress following stroke

The prevalence of stroke and related disability is high and set to increase. A considerable literature addressing emotional outcome now exists. Various factors complicate the assessment of emotional outcome in stroke. Nonetheless, the weight of the evidence suggests a high prevalence of negative emotional outcomes. There are good grounds for studying distress (both anxious and depressive symptoms) amongst stroke survivors.

It is important to increase our understanding of emotional distress following stroke because it impacts negatively on survivors' well-being, functioning and survival. Evidence for a specific organic cause for depression following stroke is weak. Psychosocial research in stroke has not been strongly theory driven. The role of patients' own subjective beliefs has not been considered in the literature as reviewed in this chapter.

Cognitive theory provides a broad and sophisticated model from which to study the relationship between beliefs and distress. As yet there is little research that has applied cognitive theory specifically to the study of distress amongst stroke patients. Knowledge of stroke-specific negative beliefs and their associations with distress may prove useful to the specific implementation of cognitive behavioural interventions and related outcome measures. To build a preliminary framework from which to conduct this study, some piloting work was done and a widened search of the medical and disability literature conducted. Based on this work, a literature review of beliefs with potential relevance to distress following stroke will be presented in Chapter 2.

Chapter 2

Beliefs in 'stroke' and 'its effects'

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2.1: Forward

Preliminary ideas were gained from relevant literature in combination with piloting (please see chapter 6) and other sources. These involved meetings with my supervisors and other local CBT therapists experienced with stroke or older adults, observation of some CBT therapy sessions, observation of stroke team meetings and allied health professional therapy sessions and volunteering at an aphasia support group. This experience convinced me of the usefulness of combining open-ended investigation with a more structured approach (please see method chapters 4,8 and 9 for further explanation)

The key observation from piloting was the difference between 'Stroke' and 'Its effects'. Frequent comments suggested that the condition following stroke was not perceived as an illness, for example:

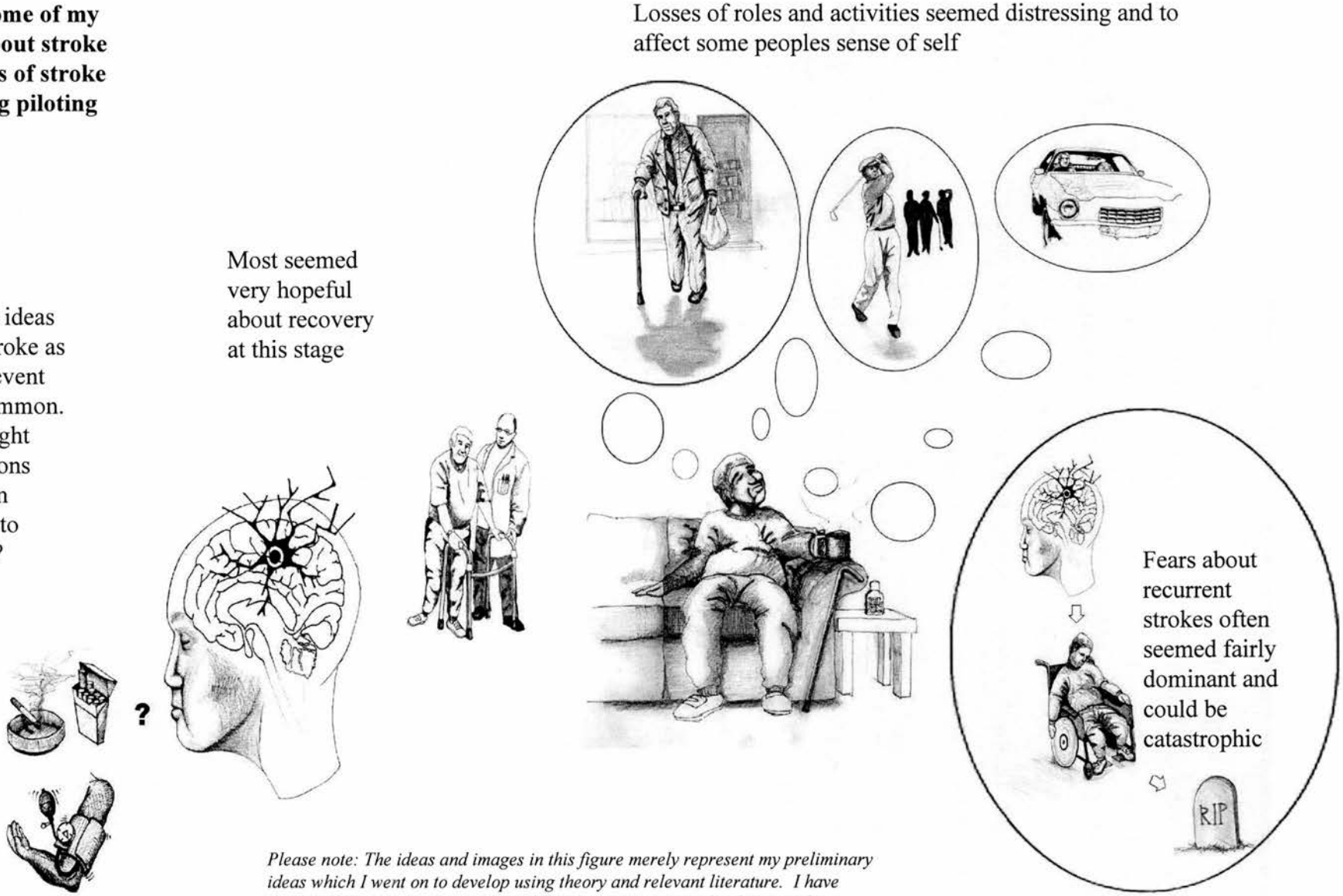
"I had an illness which caused a disability. The illness has passed and I've been left with the aftermath."

A 52yr male.

Generally 'Stroke' tended to be described as a brief initial sudden event, or illness, often as involving damage to the brain. In contrast, terms used to describe present predicaments were 'the aftermath', 'disability', 'the left-overs', or 'its effects'. 'Illness' was never used in reference to residual effects of stroke. Even severely disabled participants commented categorically that they did not 'feel ill'.

The main domains of ideas formed focused less on 'Stroke' and more on the readily apparent relevance of 'Its effects' (please see Figure 2.1). These ideas were developed using the available stroke specific literature, and supplemented with cancer and cardiac literature (for 'stroke' beliefs) and acquired disability and ageing literature (for 'its effects' beliefs). Concepts from a range of cognitive theories were adopted. Nonetheless, an emphasis on negative beliefs about the self, self-in-relation to the world and future, and meanings of threat compatible with Beck's theory of distress was maintained in the development of hypotheses. This will be discussed in further detail in section 2.5.

Figure 2.1: Some of my main ideas about stroke and the effects of stroke formed during piloting



Please note: The ideas and images in this figure merely represent my preliminary ideas which I went on to develop using theory and relevant literature. I have displayed them to emphasise that I felt it was important to develop a study addressing beliefs about the effects of stroke as much as beliefs about the illness stroke.

2.2: Attributions for the event 'stroke' and 'its effects'

2.2.i: Attributions and control

A key characteristic of stroke is that it is uncontrolled. It can happen quite suddenly, without warning and patients often report it came 'Out of the blue'. Emotional reactions to sudden events with negative consequences have been widely studied in psychology. Two central constructs that have been examined are causal attributions and control (for example; Kelley, 1971; Abramson et al., 1978; Taylor, 1983; Petrie and Weinman, 1997). When challenged by inopportune events individuals are considered to ask:

'Why?'.

The nature of the attributions they make and the implications of these assumptions for individuals' perceptions of control over their circumstances has produced a complex set of theory and results to review.

2.2.ii: Attributions per se and emotional adjustment

Attributional theory and theories of cognitive adaptation suggest that in usual circumstances, healthy individuals tend to assume a certain sense of control in the world (Kelley, 1971; Taylor, 1983, Thompson et al., 1989). Kelley's (1971) attributional theory proposed that, like scientists, lay people are motivated to rationalise why events occur. His conceptualisation of lay perceivers further specified them as 'applied scientists', therefore with a tendency to bias their causal analyses towards factors perceived as being controllable. Kelley's theory has been interpreted as a hypothesis that simply making causal attributions will positively associate with emotional adjustment (Michela and Wood; 1986; Taylor, 1983).

Research with medical populations has not always supported this position (Michela and Wood, 1986). For example, ninety-five percent of breast cancer patients were found to identify a cause (Taylor et al., 1984). Scores on a composite measure of emotional adjustment were not significantly higher amongst patients who had identified a cause, and it was concluded that simply making causal attributions was unimportant to adjustment. However, as so few women had failed to identify a

cause, the data lacked statistical variance.

Two relevant small studies with stroke patients were available for review. Forty patients, nine months following stroke, were asked:

'Have you found a cause for your stroke?'

Thompson (1991)

Sixty percent reported they had, and a just statistically significant association was found with adjustment. The measure of adjustment was a composite of a self-report depression scale plus a 'Meaningfulness of life' scale. Therefore, caution is required in interpreting this result as an indication of an independent association between having made a causal attribution and depression.

Larner and Sampson (2000) found only thirty-eight percent of twenty-one rehabilitation ward stroke patients, identified a cause. Patients, with high levels of depression according to a cut-off on a scale, were less likely to report a cause. Generalisability is limited as the sample was small and only rehabilitation patients. However, this small available evidence does seem to support a role for causal attributions and emotional adjustment to stroke.

In contrast to the proportion of participants who reported causal attributions in these studies, most patients do report some idea about the cause of their stroke in clinical practice (Tinson, 1999, personal communication). It may be that these studies used too superficial questioning to access attributions which were not well formed or confidently held. This may have confounded results with other factors such as assertiveness or deference to medical opinion. In Taylor et al.'s (1984) study in which nearly all breast cancer patients identified a cause, the line of questioning was more probing:

'...most people have some hunch or theory about why they have it. I wonder if you would mind sharing your hunch or hunches with me...'

p.492, Taylor (1984)

If most patients do hold causal attributions, the question moves on to consideration of the specific type of attributions and associated beliefs in control and the association of these with emotional distress.

Note on terminology

Beliefs in control over stroke recovery will be examined in section 2,4i. However, the interest in control here is in relation to causal explanations (perceived risk factors) for illness.

2.2iii: Objective consideration of risk factors and their controllability

Types of risk factors and their objective modifiability will be considered to elucidate how sources of information may shape stroke patients' beliefs. Firstly, behavioural risk factors (smoking, diet, exercise) are implicated in stroke and considered objectively subject to modification by individuals. They are:

'Risk factors which you can do something about yourself'

(p, 4, CHSS, 1998)

However, although there is objective potential for self-determination, the evidence suggests that awareness of behavioural causes in insufficient to motivate actual change (Ebrahim and Davey-Smith, 1997) perhaps because change is difficult. Certainly smoking is considered addictive (Irvin and Brandon, 2000) and relapse appears normative following personal attempts to tackle obesity (Garner and Wooley, 1991).

In contrast, established medical opinion is dismissive of other psychological or social risk factors for stroke, for example:

'Stress is not a cause of stroke'

(p, 5, CHSS, 1998)

However, there is emerging evidence suggesting that depression (Kennedy et al., 2001, Larson et al., 2001; Ohira et al., 2001) and distress (May et al., 2002) are

implicated as causal factors.

Whether or not other psychological or social risk factors are considered objectively modifiable is also a moot point. 'Stress', for example, is a construct with a whole theory and research base of its own, and its modifiability tends to be considered more in terms of perceived rather than objective personal and environmental resources (Lazarus, 1991). In contrast, 'Overwork', for example, could be seen as objectively modifiable, depending on personal circumstances (for example, the opportunity for early retirement).

'Unmodifiable' medical factors such as ageing, genetics and ethnic minority are, less controversially:

'...factors which can not be changed'

(p, 21, CHSS, 1998)

However, stroke is becoming a condition in which medical treatment is able to play a role in reducing risk from modifiable medical risk factors such as blood pressure, cholesterol and diabetes (Byington et al., 1999; Dyken, 2001). Control of these is largely considered to be things:

'...your doctor can do something about'

(p, 4, CHSS, 1998)

Stroke patients are not lone attributors. Health promotion campaigns and the popular media exist prior to one having a stroke (Weinman and Petrie, 1997). In our culture it is hard not to know that behaviour (smoking, diet and exercise) influences health (Blair et al.,1999) and indeed:

'Someone's life: Your own, Think about it'

(Health Education Board for Scotland, 1999).

Furthermore, following stroke, it is recommended that health professionals reinforce these messages (SIGN, 2002).

2.2.iv: A past research focus on 'Self' versus 'Other' blame attributions for illness and emotional adjustment

An oft-quoted study of spinal cord injury patients investigated coping and attributions of 'self' versus 'other' blame (Janoff-Bulman and Wortman, 1977). Blame seems to be an appropriate subject with these patients who may have been injured during leisure activities or in contrast been shot at, injured at work or as a passenger in a car. Regardless of objective blameworthiness, worse coping (operationalised as nurse and social worker ratings) associated with 'other' rather than 'self' blame. This contrasts with the attributional theory in which attributing negative outcomes to oneself is considered depressive (Peterson and Seligman, 1984). The authors explain their results in view of the finite nature of spinal cord injury impairment. Blaming others was considered to involve 'victims' in an unproductive resentful cycle, but self-blame to allow resolution with the past and therefore better future adaptation (Janoff-Bulman, 1979).

Often inspired by this study, 'self' versus 'other' blame became the main research focus regarding illness attributions and emotional adjustment. However, a review by Michela and Wood (1986) suggests that no association between distress and self blame has been found in cancer (for example, Taylor et al., 1984) or myocardial infarction research (for example, Plotkin-Israel,1984, in Michela and Wood, 1986). In stroke, self-blame neither associated with adjustment (Thompson, 1991) nor depression (Larner and Sampson, 2000).

Michela and Wood (1986) identified two breast cancer studies that found blaming another to be emotionally maladaptive (Taylor et al., 1984; Timko and Janoff-Bulman, 1985). However, they point out that most studies were unable actually to statistically test associations between emotional adjustment and 'other' blame because it was so rarely endorsed. In Larner and Sampson's (2000) study, all stroke patients disagreed with an 'other' blame statement. Agreement with the same statement was rare in Thompson's (1991) study, and an association with adjustment was not found.

Compared to the particular case of spinal cord injuries, there is simply not a direct

intuitive relevancy of blaming another person, or globally blaming oneself, for the sudden onset of stroke or other illnesses. Therefore, with hindsight it is unsurprising that empirical work has not supported an association between blame attributions and emotional adjustment.

2.2.v: Lay experience and illness attributions

More recent research in the illness representations paradigm has used open methods or wide-ranging checklists to assess attributions and a comprehensive model of causal attributions portraying everyday lay beliefs has been developed. Emotional outcomes have been studied much less than behavioural outcomes (Marteau and Senior, 1997). However, this literature provides a useful background to understanding the types of causal attributions for illness that lay people actually do make.

Many of the attributions reported by cardiac patients do actually reflect recognised medical and behavioural risk factors (family history, blood pressure, smoking, lack of exercise). However, more emotional or social causal beliefs (stress, overwork, family problems) are also found (French et al., 2001; Petrie and Weinman, 1997) even after educational sessions emphasising behavioural risk factors (Fielding, 1987). Lay representations tend to be multi-factorial (Marteau and Senior, 1997; Petrie and Weinman, 1997). For example, Myocardial infarction (MI) patients were found to make approximately three causal attributions (Fielding, 1987).

Patients' knowledge and sources of illness knowledge (for example, patient education) appear relevant to attributional choices. Knowledge has even been referred to as 'informational control' (Skinner, 1996). However, as she argues, it is questionable whether knowledge alone can guarantee a subjective sense of control. Certainly, in stroke a systematic review found that information only improved patients' knowledge but not their mood (Foster et al., 2004).

As causal knowledge may be gained only after the event it is does highlight the need to distinguish between retrospective and prospective perceived control (Skinner, 1996). From now on reference to perceptions of control may be specifically

regarded as prospective beliefs in control.

2.2vi: Types of lay illness attributions and distress

It has been suggested that behavioural attributions may be most emotionally adaptive, particularly in comparison to psychological attributions (which are sometimes referred to as 'characterlogical' in this context (Janoff-Bulman,1979, Timko and Janoff-Bulman, 1985) via the mediation of control. For example, Michela and Wood (1986) suggest that a patient who attributes his heart attack to smoking may be 'very reassured' by the decision to quit, but a patient who attributes his heart attack to nervousness, is likely to regard this as a personality trait beyond the exertion of control.

However, research has generally failed to support the proposition that behavioural attributions are especially emotionally adaptive or that psychological attributions are particularly maladaptive. Cervical cancer patients who made personality attributions were no more distressed than patients who made behavioural attributions (Gotay, 1981, in Michela and Wood, 1986; Malcerne, 1995). A composite measure of attributions including personality and worry was actually found to negatively correlate with anxiety following MI (Michela, 1981, in Michela and Wood, 1986). Affleck et al. (1987) found no relationship between type of attribution (behavioural, psychological or medical) and emotional adjustment to rheumatoid arthritis. Overall, type of attribution per se, does not seem to associate with distress.

2.2vii: Lay illness attributions control perceptions and distress

At the extreme end of the spectrum lay perceptions and objective evidence regarding uncontrollability seem to concur. With myocardial infarction (MI) patients, Fielding (1987) found causal controllability scores of zero were reported for: 'family history' and 'age'. However, more variation in perceived control regarding behavioural, psychological, or other medical risk factors may be expected and may mediate lay attributions and distress.

Fielding (1987) found that of all risk factors reported behavioural attributions (smoking, overweight, diet, lack of exercise, lifestyle) produced the highest

controllability ratings. They were rated as significantly more controllable than modifiable medical factors (atheroma/cholesterol, other illness) which were in turn rated as more controllable than psychological factors (overwork, worry, stress, frustration/anger). Unfortunately, as Fielding (1987) suggested, health professionals' opinions during three sessions of patient education may have influenced reports of control behavioural factors. It seems especially suspect that the highest control perceptions were for smoking. Also, unfortunately, emotional distress was not assessed in this study.

One breast cancer study assessed perceived control and emotional distress in relation to attributions. Characterlogical versus behavioural attributions were considered (Timko and Janoff Bulman,1985). Neither type of attribution was found to directly associate with distress. However, the proposed mediation of control perceptions was supported. Once a complex pathway of different perceived control beliefs (retrospective control, prospective control, perceived recurrence control combined with perceived mastectomy success, general perceived invulnerability to cancer) was taken into account, an inverse association between behavioural attributions and depression emerged.

The evidence reviewed suggests that apart from unmodifiable medical factors, perceived control does not associate with the type of attribution per se. However, it may well mediate between attributions and emotional distress. It has been suggested that a research focus that emphasises perceived control related to lay attributions for illness may be especially fruitful in understanding emotional adaptation to cancer or heart disease where:

'The possibility of recurrence looms large'

Michela and Wood (1986).

I would add that this is also the case in stroke.

It should be pointed out that there are many aspects that may mediate or moderate overall perceptions of control and any relationship with emotional outcomes

(Bandura, 1993; Skinner, 1996). For example, beliefs regarding the relative importance of risk factors ('potency', Fielding, 1987) belief in the utility of tackling a risk factor, for example, quitting smoking ('outcome efficacy', Bandura, 1989) and confidence in being able to do so ('self-efficacy', Bandura, 1989). Another issue concerns the perceived agent of control (Skinner, 1996). 'Self-as-agent' can straightforwardly provide a sense of 'being in' control, but also 'others-as-agents' may provide a sense that 'things are under' control (Antonovsky, 1979; Olsson et al., 2003). Independent and equally strong associations with emotional adjustment were actually found for both 'vicarious' and 'personal' control amongst breast cancer patients (Taylor; 1984). Stroke patients may gain a sense of control through medical treatments and practice (for example, reassurance that blood pressure has decreased at a check-up) as well as from their own actions.

2.2.ix: Summary and notes on developing a hypothesis for causal controllability

'Causal controllability' refers to perceived prospective control (regardless of the perceived agent of control) over perceived causes of stroke. Causal attributions for illness research provided the greatest wealth of theory and evidence to review, but a relationship between specific types of attributions and emotional adjustment has not been found. However, the proposition that causal controllability may mediate between causal attributions and distress has initial support, and concurs with the emphasis on control in Kelley's original attributional theory.

A focus on causal controllability seems particularly relevant to emotional adjustment to stroke due to the possibility of recurrence. The assessment of causal controllability necessarily involves a preliminary assessment of causal attributions. The preceding considerations of past research and information provision processes suggest that an open but probing approach to the assessment of causal attributions is to be recommended.

2.2.x: Selective incidence ('Why me?')

The title of Maria St Denys' (1998) personal testimony to coping admirably with stroke is poetically incongruous:

'Stroke of fate'

she suggests that the idea of fate is negatively symbolic and something voiced in clichés by those people with 'doubts and fears'. The perception that one is one of those who luck or fate failed to protect, but selected for stroke, may indeed be distressing.

Lerner (1965, 1980) suggests that in usual circumstances people assume good is justly rewarded and bad duly punished. His theory is supported by experimental research using students. For example, they regarded a student who had won a lottery as hardworking and deserving, but derogated another they saw subjected to uncontrollable shocks. It is as if their erroneous judgements were driven by the need to preserve their own views of their interaction with the world as just and fair.

Ordinarily, healthy people may perceive themselves as invulnerable to illness (Abramson, 1988). Given modern health campaign messages, even qualitative research has highlighted 'The Prevention paradox' whereby health risks are recognised as a statistical group phenomenon, but the observation that many 'at risk' individuals do not become ill is often made (Wiles, 1995). Healthy people who chose to focus on the latter may hold optimistically biased assumptions of justice in relation to their own illness vulnerability.

Individuals, who may have assumed that the world will treat them justly, under the illusion that they may be spared the development of illness, may be vulnerable to cognitive dissonance if actually faced with stroke and its effects. Thompson (1991) applied 'Just world' theory to the attributional beliefs of individuals who had actually experienced stroke. She hypothesised that, while assumptions of control in the world are likely to set in motion the question of 'Why?', assumptions of justice may lead to the question:

'Why me?'

She considered that assumptions of a just world may be shattered by the experience of sudden disability. this is often referred to as 'selective incidence', as if one feels selected by fate for misfortune (Abramson, 1988). This perspective has also been voiced by Turnquist et al. (1988) and corresponds well with Beck's description of a hostile view of one's position in the world. In these terms 'Why me?' would be expected to associate with distress.

Just over half of stroke patients reported having asked 'Why me?' and a moderately high association between the frequency with which this was asked and adjustment supports the selective incidence hypothesis (Thompson, 1991). A similar proportion were found to ask 'Why me?' by Larner and Sampson (2000) and a similarly sized correlation with depression was found; however, this was not statistically significant, possibly due to sample size (twenty-one participants). A relationship between distress and 'Why me?' has also been found three weeks after spinal cord injury (Silver and Wortman, 1983, in Michela and Wood, 1986) and at a longer follow-up (van der Bout et al., 1988).

Recognition that misfortune is often arbitrary ('threat-resistant life schemas') may enable cognitive adaptation to negative events (Thompson and Janigan, 1988). This may increase with age, as people become aware of their greater vulnerability to illness (Abramson, 1988; Weinman and Petrie, 1997). By middle-age, adults often report possible ill health as a prime fear and by late adulthood, maintaining 'relatively good health' tends to be a prime hope (Hooker 1999). Therefore awareness of vulnerability clearly does not stop older adults caring deeply about their health. However, it may protect them to some extent from 'Why me?' dilemmas following stroke.

For the reverse of the preceding reasons, younger individuals may struggle cognitively to come to terms with stroke. Personal accounts of younger stroke survivors suggest this may be the case. Kathleen Molloy, Scottish representative of

'Different strokes', entitled her personal account of a stroke aged fifty years 'Why me?' (Molloy, 2004). Robin Cant, a lecturer on disability, who lived a relatively healthy lifestyle before his stroke in middle age, described his feelings of injustice as:

'...if I had been some kind of negative lottery winner, Why me? After all, the world is full of middle-aged men who smoke heavily and waddle around with great beer bellies. How is it they seem to get away with it?'

Cant, p 300, 1997

2.2.xi: Summary and notes on developing a hypothesis for 'Why me?'

A small but consistent literature supports the importance of examining the relationship between 'Why me?' attributions and emotional distress following stroke. There is interest in re-establishing study of selective incidence in health psychology generally (Senior, 2002, personal communication). By addressing a sense of injustice, study of 'Why me?' adds a dimension aligned to the concept of a negative worldview. Finally, although specific hypotheses regarding possible arbitration of selective incidence, by factors such as age were not developed, it is acknowledged that they may influence any general relationship between 'Why me?' attributions and distress.

2.2xii: Finding positive meaning

Early chapters of Kirk Douglas's book on his personal experience of stroke reflect severe distress, even suicidal ideation and contradict the title:

'My Stroke of Luck'

Douglas, 2002

However, through re-evaluating the importance of loved ones, recognition of past selfishness, acting as a stroke survivor in 'Diamonds' and charitable work, he goes on to achieve a sense of finally having found positive meaning in adversity:

'We all want happiness. I've learned we achieve happiness when we seek the happiness and well-being of others.'

p,194, Douglas, 2002

Theories of cognitive adaptation suggest that the search for a 'silver lining' in an otherwise negative event may well be a fairly ubiquitous endeavour. As well as beliefs in justice, in usual circumstance people are considered to hold benign assumptions of meaning or purpose in the world (Janoff-Bulman and Frieze, 1983; Taylor, 1983; Thompson,1985). In order to be able to make a positive attribution of meaningfulness, people are considered to cognitively reinterpret events, through comparisons with others even more unfortunate, or through a refocusing on positive aspects of their lives (Thompson, 1985).

The search for positive meaning amongst medical populations has been most substantially investigated for cancer, particularly breast cancer. For example,

'A remarkable ability to construe personal benefit from potential tragedy'
Taylor (1983)

was found amongst breast cancer patients, two years post-onset, in which fifty percent reported only positive changes in their lives and only seventeen percent reported negative ones. Positive meanings in cancer range from the personal (joy in the small pleasures in life, discovery of new talents, healthier lifestyles, consideration that it could be worse) the interpersonal (greater appreciation of others, improvements in family closeness, compassion for others) to the spiritual (LaFortune Fredette, 1995; Taylor et al.,1984; O'Connor et al., 1990; Zemore et al., 1990). Seventy-seven percent of members of an amputees golf club reported something positive had happened as a result of their amputation, while fifty-five percent reported 'feeling lucky' (Dunn and Dutko, 1993, in Dunn, 1994). Quite profound meanings, often of a strong religious nature, have also been reported by spinal cord injury patients (Janoff-Bulman and Wortman, 1977).

Various classes of positive meanings were reported by half the stroke patients in Thompson's (1991) study: a greater appreciation of life, the ability to slow down, compassion for others and appreciation of family and friends. A moderate-sized association between having found meaning and the adjustment measure was found. However, as this measure was a composite of a self-report depression scale plus a

'Meaningfulness of life' scale (including meaning and purpose items) it can only be taken as tentatively supportive of a relationship between having found meaning and emotional distress. Only three of the twenty-one stroke patients in Larner and Sampson's (2000) study reported having found meaning following stroke, which precluded testing an association with depression.

Age differences may partly explain these conflicting findings. Larner and Sampsons (2000) participants were generally older than Thompson's (1991) who also found a significant association between younger age and having found meaning. She suggests this may be because younger patients have more opportunity to pursue alternative plans and goals. However, disability will surely limit opportunities for stroke patients regardless of age. It may be that younger people have a greater emotional need to search for compensatory meaning in their experience. In contrast, older people may have a greater sense of positive meaning in life stemming from past achievements and so feel less need to begin searching for more after stroke.

A review of autobiographical memory research tentatively supports this position (Fitzgerald, 1999). On the one hand, older adults have been found not to 'live in the past' because, as for younger adults, recent years predominate when memory is probed. Nevertheless, memories from early adulthood (known as 'the bump') rather than from any other period appear to remain as salient or 'flash bulb' memories. This is considered to support the importance of this period of life for people's lifetime psychological development. Fitzgerald (1992) found older adults with depression to report less 'bump' memories than non-depressed others. Fitzgerald (1999) suggests that 'bump' memories in older adulthood may possibly provide some ongoing sense of having had a meaningful life.

Thompson (1991) also found that reports of having found meaning were also associated with less severe disability. Therefore, particularly negative circumstances may well limit the extent to which people are likely to derive meaning. A meta-analysis of positive re-evaluation following a wide range of negative events other than illness did not show an association with distress (Penley et al., 2002). Indeed in very bleak circumstance, people have been found to report a sense of

meaninglessness (Lehman et al., 1987).

2.2xiii: Summary and notes on developing a hypothesis for 'Found meaning?'

The cancer literature suggests that positive meaning is often found despite the adversity of this illness. The small stroke literature is inconsistent, but tentatively supports this possibility. Elsewhere, it has been suggested that empirical testing of cognitive theory of distress should examine differences in positive as well as negative beliefs (Haaga et al., 1991). Other psychologists and psychiatrists have begun to emphasise the potential in studying positive psychological adaptation generally (Gillham and Seligman, 1999) in medical populations (DHP, 2004) and amongst stroke patients (Johnston, 1991). Study of positive beliefs amongst those faced with the negative changes stroke brings to their world appears to be an apt subject.

2.3: Negative self evaluations

2.3i: Introduction to self. identity, self-esteem in distress, and identity resiliency in normal ageing

Self-beliefs occupy a central place in a wide range of psychological theories, leading to many inter-related terms (Beck, 1987; Fiske and Taylor, 1991; Higgins, 1987; Markus and Nurius, 1986; Pervin, 1993). 'The self', or 'self concept' has been described as:

> 'The totality of the person's thought and feelings with reference to himself'
> (p. ix, Rosenberg, 1979)

These range from quite factual ('a wife') to more abstract personality domains ('caring'). Features of self will vary in their accessibility and relate to environmental contexts such as work, family, friends (Cantor and Kihlstrom; 1987).

There is a general consensus that the self develops through socialisation (Pervin, 1993) and the early self is often described in Cooley's (1902) terms as 'a looking glass self' (quoted in Fiske and Taylor, 1991). Early adulthood is seen as a time by which individuals will have a well-established sense of 'inner sameness' (Erikson, 1968) or 'Core constructs' (Kelly, 1955) or 'identity' (Atchley, 1989). This includes a moral and motivational perspective, considered integral across situations, and of relatively high personal value (Atchley, 1989; McAdams, 1991). This is reflected in open-ended research in which the 'me I know' is often described in terms of life themes 'I've always been honest' (Whitbourne, 1986). The abstract quality of developed selfhood is reflected in adults' ready ability to respond to trait adjective self-concept scales (Rosenberg, 1979).

Self-esteem may be viewed in a static way as self-evaluation in mainly positive 'high', or less positive, 'low' terms (Baumeister, 1993). Associations between this static view of low self-esteem and depressive symptoms tend to be high (Shaver and Brennan, 1991) and this is commonly recognised (Baumeister, 1993). 'Worthlessness' is included as one of the additional symptoms within diagnostic criteria for depressive disorder (APA, 1994) although it is important to recognise that not all depressed people will have very low self-esteem (Blaine and Crocker,

1993).

Self-esteem may also be viewed in dynamic evolving terms. William James (1890, cited in Atchley, 1989) actually described it as a function of perceptions of success regarding one's ideal expectations of self and his successors have also emphasised the 'ideal', 'should' or 'potential' aspects of self-esteem (Erikson,1968; Heider, 1958; Horney, 1945; Kelly, 1955; Rodgers, 1961; Stack Sullivan, 1953, cited in Pervin, 1993 or Fiske and Taylor, 1991). Higgins (1987) specifically elaborates on possible dynamics between identity, self-evaluations, and affect. He proposes that the perception of accessible discrepancies between 'present' versus 'ideal' or 'ought' self-beliefs represent ongoing fluctuations in self-esteem that are affectively involving: the greater the discrepancy, the greater the discomfort.

In normal circumstances, there appears to be no tendency for self-esteem to decline throughout life (Baltes, 1991), suggesting that adult identity appears remarkably 'resilient' to change (Atchley, 1989; Brandstater, 1999). This may be partly achieved by the ongoing active processes of assimilation and accommodation. For example Baltes (1991) suggests older adults may use mnemonic techniques to compensate for declining memory and Brandstater (1999) that they may attribute memory failure to temporary situational constraints. In addition the ageing identity may 'immunise' itself against perceived discrepancies and loss of esteem. This may be by adopting more lenient standards for performance, or by making downward comparisons to negative stereotypes of old age (Brandstater, 1999), and also by retaining 'having been' status in the present, such as occupational identity (Atchley, 1989).

The theories discussed provide a dynamic overview of identity as a comprehensive thinking, feeling and acting cognitive resource, from associations between discrepancies and distress, and yet the tendency for a continuous sense of identity. However, the non-normative adult experience has not been addressed by general self-theories (Becker, 1993). The effects of stroke may be viewed as circumstances that test accommodative processes and provide chronically accessible self-discrepancies in certain domains. Individual differences in the degree to which identity is ultimately challenged may help understand variation in distress levels

following stroke. Two theories, both developed from qualitative studies and yet with different emphases on identity change versus maintenance or adaptation will be introduced next.

2.3ii: 'Biography-body-self-conception' theory and 'Acceptance of disability theory' and their relevance to stroke

'the body is the medium by which conceptions of self are formed'
Corbin and Strauss, p155, 1987

This is the philosophy of Merleau-Ponty (1945 cited in Corbin and Strauss, 1987) that has been applied to the issue of identity amongst chronically ill patients. In relation to this thesis, Corbin and Strauss' (1987) theory serves only as background to identity change research, in particular to published qualitative studies that share this philosophical stance (please see section 2.3 v)

Corbin and Strauss (1987) see identity as subjective and dynamic (as having 'biographical time'). However, they place a particularly strong emphasis on what they view as a mainly unconscious 'very special' relationship between 'body' and identity ('body' being 'capacity for action' and 'body image'). In contrast to the broad cognitive perspective, the main thrust of this theory narrows identity down to physical and functional attributes and abilities. They actually propose that 'biography, body and self conception' exist in such a 'tightly bound relationship' that it is akin to a chain.

They frame the consequences of chronic illness for 'identity' through this chain in dramatic terms. Perceptions of a 'failed', 'useless' or 'unfamiliar' body are asserted to cause biographical disruption and profound levels of 'identity disintegration', as the following quotes illustrate:

'When chronic illness strikes, there follows to some degree a perception of body failure...ability...appearance...functioning physiologically...Such perceptions hit at the very core of a person's being' p.250

'illness brings about a failed body...the foundations of existence are shaken' p252

'body failure ...can erode or even smash conceptions of self' p257

The theory does allow for some variation in the extent of identity loss, for example by objective illness severity. Also, it allows for identity 'reconstitution', the processes of which are similar to, if less comprehensive or cognitive to 'acceptance of disability theory' processes described below.

In relation to this study, perceived 'body'/'body failure' can be seen as relevant to identity *change* because real physical losses are common following stroke. However, when contrasted against broader cognitive conceptualisations of identity, it is clear that other potentially defining domains of identity (intelligence, friendliness, patience) are neglected in Corbin and Strauss's account. The broader cognitive view of identity is preferred because it simultaneously provides the means from which to study domains of identity that may be *maintained* and so widens the opportunity for gaining understanding of individual differences. This is considered important in view of the weakness of associations between objective stroke-related functional loss and distress.

A broader view of identity is reflected in Dembo et al.'s (1956) 'Acceptance of disability theory', developed through a particularly comprehensive qualitative piece work investigating 177 injured war veterans' most 'essential' emotional problems. They describe a subjective focus on physical dysfunction as a common initial reaction, understandable through 'the perceptual factor of contrast', but not the only reaction. Acquired disabilities are conceived as 'value losses' and acceptance is conceived as an active process of 'value-change'. Acceptance is specifically not about 'resignation' to loss, nor about 'preference' for disabilities that may still be regarded as 'limiting' (Wright, 1983). It is in essence a theory about 'conditions facilitating acceptance of one's disability as non-devaluating' (p.159, Wright,1983)

The theory actually outlines the following four interactive psychological value change processes that aid an individuals' pathway to 'acceptance'.

The mourning state, in which losses dominate perception, may be overcome by 'Enlargement of the scope of values'. 'Dormant values' such as pride, may be activated. Remaining aspects of life believed to 'really matter' (such as those

discussed in section 2.2xii) may be rediscovered. Self-worth may be undermined by a focus on physical appearance and aptitude. However, 'Subordination of physique relative to other values' appreciation of positive personality characteristics ('kindness', 'wisdom') or of personal effort can counter this. Generalising from disabilities to core personal evaluation ('spread') is considered unhelpful. However, learning to mentally distinguish functional losses and personal evaluation can achieve 'Containment of the effects of disability'. Intertwined with this process is that of 'Transforming comparative values into asset values'. Low acceptance involves 'ought injunctions' (beliefs about what one should be) compared with non-disabled peers or previous non-disabled states. Acceptance is facilitated once lost abilities become viewed like possessions, tools or assets: in other words as

'...a good thing to have if you have it, but not de-valuating if you don't'.
(p183, Wright, 1983)

Someone able to accept his disability and evaluate himself positively in this way said:

'I am a long way from being worthless. I am still a good man without the leg'
(p. 39, Dembo et al., 1956)

The value change processes outlined by Dembo et al. (1956) are similar to previously considered processes of accommodation and assimilation involved in identity maintenance in normal ageing. Parallels can also be drawn between their account and more recent cognitive theories of distress. For example, devalued self-perception resulting from generalisations and 'ought injunctions' concurs with unhelpful thinking processes outlined in Beck's theory (J.S. Beck, 1995).

Unfortunately, recent reviews illustrate that subsequent research has inadequately addressed the value change processes outlined by acceptance of disability theory (Keany and Glueckauf, 1993; Mpofu and Houston, 1998). Disabled men's evaluations of everyday life situation scenarios were rated for reflecting an ability to appreciate other disabled people as a whole (to make asset rather than comparative judgements) and those judged to be better copers performed better (Butts and Shontz, 1962, quoted in Wriight, 1983). However, this does not necessarily mean that they will be so self-accepting (Keany and Glueckauf, 1993). An even more indirect approach has been to actually assess able-bodied subjects' attitudes. For

example, secretaries were assumed to value physique less than air-hostesses and the finding that they were more favourable to disabled persons is assumed to support 'subordination of physique relative to other values' in disability acceptance (English and Orberle, 1971, cited in Keany and Glueckauf, 1993); please see the latter for further studies and critique).

Linkowski (1971) developed the 'acceptance of disability' scale and his factor analysis suggests that it assesses global acceptance of disability beliefs. The research discussed in the following section has used this scale and so is essentially measuring global acceptance, not value change (Keany and Glueckauf, 1993; Mpofu and Houston, 1998). In relation to this thesis the full theory has been described mainly as theoretical background, and as reference for future discussion. As discussed previously, the main intention of this thesis is to describe beliefs rather than those thinking processes from which they developed. In this context, whether stroke patients report being more or less globally able to accept themselves despite their disability is an issue of interest.

2.3iii: Acceptance of disability research relevant to stroke

Available studies addressing global acceptance of disability beliefs support its relevance to distress amongst those with acquired visible and unseen disability. A high inverse association was found between acceptance of disability and trait anxiety amongst young rehabilitation clients who had been severely physically disabled for an average of two years with various orthopaedic impairments (Boone et al., 1978). More recently, Simpson (2001) found an inverse association between distress and acceptance beliefs amongst adults with a range of acquired disabilities, but mainly the 'unseen' disability of deafness. They also found significantly lower acceptance amongst those particular participants considered in need of counselling.

A review by Moore (1998) suggests that acceptance of disability has more commonly been studied in relation to global self-esteem and that strong and positive associations between these variables have been found amongst diverse disabled populations: students with physical disability, deaf adolescents, teenagers with oral clefts and African Americans with various disabilities.

Moore (1998) conducted a particularly large study of 1,266 individuals from a U.S.

vocational rehabilitation register (most had unseen disabilities: mental illness, learning disability, sensory impairment or chemical dependency; the minority had severe physical disability such as spinal cord injury). Acceptance of disability was found to associate highly with global self-esteem, and modestly with disability onset (suggesting less acceptance for acquired versus congenital onset). These associations remained significant even once other variables (emotional support and demographics) were controlled for. Given that global self-esteem is generally highly associated with emotional distress, this study may be tentatively interpreted as lending proxy support to the idea that beliefs regarding the unacceptability of acquired disability may be negatively emotionally involving.

As far as I am aware, acceptance of disability has not yet been specifically studied amongst stroke patients. However, there has been a very recent rapid increase in qualitative stroke studies. A systematic literature review from 1963 onwards identified twenty-three studies relevant to community service needs: twelve published since 1999, and all but two others in the decade before (Murray et al., 2003). None have been inspired by cognitive theory or refer specifically to acceptance of disability. However, some studies identified by Murray et al. (2003) and others from my own searches for studies addressing patients' subjective experience do provide information relevant to disability acceptance.

A devastating account of rehabilitation stroke patients interviewed up to fifteen times over a year is provided by Burton (2000). They are all reported to feel 'unable to accept' new circumstances and to feel 'stuck in a cage'. Also, he reported that even once re-gained 'activities previously enjoyed no longer appeared to give them pleasure' (p307, Burton, 2000) which is a key symptom of depression (APA, 1994). Given that the sample was of just six patients, generalisability is limited. Also emotional state was not actually assessed. However, these stroke patients certainly seemed unable to accept disability and it seems plausible they were emotionally distressed.

In contrast, a couple of studies suggest that with time some patients may be able to accept and gain reappreciation positive aspects of themselves and their lives, particularly Pilkington (1999). Accepting participants reported appreciation of

personally important relationships and less active pursuits. For example, a contractor appeared able to 'accept it' by shifting his values from money and work to his previously 'taken for granted' good and healthy family and wife. Other studies have highlighted the use of practical 'active and creative' strategies, such as using a diary to compensate for poor memory (Pound et al., 1999, please see for further examples).

Dembo et al. (1956) proposed that acceptance is facilitated once lost abilities become viewed like possessions, separate from essential personal qualities. A number of qualitative studies assert an 'objectification' of body parts (Becker, 1993; Bendz, 2000; Doolittle, 1992; Ellis-Hill et al., 2000). However, this is only interpreted as a beneficial self-evaluative coping strategy by Bendz (2000). In contrast, this process is emphasised as a deeply negative experience by the other authors (please see section 2.4v for further discussion).

2.3iv: Summary and notes for developing a hypothesis for acceptance of disability

As discussed, quantitative studies of functional and social loss in relation to distress following stroke have produced weak results (please see section 1.6iii). However, my preliminary impression was that valued losses appeared highly relevant to self-esteem and distress (please see Figure 2.1). Cognitive theory would suggest that it is important to consider subjective appraisals and personal meanings of such losses. Whether or not stroke patients are able to accept disability provides one such subjective perspective.

Associations between acceptance of disability and emotional distress and global self-esteem supports its relevance to emotional adaptation and acquired disability in general. Although not the intention of previous qualitative stroke studies, the preceding review provides preliminary support to the relevance of being able or unable to accept limitations of stroke in relation to self-evaluations and possibly distress.

2.3v: Negative identity change research relevant to stroke

Most qualitative studies (Doswell et al., 2000; Becker, 1993; Bendz, 2000; Burton, 2000, Doolittle, 1992; Ellis-Hill et al., 2000; Pound et al., 1998) report a tendency for stroke survivors to make negative 'present' versus 'pre-stroke' comparisons. Qualitative studies have often interpreted patients' reported 'pre-stroke' versus 'present' perceptions as indicative of negative identity change.

Some qualitative studies assert a universal 'existential' negative identity change, relating to perceived changes in body function following stroke. Doolittle (1992) describes stroke patients as experiencing brain and body in 'total opposition' and as 'suspended in a passive objectified body'(p122). Becker (1993) more specifically draws association between these body perceptions, identity and distress amongst a hundred rehabilitation patients during the first year following stroke.

'Profound changes to both body and mind led stroke victims to question whether their old selves existed... All completely self-absorbed...stroke was the only salient feature of life, a funnel through which all self-perception was drawn...All persons demonstrated anger and despair at the changes they saw in their bodies...profound disruption to self-concept...All respondents indicated they did not measure up to their own standards for normality.' p152 – 154

A similarly universal and existential experience of a 'separate precarious and perplexing' body is emphasised and related to negative feelings in Ellis-Hill et al.'s (2000) analysis of eight high-functioning stroke patients discharged to their own homes.

These accounts refer to the 'biography-body-self-conception' theory introduced in section 2.3ii. A couple of the patient quotes in these studies do somewhat support the assertion of profound identity disruption through perceived bodily dysfunction, for example:

'I'm not normal lets face it – nobody wants to be a cripple'

p154, Becker (1993)

However, others suggest only the latter (for example 'My leg is not as strong as it used to be' or 'My handwriting is not as good as it was' p.154, Becker, 1993) and are not convincing portrayals of the former. Some quotes actually suggest a lack of distinction between self-evaluation and perceived disability rather than the asserted perceptions of 'mind-body-split':

'I was completely useless, used to have to get carried to the toilet....'

p728, Ellis-Hill et al. (2000).

This theoretical perspective is also explicitly referred to or strongly echoed within other studies, particularly in concluding comments (Bendz, 2000; Clarke, 2003; Grant, 1996; Secrest and Thomas, 1999). However, these and other studies also highlight some more personal and interpersonal negative self-evaluations following stroke, particularly in results sections.

Independence, particularly regarding 'simple' things is related to feelings of frustration and helplessness (Nilsson et al., 1997; Pilkington, 1999; Pound et al., 1998). Personal high standards were linked to dissatisfaction with performance, for example one man wanted to walk 'like a soldier' (Pound et al., 1998).

Pilkington (1999) drew an association between negative emotion and a change in a sense of being 'relied on' to 'helpless'. Similarly, another study highlights perceived negative change in terms of 'giver' to 'receiver', with the following example:

'What's happened to me is that I can't help anymore...I can't bake a cake for a birthday'

p 511, Doswell et al., 2000

A sense of emptiness or sadness was related to 'not being of use' in daily work like woodwork or farming maintenance in rural Sweden (Nilsson et al., 1997). Doswell et al. (2000) highlighted that a few participants simultaneously described feeling depressed and that they had become 'a burden' to their families.

Clarke (2003) related different reactions to the relative value of pre-stroke physical ability. A man who described himself as 'Active with a capital A' prior to stroke now described feeling 'trapped'. In contrast, an equally physically impaired woman described herself as 'lucky' in relation to her ongoing pleasant relationships with people and daughters' happy marriages. Secrest and Thomas (1999) suggest a tension between continuity and discontinuity in their participants' sense of self.

One study actually reports that some participants actually felt they 'hadn't changed' (Pilkington, 1999). Although, not the authors observation, a few quotes from a study of older female stroke patients suggests a similar position. One describes

being 'not bothered' by it and another said 'I never did hurt from the stroke' (p.24, Hilton, 2002). Plausibly patients with this sort of attitude may have had relatively lenient standards and expectations for functioning in older age pre-stroke, which in Brandstater's (1999) terms may 'immunise' against negative self-evaluation in the face of loss.

Overall, most qualitative stroke research has tended to be aligned to the theory introduced in section 2.3ii that defines identity by perceptions of 'body'. This allegiance is reflected in assertions of universal profound negative identity change related to bodily dysfunction following stroke in some studies. Nevertheless, a wider and more varied perspective regarding the nature of different individuals' identity *change and maintenance* following stroke has emerged from some studies. Some stroke patients appear to see themselves more negatively following stroke in more abstract personal and interpersonal ways (less independent, less useful or helpful to others) while others may essentially see themselves as unchanged. These findings support variation amongst a broad range of negative self-evaluative beliefs relevant to perceived stroke related change. However, studies have generally not specifically attempted to seek understanding of variation in emotional distress in relation to observed variations in negative identity change.

One quantitative study supports an association between negative self-evaluation relevant to the effects of stroke and distress. Partridge (1985) developed ten constructs (for example, active–inactive, independent–not independent) from semi-structured interviews specifically addressing rehabilitation patients' beliefs regarding ways they had changed following stroke. These constructs were then used to obtain the patients' ratings of themselves for both 'before' and 'now'. Highly statistically significant moderate associations were found between 'before' ratings and depressive symptoms, and 'now' ratings and depressive symptoms. However, differences between 'before' and 'now' ratings were not calculated or studied in relation to emotional outcome in this study.

More, recently Ellis-Hill and Horn (2000) used a semantic differential scale to assess change in 'before' versus 'now' self-ratings on a broader range of constructs amongst twenty-six high functioning stroke patients. The results support variation

in negative identity change versus maintenance. Certain mean 'before' versus 'now' changes (interest, capable, independent) were statistically significant at the $p<.001$ level, other changes (in control, satisfied and active) were statistically significant at the $p<.05$ level. Other change scores (for example, patient, relaxed, attractive) were not statistically significant, and friendly and hopeful ratings reflected perceived maintenance. Mean 'now' calm ratings were very slightly, but not statistically higher than 'before' ratings, which actually suggests the possibility of positive identity change in this domain. Overall, statistically significant overall negative identity change was found at both one-month and six-months following stroke.

In a different analysis using the same data, Ellis-Hill (1998) reported that overall negative identity change was moderately and statistically significantly associated with anxious and depressive symptoms at one month, and highly and statistically significantly at six months and one year. Associations between negative identity change and distress remained statistically significant even once actual disability, and social activities were controlled for.

2.3iv: Summary and notes for developing a hypothesis for negative identity change

As discussed previously (please see section 2.3i) cognitive theories of self-esteem tend to view it in dynamic interplay between how individuals see themselves and how they would ideally like, or think they ought to be. Stroke brings about unwelcome chronic limitations, and the evidence suggests that stroke patients tend to compare themselves negatively to their pre-stroke selves. Despite the allegiance of most qualitative research to a non-cognitive perspective, qualitative and quantitative evidence supports potential for negative identity change in a broad range of domains. The small quantitative evidence base suggests that stroke patients are able to rate their perceptions of change in themselves in abstract terms following stroke. Only one small study has specifically studied associations between this perceived negative identity change and emotional distress, but it offers preliminary support to the affective relevance of this type of negative belief following stroke.

2.3v: Shame

Self-theorists tend to suggest that the 'looking glass self' of childhood continues

'more or less' through adulthood (Rosenberg, 1979). Taking the 'other's' perspectives is considered germane to social interaction (Mead, in Rosenberg, 1979) and public behaviour appears to be internalised more than private behaviour (Tice, 1992). So, as adults we continue to imagine and care what others think. However, the extent to which individuals attend to the observer perspective varies along a continuum of public to private self-consciousness (Fenigstein et al., 1975; Fiske and Taylor, 1991). In turn, how much the observer perspective is valued and contributes to overall self-esteem may vary (Leary et al., 1998).

The effects of stroke, like other disability, may result in *actual* negative societal and social responses, referred to as 'stigma' or 'enacted stigma' (Goffman, 1963). However, any such actions must be *perceived* in order to be distressing (Kent, 1999). Patients who view the effects of stroke as negative in society's eyes, particularly those who tend to fear or value others' evaluations, may be embarrassed about their disability even without any experience of actual stigma.

Authors who address negative social perceptions use various terms: 'felt' or 'perceived stigma' (the belief that one has experienced discrimination, (Kent, 1999) 'social fear' (recognised as a symptom of social phobia involving fear that 'one may act in a way that will be humiliating or embarrassing', APA, 1994) and 'shame' (the belief that real or imagined others evaluate one negatively, Goss et al., 1994). This suggests that social fear is more relevant to anxiety and the future, shame to depression and the past or present. In practice, this distinction blurs; for example, socially phobic patients' descriptions of past social experiences tends to be negative and biased towards the observer perspective (Wells et al., 1998). Arguably social fear and shame are both relevant to this study of emotional distress, but I will favour the term shame because I feel it resonates better with disabled patients' descriptions.

General or disease-specific shame measures have been associated with distress amongst patients with skin disease and facial disfigurement. Objective disease severity did not associate with depression or anxiety symptoms amongst patients with psoriasis (red heavily scaled skin plaque disease). However, a psoriasis-specific shame measure did, particularly with the depressive symptoms (Richards, 2000). In contrast (Leary et al., 1998) found that emotional well-being

did not associate with psoriasis specific shame although it did with general fear of negative evaluation. A moderate association between vitiligo-specific shame and distress was found amongst patients with this patchy skin depigmentation disease (Kent, 1999). Newell (1999) proposed an avoidance-anxiety model to explain relationships between shame, social skills and decreased social activities amongst those with facial disfigurement. This model has indirect support because distress was significantly reduced following a cognitive behavioural intervention addressing these issues (Newell and Clarke, 2000).

Authors have studied social phobia amongst disabled populations by discounting the DSMIV exclusion of those with disfiguring/disabling conditions. Over fifty percent of patients with spasmodic torticollis (condition involving involuntary jerking of head and neck) were found to be socially phobic (Gundel et al.,2001). Seventeen percent of Parkinson's disease patients were judged socially phobic and to relate their embarrassment to tremor symptoms (Stein, 1990). Plausibly, as the effects of stroke may involve both obvious (for example, poor walking gait) and less obvious but potentially embarrassing deficits (for example, slurred speech) similar results may be expected amongst stroke patients. However, the few previous studies that have assessed anxiety disorders following stroke report a low prevalence of phobias other than agoraphobia (please see Chapter 1, section 1.4ii).

Preliminary studies support the relevance of shame to distress following stroke. Symptoms of depression and a global shame measure were found to significantly associate amongst twenty-four long-term stroke survivors but not age matched controls (Vine, 1999, personal communication; Vine and Horn, 2004). Jacobsson et al. (2000) studied eating following stroke. As well as observed physical impairment (e.g. mouth praxis) and objective difficulties (e.g. dribbling and spillage), stroke patients reported feeling highly embarrassed about their poor eating in a subsequent interview. Some apparently reported such a sense of embarrassment and shame that 'they felt was like a burn-mark on the forehead' (p.262, Jacobsson et al., 2000).

Issues related to shame have also been highlighted in other qualitative stroke literature. Ironically, embarrassment has been found in relation to unrecognised disability. For example, a man, who looked fine but had weakness felt socially

misunderstood when strangers helped his wife carry shopping and others complained of dismissive attitudes such as 'Oh you look fine' (Ellis-Hill et al., 2000). Young survivors were concerned about not revealing cognitive deficits, and one middle-aged man actually chose a new city for re-training to avoid even having to even discuss his changed capacities at his old work (Bendz, 2000).

Examples of patients feeling obstructed or actively rejected are sometimes reported. Being housebound is related to actual or perceived environmental disadvantage (missing rails, too many flights of stairs, inconsiderate bus drivers) in one study (Pound et al., 1998). A prosperous Canadian woman described a husband who refused to walk with her, and neighbours who 'dropped' her, because she walked badly and because only the cleaners were expected to walk, not drive, in her neighbourhood (Clarke, 2003). Relatives may even obstruct accommodative attempts: for example this woman's husband tried to hide her filing system for remembering things. Housewives whose husbands took over housework are described as feeling 'usurped' in the housewife role (Pound et al., 1998).

A few qualitative studies report quite striking examples of shame about publicly visible disabilities. Trigg et al. (1999) found some participants to be embarrassed about their deficits in the company of those they knew well, whereas, Ellis-Hill et al. (2000) report that participants felt socially at ease in the home and only experienced what they refer to as a 'social self-body split' when outside. One reported feeling like 'a freak' and another going 'to pieces' when she saw people she knew. Some participants in other studies reported 'feeling inferior', feeling 'disadvantaged' or experiencing a loss of dignity in the view of strangers (Trigg et al.,1999; Nilsson et al.,1997).

Concern about others' reactions to walking ability was reported by two young participants but not older ones (Pound et al., 1998). For example, a forty-year-old appeared particularly embarrassed by older people offering to help and was concerned to hide her disability ('...you get suspicious... are they looking at me?' p. 342, Pound et al., 1998). Pound et al. (1998) conclude that shame was not a significant consequence of stroke amongst their older participants. As they seem to suggest, self-comparison to stereotypes of old age, may engender greater risk of

feeling socially discredited for young as opposed to old stroke patients' as the discrepancy they perceive will be broader as well as negative.

Some patients may be less prone to shame if able to interpret differential treatment positively (Susman, 1994). Disability has been reported as being occasionally advantageous in a study of leisure pursuits, for example by allowing people to feel entitled to ask for help (Bedini, 2000). Some young wheelchair users reported appreciating preferential treatment from salespeople or waiting staff when it occurred, and even occasionally soliciting unneeded help from strangers for amusement (Cahill and Eggleston, 1995). What one stroke patient may view as pity, another may regard as kindness (please see Chapter 6, section 6.7iii).

2.3vi: Summary and notes for developing a hypothesis for shame

The relevance of shame to distress following stroke has initial support from one small quantitative study (Vine and Horn, 2004), various qualitative stroke studies and studies other of disabled populations. Its inclusion broadens the study of self-evaluations to the social and public self. Originally, I chose to look at general shame for consistency with Vine and Horn (2003) but this changed to the study of stroke-specific shame (please see Chapter 6, section 6.7iii for further explanation).

2.4: Beliefs in recovery and recurrence

2.4i: Recovery pathway from the effects of stroke

Perhaps the most positive aspect of stroke is neurological potential for recovery, and the means to make good use of this potential through rehabilitation therapy. Recovery begins rapidly in the first month, and then slows down over the next few months. Improvements may continue indefinitely, but most measurable recovery is seen within six months (Warlow et al., 1987). To some extent, the measurement of initial basic functions (activities of daily living) commonly measured by 'the Barthel index' (please see Appendix D, section D.2) can predict long-term functional outcome (Wade, D and Langton-Hewer, 1987). Experience may enable clinicians to make better, although still not always accurate predictions than objective measures (Tinson, 1994). Therefore there will always be an element of uncertainty regarding recovery following stroke.

Patients' frame of reference and definitions of recovery may differ from professional measurement of basic functions and observations of change following the day after stroke (Kaufman, 1988; Pound et al., 1998). Patients' goals of recovery relate to comprehensive pre-stroke functioning: memory as well as physical functions that include many extended valued pursuits, such as work, caring for others, travelling, reading, walking for pleasure and many indoor and outdoor leisure pursuits (Burton, 2000; Hafsteinsdottir and Grypdonck, 1997; Kaufman, 1988; Murray et al., 2003; Pound et al., 1998; Trigg et al., 1999). Doswell et al. (2000) specifically highlighted patients with 'good' recoveries in terms of full Barthel index scores who nevertheless reported a lack of perceived recovery. For example one woman said 'Everything I liked has gone'. Arguably subjective belief in recovery may also include a return to feeling the same about oneself.

Given the personal nature of individuals' definitions of recovery and the uncertainty with which even functional independence may be predicted, subjective beliefs about recovery rather than objective measures are more likely to further our understanding of emotional distress following stroke.

2.4ii: Recovery locus of control

'Locus of control' refers to a specific continuous aspect of outcome expectancies. At the 'internal locus'/ 'high internality' end of the spectrum, outcomes tend to be regarded as consequences of one's own actions. At the 'external locus'/ 'high externality' end of the spectrum outcomes tend to be seen as mainly determined by forces such as chance or powerful others (Rotter, 1960). Individuals who see themselves as personally responsible for their actions may seem more likely to succeed in difficult active tasks, and greater 'internality' has been linked to problem solving, perseverance and achievement in intellectual endeavours (Rotter, 1966). A meta-analysis of ninety-seven studies supported a positive relationship between greater externality and symptoms of depression (Benassi et al., 1988). Higher internality has been associated with various aspects of physical and emotional well-being amongst medically ill populations, particularly patients with painful conditions (please see Scharloo et al., 1998 for a review).

In semi-structured interviews specifically addressing subjective perspectives about recovery, locus of control was frequently mentioned by stroke rehabilitation patients, suggesting its relevance amongst possible control belief in their attitudes to recovery (Partridge, 1985). Statements were used to develop a scale to measure recovery locus of control, in which higher levels indicate a more internal locus. Subsequent research has demonstrated associations between higher recovery locus of control and actual recovery (Partridge and Johnston, 1989). More relevant to this thesis, Sinyor et al. (1986) report that stroke patients with an external orientation to health in general reported feelings of hopelessness. Morrison et al. (2000) found that higher internal locus of control specifically regarding recovery was moderately and statistically significantly inversely associated with depression symptoms at one month. A low but nevertheless statistically significant inverse association with anxiety symptoms was also found.

A subsequent analysis suggests that recovery locus of control may predict emotional distress following stroke over time. Statistically significant moderate inverse associations were found between recovery locus of control at one month and anxiety and depression symptoms at six months (Morrison et al., 2000). This association

with depression symptoms at six months was supported even when one-month disability levels were controlled for. Furthermore, recovery locus of control at *one month* was found to produce statistically significant inverse associations with measures of depression and anxiety outcomes (i.e. depression and anxiety symptoms at *six months,* controlling for levels assessed at *recruitment* which took place between ten and twenty days following stroke). This result suggests a predictive role for recovery locus of control that is independent of earlier distress. However, this relationship may not have been supported if the estimation of depression and anxiety outcome had controlled for symptoms assessed at the same time that recovery locus of control was measured (i.e. at one month).

The relevance of locus of control orientation to distress may itself be influenced by different outcomes of recovery and service provision. Early measures of recovery were found to predict follow-up recovery locus of control and it was suggested that experience of success promotes more positive internal beliefs (Morrison et al., 2000). Experience of a poor recovery may exacerbate helpless attitudes. However, when outcomes are negative, depression appears to be less strongly associated with externality (Benassi et al., 1988). Patients may gain a sense of vicarious control from their rehabilitation professionals. Morrison et al. (2000) suggest that externally orientated patients may be more likely to experience negative feelings about discharge from their care. In Bendzs' (2000) qualitative study all patients were reported to have developed a dependent relationship with their therapists and felt 'abandoned', 'put out', or 'kept back' when discharged. Together these results suggest that association between recovery locus of control and distress may tend to increase once recovery becomes the patient's sole responsibility.

2.4ii: Summary and notes on developing a hypothesis for recovery locus of control

Previous research supports an association between less internal locus for recovery and distress following stroke both cross-sectionally and across time. It is a practical area for investigation because it has been found amenable to modification by simple intervention involving an internal locus of control for recovery enhancing pre-physiotherapy appointment letter (Johnston et al., 1992). Therefore it was considered an essential variable to include in this study.

2.4iii: Confidence in recovery

Given the uncertainty of recovery following stroke, patients' beliefs about their future outcomes is an intuitively appealing issue in relation to emotional distress. There are many different angles that could be taken from tying to assess hope, outcome expectations, or self-efficacy regarding recovery. Various approaches have been used with mixed results.

Qualitative results have produced mixed findings regarding recovery beliefs both within and across studies. Becker and Kaufman (1995) assert universal fear and uncertainty about recovery, and yet that some of their sample expected a full recovery. Ellis-Hill (1998) found uncertainty about recovery, described as a sense of 'limbo' preventing future planning to be common, but also a simultaneous sense of hopefulness about 'getting back to normal' amongst the same participants. Early optimism regarding recovery was found to decrease as progress slowed, and grief reactions were observed by Nilsson et al. (1997). In contrast in another study optimism was sometimes maintained in spite of objectively poor recoveries by patients who could still envisage moving towards a 'normal' active future (Pilkington, 1999). Taken together these somewhat contradictory results reflect a tension between uncertain expectation and hope regarding recovery.

An intuitively appealing quantitative method for studying beliefs about recovery was used by Ellis-Hill (1998) who combined the semantic differential assessment of identity change (please see section 2.2v) with assessment of how stroke patients saw themselves 'one year in the future'. Mean 'future' ratings were slightly lower than 'before' stroke ratings for a few dimensions (for example independence and in control) at one month, and for more at six and twelve months. However, none of these differences were statistically significant at any point in time. The same was found with traumatic brain-injured patients, and was interpreted as reflective of this group's tendency to be 'grandiose', 'egocentric' and have 'unrealistic optimism' for the future (Tyerman and Humphrey, 1984). Intuitively, this description just does not fit stroke patients as a group.

The lack of statistical significance in these differences may be partly due to the small sample (Ellis-Hill, 1998). Also, perceived identity change may be less extreme in stroke as opposed to traumatic brain injury in the first place. Therefore a tendency to envisage more or less returning to pre-morbid selfhood after stroke does not seem quite as 'grandiose' (although in many cases it will still not be realistic). Perhaps these visions for the future may best be regarded only as an expression of hope not expectation as the everyday saying goes. This interpretation is more compatible with the varied qualitative results described earlier that used a subset of these participants (Ellis-Hill et al., 2000). However, these semantic differential results do suggest that this method fails to capture much variation in stroke patients' responses and so can tell us little about individual differences in recovery beliefs.

Helpless/hopeful attitudes were assessed using the relevant mental adjustment to stroke subscale by Lewis et al. (2001). Moderate positive associations with depression and anxiety symptoms were found amongst a relatively large cohort of stroke patients, six months following stroke. This study demonstrates more variability in stroke patients' beliefs regarding the future. However, helpless/ hopeful beliefs subscale items are very global (for example, 'I feel that life is hopeless') and so probably tap broader future-orientated beliefs than the specific issue of recovery.

A quantitative approach that appears to have success in capturing variation in stroke patients' beliefs specific to recovery has been to simply get them to rate how confident they were about making a full recovery (Morrison and Johnston, 1999). Moderate inverse associations were found between recovery confidence at one month and anxiety and depression symptoms at six months (Morrison et al., 2000). Furthermore, in regression analyses statistically significant associations between recovery confidence assessed at one month and depression and anxiety outcomes were found, even once various disability measures and other belief variables assessed at one month were controlled for. However, it should be pointed out that the depression and anxiety outcomes measures consisted of residual scores obtained by regressing initial levels (assessed ten to twenty days following stroke) onto six month levels. As this outcome measure controlled for symptoms assessed at an

earlier stage than the recovery confidence assessment, this may have somewhat confounded the results.

As the authors suggest 'confidence in recovery' is a relatively under-developed concept, that may reflect dispositional optimism. At face value it seems to reflect a combination of self-efficacy and outcome expectations. Similarly to locus of control, over time, degrees of confidence in recovery and its relationship to distress may be influenced by different recovery outcomes and service provision. Qualitative research particularly highlights possible interaction between patients' uncertainty about recovery and messages provided by rehabilitation staff (Becker and Kaufman, 1995; Cant, 1997; Ellis-Hill, 1998). This makes the study of confidence in recovery a particularly practical subject of study and raises professional issues that will be returned to in the discussion.

2.4iv: Summary and notes on developing a hypothesis for confidence in recovery

Negative beliefs regarding the future is emphasised in Beck's theory of anxiety (the anxious patient fears negative outcomes) and depression (the depressed patient expects little improvement in negative circumstances). There appears to be a tension between hope and expectations regarding recovery following stroke. One previous study supports an associative relationship for confidence in recovery with distress, and even suggests that early confidence in recovery can predict change in distress levels over time following stroke. Given these results and objective uncertainty regarding functional improvement, confidence in recovery is considered a highly relevant subject of study regarding distress following stroke.

2.4v: Recurrence fear

'Will I have another one?' is a question stroke physicians are often asked (Becker and Kaufman, 1995). It is a difficult question to answer precisely because various factors have been identified which seem to increase risk of recurrent stroke: male sex, raised blood pressure (before and after stroke) atrial fibrillation (irregular heart beat) coexisting heart disease, increased age, stroke type and possibly smoking (Ebrahim and Harwood, 1999). Therefore there will be much variability of risk

amongst individuals, and there is a need for further medical research to elucidate how these factors interact amongst themselves and in combination with more recent treatments (Rothwell, 2001). However, some basic idea of average recurrence risk seems useful for general background information to the present study.

The Oxfordshire community project (Burn et al., 1994) is the most recent of the small number of community studies of recurrent stroke risk (Ebrahim and Harwood, 1999). Using this original cohort of 675 patients, 180 events over the next five years were classified as recurrent strokes, of which 135 were first recurrences. The cumulative probability of recurrence amongst survivors was thirty percent, and two thirds of these were severe strokes. A more optimistic perspective emerges by consideration of annual recurrence risk figures that do not take high attrition rates to death in the first few weeks into account (Ebrahim and Harwood, 1999). Risk of (first) recurrence was approximately thirteen percent in the first year and then dropped to figures in between two and seven percent for subsequent years. Often a ten percent per year risk figure is quoted, and this refers to the constant hazard figure over the study period.

Studies of stroke patients' informational needs suggest a strong interest in recurrence risk. Over eighty percent of patients indicated that they desired 'a lot' of information about reducing the chances of another stroke relative to other topics approximately a year and a half following stroke (Haske van Veenedaal et al., 1996). Forty-six percent of patients indicated still wanting more information about recurrence prevention at six-month follow-up despite having received information leaflets about risk factors at one month (Mant et al., 1998). When semi-structured interviews were used to investigate the type of information wanted, recurrence risk was the most commonly reported topic (by approximately one in five patients) at both 6 and 24 months following stroke (Hanger et al., 1998).

Concern and fear about recurrence has now been identified by various qualitative studies (Becker and Kaufman, 1995; Bendz, 2000; Ellis-Hill, 1998; Haggstrom et al., 1994; Jacobsen et al., 2000; McCormack, 2000; Pilkington, 1999; Pound et al., 1998) and even emerged as a theme in a semi-structured interview about the eating

process (Jacobsen et al., 2000). Concern about recurrence was related to not being able to understand why strokes occur amongst those who felt they had lived healthy lifestyles in one study (Ellis-Hill, 1998). Three studies highlighted a specific fear about becoming even more disabled through another stroke (Becker and Kaufman, 1995; Bendz, 2000; Haggstrom et al., 1994) and one study reported that severe dependency was feared more than death (Haggstrom et al., 1994). Reluctance to exert oneself in household chores or to go on holiday was related to the fear of bringing on another stroke or coping in the event that one did occur by Pound et al. (1998). Some young participants were reported not to go back to work or to prolong sick leave because of their 'ever present' fear of relapse (Bendz, 2000).

The reviewed qualitative studies suggest that patients often have heightened concern about and may even develop avoidances in relation to the possibility of recurrent strokes. However, studies have not specifically attempted to seek understanding of variation in emotional distress in relation to levels of recurrence fear. However, indirect support for an association between distress and recurrence fear is provided by the cancer literature. Fear of cancer recurrence and death is known to be highly prevalent (LaFortune Fredette, 1995; Lee-Jones et al., 1997; Welch-McCaffrey et al., 1984) and has actually been found to associate more highly with psychological disturbance than original diagnosis (Silberfarb and Greer, 1982). Also clinically, catastrophic fears of recurrence have been observed amongst depressed and anxious stroke patients (Laidlaw et al., 2003; Sharpe and Tinson, personal communication, 1998).

2.4vi: Summary and notes on developing a hypothesis for recurrence fear

Risk of recurrence is something stroke patients are aware of and report being very keen to obtain risk prevention information about. Also, qualitative information from clinicians and patients suggests that recurrent strokes and more severe recurrent strokes are feared and may sometimes result in avoidance behaviour. Extrapolation from the cancer literature and expert opinion suggests that recurrence fear may well associate with emotional distress. Taken together, these lines of evidence support the relevance of fear of recurrence to emotional distress following stroke.

2.5: Summary of beliefs in 'stroke' and 'its effects' in relation to cognitive theory and the hypotheses

The preceding review suggests that research regarding stroke patients' subjective beliefs and associations with distress is at an early stage. However, various beliefs in 'stroke' and 'its effects' that may have relevance to distress have been identified and discussed. Of the attributional beliefs introduced in section 2.2, causal controllability clearly relates to 'stroke', however 'Why me?' and 'Found meaning?' may relate to either 'stroke' or 'its effects'. The negative self-evaluative beliefs (acceptance of disability, negative identity change and shame) introduced in section 2.3 resonate more with 'its effects'. Beliefs in recovery (recovery locus of control and confidence in recovery) are also concerned with 'its effects' whereas recurrence fear is concerned with both beliefs about 'stroke' and 'its effects' in a future context.

As discussed (please see section 2.1 and Chapter 1, section 1.7) the cognitive adaptation literature, including theory and research related to adjustment to cancer, acquired disability and normal ageing has been used to supplement literature specifically addressing beliefs and emotional distress following stroke. Although the reviewed research has not been specifically inspired by clinical cognitive theories of distress, the set of beliefs identified may be seen as compatible with the central meanings of Beck's theory adapted to 'stroke' and 'its effects'. Very broadly negative attributional beliefs, negative self-evaluations and negative beliefs in recovery and recurrence can be seen as representing aspects of: a negative view of one's position in the world, a negative sense of self and a negative predictions for one's future respectively. Negative beliefs in recovery and recurrence, and causal controllability through its relevance to recurrence, are particularly related to ideas of future threat. As self-evaluation is an ongoing process, and the effects of stroke may not be viewed as permanent, particularly initially, negative self-evaluative beliefs may also overlap with a sense of threat.

Chapter 3

Aims and hypotheses

Aims

My main aim was to investigate beliefs in patients who have had a stroke and the relationship of these beliefs to emotional distress, taking into account demographic and social background variables. My supplementary aim was to further explore the nature of beliefs in emotional distress and disorder.

The quantitative study was designed to address my main aim and the following objectives to:

1) Investigate emotional distress
2) Investigate beliefs considered relevant to stroke patients' emotional distress
3) Examine associations between emotional distress and specific types of beliefs following stroke
4) Investigate the ability of initial beliefs to predict emotional distress over time

The structured clinical interview study was designed to address the supplementary aim and the following objective to:

5) Explore the types of beliefs and nature of symptoms related to common depression and anxiety disorders

The qualitative study was designed to address the supplementary aim and the following objective to:

6) Explore patients' own experiences and concerns using a qualitative approach

Main hypotheses *

1) A relationship between beliefs and emotional distress would be found at an initial point in time (baseline) and at a later point in time (follow-up)
2) Beliefs found at baseline would predict emotional distress at follow-up

* It was expected that the main hypotheses would be fulfilled even once demographic and social background factors had been taken into account

Specific hypotheses**

1) Certain negative attributions:
   - Lower sense of control over causes
   - Higher frequency of asking 'Why me?'
   - A failure to find meaning in the experience

   would be associated with higher levels of emotional distress

2) More negative self-evaluations:
   - Lower acceptance of ones' disability
   - A more negative change in identity
   - Higher shame

   would be associated with higher levels of emotional distress

3) More negative beliefs in recovery and recurrence
   - Lower sense of control over recovery
   - Lower confidence in recovery
   - Higher fear of recurrence

   would be associated with higher levels of emotional distress

**The specific hypotheses are intended for baseline, follow-up and across time.

Chapter 4

Introduction to the mixed method

"What can be counted doesn't always count and what counts can not always be counted"

Einstein (1879 – 1955), in Famous-Quotes-and-Quoatations.com

The main aim of this study:

'...to investigate beliefs in patients who have had a stroke and the relationship of these beliefs to emotional distress...'

will be addressed by a mainly quantitative 'counting' approach, and this is actually considered to 'count'. This chapter is intended to justify why, but also to explain the decision to combine this main study with two further more exploratory studies.

Quantitative research involves the statistical testing of hypotheses. Within the bounds of a study's power, quantitative results can be approached with some confidence that they generalise to the population represented by the study sample (Peabody, 1985). This is considered advantageous. In this context, evidence that beliefs do associate with emotional distress and knowledge about their relative importance is considered useful. It can be used to discriminate amongst hypotheses for further research and may inform clinical applications; for example, it may suggest useful outcome measures.

However, the quantitative method is limited by the content of its original hypotheses and constrained by its measurement techniques. In this thesis, theory, past research and piloting research (please see chapters 1,2, 6) has been used to try and develop hypotheses and measures with relevance (that 'count'). However, research into cognition in distress following stroke is still an early stage. Therefore the addition of exploratory work was considered a complementary source from which to corroborate quantitative findings (Casebeer & Verhoef, 1997). Convergence between the qualitative data and quantitative results can bolster the overall findings. Divergence between qualitative and quantitative results will provide alternative

explanations about 'what counts' and this may prove particularly useful in the event of quantitative findings that appear counterintuitive (Burt & Oaksford, 1997).

In addition, questionnaire items do not always reflect the idiosyncratic language, or concrete circumstances attached to individuals' beliefs. Qualitative data can, which makes it rich and living (Robson, 1993). This makes qualitative data an appealing source of information in its own right.

There is a debate regarding the validity of quantitative versus qualitative approaches, the protagonists of whom appear to assume that each method is tied to a polarised ideological view of reality (Burt & Oaksford, 1999). However, methodological choices need not be determined by historical philosophical allegiances (Bryman, 1994; Casebeer & Verhoef, 1997; Clarke, 2003) and this belief coincides with my own. I chose a mainly quantitative and partially qualitative method for the practical reasons discussed.

As regards my own reflexive philosophical position: this thesis comes from the perspective of cognitive theory, therefore from a moderately relativist perspective. Therefore the generation of both the quantitative hypotheses and the development of the qualitative strands are recognised to deliberately investigate this perspective. Subjective mental experience is considered to 'count' towards individuals' varying emotional experience. Both are considered amenable to 'valid enough to be useful' empirical measurement and exploration.

Chapter 5

Design, participants and procedure

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5.1: Introduction

This chapter will describe and justify the design, participants and procedure used in the main quantitative study. It should be pointed out that piloting work will be reported in chapter six. Also, that ethical approval was sought and obtained before commencing this study (please see Appendix A for ethics form).

5.2: Design

A cross-sectional survey and prospective cohort design was used.

Two cross-sectional surveys were conducted in order to examine both initial and longer-term adjustment to stroke. By using a prospective cohort of participants, the predictive ability of baseline variables could be tested at follow-up.

One month was chosen for the initial time point (baseline) and nine months for the later time point (follow-up) on the basis of survival and recovery rates. The first few weeks following stroke is the phase of highest mortality (Warlow et al., 1987) so one month was considered an ethical and practical time for initial interviews. Nine months was considered to be a time by which most individuals' recovery would have peaked (please see Chapter 2, section 2.4i) and they would have had time to reflect upon the impact of their stroke.

5.3: Population

Ideally a sample should represent the wider stroke population as much as possible,. to maximise the generalisability and usefulness of results. It was considered important to avoid sampling patients with a restricted range of objective disability because this would give subjective variables a clear statistical advantage. Community sampling was impractical due to financial and time constraints and so the Western General Hospital (WGH) was used as the participant population. This is a large University teaching hospital, with a specialist stroke unit, to which patients come via emergency services or a GP referral. A stroke register had been kept at this hospital during the years preceding this study that involved regular contact with GPs which would have acted to cue their referral of 'mild' as well as more severe cases of

stroke. Therefore, the population of patients admitted to this hospital is less likely to be biased towards more severe cases of stroke than the populations of other hospitals.

5.4: Inclusion/exclusion criteria

To be reasonably confident that reliable and valid data was obtained the following four inclusion/exclusion criteria were set.

5.4i: Diagnosis of a 'definite' stroke

Neurological disorders other than stroke can nevertheless present with similar histories and/or signs and symptoms (Warlow et al., 2000). These other illnesses will produce different rates and levels of recovery, which in turn may bias psychological adjustment.

This study coincided with a stroke diagnosis study at the WGH which involved very prompt examination and scanning of patients admitted with suspected stroke. Cases were then discussed by a panel of senior stroke-related consultants within days, which was considered to be the gold standard for diagnosis (Hand, 2000, personal communication). Only those considered to have a 'definite' stroke were included.

5.4ii: Health

Patients judged unlikely to survive the study period or too unwell to participate were not included. This decision was made by Dr Jo Kwan, a gerontologist at baseline, and by participants' GPs at follow-up (please see Appendix B, section B.5).

5.4iii: Severe cognitive deficit

Patients with severe cognitive deficits were excluded. This was assessed using the Hodkinson (1972) mental state test (please see Appendix D, section D.1). This is a brief test of orientation, knowledge, concentration and new learning. A cut-off of eight out of ten was used. Jutapunkul et al. (1991) found this cut-off correctly identified ninety-one percent of 168 patients aged between sixty and ninety-seven years for dementia, delirium, or 'normal' cognitive function in line with DSM-III criteria. The authors also reported a good internal reliability score for the scale ($\propto$ = .90). Ideally, a full neuro-cognitive assessment would have been conducted to capture subtle impairments; however, this was considered too time-consuming.

5.4iv Severe language impairment

Proficient use of English language was required for participants to understand and respond to the questions. The Frenchay Aphasia Screening Test (FAST; Enderby et al., 1987) was chosen as a language screen. This test was developed for use by non-specialists using stroke patients and normal controls, by comparison to speech and language therapists' standard assessments. It was found to achieve high associations with standard communication tests (r = .90) and high inter-rater (r = .97) and test-retest (r = .97) reliability results. When the minimum recommended cut-off point of thirteen out of a possible total score of thirty was used, only three of the fifty patients without aphasia were misclassified (one had severe visual neglect, one was Polish and one had dementia). These factors could be taken into account when administering the test.

5.5: Introduction of patients to the study

Lothian local research ethics committee required patients to be approached for research by a clinician. It was considered cumbersome to depend on core ward staff given the burden to them and the short length of some patients' hospital stays. Reliance on general practitioners was expected to be unsuccessful (Anderson, 1992). Fortunately, a clinical research fellow, Dr Jo Kwan, offered to incorporate an introduction to this project within the course of his 'Integrated Care Pathways' research.

Dr Kwan saw all stroke patients admitted to the WGH within the first day or so of their hospital admission. Whenever he considered a patient was well enough to participate and able to understand him, he:

- introduced the 'Impact of stroke' study
- explained who I was
- sought permission for contact to discuss participation in more depth.

If appropriate, he gave patients the 'Patient information sheet' (Please see Appendix B, section B.2) and referred contact details, GP details and medical stroke data to me. He also recorded his reason for non-referrals.

5.6: Recruitment of participants in practice

The early timing of introductions meant that short stay patients were not missed from the study. However, unfortunately, this led to the exclusion of all patients with acute aphasia. A quarter of severely aphasic patients from a community sample (Wade et al., 1986) and a third of originally aphasic patients from a hospital sample (Kauhanen et al., 2000) were found to regain near normal communication within a month. Therefore some patients unable to communicate understanding or interest when invited to participate would have improved to the required level by one month. Of course, some may have been subsequently excluded for a different reason. Nonetheless, the exclusion of these patients with aphasia by default of the introduction method is recognised as a limitation to the study and this issue will be returned to in the discussion.

In total, Dr Kwan's research (the 'first phase' of recruitment) took nine months and involved some 268 patients. About a third were not considered for this project, because approximately equal proportions:

- had died
- were diagnosed with a TIA
- were diagnosed with a different non-stroke diagnosis

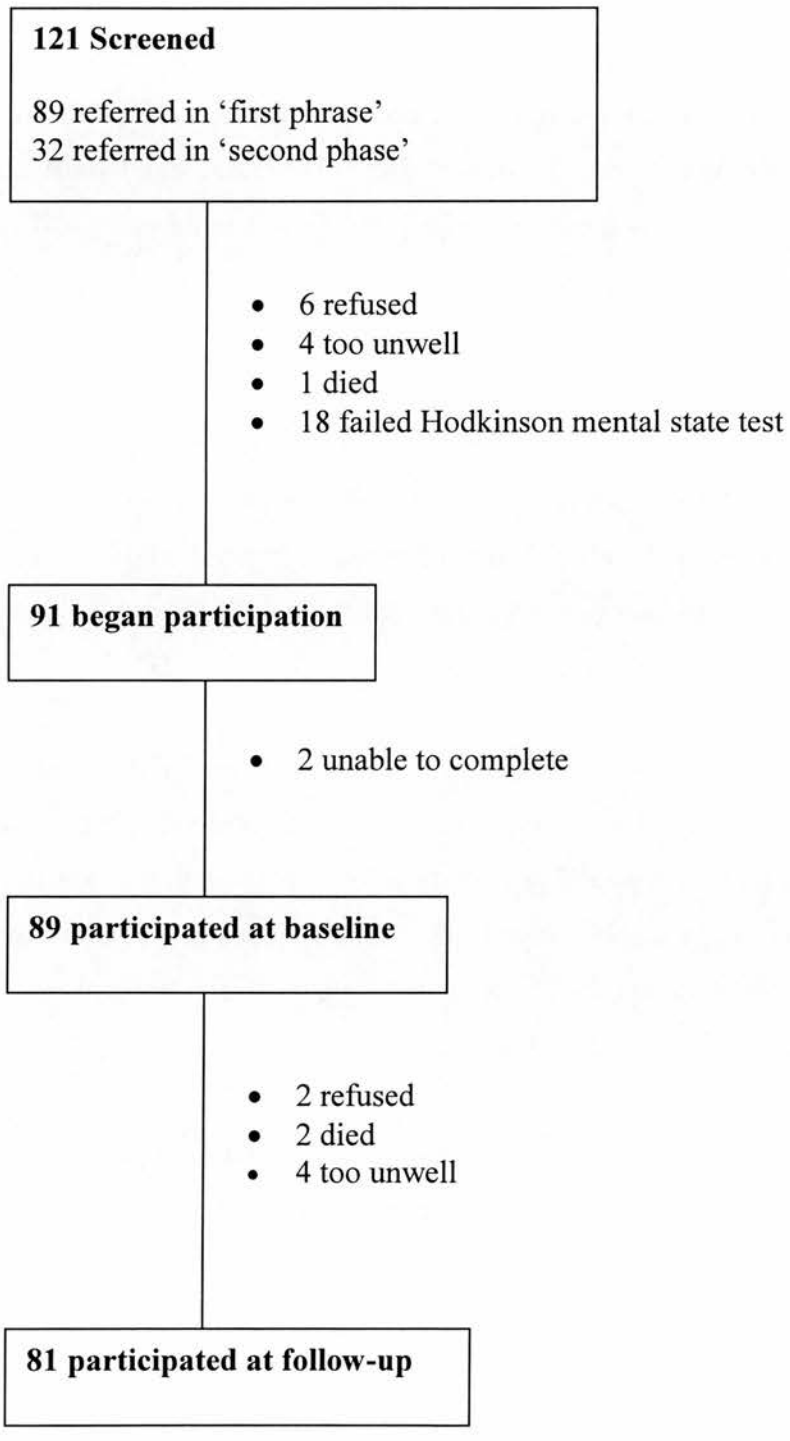
Of the remaining 188 patients Dr Kwan saw for his research, about half (eighty-nine) were referred. Reasons for not referring the others were:

- seventy patients had severe aphasia.
- thirteen patients presented other communication problems (for example deafness or a lack of proficiency in English language).
- eleven patients had clear diagnoses of severe dementia.
- five patients could not be seen or were not interested.

This 'first phase' of recruitment generated sixty-seven participants, which fell short of the number required (please see Chapter 7, section 7.3). Dr Kwan continued recruiting for a further four months ('second phase' of recruitment). He attended weekly ward rounds, and introduced the study to patients who appeared able to understand its nature and purposes. He did not have time to keep records of his reasons for not referring other patients in this 'second phase' but it is likely that they were proportionally similar to before.

In total 121 patients were referred and the results of their subsequent screening are illustrated in Figure 5.1. As shown, cognitive impairment was the main reason for exclusion at screening with one in six patients failing to obtain eight out of ten on the Hodkinson test. A minimal number of patients did not participate for other reasons. A young woman and an older man were too highly distressed to maintain concentration and complete the interview schedule (Total Hospital Anxiety and Depression scale (HADs) scores of 35/ 42 and 33/ 42 respectively). This female patient was already under the care of social and psychological services. This male patient already had a social worker but requested psychiatric help; therefore my supervisor wrote to his GP to explain the situation.

Figure 5.1: Screening of patients and participation at baseline and follow-up



Demographic data describing the eighty-nine participants at baseline and the eighty-one participants at follow-up will be reported in chapters 10 and 12 respectively Excluded participants tended to be older (Mean = 83 years, SD = 5.3 years) than included participants and this difference was statistically significant ($t = -4.2$, $p < .001$). I was able to administer the HADs scale to two people who declined participation and ten of the eighteen patients excluded due to low Hodkinson test scores. Mean HADs anxiety scores (Mean = 5.21, SD = 3.89) and depression scores (Mean = 4.50, SD = 3.06) for these twelve patients did not significantly differ from scores for the final sample.

Prior to contacting a patient I double-checked discharge status and contact information with the hospital database. Missing GP information was obtained from the local authority. Patient contact details were obtained from GP surgeries and directory enquiries. Immediately prior to contacting a patient I confirmed that he/she was still alive with his/her GP surgery in order to avoid any undue distress to relatives if someone had died.

When a patient was still in hospital, I first spoke to his/her named nurse and arranged a suitable time to visit. I had an honorary contract and trust identification and attended stroke team meetings and provided staff with information sheets in order to avoid confusion or concern about what I was doing. When a patient had been discharged, I telephoned and asked to speak to him/her. If s/he was not available I briefly explained who I was and arranged a convenient time to phone back.

When I first spoke to patients I explained who I was, the main purpose of the research, I warned that the interview might take a couple of hours and answered questions. If appropriate, we made an appointment at a convenient time. When patients had been discharged this was uncomplicated. When a patient was still in hospital this involved liaison with the staff to avoid clashes with therapy or ward rounds. Appointments were noted by patients' bedsides and in ward diaries. Despite these precautions, clashes occurred when therapy schedules changed. This unsettled participants who seemed to feel that they personally had 'put me out' when our

interview was stopped short and re-scheduled. Therefore, I began seeing patients in hospital only on therapy free Saturday mornings.

At follow-up, GPs were asked to indicate in writing whether any patient was unable to participate because s/he was too unwell or had died (please see Appendix B, section B.5). Two weeks later, surgeries were telephoned to double-check that participants were still living. Participants were then contacted in writing and telephoned a couple of days later to discuss participation in the same way as at baseline.

5.7: Screening and consent procedure

While administering screening tests, I was concerned not to 'let on' and potentially damage pride when someone was excluded so I would stay and listen to their concerns for a while and answer any questions. Whenever possible, I used the HADs to obtain some gauge of anxiety and depression amongst those too cognitively impaired to participate fully.

Prior to interviews, issues of voluntary participation, right to withdraw, confidentiality and anonymity and any other queries were discussed. Once confident that these issues were understood I requested written consent (please see 'Consent form' Appendix B, section B.3). A few participants were embarrassed about their handwriting on signing the consent form, otherwise concerns were not generally raised. I remained vigilant to participants' consent to continue throughout each interview.

5.8: Conduct of interviews

The majority of participants were interviewed at home. Just ten participants were still in hospital at baseline and one at follow-up and their interviews were conducted in a seminar room. People may have felt more relaxed in their own homes and this may have introduced some response bias. Also I felt it too intrusive to insist on total privacy in people's homes, and when people had small homes it would not have been

practical. Family members tended to stop 'chipping in' after I emphasised my interest in participants' viewpoints and often seemed to use the interview as an opportunity to go out or get on with something. However, the variation in the presence or absence of relatives may have influenced participants' responses.

All scales and open-ended questions were administered verbally and I marked all responses. In addition, participants were encouraged to read cards with the items in large font. The use of face-to-face interviews and verbal administration can be seen as a potential bias or 'experimenter effect'. However, on balance this issue was considered less serious than practical and scientific difficulties of missing data that could be expected with postal questionnaires (O'Rourke, 1996). It is estimated that one in four Scottish adults have poor literacy (Scottish Executive, 2003) and verbal administration allowed me to compensate for these difficulties, to double-check apparently conflicting responses and to compensate for other stroke-related deficits such as initiation and attention. Verbal administration also allowed continuity between the quantitative and qualitative aspects of the interview.

I continually enquired whether participants needed a break during interviews. When a participant was tiring or it became clear the interview would go beyond an hour and a half I discussed rescheduling. This became necessary approximately one third of the time, in which case interviews were carried over to the next possible day.

An opportunity for further questions was given at the end of the interview, and participants were reminded that they could contact me in future. Participants who were distressed or who had unanswered medical questions were reminded that they could contact their GP for help. One depressed participant who was still in hospital had been considering suicide and, with his permission, I informed my supervisor and the rehabilitation team. A couple of other depressed participants had already unsuccessfully sought help for depression from their GPs by follow-up. At their request we wrote to their GPs in the hope that this might be of some benefit.

Chapter 6

Piloting, the quantitative interview and measures

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6.1: Piloting

Piloting was based at the Astley-Ainsley rehabilitation hospital. For seven months, I liasied with nursing staff to set up meetings with patients they considered able to communicate. Practical constraints determined I saw twenty-two patients, aged forty-three to sixty-eight years.

I used meetings to:

- Explore acceptability and practical administration issues of scales
- Practice structured clinical interviewing and qualitative interviewing
- Develop a question route for the qualitative interview
- Obtain test-retest data for appropriate scales with fifteen patients

In choosing scales, those specifically designed for stroke patients were prioritised for reasons of validity, practicality, and comparison with past research. However, it was also necessary to consider other illness and disability scales.

Minor modifications to scales were made to avoid confusion regarding whether questions referred to the experience of 'stroke' or to 'its effects' (please see section 2.1 for discussion). Some open-ended questions were developed to supplement closed questions. One scale was particularly modified to improve its reliability and suitability for stroke patients (please see section 6.8iii*)*. Another scale was found to be unacceptable and so further piloting was used to develop an alternative. (Please see section 6.7iii).

6.2: The quantitative interview and measures

The quantitative interview was developed to assess emotional distress, variables relevant to the hypotheses and background (non-belief) variables considered relevant to the study of distress in the stroke population.

The measures used are summarised in Table 6.1 in relation to the hypotheses and described in more detail in the next section. The actual questions are displayed in the interview schedule in Appendix D. The ordering of scales was designed to begin with the less personal variables in order to allow rapport to be built before administering the distress and self scales.

Table 6.1: Summary of measures

Variable	Type of measure	Source of measure
Emotional distress		
Continuous measure of distress	Hospital Anxiety and Depression scale (HADs): 14 items, four point frequency ratings	Zigmond and Snaith, 1983
Background variables		
Age	Age in years	Hospital records
Gender	Male/ female	Hospital records
Social economic status	Carstair's index: 1-7 deprivation categories	Carstairs and Morris, 1991
Stroke severity	NIH stroke severity scale: neurological exam	National Institute of Health, 1998
Disability	The Barthel index: 10 items, two, three or four point ratings of independence in basic ADLs	Mahoney and Barthel, 1965
	The Nottingham index: 21 extended ADL items, two point rating of independence	Nouri and Lincoln, 1987
Social support	MOS social support scale: 19 items, five point ratings of availability	Sherbourne and Stewart, 1991
Life events	Life events checklist: 12 items, yes/No responses	Brugha et al., 1985
Pre-stroke history of depression	Structured Clinical Interview for DSMIV	First et al., 2001
Attributions		
Causal controllability	Open-ended questions and checklist to access causal attributions, then five point ratings of control	Fielding, 1987
'Why me?'	Single item, five point rating of frequency	Thompson et al., 1991
'Found meaning?'	Yes/No question and open ended probe	Thompson et al., 1991
Self evaluations		
Acceptance of disability	Adapted Acceptance of illness scale: 8 items, five point ratings of agreement	Felton and Ravenson, 1984
Negative Identity change	Adapted Semantic Differential Scale: 20 sets of 'before' versus 'now' items, five point ratings of agreement	Tyerman and Humphrey, 1984
Shame	10 items, five point ratings of agreement	Piloting
Recovery and recurrence		
Recovery locus of control	Recovery locus of control scale: 9 items, five point ratings of agreement	Partridge and Johnson, 1989
Confidence in recovery	Single item, ten point rating of confidence	Lewin et al., 1992
Recurrence fear	Adapted fear of recurrence scale: 8 items, five point ratings of agreement	Northouse, 1981

6.3: Measurement of emotional distress

The Hospital Anxiety and Depression Scale (HADs; Zigmond & Snaith,1983) was chosen in preference to other scales that have been used within stroke research because it:

- avoids floor effects
- aims to avoid confounding the measurement of distress with stroke
- addresses anxious and depressive symptoms equally
- is suitable for the measurement of distress
- has good criterion and concurrent validity
- has good internal and test-retest reliability
- is brief

It consists of fourteen items, split equally between two subscales (anxiety and depression). Depression items centre mainly on anhedonia (loss of pleasure) and anxiety items on non-specific worry, tension and panic. Global HADs scores were used as the distress measure; therefore a maximum scores of forty-two could be obtained. The HADs authors intended the scale to avoid floor effects by excluding severe symptom items. This appears successful as a wide range of scores was found in a study using the same population of stroke patients (O'Rourke, 1996).

The intention of the HADs to assess mood without confounding by physical illness symptoms was supported by recent exploratory factor analysis work that included stroke patients (Johnston et al., 2000). A simultaneous analysis of HADs and a physical quality of life scale demonstrated a good fit between the majority of HADs items and a psychological rather than a physical factor.

Theoretical issues concerning the choice of distress (symptoms of both anxiety and depression) as the main outcome measure were discussed in Chapter 1, section 1.2. Diverging evidence supports the use of the HADs as a global measure of distress. Zigmond and Snaith (1983) originally intended the scale to distinguish anxiety and depressive states. Nonetheless, they found the majority of their sample to report similar degrees of the two states. Subsequent studies report a high level of association between the anxiety and depression subscales. For example, Herrmann (1997) found an average correlation of $r = .63$ across eighteen studies. Experts in

the field have interpreted high levels of covariance between HADs anxiety and depression symptoms as supporting the assumption that they share a large distress component (Spinhoven et al.,1997; Chaturvedi, 1991; Razavi et al., 1989). HADs total and subscale scores have also been found to produce similarly high correlations with other measures of distress and anxiety and depression scales which supports the validity of the HADs as a measure of distress (Bjelland et al., 2002).

HADs distress scores have been tested as a screening instrument for possible psychiatric disorder and found to perform comparably to similar instruments with medical patients, including stroke patients (Hopwood et al., 1991; Lewis & Wessely, 1991; O'Rourke et al., 1998; Wilkinson and Barczak, 1988)). HADs distress scores have been found to achieve similar, and sometimes better sensitivity and specificity in the detection of possible cases of anxiety disorder or depression, than the separate subscales (Costantini et al., 1999; Smith et al., 2002; Spinhoven et al., 1997). This can be interpreted as providing concurrent validity for global HADs in relation to specific psychiatric disorders. An opportunity to study association between HADs scores and diagnoses of depressive and anxiety disorders was taken (please see Chapter 8, section 8.2).

Criterion validity for global HADs scores as a measure of distress was provided by different methods of factor analysis that have found a shared distress factor as well as anxiety and depression factors relating to the original subscales (Dunbar et al., 2000; Smith et al., 2002). Confirmatory factor analysis work conducted by Johnston and colleagues (2000) with stroke and MI patients actually made a 'stronger case' for using the overall measure 'without distinguishing between anxiety and depression' than for the separation of anxiety and depression on the HADs.

Zigmond and Snaith (1983) reported high test-retest and internal reliability for HADs subscales. More recently, Hermann (1997) reported similar coefficients with a sample of 6200 patients and Johnston et al. (2000) found high internal reliability scores for the HADs with a sample of stroke patients. Therefore it appears to be a reliable measure for this population.

Finally, the HADs is briefer than most other measures of distress and therefore low in respondent burden (Johnston et al., 2000; O'Rourke et al., 1998). The HADs can be completed with stroke and cardiac patients within a few minutes (Visser et al., 1995) and was reported as being highly acceptable to patients (Herrmann, 1997; Johnston et al., 2000; Wilkinson and Barczak, 1988).

6.4: Measurement of background variables

6.4i: Demographic data

Demographic information (age, gender and postcode for deprivation category scoring) was obtained from medical records and directory inquiries. In addition I ascertained and recorded whether or not participants lived with someone, were single or in a relationship and owned their own home at opportune moments during interviews.

6.4ii: Stroke severity and type

Dr Kwan provided the assessment of past strokes and the type and severity of index strokes. Stroke type was assessed using the Oxfordshire community stroke project (OCSP) system that classifies stroke symptoms into types that approximate the volume of infarcts in ischaemic stroke:

- Lacunar infarts (LACS; 28%)
- Posterior circulation infarction (POCS; 24%)
- Partial anterior circulation infarction (PACS; 34%)
- Total anterior circulation infarction (TACS; 17%)

These percentages were incidence rates found in the OCSP project (Warlow, 2000) and allow incidence of subtypes in the present sample to be compared to rates expected in a community sample. Stroke severity was assessed with the National Institutes of Health Stroke Scale (NIH, 1989), a graded neurological examination rating speech, language, cognition, visual field deficit, motor and sensory impairment. It is a widely used scale, with high reliability for use by neurologist and non-neurologist physicians (Goldstein & Samsa, 1997).

6.4iii: Disability

The Barthel index and the Nottingham index were used as measures of disability. The Barthel index (Mahoney and Barthel, 1965) is a ten item standard measure with well-established validity and reasonable reliability (Wade, 1992). It covers very basic daily activities of living such as bathing and continence. The Nottingham index (Nouri & Lincoln, 1987) is an inventory of twenty-one items of extended activities of daily living, covering mobility, kitchen activities, domestic tasks and leisure pursuits. By using both measures, possible 'ceiling' effects of the Barthel index and 'floor' effects of the Nottingham index were avoided.

6.4iv: Social support

The medical outcomes study social support survey (Sherbourne and Stewart, 1991) was chosen to measure social support because:

- it is relatively brief (nineteen items)
- ir has good validity and reliability
- it was recommended by the Edinburgh psychotherapy in primary care research team (Law, 2000, personal communication).

This scale was developed by the selection of items by experts following the piloting of previously developed scales. It consists of four subscales to measure perceptions of informational/emotional support, tangible support, affection, and social interaction. Factor analysis supported either the use of the separate subscales, or the use of a global index calculated by addition of the subscale means. To minimise the number of background variables in this study, the global index was used as a measure of perceived social support.

The authors reported good convergent validity (for example, loneliness, and marital and family functioning) and good discriminant validity (for example, role limitations) in a study using a large sample of chronically ill patients. Internal reliability of scale items was found to be extremely high ($\alpha = .97$) and it achieved an overall test-retest score of .78.

6.4v: Life events

Life events were measured using the twelve item 'List of Threatening Experiences Questionnaire' (LTE-Q, Brugha et al., 1985). It has been developed as a considerably less time consuming alternative to the Brown & Harris LEDS interview. In studies that have used the LEDs interview as gold standard, this questionnaire has been found to:

- capture eighty percent of 'markedly or moderately threatening' events
- to have a sensitivity of .89 and a specificity of .74
- demonstrate a high level of agreement between patients and informants reports
- produce high test-retest reliability estimates for eleven of the twelve items

(Brugha et al., 1985; Brugha and Cragg, 1990).

As recommended, participants were questioned about life events for up to six months in the past at baseline. However, at follow-up they were asked to report events that had occurred since the last interview (eight months). Index strokes were not scored as a life event, however other strokes that occurred six months prior to baseline or during the study were.

6.4vi: Pre-stroke history of depression

Previous episodes of depression were assessed during the structured clinical interview (please see Chapter 8, sections 8.2 and 8.5, and Appendix D, section D.14). GP notes were considered as sources of corroboratory evidence. However, depression is often under-recognised in general practice (please see Paykel & Priest, 1992 for discussion). Older medical records were likely to pose problems with terminology. On balance, the time-consuming task of examining general practice records did not seem worthwhile.

6.5: Note on terminology in interviews

Piloting highlighted the difference between perceptions of 'stroke' and 'its effects' (please see Chapter 2, section 2.1). Therefore, the terms 'stroke' or 'the effects of stroke', or 'since my stroke' were used to specify the intended frame of reference throughout the interview. To check my assumption that the main cohort of participants would also differentiate between 'stroke' and 'its effects' they were asked to define these terms at the start of the interview (please see Appendix D).

6.6: Measurement of attributions

6.6i: Causal controllability

Causal controllability was assessed by a two-stage process as it was necessary to elicit 'Causal attributions' before beliefs of control related to these attributions ('Causal controllability').

Assessment of causal controllability stage-one: eliciting causal attributions

Past research in stroke suggested that whether or not participants would be able to make causal attributions required consideration (please see section 2.2ii). Participants were likely to have received some relevant risk factor information from their health professionals. Their involvement in a diagnostic study meant that they would have been primed by questions about smoking, blood pressure, and previous heart conditions and strokes (Hand, 1999; personal communication).

A method designed to maximise the reporting of causal attributions involved both open-ended questions and probes to elicit perceived causes. It was emphasised to hesitant participants that it was their ideas that were of interest (please see Appendix D). This 'probing' method has been used successfully with MI patients (Fielding, 1987) and with cancer patients (Taylor et al., 1984). Finally, a checklist described as 'causes other people who have had a stroke have mentioned' was used to facilitate further reporting. This was developed using items from the Illness Perception Questionnaire (IPQ; Weinman et al., 1996) the results of Fielding's (1987) MI study and risk factors for stroke.

Beliefs regarding the relative potency of causal attributions were also assessed by asking participants to order their attributions from 'the most important' to 'the least important'. The types of causal attribution made and potency beliefs were considered supplementary to the main results and are reported in Appendix F, section F.2.

Assessment of causal controllability stage-two: beliefs in control over elicited causal attributions

The belief that causes can be avoided or controlled in future was assessed using a 5-point scale from 'difficult to control' to 'easy to control' (Fielding, 1987). From piloting work I found that I often needed to guide participants in their ratings of control in terms of orientating them to the future and/or establishing levels of control. Therefore, for each cause I would first ask participants to rate how controllable they thought it was in an open-ended way and then funnelled further questions accordingly (please see Appendix D for further details). Participants were asked to rate the controllability of each causal attribution they had made. For each participant, a mean causal controllability score was calculated.

6.6ii: 'Why me?'

Single items from Thompson (1991) were used to assess a sense of 'Why me?'. Participants were first asked whether they had thought 'Why me?' at any point since their stroke and a yes/no response was recorded. Then participants were asked to rate how often they found themselves asking 'Why me?' on a five point scale. Spontaneous remarks made in relation to this item were also recorded.

6.6iii: 'Found meaning?'

Participants were asked whether they had found any 'meaning' in their experience of stroke (Thompson, 1991) and a 'yes/no' response recorded. As the term 'meaning' was found to baffle some participants during piloting, the prompt 'Is there anything good that has come out of your experience of having had a stroke?' was used if necessary. If appropriate, participants were asked to describe the 'meaning' they had found.

6.7: Measurement of self-evaluations

6.7i: Acceptance of disability

Linkowski's (1971) original fifty-item 'acceptance of disability scale' was considered too long. Therefore a shortened version, the 'Acceptance of illness scale' (Felton and Ravenson, 1984) was chosen and reformulated to address 'the effects of my stroke' not 'illness'. On the basis of factor analysis work, Mpofu and Houston (1998) suggested that the 'acceptance of disability' scale does not address the process of value changes outlined by the theory, but is essentially only a measure of the end product of this process. This criticism is also applicable to the shorter measure. However, as a global measure of acceptance, Felton and Ravenson's scale was considered suitable for the limited aim of this quantitative study to assess negative beliefs, and not the process by which they are developed.

Felton et al. (1984) reported good internal reliability (α = .81 and .83) and seven month test-retest reliability (rho = .70) with patients with hypertension, diabetes, arthritis or cancer. They also reported a negative association between the scale and a wish fulfilling coping measure (describing a pining or longing for the illness to go away) as evidence of construct validity.

6.7ii: Negative identity change

Two similar scales originally developed for measuring changes in the personality of blunt head injury patients were considered for use (Tyerman and Humphrey, 1984; Brooks & McKinlay, 1983). Both scales were designed by expert opinion to provide face validity and consist of twenty pairs of polar opposite adjectives (e.g. 'irritable...easy going'). These are presented to respondents for evaluation in a visual analogue semantic differential format. Tyerman and Humphrey (1984) provided evidence of concurrent validity (similar results on another self-concept scale) and report high internal reliability (α = .88) for their scale. For these reasons and for continuity with past stroke research (Ellis-Hill and Horn, 2000), this scale was chosen.

Participants' evaluations of themselves 'before' the stroke versus 'now' were obtained to provide the measure of 'negative identity change'. Only about half of

stroke patients were found to use visual analogues correctly (Price et al., 1999) therefore single adjectives and Likert response options were used instead (please see Appendix D).

6.7iii: Shame

The 'Other as Shamer scale' (OAS: Goss et al., 1994) scale was chosen for piloting as it had been used successfully with stroke patients (Vine, 1999, personal communication). It essentially measures the belief that others regard one as inferior and this was supported by a factor analysis using students (Goss et al., 1994). The same study reported good convergent and discriminate validity for the scale on the basis of associations with variables such as 'internalised' shame and self-consciousness. As regards internal reliability, the authors reported that all inter-item correlations were significant at the $p < .05$ level.

However, participants' comments during piloting suggested they found the 'Other as Shamer' scale unacceptable. Interestingly, they often became defensive about 'others'. A few commented actually appreciating differential treatment by others, for example how people gave them extra space in public. This was reflected statistically with floor effects. All participants gave the minimum score for twelve of the twenty items at both times of testing. The variance on the other eight items was attributable to just three participants.

Therefore, a new stroke specific ten-item shame scale was developed in collaboration with my supervisors, whose clinical expertise provided face validity. We adapted comments from pilot interviews and items from the OAS scale. Items were made stroke-specific and the emphasis was softened with qualifiers. For example, the OAS item 'Others see me as not measuring up to them' became 'Since my stroke, I sometimes feel that others see me as not measuring up to them'. Three items were designed to reflect a positive experience of differential treatment (please see Appendix D, section D.20 for items).

Piloting of the new scale ran alongside the start of data collection for the main cohort. I continued to use the OAS until it appeared that the new measure was

working adequately. The piloting data is discussed and illustrated along with further comments in Table C2, Appendix C. Overall it did appear reasonably reliable, achieving significant test-retest scores between .62 and .97 and an internal reliability score of $\alpha = .77$.

6.8: Measurement of beliefs in recovery and recurrence

6.8i: Recovery locus of control

The Recovery locus of control questionnaire (RLOC; Partridge & Johnson, 1989) was chosen to assess personal beliefs regarding control over recovery. It is a nine-item scale for which higher scores indicate a more internal rather than external locus of control regarding recovery. So, when higher recovery locus of control scores are described in the results chapters, this refers to higher levels of internality. The validity of the scale is supported by the development of items from interviews with stroke and wrist fracture patients, and good predictive reliability has been obtained (Partridge and Johnson, 1989). Reasonable internal reliability statistics have been reported for patients assessed a few days (.64) one month (.77) and six months (.53) following stroke (Morrison & Johnson, 1999).

6.8ii: Confidence in recovery

Participants' confidence in recovery was measured using a single ten point visual analogue scale marked 'extremely confident' at one end and 'Not at all confident' at the other. This was originally developed for MI patients by Lewin et al. (1992) and has been used with stroke patients (Morrison and Johnson, 1999). The visual analogue format is less than ideal with stroke patients (Price et al., 2000) but was retained for comparative purposes. To compensate, participants were asked to indicate that they understood the meaning of both ends before being asked for their response. If they found it difficult to use, they were asked instead to imagine giving their level of confidence a mark out of ten.

6.8iii: Recurrence fear

A recurrence fear scale specific to stroke was not available. A range of fear of cancer recurrence scales were available for adaptation; however most do not report validity or reliability testing (Lee-Jones et al., 1997). The exception found was the 'Fear of recurrence questionnaire' (Northouse, 1981) which demonstrated high internal reliability, $\alpha = .92$, (Hilton, 1988). Originally developed for mastectomy patients by expert opinion, it contains twenty-two items that generally refer obliquely to recurrence fear by reference to 'concern' or 'worry' for one's 'future health'.

I involved my supervisors closely to achieve face validity in the adaptation of this scale to stroke. Obvious minor modifications were made, for example changing 'mastectomy' to 'stroke'. A few items were omitted because they were vague and could refer as much to recovery as to recurrence (for example 'I have no physical concerns at this time'). When two items were essentially duplicates in terms of meaning, that item which contained a double negative was deleted (for example 'I am not bothered by uncertainty regarding my health'). This left sixteen items to be piloted.

The piloting data (test-retest scores and association of items with HADs scores) is illustrated in Table C1, Appendix C. We decided to retain seven items mainly on the basis of reasonable retest and association scores. The item 'I do not worry about my stroke returning' was kept despite poor test results as it was considered of high face validity. However, it was rephrased as 'I worry about my stroke returning' to avoid poor performance attributable to the double negative format. Fuller reasons for excluding other items are described in Table C1, Appendix C. The internal reliability score for our final eight item 'Recurrence fear' scale was $\alpha = .78$.

6.9: Comment on the reliability and validity of measures

It is recognised that in comparison to other measures, the attributional measures and the confidence in recovery measure were weak in terms of reliability. Test-retest data has not been reported for any of them. As 'Why me?', 'Found meaning?' and confidence in recovery were single items they could not be tested for internal reliability. The measurement of causal controllability was complex being based on participants' own attributions that were likely to vary in type and number reported. However, in the absence of better alternatives I decided to go ahead and use these measures on the basis of face validity, and appropriateness to the hypotheses.

Chapter 7

Analysis of the quantitative study data, sample size and power

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7.1: Quantitative study description plan (Chapters 10 and 12)

7.1i: Résumé of relevant objectives

The main purpose of statistics employed in these chapters was to aid fulfilment of the objectives to:

1) Investigate emotional distress
2) Investigate beliefs considered relevant to stroke patients' emotional distress

Statistics were also used to describe the characteristics of the sample and background variables.

7.1ii: Description of the sample

Participants' age, gender, living situation, deprivation scores, and cognitive screening scores were described using mean scores, standard deviations, ranges and percentage scores as appropriate. In addition medical data regarding frequency of stroke type will be provided.

7.1iii: Description of emotional distress

HADs global scores were used as the distress measure, the dependent variable for hypothesis testing in Chapters 11, 13 and 14. Past research provides support for the validity of using global HADs scores as a distress scale (please see section 6. 3).

To explore the validity of the choice to use distress as the main dependent variable, I decided to report descriptive statistics for the anxiety and depression subscales as well as for the distress scale. This issue was also addressed by examination of concurrent validity between HADs anxiety, depression and distress scores and diagnoses of specific disorders (please see Chapter 8, section 8.2 and section 8.6ii).

Mean and standard deviation of HADs anxiety, depression and distress scores and distribution properties was reported and interrelationships examined using Pearson correlations.

7.1iv: Description of the other background variables

Background variables that were not included as characteristics of the sample: stroke severity, disability, social support, life events and pre-stroke history of depression were described using mean scores, standard deviations, ranges and percentage scores as appropriate. Comment was also passed on the distribution of background variables.

7.1v: Introduction to description of the belief measures

The objective to:

2) Investigate beliefs relevant to stroke patients' emotional distress

was complex due to the under-developed nature of relevant measures used in this study. Therefore I decided to test reliability and explore validity of the measures in both the pilot and the main study.

7.1vi: Initial development and reliability statistics of the belief measures

As described in Chapter 6 (please see sections 6.7iii and 6.8iii) the shame and recurrence fear questionnaires were specifically developed for this study.
Data relevant to the development of these questionnaires is reported in Appendix C (please see tables C.1 and C.2). Internal consistency and test re-test reliability data for these questionnaires obtained during piloting is reported in the measures section (please see Chapter 6, section 6.7ii and section 6.8iii).

I also decided to report internal reliability statistics for main study data, for new measures and measures that had not previously been used with stroke patients:

Acceptance of disability
Negative identity change
Shame
Recurrence fear

7.1vii: Descriptive statistics and further exploratory description of belief measures

Means and standard deviation scores and ranges (or percentage scores) for all belief variables assessed by scales was reported, and comment was passed on the distribution of variables.

Further exploration of causal attributions/controllability involved examining frequencies of raw scores and percentages of individual causal attributions/ controllability ratings (reported in detail in Appendix F). Further exploration of the identity change scale involved examination of mean changes for individual items and these were tested using t-tests (two-tailed).

I decided to use factor analysis to conceptually explore beliefs measured by multi-item scales for which no previous description of psychometric properties with the stroke population was available. These scales were:

Acceptance of disability
Negative identity change
Shame
Recurrence fear

Principal component analysis with orthogonal rotation was chosen to maximise discrimination and so to seek out conceptual differences within scales. Factor analysis results were briefly described in relation to the relevant belief variables in the main body of the thesis and in more detail in Appendix C.

Open-ended responses were categorised using standard content analysis (Robson; 1993). However, it was not considered viable to subject this data to the same depth of analysis or inter-rater reliability checks as the main qualitative data. Results from open-ended questions contained in the quantitative interview were reported briefly in parallel with those obtained for belief variables assessed by scales in the main body of the thesis and in more detail in Appendix F.

7.1viii: Consistency of background and belief variables

Consistency of baseline to follow-up background and belief variables were tested using repeated measure t-tests or McNemar tests as appropriate (both two-tailed).

7.2: Analysis plan for the hypothesis testing (Chapters 11, 13, 14)

7.2i: Résumé of the hypotheses

The purpose of statistics employed for these chapters was to aid hypothesis testing.

Main hypotheses*

1) A significant relationship between beliefs and emotional distress would be found at an initial point in time (baseline) and at a later point in time (follow-up)
2) Beliefs found at baseline would predict emotional distress at follow-up

* It was expected that the main hypotheses would be fulfilled even once demographic and social background factors had been taken into account

Specific hypotheses**

1) Certain negative attributions:
   - Lower sense of control over causes
   - Higher frequency of asking 'Why me?'
   - A failure to find meaning in the experience

would be associated with higher levels of emotional distress

2) More negative self-evaluations:
   - Lower acceptance of one's disability
   - A more negative sense of identity
   - Higher shame

would be associated with higher levels of emotional distress

3) More negative beliefs in recovery and recurrence
   - Lower sense of control over recovery
   - Lower confidence in recovery
   - Higher fear of recurrence

would be associated with higher levels of emotional distress

**The specific hypotheses are intended for baseline, follow-up and across time.

7.2ii: Choice of statistical tests

To test the hypotheses, I choose to examine:

1) Univariate associations between belief variables and distress
2) Univariate associations between background variables and distress
3) Multivariate associations between belief variables and distress while controlling for background variables

Correlation was chosen to test univariate associations, and linear regression for the multivariate analysis.

To further explore the validity of the choice to use distress as the main dependent variable, univariate associations between the independent variables and the depression and anxiety sub-scales were also examined.

7.2iii: Statistical considerations for correlative and linear regression analyses

The most important parametric assumptions involved in correlative and linear regression analyses are normality of distributions and homogeneity of variance in arrays (Howell, 1997).

Normality of distributions

Histograms of all background and belief variables were inspected visually and the degree of normality versus skewness was discussed. The pros and cons of normalising data by transformation, or of dichotomising very skewed variables was considered, a statistician's advice was sought and appropriate action was taken. Histograms are displayed in Appendix E, sections E.1 to E.4.

Homogeneity of variance in arrays

Essentially this assumption means that reasonably similar perpendicular variances should be found at all points on a line of best fit drawn between the dependent variable (HADs distress) and each independent variable (background and belief variables). As linear relationships between two variables can be significantly skewed by outliers, the five lowest and highest scores of every variable were checked for accuracy and corrected if appropriate. Scatter plots of the dependent variable against

all independent variables were inspected for homogeneity of variance in arrays. Where this assumption appeared violated following the treatment for normality of distributions described previously, and corrections for outliers, the implications in terms of type I versus type II errors was taken into consideration. Scatter-plots are displayed in Appendix E, sections E.5 to E.10.

7.2iv: Specific considerations for correlative analysis

Pearson product moment correlations, which assume data is ratio order, were chosen for comparability between univariate and multivariate associations, as Pearson correlations are used in linear regression calculations. As some of the variables would be dichotomised and others would be more safely classed as ordinal rather than ratio data, all correlations with distress were also repeated using Spearman's Rho. Any discrepancies between the parametric and non-parametric method will be taken into consideration in terms of support for the hypotheses and these tests will be two tailed.

Pearson correlations alone were reported for the HADs depression and anxiety sub-scales for comparison to the distress measure. This was to minimise the amount of information reported.

7.2v: The choice of distress as the outcome variable in regression analyses

From a practical and statistical perspective, the use of one main dependent measure (distress) rather than two (depression and anxiety) was advantageous. This halved the number of multivariate analyses and reduced the chance of type 1 errors, which was desirable given the number of independent variables (Lewis, 2000; personal communication).

7.2vi: Preparation for the regression analyses

Prior to conducting the regression analyses a correlation matrix of all independent variables was produced and examined for collinearity. High correlations between variables and any variable that showed particularly high multi-collinearity with many variables was highlighted. The possible influences of multi-collinearity was considered both before and after the analyses.

7.2vii: Method of variable selection for the preliminary regression analyses

It was decided to repeat the backward regression procedure using two different methods of selecting variables at the outset ('univariate' and stricter'). The main reason for this was a conflict between power considerations versus a more strict approach.

From my reading there are various perspectives on the power of my sample size that are discussed in section 7.3. Often, regression analyses are conducted with only those independent variables that produced significant univariate correlations with the dependent variable. The benefit of this 'univariate' method is that by minimising the number of variables at the outset, power is increased.

However, some statisticians advocate including all independent variables, particularly possible confounders, regardless of univariate significance levels because:

'...variables may contribute in an unforeseen way due to complex inter-relationships amongst the variables...'

Altman (1991)

Therefore, in the 'stricter' method, all the background variables were included and were then 'forced in' at each stage in the analysis (Altman, 1991). In this way the final results for the belief variables were less subject to the criticism that they were there by chance confounding with background variables.

An additional advantage of using two methods is that it allows for subsequent comparison and is a good way of highlighting robustness versus instability of the models (Lewis, 2003; personal communication).

7.2viii: Backward regression method of variable elimination

The backward method of variable elimination was chosen in preference to a forward or mixed stepwise regression method. The backward method allows one to manually eliminate variables until all variables in the equation are of a pre-designated significance level. Backward regression was considered preferable to forward or mixed stepwise as it is a less 'black box' or 'reliant on SPSS' method (Graham, 2002; personal communication). Backward regression is also more suited to hypothesis testing than the other methods (Field, 2000).

This method of variable elimination was used in both the cross-sectional analyses (main hypothesis 1) and for the predictive analyses (main hypothesis 2):

- Baseline background and belief variables to baseline distress: cross-sectional analyses (Chapter 11)
- Follow-up background and belief variables to follow-up distress: cross-sectional analyses (Chapter 13)
- Baseline background and belief variables to follow-up distress: predictive analyses (Chapter 14)

7.2ix: Particular analysis consideration for the predictive analyses (main hypothesis 2, Chapter 14)

To further stringently test the ability of baseline variables to predict follow-up distress, an analysis that controlled for baseline distress was also conducted. I considered doing this by using residualised distress scores as the criterion, but decided to use hierarchical analysis in which baseline distress was entered as a predictor, before the addition of other baseline variables. Essentially both methods would produce the same results. However, the hierarchical method was considered

conceptually better as it would allow assessment of increment in R^2 change between a model produced with just baseline distress and further models following addition of other baseline independent variables.

7.2x: Note on reporting of statistics and statistical significance levels

Where possible, absolute p values have been reported to three decimal places. This is not possible for Chi square because SPSS only provides rounded up 'less than' values. Also, when the significance level was very high, and SPSS provided a series of zeros, p values of .0001 were reported in tables and p<.0001 in the text. When asterisks were used to denote significance levels, common nomenclature was followed (* denotes p<.05, ** denotes p<.01, *** denotes p<.001 or even less). When t-tests or Chi square were used the statistics were reported, however this was not possible for McNemar tests because SPSS only provided the significance level.

7.3: Sample size and power considerations (Chapters 11, 13, 14)

7.3i: Prospective power considerations

Estimations of the ideal number of participants needed in terms of power, were made using power estimations for correlation, and with the help of past results.

The formula:

$\delta = đ \int N-1,$

(p,269, Howell, 1997)

and the G-power program (Buchner et al., 2002) were used to calculate power.

Previous studies of depression with the stroke population have reported moderate effect sizes for the self-evaluation variables negative identity change and shame (Ellis-Hill, 1998; Vine, 2003). However, effect sizes for other variables have sometimes been small (see for example, Morrison & Johnston, 1999). Therefore a more conservative estimate of a small effect size was used for the power calculation.

To obtain power of .80 or above with <.05 probability, the formulae suggested:

$(2.80/.30)^2 = N-1$

Therefore ideally N should have been equal to eighty-seven or more.

However, we also considered the large number of variables and:

"the rule of thumb which has been kicking around for years"
(p.522, Howell, 1997)

that suggests that we should have at least ten participants for each independent variable when using mulitivariate analysis. This rule suggested that 180 participants would have been necessary, for the nine background and belief variables intended for multivariate analyses to be analysed simultaneously.

However, Harris (1985, in Howell, 1997) has suggested that there is not strong evidence for the ten participants per predictor maxim, and that fifty participants plus the number of predictors is generally sufficient. Going by this rule of thumb it was only necessary for us to recruit sixty-eight participants.

7.3ii: Practical considerations and power

Conservative estimates based upon prior research with the same population of stroke patients and similar recruitment patterns suggested that it was only feasible to expect a sample size of approximately 120 (O'Rourke, 1996) to be recruited over the planned period of data collection of a year

In practice, participants were recruited for thirteen months and data collection took twenty months. This lower recruitment rate can be attributed to the exclusion of patients with severe dementia or aphasia (please see Chapter 5, section 5.6). In total eighty-nine participants were available at baseline and eighty-one at follow-up. Given consideration of the above, power is considered reasonable but not strong for this study.

Chapter 8

The structured clinical interview study and analysis

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8.1: The main purpose of the structured clinical interview study

Structured clinical interviews are designed to maximise the reliability with which decisions regarding the presence/ absence of psychiatric disorders characterised by pre-set criteria are made ('diagnoses'). The structured clinical interview for DSMIV (SCID-I/P, for DSM IV-TR, Patient Edition; Spitzer et al., 2001) that will be referred to as the SCID from now on, guides the diagnoses of disorders based on criteria outlined by DSMIV (APA, 1994).

As a consultant psychiatrist, Dr Sharpe was able to guide and supervise me to use the SCID (please see section 8.7 for further discussion). The SCID is highly structured in the requirement to address specific topics and the wording of questions is suggested. However, it allows some leeway with the exact wording and order of questions that may be adapted to the perceived needs of individual patients. A measured level of exploration and probing for symptoms is encouraged. Moreover patients are asked to provide their own descriptions regarding the content of certain symptoms.

During piloting, I found the SCID to be more flexible than questionnaire assessments. I was particularly taken with how patients' responses to questions about cognitive symptoms appeared to tap some stroke-specific negative beliefs. This seemed to be a relatively succinct method of generating interesting data and this led to the development of the exploratory objective to:

5) Explore the type of beliefs and nature of symptoms related to common depression and anxiety disorders

In this context DSMIV criteria were treated as 'working definitions' and the process of exploring beliefs accessed by the SCID, essentially allowed appraisal of the 'fit' between stroke-related issues and DSMIV criteria for specific disorders.

8.2: Other uses of the structured clinical interview study

The SCID enabled the main quantitative study background variable (a pre-stroke history of depression) to be assessed using recognised criteria (please see Chapter 6, section 6.4vi). Also, participants with depressive disorder or GAD could be distinguished from those without for comparison within the qualitative study (please see Chapters 9 and 16). Concurrent validity between continuous measurement of emotional distress, depression and anxiety symptoms (HADs scores) and emotional disorders (SCID diagnostic categories) was studied primarily to provide a link between all three sets of data.

The use of the SCID was also considered beneficial in supplementary ways that were interesting to clinical practice or ongoing debates in the stroke literature. Using the SCID and the HADs allowed me to develop my own ideas about the issue of emotional awareness and the testing of concurrent validity between the two was considered of interest to clinical practice (please see Appendix G, section G.4 for further discussion). The ongoing debate about the use of cognitive versus somatic symptoms for the assessment of depression (please see Nicholl et al., 2002 for discussion) could be explored with SCID data. Given the neglect of anxiety research relative to depression in stroke, obtaining prevalence rates for anxiety disorders was considered a useful spin-off in and of itself. Comparison between those with/without emotional disorders and key background characteristics was considered an interesting complement to the reporting of overall prevalence rates.

Finally the opportunity was taken to develop two minor additional hypotheses comparing two types of specific fears and specific anxiety disorder. These were:

i) Higher shame scores would be found amongst those with social phobia and agoraphobia

ii) Higher fears of falling would be found amongst those with agoraphobia

8.3: The depression and anxiety disorders that were assessed

In keeping with DSM-IV a diagnosis of depression was made on the basis of depressed mood and/or a loss of interest or pleasure in life over a two-week period. Additionally, four, or, two further symptoms, such as feelings of worthlessness or disturbed sleep were required to meet the criteria for major, or, minor depression respectively. All participants were asked about all symptoms of depression (please see Appendix D, section D.14).

Criteria used for the anxiety disorders are illustrated by the interview schedules in Appendix D section D.15. The repetition of many arousal items across the different anxiety disorders was considered burdensome, therefore SCID screening questions were used, and further questioning as appropriate. An exception was made for agoraphobia without panic disorder as the interview was short. In general DSMIV criteria were applied; exceptions that were made are highlighted in the following brief descriptions of disorders:

General anxiety disorder (GAD) involves excessive levels of worry in various areas of life, difficulty controlling the worry, the presence of three or more anxious symptoms and significant impairment or distress. The criterion that symptoms have persisted for six months was discounted because of interest in the development of GAD since stroke.

Agoraphobia (with/without panic disorder) involves the hallmark fear of situations in which escape may be difficult and subsequent avoidance, or endurance with marked distress, or the need for a companion. Agoraphobia with panic disorder also involves recurrent panic attacks (please see Appendix D, section D.14 for panic disorder criteria). Additionally, participants were asked whether physiotherapists had advised them not to attempt going out alone.

Social phobia involves a marked and persistent fear of social situations such as speaking to strangers or eating in public. The symptoms I was most interested in were: A) the fear of acting in a humiliating or embarrassing way B) anxiety in the feared situation C) a recognition that one's level of fear is excessive or unreasonable

D) avoidance and E) significant impairment or distress. The criteria that symptoms have persisted for at least six months and are not due to a general medical condition were discounted because I was specifically interested in social phobic symptoms related to stroke.

Post traumatic stress disorder (PTSD) involves persistent re-experiencing of an event that threatened death or serious injury. All stroke survivors were considered to have undergone an event that threatened death so PTSD was screened by enquiring about re-experiences (intrusive thoughts, nightmares, or a sense of reliving the stroke). Additionally PTSD involves symptoms of numbing or avoidance and increased arousal (please see Appendix D. section D.15).

8.4: Measures used for the minor hypotheses

The measure of shame has been described previously (please see Chapter 6, section 6.7iii). A fear of falling scale could not be found in the literature. Therefore I developed comments from patients who reported fear of falling into four items addressing fear, confidence, and coping regarding falls (please see Appendix D, section D.6). This brief scale achieved a high internal reliability score during piloting ($\alpha = .78$) and moderate to low test-retest scores for individual items (.57, .53, .60, .41) with an overall test-retest score of .67. In addition I asked individuals whether they had fallen since their stroke.

8.5: Sample and procedure for the structured clinical interview study

This study was embedded within the main quantitative study. Therefore sample characteristics and the procedure previously described in Chapter 5 applied to this subsidiary study.

I conducted the SCID interviews and collated information for each participant. All possible cases of depression, GAD, agoraphobia, and social phobia were discussed in depth with Dr Sharpe and all possible cases of PTSD with Dr Tinson, and consensus agreement was reached. Please also see section 8.7 for further comment.

Participants who met criteria for depression were given a 'diagnosis' regardless of whether or not they met criteria for an anxiety disorder and vice versa.

8.6: SCID data description and analysis plan (Chapter 15)

8.6i: Description and analysis of frequency of disorders

Prevalence rates of emotional disorders were described using both raw numbers and percentage frequencies for the whole sample at both baseline and follow-up. Frequencies were also described amongst subgroups based on 'key' background variables:

Gender (.male' and 'female')

Pre-stroke history of depression ('yes' and 'no')

Age ('older' and 'younger')

Disability ('lower' and 'higher')

These were chosen as key comparisons to make based on previous research (please see chapter 1, section 1.6ii). Sufficient numbers of very old or particularly young participants to allow special consideration of these interesting groups was not expected. Therefore retirement age (sixty-five years) was chosen as a relatively meaningful point for the division of participants into 'older' and 'younger' groups. Participants were dichotomised into groups of 'higher' and 'lower' disability following examination of Barthel and Nottingham indices of activities of daily living scores (Please see Appendix F, section F.4 for an explanation and description of how this was done).

Chi square (two-tailed) was chosen to statistically compare frequency of emotional disorder amongst these key groups.

McNemar tests (two-tailed) were chosen to test consistency in the diagnosis of the emotional disorders between baseline and follow-up.

8.6ii: Exploration of the emotional disorders

To address the objective to:

5) Explore the type of beliefs and nature of symptoms related to common depression and anxiety disorders

issues were chosen for exploration based on my knowledge of DSMIV descriptions of the disorders, knowledge of issues from the stroke literature, my observations during the SCID interviews and discussion from our consensus meetings.

Depression

Raw numbers and percentage frequencies of each symptom of depression was reported for those with depression (major or minor) and those without. Chi square (two-tailed) was chosen to statistically compare frequency of individual symptoms between those with and without depression. It is emphasised that this analysis was solely exploratory.

Observations regarding the nature of specific symptoms, in particular the content of cognitive symptoms and issues with the interpretation of criteria, was commented upon and patient quotes provided.

Anxiety disorders

Stroke-specific content of beliefs related to symptoms of fear and avoidance was discussed and illustrated with patient quotes. Raw numbers and percentage frequencies of symptoms amongst sub-groups (for example those with/without an anxiety disorder) were reported and used to explore the nature of disorders. The 'fit' between DSMIV criteria and the nature of stroke specific problems observed was commented upon.

8.6iii: Comparison of SCID diagnostic categories and HADs scores

MANOVA was chosen to compare HADs scores (depression, anxiety and distress scores) across diagnostic groupings of emotional disorders:

- Major depression c.f. Minor depression c.f. Not depressed
- GAD c.f. No GAD
- Agoraphobia c.f. No agoraphobia
- Social phobia c.f. No social phobia

The results for these analyses are presented and commented upon in Appendix G, sections G.4i, G.4ii and G.4iii.

8.7: Note regarding the reliability of 'diagnoses' made

It should be borne in mind that the SCID was administered within a larger set of measures that would have 'un-blinded' me to various issues that were found of interest in SCID data (please see Appendix D for order of all assessments and measures administered). In addition, when I saw patients at follow-up I could probably remember most participants' diagnostic status from baseline before readministering the SCID, and this may have in some way biased what was reported and/ or what I found.

Dr Sharpe has experience in training researchers to use the SCID and I was instructed using role-play and discussion of tape-recorded pilot interviews. This was similar to the training of interviewers with similar backgrounds to mine, which was found to result in high inter-rater reliability, diagnostic accuracy and interview skill (Ventura et al., 1998). Also, consensus agreement was used throughout the study. However, it should be acknowledged that the SCID was originally developed to improve the reliability of diagnosis by trained clinicians (Spitzer et al., 2001) and I am not a clinician.

Chapter 9

The qualitative study

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9.1: The purpose of the qualitative study

The purpose of the qualitative study was to fulfil the objective to:

6) Explore patients' own experiences and concerns using a qualitative approach

Intrinsic advantages of obtaining qualitative data that reflects patients' own idiosyncratic perspectives, and supplementary advantages to the main quantitative approach have been described (please see Chapter 4). Because I was particularly interested in beliefs amongst more highly distressed participants, I decided to compare participants with major or minor depression (which will be referred to as depression for brevity) or with generalised anxiety disorder (GAD) to those without in the analysis.

9.2: Development of the qualitative interview

Various approaches were piloted. Other qualitative stroke researchers have used a narrative approach that involves asking patients to tell the story of their illness (Pound et al., 1998) or even their life (Ellis-Hill et al., 2000). However, I found that asking patients for the story of their stroke tended to prompt rather 'auto-pilot' and time-consuming history giving. I found that, having established rapport during administration of quantitative interview measures, patients appeared to accept an immediate focus on the questions of interest.

The overall content of the interview questions was developed to address participants' main concerns in life, their main concerns relating to stroke and how participants thought their lives had changed following stroke. The wording and order of questions varied from participant to participant but followed the general structure outlined in the question route. Dr Tinson and Dr Sharpe helped me to develop a probing interview approach that was nevertheless open-ended. For example, when a participant was not immediately forthcoming the question was repeated in a slightly different way with slightly different emphasis. The sort of questions I found most useful when trying to capture feelings and beliefs related to

areas of concern are illustrated in the question routes. Please see Appendix D, sections D.11 and D.22 for the question routes.

The 'concerns' part of the interview was placed within the main quantitative interview at the point by which I felt a good rapport tended to be established but before the assessment of emotional disorder and distress (please see Appendix D, D.11). I used the 'important areas' questions to end the interview. I always ended with a brief summary of what participants had told me overall, double-checked my understanding and thanked participants for sharing things to help in research.

9.3: Sample and procedure for the qualitative study

I decided to include sixty participants in the qualitative analysis. This number was chosen to capture enough participants with depression/GAD for comparison to those without. The subset of participants who were used in the qualitative study consisted of participant 21 to participant 80 from the main quantitative study at baseline. Their demographics, disability and emotional disorder status is displayed in Table F.4 in Appendix F. As can be seen, characteristics of this sub-sample are similar to characteristics for the total sample of participants from the quantitative study.

Because the qualitative interview was embedded within the main quantitative study, the procedure for recruiting participants, gaining consent and scheduling appointments was the same as that described in Chapter 5. For all interviews, notes were taken and typed out as soon as possible.

9.4: The qualitative analysis

9.4i: Choice of analysis method

Content analysis using the 'Frameworks' method (Ritchie and Spencer; 1994) was chosen because it is suitable for use with a wide range of data, including interview notes. Also, content analysis has a precedent for bridging quantitative and qualitative data. This was ideal for the purposes of comparing responses between participants with/without depression or GAD.

9.4ii: Coding development and consensus agreement

I conducted most of the analysis but Dr Sharpe and Dr Tinson were closely involved. Initially, notes were labelled only with participants' gender, age and identification numbers. In this way any bias in my judgement due to recognition of participants' diagnoses was minimised, and avoided for Dr Sharpe and Dr Tinson.

The process began with intensive immersion in the data (reading and rereading notes). I developed codes (minor themes) via constant comparisons within the data, or by recognition of issues suggested by theory. These codes were grouped together to form preliminary frameworks (major themes). As more codes were developed, compared amongst each other, and slotted into the frameworks, the nature of both codes and frameworks went through various modifications. In order to manage the large number of codes going into each framework and draw similarities between them, sub-themes were also developed. To clarify there were:

1) **Frameworks** (major overarching themes to which codes were allocated and in which sub-theme divisions were made)

2) **Sub-themes** (clusters of minor themes/codes within a framework)

3) **Minor themes** (codes representing minor themes within the data)

In general, minor themes clearly tended to fit into a framework, and cluster together conceptually into sub-themes. Some codes were seen as 'floaters' during early

stages, because they did not fit well into a framework or because they overlapped between frameworks. These crossovers of relevancy were to be expected given the complexity of qualitative data.

I produced the first draft comprehensive scheme of codes and frameworks, Dr Sharpe and Dr Tinson studied this and then we met for discussion. The 'Frameworks' method allows codes to be named as well as identified by theoretical concepts. We agreed that theory was bound to play a role, but that it was preferable to maximise the use of participants' language in code labels.

Secondly, we observed that the content of the coding schemes for the first two frameworks was predominantly functional, and did not in itself always capture the more psychological aspects of participants' experiences. For example, within the framework 'Being like this', the 'Can't do what I did before' codes had been developed but the 'Meanings and feelings' codes had not (please see Chapter 16, main theme 1). This was to be expected with the 'Frameworks' analysis where the coding is intended largely just as a means for labelling data into manageable bites for subsequent retrieval and more interpretative analysis. However, we decided to award all psychological aspects in the data independent coding. In many respects our development of the 'Frameworks' method pushed the analysis more towards the method of 'Interpretative Phenomenological Analysis' (Smith et al., 1999).

The coding scheme was reformulated over a period of a couple of months. Dr Tinson and I met regularly to discuss the process. When there were areas of disagreement, pilot categorising exercises were used which involved trying codes out on all relevant data and then refining them through extensive discussion.

As the frameworks became more developed most 'floating' codes could be incorporated. Some floaters were sub-divided to illustrate a difference of emphasis in relation to different frameworks. For example, dislike of needing help was coded both as 'Feeling reliant' (that emphasised loss of valued independence) and as 'Being a burden' (that emphasised concern about inconveniencing others). These were considered relevant to main theme 1- Being like this, and main theme 4-

They're OK, I'm OK, or not, respectively (please see Chapter 16, sections 16.2 and 16.5).

Overall, the iterative process of coding, discussion, and re-coding went through three full cycles until consensus was achieved. Altogether ninety-two codes were developed and these are presented in Chapter 16. To double-check the operation of the coding scheme, Dr Tinson independently coded ten sets of interview notes using the final frameworks coding schemes are presented in Chapter 16. Dr Sharpe then examined this material for disagreement. Dr Tinson's coding concurred with my own, although I was more likely to award more than one code to each statement. In turn, Dr Sharpe agreed with Dr Tinson's codings. Therefore, there was a good level of consensus amongst us.

9.4iii: Conduct of the final analysis

All responses relating to each individual code were collated to enable a systematic charting of the prevalence of codes and easy sorting between groups of participants across themes. Transcripts were now marked according to depression and GAD status. Diagnoses of agoraphobia or social phobia were also considered due to their relevance to the 'Specific fears and issues codes' in the first 'Being like this' theme (please see Chapter 16, 16.2). Common or interesting associations within the data were searched for and notes made. In many ways a large degree of this work had been accomplished via the process of such detailed coding and re-coding. The beliefs that appeared to associate with depression/GAD were focused on in this final stage. Patient quotes were chosen that captured the overall nature of themes or that distinguished between the participants' with/without depression or GAD.

I decided to report numbers of participants who reported each theme. These 'quantified' results cannot be considered to represent prevalence counts because participants were not systematically questioned about every issue. However, these numbers were considered to help 'bridge' comparisons to the quantitative and structured clinical interview results. The reporting of issues in the context of the qualitative interviews, as compared to the context of a systematically structured

interview was considered to aid consideration of the relative importance of issues. Differences in the content or strength of beliefs reported by participants with/without depression or GAD were generally captured by description or with quotes. However, often differences observed between those with depression/GAD and those without emerged once the proportion of each group reporting an issue was compared. Therefore, when appropriate, numbers and percentages were used to illustrate these findings.

The results are reported in Chapter 16 and Appendix H. All the codes that were developed within sub-themes and the five main themes are presented across these chapters in their respective frameworks.

Chapter 10

Description of sample, background and belief variables at baseline

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10.1: Description of the sample at baseline

10.1i: Final sample at baseline

Eighty-nine eligible consecutive stroke survivors from the Western General Hospital were recruited for the quantitative study at baseline. On average participants tended to be interviewed after one month following their stroke (Mean = 36.72 days, SD = 9.52 days). Often this was because patients were discharged at approximately the one-month stage and preferred to settle in at home before the interview.

10.1ii: Demographic and cognitive ability of the sample at baseline

Demographic and cognitive ability data for participants at baseline is illustrated in Table 10.1. Sixty percent of participants were male, which was not surprising as being male is a risk factor for stroke, (Warlow et al., 1987). However this figure still seems slightly high because women are as likely to have strokes once they are in old age and are more likely to live into old age (Warlow et al., 1987). However, old age also brings an increasing likelihood of dementia. Twelve of the eighteen patients I excluded with low Hodkinson scores were female. On balance the higher proportion does not appear particularly unusual once the screening procedure was taken into account.

The age of participants in this sample produced a fairly normal distribution, and approximately two thirds of participants' ages fell between one standard deviation below or above the mean age of seventy years. Compared to general stroke population incidence rates 'younger' stroke patients are probably over-represented in this sample, as young patients tend to be referred to this specialist stroke unit from a wide geographical area (O'Rourke, 1996). In contrast 'older' stroke patients were more likely to have been lost during screening and so are probably under-represented. The actual numbers of both 'young' (less than fifty years) participants and 'old' (greater than eighty-five years) participants were very low and would preclude testing of age differences at these levels. A quarter of participants' ages fell below retirement age which made this a reasonable dividing point for 'younger'/'older' comparisons for the SCID data (please see chapter 15).

Table 10.1: Demographic and cognitive ability data for all participants at baseline

	Number and percent, or Mean and SD as indicated.	Median	Range
Gender			
Female [1]	36 (40%)		
Age			
Age in years [2]	70.13 (11.29)	71	32 – 90
≤ 50 years [1]	5 (6%)		
51 – 60 years [1]	10 (11%)		
61 – 70 years [1]	26 (29%)		
71 – 80 years [1]	34 (38%)		
81 – 90 years [1]	14 (16%)		
≥ 85 years [1]	6 (7%)		
'Younger' participants < 65 years [1]	22 (25%)		
'Older' participants ≥ 65 years [1]	67 (75%)		
Social economic status			
Carstairs index scores [2]	3.60 (1.55)	4	1 – 7
Deprivation category 1 or 2 [1]	21 (34%)		
Deprivation category 3 or 4 or 5 [1]	61 (58%)		
Deprivation category 6 or 7 [1]	7 (8%)		
Living situation			
Living alone [1]	33 (37%)		
Living with spouse [1]	47 (53%)		
Living with son, daughter or sibling [1]	9 (10%)		
Cognitive status			
Hodkinson scores [2]	9.54 (.64)	10	7 – 10
FAST scores [2]	26.31 (3.81)	27	15 – 30

[1] Number and percentage of participants [2] Mean and standard deviation of scores

A larger proportion of participants was found with low than high deprivation scores was found. Specific epidemiological data concerning deprivation scores amongst the stroke population was not available for comparison. This finding is likely to be unusual in comparison to the stroke population at large, because Edinburgh is one of the most affluent areas of Scotland (Carstairs and Morris, 1991).

As shown in Table 10.2 below, female participants were more likely to be single or to live alone which was to be expected amongst participants of this age range. Despite broad ranges, high average cognitive status scores were found, suggesting levels of ability higher than those amongst the general stroke population (Warlow et al., 1987). However, these levels may be comparable to other samples in the psychological stroke literature where similar exclusion/inclusion criteria have been used.

Table 10.2: Living arrangements for male and female participants at baseline

	Living alone and single	**Living alone but has partner**	**Living with spouse**	**Living with offspring or sibling**
Female participants (N = 36)	19 (38%)	0	12 (33%)	5 (14%)
Male participants (N = 53)	12 (22%)	2 (4%)	35 (66%)	4 (8%)

10.1iii: Medical data at baseline

Relevant medical data concerning previous strokes, stroke types, and stroke severity was missing for four participants, but available for eighty-five participants and is illustrated in Table 10.3. As can be seen, participants with TACs strokes had higher mean stroke severity scores and this difference was significant $F(3, 79) = 4.29$, $p<.01$. In the general stroke population, a lower proportion of LACS, a higher proportion of TACS would be expected (Warlow et al., 2000). However, the proportions of stroke types seen here was to be expected given the higher likelihood of death or severe cognitive impairment following a TAC stroke, which would

increase exclusion rates, and the absence of speech impairments following a LAC stroke which would decrease exclusion rates.

Table 10.3: Medical stroke data for participants at baseline

Previous history of stroke [1]	22 participants (25%)	
National Institute for Health Stroke Severity Scores [2]	Mean = 4.48, SD = 3.35 Median = 4.00, Range = 1 - 21	
Oxford Community Stroke Project OCSP stroke type:	*Number and percent with that stroke type*	*Mean and SD stroke severity score per stroke type:*
- TACS (Total Anterior Circulation stroke) [2]	7 (8%)	12.57 (7.30)
- PACS (Partial Anterior Circulation stroke) [2]	22 (27%)	6.27 (6.57)
- LACS (Lacunar Circulation stroke) [2]	34 40%)	5.94 (5.87)
- POCS (Posterior Circulation stroke) [2]	22 (25%)	3.81 (3.78)

[1] Available for all 89 participants [2] Available for just 85 participants

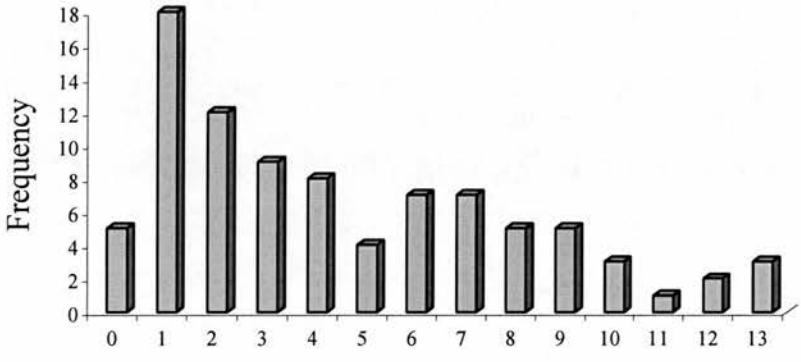
As regards psychoactive drug treatment at baseline, four participants reported that they were on anti-depressants and five that they used prescribed sleeping pills. In all cases this medicine had been prescribed by GPs prior to stroke. Of those on antidepressants, two met criteria for major depression, but two did not meet criteria for major or minor depression. Of the five who used sleeping pills, four reported that they worked, but one still described herself as an insomniac.

10.2: The continuous measure of emotional distress (HADs scores) at baseline

10.2i: HADs distributions at baseline

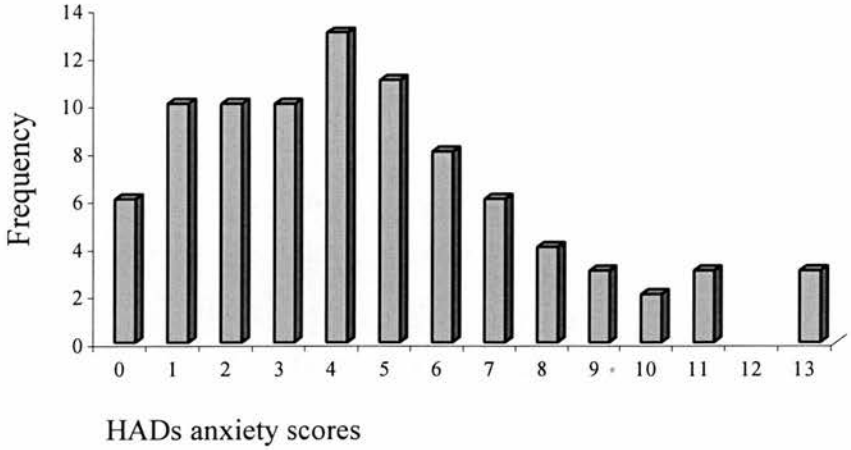
As shown in Histogram 10.1, a fairly positively skewed distribution for HADs depression was found across a range of scores from 0-13. A low mean depression score for the total group was found, M = 4.51 (SD = 3.54) and the median was 4.

Histogram 10.1: Baseline HADs depression scores



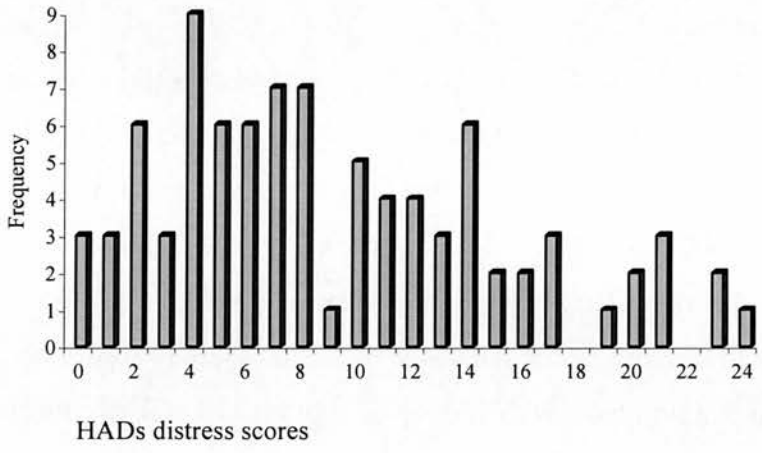
Anxiety HADs scores also ranged from 0-13 and produced a fairly positively skewed distribution but with slightly less kurtosis, which is shown in Histogram 10.2. Similarly, the mean anxiety score for the total group was low, M = 4.58 (SD = 3.20) and the median was 4.

Histogram 10.2:Baseline HADs anxiety scores



Depression and anxiety scores were totalled to give the global measure of distress, please see Histogram 10.3. This was also a fairly positively skewed distribution with a range of 0-24. The mean distress score was 9.10 (SD = 6.08) and the median was 8.

Histrogram 10.3: Baseline HADs distress scores



10.2ii: Inter-correlations between HADs scores at baseline

Pearson correlations were used to examine inter-relationships between HADs scores. Depression and anxiety were found to associate highly together ($r = .63$, $p < .0001$) and very highly with global distress scores (depression and distress, $r = .91$, $p < .0001$; anxiety and distress, $r = .89$, $p < .0001$).

10.2iii: Comment on HADs scores at baseline

Scores were generally low and distributions were fairly positively skewed. The level of association between HADs anxiety, depression and global distress symptoms was considered high enough to indicate a large degree of overlap. Therefore, the use of the HADs global distress scores for future tests of associations between distress and belief variables and as the dependent variable in the regression analyses was considered reasonable.

10.3: Descriptive data for background variables at baseline

Demographic data, cognitive ability and medical stroke data was described at the beginning of this chapter (please see Table 10.1 and Table 10.3). Basic descriptive data for the remaining background variables is provided in Table 10.4. Further details regarding disability measures, social support, life events pre-stroke history of depression are provided next.

10.3i: Disability at baseline

Over half the participants were found to have low levels of basic disability as they achieved the median score of full marks on the Barthel index (49/89; 55%). A ceiling effect for Barthel scores was reflected by a very high mean and low standard deviation (Mean = 18.27, SD = 2.83) as well as an extremely negatively skewed distribution (please see Histogram in Appendix E). However, scores for a few participants were fairly low, showing the relevance of this measure to some people who were still experiencing problems with very basic activities of daily living at one month after their stroke.

Scores for the Nottingham extended ADL index were more varied across participants, suggesting a wide range of ability regarding more advanced activities of daily living (please see Histogram in Appendix E). This variation was reflected in a less high mean score and wider standard deviation (Mean = 13.97, SD = 5.57). Interestingly, the distribution of scores was bimodal but it was beyond the bounds of this thesis to explore this issue further. Overall, the distribution of scores was fairly negatively skewed showing that participants were more likely to report high than low levels of ability in extended activities of daily living.

10.3ii: Social support at baseline

On average very high support scores were reported, indicated by a mean score of 73.97 (SD = 20.99) where the top possible score was 100. Additionally, mean scores for the four subscales where similar to the global scale, ranging from 72.05 to 75.91, with similar-sized standard deviations. Therefore most participants indicated that most types of support were available to them 'all the time', and if not that they were available 'most of the time', or 'some of the time'.

Table 10.4: Basic descriptive data for background and belief variables at baseline

	Number and percent, or Mean and SD as indicated.	Median	Range
Background variables [1]			
Disability: Barthel index [3]	18.27 (2.83)	20	6 - 20
Disability: Nottingham index [3]	13.17 (5.57)	15	3 - 21
Social Support [3]	73.97 (20.99)	75.78	14 - 100
Life Events [2]	53 (60%)		
Pre-stroke history of depression [2]	23 (26%)		
Attributions			
Causal controllability [3]	1.48 (.91)	1.50	0 - 4
'Why me?' (Rating of frequency now) [3]	.80 (1.09)		
'Found meaning?' [2]	31 (35%)	0	0 - 4
Self-evaluations			
Acceptance of disability [3]	18.61 (5.96)	18	6 - 32
Negative identity change [3]	7.91 (8.57)	5	-8 - 34
Shame [3]	12.31 (4.79)	12	0 - 27
Attitudes to recovery and recurrence			
Recovery locus of control [3]	24.61 (3.91)	25	12 - 33
Confidence in recovery [3]	7.94 (2.28)	8	0 - 10
Fear of recurrence [3]	15.38 (4.56)	16	3 - 26

[1] Other background variables were described in Tables 10.1 and 10.3
[2] Number and percentage of participants
[3] Mean and standard deviation of scores

10.3iii: Life events at baseline

Three fifths of participants reported at least one life event other than the stroke from the last six months (53/89; 60%). Some of these participants reported two life events (9/89; 10%) a few reported three (4/89; 5%) and one person actually reported four life events in addition to stroke.

10.3iv: Pre-stroke history of depression

Twenty-three (23/89; 26%) participants reported a history of depression previous to their stroke. Having already been interviewed regarding current mood, participants seemed able to comprehend what was meant regarding their past experience of depression. Often episodes of grief were mentioned as being times when they felt depressed. However this was discounted as low mood as grief is not recognised as abnormal. Relationships between pre-stroke history of depression and present depression status are described in Chapter 15, section 15.3.

10.4: Descriptive data for belief variables at baseline

This presentation of descriptive data for the belief variables will include conventional statistics, reporting of spontaneous comments and internal reliability statistics. A more detailed report on attributions is reported in Appendix F, section F.2 and factor analysis results for the acceptance of disability, negative identity change, shame and recurrence fear scales are reported in Appendix C, section C.2.

10.5: Attributions at baseline

10.5i: The difference between 'stroke' and 'its effects'

As discussed previously (Chapter 6, section 6.5i) participants' definition of 'stroke' and 'the effects of stroke' were sought to further clarify this distinction and its relevance to stroke research. Regardless of the accuracy or confidence of participants' reports, they did seem to talk about 'stroke' as a time-limited past event and 'its effects' in terms of present consequences. Having been prompted and asked to describe 'the effects of stroke', participants' responses were all related to later consequences rather than to the event of a stroke. This supports using the

distinction between 'stroke' and 'its effects' in this study. Please see Appendix F.2, sections F.1i and F.1ii for a more detailed description of participants' responses.

10.5ii: Causal controllability at baseline

The majority of participants (84/89; 94%) made at least one causal attribution, on average, they reported 2.46 causes (SD = .91, Median = 3, Range = 4). Please see Appendix F, section F.2 for detailed description of type, frequency and potency of attributions.

The main finding regarding causal controllability was that it tended to be low. For each participant, controllability ratings were first summed and then divided by the number of causes reported to calculate an average controllability score (please see Table 10.4 for relevant descriptive statistics). Given a mid-point of 2, this shows that participants tended to feel that they were less than moderately able to control causes of stroke in future (please see Appendix F, section F.2 for further details regarding controllability ratings of different causes).

10.5iii: 'Why me?' at baseline

Participants were first questioned whether they had asked 'Why me?' in relation to their stroke at any time and thirty-eight participants (38/89; 43%) reported that they had.

Immediately afterwards they were asked to indicate how frequently they asked this question now and respond in terms of: 'never', 'rarely', 'sometimes', 'often', or 'nearly all the time'. This was the measure that was used as the 'Why me?' variable in subsequent analyses. Thirty-nine participants (39/89; 44%) gave responses between 'rarely' and 'nearly all the time', while the others indicated that they 'never' asked 'why me?' nowadays.

Thirty-three participants indicated that they asked 'Why me?' to both questions. Six participants indicated that they used to, but had now moved on to think in terms of 'Why not me?'. Seven participants indicated they had never asked 'Why me?' but then contradicted themselves by responding 'rarely' or 'sometimes' when asked how

frequently they asked the question now. The youngest participant, a thirty-two year old female, explained that her family often asked 'Why you?' and only that made her consider the issue. Open-ended responses from the other six participants were less illuminating. They said things such as they did 'not really' think this way. Perhaps their apparently contradictory responses were due to coping by trying to overcome 'Why me?' thoughts.

The very low mean and large standard deviation (Mean = 80, SD = 1.09) and median score of zero regarding the frequency of how often 'Why me?' was asked illustrates that the distribution of scores was heavily positively skewed. The actual numbers of participants giving each frequency response for 'Why me?' were as follows:

'Never': 50 participants
'Rarely': 18 participants
'Sometimes': 12 participants
'Often': 7 participants
'Nearly all the time': 2 participants

Participants who reported asking 'Why me?' the most frequently made some interesting open-ended remarks. A few of these related to the belief they had been 'too healthy' to have a stroke. Others' comments related more to a sense of injustice 'Oh, what have I done?'. Some suggested their stroke was unjust because they had had to bear other misfortunes in life already (for example a murdered husband or cancer). These participants sometimes came back to the question of 'Why me?' in the qualitative interview (please see Appendix H, section H.2i).

10.5iv: 'Found meaning?' at baseline

Similarly to piloting, participants quite often appeared bemused when asked if they had 'Found meaning?' in their experience, and it was necessary to enquire whether 'anything good...?' had come of their experience to get a response. Nevertheless, thirty-one participants (31/89; 35%) did report a meaning. Two broad themes of meanings were reported: health gains, and appreciation of friends and family.

Most commonly, participants reported an advantage in terms of health. A few seemed to have felt the stroke acted as a 'warning' regarding their weight. One man

described his overall experience as a 'net gain' because his diabetes had been identified A few reported that 'the need to stop smoking' had been brought home to them. This was a sobering experience for one who described it as happening in 'the hardest possible way'. A few men reported the fairly sober realisation that they were 'fallible' after all and needed to take health into account. For example one man said:

'I think about health more and wonder what I can do to make it better. So it's a brief reminder of your mortality, but that's not really a good thing. I'd rather be thirty years younger.'

A few participants emphasised the role hospital staff played in their health gains. One man reported never having listened to smoking advice before but having realised 'They're only trying to save my life' and quitting, after a doctor had rushed down the corridor to plead with him not to go for a smoke. Another appeared really impressed by how much of a 'great lad' the doctor who had found a blood clot in his leg had been. One man reported finding the staff 'so caring' as comforting to him as he had seen his deceased wife 'helpless' in hospital for so long.

A couple of female participants reported having decided to prioritise their own needs. They felt they had been doing too much for other people previously, but did not need to feel responsible for everyone else anymore. Another participant reported using her experience to try to help others realise they needed to 'slow down'. Her message was also based on her mother's belief:

'Every morning is a good morning if your health is good'

A deepened appreciation of how caring friends or family were, or just the realisation one was lucky to have them was often reported as meaningful. A couple of younger participants reported more profound changes in their attitudes to family. A fifty-seven year old female participant reported having re-established contact with an estranged sister because:

'Life's too short to bear grudges'

A forty-seven year old male described himself as a 'bad visitor' to his sister prior to stroke but now wanting to make amends following her visits while he was in

hospital. The importance of family and friends emerged as a strong theme for a good proportion of participants in the qualitative analysis and will be discussed later (please see section 16.5).

A few participants reported other meanings in their experience. A fifty-two year old male participant described the cancellation of their plans to move house and the loss of his landscape gardening business as 'serendipity'. He figured that it was probably meant to be, and that his business had been unprofitable anyway. A female participant reported being proud that she had coped. A seventy-nine year old participant found it had given her a re-appreciation of life in general:

'You realise life is sweet and you want to live'

One participant reported feeling lucky in comparison to others who had had worse strokes.

10.6: Self-evaluations at baseline

10.6i: Acceptance of disability at baseline

Overall, given a mid-point of sixteen, average score statistics indicated that participants tended towards moderate acceptance of disability levels (please see Table 10.4). The range of scores was wide and slightly positively skewed with a moderate sized standard deviation. Overall, just over a third of participants (30/89; 34%) scores were below the mid-point suggesting low levels of feeling able to accept their disability.

Internal reliability for this measure was very high ($\alpha = .87$). Factor analysis produced a solution that explained 66% of the variance and produced two factors:

- Unhappy about limitations and dependency
- Feeling burdensome and inadequate

Please see Appendix C, Table C3 for a full report.

10.6ii: Negative identity change at baseline

As we expected negative rather than positive changes in identity were reported by the great majority of participants (75/89; 84%). However, some participants reported no change at all (10/89; 11%) and a few even reported a slight positive change (4/89; 5%). The distribution of change scores across participants was fairly wide but positively skewed. The low mean score and lower median score suggest that most participants saw themselves in only slightly more negative terms. However, the high standard deviation indicates a large degree of variation amongst individuals.

Internal reliability was found to be very high both for responses relating to 'before' the stroke ($\propto = .83$) and for responses relating to 'now' ($\propto = .86$). Factor analysis was conducted for both sets of responses, and a fairly complex solution was found for each, with five factors for 'before' responses and six factors for 'now' responses. Only the first three factors are discussed here, but please see Appendix C for the others. As can be seen, roughly similar concepts generally seemed to be found across both analyses. However, these were not necessarily obtained in the same order and were different enough in themselves to suggest a difference of emphasis in the way participants saw themselves now as opposed to before.

The first three factors for 'before' the stroke identity ratings seemed to represent:

- Ability
- Feeling down
- Grumpy/patient

The first three factors for identity ratings 'now' seemed to represent:

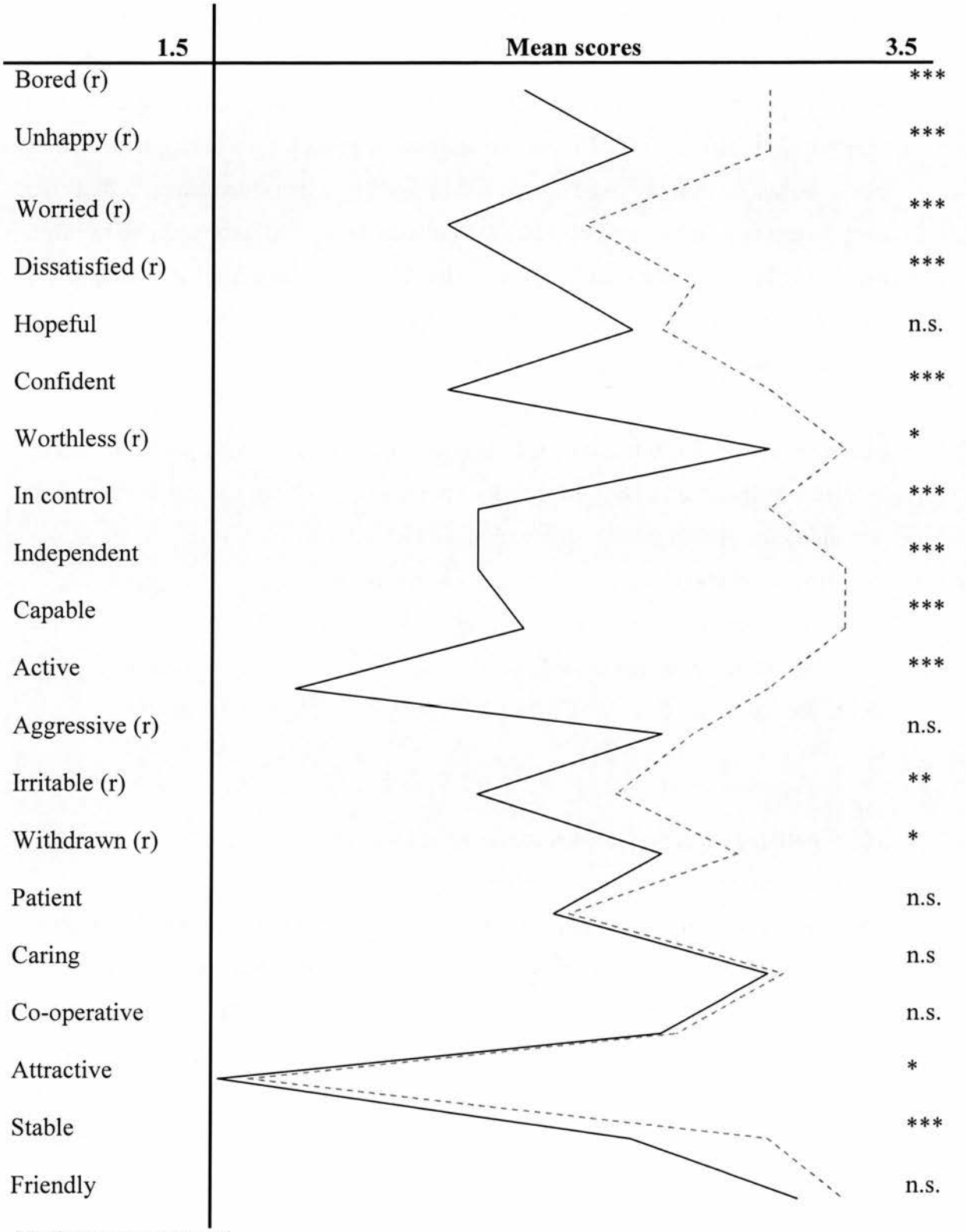
- Ability/negative emotional reaction to disability
- Sense of worth
- Fed up

The first factor for both 'before' and 'now' was the most similar of these in terms of shared items as both contained: 'in control', 'confident', 'independent', 'capable' and 'active'. However, two negative affect items, 'bored' and 'unhappy' were included in the first factor found for 'now' ratings. This indicates that within participants' ratings of themselves 'now', unhappiness and boredom appear to be intimately bound up with a sense of ability. This actually makes this factor conceptually very

similar to the first and main factor found for the acceptance of disability measure {'unhappy about limitations and dependency').

Table 10.5 displays mean 'before' the stroke and mean 'now' scores for each item. These were compared using t-tests and the significance levels are also displayed. As shown, the level of change reported for individual items varied greatly. In conceptual terms, the largest changes were seen for those items relating to ability (for example 'active', 'confident'). Relatively moderate changes were seen for adjectives relating to affect (for example 'worried', or 'unhappy'). Much smaller and often insignificant changes were seen for items reflecting interpersonal personality characteristics (for example 'friendly', or 'hopeful').

Table 10.5: Mean differences in scores from 'Before I had my stroke' to 'Now I've had my stroke' at baseline



(r) = items reverse scored

'Before my stroke' mean scores: - - - - - - - - - - - - 'Now I've had my' stroke mean scores: ————

n.s. Non-significant, * p<.05, ** p<.01, ***p<.001

10.6iii: Shame at baseline

Taking into account a mid-point of twenty, descriptive statistics indicate that levels of shame were typically rather low (please see Table 10.4). The same indication appeared to be given by the negatively and positively constructed items. The median and modal scores of all items was one, and mean scores were low, ranging from 1.66 (SD = 1.05) to 1.00 (SD = .58). So, typically participants tended to disagree with items suggesting others looked down on them and agree they appreciated differential treatment. Only four participants (4/89; 5%) actually reported scores above twenty suggesting higher than moderate shame. The difference between most participants then seemed to rest with how strongly they rejected shame items, whether they felt, very low, low or moderate levels of shame.

The measure was found to have high internal reliability (α = .78) however this may be partly attributable to floor effects. Factor analysis produced a solution that accounted for 64% of the variance with three factors:

- Considered feeble and in need of protection
- Considered relatively incompetent
- Given welcome consideration

please see Appendix C, Table C6 for a table showing the full factor structure.

10.7: Beliefs in recovery and recurrence at baseline

10.7i: Recovery locus of control at baseline

This scale is constructed such that higher scores indicate a more 'internal' and lower scores a more 'external' locus of control, scores may range from zero to thirty-six with a mid-point of eighteen. Taking this into account, indicators of average scores illustrated in Table 10.4 suggest that participants' responses indicated a generally more internal locus of control. If scores below the midpoint of eighteen are taken to indicate an 'External' locus of control, then only six participants' (6/89; 7%) could be labelled as such. Therefore the variation in scores for most participants seems to indicate a more or less internal locus of control.

10.7ii: Confidence in recovery at baseline

The high mean and median scores shown in Table 10.4 suggests that in general participants were very confident that they would make a full recovery. Just over a third of participants (30/89; 34%) responded with the modal score of ten out of ten and a similar number gave sores of either eight or nine (22/89; 25% and 11/89; 12% respectively). Only three participants (3/89; 3%) indicated they were 'Not at all confident' by giving scores of zero. Scores for the remaining participants (23/89, 26%) were between five and seven suggesting more moderate levels of confidence for about a quarter of participants.

10.7iii: Recurrence fear at baseline

Taking into account a mid-point of sixteen, descriptive statistics indicate that typically recurrence fear scores were moderate (please see Table 10.4). The distribution of scores was slightly negatively skewed, and the standard deviation was moderate showing that participants appeared more likely to indicate moderate to high levels of concern, than little concern.

Over half of the participants (50/89; 56%) did actually 'Agree' or 'Strongly agree' with item 6 which was the most direct recurrence fear item:

'I worry about my stroke returning'

Interestingly, eleven participants (11/89; 12%) who did not agree with this item went on to comment that although they did not 'Worry' about another stroke, they did 'Think' about it.

This measure was found to have high internal reliability ($\alpha = .78$). Factor analysis produced a solution with two factors that accounted for 49% of the variance:

- 'Increased health worry following stroke'
- 'Increased health consideration following stroke'

(please see Appendix C, Table C7 for a full report). Interestingly the only item that loaded onto both factors with a value of at least .40 was item 6. This finding could be taken to suggest that this was simply a less discriminate item. However, taken along with spontaneous think' not 'worry' comments made by participants it could

be taken to indicate something more meaningful. Perhaps direct questioning about 'worry' regarding another stroke was unsettling for some participants because they were trying so hard not to. This issue is discussed further in relation to relevant data from the qualitative interviews (please see section 16.4).

Chapter 11

Associations with distress at baseline

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11.1: Résumé of the hypotheses

Examination of associations with distress at baseline relates to the following main hypothesis and specific hypotheses:

Main hypothesis

1) A significant relationship between beliefs and emotional distress would be found at an initial point in time [at baseline].

It was expected that this main hypothesis would be fulfilled even once demographic and social background factors had been taken into account.

Specific hypotheses

1) Certain negative attributions[at baseline]:
   - Lower sense of control over causes
   - Higher frequency of asking 'Why me?'
   - A failure to find meaning in the experience

   would be associated with higher levels of emotional distress [at baseline]

2) More negative self-evaluations [at baseline]:
   - Lower acceptance of ones' disability
   - A more negative change in identity
   - Higher shame

   would be associated with higher levels of emotional distress [at baseline]

3) More negative beliefs in recovery and recurrence [at baseline].
   - Lower sense of control over recovery
   - Lower confidence in recovery
   - Higher fear of recurrence

   would be associated with higher levels of emotional distress [at baseline].

11.2: Statistical considerations at baseline

11.2i: Consideration of normality of distributions at baseline

As illustrated previously (please see chapter 10) the dependent variable distress is fairly positively skewed to the left. I considered transforming the data to produce a normal distribution as is often recommended by medical statisticians (for example, Altman, 1991). However, on balance, a complex transformation of the dependent variable was considered disadvantageous. It seemed inaccurate to normalise distress because theory and practice suggests it should be skewed. After all, the most distressed participants were the ones we were interested in and a transformation would produce data that was less intrinsically meaningful. Dichotomisation was not considered for the dependent variable as it would violate the linearity assumption (Field, 2000). I was advised that the fairly 'flat' distribution of distress would mitigate against its skewness affecting parametric statistical tests (Lewis, 2003; personal communication). On balance, I decided to leave the dependent variable in its original form.

Histograms of all background and belief variables relevant to the main hypotheses at baseline are illustrated in Appendix E, sections E.1 and E.2. As can be seen, few variables produced idealised normal distributions. Also, the five most skewed continuous independent variables were:

- Barthel index (Very negatively skewed and limited range)
- Nottingham index (Bimodal)
- Life events (Very negatively skewed)
- 'Why me?' (Fairly negatively skewed)
- Confidence in recovery (Fairly positively skewed and limited range)

Complex transformations for the independent variables were considered unbeneficial for the same reasons as have been described for the dependent variable. However, following statistical advice (Lewis, 2003; personal communication) I decided to dichotomise these five variables. Where possible this was done on ad hoc theoretical meaningful grounds rather than on statistical information.

Wade et al. (1987) found that a categorisation of patients into those with full Barthel index scores and those with scores of nineteen or less was able to differentiated well between those with and without functional independence. For example only 3% of those with scores of nineteen or below could bathe alone and only 14% could dress alone. More recently, Hankey et al. (2002) have reviewed nine studies that have used this classification demonstrating its wide acceptance. Also, examination of histograms using a four-way split, the three-way split and the two-way fit, showed that only the latter was able to reduce the skew in the data.

Nottingham index items can be divided approximately by half on the basis of whether they refer to activities within compared to outside the home. This half-way split also coincided with the bi-modal distribution, and so this variable was dichotomised at the mid-point. Two thirds of participants reported a life event but very few reported more than one (please see Chapter 10, section 10.3iii). Therefore this variable was dichotomised by whether or not life events were reported (regardless of the number of life events) in order to reduce the skew in the data.

As described, just over half of participants reported they 'never' asked 'Why me?' and increasingly smaller numbers of participants reported asking this question more frequently (please see Chapter 10, section 10.5iii). Therefore it was necessary to dichotomise this variable into a 'never' group and a 'rarely' to 'nearly all the time' group in order to reduce its' skew. On examination of the histogram for confidence in recovery, it was clear that a cut-off of eight or greater appeared to be a meaningful place to use for dichotomising the data; this reduced the skew considerably.

11.2ii: Homogeneity of variance in arrays at baseline

Data relevant to the hypotheses was checked for inaccuracies regarding outliers. In all cases the five highest and five lowest scores for each variable recorded in the database corresponded with the scores recorded on paper during interviews, or obtained from Dr Kwan (stroke severity, age). Therefore, extreme values were not attributed to error and were considered to reflect relevant participants' characteristics as legitimately as more typical values did other participants.

Scatter plots of all variables relevant to the hypotheses against distress scores were produced and are illustrated in Appendix E, sections E5 and E6. These were examined visually for biasing effects toward type I or type II errors from extreme values. Regarding background variables, extreme values that pulled the data one way seemed to be balanced by other extreme values working in the opposite direction (in particular, please see the scatter plots for age and social support).

Regarding belief variables, the scatter plots generally suggested that, if anything extreme values seemed to be working against the hypotheses (i.e. more likely to increase chances of a type II error). This was particularly the case for the two variables that went on to produce the strongest associations with distress (acceptance of disability and identity change). The points outside the general linear pattern for these variables would have worked to produce a more conservative correlation. Therefore the issue of homogeneity of variance was not considered problematic to a strict test of the hypotheses.

The exception was shame. As described previously most participants reported 'very low', or 'low to moderate' shame and only a few reported 'moderately high' shame (please see Chapter 10, section 10.6ii). The scatter plot, suggested little lawful relation between 'low to moderate' shame and distress levels. However, a good 'chunk' of 'very low' shame scores clustered with very low distress scores to produce a step down to the left in the scatter-plot. Then a few 'moderately high' shame and high distress scores seemed to create an opposing 'blip' pulling the data up towards the right top corner. So the homogeneity of variance in arrays assumption was violated for this variable. I considered dichotomising this variable

but that this would lose the variation in the data at tail ends and so increase chances of a type II error. Therefore it was left as a continuous measure, but it is recognised that any significant correlations should be considered mainly attributable to a minority of individuals with 'very low' and a minority with 'moderately high' shame.

11.3: Hypothesis testing at baseline stage 1: Correlations between baseline belief and background variables by baseline distress

11.3i Univariate correlations between baseline belief variables and distress

Univariate correlative relationships between belief variables and distress were first tested with Pearson correlations and the results are displayed in Table 11.1. As can be seen, variables are grouped in relation to the specific hypotheses. Please refer to the hypotheses in section 11.1 for the expected direction of the relationship between distress and the individual belief variables.

Specific hypothesis 1: Negative attributions

As can be seen from Table11.1, attributions produced low associations with distress. However, higher distress levels were significantly associated with a lower sense of control over causes, and a failure to have found meaning in the experience. There was a tendency for 'Why me?' to associate with distress but this was not statistically significant.

Specific hypothesis 2: Negative self-evaluations

As shown in Table 11.1, moderate to reasonably large associations between distress and variables indicating a more negative view of self were found. The strongest relationships between distress and individual variables were for acceptance of disability and negative identity change. However, these two variables were actually quite highly inter-correlated (please see later).

Specific hypothesis 3: Negatives beliefs in recovery and recurrence

A low but significant negative association between recovery locus of control and distress was found. Meanwhile, lacking confidence in one's recovery and having a

higher fear of recurrence were moderately and statistically significantly associated with distress.

Table 11.1: Univariate correlations between baseline belief variables and distress relating to specific hypotheses 1, 2, and 3 using Pearson correlations (N = 89)

	Distress (Global HADs scores)	**p value**
Specific hypothesis 1: Negative attributions		
Causal controllability	-.27	.016*
'Why me?'	.20	.067
'Found meaning?'	-.25	.018*
Specific hypothesis 2: Negative self-evaluations		
Acceptance of disability	-.59	.0001***
Negative identity change	.63	.0001***
Shame	.36	.0001***
Specific hypothesis 3: Negative beliefs in recovery and recurrence		
Recovery locus of control	-.26	.015*
Confidence in recovery	- .45	.0001***
Recurrence fear	.49	.0001***

As discussed (please see Chapter 7) to control for violations of parametric assumptions, associations were also tested using Spearman's Rho. Extremely similar results were obtained (please see Appendix G, section G3i, Table G.3)

Table 11.2: Univariate correlations between baseline belief variables and HADs depression, and baseline belief variables and HADs anxiety relating to specific hypotheses 1,2 and 3 using Pearson correlations (N = 89)

	HADs depression scores		HADs anxiety scores	
	Correlation coefficient	p value	Correlation coefficient	p value
Specific hypothesis 1: Negative attributions				
Causal controllability	-.21	.057	-.21	.013*
'Why me?'	.12	.247	.24	.022*
'Found meaning?'	-.28	.008**	-.18	.094
Specific hypothesis 2: Negative self-evaluations				
Acceptance of disability	-.57	.0001***	-.50	.0001***
Identity change	.53	.0001***	.62	.0001***
Shame	.35	.001***	.29	.006**
Specific hypothesis 3: Negative beliefs in recovery and recurrence				
Recovery locus of control	-.23	.032*	-.24	.023*
Confidence in recovery	-.50	.0001***	-.32	.002**
Recurrence fear	.44	.0001***	.44	.0001***

To further explore the validity of using the depression and anxiety sub-scales of the HADs as a combined global distress measure, correlations for the separate depression and anxiety sub-scales were also conducted and the results are displayed in Table 11.2

The pattern of results found for the individual depression and anxiety subscales were very similar to the results found for the global measure of distress, although in

general slightly lower correlation coefficients were obtained for the individual subscales. However, 'Found meaning?' was only statistically significantly associated with depression but not anxiety. Although 'Why me?' had not produced a statistically significant correlation with distress, it did with anxiety. Overall, a high level of similarity in results between the depression and the anxiety subscale were found. This seems to indicate a high degree of interdependence between these two measures, and suggests that the use of the global measures of distress in subsequent multivariate analysis was reasonable.

11.3ii: Univariate correlations between baseline background variables and distress

Association between background variables and distress were first examined using Pearson correlations, and are displayed in Table 11.3. As can be seen, a statistically significant result was only found for one demographic variable, showing that female participants tended to report higher distress levels.

When Pearson correlation was used, stroke severity and basic disability (Barthel index) did show trends towards statistically significant association with distress, disability measured by the Nottingham index produced a low but statistically significant correlation. The strongest association for the background variables was found between present distress levels and reports of a pre-stroke history of depression. Surprisingly social support was not found to be statistically significant, but life events were.

Table 11.3: Univariate correlations between baseline background variables and distress using Pearson correlations (N = 89 unless indicated otherwise)

	Distress (Global HADs scores)	p value
Demographic variables		
Age (in years)	-.02	.865
Gender	.25	.019*
Deprivation: Carstairs index	-.03	.750
Other background variables		
Stroke severity [1]	.19	.076
Disability: Barthel index	-.18	.086
Disability: Nottingham index	-.26	.014*
Social support	-.11	.308
Life events	.21	.049*
Pre-stroke history of depression	.36	.0001***

[1] Stroke severity data was missing for four participants; therefore this whole analysis is based on eighty-five rather than eighty-nine participants

To control for violations of parametric assumptions, associations between the background variables and distress were also tested using Spearman's Rho. The results were generally similar (please see Appendix G, section G.3i, Table G.4).

Table 11.4: Univariate correlations between baseline background variables and HADs depression and baseline background variables and HADs anxiety using Pearson correlations (N = 89 unless indicated otherwise)

	HADs depression scores		HADs anxiety scores	
	Correlation coefficient	p value	Correlation coefficient	p value
Demographic data				
Age (in years)	.05	.653	-.09	.381
Gender	.19	.069	,25	.018*
Deprivation: Carstairs index	- .09	.392	.04	.693
Other background variables				
Stroke severity [1]	.19	.079	.16	.139
Disability: Barthel index	-.26	.013*	-.06	.569
Disability: Nottingham index	-.35	.001**	-.11	.296
Social support	-.14	.183	-.05	-.662
Life events	.16	.137	.23	.028*
Pre-stroke history of depression	.31	.003**	.34	.004**

[1] Stroke severity data was missing for four participants; therefore this whole analysis is based on eighty-five rather than eighty-nine participants

Association between the individual HADs depression and anxiety sub-scales and distress were also examined and the results are displayed in Table 11.4. These results were similar in terms of the size of associations, and the variables found were statistically significant, but were more varied in terms of significance levels than the results for distress. This is perhaps not surprising given the generally small sizes of associations. Only a pre-stroke history of depression was found to be statistically significantly associated with both anxiety and depression. Two background variables that had been statistically significantly associated with distress (gender and life events) were found to statistically significantly associate with anxiety but not

depression. Both disability measures statistically significantly associated with depression but not anxiety.

11.3iii: Comment on univariate correlative results at baseline in relation to the hypotheses

Highly similar results for the belief variables were found using HADs global distress scores, the depression subscale and the anxiety subscale. Reasonably similar results were also found for the background variables. This indicates the interdependence of the anxiety and depression subscale in this study. It also supports the use of the HADs global scores as the measure of distress for the subsequent multivariate analyses.

Regardless of whether parametric or non-parametric correlation coefficients were used, statistically significant small to moderately large associations between distress and eight belief variables were found. The largest two associations were for two of the self-evaluation variables: acceptance of disability and negative identity change (two of the variables relevant to specific hypotheses 2). In contrast, only four of the nine background variables were consistently found to statistically significantly associate with distress.

Overall, at the univariate level, the relationship between the background variables and distress appeared weaker than the relationship between the belief variables and distress. These results offer preliminary support to main hypothesis 1 and the specific hypotheses, particularly specific hypothesis 2. However, these results do not take into account the possibility that associations between the belief variables and distress may be confounded by the background variables. To test the hypotheses fully associations between the belief variables and distress needed to be tested with the background variable taken into account.

11.4: Hypothesis testing at baseline stage 2: Multiple regression analyses for distress at baseline

11.4i: Multi-collinearity considerations at baseline

Prior to conducting the analysis, the belief and background variables were examined for multi-collinearity. Some multi-collinearity was to be expected particularly between conceptually similar measures, and multiple regression can withstand low to moderate inter-correlations between variables (Howell, 1997). As can be seen in Table G.1 (Appendix G, section G.1) most inter correlations between variables were low enough to be considered unproblematic. However, a high level of correlation was found between the two measures of disability ($r = .79$, $p<.0001$) which was unsurprising. I decided not to combine these measures in the regression analyses as I was advised that some information would be lost in doing so.

Regarding the belief variables, the largest number and size of inter-correlations were observed for the self-evaluation variable: acceptance of disability. On the one hand this seems to suggest that it is a good global measure that seems to be tapping aspects of all the other belief variables. However, this also means that it would be expected to behave unusually in the regression analysis, either by overwhelming the other variables, or by appearing redundant as its variance could be accounted for by the others. Negative identity change was similarly, but less strongly, inter-correlated with the other variables, as was acceptance of disability. High levels of associations between other belief variables were not found.

Overall, the strongest, correlation amongst the belief variables was actually between acceptance of disability and negative identity change ($r = -.69$, $p<.0001$). Statistically this suggests that they were measuring highly similar beliefs, as if perceptions of change in oneself, was tantamount to not being able to accept one's level of disability. Therefore, it was to be expected that when analysed simultaneously, one may render the other redundant. The possibility of combining these two variables was considered unhelpful, as subsequent results would be conceptually and statistically difficult to untangle. Therefore, it was decided to include both variables in the analysis.

11.4ii: *Résumé of the 'univariate' and 'stricter' regression method*

As discussed previously the backward stepwise method was chosen to simultaneously examine the association between the belief and background variables with distress (please see Chapter 7). Also, as discussed previously, two methods of analysis ('univariate' and 'stricter') were conducted (please see Chapter 7). Results for the 'univariate' method (uses only variables with significant univariate correlations with distress) will be presented first, then results for the 'stricter' method (includes all background variables regardless of univariate significance levels) will be presented. Comment in relation to the hypotheses will then be made.

11.4iii: Results for the 'univariate' multiple regression analyses at baseline

The results of the first 'univariate' analysis in which all twelve univariate statistically significant belief and background variables were included are presented in Table 11.5. Overall this model was highly significant, **R^2 = .67, p<.0001**, which suggests that almost half the variance in distress scores were accounted for by these variables.

Table 11.5: Preliminary regression model for baseline distress using all baseline background and belief variables that had produced statistically significant univariate correlations (N = 89)

	B*	Std. error	t	Significance of t	Partial Correlation
Background variables:					
Gender	2.16	.93	2.34	.022*	.26
Disability: Nottingham index	.00	.96	.07	.941	.01
Life events	1.29	.83	1.56	.123	.18
Pre-stroke history of depression	3.50	1.01	3.48	.001***	.37
Belief variables:					
Causal controllability	-.96	.47	-2.03	.046*	-.23
'Found meaning?'	-1.71	.97	-1.75	.083	-.20
Acceptance of disability	.13	.11	-1.10	.274	-.13
Negative identity change	.20	.07	2.86	.005**	.31
Shame	.24	.10	2.45	.017*	.27
Recovery locus of control	.00	.13	.78	.436	.09
Confidence in recovery	-1.33	1.10	-1.21	.231	-.14
Recurrence fear	.28	.11	2.65	.010**	.29

*Beta values quoted are the un-standardised coefficients

As seen in Table 11.5, gender, a pre-stroke history of depression and four belief variables were found to be statistically significant at the p<.05 level in this model.

The least significant variable was eliminated from the second analysis, and then the next least significant variable from the following analysis. This process was continued until a model was produced in which all variables were statistically

significant at the p<.05 level. The variables that were eliminated, in order of removal, were:

- Disability: Nottingham index
- Recovery locus of control
- Confidence in recovery
- Acceptance of disability
- Life events

The final model is illustrated in Table 11.6.

Table 11.6: Final regression model for baseline distress using all baseline background and belief variables that had produced statistically significant univariate correlations and remained statistically significant following the backward regression procedure (N = 89)

	B *	Std. error	t	Significance of t	Partial Correlation
Background variables:					
Gender	2.08	.87	2.39	.019*	.16
Pre-stroke history of depression	3.94	.97	4.08	.0001***	.27
Belief variables:					
Causal controllability	-.96	.47	-2.04	.045*	-.14
'Found meaning?'	-1.99	.89	-2.24	.028*	-.15
Negative identity change	.25	.06	4.46	.0001***	.30
Shame	.29	.09	3.23	.002**	.21
Recurrence fear	.33	.10	3.34	.001**	.22

*Beta values quoted are the un-standardised coefficients

As can be seen in Table 11.6, the background and belief variables in this final model were those that were statistically significant in the first analysis, and also the belief variable 'Found meaning?'. Together they produced a similar overall association with distress: **R^2 = .65, p<.0001.**

Comment on the 'univariate' regression results in relation to the hypotheses is made in section 11.5.

11.4v: Results for the 'stricter' multiple regression analyses at baseline

The backward stepwise regression procedure was repeated, except this time all background variables were included at each stage regardless of significance. The results of the first analysis produced a highly significant overall model, **$R^2 = .69$, $p<.0001$,** and is detailed in Table 11.7 below.

Table 11.7: Preliminary regression model for baseline distress using all baseline background and those belief variables that had produced statistically significant univariate correlations' (N = 85 [2])

	B [1]	Std. error	t	Significance of t	Partial Correlation
Background variables:					
Age	.00	.05	-.96	.341	-.12
Gender	1.86	1.04	1.78	.080	.21
Deprivation: Carstairs index	.00	.29	-.21	.832	-.03
Stroke severity [2]	-.23	.17	-1.41	.162	-.17
Disability: Barthel index	-.23	1.29	-.18	.860	-.02
Disability: Nottingham index	-.34	1.41	-.24	.812	-.03
Social support	-.00	.02	-.35	.730	-.04
Life events	1.44	.87	1.65	.103	.20
Pre-stroke history of depression	3.05	1.10	2.77	.007**	.32
Belief variables:					
Causal controllability	-1.05	.50	-2.11	.038*	-.25
'Found meaning?'	-2.19	1.09	-2.00	.049*	-.24
Acceptance of disability	-.15	.12	-1.22	.227	-.15
Negative identity change	.22	.08	2.88	.005***	.33
Shame	.21	.10	2.03	.046*	.24
Recovery locus of control	.00	.14	.71	.476	09
Confidence in recovery	-1.34	1.20	-1.12	.267	-.14
Recurrence fear	.28	.11	2.52	.014*	.29

[1] Beta values quoted are the un-standardised coefficients
[2] Stroke severity data was missing for four participants; therefore this whole analysis is based on eighty-five rather than eighty-nine participants

The least significant belief variables were removed from subsequent analyses until all the belief variables in the model were significant at the p<.05 level. The final model produced by this method was similar in size and significance to that obtained before, **R^2 = .67, p<.0001**, and is detailed in Table 11.8.

Table 11.8: Final regression model for baseline distress using all baseline background variables and belief variables that remained statistically significant following the backward regression procedure (N = 85 [2])

	B [1]	Std. error	t	Significance of t	Partial Correlation
Background variables:					
Age	.00	.05	-1.28	206	-.15
Gender	1.70	1.03	1.65	.103	.19
Deprivation: Carstairs index	-.11	.29	-.36	.719	-.04
Stroke severity [2]	-.22	.17	-1.28	.204	-.15
Disability: Barthel index	-.39	1.27	-.31	.757	-.04
Disability: Nottingham index	-.89	1.36	-.65	.516	-.08
Social support	-.00	.02	-.59	.560	-.07
Life events	1.51	.87	1.74	.086	.20
Pre-stroke history of depression	3.24	1.08	3.01	.004**	.34
Belief variables:					
Causal controllability	-1.01	.49	-.15	.045*	-.24
'Found meaning?'	-2.43	1.04	-.19	.022*	-.27
Negative identity change	.27	.06	.38	.0001***	.45
Shame	.25	.10	.20	.009**	.30
Recurrence fear	.34	.10	.25	.002**	.36

[1] Beta values quoted are the un-standardised coefficients
[2] Stroke severity data was missing for four participants, therefore this whole analysis is based on eighty-five rather than eighty-nine participants

The variables that were removed the same ones that had been in the 'univariate' analysis. The order of variable removal was also the same:

- Recovery locus of control
- Confidence in recovery
- Acceptance of disability

Extremely similar results were produced using this 'stricter' method. The only really apparent difference that the inclusion of all the background variables meant the significance of gender dropped to the $p<.10$ level, and a trend for life events was found. It is hard to speculate how the balance of associations between variables may have led to these slight differences. However, the conclusions in relation to the belief hypotheses remain essentially the same.

Comment on the 'stricter' regression results in relation to the hypotheses is made in section 11.5.

11.5: Comment on the multiple regression results for baseline distress using baseline belief and background variables in relation to the hypotheses

The first main hypothesis that beliefs and distress would associate was tested in analyses that took associations between background variables and distress into account.

Background variables produced few independent associations in both the 'univariate' analyses and 'stricter' analyses (in which background variables were included regardless of univariate association with distress). Gender and pre-stroke history of depression were the only two background variables left in the final 'univariate' model. Pre-stroke history of depression was the only background variable that was statistically significant in the final 'stricter' model. Interestingly, these variables did not generally correlate with the belief variables in the equations (please see Appendix G, section G.1, Table G.1) and so something about being female or having been depressed in the past appeared associated with distress in a way that was largely independent of the belief variables. Both disability variables were dropped from the equation, suggesting that participants' beliefs about the meaning of their disability were better associated with distress.

A statistically significant relationship between emotional distress and over half of the belief variables was found once all variables that had been statistically significant at the univariate level were tested together in the 'univariate' model. The same result was obtained in the 'stricter' regression analyses and bolsters this finding. Together these results offer support to the first main hypothesis, and suggest that the relationship between emotional distress and certain beliefs was largely un-confounded.

Specific hypothesis 1: Negative attributions

Both causal controllability, and 'Found meaning?' were univariately associated with distress at the $p<.05$ level and both were found statistically significant in the final 'univariate' and 'stricter' method equation. Therefore these analyses offer firm but partial support to specific hypothesis 1.

Specific hypothesis 2: Self-evaluations

Only one of the two self-evaluation variables that had produced strong univariate associations with distress, but also a very strong association with each other and multi-collinearity with other belief variables, remained in the final models. 'Negative identity change' was found to remain highly statistically significant and to produce the largest partial equation. However, acceptance of disability was lost from the models. This may have been because negative identity change was generally less collinear with the other belief variables. Alternatively, acceptance of disability may have been relatively disadvantaged because it spanned a narrower range of points (Lewis, 2003; personal communication). If negative identity change had not been measured, acceptance of disability may have taken its place in these models. Interestingly, shame remained in the final models and produced a partial correlation that was hardly reduced in size from its' univariate correlation with distress. Overall, these results firmly but partially support specific hypothesis 2.

Specific hypothesis 3: Beliefs to recovery and recurrence

Both of the variables measuring participants' beliefs to recovery (confidence in recovery and recovery locus of control) failed to statistically significantly associate with distress once other variables were taken into account. However, recurrence fear remained able to independently associate with distress. Overall these results partially support specific hypothesis 3. More specifically, these results fail to support beliefs in recovery, but firmly support fear of recurrence as associating with distress independent of background variables.

In summary, these results suggest that at baseline distress was associated with a sense of having changed for the worse as a person and in the eyes of others, without being able to find any compensatory positive meaning. Participants who believed they had their perceived risk factors under control tended not to be distressed. Conversely, distress was positively associated with greater fear of recurrent stroke. These results appear to be statistically independent of confounding by background variables.

Chapter 12

Description of sample, background and belief variables at follow-up

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12.1: Description of the sample at follow-up

12.1i: Final sample at follow-up

The majority of the original sample (81/89; 91%) was followed up. Of those eight participants who were not; two people had died, two declined, four were too ill due to severe further strokes, one had cancer and another had significant problems with alcohol abuse. The average time-point when participants were interviewed was just under nine months following their stroke (Mean = 273 days, SD = 37 days and Median = 262 days) with a range between 219 days and 396 days. The distribution of time actually produced a fairly normal curve, but with seven outliers who were seen much later. The reasons for these long delays were due to postponements following death or illness in the family, going back to work, or a change of address that took months before registration with GP records.

12.1ii: Demographic and cognitive ability of the sample at follow-up

The high follow-up rate meant demographic and cognitive statistics at follow-up were very similar to baseline. Distribution of gender, age and social-economic status and participants' living situation and cognitive ability were very similar at this later point in time. Therefore the same comments made in relation to demographic and cognitive ability characteristics apply now. Please see 10.1ii for comments and Appendix F, section F.3 for actual follow-up statistics.

12.1iii: Medical data at follow-up

Original scores for stroke severity were reused at follow-up. Descriptive statistics for the seventy-eight participants for whom stroke severity data was available are illustrated in Table 12.1. Similar proportions of participants were found for each OCSP stroke type as at baseline (please see Chapter 10, Table 10.3 and Table 12.1 above). Two participants who were unavailable due to a further severe stroke had both originally sustained a TACs stroke, a participant who had died originally had a LACs stroke and another a POCs stroke. Higher stroke severity scores amongst remaining participants with a TACs stroke were found and this difference was statistically significant [$F(3, 73) = 4.52$, $p<.01$]. Four participants reported having experienced a further stroke. They all reported these to be of mild severity, but actual objective data regarding these strokes was not obtained.

Table 12.1: Medical stroke data for seventy-seven participants at follow-up

Previous history of stroke [1]	19 participants	(25%)
New stroke during study [1]	4 participants	(5%)
National Institute for Health Stroke Severity Scores [2]	Mean = 4.33, Median = 4.22,	SD = 3.25 Range = 1 – 18
Oxford Community Stroke Project OCSP stroke type:	**Number and percent With that stroke type**	**Mean and SD stroke severity score per stroke type**
- TACS (Total Anterior Circulation stroke) [2]	5 (6%)	8.86 (5.97)
- PACS (Partial Anterior Circulation stroke) [2]	22 (27%)	4.86 (3.77)
- LACS (Lacunar Circulation stroke) [2]	32 (42%)	3.94 (2.26)
- POCS (Posterior Circulation stroke) [2]	18 (22%)	3.39 (2.17)

[1] Available for all 89 participants [2] Available for just 85 participants

As regards psychoactive drug treatment, participants generally reported that their status regarding medication for emotional problems during the study remained unchanged. As before there were five participants who used sleeping pills, four of whom reported that they worked and one who still regarded herself as an insomniac. One man reported he had had a short course of sleeping pills prescribed during the study and that his sleep problems had 'totally resolved'. Another man had been prescribed minor tranquillizers for his anxiety about leaving the house. He reported that he had used a few and that they had helped get him out, but that he was still unable to enjoy going out as before.

Six participants reported currently taking anti-depressants at follow-up. Four of these had been on anti-depressants pre-stroke and right through the study: two met criteria for major depression both at follow-up and at baseline, one did not meet criteria for depression either at follow-up or at baseline, one met criteria for minor depression at follow-up but had not done so at baseline. The other two had not been on anti-depressants at baseline: one had been pre-stroke but hers had been stopped while she was in hospital. She reported that her GP had represcribed it, but she still met criteria for major depression. One of the youngest participants, a fifty-two year

old, reported developing depression during the study and being prescribed an anti-depressant by his GP. He met criteria for major depression at follow-up (please see Chapter 15, section 15.6).

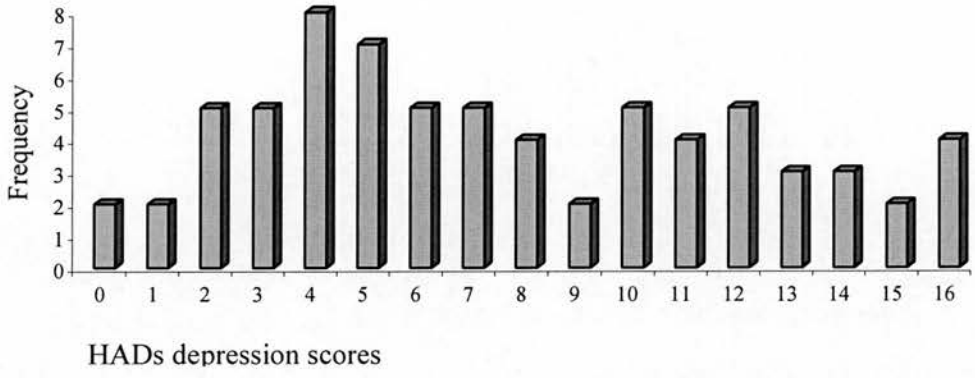
One participant who had met criteria for minor depression at baseline had been prescribed an anti-depressant during the study period. She was no longer taking it and no longer met criteria for depression. The participant who met criteria for major depression and reported suicidal intentions at baseline reported that the hospital doctors had considered him for an anti-depressant but had not prescribed one. Another participant who met criteria for major depression at both baseline and follow-up had requested 'a course' from her GP but been refused. A thirty-two year old female reported developing depression during the study and she now met criteria for major depression (please see Chapter 15, section 15.6). Her GP had offered her an antidepressant and she was considering it.

12.2: The continuous measure of emotional distress (HADs scores)

12.2i: HADs distributions at follow-up

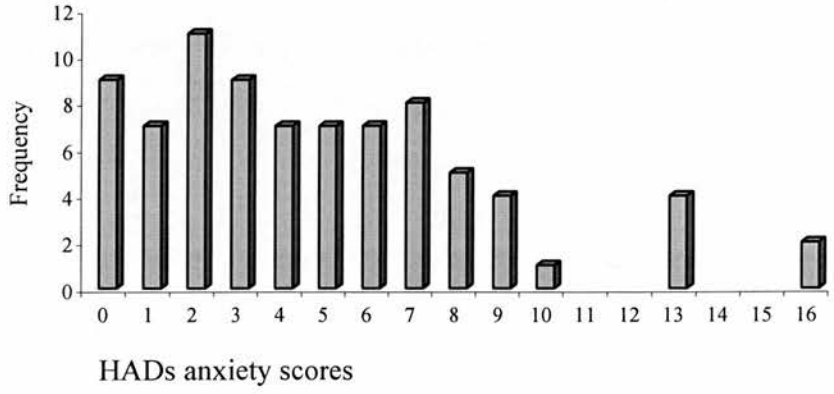
A fairly flat shaped and slightly positively skewed distribution for HADs depression scores was found which was similar to that seen at baseline, please see Histogram 12.1 and Histogram 10.1. Similarly to baseline, the median was 4. The mean score was very slightly higher, Mean = 4.62 (SD = 3.47) but not statistically significantly, t = -323, n.s.

Histogram 12.1: Follow-up HADs depression scores



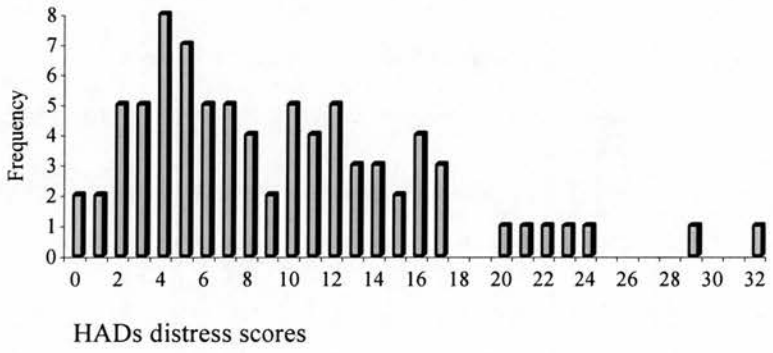
HADs anxiety scores produced a similar distribution to that found at baseline (please see Histogram 12.2 and Histogram 10.2). Like the depression distribution, it was skewed positively but with less kurtosis. Similarly to baseline, the median was 4. The mean score was very slightly higher, Mean = 4.78 (SD = 3.78) but this was not statistically significant, t = -414, n.s.

Histogram 12.2: Follow-up HADs anxiety scores



The distribution of global distress scores was also similar to that found at baseline being slightly positively skewed but with a wider range (2 –32) due to a couple of extreme scores, please see Histogram 12.3 and Histogram 10.3. Similarly to baseline, the median was 8. Overall the mean was just slightly higher, Mean = 9.38 (SD = 6.63) but not statistically significantly so, t = -.386, n.s.

Histogram 12.3: Follow-up HADs distress scores



12.2ii: Inter-correlations between HADs scores

Depression and anxiety scores correlated highly together (r = .68, p<.0001) and with global distress scores (Depression and distress, r = .91, p<.0001; Anxiety and distress, r = .92, p<.0001).

12.2iii: Comparison of baseline to follow-up HADs scores

High levels of consistency between baseline and follow-up HADs scores were found shown by the three insignificant paired t tests in Table 12.2 below. Pearson correlations are also reported in Table 12.2 as these are relevant to the final predictive analyses in Chapter 14.

Table 12.2: Correlations between baseline and follow-up HADs and t test results

Baseline – Follow-up	Correlation	Significance of correlation	t value	Significance of t
HADs Depression	.57	<.0001	-.32	n.s.
HADs Anxiety	.59	<.0001	-.41	n.s.
HADs Distress	.64	<.0001	-.39	n.s.

12.3: Descriptive data for background variables at follow-up

Demographic data and cognitive ability is reported in Table F.3, Appendix F, and stroke severity data was described in section 12.1ii at the beginning of this chapter. Descriptive data for the disability measures, social support and life events and pre-stroke history of depression is illustrated in Table 12.3.

12.3i: Disability at follow-up

The majority of participants (48/81; 59%) gained full marks on the Barthel index. Overall, mean scores for Barthel index and for the Nottingham extended ADL index had increased slightly since baseline (please see Table 12.3 and Table 10.4). The increase in Barthel index scores was not significant ($t = -.87$, n.s.), showing that there had been no significant increase in basic levels of independence. In contrast, the mean increase in Nottingham index scores was significant, showing that some participants had increased their ability to carry out more extended daily activities ($t = -3.46$, $p<.001$).

12.3ii: Social support at follow-up

Social support was not reassessed at follow-up, and so scores from baseline were reused. Descriptive statistics for this smaller sample again showed a high level of support, please see Table 10.4 for further description.

12.3iii: Life events at follow-up

Half the participants (42/81; 49%) reported one or more life events between baseline and follow-up. Most had experienced just one, but six had experienced two events, two had experienced three events and one man had experienced five life events. He reported that his friends had been 'dropping like flies' but nevertheless he was not depressed. Again, some participants reported events they still found upsetting but which were not counted as they fell out of the time-scale. Interestingly, the number of life events reported at baseline and follow-up overlapped, indicated by a statistically insignificant McNemar test ($p=.121$). In fact most participants who reported a recent life event at follow-up had done so at baseline (26/42; 62%).

12.3iv: Pre-stroke history of depression at follow-up

Exactly the same proportion of participants reported having been depressed (21/81; 26%) prior to their stroke at follow-up as had done at baseline. A cross-tabulation table showed they were the same participants, suggesting that the assessment of pre-stroke history of depression was consistent. Relationships between pre-stroke history of depression and present depression status is described in Chapter 15, section 15.6.

12.4: Descriptive data for beliefs at follow-up

This presentation of descriptive data for the belief variables will include conventional statistics, reporting of spontaneous comments and internal reliability statistics. A more detailed report on attributions is reported in Appendix F, section F.2, and factor analysis for the negative identity change, shame and recurrence fear scales are reported in Appendix C, section C.2.

12.5: Attributions at follow-up

12.5i: The difference between 'stroke' and 'its effects'

The conceptual difference between 'stroke' and 'its effects' was evident in patients descriptions at follow-up (please see Appendix F, sections F1.i and F1.ii for more detailed description).

12.5ii: Causal controllability at baseline

On average 2.68 causes (SD =.79, Median=3, Range=0-5) were reported at follow-up. Please see Appendix F, section F.2 for detailed description of types, frequency and potency of attributions.

Similarly to baseline, causal controllability scores were typically low (please see Table 12.3 for relevant descriptive statistics). Given a mid-point of 2, this suggests that participants typically felt less than moderately able to control causes of stroke in future (please see Appendix F, section F.2 for further details regarding controllability ratings for different causes).

Table 12.3: Basic descriptive data for numerical background variables and beliefs at follow-up

	Number and percent, or Mean and SD as indicated.	Median	Range
Background variables [1]			
Disability: Barthel index [3]	19.44 (2.78)	20	7 - 20
Disability: Nottingham index [3]	14.72 (5.56)	17	2 - 21
Social support [3]	73.69 (21.32)	75.78	14 - 122
Life events [3]	.69 (.51)	1	0 - 5
Pre-stroke history of depression [2]	21 (26%)		
Attributions			
Causal controllability [3]	1.74 (.79)	3	2 – 5
'Why me?' (Rating of frequency now) [3]	.67 (.91)	2	2 - 5
'Found meaning?' [2]	17 (21%)		
Self-evaluations			
Acceptance of disability [3]	19.49 (6.92)	22	5 - 32
Negative identity change [3]	7.79 (8.13)	5	-1 - 38
Shame [3]	12.33 (5.56)	12	2 - 27
Negative beliefs in recovery and recurrence			
Recovery locus of control [3]	23.89 (3.27)	25	13 - 31
Confidence in recovery [3]	6.59 (2.93)	7	2 - 12
Fear of recurrence [3]	15.42 (4.66)	15	4 - 25

[1] Other background variables (demographics and stroke severity) are described in Appendix F, Table F.3. and in Table 12.1 earlier in this chapter.
[2] Number and percentage of participants
[3] Mean and standard deviation of scores

12.5iii: 'Why me?' at follow-up

As can be seen, a median of zero indicates that participants were unlikely to report thinking 'Why me?' at follow-up. The data was skewed and nobody now reported that they questioned why they had a stroke 'nearly all the time'. The numbers of participants who gave other responses were:

'Never':	47 participants
'Rarely':	18 participants
'Sometimes':	12 participants
'Often':	4 participants

Overall there was little change in responses across time, as shown in Table 12.3 and Table 10.4. Participants generally gave the same response or indicated a frequency of asking 'Why me?' just slightly lower or higher than before. Once 'Why me?' scores were dichotomised and compared to baseline responses, using a McNemar test, the result ($p<.122$) suggested no statistically significant change in responses across time.

12.5iv: 'Found meaning?' at follow-up

A very low proportion of participants (17/81; 21%) reported they had found meaning in their experience at this point in time. Thirteen participants who had reported finding something positive in their experience at one month no longer did so. Only one participant who had not reported finding meaning at baseline, now reported that they had. She was an eighty-six year old lady who now reported feeling empathy for young people with strokes. The nature of meanings reported by other participants could be broadly classified either as health gains in terms of a warning, or as a new-found appreciation of friends and family. These meanings were very similar to the meanings reported at baseline (please see Chapter 10, section 10.5iv). The range of these meanings did not appear to be particularly different amongst those who reported them at both points in time, and those who reported them only at baseline.

The overall drop in proportion of participants who reported finding meaning in their experience was found to be statistically significant using a McNemar test ($p=.221$).

12.6: Self -evaluations at follow-up

12.6i: Acceptance of disability at follow-up

Overall a tendency towards moderate acceptance levels was suggested. Although the range of scores was wide, the standard deviation was moderate, and the overall distribution produced was slightly negatively skewed. Nevertheless, nearly half of participants' (36/81; 44%) scores fell below the mid-point, suggesting a low level of acceptance regarding the personal limitations and dependencies imposed by their disability.

On average, participants reported only slightly higher acceptance of disability levels than they had at one month (please see Table 12.3 and Table 10.4) and this increase was not significant, $t = -1.49$, n.s.

As before internal reliability for this measure was extremely high ($\alpha = .92$). Factor analysis produced a solution that explained 66% of the variance, and produced just one global acceptance of disability factor, with loadings between .75 and .92 for each item.

12.6ii: Negative identity change at follow-up

The mean identity change score was relatively low and the distribution was positively skewed suggesting that, at this nine-month stage, most participants saw themselves as slightly negatively changed from their pre-stroke self. Some participants reported no change (11/81; 14%) and only a few reported an overall positive change of one point (3/81; 4%). However, the standard distribution and range of scores were high indicating that some saw themselves in very negative terms 'now' as opposed to 'before'.

The descriptive data obtained for this measure was extremely similar to that obtained at baseline. The mean identity score was slightly lower, but not significantly, $t = -.187$, n.s. (please see Table 12.4 and Table 10.4).

Internal reliability scores for both the 'before' stroke and 'now' set of responses was high ('Before' $\alpha = .79$; 'Now' $\alpha = .87$). Factor analysis produced sets of six factors

for both 'before' and 'now' responses. Only the first three factors will be discussed here but please see Appendix C, Tables C8 and C9 for the full results. As can be seen similar but not identical results for baseline and follow-up, and for the 'before' and 'now' responses were found.

The first three factors for 'before' the stroke identity ratings seemed to represent:

- Ability
- Grumpy/or patient
- Fed up

The first three factors for identity ratings 'now' seemed to represent:

- Feeling down/or not
- Ability
- Grumpy/or patient

So, although the order was different, these factors for 'before' and 'now' were conceptually alike. These factors both bore more resemblance to the first three factors obtained for baseline 'before' the stroke rather than 'now' factor analyses results (please see Appendix C, Tables C4 and C5). While unhappiness and boredom seemed to be intimately bound up with a sense of ability in participants' ratings of themselves one month following stroke, at this nine month stage they seemed to differentiate between ability and negative reactions or personality patterns more clearly.

Nevertheless, negative reactions do appear particularly important in participants' sense of identity 'now' because the adjectives: 'bored', 'unhappy', 'worried' 'dissatisfied', 'hopeful', 'confident' and 'worthless' combined to produce the first and main factor 'feeling down/or not'.

Mean changes reported for individual adjectives were very similar to those at baseline (please see Table 12.4, and Table 10.5), but significant negative changes were now found for all but two adjectives. The largest changes were still seen for items relating to ability (for example 'confident' and 'capable') and then moderate changes were found for negative affect items (for example 'unhappy' and 'irritable'). Changes in most interpersonal characteristic items were smaller. However, in contrast to baseline, significant levels of change were now seen for three more of these ('patient', 'caring', 'co-operative'). Also, in contrast to baseline, participants

indicated that they 'now' considered themselves significantly less 'hopeful' than they had been before their stroke.

12.6ii: Shame at follow-up

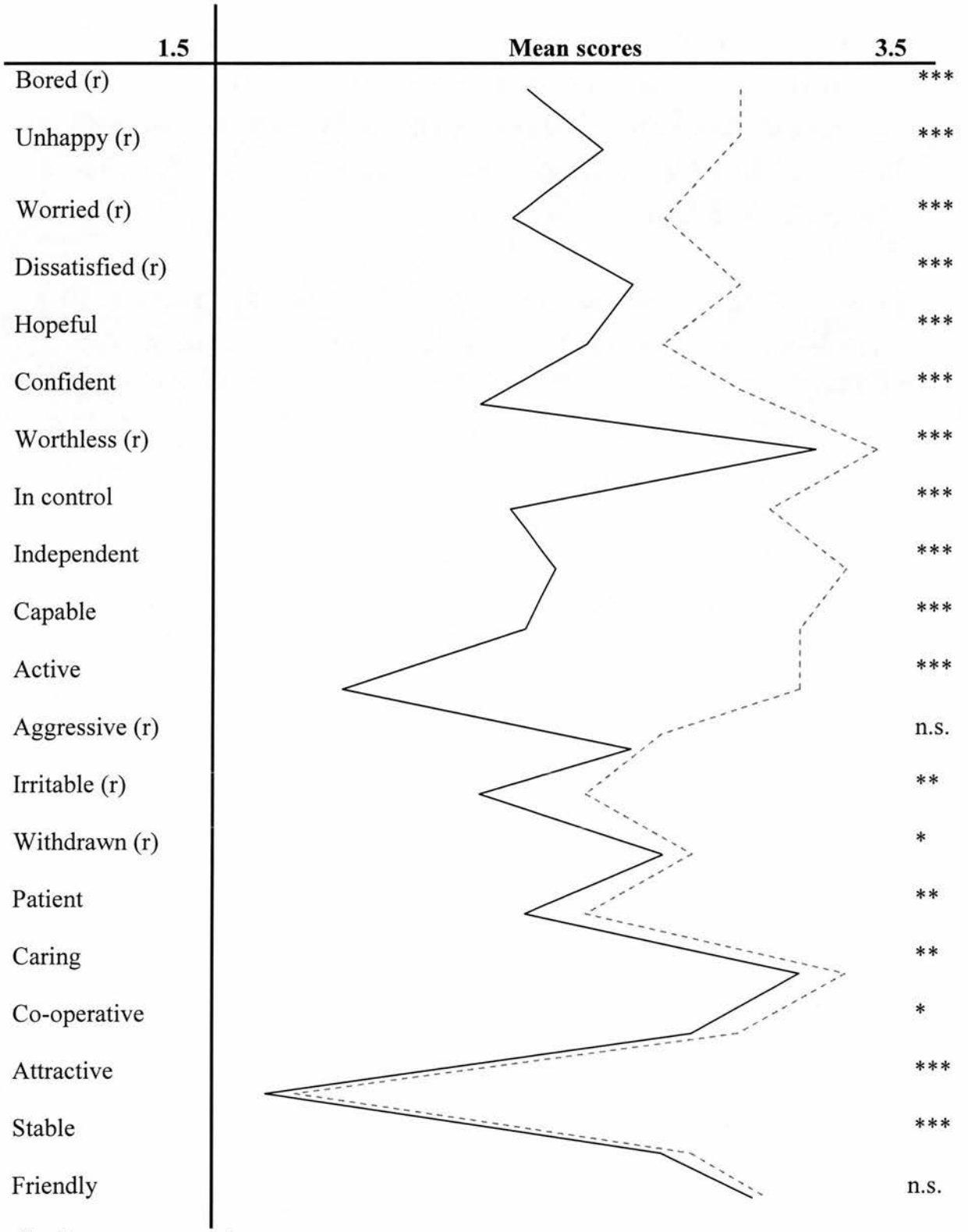
In general participants indicated that they typically experienced low levels of shame in relation to others' attitudes. Descriptive data showed very little change across time (please see Table 12.3, and Table 10.4) and the slight decrease in the mean was not significant, $t = .24$, n.s.

Internal reliability for the measure was found to be high ($\alpha = .84$). Factor analysis produced a solution accounting for 63% of the variance, which contained two factors:

- Considered weak and less able
- Given welcome consideration

Please see appendix C, Table C10 for further details. Similarly to at baseline, a positive appreciation of allowances and protective behaviours from others was shown by a tendency to agree with relevant items and the production of the second factor. However, this data produced just one main factor for all the more negative items at this point in time.

Table 12.4: Changes in Identity scale mean scores from 'Before I had my stroke' to 'Now I've had my stroke' at follow-up



(r) = items reverse scored
'Before my stroke' mean scores: - - - - - - - - - - - - 'Now I've had my stroke' mean scores: ————————
* p<.05, ** p<.01, ***p<.001

12.7: Beliefs in recovery and recurrence at follow-up

12.7i: Recovery locus of control at follow-up

A slightly lower mean recovery locus of control score was obtained (please see Table 12.3, and Table 10.4) suggesting that participants had tended to become slightly less 'internal'; however, this difference was not significant, t = 1.46, n.s. Scores on this measures was not obtained for eleven participants because they felt they had recovered fully and so their responses would be hypothetical.

12.7ii: Confidence in recovery at follow-up

This was the only variable for which a significant change between baseline and time two was observed (please see Table 12.3 and Table 12.4). The lower mean and median score now indicated that participants were generally less confident in making a full recovery at this nine month stage, t = 5.49, p<.001. This was despite eleven participants' opinion that they were already fully recovered, and the decision to give them a score of ten out of ten for confidence in recovery.

12.7iii: Fear of recurrence at follow-up

Descriptive data indicated a general decrease in fears of another stroke (please see Table 12.3 and Table 10.4); however, this tendency was not quite statistically significant, t = 1.76, p<.12. The distribution of scores was normal suggesting an even spread of concern across participants. This was also reflected in the results for item 6 'I worry about my stroke returning', which was considered most direct. At this stage just under half of participants (36/81; 44%) agreed or strongly agreed with this item, compared to over half at baseline.

Factor analysis produced two factors which accounted for 58% of the variance:

- Concern about health, particularly for the future
- Worried feelings about health and the possibility of stroke

This solution was fairly different from that found at baseline (please see Appendix C, Table C11). Instead of emphasising a difference between thoughts and worry about health and stroke, these factors appear to distinguish between the more immediate experience of concern, and concern for the more distant future.

Chapter 13

Associations with distress at follow-up

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13.1: Résumé of the hypotheses

Examination of associations with distress at follow-up relates to the following main hypothesis and specific hypotheses:

Main hypothesis

1) A significant relationship between emotional distress and beliefs would be found at a later point in time [at follow-up].

It was expected that the main hypotheses would be fulfilled even once demographic and social background factors had been taken into account

Specific hypotheses

1) Certain negative attributions[at follow-up]:
   - Lower sense of control over causes
   - Higher frequency of asking 'Why me?'
   - A failure to find meaning in the experience

   would be associated with higher levels of emotional distress [at follow-up]

2) More negative self-evaluations [at follow-up]:
   - Lower acceptance of ones' disability
   - A more negative change in identity
   - Higher shame

   would be associated with higher levels of emotional distress [at follow-up]

3) More negative beliefs in recovery and recurrence [at follow-up].
   - Lower sense of control over recovery
   - Lower confidence in recovery
   - Higher fear of recurrence

   would be associated with higher levels of emotional distress [at follow-up].

13.2: Statistical considerations at baseline

13.2i: Consideration of normality of distributions at follow-up

As illustrated previously the dependent variable distress is fairly positively skewed to the left, but also fairly flat (please see Chapter 12, section 12.2i). Having sought statistical advice (Lewis, 2003; personal communication), I decided that on balance it was best to leave the dependent variable in its original form for continuity with baseline and for the same statistical considerations described at baseline (please see Chapter 11, section 11.2i)

Histograms of all background and belief variables relevant to the main hypotheses are illustrated in Appendix E, section E.3 and E.4. As can be seen, few variables produced idealised normal distributions. Similarly to baseline, the most skewed continuous independent variables were:

- Barthel index (Extremely negatively skewed)
- Nottingham index (Fairly negatively skewed and bimodal)
- Life events
- 'Why me?'
- Confidence in recovery
- Negative identity change

Following statistical advice (Lewis, 2003; personal communication) I decided to treat these variables in the same way as I had at baseline. Therefore, the first five listed here were dichotomised using the same cut-offs as at baseline (please see Chapter 11, section 11.2i) However, negative identity change was not dichotomised to maintain consistency in the treatment of this variable within the study.

13.2ii: Homogeneity of variance in arrays

Follow-up data was checked for outliers as described previously (see Chapter 11, section 11.2ii) and the highest and lowest values of each variable were found to be accurate. Scatter-plots were produced and are illustrated in Appendix E, sections E7 and E8. These were examined visually for biasing effects toward type I or type II errors from extreme values.

Regarding background variables, some changes in the data were observed from baseline. There was more variability in distress by age, particularly amongst younger to middle-aged participants, who tended to report particularly high or low distress. As the vast majority of participants were older, this apparent polarisation in emotional adjustment for younger stroke survivors was likely to be suppressed in the following analyses. The scatter-plot for stroke severity suggested a tendency for a stronger relationship between stroke severity and distress at the higher end of the stroke severity spectrum. However, due to the relatively small numbers of participants with severe stroke, this relationship may also be suppressed in this study. Similarly, the scatter-plot for life events shows that participants with very high distress did tend to report a life event at follow-up; however this was likely to be suppressed by large numbers of participants reporting a life event with low to moderate distress. These differences amongst sub-groups were interesting and created some lack of homogeneity in arrays for these variables. However, the small numbers of participants involved meant that this was unlikely to strongly skew correlative or regression results.

Regarding, belief variables, the scatter plots generally portray more lawful linear relationships than they did at baseline. The scatter-plot for shame seemed to be particularly less subject to skewing by extreme values. The most heterogeneity in arrays was seen for causal controllability, which was less variable for the high end of the distress spectrum than for the low end. However, as most participants' scores fell in the middle, heterogeneous variance was not a problem for most. Outliers were most apparent for identity change and recovery locus of control and identity change; however extreme values puling the data one way seemed to be counterbalanced by other extreme values pulling the data in the opposite direction. Therefore, on balance heterogeneity of variance in arrays did not seem too problematic for this data set.

13.3: Hypothesis testing at follow-up stage 1: Correlations between follow-up belief and background variables by follow-up distress

13.3i: Univariate correlations between follow-up belief variables and follow-up distress

Univariate correlative relationships between belief variables and distress were first tested with Pearson correlations and the results are displayed in Table 13.1. Please refer to the hypotheses in section 13.1 for the expected direction of relationships between individual belief variables and distress

Specific hypothesis 1: Negative attributions

Small associations, but with high values of statistical significance were found between distress and a lower sense of control over causes, and a greater frequency of continuing to ask 'Why me?'. However, distress levels were not statistically significantly associated with whether or not participants reported having 'Found meaning' in the experience at this nine-month stage.

*Specific hypothesis 2: Negative s*elf-evaluations

As shown in Table 13.1, large associations between distress and variables indicating a more negative view of self were found. Extremely strong relationships between distress and acceptance of disability and negative identity change were found. However, similarly to baseline, these two variables were again highly inter-correlated (see later). A fairly high univariate correlation between distress and the perception that others saw one negatively (shame) was also found. All these associations were statistically significant.

Specific hypothesis 3: Negative beliefs in recovery and recurrence

Distress levels were not statistically significantly associated with recovery locus of control; however a trend for greater distress with lower levels of internality was seen. Lacking confidence in one's recovery was moderately and statistically significantly associated with distress. A fairly high and statistically significant association between distress and fear of recurrence was found.

Table 13.1: Associations between follow-up belief variables and distress relating to specific hypotheses 1, 2, and 3 using Pearson correlations (N = 81, unless indicated otherwise)

	Distress (Global HADs scores)	p value
Specific hypothesis 1: Negative attributions		
Causal controllability	-.39	.0001***
'Why me?'	.32	.004**
'Found meaning?'	-.10	.358
Specific hypothesis 2: Negative self-evaluations		
Acceptance of disability	-.73	.0001***
Negative identity change	-.73	.0001***
Shame	.59	.000***
Specific hypothesis 3: Negative beliefs in recovery and recurrence		
Recovery locus of control [1]	-.19	.125
Confidence in recovery [1]	-.34	.002**
Recurrence fear	.57	.0001***

[1] Eleven participants believed they had now fully recovered. They could not be assessed for locus of control so this correlation was based on just seventy participants. They were scored as fully confident in recovery and included in this correlation calculation.

To control for violations of parametric assumptions, associations were also tested using Spearman's Rho. Extremely similar results were obtained (please see Appendix G, section G.3ii).

To further explore the use of the depression and anxiety sub-scales of the HADs as a combined global distress measure, correlations for the separate depression and anxiety sub-scales were also conducted and the results are displayed in Table 13.2

Table 13.2: Associations between follow-up belief variables and HADs depression, and follow-up belief variables and HADs anxiety relating to specific hypotheses 1, 2 and 3 using Pearson correlations (N = 81, unless indicated otherwise)

	HADs depression scores		**HADs anxiety scores**	
	Correlation coefficient	p value	Correlation coefficient	p value
Specific hypothesis 1: Negative attributions				
Causal controllability	-.24	.029*	-.41	.0001***
'Why me?'	.21	.056	.24	.032*
'Found meaning?'	-.16	.362	-.02	.913
Specific hypothesis 2: Negative self evaluations				
Acceptance of disability	-.70	.0001***	-.64	.0001***
Identity change	.71	.0001***	.63	.0001***
Shame	.57	.0001***	.50	.0001***
Specific hypothesis 3: Negative beliefs in recovery and recurrence				
Recovery locus of control [1]	-.36	.004**	-.13	.280
Confidence in recovery [1]	-.36	.001***	-.28	.011*
Recurrence fear	.48	.0001***	.57	.0001***

[1] Eleven participants believed they had now fully recovered. They could not be assessed for locus of control so this correlation was based on just seventy participants. They were scored as fully confident in recovery and included in this correlation calculation.

In general, the pattern of results found for the individual depression and anxiety subscales were very similar to the results found for the global measure of distress. However, a few exceptions can be seen. A moderate and highly statistically significant correlation for causal controllability and anxiety was found ($r = -.41$, $p<.0001$) but a lower and less statistically significant association for depression ($r = -.29$, $p = .029$). Neither depression or anxiety was statistically significantly associated with 'Found meaning?', however the lack of a relationship was more evident for anxiety. While an almost null relationship between locus of control and anxiety was found, a negative association between greater levels of internality and depression was actually significant ($r = -.34$, $p = .004$).

In general a high level of interdependence between depression and anxiety symptoms was indicated by these results and so using the global measure of distress for the subsequent multivariate regression analyses seems generally reasonable. It is recognised that the low but significant relationship between a less internal locus of control and depression would not be taken into account in the regression analyses due to the lack of a significant relationship at the $p<.05$ level between this variable and global distress. Therefore, the 'stricter' analysis was rerun including recovery locus of control, and the essentially the same results in terms of variables remaining in the equation were found.

13.3ii: Univariate correlations between follow-up background variables and follow-up distress

Association between background variables and distress were first examined using Pearson correlations, and are displayed in Table 13.3. As can be seen, a statistically significant result was only found for one demographic variable, showing that female participants were more likely to report higher distress levels.

Table 13.3: Associations between follow-up background variables and distress using Pearson correlations (N = 81, unless indicated otherwise)

	Distress (Global HADs scores)	**p value**
Demographic variables		
Age (in years)	-.14	.224
Gender	.25	.024*
Deprivation: Carstairs index	.01	.948
Other background variables		
Stroke severity [1]	.24	.036*
Disability: Barthel index	-.22	.054
Disability: Nottingham index	-.27	.015*
Social support	-.17	.134
Life events	.04	.707
Pre-stroke history of depression	.42	.0001***

[1] Stroke severity scores were missing for three of the participants seen at follow-up, and so this correlation was based on just seventy-eight participants.

A small, yet statistically significant association between stroke severity measured within a few days of the event and distress levels at this later follow-up was found. Participants' self-reported basic disability measured by the Barthel index did not

quite produce a statistically significant association with distress; however their extended ADL disability measured by the Nottingham index did. Neither of the more social variables, life events, or social support were found to be statistically significant. The strongest association for the background variables was found between present distress levels and reports of having been depressed during life before the stroke.

To control for violations of parametric assumptions, associations between the background variables and distress were also tested using Spearman's Rho. The results were generally similar (please see Appendix G, section G.3ii).

Associations between background variables and the individual HADs depression and anxiety sub-scales were also examined and the results are displayed in Table 13.4.

A fairly similar pattern of results for the individual depression and anxiety subscales as for the global measure of distress was found. However some minor differences were seen. Overall, demographic variables were more associated with anxiety than depression. Similarly to global distress, there was no relationship between age and depression, however, younger age showed a tendency to associate with anxiety scores. Gender was statistically significantly associated with anxiety, but only showed a tendency to associate with depression.

Stroke severity not only showed a tendency to associate with depression but was statistically significantly associated with anxiety. Barthel and Nottingham index disability scores were associated with depression at a statistically significant level but not with anxiety.

Similarly to results for global distress, no associations for either social support or life events were found with depression or anxiety. Also, the strongest most statistically significant association for both depression and anxiety was found for reports of a pre-stroke history of depression.

Table 13.4: Associations between follow-up background variables and HADs depression and follow-up background variables and HADs anxiety using Pearson correlations (N = 81, unless indicated otherwise)

	HADs depression scores		HADs anxiety scores	
	Correlation coefficient	p value	Correlation coefficient	p value
Demographic data				
Age (in years)	-.04	.745	-.21	.057
Gender	.19	.092	.27	.015*
Deprivation: Carstairs index	- .04	.707	.06	.628
Other background variables				
Stroke severity [1]	.19	.096	.24	.032*
Disability: Barthel index	- .25	.023*	-.14	.204
Disability: Nottingham index	- .29	.008**	-.20	.071
Social support	-.15	.175	-.15	.177
Life events	.03	.815	.05	.637
Pre-stroke history of depression	.43	.0001***	.35	.001***

[1] Stroke severity scores were missing for three of the participants seen at follow-up, and so this correlation was based on just seventy-eight participants

Overall, a fair level of correspondence for associations of the background variables with the depression subscale, with the anxiety subscale, and with the global measure of distress was seen at follow-up.

13.3iii: Comment on the univariate correlative results at follow-up in relation to the hypotheses

Overall, the main hypothesis was supported by these results as statistically significant small to large associations between distress and most belief variables (seven out of nine) were found.

Specific hypothesis 1: Negative attributions

This hypothesis was partially supported at follow-up by statistically significant associations between distress and two attributional variables: causal controllability and 'Why me?'. However, in contrast, whether or not participants had 'Found meaning?' did not appear related to distress. A generally low rate of reporting of having 'Found meaning?' was observed at follow-up (please see Chapter 12, section 12.5iv) and this may partly explain its lack of association with distress.

Specific hypothesis 2: Negative self-evaluations

This hypothesis was strongly supported at follow-up at the univariate correlation level which found large and statistically significant associations between distress and all three self-evaluative variables: acceptance of disability, negative identity change and shame. However, these variables were all significantly inter-correlated (please see Appendix G, section G.2, Table G.2) which threw some doubt on their ability to produce independent association with distress when tested together in the subsequent multivariate regression analyses.

Specific hypothesis 3: Negatives beliefs in recovery and recurrence

This hypothesis was partially supported at follow-up by statistically significant associations between distress and confidence in recovery and recurrence fear. However, association between recovery locus of control and distress was not found. Participants' own sense of control over recovery may simply be less relevant at this stage now most recovery has taken place and some even believe they are recovered. Background variables were found to associate statistically significantly with distress less often and to produce lower correlations than belief variables. The only moderately sized association between a background variable and distress at follow-up was for a pre-stroke history of depression. Nevertheless gender and disability

measured by both the Barthel and Nottingham index were consistently associated with distress at follow-up at a statistically significant level. A less consistent relationship was seen for stroke severity, that produced a statistically significant association only using the parametric method.

Overall, univariate correlations at follow-up suggest a generally stronger relationship between the belief variables and distress as compared to the background variables and distress in terms of the number, size, significance levels and consistency of associations. However, these results do not take into account the possibility that associations between the belief variables and distress may be confounded by the background variables. To test the hypotheses more strictly, associations between the belief variables and distress needed to be tested with the background variables taken into account.

13.4: Hypothesis testing at follow-up stage 2: Multiple regression analyses for distress at follow-up

13.4i: Multi-collinearity considerations at follow-up

Prior to conducting the analysis, the belief and background variables were examined for multi-collinearity. As can be seen in Appendix G, section G.2, Table G.2) a fair degree of multi-collinearity was observed, but most of these correlations were low enough to be considered unproblematic. Similarly to baseline, the highest inter-correlation amongst background variables was found between the two measures of disability ($r = .77$, $p<.0001$). Again, similarly to baseline, some multi-collinearity was observed between belief variables, in particular a strong correlation between acceptance of disability and negative identity change ($r = -.75$, $p<.0001$). Therefore the issues surrounding multi-collinearity were relevant to both methods of variable selection and the same as those discussed at baseline (please see Chapter 11, section 11.4i).

13.4ii: Résumé of the 'univariate' and 'stricter' regression method

As discussed previously, the backward stepwise method was chosen to simultaneously examine the association between follow-up belief and background variables with follow-up distress (please see Chapter 7). As before, a typical 'univariate' method of variable selection using only those variables with statistically significant univariate correlations with distress, seemed reasonable due to considerations of power and the number of participants. However, in recognition of the position of some statisticians (Altman, 1991), I also conducted a second 'stricter' analysis that included all background variables throughout.

13.4iii: Results for the 'univariate' multiple regression analyses at follow-up

The result of the preliminary analysis which included all eleven belief and background variables with univariate statistically significant correlations with distress is presented in Table 13.5. Overall this model was highly significant, $\mathbf{R^2 = .75, p<.0001}$, which suggests that over half the variance in distress scores was accounted for by these variables. As seen in Table 13.5, a pre-stroke history of depression and two of the belief variables produced statistically significant t values and larger partial correlations in this model.

Table 13.5: Preliminary regression model for follow-up distress using follow-up background and belief variables that had produced statistically significant univariate correlations

	B[1]	Std. error	t	Significance of t	Partial Correlation
Background variables:					
Gender	.58	.97	.60	.551	.04
Stroke severity [2]	.00	.15	-.12	.904	-.01
Disability: Barthel index	.14	1.30	.11	.913	.01
Disability: Nottingham index	1.62	1.39	1.17	.248	-.07
Pre-stroke history of depression	3.03	1.21	2.72	.008***	.17
Belief variables:		1			
Causal controllability	-.80	.62	-1.27	.208	-.08
'Why me?'	.97	1.02	.95	.345	.06
Acceptance of disability	-.36	.16	-2.21	.031*	-.14
Negative identity change	.27	.08	3.24	.002***	.20
Shame	.00	.14	.30	.766	.02
Confidence in recovery	.00	1.01	-.08	.936	-.005
Recurrence fear	.21	.11	1.92	.060	.12

[1] Beta values quoted are the un-standardised coefficients

The backward regression procedure involved elimination of the other variables in the following order:

- Confidence in recovery
- Disability: Barthel index
- Stroke severity
- Shame

- 'Why me?'
- Gender
- Causal controllability
- Disability: Nottingham index

A large and highly statistically significant final regression model for follow-up distress $\mathbf{R^2 = .73, p<.0001}$ was found with this 'univariate' method and is illustrated in Table 13.6. As can be seen, the variables remaining were those that had been statistically significant in the preliminary analysis, and also recurrence fear.

Table 13.6: Final regression model for follow-up distress using follow-up background and belief variables that had produced significant univariate correlations and that remained statistically significant after the backward regression procedure

	B [1]	Std. error	t	Significance of t	Partial Correlation
Background variables:					
Pre-stroke history of depression	4.15	.95	4.38	.0001***	.45
Belief variables:					
Acceptance of disability	-.39	.09	-.4.28	.0001***	-.44
Negative identity change	.23	.08	3.09	.003**	.33
Recurrence fear	.26	.10	2.64	.01**	.29

[1] Beta values quoted are the un-standardised coefficients
[2] Stroke severity data was missing for three participants, therefore this whole analysis is based on seventy-eight rather than eighty-one participants

Comment on the 'univariate' regression results in relation to the hypotheses will be made in section 13.5.

13.4iv: Results for the 'stricter' multiple regression analyses at follow-up

The backward stepwise regression procedure was repeated, except this time all background variables were included at each stage regardless of significance. The results of the preliminary analysis produced a highly statistically significant overall model: $\mathbf{R^2 = .76, p<.0001,}$ and is detailed in Table 13.7 below.

Table 13.7: Preliminary regression model for follow-up distress using all follow-up background variables and follow-up belief variables that had produced statistically significant univariate correlations with distress

	B [1]	Std. error	t	Significance of t	Partial Correlation
Background variables:					
Age	.00	.05	-1.43	.157	-.18
Gender	.23	1.02	.22	.823	.03
Deprivation: Carstairs index	.00	.30	.27	.792	.03
Stroke severity [2]	.11	.16	-.70	.486	-.09
Disability: Barthel index	.00	1.37	.07	.948	.01
Disability: Nottingham index	.74	1.54	.48	.630	.06
Social support	-.00	.02	-.91	.369	-.12
Life events	-.00	.91	.00	.998	-.00
Pre-stroke history of depression	3.11	1.25	2.49	.016*	.31
Belief variables:					
Causal controllability	-.87	.65	-1.36	.180	-.17
'Why me?'	.79	1.06	.74	.460	.10
Acceptance of disability	-.40	.17	-2.40	.019*	-.30
Negative identity change	.25	.09	2.88	.005**	.35
Shame	-.00	.14	-.02	.988	-.00
Confidence in recovery	-.21	1.06	-.20	.844	-.03
Recurrence fear	.21	.11	1.90	.063	.24

[1] Beta values quoted are the un-standardised coefficients
[2] Stroke severity data was missing for three participants, therefore this whole analysis is based on seventy-eight rather than eighty-one participants

The least significant belief variables were systematically removed until all in the model were significant at the p<.05 level. However, background variables continued to be included regardless of significance. Eliminated variables, in order of removal were:

- Shame
- Confidence in recovery
- 'Why me?'
- Causal controllability

The overall final model for this 'stricter' method was large and highly statistically significant: **R^2 = .75, p<.0001.**

Table 13.8: Final regression model for follow-up distress using all follow-up background variables and follow-up belief variables that had produced statistically significant univariate correlations with distress and that remained statistically significant after the backward regression procedure

	B [1]	Std. error	t	Significance of t	Partial Correlation
Background variables:					
Age	.00	.05	-1.19	.237	-.15
Gender	.30	.95	.31	.755	.04
Deprivation: Carstairs index	.18	.29	.62	.541	.08
Stroke severity [2]	-.11	.16	-.72	.476	.09
Disability: Barthel index	-.12	1.31	-.10	.925	.01
Disability: Nottingham index	1.04	1.48	.70	.485	.09
Social support	.00	.02	-1.13	.264	-.14
Life events	.00	.85	.05	.957	-.01
Pre-stroke history of depression	3.73	1.07	3.49	.001***	.40
Belief variables:					
Acceptance of disability	-.44	.10	-4.41	.0001***	-.48
Negative identity change	.24	.08	2.86	.006**	.33
Recurrence fear	.24	.11	2.29	.025*	.27

[1] Beta values quoted are the un-standardised coefficients
[2] Stroke severity data was missing for three participants, therefore this whole analysis is based on seventy - eight rather than eighty - one participants

13.5: Comment on the multiple regression results for follow-up distress using follow-up belief and background variables in relation to the hypotheses

The first main hypothesis that beliefs and distress would associate was tested in analyses that took associations between background variables and distress into account.

Highly statistically significant and large regression models were produced for follow-up distress. Only extremely slight differences in the size of models exist between the 'univariate' and 'stricter' method and preliminary and final models. Also, regardless of how other variables were controlled for, just four variables were consistently found to independently enter these regression models at a statistically significant level. Therefore these four variables alone appear able to account for practically as much of the variance in follow-up distress levels as all variables taken together. Of these just one was a background variable (pre-stroke history of depression) and three were belief variables (acceptance of disability, negative identity change and recurrence fear).

These results offer strong support to the main hypothesis, as a relationship between emotional distress and certain beliefs was found to be both highly statistically significant and relatively un-confounded by background variables. However, support for the specific hypotheses was more patchy.

Specific hypothesis 1: Negative attributions

Once all variables were taken into account, this hypothesis failed to be supported at follow-up. Statistically significant associations between distress and causal controllability and 'Why me?' had been found at the univariate level; however they failed to remain in the regression analyses.

Specific hypothesis 2: Self-evaluations

Once all variables were taken into account the hypothesis that self-evaluations and distress would be related was strongly but partially supported. Despite being highly inter-correlated, both acceptance of disability and negative identity change were found to produce highly statistically significant associations with distress in the

follow-up regression analyses. However, shame failed to contribute to follow-up distress at a statistically significant level once other variables were taken into account. It was very highly inter-correlated with acceptance of disability ($r=.75$, $p<.0001$) and so therefore possibly at a statistical disadvantage.

Specific hypothesis 3: Beliefs to recovery and recurrence

Once other variables were taken into account these results clearly failed to support the first half of this hypothesis- that beliefs in recovery would be related to distress at follow-up. However, the regression results firmly support the second half of this hypothesis - that fear of recurrence and distress would be statistically significantly related at follow-up.

In summary, these results suggest that at follow-up distress was associated with a sense that one had changed for the worse as a person, being unable to accept ones reduced capabilities and also, ongoing fears of having further strokes. These results appear to be statistically independent of confounding by background variables.

Chapter 14

Prediction of follow-up distress using baseline variables

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14.1: Résumé of the hypotheses

Prediction of distress at follow-up relates to the second main hypothesis and specific hypotheses:

2) Beliefs found at baseline would predict emotional distress at follow-up

It was expected that the main hypotheses would be fulfilled even once demographic and social background factors had been taken into account

Specific hypotheses

1) Certain negative attributions[at baseline]:
   - Lower sense of control over causes
   - Higher frequency of asking 'Why me?'
   - A failure to find meaning in the experience

   would be associated with higher levels of emotional distress [at follow-up]

2) More negative self-evaluations [at baseline]:
   - Lower acceptance of ones' disability
   - A more negative change in identity
   - Higher shame

   would be associated with higher levels of emotional distress [at follow-up]

3) More negative beliefs in recovery and recurrence [at baseline].
   - Lower sense of control over recovery
   - Lower confidence in recovery
   - Higher fear of recurrence

   would be associated with higher levels of emotional distress [at follow-up].

14.2: Statistical considerations from baseline to follow-up

There was little participant attrition during the study (eighty-nine participants at baseline and eighty-one at follow-up). The same statistical issues, advice and decisions for the treatment of distress at follow-up made earlier were applicable to the testing of the hypotheses across time (please see Chapter, 13.2i). Histograms and descriptive statistics of baseline belief and background variables were examined using only those who participated at follow-up and distributions were observed to be extremely similar to those found with all eighty-nine baseline participants (please see Appendix E, sections E.1 and E.2). Therefore, the same comments made earlier applied at follow-up, as did the same decisions regarding dichotomising the most skewed variables (please see Chapter 11, section 11.2i).

Scatter-plots of follow-up distress by baseline background variables and belief variables by follow-up distress were produced and are displayed in Appendix E, sections E.9 and E.10. Regarding background variables, more variability in distress was observed amongst younger participants, but their small numbers suggested that this would be suppressed in subsequent analyses. Otherwise little heterogeneity of arrays was observed.

Regarding belief variables compared to cross-sectional scatter-plots, in which causal controllability tended towards a funnel shape in its relationship to distress, the scatter- plot for baseline causal controllability and follow-up distress was step shaped with an absence of points in the top right corner (please see Appendix E, section E.10). Follow-up distress levels varied widely when baseline causal controllability scores were low to moderate, but were less varied and on the low side when baseline causal controllability scores were high. Therefore, any statistically significant association found between baseline causal controllability and follow-up distress is likely to be attributable to this minority who reported a greater sense of control over causes at one month. Similarly to the baseline shame by baseline distress scatter-plot, this baseline shame to follow-up distress scatter-plot lacked homogeneity (please see Chapter 11, section 11.2ii for relevant comments). However, there appeared to be less of a 'blip' to the top right corner; similar distress levels were seen in relation to the lowest and highest baseline shame scores.

Therefore, although this relationship did not appear linearly lawful, it did not seem to pose much threat of a type II error.

14.3: Hypothesis testing from baseline to follow-up stage 1: Correlations between baseline belief and background variables with follow-up distress

14.3i: Univariate correlations between baseline belief variables with follow-up distress

Univariate correlative relationships between belief variables and distress were first tested with Pearson correlations and the results are displayed in Table 14.1. Please refer to the hypotheses in section 14.1 for the expected direction of relationships between individual belief variables and distress. Small to moderate significant associations were found between two thirds of the baseline belief variables and follow-up distress.

Specific hypothesis 1: Negative attributions

Associations between both causal controllability and 'Why me?' at baseline and distress at follow-up were small but statistically significant. However, whether or not participants had reported having found meaning at one month appeared to have little bearing on their levels of distress nine months following stroke.

Specific hypothesis 2: Negative self-evaluations

Both acceptance of disability and negative identity change at baseline were found to produce reasonably moderate statistically significant correlations with follow-up levels of distress. However baseline shame failed to significantly predict follow-up distress at a statistically acceptable level.

Specific hypothesis 3: Negative beliefs in recovery and recurrence

Participants' early sense of personal responsibility for their recovery (i.e. internal locus of control levels) did not predict distress at nine months. However, baseline confidence in recovery was inversely related to follow-up distress at a statistically significant level. Fears of recurrence reported at one month also appeared to predict later distress in a small but statistically significant way.

Table 14.1: Associations between baseline belief variables and follow-up distress relating to specific hypotheses 1, 2, and 3 using Pearson correlations (N = 81)

	Distress (Global HADs scores)	p value
Specific hypothesis 1: Negative attributions		
Causal controllability	-.36	.001***
'Why me?'	.21	.045*
'Found meaning?'	-.14	.197
Specific hypothesis 2: Negative self-evaluations		
Acceptance of disability	-.46	<.0001***
Negative identity change	.43	<.0001***
Shame	.21	.057
Specific hypothesis 3: Negative beliefs in recovery and recurrence		
Recovery locus of control	-.14	.220
Confidence in recovery	- .39	<.0001***
Recurrence fear	.24	.028*

To control for violations of parametric assumptions, associations were also tested using Spearman's Rho. Extremely similar results were obtained (please see Appendix G, section G.3iii, Table G.7)

To further explore the use of the depression and anxiety subscales of the HADs as a combined global distress measure, correlations for the individual subscales were also calculated. These are displayed in Table 14.2.

Table 14.2: Associations between baseline belief variables and follow-up HADs depression, and baseline belief variables and follow-up HADs anxiety relating to specific hypotheses 1,2 and 3 using Pearson correlations (N =81)

	HADs depression scores		**HADs anxiety scores**	
	Correlation coefficient	p value	Correlation coefficient	p value
Specific hypothesis 1: Negative attributions				
Causal controllability	-.30	.007**	-.35	.001**
'Why me?'	.14	.212	.25	.024*
'Found meaning?'	-.16	.145	-.11	.344
Specific hypothesis 2: Negative self- evaluations				
Acceptance of disability	-.46	<.0001***	-.43	<.0001***
Identity change	.36	.001***	.43	<.0001***
Shame	.28	.012*	.12	.286
Specific hypothesis 3: Negative beliefs in recovery and recurrence				
Recovery locus of control	-.18	.101	-.08	.508
Confidence in recovery	-.40	<.0001***	-.31	.005**
Recurrence fear	.17	.140	.28	.011

The results for the individual depression and anxiety subscales were similar to those found with the global distress measure. However, a statistically significant association between baseline shame and follow-up depression was found, whereas, the association between baseline 'Why me?' and follow-up depression was not

statistically significant. Also, the correlation between baseline recurrence fear and follow-up anxiety was larger and statistically significant, but the correlation between baseline recurrence fear and follow-up depression was lower and statistically insignificant. Overall, a high degree of correspondence between results for the depression and anxiety subscales and the global measure was seen. This suggests that subsequent analysis using the global distress measure would reflect both depression and anxiety symptoms well.

14.3ii: Univariate correlations between baseline background variables and follow-up distress

Associations between baseline background variables and follow-up distress were first examined using Pearson correlations and are displayed in Table 14.3. As can be seen, a slight but statistically significant association between follow-up distress and one demographic variable, gender, was found. A small yet statistically significant association was found for stroke severity. However, self-reported baseline disability was inconsistently associated with follow-up distress. The more basic Barthel index did not produce a statistically significant association, but the extended ADL Nottingham index did produce a trend.

Associations between baseline background variables and follow-up distress were also tested using the non-parametric method. The results were generally similar (please see Appendix G, section G.3iii, Table G.8).

Table 14.3: Associations between baseline background variables and follow-up distress using Pearson correlations (N = 81 unless indicated otherwise)

	Distress (Global HADs scores)	p value
Demographic variables		
Age (in years)	-.14	.224
Gender	.25	.024*
Deprivation: Carstairs index	.01	.948
Other background variables		
Stroke severity [1]	.24	.036*
Disability: Barthel index	-.15	.188
Disability: Nottingham index	-.20	.067
Social support	-.17	.134
Life events	.17	.130
Pre-stroke history of depression	.42	<.0001***

[1] Stroke severity scores were only available for seventy-eight participants seen at follow-up

Associations between baseline background variables the individual follow-up HADs depression and anxiety subscales were also examined and are displayed in Table 14.4.

Associations between pre-stroke history of depression with both the anxiety and depression sub-scales were both of high significance and this was consistent with the results found for overall distress. However, gender and stroke severity were significantly correlated with anxiety but not with depression, while the reverse was found for Nottingham index disability.

Table 14.4: Associations between baseline background variables and follow-up HADs depression and baseline background variables and follow-up HADs anxiety using Pearson correlations (N = 81 unless indicated otherwise)

	HADs depression scores		HADs anxiety scores	
	Correlation coefficient	p value	Correlation coefficient	p value
Demographic data				
Age (in years)	-.04	.745	-.21	.057
Gender	.19	.092	.27	.015*
Deprivation: Carstairs index	-.04	.707	.06	.628
Other background variables				
Stroke severity [1]	.19	.096	.24	.032*
Disability: Barthel index	-.19	.085	-.08	.482
Disability: Nottingham index	-.23	.042*	-.15	.188
Social support	-.15	.175	-.15	.177
Life events	.11	.312	.20	.079
Pre-stroke history of depression	.43	<.0001***	.35	.001***

[1] Stroke severity scores were only available for seventy-eight participants seen at follow-up

Overall associations between these baseline background variables and follow-up anxiety and depression varied quite a bit in terms of significance levels. However, this is not surprising given their small sizes. The size of associations and the baseline background variables that did produce statistically significant correlations across the parametric and non-parametric analyses with distress and the parametric analyses with anxiety and depression were fairly consistent.

14.3iii: Comment on univariate correlative results for baseline belief and background variables and follow-up distress in relation to the hypotheses

The main hypothesis was supported by the univariate results, as six out of nine baseline belief variables were consistently associated with follow-up distress. However, the size of correlations tended to be smaller than those found for the cross-sectional baseline and follow-up results (please see Chapters 11 and 13).

Specific hypothesis 1: Negative attributions

This hypothesis was partially supported. A baseline belief in control over causes was positively predictive and asking 'Why me?' was statistically negatively predictive of follow-up levels of distress using univariate associations. However, no statistically predictive association was seen between baseline attributions of meaning and follow-up distress.

Specific hypothesis 2: Negative self- evaluations

This hypothesis was also partially supported. Baseline levels of acceptance regarding one's disability were inversely related to follow-up distress. The belief that one had changed for the worst (negative identity change) was positively related to distress levels at nine months. Both at levels of statistical significance. However, baseline shame scores were not associated with follow-up distress at a statistically significant level.

Specific hypothesis 3: Negative beliefs in recovery and recurrence

Again only partial support was found for this hypothesis. Baseline recovery locus of control was not associated with follow-up distress levels. However, participants' reported degree of confidence that they would eventually make a full recovery measured at one month did inversely associate with subsequent distress at nine months at a statistically significant level. These univariate results also support the idea that baseline fears of recurrent strokes were predictive of follow-up distress.

Background variables

Participants who reported having experienced depression at some point in life before their stroke were found to be more distressed nine months following their stroke. This was shown by firm statistically significant correlation coefficients with follow-up anxiety and depression and global distress scores. Gender also correlated with follow-up emotional distress at a statistically significant level. Stroke severity produced a statistically significant correlation with the parametric method and Nottingham index scores with the non-parametric method. The results showed some inconsistency dependent on parametric versus non-parametric method with distress, and use of anxiety versus depression sub-scale scores. Overall baseline background variables were less associated with follow-up distress than baseline belief variables.

Nevertheless to test the hypotheses fully, associations between the baseline belief variables and follow-up distress needed to be tested with the baseline background variables taken into account.

14.4: Hypothesis testing from baseline to follow-up stage 2: Multiple regression analyses for follow-up distress using baseline variables

14.4i: Multi-collinearity considerations for baseline variables with follow-up sample

Inter-correlations between baseline belief and background variables were examined for this follow-up sample of eighty-one participants. The results were almost identical to those found using the full baseline sample of eighty-nine participants (please see Appendix G, section G.1, Table G.1). All significance levels were identical and the size of correlation coefficients were either identical or they differed by a decimal place. Therefore the previous discussion regarding issues of multi-collinearity is applicable now (please see Chapter 11, section 11.4i). However, because disability measured by the Barthel index was not univariately associated with distress, its multi-collinearity with the Nottingham index measure was not relevant to the 'univariate' analyses. Also, the inclusion of stroke severity in the 'univariate' method is recognised as potentially controversial as a significant association with follow-up distress was not found with the non-parametric method. However, its inclusion errs towards a stricter test of the belief variables.

14.4ii: Results for the 'univariate' multiple regression analyses for follow-up distress using baseline belief and background variables

Results of the preliminary 'univariate' method that included only the six belief variables and three background variables found significant with Pearson correlations is displayed in Table 14.5. Overall this model was highly significant but smaller in size than cross-sectional models, **R^2 = .47, p<.0001,**

A pre-stroke history of depression was the only background variable that was significant in this equation. Just two belief variables were found to be significant. Of these, causal controllability was the strongest. The self-evaluation variable acceptance of disability was also significant, but only at the $p<.05$ level.

Table 14.5: Preliminary regression model for follow-up distress using baseline background and belief variables that had produced statistically significant univariate correlations (N = 78 [2])

	B [1]	Std. error	t	Significance of t	Partial Correlation
Background variables:					
Gender	1.91	1.32	1.45	.152	.13
Stroke severity [2]	.17	.20	.83	.409	.07
Pre-stroke history of depression	5.18	1.50	.34	.001***	.30
Belief variables:					
Causal controllability	-2.18	.68	-.30	.002**	-.28
'Why me?'	.00	1.33	-.01	.947	-.01
Acceptance of disability	-.31	.15	-.27	.044*	-.18
Negative identity change	.00	.10	.01	.916	.01
Confidence in recovery	-1.61	1.51	-.11	.288	-.09
Recurrence fear	.00	.15	.01	.961	.00

[1] Beta values quoted are the un-standardised coefficients
[2] Stroke severity data was missing for three participants, therefore this whole analysis is based on seventy-eight rather than eighty-one participants

The backward regression process was executed until a model in which all variables were significant at the $p<.05$ level was produced. The variables that were eliminated, in order of removal, were:

- Recurrence fear
- 'Why me?'
- Negative identity change
- Stroke severity
- Confidence in recovery
- Gender

A highly statistically significant but modestly sized final model was obtained, **R^2 =.43, p<.0001,** in which just one background variable and two belief variables remained. These variables (pre-stroke history of depression, causal controllability and acceptance of disability) were those significant in the preliminary model.

Table 14.6: Final model for follow-up distress using baseline background and belief variables that had produced statistically significant univariate correlations and which remained statistically significant after the backward regression procedure (N = 81)

	B [1]	Std. error	t	Significance of t	Partial Correlation
Background variables:					
Pre-stroke history of depression	5.66	1.30	4.37	<.0001***	.45
Belief variables:					
Causal controllability	-1.97	.62	-3.16	.002**	-.34
Acceptance of disability	-.43	10	-4.38	<.0001***	-.46

[1] Beta values quoted are the un-standardised coefficients

Comment on the 'univariate' results for prediction of follow-up distress using baseline variables will be made in section 14.6i

14.4iii: Results for the 'stricter' multiple regression analyses for follow-up distress using baseline belief and background variables

For a more strict test of the hypotheses, prediction of follow-up distress was also studied using all background variables regardless of univariate significance and baseline belief variables with significant univariate correlations with follow-up distress. The results of the preliminary model using this 'stricter' method are illustrated in Table 14.7.

Table 14.7: Preliminary regression model for follow-up distress using all baseline background variables and those baseline belief variables that had produced statistically significant univariate correlations (N = 78 [2])

	B [1]	Std. error	t	Significance of t	Partial Correlation
Background variables:					
Age	-.13	.08	-1.75	.085	-.15
Gender	2.27	1.46	1.56	.125	.14
Deprivation: Carstairs index	-.22	.41	-.54	.591	-.05
Stroke severity [2]	.00	.25	-.01	.993	-.00
Disability: Barthel index	.98	1.81	.54	.590	.05
Disability: Nottingham index	-.99	1.92	.52	.607	-.05
Social support	.00	.03	-.98	.332	-.09
Life events	1.62	1.24	1.34	.197	.11
Pre-stroke history of depression	4.58	1.53	2.99	.004**	.26
Belief variables:					
Causal controllability	-2.40	.69	-3.05	.001***	-.31
'Why me?'	-1.97	1.63	-1.20	.234	-.11
Acceptance of disability	-.33	.16	-2.03	.047***	-.18
Negative identity change	.00	.11	.61	.546	.05
Confidence in recovery	-1.06	1.61	-.65	.515	-.06
Recurrence fear	.00	.16	.03	.975	.00

[1] Beta values quoted are the un-standardised coefficients
[2] Stroke severity data was missing for three participants, therefore this whole analysis is based on seventy-eight rather than eighty-one participants

Overall this preliminary 'stricter' model was highly significant if not large in size, **R^2 = .52, p<.0001.**

The backward regression elimination process led to removal of the following variables:

- Recurrence fear
- Negative identity change
- Confidence in recovery
- 'Why me?'

The final 'stricter' model is illustrated in Table 14.8.

Table 14.8: Final regression model for follow-up distress using all the baseline background variables and those baseline belief variables that had produced statistically significant univariate correlations and which remained statistically significant after the backward regression procedure (N = 78 [2])

	B [1]	Std. error	T	Significance of t	Partial Correlation
Background variables:					
Age	.00	.06	-1.22	.225	-.11
Gender	2.11	1.38	1.54	.128	.13
Deprivation: Carstairs index	-.18	.40	-.45	.655	-.04
Stroke severity [2]	.12	.22	.54	.591	.05
Disability: Barthel index	1.39	1.72	.81	.420	.07
Disability: Nottingham index	-.96	1.87	-.51	.613	-.04
Social support	.00	.03	-1.29	.203	-.11
Life events	1.28	1.18	1.09	.282	.09
Pre-stroke history of depression	4.66	1.46	3.20	.002**	.28
Belief variables:					
Causal controllability	-2.44	.67	-3.68	<.0001***	-.32
Acceptance of disability	-.38	.12	-3.20	.002**	-.28

[1] Beta values quoted are the un-standardised coefficients
[2] Stroke severity data was missing for three participants, therefore this whole analysis is based on seventy-eight rather than eighty-one participants

This final 'stricter' model was similar in size to the preliminary model, **R^2 = .51, p<.0001,** and as shown in Table 14.11, the three significant variables were those also significant in the preliminary model.

Comment on the 'stricter' results for prediction of follow-up distress using baseline variables will be made in section 14.6i

14.5: Hypothesis testing from baseline to follow-up stage 3: Hierarchical multiple regression analyses for follow-up distress using baseline distress and baseline belief and background variables

14.5i: Results for the 'univariate' hierarchical regression analyses for follow-up distress using baseline variables

The following hierarchical analyses were to test whether baseline belief variables were able to predict follow-up distress once baseline distress, as well as baseline background variables, were controlled for. Baseline distress was regressed onto follow-up distress first and then any further variables were added in a second block and subjected to the backward regression procedure. As described previously (please see Chapter 12, section 12.2iii) the level of association between baseline distress and follow-up distress was high (r=.64, p<.0001). This made the likelihood of other baseline variables being able to 'add anything' further to the prediction of follow-up distress low. Nevertheless, the following tests were still considered to be valuable further stringent tests of the hypotheses.

Baseline distress regressed onto follow-up distress to produce a highly significant model R^2 = .41, p<.0001. Following addition of other variables an overall model of **R^2 = .53, p<.0001,** was produced. Results of the preliminary 'stricter' method are displayed in Table 14.9.

As can be seen, in addition to baseline distress, just one background variable (pre-stroke history of depression) and one belief variable (causal controllability) were found to be statistically significant.

Table 14.9: Preliminary regression model for follow-up distress using baseline distress and all the baseline background and belief variables that had produced statistically significant univariate correlations with follow-up distress (N = 78 [2])

	B [1]	Std. Error	t	Significance of t	Partial Correlation
Baseline distress	.41	.15	2.75	.008**	.32
Background variables:					
Gender	1.26	1.28	.98	.329	.12
Stroke severity [2]	.23	.20	1.15	.256	.14
Pre-stroke history of depression	3.57	1.55	2.30	.024*	.27
Belief variables:					
Causal controllability	-1.68	.67	-2.51	.015*	-.29
'Why me?'	.24	1.27	.19	.851	.02
Acceptance of disability	1.23	.15	-1.56	.125	-.19
Negative identity change	.00	.10	-.71	.482	-.09
Confidence in recovery	-.72	1.47	-.49	.628	-.06
Recurrence fear	-.12	.15	-.78	.440	-.09

[1] Beta values quoted are the un-standardised coefficients
[2] Stroke severity data was missing for three participants, therefore this whole analysis is based on seventy-eight rather than eighty-one participants

The backward regression process was executed until a model in which all variables were significant at the $p<.05$ level was produced. The variables that were eliminated, in order of removal were:

- 'Why me?'
- Confidence in recovery
- Negative identity change
- Recurrence fear

- Stroke severity
- Gender
- Acceptance of disability

A highly statistically significant but modestly sized final model was produced, **R^2 =.49, p<.0001.** This contained baseline distress and the background variable (pre-stroke history of depression) and belief variable (causal controllability) that were significant in the preliminary model (please see Table 14.10).

Table 14.10: Final regression model for follow-up distress using baseline distress and all the background and belief variables that had produced statistically significant univariate correlations and which remained statistically significant after the backward regression procedure (N = 81)

	B [1]	Std. error	t	Significance of t	Partial Correlation
Baseline distress	.53	.09	5.39	<.0001***	.52
Background variable:					
Pre-stroke history of depression	3.20	1.34	2.38	.020*	.26
Belief variable:					
Causal controllability	-1.48	.61	-2.43	.017*	-.27

[1] Beta values quoted are the un-standardised coefficients

Comment on the 'univariate' regression results for prediction of follow-up distress using baseline variables and baseline distress will be made in section 14.6ii

14.5ii: Results for the 'stricter' hierarchical regression analyses for follow-up distress using baseline variables

The hierarchical process was repeated using the 'stricter' method that used all baseline background variables regardless of their univariate significance with follow-up distress.

Table 14.11: Preliminary regression model for follow-up distress using baseline distress, all the baseline background variables and those baseline belief variables that had produced statistically significant univariate correlations (N = 78 [2])

	B [1]	Std. error	t	Significance of t	Partial Correlation
Baseline distress:	.34	.16	2.13	.037*	.26
Background variables:					
Age	-.10	.08	-1.35	.183	-.17
Gender	1.63	1.45	1.12	.266	.14
Deprivation: Carstairs index	-.16	.40	-.40	.691	-.05
Stroke severity [2]	.00	.25	.39	.698	.05
Disability: Barthel index	1.08	1.76	.61	.544	.08
Disability: Nottingham index	-.76	1.87	-.41	.685	-.05
Social support	.00	.03	-.90	.371	-.12
Life events	.80	1.27	.63	.530	.08
Pre-stroke history of depression	3.41	1.59	2.15	.036*	.27
Belief variables:					
Causal controllability	-1.95	.70	-2.79	.007**	-.34
'Why me?'	-1.14	1.64	-.70	.490	-.09
Acceptance of disability	-.27	.16	-1.68	.099	-.21
Negative identity change	.00	.11	-.15	.880	-.02
Confidence in recovery	-.48	1.59	-.30	.763	-.04
Recurrence fear	.11	.16	-.67	.507	-.09

[1] Beta values quoted are the un-standardised coefficients
[2] Stroke severity data was missing for three participants, therefore this whole analysis is based on seventy-eight rather than eighty-one participants

Once all baseline background variables and baseline belief variables that were statistically significant univariate correlates were added to the regression of baseline distress onto follow-up distress, a model of **R^2 = .53, p<.0001,** was produced.

Results for individual variables involved in the preliminary 'stricter' hierarchical analyses are illustrated in Table 14.11. As can be seen, a pre-stroke history of depression and causal controllability were the only statistically significant variables other than baseline distress.

The backward regression procedure eliminated the following variables in this order:

- Negative identity change
- Confidence in recovery
- Recurrence fear
- 'Why me?'
- Acceptance of disability

The hierarchical 'stricter' method produced a highly statistically significant model, **$R^2 = .53$, $p<.0001$.** Results for individual variables are illustrated in Table 14.12. In addition to baseline distress, both the background variable (pre-stroke history of depression) and the belief variable (causal controllability) that were statistically significant in the preliminary analyses were found to remain so.

Table 14.12: Final regression model for follow-up distress using baseline distress, all baseline background variables and those baseline belief variables that had produced statistically significant univariate correlations and which remained statistically significant after the backward regression procedure (N = 78 [2])

	B [1]	Std. error	t	Significance of t	Partial Correlation
Baseline distress	.43	.11	3.76	<.0001***	.42
Background variables:					
Age	.00	.06	-1.21	.231	-.15
Gender	1.24	1.36	.91	.365	.11
Deprivation: Carstairs index	-.18	.38	-.47	.637	-.06
Stroke severity [2]	.20	.21	.96	.341	.12
Disability: Barthel index	.80	1.68	.48	.635	.06
Disability: Nottingham index	-1.28	1.81	-.71	.481	-.09
Social support	.00	.03	-1.07	.288	-.13
Life events	.48	1.18	.41	.682	.05
Pre-stroke history of depression	3.06	1.52	2.01	.049*	.24
Belief variables:					
Causal controllability	-1.88	.68	-.2.77	.007***	-.32

[1] Beta values quoted are the un-standardised coefficients
[2] Stroke severity data was missing for three participants, therefore this whole analysis is based on seventy-eight rather than eighty-one participants

Comment on the 'stricter' regression results for prediction of follow-up distress using baseline variables and baseline distress will be made in section 14.6ii

14.6: Comment on the regression analyses for follow-up distress using baseline variables

14.6i: Comment on the multiple regression analyses for follow-up distress using baseline belief and background variables in relation to the hypotheses

Both the 'univariate' and the 'stricter' methods produced statistically significant models for follow-up distress using baseline belief and background variables. However, they were smaller in size than cross-sectional models for distress (please see chapter 11 and chapter 13). The 'univariate' final model of $R^2 = .43$, suggests that less than a fifth of variance in follow-up distress was accounted for, while the 'stricter' model of $R^2 = .51$, suggests that just over a quarter was accounted for. Regardless of how baseline background variables were controlled for, just three variables (pre-stroke history of depression, causal controllability, acceptance of disability) were found to enter these regression models at the level of statistical significance

These results do provide some support for the main hypothesis that participants' baseline beliefs would predict follow-up distress. However, when each specific hypothesis is considered in turn, the results are patchy:

Specific hypothesis 1: Negative attributions

Once baseline variables were considered in combination, just one of three attributional variables, causal controllability- was able to offer independent prediction of follow-up distress levels. Therefore, this hypothesis was only partially and weakly supported.

Specific hypothesis 2: Negative self-evaluations

This hypothesis was also partially and weakly supported as one of three baseline self-evaluative variables (acceptance of disability) was seen to statistically significantly contribute to follow-up distress in the regression. Interestingly this variable was collinear with three background variables (stroke severity, Barthel index and Nottingham index scores) and appeared to tap elements of all baseline belief variables other than causal controllability, particularly negative identity

change (please see Chapter 11, section 11.4i for relevant discussion, Appendix G, section G.1, Table G.1 for inter-correlations).

Specific hypothesis 3: Negative beliefs in recovery and recurrence
This hypothesis failed to be supported. Baseline recovery locus of control was not univariately statistically significantly associated with follow-up distress. Baseline levels of confidence in recovery and recurrence fear were, however, neither variable was found significant in the regression analyses.

Overall, as only baseline causal controllability and acceptance of disability out of the nine belief variables were in the final models, overall support for the second main hypothesis seems fairly weak. However, the collinearity of acceptance of disability with all other baseline belief variables except causal controllability (please see Appendix G, section G.1, Table G.1) is worthy of consideration. Statistically, this collinearity could have led acceptance of disability to 'overwhelm' these other variables in the regression analyses. Conceptually, to the extent that other belief variables, particularly negative identity change, were associated with acceptance of disability, its position in the final model suggests that they may be involved, as it were by proxy. The hypothesis that a range of baseline beliefs would predict follow-up distress is more widely supported by this interpretation of the results. It is interesting that the reverse pattern of results was found in the cross-sectional analyses at baseline (please see Chapter 11, section 11.5).

There is good indication that the belief one has little control over perceived causes of stroke and a sense that one is unable to accept the limitations imposed by the effects of stroke reported at one month predicted distress at nine months following stroke.

However, these analyses did not include baseline distress levels. Hierarchical regression was used to investigate whether belief variables were able to offer any predictive power additional to baseline distress by repeating these results with the latter included.

14.6ii: Comment on the hierarchical regression analyses for follow-up distress using baseline variables in relation to the hypotheses

Baseline distress regressed onto follow-up distress levels to produce a highly significant but modestly sized model, R^2 =.41, p<.0001. When other baseline variables were taken into consideration, small gains in the prediction of follow-up distress were made. An increment of just R^2 =.08 was achieved with the 'univariate' method to give a final model of R^2=.49, p<.0001. An increment of just R^2=.12, <.0001 was achieved with the 'stricter' method to give a final model of R^2=.53, p<.0001. Causal controllability was the only baseline belief variable in these final models.

Overall, support for this more stringent test of the hypothesis that:

2) Beliefs found at baseline would predict emotional distress at follow-up

after having controlled for baseline distress was tenuous. It could be argued that the hypothesis was supported by the small but consistent and significant independent relationship seen between causal controllability and follow-up distress. However, it is recognised that one out of nine variables under consideration represents a fairly tenuous argument, and may constitute a Type I error.

In terms of the specific hypotheses, these results weakly support specific hypothesis 1 (one out of three variables) but with no statistically significant relevant results specific hypotheses 2 and 3 were clearly not supported (please see section 14.1 for the outline of the specific hypotheses).

14.6iii: Overall comment on the regression analyses for follow-up distress using baseline variables

Compared to the robust cross-sectional models of association between belief variables and distress described in Chapters 11 and 13, these results appear weak. Baseline belief variables demonstrated only limited success at predicting follow-up distress, nevertheless causal controllability and acceptance of disability were found to be predictive. However, once baseline distress levels were taken into account, only one baseline belief variable (casual controllability) was seen to independently predict follow-up distress.

Table 14.13: Summary of final regression models for follow-up distress using baseline variables

	Univariate method	Stricter method
Baseline belief and background variables used as predictors	R^2 =.43 [a]	R^2 =.51 [b]
Baseline distress, baseline belief and background variables used as predictors	R^2 =.49 [c]	R^2 =.53 [d]

[a] Please see section 14.4ii for individual variables included in this model and their relevant results
[b] Please see section 14.4iii for individual variables included in this model and their relevant results
[c] Please see section 14.5i for individual variables included in this model and their relevant results
[d] Please see section 14.5ii for individual variables included in this model and their relevant results

However, on a more positive note, the final hierarchical models that included baseline distress were not much stronger than those that did not (please see Table 14.13). This is consistent with the finding that baseline belief variables and baseline distress levels were highly associated (please see Chapter 11, section 11.3). This issue will be returned to in the discussion.

Chapter 15

Description of emotional disorders and exploration of beliefs from the structured clinical interview

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15.1: Forward

The main purposes of this structured clinical interview study were (1) to make DSM diagnoses (2) to meet objective 5 to:

Explore the types of beliefs and nature of symptoms related to common depression and anxiety disorders

DSMIV criteria for the chosen disorders were used (APA, 1994). These criteria were not originally designed to describe the nature of stroke patients' emotional problems, for example, general medical patients are actually excluded from diagnostic criteria for social phobia. However, they were considered to be a good starting point. The process of exploring beliefs accessed by the structured interview for a specific disorder, effectively went hand in hand with appraising the 'fit' between pre-determined criteria and stroke related issues. For heuristic purposes the language of diagnosis will be used. The reader is trusted to understand that this does not imply that the suitability of diagnostic groupings is unquestioningly promoted.

An opportunity was taken to develop two subsidiary hypotheses comparing levels of shame and fears of falling amongst those with specific disorders:

Higher shame scores would be found amongst those with social phobia and agoraphobia

Higher fears of falling would be found amongst those with agoraphobia

15.2: Diagnosis of depression and anxiety disorders at baseline

Forty participants (45%) were diagnosed with an emotional disorder, and the number and percentage of participants with each specific disorder is illustrated in Table 15.1. There was a large degree of co-morbidity between depression and anxiety diagnoses: nine (10%) with just depression, eleven (12%) with just an anxiety disorder and twenty (23%) with both depression and an anxiety disorder.

Table 15.1: Number and percentage of diagnosed emotional disorders amongst participants at baseline [1]

Emotional disorders (SCID)	Number and percent of participants (N = 89)
Depression	
Major depression	14 (16%)
Minor depression	15 (17%)
Total of participants with depression	29 (33%)
Anxiety disorders	
Generalised Anxiety Disorder	12 (14%)
Agoraphobia (with or without panic attacks)	19 (21%)
Agoraphobia with panic attacks	3 (3%)
Social Phobia	10 (11%)
Post Traumatic Stress Disorder	3 (3%)
Total of participants with an anxiety disorder	31 (35%)

1: Participants were awarded diagnoses for all disorders in which criteria was met regardless of the presence of other disorders

15.3: Depression at baseline

A third (29/89; 33%) of participants were found to be depressed, with approximately equal proportions of major depression (14/89; 16%) and minor depression (15/89; 17%). Female participants were approximately twice as likely to be diagnosed as depressed than male participants (17/36 females; 47%: 12/53 males; 23%). As shown in Table 15.2, females were approximately twice as likely to be diagnosed with both major and minor depression, and this difference was statistically significant, $\chi^2 = 8.58$, $p = .044$.

Over half (13/23; 56%) of participants with a pre-stroke history of depression, but only about a quarter (16/66; 24%)) of those without were diagnosed with depression at baseline. As can be seen in Table 15.2, minor depression was actually diagnosed in equal proportions amongst those with and without a pre-stroke history. However, major depression was determined far more frequently amongst participants who reported a pre-stroke history of depression than those who did not (9/23; 39% c.f. 4/66; 6%). The association between pre-stroke and present depression was statistically significant, $\chi^2 = 13.44$, $p < .001$.

As can be seen in Table 15.2, participants who reported a higher level of disability were approximately twice as likely to be diagnosed with either major or minor depression, and this association was statistically significant $\chi^2 = 8.58$, $p = .003$ (please see Appendix F, section F.4 regarding the categorisation of disability). When participants were categorised by retirement age, essentially similar rates of major and minor depression were found amongst 'older' and 'younger' groups ($\chi^2 = .73$, $p = .694$).

Table 15.2: Depression diagnosis grouping in relation to gender, pre-stroke history of depression, disability, and age group at baseline

	Females (N = 36)	Males (N = 53)	Pre-stroke history of depression (N = 23)	No pre-stroke depression (N = 66)	'Higher' levels of disability [1] (N = 33)	'Lower' levels of disability [1] (N = 56)	'Younger' participants [2] (N = 22)	'Older' participants [2] (N = 67)
Major depression (N = 14)	9 (23%)	5 (9%)	9 (39%)	4 (7%)	8 (24%)	6 (11%)	3 (14%)	11 (16%)
Minor depression (N = 15)	8 (22%)	7 (13%)	4 (17%)	11 (17%)	9 (27%)	6 (11%)	3 (14%)	12 (18%)
Not depressed (N = 69)	19 (53%)	41 (77%)	10 (44%)	50 (76%)	16 (48%)	44 (78%)	16 (73%)	44 (66%)

[1] Participants were categorised as having 'Higher' levels of disability if Nottingham ADL scores were <10 (please see Appendix F, section F.4 for explanation)
[2] Participants were categorised as 'Younger' if they were < 65yrs and as 'Older' if they were ≥ 65yrs

The prevalence of the different depressive symptoms is illustrated in Table 15.3. As can be seen those diagnosed with depression were more likely to report depressed mood (83%) than diminished pleasure (35%). Five participants with depression (17%) reported both these key symptoms. Often participants attributed their generally low mood to not being able to do 'what they wanted' most of the time, but still reported being able to enjoy pleasant events. Neither depressed mood nor loss of pleasure was reported by anyone who was not depressed.

Although whether or not a patient experienced low mood could be established in this interview, it was harder to decide whether it was experienced enough of the time to meet criteria for this symptom. I interpreted the instruction to establish 'most of the day, nearly every day' (APA, 1994) to mean over half the time, someone else may have interpreted this instruction differently.

I was taken by how often and readily depressed participants reported a sense of worthlessness while I was conducting the interviews. Typically, when asked how they had been feeling about themselves lately, the depressed participants would describe themselves as feeling 'useless'. Some made quite strong comments to describe this feeling, for example 'I feel a waste of space'. Others revealed anger or shame in their negative self-descriptions, for example:

'I'm frustrated that I can't walk, I feel stupid'.

As shown in Table 15.3, a sense of worthlessness was reported by two thirds of depressed participants but by only five percent of participants who were not depressed. This supports the idea that this symptom was characteristic of depression following stroke as it was both common amongst, and particular to, depressed participants.

However, again for me the criterion for this symptom was not entirely definitive. Worthlessness is described as being 'not merely self-reproach or guilt about being sick' (APA, 1994). A different interviewer may not choose to interpret physically disabled patients' descriptions of themselves as 'useless' as indicating personal worthlessness.

Table 15.3: Depressive symptoms amongst all participants and those diagnosed with and without depression at baseline [1]

	Participants with depression (N = 29)	Participants without depression (N = 60)	All Participants (N = 89)	χ^2 and significance level [2]
Depressed mood [3]	24 (83%)	0	24 (27%)	99.27***
Diminished pleasure [3]	10 (35%)	0	10 (11%)	23.31***
Sense of worthlessness	19 (66%)	3 (5%)	22 (25%)	40.31***
Pre-occupation with death/suicide	9 (31%)	1 (2%)	10 (11%)	16.91***
Insomnia/hypersomnia	19 (66%)	16 (27%)	35 (39%)	12.37**
Psychomotor agitation/retardation reported	17 (57%)	7 (12%)	24 (27%)	25.86***
Psychomotor agitation observed	5 (17%)	0	5 (6%)	10.96**
Fatigue	20 (68%)	36 (60%)	56 (63%)	.63
Unusual weight or appetite change	9 (31%)	11 (18%)	21 (24%)	1.39
Diminished concentration	15 (52%)	6 (10%)	21 (24%)	17.40***

1: With the SCID an 'uncertain' score can be made if it is difficult to determine the presence versus absence of a symptom. However, only certain scores were used for the construction of this table.
2: Chi square tests were computed between participants with and without depression: * indicates $p<.05$, ** indicates $p<.01$, *** indicates $p<.001$

Only one depressed participant reported having considered suicide to the extent of forming a plan. The other eight reported often wishing they could die or had died. Of these, a couple reported feeling 'too cowardly' to contemplate suicide, but the others had not even contemplated suicide. An eighty-two year old female participant who was not at all depressed or anxious but had been disabled for fifteen years from previous strokes described often wishing for death. She was quite matter of fact but argued that after having had a 'wonderful life and marriage' that she would be 'happy to go'.

Nearly all the depressive symptoms were found to be statistically discriminatory when tested with Chi-square with the exceptions of fatigue and weight/appetite change. This may suggest that these are less good indicators of depression

following stroke. Loss of appetite post-stroke can be due to swallowing difficulties, however this was not reported by any of these participants probably because of the screening procedure (please see Chapter 5, section 5.6). Hospital food appeared to be to blame for one male participant with major depression who strongly missed his wife's cooking.

The overall prevalence of 'fatigue' is notable. The comments participants made to describe their fatigue did generally portray a pervasive sense of tiredness or lack of energy. However, some people described a situation in which they tended to feel energetic initially but then tire much more easily than normal. In addition to reporting pervasive tiredness a couple of participants actually described something more like 'initiation' than of fatigue. They described finding it 'hard to get things started' yet that they could keep going as well as before once they did. For example, one man described feeling he needed someone to 'prod him'. Therefore questioning about fatigue may have actually been tapping into various other post-stroke problems.

15.4: Anxiety Disorders at baseline

15.4i: Overview of anxiety disorders at baseline

Of the thirty-one (35%) participants found to have an anxiety disorder, almost a third of them (10/31; 32%) met criteria for more than one type of anxiety disorder. A significantly larger proportion of female participants were diagnosed with an anxiety disorder (18/36 females; 47%) than male participants (13/53 males; 23%) and this difference was found to be statistically significant ($\chi^2 = 6.13$, p =.013). Similarly, approximately twice as many participants with a pre-stroke history of depression (13/23; 56%) were determined to have an anxiety disorder than those without (18/66; 27%) and this difference was statistically significant, $\chi^2 = 6.43$, p = 011. Diagnosis of an anxiety disorder was more frequent amongst participants with 'higher' as opposed to 'lower' levels of disability (15/33; 46% c.f. 16/56; 27%) but this was not statistically significant, $\chi^2 = 2.61$, p =.110. Likewise, 'older' participants were determined as having an anxiety disorder more often than 'younger' participants (11/41; 27% c.f. 20/48; 42%) but this was not statistically significant, $\chi^2 = 2.15$, p =.143.

15.4ii: Generalised Anxiety Disorder (GAD) at baseline

Twelve participants (13%) were diagnosed with GAD. A striking level of co-morbidity between GAD and depression was observed. Only one participant determined as having GAD was not also diagnosed with depression. Participants with GAD were also more likely to have major depression (7/14; 50%) than minor depression (4/15; 27%).

As would be expected with uncontrollable worry, topics of concern were wide-ranging. Family problems were mentioned most frequently (9/12; 75%). Participants with GAD often mentioned their children's problems such as divorce, being a single parent or alcoholism. Concerns about spouses' health, or about the effects of their strokes on their partners were also frequently mentioned. For example, one man worried about how he'd be able to cope if his diabetic wife had a 'hypo', also about whether she'd be able to cope if he had another stroke and died. Half the participants with GAD (6/12; 50%) reported worrying about personal restrictions or fears related to stroke. For example, three participants mentioned fears of falling and four participants reported being extremely worried about a recurrent stroke. Other issues ranged from more general health issues (3/12; 25%) to household or gardening chores (5/12; 42%) to the political situation (2/12; 17%).

On average, participants with GAD reported just over four of the six anxiety symptoms, and two participants reported experiencing all six.

15.4iii: Agoraphobia at baseline

This was the most commonly found disorder, and approximately one in five of all participants were given the diagnosis (19/89; 21%). No one met criteria for panic disorder without agoraphobia. Only three participants were found to meet criteria for agoraphobia with panic disorder (one of these also reported claustrophobia and had panicked before her scan). The other sixteen participants were found to be agoraphobic without panic disorder, therefore they were cognitively (fear) and behaviourally (avoidant) agoraphobic but did not experience the physiological symptoms.

A proportion of participants (18/89; 20%) were unclassifiable for agoraphobia because they were physically not able to go out. Of these, eight participants were still in hospital and not able or allowed to walk unaccompanied. Two participants were almost completely wheelchair-bound in their own homes. Six participants in lived in flats and were effectively house-bound as physiotherapists had advised them against using stairs unaccompanied. A further two male participants reported that they were forbidden to go out by their wives. When these participants were excluded, the rate of agoraphobia amongst those feasibly able to go out was actually over one in four (19/73; 26%).

Giving a diagnosis of agoraphobia implies the behaviour is problematic. However, as can be seen from Table 15.4, the avoidance behaviour of just over a third of those diagnosed as agoraphobic could be described as successful adaptation because they reported being quite content to stay in. A few reported having adapted to a house bound life by bringing their social life to them. Others reported having no desire to face the crowded or dangerous outside environment. For example an eighty-year old woman who lived with her daughter and granddaughters was diagnosed with agoraphobia and panic disorder and reported an onset of symptoms a few years prior to her stroke. However, she reported no longer missing trips into town because:

'Life is sweet in here'

Table 15.4: Agoraphobic fear and avoidance, and reported distress about staying in at baseline

	Participants diagnosed with Agoraphobia (N = 19)	Participants considered unclassifiable for agoraphobia [1] (N = 18)	Other participants (N = 52)	Total sample (N = 89)
Agoraphobic fear reported [2]	19 (100%)	5 (27%)	5 (10%)	29 (33%)
Did not go out [2]	19 (100%)	18 (100%)	N/A	37 (42%)
Staying in reported as a problem [3]	12 (63%)	10 (55%)	N/A	22 (25%)

[1] 16 participants were considered physically unable to go out and 2 male participants were forbidden to attempt going out by their wives and so were unclassifiable for agoraphobia
2 These are the DSMIV criteria for agoraphobia without panic disorder
3: This is not specified as a criterion for agoraphobia in DSMIV but I began recording it when I found my first 'agoraphobic' participant reported being content to stay in

Interestingly, a similar proportion of participants who were physically unable to go out reported being content with this situation. For example a seventy-five year old female participant reported:

'I'm quite happy sitting here letting life go by without making a noise in it any more'

However, approximately two-thirds of participants with agoraphobia did regard staying in as problematic, and for them the diagnosis of a psychiatric disorder seems more reasonable. Additionally, a further ten participants reported agoraphobic fear but were not diagnosed with agoraphobia because they were not yet avoidant or were considerable unclassifiable due to physical inability. However, these participants could still be seen as at risk of agoraphobia.

The content of participants' agoraphobia-related fears are illustrated in Table 15.5. Fears of falling and its' consequences were reported most frequently. A few mentioned the fear of being left in the street if they did fall, and others reported a fear of being run over, for example an eighty-five year old female reported:

'If I trip I could get killed by a car'

Some reported social fear consisting of embarrassing thoughts of how others may see them. For example a ninety-year old female participant was embarrassed about using her walking aid to go and sit in the park outside her house as people may think:

'Silly old besom, that silly old besom should stay indoors'

Quite commonly, a combination of shame and fears of falling and stroke were mentioned, for example, an eighty-six year old female reported having a stroke, falling and exposing herself in an undignified way, because this had happened when she had a TIA in church (which she now avoids).

In addition a couple of male participants feared being attacked. A sixty-one year old male had developed a specific fear and avoidance of walking alone at night because he felt he would no longer be able to defend himself. A forty-two year old male reported having agoraphobia with panic prior to his stroke due to a mugging; however he was not classified as agoraphobic because he was not physically able to go out.

Table 15.5: Types of agoraphobic fears reported by participants at baseline

	Participants with agoraphobia (N = 19)	**Participants without agoraphobia (N = 70)**
Falling or being run over [1]	13 (68%)	9 (13%)
Shame due to appearance [1]	6 (32%)	1 (1%)
Shame related to possibility of falling or stroke in public [1]	5 (26%)	3 (4%)

1: The percentages do not add up as some were scored for more than one category and some did not report any fear

15.4iv: Social phobia at baseline

Ten participants (11%) were classified as having social phobia. However, three participants' social phobia was not stroke-related. A sixty-six year old male reported feeling a 'loss of social status' following the removal of his top set of teeth, the fear others would consider him 'unintelligent' due to his lisp and avoidance of social engagements. An eighty-two year female reported messy eating due to her recent loss of sight from macular degeneration and embarrassment that others may think 'What's wrong with her?' and avoidance of lunching out. A male participant reported a lifelong lack of confidence with strangers ('I always knew they'd think I was stupid'). He felt his shyness had been disadvantageous to his career in his youth, but he reported being content with life now.

Of the seven participants whose social phobia was stroke-related, three were embarrassed about appearing disabled or old, two were embarrassed about emotionalism, one was embarrassed about his handwriting and one about the possibility of having a stroke in public. For example, a sixty-year old male participant had been avoiding going to restaurants or bingo because of his tendency to limp and his slow hand:

'I'm not wanting people to take pity…They're pitying you and they're no real meaning it'

A forty-eight year old male had developed the habit of leaving the room whenever anything sad came on TV to avoid the possibility of being seen crying, and had avoided going out socially since his stroke. A forty-seven year old female participant who was considered agoraphobic due to her fear of falls and of being seen having a stroke in public, was also classed as socially phobic because her fear of the latter was so extreme. Her friends had even tried to persuade her to go out by coming to collect her in the car, but she refused even to go to their homes.

Eight other participants described social fears but were not classed as being socially phobic, because these fears did not interfere with their normal lives or cause distress. This was often because the embarrassment participants reported was not related to something they considered highly important, or because it was not sufficient to

cause avoidance. For example, a female participant with 'atrocious' handwriting only needed to write cheques very occasionally, another feared public speaking, but no longer needed to in life, and a male participant who complained of slurred speech was not sufficiently put off from socialising.

The diagnoses of participants with social phobia tended to rest on the description of socially fearful beliefs (criteria A) and subsequent reports of related interference or distress (criteria E). As can be seen from Table 15.6, not all participants considered to have something meriting 'social phobia' met criteria B, C or D. Four participants given the diagnosis of social phobia had not tried out their feared situations, and so could not report whether anxious symptoms were experienced (criteria B).

About half of participants with social fears 'failed' to recognise that their fears were excessive or unreasonable (criteria C). For example, when asked whether she considered herself 'more afraid' of her experience of emotionalism than she 'should be, or that makes sense' an eighty-five year old female participant, told me:

'Well it doesn't make sense, it makes me feel very sorry for myself and ashamed of myself'

I felt that that the belief that participants considered their social 'fears' as truly shameful or embarrassing did not make them any less serious than if they did recognise them as excessive or unreasonable. Also, avoidance (criteria D) was not possible for a few participants, whose 'fears' were based on issues they had no physical control over. For example, the above participant was not able to avoid her emotional liability despite her best efforts.

Table 15.6: Social phobic criteria [1] in relation to numbers and percent of participants with social phobia and those with social fear but not 'phobia' at baseline

	Participants with social phobia (N = 10)	Participants with social fear but not judged 'phobic' (N = 8)	All Participants (N = 89)
A) 'Socially phobic' type fear	10 (100%)	8 (100%)	18 (20%)
B) Experiences unpleasant sensation when faces situation	6 (60%)	5 (63%)	11 (12%)
C) Recognises fear is excessive/ unreasonable	5 (50%)	0	5 (6%)
D) Avoidance	7 (70%)	0	7 (8%)
E) Significant interference or distress	9 (90%)	0	9 (10%)

1: Only DSM IV criteria A - E for social phobia are listed. Criterion F (Duration > 6 months) and criterion H (Fear is unrelated to a general medical disorder) were discounted in this study. Criterion G (Fear not due direct physiological effects of substance, or better accounted for by another mental disorder) applied to all participants.

I felt this data highlighted the interaction between social reality and participants' own belief systems, and that participants' social fears were possibly more realistic than DSM IV implies those of typical social phobics to be. For example, a male participant expected to be pitied and that people might think:

'Old geezer who's past his time'

but, he did walk with a bad gait and reported that other members in his golf club had already begun to show pity, for example by offering their seats, following a previous recent stroke, so he was probably not unrealistic. In relation to social phobia, DSM IV notes do actually state that '...the diagnosis should not be given if the fear is reasonable given the context of the stimuli...' (APA, 1994). When participants' social fears were based on real visible disabilities they could be seen as relatively reasonable.

In light of these issues and the failure to find this group of participants fully meeting the DSM IV criteria I had reservations about describing them as 'socially phobic'. Nevertheless, despite my reservation about implying 'excessive and irrational' with this diagnostic label I felt that highlighting 'having a problem with social shame/fear' could be usefully applied. In addition to reasonable estimations of potentially negative reactions from others, embarrassment seemed to be driven by harsh self-judgement and by actually caring about others' negative reactions. These more personal beliefs could be amenable to change, and this seemed to justify highlighting these participants' 'problem'. This issue and discussion of the different terms 'fear' and 'shame' will be returned to in the discussion.

15.4v: Post traumatic stress disorder (PTSD) at baseline

Three participants (3/89; 3%) were classified as having PTSD as they reported re-experiencing type symptoms and evidence of a general sense of alienation and over-arousal.

As well as reporting symptoms of hyper-vigilance and general over-arousal, and an ambivalent interest in his friends and family, a forty-two year old man reported a particularly striking fantasy. He imagines seeing a giant jigsaw puzzle that he eventually solves and it reads **'WHY ME?'**. A seventy-one year old was one of only two participants who reported nightmares. These remind her of her stroke and cause her to awaken covered in sweat. She also takes 'wee funnies' or headaches accompanied by difficultly catching breath and sweating that mimic the symptoms she experienced when she had her stroke. These occur when she is unable to 'shove off' the idea she may take another. Another seventy-three year old described becoming particularly afraid of another stroke at night and sometimes her throat begins to tighten painfully as it did before. She also reported feeling permanently on guard because:

'I try not to be but I'm always waiting for another!'

However, the diagnosis of PTSD was made with some reservation because their 'traumatic' thoughts and symptoms were not often focused on the event of their stroke per se. This young man's PTSD-like distress and beliefs were often focused

on his present disabilities, while the others experienced PTSD-like symptoms related to the possibility they may have another stroke.

Some quite intriguing symptoms were observed amongst other participants in the PTSD interview, although they did not meet criteria for the disorder. 're-living' experiences related to bodily symptoms, or the place stroke occurred were reported most commonly. For example, one man, who had had his stroke in the shower, reported experiencing the same 'numbish' feeling whenever he takes a shower. Other interesting examples are described later (please see Chapter 16, section 16.2ii). Other participants reported avoidance behaviour similar to superstitions. For example, one woman no longer uses the kitchen shelf she had used just prior to her stroke and another avoids walking down the same bit of street. Interestingly, participants often seemed very aware that these measures to avoid tempting fate were quite 'silly' but nevertheless persisted.

Overall, it was interesting to find that reliving experiences and stroke-related avoidances were quite common amongst stroke patients, some of whom were not otherwise depressed or anxious. The PTSD syndrome and the idea of being 'traumatised' resonated well with the experience of a few participants. These participants did all have major depression and GAD diagnoses already. However, the PTSD interview brought out further distressing symptoms and beliefs relating to stroke, its effects, and the possibility of further strokes.

15.5: Diagnosis of depression and anxiety disorders at follow-up

A similarly high proportion of participants (36/81; 44%) were diagnosed with an emotional disorder at this point in time (please see Table 15.7) as were at baseline (please see Table 15.1).

Table 15.7: Number and percentage of diagnosed emotional disorders amongst participants at follow-up

Emotional disorders (SCID)	**Number and percent of participants (N = 81)**
Depression	
Major depression	12 (15%)
Minor depression	12 (15%)
Total of participants with depression	24 (30%)
Anxiety disorders	
Generalised Anxiety Disorder	15 (19%)
Agoraphobia (with or without panic attacks)	20 (21%)
Agoraphobia with panic attacks	4 (5%)
Social Phobia	7 (9%)
Post Traumatic Stress Disorder	2 (3%)
Total of participants with an anxiety disorder	27 (33%)

1: Participants were awarded diagnoses for all disorders in which criteria was met regardless of the presence of other disorders

15.6: Depression at follow-up compared to baseline

Just under a third of participants (24/81; 30%) were found to be depressed with equal proportions of minor and major depression. Diagnoses of major depression appeared particularly persistent across time (please see Table 15.8). Only one participant with major depression at baseline had recovered by follow-up, and she had been treated with anti-depressants. Meanwhile, a further four participants are shown to have gone from major to minor depression, who would be more accurately described as having 'major depression partially resolved' (please see Table 15.8). Participants with minor depression appeared to have fared much better across time. Less than half of them were found to still have minor depression, and none had developed major depression. Meanwhile, a further five participants had developed depression over time. When diagnoses of either major or minor depression at follow-up and baseline were compared using McNemar test, the statistically insignificant result obtained ($p = .414$) is indicative of consistency across time.

Table 15.8: Depression diagnoses from baseline to follow-up (N = 81)

		Follow-up		
		Major depression (N = 12)	Minor depression (N = 12)	Not depressed (N = 57)
Baseline	Major depression (N = 14)	9 (75%)	4 (33%)	1 (2%)
	Minor depression[1] (N = 15)	0	6 (50%)	8 (14%)
	Not depressed[2] (N = 60)	3 (25%)	2 (17%)	48 (84%)

[1] One participant with minor depression at baseline died before follow-up
[2] Seven non-depressed participants at baseline could not be followed up

The reasons for development of major depression for two young participants (a thirty-two year old female and fifty-two year old male) really stood out. The male participant's gardening business had collapsed following his stroke, he had had to go to a tribunal for benefits and was unable to afford the cost of retraining in his former profession as a graphic designer. He was also experiencing a collapse in his marriage. Similarly, this young female participant had various credit debts, a new

mortgage and had previously had two jobs. Now she was financially trapped: she could only afford to work if she could manage full time but was not able to take this on yet. She had been unable to keep up with her friends and was increasingly isolated. The emotional reaction of these participants appeared much more affected by contextual factors than the reactions of older participants, whose relationships and finances perhaps tended to more stable, or less heavily dependent on physical ability.

'Younger' participants were more likely to have major depression, and 'older' participants to have minor depression, please see Table 15.9. However, an age group by depression diagnoses association was not statistically significant, $\chi^2 = 3.59$, $p = .166$. Females tended to be diagnosed with depression more than males, however this difference was also not statistically significant, $\chi^2 = 2.25$, $p = .324$. Similarly, those with 'higher' levels of disability were more likely to be depressed than those with 'lower' levels, but this was not statistically significant, $\chi^2 = 1.37$, $p = .504$. As at baseline, major depression was found far more frequently amongst participants who reported a pre-stroke history of depression than those who did not (9/21; 43% c.f. 3/60; 7%). Overall the association between a history of depression prior to stroke and present diagnosis of depression was highly statistically significant, $\chi^2 = 13.44$, $p < .0001$.

Table 15.9: Depression diagnosis grouping in relation to gender, pre-stroke history of depression, disability, and age group at follow-up

	Females (N = 34)	Males (N = 47)	Pre-stroke history of depression (N = 21)	No pre-stroke depression (N = 60)	'Higher' levels of disability [1] (N = 20)	'Lower' levels of disability [1] (N = 61)	'Younger' participants [2] (N = 20)	'Older' participants [2] (N = 61)
Major depression (N = 12)	7 (21%)	5 (11%)	9 (43%)	3 (5%)	4 (20%)	8 (13%)	5 (25%)	7 (11%)
Minor depression (N = 12)	6 (18%)	6 (13%)	3 (14%)	9 (15%)	4 (20%)	8 (13%)	1 (5%)	11 (18%)
Not depressed (N = 57)	21 (61%)	36 (77%)	9 (43%)	48 (80%)	12 (60%)	45 (74%)	14 (70%)	43 (71%)

[1] Participants were categorised as having 'Higher' levels of disability if Nottingham ADL scores were <10 (please see Appendix F, section F.4 for explanation)
[2] Participants were categorised as 'Younger' if they were < 65yrs and as 'Older' if they were ≥ 65yrs

Frequencies of depressive symptoms between those diagnosed with depression and those without depression are displayed in Table 15.10. As can be seen, an essentially similar symptom pattern was observed at this nine-month stage to that found at one month (please see Table 15.3). Therefore the observations made earlier are applicable now. As before, these results suggest that depression following stroke is most strongly associated with 'depressed mood' rather than 'diminished pleasure' at nine months.

Table 15.10: Depressive symptoms amongst all participants and those diagnosed with and without depression at follow-up[1]

	Participants with depression (N = 29)	Participants without depression (N = 60)	All Participants (N = 89)	χ^2 and significance level [2]
Depressed mood [3]	22 (92%)	0	22 (27%)	71.73***
Diminished pleasure [3]	4 (17%)	0	4 (5%)	9.99**
Sense of worthlessness	14 (58%)	6 (11%)	20 (25%)	20.76***
Pre-occupation with death/suicide	7 (29%)	1 (2%)	8 (10%)	14.26***
Insomnia/hypersomnia	16 (67%)	7 (12%)	23 (28%)	24.57***
Psychomotor agitation/retardation reported	11 (46%)	7 (12%)	18 (22%)	11.00***
Psychomotor agitation observed	2 (8%)	0	2 (3%)	4.87*
Fatigue	22 (92%)	22 (39%)	44 (54%)	19.17***
Unusual weight or appetite change	7 (29%)	4 (7%)	11 (14%)	7.06**
Diminished concentration	13 (54%)	4 (7%)	17 (21%)	22.64***

1: With the SCID an 'uncertain' score can be made if it is difficult to determine the presence versus absence of a symptom. However, only 'certain' scores were used for the construction of this table.
2: Chi tests were computed between participants with and without depression.

* indicates p<.05, ** indicates p<.01, *** indicates p<.001.

Feelings of worthlessness, typically expressed as feelings of 'uselessness' were expressed commonly by depressed patients at nine months, but were found to be slightly less exclusive than at one month (please see Table 15.3, and Table 15.10).

No one reported suicidal intent at follow-up; however, some participants did still report sometimes wishing they had died/were dead, including the same non-depressed female participant as before. Other symptoms were reported in similar ways and with similar frequencies. The high prevalence of fatigue was still notable across all participants (44/81; 54%). However, a slight decrease in the prevalence of depressive symptoms of fatigue and appetite loss was noted. This may be partly due to lessened potential confounding from the hospital environment or of stroke. These two depressive symptoms were now able to discriminate between depressed and non-depressed participants to a statistically significant level (please see Table 15.10).

15.7: Anxiety disorders at follow-up

15.7i: Overview of anxiety disorders at follow-up

A large proportion of participants were found to have an anxiety disorder (36/81; 44%). The majority (27/36; 75%) had been diagnosed with an anxiety disorder at baseline, and this overlap was supported by a McNemar test showing no statistical difference (p = .791

Approximately half of female participants (18/34; 53%) were found to have an anxiety disorder, whereas only about a fifth of male participants (9/47; 19%) were, and this difference was statistically significant, $\chi^2 = 10.14$ p<.001. Twice as many participants with a history of depression pre-stroke (12/21; 57%) were diagnosed with an anxiety disorder than those without (15/60; 25%) and this was also statistically significant, $\chi^2 = 7.23$ p = 007. Anxiety disorders were more common amongst those with a higher level of disability (9/20; 45%) than those with lower levels (18/61; 30%) but this difference was not statistically significant, $\chi^2 = 1.63$, p = .203. Similarly, 'younger' participants (8/20; 40%) were somewhat more likely to have an anxiety disorder than 'older' participants (19/61; 31%) but not at a statistically significant level, $\chi^2 = .53$, p = .466.

15.7ii: Generalised Anxiety Disorder (GAD) at follow-up

Of all the disorders, there was a slight increase in the proportion of participants determined to have GAD at follow-up (15/81; 19%) as compared to baseline (12/89; 13%). Nine participants who were found to have GAD at baseline still did at follow-up, while a further six participants had developed the disorder. An insignificant McNemar result (p = .508) offered statistical support to an overlap between GAD diagnoses across time. Similarly to baseline, a high level of co-morbidity between GAD and depression was found. Almost three quarters of those with GAD (11/15; 73%) were also diagnosed with depression.

A similar range of topics was reported as worrying to participants with GAD as those found at baseline. Most were worried about a family matter (13/15; 87%) and their functional disabilities resulting from the stroke (11/15; 73%). Concerns about health problems were commonly reported (9/15; 60%), in particular fear of another

stroke (8/15; 53%). A few people were also worried about the upkeep of their garden or home, or about the political situation. In contrast to baseline, a few participants (4/15; 27%) reported being worried about finances. On average participants with GAD were found to have five of the six possible anxiety symptoms (Mean = 4.67, SD = 1.23).

15.7iii: Agoraphobia at follow-up

Similarly to baseline, approximately one in five of all participants were found to have agoraphobia (18/81; 22%). Just four participants with agoraphobia also reported adjunct panic attacks (this accounted for all the participants with panic attacks). Almost two-thirds of agoraphobic participants had been agoraphobic at baseline (11/18; 61%) six participants had improved and seven had developed this disorder. Consistency in this diagnosis across time was statistically supported by an insignificant McNemar test p = 1.00).

Table 15.11: Agoraphobic fear and avoidance, and reported distress about staying in at follow-up

	Participants diagnosed with Agoraphobia	Participants considered unclassifiable for agoraphobia [1]	Other participants [4]	Total sample
Agoraphobic fear reported [2]	18 (100%)	5 (42%)	6 (15%)	29 (36%)
Did not go out [2]	18 (100%)	12 (100%)	0	30 (37%)
Staying in reported as a problem [3]	9 (50%)	5 (42%)	0	14 (17%)

1: 11 participants were considered physically unable to go out and 1 male participant was forbidden to attempt going out by his wife and so were unclassifiable for agoraphobia
2: These are the DSM IV criteria for agoraphobia without panic disorder
3: This is not actually a specified criterion for agoraphobia in DSM IV
4: These participants could and did go out without marked distress but reported some loss of confidence

Twelve participants were considered unclassifiable for agoraphobia: eight were only able to walk with an aid and had been advised to stay housebound by a physiotherapist, three were wheelchair-bound and one man was still forbidden to go outside alone by his wife. Once this was taken into consideration, a rate of approximately one in four participants with agoraphobia (18/69; 26%) was found amongst those who were physically able to go out

However, only half diagnosed as agoraphobic and less than half of participants considered unclassifiable for agoraphobia actually reported staying in as being problematic (please see Table 15.11).

Fears of falling were as commonly reported amongst those with agoraphobia as they were at baseline. However, shame regarding others' perceptions was reported as the reason for avoiding going out alone twice as often now as it was previously (please see Table 15.5 and Table 15.11).

A few participants' fears classified as 'shame' seemed to stem from reported experience of stigma. A forty-two year old male participant said he had actually been taunted for walking as if he had 'shat himself' by teenage boys. A fifty-three year old man reported that old ladies often made derogatory remarks to imply he was 'a fake' regarding his use of a stick and the disabled bus seat. A sixty-eight year old man had been rehoused on the ground floor for accessibility. However, he reported believing there were 'plenty of idiots' around and feared being mugged. this was not based on personal experience, but he pointed out a police car opposite as he was describing his fear. He lives in a very deprived part of the city and so his fear seemed to be grounded in good reason.

On the more positive side, a couple of other participants described how they had been helped by family or friends to regain confidence by gradually building up distances travelled and tailing off companionship. Also, one participant reported that she was finding it very helpful to learn how to rise from a fall in physiotherapy, and that she was gaining the confidence to go out alone as a result.

Table 15.12: Types of agoraphobic fears reported by participants at follow-up

	Participants with agoraphobia (N = 18)	Participants without agoraphobia (N = 63)
Falling or being run over [1]	11 (61%)	8 (13%)
Shame due to appearance [1]	12 (67%)	1 (2%)
Shame related to possibility of falling or stroke in public [1]	5 (28%)	0

1: The percentages do not add up as some were scored for more than one category and some did not report any fear

15.7iv: Social phobia at follow-up

Just seven participants (7/81; 9%) were found to have social phobia at this point in time. Most had been considered to have this problem at baseline (5/7; 71%) and they tended to report the same problems and embarrassments now. Of these, two were still distressed by emotionalism, one by her clumsiness and blindness, one by her extreme fear of having a stroke in front of strangers. The other was someone whose social phobia had been lifelong.

One participant who had social phobia before had since died. Three male participants ceased feeling ashamed following improvements in the disabilities that had been the causes of their distress. A fifty-seven year old ex-psychiatric nurse had experienced little physical improvement but she had recovered from depression and showed a turn-around in her social attitudes. She now challenges negative attitudes, and suggested that, if she had the energy, she would like to educate the public and health workers on how to treat disabled people. Generally though consistency in social phobia diagnosis across time was statistically supported by an insignificant McNemar result ($p = .687$).

The two young participants who had developed major depression during the study (please see section 15.6) had also developed extreme social shame and avoidance. They both reported lacking the stamina to socialise as expected by their peers and extreme embarrassment at their stroke-related disabilities in venues such as bars and

gigs. The young female participant had also recently become uncontrollably tearful which, like other participants with emotionalism, she seemed to regard out-right as 'unacceptable social behaviour'. Similarly to baseline, participants who were regarded as having a disorder did not necessarily recognise their fears as excessive or unreasonable (criteria C) one had not actually faced his feared situation (criterion B) while a few were unable to avoid the source of their embarrassment (criterion D) (please see Table 15.6, and 15.13).

Similarly to baseline, I felt these participants' experience was better described as 'having a problem with social shame/fear' than by the diagnostic label 'social phobia' for the same reasons as before (please see section 15.4iv).

Table 15.13: Social phobic criteria [1] in relation to numbers and percentage of participants with social phobia and those with social fear but not 'phobia' at follow-up

	Participants with social phobia (N = 7)	Participants with social fear but not judged 'phobic' (N = 5)	All Participants (N = 81)
A) 'Socially phobic' type fear	7 (100%)	5 (100%)	12 (15%)
B) Experiences unpleasant sensation when faces situation	6 (86%)	0	7 (9%)
C) Recognises fear is excessive/ unreasonable	2 (29%)	0	2 (2%)
D) Avoidance	5 (71%)	2 (40%)	7 (9%)
E) Significant interference or distress	7 (100%)	0	6 (7%)

1: Only DSM IV criteria A - E for social phobia are listed. Criterion F (Duration > 6 months) and criterion H (Fear is unrelated to a general medical disorder) were excluded.
Criterion G (Fear not due direct physiological effects of substance, or better accounted for by another mental disorder) applied to all participants.

15.7: Post traumatic stress disorder (PTSD) at follow-up

Just two participants were determined as having PTSD at follow-up and they were two of the three diagnosed at baseline. As at baseline, a forty-two year old still reported spending a lot of time puzzled over 'Why me?'. He was discharged at six months on September 11 2001 and felt that this did not bode well for his future. He had now avoided going to sleep in the same position he fell from when he had the stroke in his bedroom for fear of the event repeating itself. As at baseline, a seventy-one year old described essentially the same nightmares and fears of another stroke as she did at baseline (please see section 15.4v). She also reported that having been such 'a bitch' to others that now she was effectively, as well as emotionally, cutoff from them. In contrast, the trauma-type symptoms reported by a seventy-three year old at baseline had lessened. She still feared another stroke but was less on guard and no longer experienced tightening in her throat. She was also no longer uninterested in her family but instead met criteria for GAD and was extremely concerned for their welfare.

Interestingly, the two younger participants who had developed major depression over time were also experiencing some traumatic symptoms. The thirty-two year old female suggested that perhaps she had been numbed until recently as she now thinks she 'should' have been more 'freaked out before'. She also reported being bothered about her behaviour during her stroke and that she often remembers it in a 'surreal fashion'. The fifty-two year old male described feeling that no one could understand him not even his wife, and finding himself easily startled. He had begun to re-experience the sensation of having a stroke as he drops off to sleep, but actually as a 'warm, comforting' feeling. He often fantasises about hitting out at his past reckless lifestyle but never quite manages to hurt it. Taken together these results tentatively suggest that PTSD type symptoms may tend to be more relevant to younger stroke survivors.

In contrast to baseline, participants who were otherwise not anxious or depressed no longer reported re-living type experiences. For example, the participant who saliently described seeing pictures on her wall 'swirling' as they had during her stroke when she was interviewed at baseline (please see Chapter 16, section 16.2iv)

did not even mention this at follow-up. I felt that this was interesting as it suggests that these symptoms can occur and fade in the natural course of emotional adaptation.

15.8: Comparison between levels of shame and fear of falling with agoraphobia and social phobia diagnoses

These results relate to the following minor additional hypotheses:

1) Higher shame scores would be found amongst those with social phobia and agoraphobia

2) Higher fears of falling would be found amongst those with agoraphobia

15.8i: Comparison between shame and social phobia and agoraphobia diagnoses at baseline

Descriptive results for shame are described in Chapter 10, section 10.6ii. Relevant shame by diagnoses data is displayed in Table 15.14.

Table 15.14: Shame scores by diagnoses of agoraphobia and social phobia at baseline

		Mean (standard deviation)		Median	Range
Participants with agoraphobia	(N = 19)	11.95	(4.31)	11	0 – 20
Participants without agoraphobia	(N = 70)	12.41	(4.92)	12	0 – 27
Participants with social phobia	(N = 10)	14.30	(3.34)	14	0 – 20
Participants without social phobia	(N = 79)	12.06	(4.89)	12	0 – 27

As can be seen, there was a wide variation in the range of shame scores within diagnostic groupings of agoraphobia and social phobia. Participants with agoraphobia actually reported slightly lower shame scores than participants without

agoraphobia. However, this difference was not found to be statistically significant, t = 0.405, p = .344. On average, higher shame scores were reported by participants with social phobia, and this difference was found to be statistically significant, t = -1.88, p = .040.

The hypothesis that participants with social phobia and agoraphobia would have higher shame scores was only partially supported at baseline. Participants who were diagnosed as socially phobic were found to have higher shame, but participants diagnosed with agoraphobia were not.

15.8ii: Comparison between fear of falling and diagnoses of agoraphobia at baseline

Descriptive results for fears of falling are described in Appendix F, section F5. Relevant fears of falling by diagnoses data is displayed in Table 15.15.

Table 15.15: Fear of falling scores for participants with and without agoraphobia at baseline

	Mean (standard deviation)	Median	Range
Participants with agoraphobia (N = 19)	8.47 (2.84)	8	3 – 13
Participants without agoraphobia (N = 70)	6.50 (2.59)	7	0 – 13

As can be seen, participants with agoraphobia reported higher fear of a fall than participants not determined to have agoraphobia, and this difference was statistically significant, t = -2.73, p = 004.

Out of interest, reports of actual falls and agoraphobia diagnosis were compared. Participants with agoraphobia (13/19, 68%) were statistically significantly more

likely to have had a fall than participants without agoraphobia (18/70, 26%), χ^2 = 12.01, p <.001.

This hypothesis was fully supported: higher fears of falling were found amongst those with agoraphobia at baseline.

15.8iii: Comparison between shame and social phobia and agoraphobia at follow-up

Descriptive results for shame are described in Chapter 12, section 12.6ii. Relevant shame by diagnoses data is displayed in Table 15.16. In contrast to baseline, higher shame scores were now found for participants with agoraphobia compared to those without, and this was found to be statistically significant, t = -2.75, p = .013. In general, higher shame scores were also reported by participants with social phobia rather than those without, and this difference was statistically significant too, t = -3.37, p = .005.

This hypothesis was fully supported, higher shame scores were found amongst those with agoraphobia and social phobia at follow-up.

Table 15.16: Follow-up shame scores by diagnoses of agoraphobia and social phobia at follow-up

		Mean (standard deviation)	**Median**	**Range**
Participants with agoraphobia	(N = 18)	15.78 (6.29)	16	2 – 27
Participants without agoraphobia	(N = 63)	11.35 (4.97)	11	0 - 27
Participants with social phobia	(N = 7)	18.71 (5.96)	17	13 – 27
Participants without social phobia	(N = 74)	11.73 (5.17)	12	0 - 26

15.8iiv: Comparison between fear of falling and diagnoses of agoraphobia at follow-up

Descriptive data relating for fears of falling are described in Appendix F, section F.5. Relevant fears of falling by diagnoses data is displayed in Table 15.17.

Table 15.17: Fear of falling scores for participants with and without agoraphobia at follow-up

		Mean (standard deviation)		Median	Range
Participants with agoraphobia	(N = 18)	7.94	(3.17)	8	3 – 14
Participants without agoraphobia	(N = 63)	6.11	(2.55)	6	2 - 13

As can be seen, participants with agoraphobia reported higher fear of a fall than participants not found to have agoraphobia, and this difference was significant, $t = -2.54$, $p = .007$.

Out of interest, reports of actual falls and agoraphobia diagnosis were also compared. Participants with agoraphobia (13/18, 72%) were more likely to report having had a fall than participants without agoraphobia at follow-up (21/63, 33%), and this was statistically significant, $\chi^2 = 8.89$, $p < .005$.

15.8v: Comment regarding shame and fear levels by agoraphobia and social phobia diagnoses

The finding that participants who fitted the criteria I used for social phobia reported higher levels of shame at both points in time, and those who met criteria for agoraphobia did at follow-up is theoretically pleasing. This gives some support to the validity of this shame measure and the importance of these stroke-specific negative social beliefs to the social and emotional well-being of this small minority of patients.

Material generated during the administration of the fears of falling questionnaire and the clinical interview did suggest ways in which it could be improved (please see

Appendix F, section F.5). Nonetheless scores were statistically higher amongst those who met criteria for agoraphobia, and participants often cited fear of falling during the agoraphobia interview. Together this can be taken as an indication of the relevance of a specific fear of falling to emotional well-being amongst some stroke patients, particularly those who are not content to avoid going out.

15.9: Overall comment on description of emotional disorders and exploration of beliefs from the structured clinical interview

A high prevalence of depressive and anxiety disorders has been described at both baseline and follow-up. A high level of consistency in the data was observed across time and major depression appeared to be particularly persistent. Generalised anxiety disorder was not very common and over-lapped with depression a lot. Of the specific anxiety disorders, agoraphobia was common but social phobia uncommon and PTSD rare.

The structured clinical interview for DSM IV (SCID) is designed only to provide quantitative diagnoses of disorders. However, it also provided descriptive exploratory data concerning the nature of affective beliefs and emotional problems following stroke. These results relate to objective 5 to:

To explore the types of beliefs and nature of symptoms related to common depression and anxiety disorders

The exploration of depression suggested that a sense of being unable to experience pleasure or contemplate taking one's life was rare whereas somatic symptoms were common and not strongly discriminatory between depressed and non-depressed stroke patients. Low mood was most often the key symptom on which the decision that a patient had depression rested. Depressed patients characteristically reported low self-worth, and they tended to do this by describing a sense of 'uselessness' in relation to their limited abilities.

From my own personal experience of conducting these interviews and our consensus meetings, I felt that there was a reasonable 'fit' between the content of symptoms described as depressive disorder by DSMIV criteria and what I found with these patients. The distinction between major depression and minor depression was subsequently supported by comparison with HADs scores (please see Appendix G, section G4). However, conducting these interviews highlighted to me ways in which the severity of specific symptoms could be subject to different interpretation

by different interviewers. The comparison with HADs scores suggested low levels of symptoms despite meaningful statistically significant differences amongst groups.

As regards anxiety disorders, in general the 'structured' interview appeared to be accessing meaningful negative anxious symptoms and beliefs. Agoraphobia was often related to stroke specific issues (falling and shame) but some participants' avoidance could sometimes be seen as successful adaptation (They reported being content to stay in). The diagnostic interviews for social phobia and PTSD highlighted emotional and avoidance issues that were problematic to some participants. I felt that these problems did not perfectly match standard DSMIV criteria or descriptions of these disorders, but had usefully highlighted similar clusters of symptoms.

Chapter 16

Qualitative results

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16.1: Overview of the qualitative main themes and sub-themes

The final five overarching main themes and the sub-themes that were developed are listed below.

Main theme 1- Being like this

Sub-themes- Can't dos
Meanings and feelings
Specific fears and issues

Main theme 2- Getting back to normality, feeling normal, or not

Sub-themes- Getting back
What the future holds
Acclimatising (coping)

Main theme 3- Taking another, or not

Sub-themes:- Concerns about taking another
Prevention issues

Main theme 4- They're OK, I'm OK, or not

Sub-themes- Family concerns
Spouses and friends

Main theme 5- Maintaining way of living or thinking, or making changes

Sub-themes- It's a bad world, but it's nice to be nice
Keeping healthy
Work
Money helps
Getting/ staying at home
Getting old and to the end of life

This chapter is divided into sections based on the first three main themes and subsections based on the sub-themes. Each section begins with a presentation of the main theme in the framework format, that includes all its relevant codes (minor themes) clustered into its sub-themes.

Quantitative study characteristics of the sixty participants, including diagnoses of emotional disorders, are presented in Appendix F, F.4. Twenty-one participants had major or minor depression (that will be referred to as depression for brevity). Seven participants had generalised anxiety disorder (GAD). Six of the seven participants with GAD also had depression. Comparisons between participants with depression/ GAD have been highlighted when differences were found in the final analysis (please see Chapter 9, section 9.4iii for a description of this process) but when beliefs seemed particularly related to depressed feelings only depression has been referred to. Also associations that were observed to be stronger between beliefs and participants who had GAD in addition to depression has been highlighted, and when relevant diagnoses of agoraphobia and social phobia has been referred to.

The first three main themes:

Being like this

Getting back to normality, feeling normal, or not

Taking another, or not

were considered to cross-over most obviously with the main quantitative study results. Therefore each section for these themes will end with a summary of the main relationships that emerged between relevant codes and depression/ GAD. This was to aid the exploration of convergence and divergence between quantitative and qualitative results. In contrast the last two main themes:

They're OK, I'm OK, or not

Maintaining way of living or thinking, or making changes

were considered to provide qualification of the quantitative results in and of themselves, because they raised mainly different issues. These will be presented in Appendix H.

<u>Note regarding organisation and cross-referencing in this chapter</u>

Participant codes used in this chapter indicate gender/ subject number/ age in that order. To aid cross-referencing, chapter section numbers and main theme headings will be displayed at the foot of pages in addition to the chapter title from now on.

Main theme 1- Being like this

Can't dos

(Please see main theme 4 for 'Being there' and 'Social life' and main theme 5 for work issues)

CDBI Can't do basic physical activity
Restrictions on being able to carry out physical activity such as walking or issues with weakness or numbness

CDWW Can't do what I want
Restrictions in carrying out extended activities of daily living such as shopping or leisure activities, for example, shopping for pleasure, playing dominoes, reading or knitting.

CDT Can't do as tired
Reports of tiredness, lacking energy, or sleeping more which they attribute to the stroke.

CDF Can't do family or home duties
Restricted ability to carry out valued roles in the home (efficient housekeeper/ manly tasks) or as the driver of the family.

CDJ Can't do job
Restricted ability to carry out role at work in a part time job or with voluntary work. *(Please see theme 5 for work as a sub-theme)*

Meanings and feelings

(Please see main theme 3 for 'Being a burden' and 'Social isolation')

TIH That it happened
Memory of the stroke or early hospital days as a strange or frightening experience, or just bafflement that he/she should have had a stroke.

NaG Not as good
Comments that imply that although he/ she can still do things, it's just not as good or she can't enjoy things as much as before.

NN Not normal
Statements which imply a lost sense of normality, or proper way of doing things

B Boredom
Comments that state or imply that present restrictions cause boredom, or there's less to occupy one's time with.

FR Feeling reliant
Feelings about needing help, from feelings of helpless dependency to expressed preferences that would just prefer to not rely on others

FU Feeling useless
Negative comments about self, ideas one should or could be doing something useful if it wasn't for their stroke or the chore of rehabilitation

FD Feeling down
Negative feelings about present restrictions from missing doings things to stronger feelings of anger and frustration about what he/ she can't do, or, about being in hospital.

FA Feeling annoyed
Feelings of annoyance about present situation from mild annoyance to descriptions of anger and great frustration

Specific fears and issues

CF Confidence and falls
Lacking the confidence to get about, fearing a fall or being run over.

S Shame
Shame because of the way treated, or fear will be treated by people, embarrassment at incontinence or being cared for.

Twenty-eight participants reported limitations in being able to do things they wanted to do. Sometimes limitations were talked about in general terms of 'being like this' and so not being able to do what they 'used to' or would 'like to' do. More often participants went on to report concern about specific activities that they could not do or were less able to do. Some reported being unable to carry out day to day tasks, for example, grocery shopping or household chores. Even more participants voiced concerns about not being able to partake in social or leisure activities. A range of indoor pursuits were mentioned such as reading, knitting, writing, baking or doing DIY. Many participants complained about no longer being able to walk for pleasure, or to go to the shops for the sake of it. Sometimes these were also social activities, for example one man could no longer go walking with his church group. Similarly, a female participant described how she used to enjoy the shops:

'I enjoyed it for its own sake. I liked to go to Princes street and Leith, it dinnae bother me if I was buying or not. You'd enjoy a coffee and a chat and comparing prices. I don't like to get done, I feel good if it's a true bargain.' **f26**, 84yrs.

Participants reported having enjoyed a diverse range of socio-cultural activities such as dancing, day clubs, the pub, bridge, bingo or the theatre but being no longer able to do them. Quite a few participants were concerned about their lack of ability to engage in more strenuous leisure pursuits such as golfing, fishing, bowling, or even sponsored abseils. The implications of these loses were also often expanded on and these will generally be examined in the following 'meaning and feelings' section. Particularly social losses and their implications ('Social life' and 'Going places') are described in the fourth more social theme (please see Appendix H, section H.1ii).

Eleven participants reported concerns that tiredness prevented them from being able to do things to the same level as before. A few described feeling slowed down since their stroke or that they felt a lack of energy. Others reported that they became tired, or ran out of energy, more easily than before. A few described both aspects, for example, a male participant said:

'It's the fact you cannae get the energy to do things. I can sleep eight hours in bed and take naps during the day and still feel sleepy. If the TV is on I will drop off after a short while… I just feel sleepy, "Oh I'm sleepy again"' **m69**, 65yrs

Ten participants were judged to have experienced a loss of role concerning family or household duties. Female participants quite often stressed housework as an important role, and a few who could no longer do it cited it as a concern, for example:

'All my life it's been I like it just so. It's not just so at the moment' **f62**, 87yrs

A few male participants seemed to hold more stereotypically male household chores such as gardening, DIY or doing the bills with the same sort of duty bound emphasis. For example a male participant with depression who was still in hospital said:

'Is my wife coping?...With things coming through in the post to be dealt with. I just said to my wife "Just take out the cheques and bin the rest" – she gets a bit uptight' **m59**, 75yrs

A few female participants raised concern over no longer being able to mind and nurture their grandchildren, for example to give them 'Granny's home cooking'. Five male participants emphasised being unable to drive as a serious loss of role. Two men had provided regular lifts to their grandchildren to help their daughters out. One man's wife was resident in a long-term care ward and driving had enabled him to visit daily. The other men were concerned as their wives depended on their driving. For example, one man with depression and GAD explained:

'She's reasonably healthy but has Meniere's disease and chronic sickness and for years at a time has had to have anti-emetics and now permanently. As a result she's lost confidence about going out on her own. I used to take her out and now I can't... Well these are just the thoughts of someone stuck in a chair who feels they should be up doing things' **m58**, 80yrs

Essentially the decision to code 'can't do' activities as roles rested on the implication that participants felt these were things they 'should be' doing rather than they would just like to be able to do them. In this way the actually coding of roles became somewhat circular with its implied adjunct meaning (please see section 16.2ii). However, we felt it was important to distinguish between 'can't dos' per se

and those 'can't do' issues that seemed to imply a sense of moral or social responsibility.

Nine participants' jobs were affected by the stroke. Six of these participants were of working age, three had been in full-time paid employment (a lecturer, a kitchen assistant and a printer technician) but were now on sick leave. One female participant was the administrator for her family business and so was not benefiting from sick leave or compensation for her stroke. One female participant had provided respite care for a child with physical disability and a teenager with learning difficulties on a part-time basis. A man who was a mental health services user, had been working in 'therapeutic' part-time work as a clerical assistant. Three participants had worked part-time, one as a voluntary carer on her church visiting list, one as a voluntary verger for his church, and the other as a driver for a residential home.

Not being able to work could technically always be seen as a loss of role. However, participants varied tremendously in how much they seemed to value work, and their levels of concern related to not working. Additionally, some retired participants raised various work issues. The meaning of work was considered to push beyond the boundaries of this theme and was awarded its own sub-theme (please see Appendix H, section H.2iii).

16.2ii: Being like this sub-theme 2- Meanings and feelings

Only a small number of participants reported concern about the actual event of the stroke. A couple still seemed to be slightly upset by their experience in hospital. One man had thought the doctors must have written of his chances of survival, because he was introduced to a drug trial but then actually not included. One lady reported feeling ashamed of her behaviour in hospital but now seemed actually able to joke about it:

'Not knowing where I was. I was trying to find the loo in the ward, I couldn't find the button for the nurse and I wet the bed. I felt terrible, really ashamed. I didn't want to shout "Would someone come and help me" you're the only one I've told…It disnnae bother me now – I always make sure I know where the toilet is!'

f42, 70yrs

Another lady gave this graphic report of waking on the sofa with her stroke and looking over to the opposite wall on which twelve small pictures were hung:

'I couldn't think what on earth was happening, everything was swirling. When my daughter saw my mouth had dropped I thought it was a stroke and I was still very frightened as I felt it was worse than the last one. I often think about how frightening it was. The pictures, I can still imagine them swirling around'

f36, 79yrs

Nevertheless, she went on to report that really she had 'no concerns' in life generally and was not anxious or depressed. A couple of other participants were still concerned about why they had 'taken' a stroke because it had been unexpected, and these were patterns of thought that fed into fearing another stroke (please see section 16.4ii) and 'Why me?' (please see Appendix H section H.2i).

Various negative meanings and feelings were related to participants' concerns about what they couldn't do now. Five participants reported that things were just not as good as before. Generally this was in relation to things they could do, but not as well, because of weakness, slowness or tiredness. For example, a seventy-six year old lady who had been wheelchair-bound pre-stroke, reported that she could still do transfers, but found them such 'hard work' that she enjoyed going out in the car with her husband a lot less.

Nine participants expressions suggested a lost sense of normality or proper way of doing things. They complained about how they used to take being able 'for granted' or do things without a 'second's thought'. Sometimes they made quite global comments to suggest that their lives seemed to have changed 'completely' now they were unable to do the same things, or do things the 'right' way. A young male participant with depression reported concern that he may have lost normal sexual functioning. Another depressed male's reported concern about being unable to eat as before, also conveyed a more general sense of lost normality:

'At the present moment I can't grip my left hand normally and normal daily life, for example, using a knife and fork properly' **m59**, 75yrs

This participant also reported feeling that 'time drags' and complained about the 'daily monotony' of hospital life. A few other participants cited boredom as a problem or as a concern for the future.

Ten participants emphasised that they found reliance on others aversive. Three male participants who were still in hospital were concerned about their reliance on staff. One reported feeling grateful but yet that he really wanted 'to be able to do' for himself, another reported disliking being at their 'mercy'. Some participants who were at home receiving care from spouses or children emphasised their own sense of independence as a loss. One female participant reported feeling the stoke had 'definitely taken away my independence'. A couple of participants described recent events that had made them recognise their dependency. For example, a depressed lady described feeling 'completely helpless' while her husband was laid up with flu. Her inability to go and get basic supplies made her recognise her dependency but she doesn't want 'to have to rely on him'.

Some participants seemed to find reliance on others very difficult in terms of pride. One man stated 'you just can't rely on others' and a female participant with depression said:

'I don't like to ask F____ and M____ [her neighbours] as I'm very independent. I don't like to be beholden.'

f62, 87yrs

One lady with depression who was discharged into sheltered housing but waiting for a nursing home place gave a particularly negative account:

'When you can't do for yourself, you feel so stupid, so useless, the simplest wee thing like trying to walk… You sit here, you go to get up and you can't walk, so you have to phone your daughter-in-law. Everything that goes wrong, I have to phone someone. Dependency is the worst thing… Some people like being looked after hand and foot. I like doing for myself'

f71, 81yrs

Altogether, eleven participants reports implied a loss of self-esteem related to their limited ability. Typically, they tended to describe themselves as 'useless'. A few described feeling useless because they could not maintain their pre-stroke interests, for example being able to bake, play bridge, or do the garden as effectively. One man described feeling he had changed as a person because he could not do as he wanted. More often participants tendency to see themselves as 'useless' seemed to hang on the implication that were failing to do what they 'should'. Their reactions tended to relate to losses that could be described as family or home roles discussed earlier. For example, a male participant with depression who was concerned about his wife's ability to cope while he was in hospital said:

'What on earth am I doing lying here for when I could be doing something useful?'

m59, 75yrs

Other participants echoed this kind of self-reproach with comments that they 'should' be able to do more or others 'shouldn't' have to help them.

Many participants described negative emotional reactions to their lost ability to do what they used to. Conversely, sometimes a sense of loss could be inferred because participants gave emotionally positive descriptions of activities as important areas of life before their stroke but were now not able to do them. For example, a male participant with depression described his love of woodwork in this way:

'I enjoy making stuff, I like working with wood, I like the smell. I feel smashing when I do a job well' **m41**, 69yrs

However, he was now only just beginning to walk and still in hospital. Similarly, others described how they used to 'feel good', 'proud' or 'excited' when they achieved things in their pursuits such as having done some baking, finished a complicated knitted article or caught a fish. In this way the emotional meaning of losses were implicit through the absence of these positive sources of pleasure.

Twenty-five participants reported emotional reactions that were coded as feeling down. Participants with depression (15/22) were particularly likely to describe feeling down or sad. The commonest way in which participants expressed sadness was to report that they missed what they could no longer do, for example one lady said:

'I've started a book but only read fifty pages so far, but I would have had it finished. I miss that' **f36**, 79yrs

Others used terms such as feeling 'a wee bit disappointed' or 'a bit cheesed off' or 'a wee bit dismal'. Some participants described much stronger or darker feelings and they were typically depressed participants. For example one depressed man talked about missing fishing in this way:

'That's a bit disappointing and cuts you and you think "What can you do?". Life's got to carry on, but I've been enjoying it for forty years'

m55, 66yrs

A depressed female participant who used regularly to go hill walking and raised money for an arthritis charity stated:

'If you've led an active life and then something like this hits you, it knocks you right down' **f71**, 81yrs

A few depressed participants portrayed feelings of being trapped through emotive images or analogies. One man with depression seemed to talk about the restrictions on his life and of being in hospital metaphorically as a job without a day off:

'I used to play bowls and sort of miss it. I used to watch the kiddies play football and enjoyed it. It's just something you miss, you think "If I were off today what would I be doing?" and if it were raining it would just be a different day and you'd go to the pictures.' **m64**, 74yrs

Another depressed male participant revealed how devastating the loss of driving was to him by actually using a driving metaphor:

'I was out in the car every day of my life, local shopping, the theatre, for meals...a good part of my life in general and now I'm afraid that's taken a back seat since I had the accident and the stroke...That's me, it puts you out the picture for now' **m59**, 75yrs

One depressed male participant described his loss of independence as 'hellish', and another described his situation as being similar to prison:

'Once you have it, it's like being in prison. I won't even put a dog in prison.' **m55**, 66yrs

Eighteen participants were coded as feeling annoyed or frustrated in some way. However, the emotion range varied from slight annoyance to fairly strong expressions of anger. Similarly to reports of sadness, participants with anxiety and depression were more likely to express feelings of annoyance (10/22) than participants without anxiety or depression (8/38).

Feelings of annoyance usually stemmed from losses of ability to do things and ranged from housework to being able to drive or partake in physical activities such as golf or fishing. For example, a female participant described not being able to do her own housework:

'It's the home help not me doing it. I like pottering about on my own. I'm annoyed that I can't get into the corners' **f26**, 84yrs

Sometimes participants expressed frustration at not being able to do things as-well as before, for example, one man described how he feels when he can't hurry to get a bus:

'I go mental cos' I know I will have to try and not walk faster because I get all out of sequence' **m43**, 60yrs

A female participant with depression was unusual because she brought memory loss up as a stroke-related concern and she felt annoyed at herself that she had missed appointments with her nurse and hairdresser as a result. Another female participant was unusual as she actually reported feeling 'a bit jealous' of her friends for being able to go out shopping and to Christmas parties.

Stronger feelings of frustration seemed to be vented by those who had multiple losses and were depressed. A male participant with depression listed various things he found frustrating and made the global comment that 'Generally if it wasn't for the stroke, life would be marvellous'. A lady with depression reported feeling frustrated about not being able to look after her grandchildren or go to the shops and that it was 'a bloody nuisance'.

A few depressed female participants seemed to direct feelings of angry towards various authorities for being against them or not sufficiently for them. A sixty-three year old depressed participant reported having battled with social services for a long time about her health and ability to physically care for foster children. Her stroke put an end to this but she described feeling it had 'been taken out my control'. One depressed lady described feeling 'mad' at the Church of Scotland because they had taken nearly a week to phone back about a home help and talked at length about her dissatisfaction with the regulations and expense that goes with employing home helps generally. Another, described feeling 'very angry' that her carers were not insured to take her out and her feeling that:

'There's something more against the disabled'. **f71,** 81yrs

The strongest description of anger came from a young male participant with depression who was 'really angry and frustrated' about his restricted life and having to learn to walk. He talked aggressively about his stroke and the chore of rehabilitation as if they were things to be reckoned with:

'Damn this stroke and damn all this carry on' **m65**, 42yrs.

16.2iii: Being like this sub-theme 3- Specific fears and issues

Eight participants reported concerns about falling or fears related to going out and about alone in this interview. Often they talked in terms of a lack or loss of confidence. A participant who also had severe arthritis reported fearing a broken bone if she fell. Other participants tended to relate their fears of falling to dangerous traffic and the possibility of being run over, for example:

'The problem is getting out and I think "Will I fall?...Is there anything to fall on to?". With roads I have to turn to see round and think "Would that go off balance?"'
f50, 71yrs

Interestingly, this participant, who was diagnosed with agoraphobia, had a stepsister who is a support worker, who appeared to have been using graded exposure with her. So far she had been accompanied but had learnt to hold her bag and get on the bus unaided and her next step was to take a short bus ride alone to meet her sister. Another participant reported her GP encouraged her to get out even if it meant using taxis, but she resented paying for them.

Two participants who were physically unable to walk outside alone reported fear about falls inside. A young male participant reported fearing a serious bang to his head and, as with other restrictions in his life, he reported feeling angry when he fell. A female participant graphically described her fear:

'Once you've fell, the fear is always there... I hold on like grim death, and I'm sometimes afraid to put one foot in front of the other' **f71,** 81yrs

She was also the only participant to report feeling let down and unconfident due to the termination of physiotherapy; she described feeling 'forgotten about'.

Seven of these eight participants had depression, and five of the six who could physically go out met criteria for agoraphobia. Most of them linked sadness or frustration to their lack of ability to go out, for example, one female participant reported:

'It is an awful thing to be shut in doors all on your own' **f62**, 87yrs

Twelve participants reported feelings of shame Four participants reported feeling ashamed or upset by incontinence or personal care issues. The involvement of children seemed to be particularly upsetting for a few. One man with social phobia reported feeing embarrassed that his son should have to launder his soiled garments. Participant **f71,** 81yrs explained her dependence in personal care as embarrassing both to herself and her daughter in law, but that it would be better if she had a birth daughter to do it.

Other participants were concerned about feeling embarrassed or devalued in public. A retired opera singer who was in hospital explained:

'I know people would treat me fine but I would like to be able to enter the social world in the same way as before' **m31**, 74yrs

He was concerned because he tended to socialise with younger people, including his girlfriend and wanted to chat, flirt and do karaoke with them as before. A similar idea that disability is more embarrassing amongst young people was echoed by a sixty year old who tended to socialise with a predominantly younger crowd.

Most participants who reported a lack of confidence with appearing in the public eye were diagnosed with social phobia. A forty-seven year old female participant, with

social phobia related to the possibility of a stroke in public, described walking her dogs very late at night with her hood pulled up round her face. A forty-seven year old male participant whose diagnosis of social phobia related to embarrassment about emotionalism, reported being unconfident about going back to the pub to play darts in case others saw him 'throwing bad'. A female participant, also later diagnosed with social phobia, felt that she had been made to feel embarrassed in a restaurant:

'People do look at you. We all do it and anyone who says they don't is lying. I want to go back to just eating normally. I knocked a glass of wine over and people looked more because there was something wrong with me… It made me feel like watching every move I made' **f52**, 57yrs

Finally, a female participant diagnosed with social phobia voiced concern about being patronised by her family since her stroke. She described their manner as 'annoying':

'People are inclined to treat you as if you're unintelligent. My family appear to do that when they speak slower.' **f46**, 82yrs.

16.2iv: Summary of relationship between Being like this and depression/GAD

In general, participants without depression/GAD raised concerns about 'can't do' issues as much as those who did have depression/GAD please see Table 16.2.1. However, participants with depression/GAD were more likely to emphasise the family or home role aspect of activities as if they felt a moral duty towards housework, helping the wife, or ferrying one's grandchildren about and so on.

Table 16.2.1: Types and frequencies of 'Can't do' concerns

	Can't do: Basic physical	**Can't do: What I want**	**Can't do: As tired**	**Can't do: family or home role**	**Can't do: Job**
Participants with Depression/GAD (N = 22) [1]	3 (14%)	12 (54%)	4 (18%)	7 (32%)	3 (14%)
Participants without depression/GAD (N = 38)	2 (5%)	16 (42%)	7 (18%)	3 (8%)	6 (16%)
Total number of participants (N = 60)	5 (8%)	28 (47%)	11 (18%)	10 (17%)	9 (15%)

[1] Diagnoses of depression/GAD were made using DSMIV criteria, please see Chapter 8, section 8.3

The 'should' element that permeated participants' descriptions of family or home roles linked in with feelings of uselessness, and those with anxiety and depression also tended to talk about feeling useless more often (please see Table 16.2.2).

Concerns about being beholden to or having to rely on others were more often reported by participants diagnosed with depression/GAD. They also reported feelings of being down three times more frequently and feelings of annoyance twice as frequently. When stronger feelings of disappointment and anger were expressed, it was always by participants who were diagnosed as having depression/GAD.

Table 16.2.2: Types and frequencies of meanings and feelings

	Not 'normal'	Feeling reliant	Feeling useless	Feeling down	Feeling annoyed
Participants with Depression/GAD (N = 22) [1]	4 (18%)	7 (32%)	6 (27%)	15 (68%)	10 (45%)
Participants without depression/GAD (N = 38)	5 (13%)	3 (8%)	5 (13%)	10 (17%)	8 (21%)
Total number of participants (N = 60)	9 (15%)	10 (17%)	11 (18%)	25 (42%)	18 (30%)

[1] Diagnoses of depression/GAD were made using DSMIV criteria, please see Chapter 8, section 8.3

Twelve participants in this group had been found to meet criteria for agoraphobia during the structured clinical diagnostic interview. In this less structured interview in which they themselves raised issues, seven agoraphobic participants brought up relevant fears. Five reported a fear of falling or the danger of being run over and two issues of shame. Similarly to the structured clinical interview results (please see Chapter 15, section 15.4iii) this emphasises the relative importance of agoraphobic issues to just a proportion of those who can be diagnosed with the disorder following stroke.

Seven participants in this group had been diagnosed with social phobia, and six of them reported relevant feelings of shame themselves in this interview, which seems to underlie the importance of these issues. Interestingly, a few of them raised different embarrassing issues in this interview from those they brought up during the structured clinical interview.

16.3: Main theme 2- Getting back to normality, feeling normal, or not

Codes and sub-themes regarding 'Getting back to normality, feeling normal, or not' are outlined on the following page. As can be seen, this theme broadly concerns beliefs about recovery, anticipation of its likelihood and coping with this uncertain situation.

16.3i: Getting back to normality, feeling normal, or not sub-theme 1- Getting back

When participants expressed concern about making recovery, they tended to talk in terms of 'wanting' or 'getting' or 'coming back'. Nine participants talked very broadly about 'Getting back', for example:

'I want to get back ' **m79,** 83yrs

Similarly to the range of activities participants complained that they could not do now, goals of recovery ranged from: doing basic physical things, getting back to doing what s/he wanted, or, to regaining a role.

Five participants reported wanting to see improvements in physical ability, for example:

'I just wish I could get the leg going better – get walking around and about'
f47, 82yrs

More commonly participants (18/60) reported wanting to regain functions and to be able to do what they wanted. A few emphasised wanting improvements in terms of independence in the home, for example:

'If I can manage on my own I'll be alright' **m57,** 80yrs

A few wanted to see improvements in their indoor pursuits such as knitting or baking. Others talked about wanting to being able to walk to go out and about or to 'jump on a bus' so they could start doing the shopping again or get their social life back.

Main theme 2: Getting back to normality, feeling normal, or not

Getting back

GB Getting back
Statements about wanting to get back, or come back to functioning as he/she did before.

GBBI Getting back basic physical ability
Statements about wanting to get back physical strength or ability

GBWW Getting back what I want to do
Statements about wanting to be able to return to pleasurable activities.

GBR Getting back a role
Statements about needing or longing to be able to return to work, drive etc.

FN Feeling normal
Statements about needing recovery in order to feel normal or just longing to feel normal again.

In contrast to issues of wanting back and what the future holds covered above, some participants reported:

BtN Back to normal
Thoughts that one is feeling good health wise or has come back to normal already

What the future holds

IC It'll come
Confidence that he/ she will recover, or implied through ideas of being recovered in future.

WI? Will I?
Uncertainty about whether can expect recovery, how long it will take or how successful it may be

MN Might nevers
More negative expectancies than the idea of 'Will I?' or even cynicism about future recovery

WB Would bes (If not, then bad)
Conditional type statements about negative feelings if insufficient/ unsatisfactory gains are made

Acclimatising (coping)

NWd Not worried
Comments that s/he is not concerned, may mention that worrying or getting depressed is not in his/her nature

TNW Trying not to worry
Comments that he/ she is trying not to worry, putting things to the back of his/ her mind or that being upset is pointless, may choose to ignore it.

A Acceptance
That he/ she just accepts or can put up with the way things are, may comment that what's happened has happened.

It's bad... but:
DM Don't mind
Devaluing of past activities to suggest he/ she is not bothered or doesn't mind
OKFN OK for now
Comments suggesting he/ she is able to hold off disappointment because the restriction is temporary
AL At least I can
Compensatory remarks about at least being able to do some things
CBW Could be worse
Comments that s/he is lucky in comparison to others with strokes or other illnesses like Alzheimer's.

T Trying
Reports of determination to put effort in, fight it or put one's mind into recovery.

H Hoping
Wishing and, or, hoping for recovery

DD Did do/ Will do
The use of happier memories or thoughts as a coping strategy perhaps thinking about how enjoyed doing things, or things to look forward to

J Joking
Making jokes about difficulties, emphasis on importance of humour in life generally, using it to show his/ her mood is good

Seven participants whose strong concerns about not being able to carry out their driving or housework roles were discussed earlier (please see section 16.2i) also emphasised the importance of regaining them. For example, a depressed male participant used repetition to stress the importance of being able 'to get up and get out' in the car again. A female participant with depression emphasised how important she felt it was to do her own housework again by her reference to it as 'work' and as part of having her own life:

'I'm concerned about being able to do my own housework and live my own life…I would like to do my own work and house work. Two times now my second cousin has come and done the house. I don't want to trouble her, I don't want her to make a habit of this.' **f62,** 86yrs

Seven participants talked about getting back alongside the idea of becoming 'normal' or 'right' again. Sometimes the emphasis was on the importance of being able to function normally or properly. For example:

'Getting self right again, I'm not used to this immobility' **m43,** 60yrs

At other times, it seemed to be the sense of being able to get back to feeling normal, or like a normal person that was craved. In the context of discussing regaining the ability to walk, and his fears of not being able to have sex or produce children, the youngest male participant said:

'If I never get better people may look down on me because I'm an invalid… I just want to feel like everyone else' **m65,** 42yrs

Overall, participants tended to express concerns about 'getting back' less often than 'can't dos'. However, it is assume that the appeal of recovery had been pretty much implied through many peoples concerns about what they could not do. Regardless of whether participants talked about dissatisfaction with not being able, or wanting to get back ability, they tended to emphasise function, roles and normality as much, or more than physical ability.

However, in contrast to most participants' concerns to get back to normality and being able to feel normal, seven participants actually felt they were already back to normal. A couple of them recognised they had some residual effects remaining but tended to emphasise that they were feeling 'excellent' or that they were very pleased with their progress. Their disability levels did tend to be low; however, a seventy-five year old female participant was the exception to the rule. She was actually housebound in a third floor flat, but nevertheless appeared cheerfully free from concern about her stroke and joked:

'It came it went and conga!' **f25,** 72yrs

16.3ii: Getting back to normality, feeling normal, or not sub-theme 2- What the future holds

Eleven participants expressed beliefs that their abilities would come back. Often their confidence was built on their recovery so far; for example a ninety year old man said:

'As time goes on it will gradually get better. I'm not sure it will be permanent because the slight feeling in my lower lip has gone now' **m44,** 90yrs

Sometimes the idea that 'It'll come' was implied because participants spoke with certainty about themselves as back to their pre-stroke selves in the future. For example, a lady who was presently depressed and agoraphobic nevertheless said:

'I've never been out socialising, but once I get back I will be back as normal' **f50,** 71yrs

Ten participants expressed uncertainty, often through 'Will I?' type questions, about whether and how much they could expect to get back. Their uncertainty often seemed very reasonable especially for the four who were still in hospital. As one man said:

'Will I be able to do my own shopping? They assure me I will, I'm walking now here but I will be in a different environment…Will I improve? Will I get back to somewhere near normal?' **m31,** 74yrs

Another man pointed out that it was hard to estimate whether one would recover because the doctors and physiotherapists were uncertain themselves. Another queried why some people seemed to get better in a month while he was taking a lot longer.

Five participants suggested they may never get back to their pre-stroke ability levels. A few spoke of quite specific issues: the eldest participant doubted he would play golf again, one lady doubted she would dance again and another that he would travel as far as Africa. Meanwhile, the youngest participant who was depressed spoke more globally:

'I might not get better, it's pretty bad...I might never be able to live a normal life again' **m65,** 42yrs

His negative perspective was not unrealistic, as he had not managed to walk yet. However, another depressed man's cynical comments in reference to getting home, for example:

'I just don't see it happening' **m59,** 75yrs

appeared out of proportion to the actual situation as he was now walking and had a home visit scheduled.

Ten participants remarked that things would be bad if they did not get back some level of ability or a specific function. Often they suggested that they would be sad or 'miss it' otherwise. Driving was the most commonly reported function in this context and was brought up by four male participants. One depressed man said he'd be 'useless' to his family if he could not drive in future and another said that it would be 'a big loss'. A depressed female participant who wanted to regain driving to enable visiting her children and getting to bridge club said that otherwise:

'Life would be hell.' **f80,** 75yrs

A man who was still wheelchair-bound in hospital reported he would feel sad and embarrassed if he was not able to get home. Other activities mentioned as holding

potential for sadness if not regained were walking in a social club, golf, bowls and woodwork.

16.3iii: Getting back to normality, feeling normal, or not sub-theme 3- Acclimatising

Participants comments revealed various ways of thinking to cope with or 'acclimatise' to what they could no longer do, or might not be able to get back to. However, for eighteen participants this was apparently not necessary. They stated quite clearly that they were simply not worried or concerned about anything. They tended to make these statements at the beginning of the qualitative interview, for example:

''I'm not concerned about anything' **m23,** 71yrs

A few explained that they were characteristically not worriers, for example:

'I think that once you get to eighty years old that unless you're the worrying type you're not suddenly going to get depressed or sad' **f27,** 80yrs

With further probing questions most of these participants maintained that they had no concerns about what they could not do, or about recovery or recurrence, but four participants did go on to report some stroke-related concerns after all.

Five participants appeared to be making a conscious effort not to worry, or admit to worrying about disability or recovery. They statements of not worrying were less convincing as they contradicted themselves elsewhere and did reveal concerns. For example, one man described himself as someone who had never been one to 'think negative' and as being concerned about 'nothing really', but went on to say:

'You must worry, but it's not like I talk to myself or anything like that. I'm not always thinking about health all the time. I don't think about it when I wake in the morning: "Will I be able to walk?"' **m54,** 62yrs

One lady who actually described herself as constantly worried and was found to have GAD in the diagnostic interview. However in this interview she insisted that she didn't 'worry' about recovery, but was just 'thinking about it'.

Ten participants made comments stating or implying they had accepted what they could not do. Often they used clichés like 'that's life' or 'what's happened has happened' to show their stoicism. A few implied that their ability to accept reflected the type of people they were, for example, one lady said:

'I'm not dying to get back, it's just my passive nature' **f73,** 74yrs

For others, their acceptance was something they had seemed to have had to work at, for example one man described himself as becoming 'acclimatised' to things. Another man's comments portrayed a very sober kind of acceptance:

'I have to accept it, that I can't do much…You've got to do your best, so I'm just resigned. No one has a magic wand to wave.' **m57,** 80yrs

His acceptance was perhaps better described as resignation whereas the others in this group tended to convey a more convincing upbeat state of acceptance.

Many participants made 'It's bad… but' compensatory-type remarks, often as tail ends to statements of concern about what they would like to get back to or could no longer do. Thirteen participants implied they didn't mind being unable to do something. Often participants made 'don't mind' type remarks about hobbies such as bowls, woodwork, a holiday or gardening. One lady who had attended bingo weekly for years now said that actually she 'weren't that into it' after all. In contrast to some female participants' angst about the housework (please see 16.2i) one lady reported she was quite happy to put the spring cleaning off until she felt up to it.

The implication tended to be that in retrospect things that were no longer possible had never been important anyway, and so they were easy to let go. A couple of people reported that they could not write well following stroke, but one lady said she had never been a 'great writer' anyway and another described not being able to send Christmas cards as 'not a great inconvenience'. A forty-seven year man appeared to

have undergone a fairly striking turn around in his attitudes to drinking. He described himself as someone whose dream had been to 'drink the pub' in his youth, but now said:

'I've just been once during the daytime, just had one pint and it tasted rotten, I think it may have been a bad pint' **m53,** 47yrs

Fifteen participants made remarks implying 'OK for now'. These sort of statements suggested that relevant activities were still valued, but that a restriction could be accepted, so long as it was temporary. People tended to talk about activities outside the home in this way, for example, socialising, going for car rides, and church. A couple made 'OK for now' remarks about DIY, one about reading, and a man who was still in hospital said he coped with the separation from his family only because it was time - limited. Slightly ironically, three participants mentioned that the winter weather made it easier to accept being unable to do things outside. For example, although one man wanted to get back to gardening eventually, he said:

'I can't do anything at the moment anyway, the weather won't permit it at the moment with soaked ground, which is good in a way' **m32,** 74yrs

Seventeen participants reported that 'At least' they could do some things, even though they were concerned about others. A few participants comments implied that they at least felt grateful for what they could still do, for example, one man said:

'At least I can still walk, I just will never be able to run or kick a ball.'
m54, 62yrs

Some participants seemed to have behaviourally substituted losses by increasing other equally valued pursuits, for example a lady who used to enjoy dancing now went to the theatre more often to 'make up for it'. Others were grateful that they could still maintain interests, even if it was in a different capacity. For example, a man who loved music and was missing his CD collection in hospital said he was pleased to be able to listen to tapes his son had made.

A house-proud man with GAD, who liked to do his own DIY hadn't felt confident enough to mend a door so had hired someone else to do it. As he said:

'I felt rotten about getting someone in, but still pleased I was getting it done.'
m45, 76yrs

Nine participants made remarks to imply they were glad because after all their predicament 'Could be worse'. Most of them reported feeling fortunate in comparison to other people with worse strokes, for example:

'I've had it lucky compared to some folk who cannae do a thing' **f63,** 83yrs

One man pointed out he was glad to have had a right-sided stroke, as he is left-handed and an artist. Another reported feeling lucky that at least he did not suffer the kind of 'mental blockage' associated with Alzheimer's disease.

Ten participants reported trying to make improvements. Some talked in very positive terms, for example one man said:

'I will fight it and still make it…I never lie down to anyone.' **m35,** 84yrs

A couple of depressed participants' reports contained an element of self-reprimand, for example one man said:

'I've just got to make my mind up to get on with it' **m58,** 75yrs

One man specifically voiced enthusiasm about the importance of trying in physiotherapy, for example:

'I'm putting all my energies into this physio, I never miss a chance.' **m79,** 83yrs

Twelve participants reported hoping for improvements. Statements of hope, or wishing and waiting were made in reference to getting back to various activities such as going shopping, driving, gardening, travelling. Generally participants tended to make very simple statements of hope. One man who was very keen to get back to

his normal life outside the hospital made slightly more complex comments and seemed to be mentally bargaining with what he hoped for:

'I hope I will come back to normal, maybe not so good but so I'm able to give it a try' **m29,** 76yrs

Nine participants seemed to be actively mentally coping by looking forwards ('Will dos') or backwards ('Did dos') with pleasure. A few reported looking forward to positive events or being able to manage certain things again in the future, such as seeing the family at Christmas if not this summer, or getting into the garden by spring. For example, one man reported disappointment that a walk round the block had made him exhausted but reported:

'I maybe overdid it, if I do it routinely it will improve' **m44,** 90yrs

More often, participants reported that they used past happier memories as comforts. For example, a lady who missed being able to dance said:

'I miss it but I still enjoy the fact that I did dance' **f47,** 82yrs

She had won awards dancing awards and went and fetched the photographs to prove the point. Similarly, a retired forestry commissioner who was now housebound made the point:

'There's something of me in the countryside that wouldn't be there apart from me…I still look back with pleasure, although I can't do' **m68,** 88yrs

Seven participants made jokes about their predicament. No one actually explicitly stated that they used it as a coping strategy; however one participant valued 'being funny' as the most important part in her life and her continual joking certainly worked to imply her mood was good. Being depressed, didn't seem to deter a few participants from being able to make a joke, for example one man said:

'At least my stroke has given us another talking point, which is a change from hips etcetera' **m58,** 80yrs

16.3iv: Summary of relationship between Getting back to normality, feeling normal, or not and depression/GAD

In terms of issues participants talked about wanting to get back, these results paralleled those for concerns about 'Being like this' (please see section 16.2i). In general participants with and without depression wanted to get back to valued activities and normal life. However, those with depression/GAD appeared to emphasise the need to regain valued roles to feel useful. Also the strongest craving for being able to feel normal again was expressed by a young depressed man.

Interestingly, apparent confidence in recovery, shown by remarks that 'it'll come' back, were not made more frequently by those without depression/GAD as by those with. Also, participants without depression/GAD actually reported uncertain 'Will I?' comments more often. However, participants with depression/GAD were more likely to make stronger statements of uncertainty and suggest that recovery might never occur (please see Table 16.3.1). One depressed male's comments suggested particularly unrealistic pessimism. Also, participants with anxiety or depression more often commented that life would be bad, without sufficient recovery.

Table 16.3.1 Types and frequencies of 'What the future holds' beliefs and beliefs in good progress

	Positive beliefs		**Negative beliefs**		
	Back to normal	**It'll come**	**Will I?**	**Might never**	**Would bes (If not then bad)**
Participants with anxiety or depression (N = 22)[1]	0	4 (18%)	1 (5%)	3 (14%)	5 (23%)
Participants without anxiety or depression (N = 38)	7 (18%)	7 (18%)	10 (24%)	2 (5%)	5 (13%)
Total number of participants (N = 60)	7 (12%)	11 (18%)	11 (18%)	5 (8%)	10 (17%)

[1] Diagnoses of depression/GAD were made using DSMIV criteria, please see Chapter 8, section 8.3

The belief that a good recovery had already been made, shown by remarks that they felt 'Back to normal' were made by some participants who were not anxious or depressed. Many participants with depression/GAD were also quite physically well

recovered, but not one of them appeared to share the highly positive belief that they had got back to normal.

A strong sense of resiliency emerged from the reports of participants who were not anxious or depressed. They often said they were just not worried or concerned period. Many acknowledged but yet accepted losses or they seemed to devalue past endeavours and say they didn't really mind their absence. This was rarely the case for participants who were anxious or depressed (please see Table 16.3.2).

Table 16.3.2: Types and frequencies of acclimatising (coping) beliefs compared to reports of being 'Not worried'

		Acclimatising (coping) beliefs									
	Not worried	Trying not to worry	Acceptance	Don't mind	OK for now	At least	Could be worse	Trying	Hoping	Did do/will do	Joke
Participants with depression/GAD (N = 22)	2 (9%)	1 (5%)	1 (5%)	1 (5%)	5 (23%)	5 (23%)	3 (14%)	3 (14%)	5 (28%)	3 (14%)	3 (14%)
Participants without depression/GAD (N= 38)	16 (42%)	5 (13%)	12 (32%)	12 (32%)	10 (26%)	12 (32%)	6 (16%)	6 (16%)	7 (18%)	6 (16%)	4 (11%)
Total number of participants (N=60)	18 (32%)	6 (10%)	13 (22%)	13 (22%)	15 (25%)	17 (28%)	9 (15%)	9 (15%)	10 (17%)	9 (15%)	7 (12%)

[1] **Diagnoses of depression/GAD were made using DSMIV criteria, please see Chapter 8, section 8.3**

Various more effortful reasoning strategies were apparent amongst some participants with and without depression/GAD. They seemed to be mentally weighing things up to try and see a more positive side, sometimes by focusing on the temporary nature of things, or alternatively by thinking about what 'at least' they could do or about how things might be worse. Some participants were actually doing more of what 'at least' they could and some were putting effort into recovery. A few participants joked about problems and some seemed to be comforted by looking to the future or by reminiscences of the past. Participants who had depression/GAD may have been less hopeful about the likelihood of recovery (see earlier) however they were even more likely to say they were wishing or hoping things would get better.

Overall this theme suggests that participants own perceptions of change and recovery seem to play some part in the explanation of distress. Some participants who were not anxious or depressed were not worried, had accepted changes, or even felt they were almost back to normal. For them coping strategies were apparently not needed. Regardless of diagnostic status, some participants were uncertain about their recovery and those with anxiety and depression were more likely to seem cynical. Various ways of thinking to cope with an uncertain recovery were reported but these tended to be as frequent amongst those who were and those who were not found to have depression/GAD.

16.4: Main theme 3- <u>Taking another, or not</u>

Codes and three sub-themes for 'Taking another, or not' are outlined on the following page. As shown this main theme is organised into sub-theme 1 'Concerns about taking another one' and sub-theme 2 'Prevention issues'

16.4i: Taking another, or not sub-theme 1- <u>Concerns about taking another</u>

Fear of a further stroke clearly emerged as a major theme from the present data. When participants raised concern about the possibility of recurrent strokes they talked in terms of 'another one' and commonly about 'taking' another one.

<u>Fearing 'taking another' was common</u>, and in total three quarters of participants (44/60; 73%) brought it up in some context.

A couple of single people mentioned their fear of being left alone in the house unable to get help if they did take another. However, in general the content of fears were orientated towards more long-term potential consequences: the possibility of dying, or of having a more severe stroke.

<u>The fear of death was reported by ten participants.</u> This was generally reported matter of fact and not expanded on. Only two participants, both of whom were depressed gave more detailed responses. For one depressed lady just the possibility of death itself was what appeared frightening:

'I could die. I'm not sure what it is I'm scared of, I've just got a fear of it. It's come on since the stroke, that it really could happen. I just blame this stroke, I could have another.' **f77,** 73yrs

Main theme 3: Taking another, or not

Concerns about taking another

A_1 Another one
Any mention of the possibility of a further stroke regardless of predicted consequences or level of concern.

BL Being left
Concern that may be left alone or unable to get help if it reoccurred.

D Dying
Any mention or fear that a further stroke may cause death.

S_1 A severe one
Fears that a further stroke may be more severe and cause more dependency and what that would be like

SSvD Severe stroke versus death
Ideas that a severe stroke would be worse than dying or that dying is less frightening.

WWC Would we cope?
Concerns whether self, spouse or family would be able to get used to it, or deal with it if he/ she had a severe stroke.

WSE Will someone else?
Fears that a loved one will take a stroke or is at risk of something similar

KS Knowing someone
Recognise possibility of recurrence through having known someone who experienced it.

ST Seen them
Fear of recurrence stems from having seen or met people with further strokes in hospital.

HB Happened before
Has already had more than one stroke, TIA or heart attack, may have learnt this from the Doctors' information about scan.

NWg No Warning
The idea that it happens so unpredictably, it could happen again

Prevention Issues

NCSI Nothing can stop it
Fatalistic ideas, that if it is going to occur it will.

WW? Why worry?
Comments that worrying about another is pointless, meanings may vary: some are fatalistic, but some waver between wanting to know or block it out.

CICI Can I/ can't I?
Issues with lacking confidence, or motivation to change a behaviour, e.g. smoking.

WIWI Will I/ won't I?
Weighing up of risks, questioning or estimating the probability of another.

SISI Should I/ shouldn't I?
Concerns about whether they should be doing certain things or avoiding them and how behaviours/ stresses may exacerbate or trigger another one.

CS Control seeking
A questioning stance about prevention. Some know what's important and where to get help, while others are posing questions but are not sure what to do.

LR Lacking reassurance
Beliefs that the Doctors can't reassure them or do anything prevention wise, or just haven't obtained that reassurance.

A/P Ageism/ Prejudice
Feelings about Doctors passing them over because of their age or because he/ she was a smoker.

FM Faith in Medicine
Statements suggesting belief that doctors or treatment will help prevention.

A relatively young participant, who also met criteria for GAD, stated that her main concern in life was 'not being here for my family'. She was concerned whether her recently divorced son and lone parent daughter would cope, and about the future of her granddaughter's welfare and education:

' I don't know how she'd cope without me, she'd really miss me. I'm not going to be here when she's sixteen years, seventeen years old. I don't want her not using her brains and just getting a job. My daughter's not strong enough without a husband...If I'm not here what are you all going to do?...What are any of you going to do?' **f78,** 63yrs.

The fear that a further stroke could be more severe was reported more often than the fear of death. Sixteen participants expressed fearing 'a more severe one' generally, and some expanded this fear with thoughts such as: being wheelchair-bound, unable to communicate, or, ending up a 'vegetable'. For example, a male participant with major depression and GAD said:

'How much more could you be disabled?...It would be terrible not to communicate normally. I would find it awful to get used to and I don't think I could.'
m59, 75yrs

Anxiety appeared common amongst this group. Five of the eight participants diagnosed with GAD expressed concerns about a more severe stroke.

The nature of concerns often centred on being able to cope with 'becoming disabled'. A few participants expressed views that they felt unable to cope with something so 'awful' and others expressed their aversion to the idea of their family having to cope with 'this vegetable'. For example, a male participant with minor depression and GAD said:

'The thought of the disability that could follow stroke could be monumental for me, and my family, for example, speech and movement. I would think "What the hell is the point?" I couldn't deal with that. It worries me of how this could lead to a reoccurrence of any more disability' **m58,** 80yrs

The sharing of experience, and interpersonal nature of concerns, was apparent for four participants who worried about a loved one taking a stroke. For example, one man wished his wife would slow down, because:

'This stroke hit me like that, so could her…It's just that if this happened what would we do? That's why I want to get back to cutting the grass' **m66,** 62yrs

A female participant with minor depression expressed a similar sentiment:

'If my husband took one, how would it affect my quality of life, mine as well as his?' **f52,** 66yrs

The view that death would be preferable to a more severe stroke was expressed by eight participants. One man suggested he would consider euthanasia if he had a severe stroke. Concerns for others welfare and quality of life, permeated participants' views that severe disability would be worse than death For example, one husband said:

'It would be worse if not fatal and lingering on in a vegetative state. Rather better to have a quick "Goodbye" than have this vegetable you're going to take care of' **m33,** 66yrs

In general, a preference for death compared to a more severe stroke was reported matter of fact.

Participants' fears of recurrence often seemed to stem from their own personal experience, or, from their observations or knowledge of others experience. Some mentioned they had already had more than one stroke, and some the unpredictable nature of stroke as if to suggest it could be expected again. A few described having known someone who experienced recurrent strokes, and some participants recounted their observations of other patients in hospital, please see Table 16.4.1.

Table 16.4.1: Sources of recurrence fears from personal experience or observation

	Personal experience of more than one stroke	Unpredictable nature of stroke	Known someone who had progressively worse strokes	Observed other patients with recurrent strokes
Participants with depression/GAD (N = 22) [1]	1 (5%)	1 (5%)	2 (9%)	3 (9%)
Participants without depression/GAD (N = 38)	5 (13%)	5 (13%)	1 (3%)	7 (18%)
Total number of participants (N = 60)	6 (10%)	6 (10%)	3 (5%)	10 (17%)

[1] Diagnoses of depression/GAD were made using DSMIV criteria (please see Chapter 8, section 8.3)

Four participants who reported a prior hospital admission for a stroke mentioned it in the context of their chances or fears of recurrence. For example, one man's previous experience seemed to lead him to suggest that the doctors could not reassure him, and, he made a high estimation of the probability of a recurrence:

'Well they know and have a lot more experience, but as I've had two or three already they can't say "Alright now"...probably about five in ten' **m57,** 80yrs

Other participants who mentioned a previous history of stroke did not seem particularly concerned about recurrences. One female participant actually joked about it:

'That I've had it four times! Somebody up there is wanting me in a hurry, it's me who's not in a hurry to go!' **f47,** 82yrs

So it seems that participants who had survived multiple strokes often remained admirably stoic against the fear of future recurrences. Paradoxically, the experience of a second mild stroke seemed to make the possibility of a severe one seem less rather than more likely, for a male participant who did have GAD:

'I've often thought it could happen to me. But, it's never been that bad, for example, my memory is perfect...I've had two well ones so I could have another well one, but it's always at the back of my mind that I could have a severe one.' **m45,** 75yrs.

Interestingly, a male and a female participant not previously aware of previous strokes reported that they'd had more than one. Scans can sometimes reveal evidence of old lesions, which physicians may feel patients have a right to know about. However, while appreciative of the doctor's information giving, these participants appeared perturbed by the knowledge:

'I was quite surprised when the doctor said I'd had two…If I've had two strokes, I could have three or four! I used to think once you've had a stroke that was it'
m79, 83yrs

The lack of any forewarning prior to stroke, and its unexpected sudden onset was mentioned by six participants during this interview, for example:

'I felt so well pre-stroke, I felt fine, absolutely great, it was out the blue'
m66, 62yrs

The unpredictable nature of stroke seemed to enhance the idea that it could be expected again, for example:

'It just happens so suddenly, there's not even a warning…It can happen to anyone, anytime, that's all really' **f75,** 68yrs

This pattern of thought was actually mentioned by a man, diagnosed with depression, when he was asked to describe his understanding of 'What a stroke is?' at the beginning of the quantitative interview. His idea that a stroke is 'a dirty thing' which can 'strike' in the night was emotionally powerful:

'I'll tell you what a Stroke is, it's a dirty thing, I think it's a dirty thing. It means you're losing half the power of your body practically, you're going to bed normal and waking up not being able to speak or move and depending on other people to do things you'd normally do yourself. It's the dirtiest thing you can get. You've no idea when it will strike, how it will strike or what side effects it will bring'
m41, 69yrs

Only a few participants described personally knowing someone who had experienced a recurrent stroke in the context of recurrence fears. However, when they did, their accounts were highly salient. One man described his best friend's progressive deterioration through three successive strokes:

'Each one got worse, and now he is in a chair and can't speak' **m67,** 66yrs

A male participant with GAD, was afraid of re-enacting his father's very severe and eventually fatal stroke. Likewise, a female participant with GAD and depression reported:

'I'm concerned it could be like my mother's which was fatal...For two months she had TIAs and recovered, then one night I was restless and went to visit. It was the weekend so I got the Doctor to come in the morning and she slipped into unconsciousness for two days and then haemorrhaged and died. I thought she was doing quite well...So if I did have one it could be fatal' **f52,** 57yrs

Fears of taking another oneself were commonly accompanied by comments about having seen others with recurrent strokes in hospital. For example, one man was concerned, as he'd noticed patients already known by the nurses being admitted during his stay. Sometimes, the idea that another stroke would be more severe was implied through observations of others, for example, one man with depression said:

'Others have to be in wheelchairs, they can't talk and their memories are away' **m55,** 66yrs

Altogether, ten people mentioned observations of other patients with more severe or recurrent strokes. Interestingly, three of these participants were amongst the seven who were still in hospital at the time of the interview. They reported having listened to or talked to others, and gave fuller accounts of others' 'misfortunes', for example:

'Wee T___ in the bed opposite, that's his fourth! After listening to people who've had three or four, I think, I'm not having any more of this hospital! It would be frustrating to have to start doing all this again.' **m79,** 83yrs

16.4ii: Taking another, or not sub-theme 2- Prevention Issues

Some participants' accounts did reveal an orientation to risk factors or prevention issues. Some took a questioning stance, and a few had been thinking in depth their risk of recurrence or what they could do to prevent it. Others had specific issues about what they should or shouldn't be doing, or what they could or couldn't do to decrease their risks of further strokes.

A couple of participants actually estimated how likely they thought a recurrence would be. One man felt he had a fifty-fifty chance, while a participant, who was depressed, reported

'I'm just hoping it doesn't but there's a quite good possibility I could... I think it's more than likely' **m59,** 75yrs

In contrast, one man argued that he now considered himself unlikely as he had 'come a long way' so far. Retrospectively, it would have been interesting to directly enquire after all participants perceived chances of recurrence, because the above two estimations are troublingly high.

A couple of participants appeared to be weighing up their relative risks, partly by comparison to others. On the one hand, **f52,** 57yrs, who had depression and GAD was anxious about strokes in the family, but she also recognised that her chances were favourable in other respects:

'I feel myself I won't, but my mother did, she was sixty-four years and had a different kind of stroke. It has crossed my mind, but I don't think I will just because she did. In the family Aunties and Uncles have had strokes and heart problems. I would be worried about taking another, but age is for me' **f52,** 57yrs

Similarly, **m67,** 66yrs compared himself to his best mate who'd had three strokes. He was concerned because they were both active, but heavy drinkers. But, then he argued that he was never as overweight as his friend. However, he was also concerned that his heart problems might lead to a stroke:

'Especially as I've not got rid of angina. Two arteries behind my heart are not working, so I could have another one, even if I never had angina, it could happen for no reason anyway.' **m67,** 66yrs.

A questioning stance about prevention was fairly common, and fourteen participants brought up control-seeking issues. Five of these participants were men who revealed a proactive stance to controlling risk. They had already all made steps to have their blood pressure taken. One man asserted he was going to 'find out' how to 'narrow' his chances further and 'nip this in the bud'. Another had already read leaflets and was intending to learn more about exercise. Their assertiveness and sense of entitlement to doctors as a resource was apparent. Although they varied in how satisfied they were with their GPs, this did not seem to have hindered their determination, for example:

'I had to argue him down from a month to two weeks for my blood pressure checks!'

m48, 60yrs

Other participants who raised control-seeking issues, seemed to have been less assertive with professionals. Although they were interested in knowing more they hadn't sought medical advice or made plans to do so. Their knowledge levels varied and a few even asked me about recurrence and prevention in the interview. For example, a man concerned about recurrence asked:

'Whether it will? You tell me, do they come in cycles or what?' **m54,** 62yrs

Two participants seemed to be confused by the 'one side, other side' issue of brain to body function, and wondered whether they were more likely to have a stroke on the other side of the body. Sometimes their more passive orientation may have been because they feared what they might find out if they did make enquires. For example, one depressed female, had been refused medical insurance and reported being unsure whether go and see her GP to ask as 'at the back of my mind I don't want to know'.

A particularly troubling lack of knowledge was apparent for two male participants, with depression, who was still in hospital. One asked:

'What can be done to prevent it happening again?...Stress and worry may be important?...I haven't a clue how to control this!' **m41,** 69yrs

Then, he commented that he hadn't asked his named nurse about his concerns because he felt she had far too much to do. They were both unusual because, even with the aid of the checklist, they had been unable to make even one causal attribution in the quantitative interview. The other initially reported:

'I'm very curious to know what caused it for the simple reason to try and make sure it never happens again' **m64,** 74yrs

However, at another point he said he was concerned to learn more as 'I'd hate to think it could go any deeper'. Overall the less assertive participants with control- seeking issues were quite likely to be depressed (five out of nine) whereas none of the more assertive participants were.

Some participants raised concerns about whether they should or shouldn't avoid certain activities for fear they might 'trigger it off again'. For example, a participant with depression and GAD reported:

' Should I be doing the hoovering that's the big question? Someone told me the spring cleaning gave me the stroke. I'm frightened to do things in case of another stroke' **f62,** 87yrs

Likewise, a retired bar lady, with depression and GAD, wanted to clean her windows. But she was afraid of overexertion and 'getting a row for it' from her concerned daughter. The 'Should I/shouldn't I?' question seemed so anxiety provoking, as it created a tension between the idea one should not risk one's health and an almost moral compulsion that one 'should' be doing the house.

This paralleled the sense of having a role and continuity with a working life discussed in previously (please see section 16.2i) for example:

'Am I affecting myself by doing this? But, what's for you won't go past you…I'm one who cannae sit still, I've worked all my life…I would like to clean the windows, I feel I should be up doing something…Should I stop exerting myself? But, I don't want to be lying in bed' **f74,** 64yrs

A similar dilemma was faced by **f52,** 57yrs, who was very motivated to get back to work but who was worried that doing so may cause another stroke. Overall, four of the eight participants with 'Should I/shouldn't I?' issues had depression, and three of them were females with GAD.

For ten participants, the question was whether they could or couldn't change something, to help prevent exacerbating a recurrence. Some were concerned with reducing physical or mental stress in their lives. For example, one man hoped to be able to 'enjoy it without pushing it' in the garden next spring. Another hoped he could arrange to do less when he returned to work. Sometimes the issue was to avoid the stress of others problems. One man reported wanting to address his frail mother in law's living situation, partly to decrease his own stress. Two female participants reported conserving their emotional energies for themselves for the time being, for example:

'Putting myself higher on the list…not letting others stresses stress me. On the phone I felt a friends stress was off loading on me – I managed to distance myself which was difficult as it's not in my nature to do that.' **f49,** 60yrs

Participants who brought up the need to do less or be less involved with others generally seemed quite confident that they could or had done so.

Two participants reported they did not want to give up smoking. One man said it was just a problem for his sister and he didn't appreciate her nagging. A female participant, who attributed her depression to her blindness not the stroke, reported:

'It's an important indulgence in my limited life'

f46, 82yrs

Two other participants with depression/GAD reported struggling with giving up as they used smoking to cope in life. Despite the motivation of asthma as well as stroke, and having stopped in hospital, a female participant with GAD and depression reported starting again once she was home:

'I'm a fool but I do enjoy a cigarette…if worried grab for a fag' **f24,** 70yrs

A similar sense of powerlessness and lack of belief in his ability to stop smoking was reported by a young male participant, who had major depression:

'I can't stop smoking… I need to know how to deal with craving and other things to do instead' **m65,** 42yrs

Overall, three of ten participants with 'Can I?/can't I?' issues had depression, and they all reported smoking cessation as the issues.

A small number of participants seemed to be coping by countering recurrence fears with positive comments about their doctors or medical treatment. For example, one participant reported her concern about another one, but then that she'd 'put her faith' in her new prescription. Similarly, a male participant reported:

'I'm quite happy about the doctors doing their job. As an expert in one area, I'm quite happy to let them get on with it and follow their advice' **m38,** 60yrs

Interestingly, none of these participants had depression/GAD.

However, participants were more likely to seem lacking in medical reassurance, or to express concerns about negative attitudes from their doctors. A couple of the assertive participants criticised their GPs lack lustre approach. One man reported he had had to ask for blood pressure monitoring and was wary about 'being passed over' because of age. Another described, asking for physiotherapy and blood pressure checks as like 'arguing for concessions'. A female participant, with depression reported reluctance to ask her GP about causes for fear of 'holding him back'. Meanwhile, a male participant expressed the view he didn't think his doctors knew any more than he did.

Two depressed participants held particularly suspicious and saddening views. One participant thought her consultant may have decided not to see her because he suspects she still smokes:

'I think they never bothered sending me one because I smoked, I don't think he believes me *[about having given up smoking]...*' **f77,** 73yrs

She described feeling 'miserable' about not getting an appointment and being particularly worried because she has had a leaky valve for fifty years and her grandson (who worked in the Royal Infirmary as a porter) had told her this was too long. The young male participant with depression suspected his stroke was associated with the general anaesthetic he'd had for a cancer biopsy two days previously. However, he didn't believe he could have a frank discussion about this:

'I've never asked the doctors, I don't think they will give me a definite answer or will blame it on something that's not the cause at all' **m65,** 42yrs

Altogether six of the ten people scored as lacking reassurance or having an issue with 'ageism or prejudice' were also found to be depressed.

In contrast to the range of ways participants coped mentally with the issue of recovering or not (please see section 16.3iii) they appeared to be just trying not to worry about recurrence. This was done in various ways. Some participants reported attempts to block worrying about recurrence out, or to only permit thinking about it. This did not seem particularly successful for this participant, with depression and GAD:

'Am I going to take another one? I don't let it worry me, but it's the first thing I think.' **f24,** 70yrs

Similarly, others mentioned putting it 'to the back of their minds' but that it was still there, albeit 'deep down'. One man described feeling it 'at the back of my mind particularly' when he was reminded about it in the company of his friend who was severely disabled by stroke. Some argued that they resisted worry by: seeing it as a fruitless activity. Paradoxically others used the suddenness of stroke as an argument

for not worrying. This female participant seemed to using all these ideas, and more, to resist the temptation to worry:

'It is so sudden, there's no point worrying about it. I never really think about it – you die if you do and you die if you don't so why worry?' **f42,** 70yrs

The efficacy of strategies to block out or rationalise away worry about further strokes is ambiguous in this data. On the one hand, most of the eleven participants who made 'Why worry?' type comments were not depressed or anxious, however, three were depressed and had diagnoses of GAD.

Fatalistic ideas that nothing could be done to prevent a recurrence were expressed by eight participants. For example:

'If I will, I will and nothing is going to stop it' **f24,** 70yrs

The idea that 'nothing could be done to prevent a stroke' in isolation appears highly anxiety provoking. However, often participants' expressions of fatalism, seemed to be used as an adjunct to the argument that worrying was pointless. For example, **f42,** 70yrs above, and a male participant who stated:

'Nothing really, it's been and gone. If it comes back it does and que sera sera' **m69,** 65yrs.

The strength of some people's actual belief in fatalism was not convincing because they expressed it within a broader discussion of risk. For example one woman with GAD commented 'What's for you won't go by you' but continued to question whether over-exertion was a risk. Likewise, one man commented 'It could happen for no reason anyway' after a careful consideration of his behavioural and medical risk. Discussion of risk factors implies some belief in the possibility of control, and so, they seem to be using fatalistic sayings idiomatically, to imply only so much can be done and so why worry?.

Overall, depressed participants were slightly more likely to make fatalistic comments that 'nothing can be done'. The thoughts of a relatively young participant, with major depression, were particularly saddening and stronger than the

others. She actually expressed the belief that she was fated to have a further and severe stroke. Indeed, she reported 'not being totally unconvinced' that she had not already had further strokes. She had experienced 'fizzy feelings' in her head prior to her stroke and had been experiencing the same sensation since. She questioned whether 'it was worth it anymore?' and suggested that death would resolve her from her present worry and concern about recurrence:

'If something really serious happened and I died I wouldn't have these problems'
f21, 47yrs

16.4iii: Summary of relationship between Taking another, or not and depression/GAD

Overall, a wide range of negative and few positive beliefs about taking another stroke were reported. Three main beliefs concerning the nature of a recurrent stroke were reported ('death', 'a more severe stroke' and 'preference for death versus a severe stroke'). Various personal and vicarious experiences appeared to lie at the root of participants fears of recurrence ('personal experience of more than one stroke', 'unpredictable nature of stroke', 'known someone who had recurrent strokes' or 'observed other patients with recurrent strokes'). Many of these beliefs represented misconceptions, particularly recurrence fears seeming from seeing other patients in hospital with recurrent stroke, or ideas that it may happen again because when it does it happens suddenly.

Unlike previous main themes participants with depression/GAD only occasionally tended towards stronger or more emotive descriptions of the various negative beliefs about recurrence. However a few exceptions to this general pattern were notable. Participants with GAD as well as depression (5/8) seemed particularly likely to report fearing a severe stroke. Also two of the three participants whose fear was of repeating the fate of someone close to them had depression/GAD, but it is recognised that the numbers here are small.

Table 16.4.2: Number of 'Taking another, or not' beliefs and whether recurrence fear was reported as a main concern in life amongst participants with and without depression/GAD

	Recurrence fear a 'main concern in life'	Number of 'Taking another, or not' beliefs reported		
		0	1 or 2	3 or more
Participants with depression/GAD [2] (N=22)	7 (32%)	4 (19%)	6 (27%)	11 (53%)
Participants without depression/GAD (N=38)	1 (3%)	12 (31%)	13 (34%)	14 (36%)

[1] In the calculation, the codes WW? And NCSI were counted as one, as there was so much overlap between the two, and the code FM was ignored as it was not regarded as a fearful belief

[2] Diagnoses of depression/GAD were made using DSMIV criteria (please see Chapter 8, section 8.3)

Participants with depression/GAD were compared to those without in terms of numbers of 'Taking another, or not' beliefs and this is illustrated in Table 16.4.2. As can be seen, less participants with depression/GAD reported no 'Taking another, or not' beliefs, and more reported three or more 'Taking another, or not' beliefs than participants without depression/GAD. Also, more participants with depression/GAD reported fears of recurrence as a 'main concern in life' suggesting that it was a more dominant pre-occupation amongst them than amongst participants without depression/GAD.

Compared to the range of mental coping strategies to deal with the uncertainty of recovery reported in qualitative interviews (please see section 16.3iii) participants often appeared to be just trying to block recurrence fears. Some participants brought up issues of control and objective risk factor issues Of those who did, only a few reported being reassured by medical treatment or taking a proactive stance to getting it. Others appeared to lack basic knowledge, have unanswered questions or hold misconceived notions of behavioural triggers. In contrast to the common reporting of behavioural risk factors when specifically probed to do so in the quantitative interview, only a few brought up behavioural risks in this interview. The few who did were depressed and lacked confidence that they could quit smoking. Sadly, one depressed woman who had successfully stopped believed she had not been given a follow-up appointment or heart treatment because her consultant did not believe her.

Also relevant to this theme is the young woman who was too distressed to participate fully (please see Chapter 5, section 5.6). She reported having been told one of her arteries was 'thin as a piece of thread' and she explained that her reason for sitting holding her neck with her hands was due to the fear it would snap. The depressed participant described earlier as believing 'fizzy feelings' were multiple strokes, reported that her G.P had agreed with her at follow-up. A forty-two year old man, who met criteria for PTSD reported similar beliefs at nine months (please see Chapter 15, section 15.7) and he said that his physiotherapist had agreed. These views and the lack of alternative more optimistic views are very concerning.

Chapter 17: Comparative summary of main findings

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17.1: Forward

Quantitative univariate and multivariate results have been summarised in relation to the specific hypotheses (please see Chapter 11, sections 11.3iii.and 11.5; Chapter 13, sections 13.3iii and 13.5; Chapter 14, sections 14.3ii, 14.6). In this chapter the main findings from the quantitative study, the structured clinical interview study and the qualitative study will be summarised in relation to the objectives, which were to:

1) Investigate emotional distress
2) Investigate beliefs considered relevant to stroke patients' emotional distress
3) Examine associations between emotional distress and specific types of beliefs following stroke
4) Investigate the ability of initial beliefs to predict emotional distress over time

5) Explore the types of beliefs and nature of symptoms related to common depression and anxiety disorders
6) Explore patients' own experiences and concerns using a qualitative approach

Where appropriate comment will be made on the convergence/divergence of findings across the different methods of investigation.

17.2: Summary of the sample characteristics and results for the background variables

Sample characteristics

A consecutive series of eighty-nine stroke patients, without severe cognitive or language impairment made up the sample at baseline. Eighty-one of these patients were seen again at follow-up. There were approximately equal proportions of male and female participants. Their ages ranged from thirty-two-years-old to ninety-years-old and were normally distributed around the mean age of seventy-years-old (M=70.13, SD=11.29). Their social economic status tended to more affluent than deprived. Stroke severity scores suggested that the sample tended towards the lower end of the severity spectrum.

Descriptive results for other background variables

A majority of patients were found to be independent in basic activities of daily living according to the Barthel index (55% at baseline and 59% at follow-up) and a ceiling effect for this variable was found at baseline (M=18.27, SD=2.83) and at follow-up (M=19.44, SD=2.78). Ability to carry out more extended activities of daily living was more varied according to the Nottingham index (M=13.97, SD=5.57 at baseline) and was found to statistically significantly improve during the study period (M=14.72, SD=5.56 at follow-up).

Participants reported that they had high levels of social support available, indicated by a mean score of 73.87 (SD=20.99) where the top possible score was 100. Three fifths of participants reported having experienced at least one life event during the six-month period prior to their stroke. About half of participants reported having experienced at least one new life event during the course of the study period, and surprisingly most of these participants were those who reported having experienced life events prior to stroke. About a quarter of participants reported a pre-stroke history of depression at baseline (23/89; 26%) and at follow-up (21/89; 26%) and a cross-tabulation of these participants suggested that their reporting was entirely consistent across time.

Note on the reporting of univariate associations

Associations between independent variables and distress were tested with both Pearson correlations and Spearman's Rho. The findings were extremely similar (please see Appendix G, section G.3), which bolsters the findings. However, for brevity only the results for Pearson correlations will be summarised in this chapter.

Univariate associative results between background variables and distress using Pearson correlation

Female gender was found to associate with distress at baseline and at follow-up and across time using Pearson correlation. However, the correlation coefficients it produced were low and only statistically significant at the $p<.05$ level. Neither age, nor deprivation level produced a statistically significant association with distress in any of the analyses (please see Chapter 18, sections 18.6i and 18.6ii for discussion).

Stroke severity was not associated with distress at baseline, but was at follow-up and across time using Pearson correlation. The correlation coefficients it produced were low and only statistically significant at the $p<.05$ level.

Disability relating to more extended activities of daily living (Nottingham index) was associated with distress in both the cross-sectional analyses at baseline and at follow-up, but not across time as tested by Pearson correlation. The correlation coefficients it produced were low and only statistically significant at the $p<.05$ level. Disability relating to basic activities of daily living (Barthel index) was not associated with distress in any of the analyses.

Whether or not participants reported at least one life event was associated with distress at baseline using Pearson correlation, but not at follow-up or across time. The correlation coefficient it produced at baseline was low and only statistically significant at the $p<.05$ level. Social support was not associated with distress in any of the analyses.

Pre-stroke history of depression was associated with distress at baseline, at follow-up and across time using Pearson correlation. Unlike results for other background variables, the correlation coefficients produced between a pre-stroke history of depression and distress were moderate in size and statistically significant at the $p<.0001$ level.

Note on the summaries of the multiple regression results

In order to test the hypotheses as stringently as possible, two methods of backwards multiple regression analysis were used: the 'univariate' method (only independent variables with statistically significant univariate correlations with distress entered into the equation) and the 'stricter' method (all background variables entered into the first equation to control for the possibility that they may contribute in otherwise unforeseen ways). The findings between both methods were extremely similar (please see Chapter 11, sections 11.4; Chapter 13, section 13.4 and Chapter 14, section 14.4 and 14.5), which is pleasing and strengthens the findings. However,

for brevity only the results for the 'univariate' method will be referred to in this chapter.

Backward multiple regression results for the background variables

At baseline, two background variables (Gender and a pre-stroke history of depression) remained in the final regression model for distress. Gender was statistically significant at the $p<.05$ level and pre-stroke history of depression was statistically significant at the $p<.0001$ level. A pre-stroke history of depression was the only background variable to remain in the final regression models in all other multiple regression analyses and in all cases it was found to be statistically significant at the $p<.0001$ level. Therefore it was found to independently associate with distress at follow-up and to predict distress at follow-up even when baseline levels of distress had been controlled for.

17.3: Summary description of emotional distress

These findings relate to the first objective to:

- Investigate emotional distress

HADs distributions and means

Both at baseline and at follow-up the distribution of the distress measure (global HADs scores) was slightly positively skewed. Highly similar distributions were found for the HADs depression and anxiety sub-scales that made up the distress measure. Despite this variation in scores, mean HADs scores were low, please see Table 17.1.

Table 17.1 Summary table of mean HADs scores at baseline and follow-up

HADs scores at baseline		HADs scores at follow-up	
	Mean and (SD)		Mean and SD
HADs distress	9.10 (6.08)	HADs distress	9.38 (6.63)
HADs depression	4.51 (3.54)	HADs depression	4.62 (3.47)
HADs anxiety	4.58 (3.20)	HADs anxiety	4.78 (3.78)

Association between HADs distress, HADs depression and HADs anxiety scores

HADs distress scores were highly associated with HADs depression scores (r= .91, p<.0001 at baseline and r=.91, p<.0001 at follow-up).

HADs distress scores were highly associated with HADs anxiety scores (r= .89, p<.0001 at baseline and r=.92, p<.0001 at follow-up).

HADs depression and anxiety subscales were highly associated (r= .63, p<.0001 at baseline and r=.68, p<.0001 at follow-up).

This degree of inter-correlation between the sub-scales and the HADs global distress scores suggested it had good validity as the dependent variable distress measure.

Consistency in emotional distress across time

Emotional distress was found to be fairly consistent across time, using repeated measure t-tests and Pearson correlations (please see table 17.2).

Table 17.2: Correlations between baseline and follow-up HADs scores and t test results

Baseline – Follow-up	Correlation	Significance of correlation	t value	Significance of t
HADs Depression	.57	<.0001	-.32	n.s.
HADs Anxiety	.59	<.0001	-.41	n.s.
HADs Distress	.64	<.0001	-.39	n.s.

Comparison to the emotional disorder results obtained in the structured clinical interview study

The HADs global distress scores, and anxiety and depression sub-scales were all highly associated with the anxiety and depressive disorders (please see Appendix G, section G.4). This high level of correspondence offers support to comparisons that have been made between the quantitative study, the structured clinical interview study and the qualitative study results. It provides an indication of concurrent validity of the measure of distress with the emotional disorders, and vice versa.

17.4: Summary of descriptive results for the belief variables

These findings relate to the second objective to:

- Investigate beliefs considered relevant to stroke patients' emotional distress

Attributional belief variables

Casual controllability

Given a possible range of 0-4, the mean causal controllability scores reported were low and no statistically significant change in scores was found across time [M=1.48 (SD=.91) at baseline and M=1.74 (SD=.79) at follow-up].

'Why me?'

A minority of participants reported ever having asked 'Why me?' and no statistically significant change was found across time (39/89; 44% at baseline and 34/81; 42% at follow-up).

'Found meaning?'

Few participants reported they had found a positive meaning in having a stroke at baseline (31/89; 35%). An even lower proportion reported having found a positive meaning at follow-up (17/81; 21%) but this drop in scores was not statistically significant.

Self-evaluative variables at baseline

Acceptance of disability

Mean acceptance of disability scores were moderate at baseline, given a possible range of 0-32 on the scale [M=18.61 (5.96)]. They increased slightly at follow-up [M=19.49 (6.92)] but not to a statistically significant level.

Negative identity change

Mean negative identity change scores were low [7.91 (8.57) at baseline and 7.79 (8.13) at follow-up] and these scores were found to be statistically significantly consistent across time. The high standard deviation scores, median scores below the

mean (Median=5 at baseline and at follow-up) indicate a skewed distribution and a large degree of variation amongst participants.

As regards individual adjective items, the largest changes in 'before' versus 'now' identity ratings were for those items relating to ability (for example 'active', 'confident'). Relatively moderate changes were seen for adjectives relating to affect (for example 'worried', or 'unhappy'). Much smaller and often insignificant changes were seen for items reflecting interpersonal personality characteristics (for example 'friendly', or 'aggressive'). However most 'before' versus 'now' mean changes were found to be statistically significant at baseline and nearly all were at follow-up suggesting a tendency to see oneself less positively in many ways following stroke.

Shame

Given a possible range of 0-40, mean shame scores were low [M=12.31 (SD=4.79) at baseline and M=12.33 (SD=5.56) at follow-up] and these scores were found to be statistically significantly consistent across time. However, a few participants did report moderate levels of shame at both points in time.

Recovery and recurrence variables at baseline

Recovery locus of control

Given a possible range of 0-36, mean recovery locus of control scores indicated that participants typically reported a high internal locus of control regarding their recovery from stroke [M=24.61 (3.91) at baseline and M=23.89 (3.27) at follow-up]. Consistency testing suggested that the slight drop in scores across time was not statistically significant.

Confidence in recovery

Given a possible range of 0-10, mean scores indicated participants typically felt very confident about making a full recovery at baseline [M=7.94 (2.38)]. However, the mean score found at follow-up suggested a decrease in recovery confidence across time [M=6.59 (2.93)]. This drop in scores was found to be statistically significant.

Recurrence fear

Given a possible range of 0-32, mean recurrence fear scores suggested that fear levels were typically moderate [M=15.38 (4.56) at baseline; M=15.42 (4.66) at follow-up]. No statistically significant change in scores was found across time.

17.5: Summary of associations found between emotional distress and the belief variables

These findings relate to the third objective to:

- Examine associations between emotional distress and specific types of beliefs following stroke

Univariate associative results between belief variables and distress using Pearson correlation at baseline

Statistically significant small to moderately large associations between distress and all of the belief variables except 'Why me?' were found. Two of the self-evaluation variables were particularly highly associated with distress: acceptance of disability ($r=-.59$, $p<.0001$) and negative identity change ($r=.63$, $p<.0001$).

Comparison between background and belief variables at baseline

In contrast to 8/9 belief variables only 4/9 background variables were found to statistically significantly associate with distress at baseline. Overall, at the univariate level, the relationship between the belief variables and distress appeared stronger than the relationship between the background variables and distress in terms of the number, size and significance of associations.

Backward multiple regression results for the belief variables as compared to the background variables at baseline

All variables statistically significant at the univariate level were tested together and a highly significant final model ($R^2 = .65$, $p<.0001$) was obtained which suggests that almost half the variance in distress scores was accounted for. Over half of the belief variables (casual controllability, 'Found meaning?', negative identity change, shame

and recurrence fear) remained in this final model, suggesting that their statistically significant relationship with emotional distress was largely independent. Both disability variables were dropped from the equation, suggesting that participants' beliefs about the meaning of their disability were better associated with distress. Only two background variables (gender and pre-stroke history of depression) remained in the final model.

In summary, these results suggests that at baseline distress was associated with a sense of having changed for the worse as a person and in the eyes of others, without being able to find any compensatory positive meaning. Also, a lack of belief about being able to control risks associated with stroke and fearing one may have another one. These results appeared to be statistically independent of confounding by background variables.

Univariate associative results between belief variables and distress using Pearson correlation at follow-up

Statistically significant small to moderately large associations between distress and all of the belief variables except ''Found meaning?' and recovery locus of control were found. Two of the self-evaluation variables were particularly highly associated with distress: acceptance of disability ($r=-.73$, $p<.0001$) and negative identity change ($r=.73$, $p<.0001$).

Comparison between background and belief variables at baseline

In contrast to 7/9 belief variables only 4/9 background variables were found to statistically significantly associate with distress at baseline. Overall, at the univariate level, the relationship between the belief variables and distress appeared stronger than the relationship between the background variables and distress in terms of the number, size and significance of associations.

Backward multiple regression results for the belief variables as compared to the background variables at follow-up

All variables statistically significant at the univariate level were tested together and a highly significant final model ($R^2 = .73$, $p<.0001$) was obtained which suggests that almost half the variance in distress scores was accounted for. Three belief variables (acceptance of disability, negative identity change and recurrence fear) remained in this final model, suggesting that their statistically significant relationship with emotional distress was largely independent. Most background variables including disability variables were dropped from the equation, suggesting that participants' beliefs about the meaning of their disability were better associated with distress. In contrast only one background variable (pre-stroke history of depression) remained in the final model.

In summary, these results suggest that at follow-up distress was associated with a sense that one had changed for the worse as a person, being unable to accept ones reduced capabilities and also, ongoing fears of having further strokes. These results appeared to be statistically independent of confounding by background variables.

17.6: Summary of predictive results

These findings relate to the fourth objective to:

- Investigate the ability of initial beliefs to predict emotional distress over time

Univariate associative results between baseline belief variables and follow-up distress using Pearson correlation

Statistically significant small to moderate associations between distress and six belief variables were found (casual controllability, acceptance of disability, negative identity change, confidence in recovery and recurrence fear).

Comparison between background and belief variables at baseline

In contrast to 6/9 belief variables only 3/9 background variables were found to statistically significantly associate with distress at baseline. Overall, at the

univariate level, the relationship between the belief variables and distress appeared stronger than the relationship between the background variables and distress. However these results were not as strong as the cross-sectional results.

Multiple regression results for follow-up distress using baseline variables

All variables statistically significant at the univariate level were tested together and a highly significant final model (R^2=.43, p<.0001) was obtained. This was more moderate in size than models found in cross-sectional analyses. Two belief variables (acceptance of disability and causal controllability remained in this final model and one background variable (pre-stroke history of depression).

Given that acceptance of disability appeared to operate as a global representative of the belief variables (due to inter-correlations) this result broadly supports the ability of initial belief variables to predict emotional distress at follow-up However, not that much variance in distress was explained. To more stringently test the ability of belief variables to predict distress 'over time' the analysis was repeated taking baseline distress into account.

Hierarchical multiple regression results for follow-up distress using baseline variables and controlling for baseline distress

The final model obtained from this analysis that entered baseline distress before other baseline variables produced a final model (R^2=.49, p<.0001) that was not much larger than the one that did not control for baseline distress. Just one belief variable (causal controllability) and one background variable (pre-stroke history of depression) remained in this final model. This may be explained by consideration of the level of consistency in distress levels across time (please see section 17.3), which would have statistically disadvantaged those beliefs variables that were highly associated with distress from remaining in the model. As they stand these results suggest that a higher initial sense of control over perceived causes of stroke played a protective role against distress across time.

17.7: Summary of findings from the structured clinical interviews and comparison to quantitative and qualitative results

These findings relate to the fifth objective to:

- Explore the types of beliefs and nature of symptoms related to common depression and anxiety disorders

A high prevalence of depressive disorder was found (33% at baseline and 30% at follow-up). Approximately equal proportions of minor and major depressive disorder were found. Participants who were considered to have the cognitive symptom of worthlessness tended to report thinking about themselves as 'useless' because of their disabilities. Non-somatic symptoms discriminated between those with/without a depressive disorder better than somatic symptoms, particularly at baseline. Major depression was found to be more persistent across time than minor depression.

A high prevalence of anxiety disorder was found (35% at baseline and 33% at follow-up). Twelve participants (13%) at baseline and fifteen participants (19%) at follow-up met criteria for GAD. Only one participant who met criteria for GAD did not also meet criteria for one of the depressive disorders, suggesting a very high level of co-morbidity between depressive and non-specific anxious symptoms.

The exploration of beliefs and symptoms in relation to the criteria for the specific anxiety disorders (agoraphobia, social phobia and PTSD) suggested that there was not a perfect fit between DSMIV nomenclature and patients' reported experiences. Nonetheless, the data obtained from the structured clinical interview usefully highlighted the nature and relative importance of specific anxiety symptoms and beliefs:

- Symptoms of panic were rare
- Agoraphobia was common, but not always reported as problematic
- Stroke-specific fears of falling and shame were reported by participants with agoraphobia.

- Statistically higher levels of the continuous measure of fears of falling were found amongst participants with agoraphobia at baseline and follow-up
- A small proportion of participants reported severe levels of stroke-specific social shame/fear and high levels of related social avoidance
- Statistically higher levels of the continuous measure of shame were found amongst these participants at both time points and amongst participants with agoraphobia at follow-up
- Most PTSD symptoms were rare, however re-living symptoms were quite common but tended not to cause much distress and to fade with time
- A few patients reported severe PTSD like symptoms in association with catastrophic fears of recurrent stroke

Comparison to the quantitative and qualitative study

As described (please see section 17.3), a high level of correspondence was found between depressive and anxious disorders and HADs distress, anxiety and depression scores and this provides an indication of concurrent validity.

The sense of uselessness described in the depression interview corresponds to the quantitative study finding that negative self-evaluations and distress were highly statistically associated.

Beliefs about shame and fears of falling reported in the interviews for agoraphobia and social phobia correspond with qualitative reports and the quantitative finding that shame and distress were associated.

17.8: Summary of findings from the qualitative interviews and comparison to quantitative and structured clinical interview results

These findings relate to the sixth objective to:

- Explore patients' own experiences and concerns using a qualitative approach

Five main themes emerged from qualitative data, these were:

Main theme 1- Being like this

Sub-themes- Can't dos
Meanings and feelings
Specific fears and issues

Main theme 2- Getting back to normality, feeling normal, or not

Sub-themes- Getting back
What the future holds
Acclimatising (coping)

Main theme 3- Taking another, or not

Sub-themes:- Concerns about taking another
Prevention issues

Main theme 4- They're OK, I'm OK, or not

Sub-themes- Family concerns
Spouses and friends

Main theme 5- Maintaining way of living or thinking, or making changes

Sub-themes- It's a bad world, but it's nice to be nice
Keeping healthy
Work
Money helps
Getting/ staying at home
Getting old and to the end of life

The first three main themes were considered most centrally relevant to this study of beliefs in 'stroke' and 'its effects' and these results have been summarised in relation to depression/GAD previously (please see Chapter 16, sections 16.2iv,

16.3iv and 16.4iii). What I consider to be the most essential key findings will be summarised here.

Main theme 1- 'Being like this'- summary of key findings

- Most participants reported missing being able to do things.
- Participants with depression/GAD emphasised aversion to feeling reliant and the belief that one 'should' still be able to carry out valued roles.
- Participants with depression/GAD were more likely to describe themselves as useless.
- Participants with depression/GAD reported feeling down or annoyed more frequently and in stronger terms.
- Participants with social phobia and agoraphobia reported shame and fears of falling most often.

Comparison to the quantitative and structured interview study

- These results cross validate the diagnoses of depression/GAD as these participants were more likely to report negative feelings and more often reported strong feelings. However they also suggest that frustration/annoyance are emotions often experienced by stroke patients.
- In parallel to the association between distress and the belief variables acceptance of disability and negative identity change (for which the largest changes for 'before' to now' were found for items such as and 'independence' 'ability'); these qualitative findings reflect aversion to reliance and a sense that reduced capacity is unacceptable amongst participants with depression/GAD.
- Descriptions of believing one had become 'useless' amongst participants with depression/GAD corresponds to the structured clinical interview findings for depressive disorder.
- The spontaneous reporting of shame and fears of falls corresponds to the association found between the distress and shame measure and the agoraphobia and social phobia data.

Main theme 2- 'Getting back to normality, feeling normal, or not'- summary of key findings

- Participants reported wanting to get back to valued activities and normal life.
- A few participants without depression/GAD reported feeling they were back to normal already.
- Some participants reported uncertainty about recovery.
- Participants with depression/GAD were more likely to be pessimistic or suggest that life would be bad without sufficient recovery.
- Participants with/without depression/GAD reported a range of effortful coping strategies such as thinking about what at least they could still do.
- Participants without depression/GAD often said they were not worried about things, didn't mind their losses or that they were able to accept them.

Comparison to the quantitative and structured interview study

- These findings suggest that some participants with/without depression/GAD were perhaps more uncertain about recovery than the quantitative data suggests, but also backs up the association between distress and confidence levels.
- The finding that some participants reported devaluing, disregarding or accepting their limitations corresponds with the positive association found between acceptance of disability and distress in the quantitative study.

Main theme 3- 'Taking another one, or not'- summary of key findings

Most participants reported concern that they may have another stroke.

- A wide range of negative beliefs about recurrence were reported, such as concern about family history of stroke, fear of a severe stroke, or preference for death in comparison to a severe disabling stroke.
- A few participants without depression/GAD reported taking a proactive stance to prevention or that they felt reassured by their medical treatment.
- Other participants reported fatalistic beliefs that 'nothing' could stop another one, or misconceived notions of behavioural triggers, and there was a general tendency for participants to be coping by just trying not to worry.

- Few participants brought up issues involving the control of objective risk factors, those who did had depression/GAD and were worried about not being able to stop smoking.
- Participants with depression/GAD were much more likely to report that their fear of having another stroke was a main concern in their lives.
- One very depressed and anxious participant reported the catastrophic belief that she was experiencing ongoing tiny strokes in the qualitative interview and a couple of other very depressed participants did so elsewhere.

Comparison to the quantitative and structured interview study

- These findings, particularly the finding that some participants with depression/GAD rated recurrence fear as a main concern in their lives, correspond with the quantitative finding that recurrence fear and distress were highly associated.
- Insight into the nature and origins of recurrence fears is provided and the results suggest that it is not just the possibility of another stroke, but also the potentially severe nature of future stroke that is concerning.
- The finding that the few participants who reported a proactive stance to controlling risk did not have depression/GAD is correspondent with the finding that causal controllability scores were positively associated with distress. So is the finding that a few participants with depression/GAD reported being concerned that they could not stop smoking.
- However, these findings diverge in the sense that many participants reported very fatalistic ideas about prevention and misconceived ideas about triggering factors. This contrasts with the types of causal factors they had reported in the quantitative interview.

Main theme 4- They're OK, I'm OK, or not- summary of key findings

- Participants in general reported feeling reassured by the knowledge that their children and grandchildren were OK and derived pleasure from their company.
- Being able to provide family members with support was considered important and a few participants with depression/GAD were worried that they would not be able to do so in future.

- Participants with depression/GAD tended to be more concerned about burdening family members.
- A few participants reported feeling lonely and they tended to be single female participants with depression/GAD.

Comparison to the quantitative and structured interview study

- These results largely correspond with the quantitative results that found high levels of social support, but no association with distress. However, it may be that loneliness is relevant to a minority of distressed individuals particularly single females.
- Interpersonal concerns to be able to 'be there' for one's family and concern about burdening them with one's new disabled status may be more relevant to distressed reactions.

Main theme 5- Maintaining ways of living or thinking, or making changes- summary of key findings

- Participants who reported asking 'Why me? in qualitative interviews were all depressed. They often emphasised feeling it was unjust because they were young or had already had their fair share of misfortune in life.
- Many other concerns about changes in life or day to day life issues such as money were included in this theme but most did not seem to discriminate between participants with/without depression/GAD.
- The exception to the above was that participants with depression/GAD were more likely to report concern about other medical conditions such as cancer or heart problems.

Comparison to the quantitative and structured interview study

- Concerns about other medical conditions was not that surprising given the co-morbidity of stroke with other illness and the age of the sample, however it raises a methodological issue with the recurrence fear measure.
- The finding that 'Why me?' was reported by participants with depression/GAD qualitatively contradicts the lack of a statistically significant association between

this variable and distress at baseline. However, these findings suggest that a sense of injustice about having a stroke is distressing amongst a certain sub-set of distressed participants. This finding is actually consistent with the quantitative inter-correlative results for 'Why me' which is associated with age and a pre-stroke history of depression.(please see Appendix G, section G.1).

18: Discussion of methodological issues

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18.1: Limitations of the sample

The sample was drawn from a population of consecutive admissions to a specialist stroke unit in a University hospital in Edinburgh. This is less ideal than consideration of all strokes occurring in a well-defined representative community population. However the sample population may only represent a slight selection bias in terms of stroke severity (please see Chapter 5, section 5.3). Issues relating to the age and social economic status of participants are discussed in sections 18.6i and 18.6ii.

Approximately two fifths of patients who received a definite diagnosis of stroke and who survived the acute stage of stroke, were not introduced to this study because of communication deficits, mainly aphasia. Approximately a fifth of remaining participants, not already known to have a clear diagnosis of dementia, were then excluded on the basis of cognitive impairment screening (please see Chapter 5, section 5.6).

The exclusion of patients with severe cognitive impairment was merited on the grounds of the large number of questionnaire measures used and the considerations of reliability and validity (please see Chapter 5, section 5.4). The exclusion of patients with severe cognitive impairment represents a limitation to all quality of life research with older adults and medical populations in which there is a high proportion of these individuals (Sampson et al., 2003). The future development of alternative methods to assess subjective experience with reasonable reliability and validly amongst cognitively impaired individuals is a challenge for the future (UK Alzheimer's Society, 2004; Bedard et al., 2003; Lawton, 1997).

The high prevalence of aphasia following stroke suggests that the development of reliable valid tools to assess distress amongst aphasic patients should be prioritised in future stroke research (Lincoln, 2003). Avenues for the development of assessment of subjective experience may involve collaboration with speech and language therapists and the adoption of supportive communication techniques (Kagan, 1998). At the very least future

research should aim to avoid the inconsistent assessment, inclusion/exclusion and even reporting of aphasia common to past stroke research (Carson et al., 2000; Spencer et al., 1997).

In this study the language impairment assessment used and the criteria for exclusion (please see Chapter 5, section 5.4iv) was comparable to quality of life research conducted by speech and language therapy aphasia specialists (Hilari & Byng, 2001). Therefore it was a relatively inclusive approach that made efforts to recognise aphasic individuals residual capacities, in line with current incapacity recommendations (Scottish Executive, 2000). It was actually a combination of ethical committee regulations and the logistics of recruitment that led to the broad exclusion of patients who had aphasia immediately following stroke in this study (please see Chapter 5, section 5.6). This highlights a tension between protection and prejudice in the regulations that influence research practice.

In conclusion, this study aimed to achieve a balance between an inclusive sample selection and valid and reliable results, however this was constrained by the logistics of recruitment. Participation rates at baseline and follow-up were very high (please see Chapter 5, section 5.6) thus reducing bias from self-selection characteristics. However, the generalisability of this study is limited to stroke patients without severe cognitive or language impairment. However, within this limitation, it can be argued that the present sample is comparable to those in most other psychological stroke research studies reviewed in Chapter 2 that generally indicated exclusion of participants with severe communication and cognitive impairment.

18.2: Power and statistical methods

The sampling limitations discussed resulted in a sample size that was smaller than originally anticipated. However, as described previously (please see Chapter 7, section 7.3) the size of the sample was considered large enough to detect moderate sized effects.

The hypotheses were tested with both parametric and non-parametric correlative statistics to compensate for violation of parametric assumptions (please see Appendix G, section G.2). The findings across both methods were extremely similar, and this makes the results more robust. In addition, more rigorous testing of the hypotheses was conducted with both a 'univariate' and 'stricter' method of backward regression analysis to explore the possibility that background variables may be confounding association between belief variables and distress. The findings between both methods were extremely similar (please see Chapter 11, sections 11.4; Chapter 13, section 13.4 and Chapter 14, section 14.4 and 14.5). This is pleasing and makes the results more robust.

The findings for the cross-sectional analyses support the first main hypothesis that a relationship between distress and beliefs would be found at baseline and follow-up (please see Chapter 11, section 11.5 and Chapter, section 13.5 for description of support for the specific hypotheses). However, it is important to recognise that associations between beliefs variables and distress in cross-sectional analyses, even the independence of these associations as tested by regression analyses, do not tell us about the direction of the relationship. They do not show that negative beliefs cause distress.

The longitudinal design and statistical model used (please see 'stage 2' in Chapter 14, section 14.4, pages 221-225) allowed the second main hypothesis that negative stroke-related beliefs predict distress un-confounded by initial background variables to be tested. The hierarchical statistical model employed (please see 'stage 3' in Chapter 14, section 14.5, pages 226-231) allowed this hypothesis to be even more stringently tested by taking into

account baseline distress. However, predictive testing can only imply causality if predictor variables can be assumed to exist prior to the onset of the criterion (Haaga et al., 1991). This was not the case, I cannot assume that the negative beliefs studied developed prior to distress at baseline, and distress remained fairly consistent across the study period (Chapter 12, section 12.2iii).

At face value the findings only weakly support the second main hypothesis as both 'stage 2' and 'stage 3' testing only explained a small proportion of the variance in follow-up distress (please see Chapter 14, section 14.6i and 14.6ii). However, as discussed, the baseline belief variable acceptance of disability was collinear with most other baseline belief variables suggesting it was a global representative of the beliefs studied (Chapter 11, section 11.4). Its position, alongside causal controllability in the 'stage 2' predictive models of follow-up distress conceptually supports the involvement of the negative beliefs generally in the prediction of distress across time (please see Chapter 14, section 14.6i).

Causal controllability was the only belief variable involved in the final hierarchical/'stage 3' analyses. As it was not collinear with other belief variables, the general involvement of negative beliefs in the prediction of follow-up distress once baseline distress was accounted for was less supported (please see Chapter 14, section 14.6ii). However, it is worth considering that the lack of change in baseline to follow-up distress variables statistically disadvantaged other baseline variables from being able to 'add anything further' in these analyses (please see Chapter 12, section 12.2iii, Chapter 14, section 14.5i,). Also, that the hierarchical models (that included baseline distress), were not much stronger than those obtained using just the baseline variables pre-stroke history of depression, causal controllability and acceptance of disability (please see Chapter 14, section 14.6iii). Paradoxically, the very strength of association between some baseline belief variables with baseline distress actually would have put them at a statistical disadvantage in the prediction of follow-up distress once baseline distress was controlled for.

The theoretical implications of the cross-sectional and predictive analyses results and the support for the hypotheses are discussed in relation to cognitive theory and past stroke research in Chapter 19.

The quantitative results can be viewed with confidence in generalisability to other patients that the sample represents (Peabody, 1985). Statistical tests are based around group means. Therefore the results of this study provides information about the type of negative belief most likely to be encountered within the group of interest, or what may be regarded as a prototype distressed individual following stroke. However, while valuable, this process can gloss over important exceptions to the rule that may be encountered in clinical practice. Examples of this have been highlighted by the use of a mixed method, and will be discussed as appropriate.

18.3: Use of a mixed methodology

Quantitative and qualitative methods were used simultaneously. In addition to the main quantitative study of negative beliefs and distress, structured clinical interviews allowed 'quantitative' diagnoses of emotional disorders to be made and subjective beliefs relevant to specific disorders to be explored. Brief qualitative interviews were used to further explore participants' concerns. It was argued that convergent results across the different methods would bolster and extend main findings but that divergence could offer alternative explanations about 'what counted' to be generated (please see Chapter 4). The interest in this chapter is in methodological issues highlighted by the mixed method.

18.4: Self-report biases

Issues of bias in self-report have always been recognised in psychological research (Edwards, 1957). As face-to-face interviews were used, some individuals may have wittingly/unwittingly-biased responses towards what they thought I wanted to hear, known as 'demand characteristics' (Cooligan, 1994). In turn, as the interviewer 'un-blinded' to the hypotheses, I may have unwittingly socially reinforced questionnaire responses in line with my expectations (Barber, 1976, cited in Cooligan, 1994). In the clinical and qualitative interviews, this process is viewed in a different light and the interviewer is encouraged to probe for emotional symptoms or for patients' concerns because the purpose of enquiry is more questioning and exploratory.

Sometimes participants' responses may be constrained by social desirability, or beliefs about what is proper in the eyes of society (Fiske & Taylor, 1991). This may be relevant to the assessment of social support (please see section 18.6v). Patients may even be reticence about admitting to things ('deny') that they regard as very socially undesirable, or that makes them feel apprehensive (Cooligan, 1994). This issue may be relevant to smoking and incontinence (please see sections 18.6iii and 18.7i). Often authors have discussed potential bias in the assessment of emotional distress and disorder following stroke due to denial.

Denial may be common in the early stage of an emotional disorder (Stravraki and Vargo, 1986). House et al. (1989) report that a few of their stroke patients appeared to 'down-playing depressives' because they did not offer symptoms when first asked how they felt but could when they were questioned more specifically in a structured clinical interview. Fedoroff et al.(1991) and Kishi et al. (1996) report similar findings (please see Appendix G, section G.4).

A similar but more paradoxical construct, emotional agnosognosia (actual unawareness of emotional state) is described in the stroke literature (Black, 1993; Gordon et al., 1991; Hibbard et al., 1993; Spencer et al., 1997). It appears to be operationalised as a discrepancy between observed and reported

low mood (as denial would be), considered attributable to the stroke lesion site, and to bias the assessment of emotional symptoms by self-report questionnaires due to under-reporting (Spencer et al., 1997).

Both the HADs self-report questionnaire and the SCID interview were used in this study. The general correspondence found between them strengthens the findings of this study (please see Appendix G, section G.4). Specific methodological issues regarding the different assessments, including observation of denial or emotional unawareness are considered in the next section.

In summary, subjective bias within the data and results is acknowledged due to the possible influence of demand characteristics, social desirability, or denial. However, on balance, face-to-face interviews enabled benefits that are considered to outweigh these possible limitations. These were the participation of patients who could not read or who had visual neglect, and avoidance of problems with missing data.

18.5: Methodological issues-emotional distress and disorder

Comparison between the HADs and the SCID has highlighted certain methodological issues that will be discussed. These are not all necessarily relevant to the aims and hypotheses of the present study, but all are considered of general interest to emotional stroke research and/or clinical practice.

18.5i: Low mean HADs scores

Mean HADs scores obtained in this study were lower than may be expected given the prevalence of emotional disorders found. Mean HADs scores amongst those diagnosed with emotional disorders were meaningfully higher than amongst those without, but still lower than may be expected (please see Appendix G, section G.4, Tables 9 and 10). Higher mean HADs scores are usually found amongst other medically ill patients diagnosed with an emotional disorder (Bjelland et al., 2001; Herrman et al., 1997; Johnston et al.,

2000; Zigmond and Snaith, 1983). This concurs with previous results using this population (O'Rourke et al., 1998) and raises the possibility that the symptoms sampled by the HADs does not match the range of symptoms relevant to stroke patients.

The HADs depression sub-scale contains two mood items but particularly focuses on anhedonia (5 items) because this aspect of depression was considered most amenable to anti-depressant therapy (please see p362, Zigmond and Snaith, 1983). The results (please see Chapter 15, section 15.3 and 15.6) suggest that low self-esteem and worthlessness are non-somatic depressive symptoms with high relevance to stroke patients. Their absence in the HADs may partially explain the low mean depression sub-score obtained. However, this also has the benefit of limiting confounding between the HADs and the self-evaluative belief measures used in this study.

The HADs anxiety sub-scale was designed to address non-specific worry (two items), tension (three items), and panic (two items). The diagnostic results show that agoraphobia was very- and social phobia was relatively- common but rarely accompanied by panic symptoms (please see Chapter 15, section 15.4 and 15.7). This may be due to participants' phobic avoidance, and concords with epidemiological research with older adults (please see Chapter 1, section 1.3ii). HADs scores were higher amongst those with GAD than agoraphobia and social phobia (please see Appendix G, section G.4), which corresponds with the higher reporting of physiological symptoms for GAD in diagnostic interviews (please see Chapter 15, section 15.4ii and 15.7ii).

The overall low HADs anxiety sub-scale mean may be partially accounted for by inclusion of two panic items. Relatively low HADs anxiety sub-scale scores appear to accurately reflect the lack of physiological symptoms amongst those with agoraphobia and social phobia, but do not reflect the specific fears and avoidances involved in these disorders. However, this has the benefit of avoiding confounding between the HADs and the shame and fear of falling measures used in this study.

Despite low mean scores adequate variation in HADs distress scores for the testing of associations with independent variables was found (please see Chapter 10, section 10.2i and Chapter 12, section 12 2i) and this served the purposes of the main quantitative study effectively.

The operation of the HADs as a screening measure for emotional disorder is not relevant to the aims or hypotheses of this study. However, the results support the finding that a relatively low cut-off point may be appropriate if it is to be used as such (O'Rourke et al., 1998). Also that the inclusion of items addressing low self esteem, worthlessness and specific fears could be considered in the development of a questionnaire screening tool for use with stroke patients.

18.5ii: The issue of denial/emotional unawareness

As described in section 18.4, the possibility that stroke patients may deny or even be unaware of low mood is often discussed in the stroke literature. I did find that some patients appeared to 'downplay' low mood initially, but not other depressive symptoms during the SCID, as described by House et al. (1989). This may represent a witting/unwitting 'denial' similar to that encountered in other populations perhaps due to a coping response or culturally influenced reticence about discussing feelings amongst mainly older British adults (Watkins et al., 2001), or emotional unawareness attributable to brain damage (Black, 1993; Gordon et al., 1991; Hibbard et al., 1993). Some stroke patients may seem to struggle to describe their mood due to alexithymia or an 'absence of words for emotion' (Sifneos, 1972), that is fairly prevalent in the general population (Lane et al., 1996). Comparative studies are not yet available to enlighten this discussion (Spencer et al., 1997).

Statistical comparison between the HADs and the SCID suggests that despite potential under-reporting on mood items, the HADs was still meaningfully highly related to depression diagnoses (please see Appendix G, section G.4). It would be interesting in future research, to investigate under-reporting on specific self-report distress questionnaire items by comparing responses

amongst patients diagnosed with depressive disorder who do/do not seem to 'downplay' low mood in a structured interview. Also to conduct research that compares the issues of denial, alexithymia and emotional unawareness between stroke patients and age matched non-neurologically impaired populations.

18.5iii: Symptom thresholds for SCID items

The technique of the structure clinical interview that allows some leeway with the wording of questions and probing of responses provided confidence that participants were actually responding in line with the intended meaning of questions. However, a few issues regarding the clarity of certain symptom thresholds has been discussed (please see Chapter 15, section 15.3i). This issue may have relevance to the reliability of diagnoses and variation in prevalence estimates (please see Chapter 1, section 1.4ii).

18.5iv: The suitability of DSMIV defined emotional disorders

As discussed previously, the content of DSMIV criteria for depressive disorder appeared to reasonably 'fit' the pattern of symptoms reported by highly distressed participants. However, for many highly distressed participants, the criteria for GAD did too. Only one participant with GAD did not also meet criteria for major or minor depressive disorder. This supports Johnston's (1991) suggestion that a mixed anxiety-depression diagnosis may prove useful with stroke patients. However, the proposed DSMIV criteria for 'Mixed anxiety-depressive disorder' (Zinbarg et al., 1994), does not delineate symptom thresholds in detail and therefore may be difficult to apply reliably.

Findings obtained from the structured clinical interviews for common anxiety disorders have been summarised (please see Chapter 17) and the usefulness of these interviews for gaining insight into stroke-specific symptoms has been discussed (please see Chapter 15, section 15.9). A less good fit between DSMIV criteria and descriptions of agoraphobia, social phobia or PTSD and highly distressed participants' reported experiences was found. The

discussion of these issues is theoretically as well as clinically relevant and will be presented in Chapter 19 sections 19.4iii and 19.4vi.

18.5v: Construct validity of distress

The results of this study support the position that anxious symptoms and disorder are worthy of consideration in addition to depressive symptoms and disorder (please see Chapter 1, section 1.3ii). As discussed, there was much overlap between generalised anxiety disorder and depressive disorder (please see section 18.5iv).

HADs global distress scores were highly inter-correlated with the anxiety and depression sub-scales suggesting that the sub-scales are sampling a large degree of common variance (please see Chapter 12, section 12.2ii). The associations between HADs distress and the background and belief variables were similar in size and statistical significance levels to the associations between depression symptoms alone- and anxious symptoms alone- and these variables (please see Chapter 11, sections 11.3i and 11.3ii ; Chapter 13, sections 13.3i and 13.3ii ; Chapter 14, sections 14.3i and 14.3ii).

The HADs global distress scores, and anxiety and depression sub-scales were all highly associated with the anxiety and depressive disorders (please see Appendix G, section G.4). This high level of correspondence offers support to comparisons that have been made between the quantitative study, the structured clinical interview study and the qualitative study results. It provides an indication of concurrent validity of the measure of distress with the emotional disorders, and vice versa.

These results converge to provide construct validity to the use of the continuous measure of distress in this study.

18.5vi: Emotional distress reported in the qualitative interviews

The qualitative interviews involved questioning participants about their main concerns and also their main stroke-related concerns in a fairly probing manner. This may have been more conducive to accessing fearful beliefs than a more narrative approach (please see Chapter 9, section 9.2). For example, an extensive range of recurrence and preventative beliefs clearly emerged as the 'Taking another one, or not' main theme (please see Chapter 16, section 16.4). In contrast, previous qualitative studies have only reported one or two of these beliefs (please see Chapter 2, section 2.4vi).

Despite being based around 'concerns', meanings and feelings about what participants could no longer do (please see Chapter 16, section 16.2ii), ranged from missing things, having lost a sense of normalcy to a sense of low self-esteem or even uselessness which also supports the relevance of the dimension of depression/sadness following stroke. In addition, the qualitative results indicated that many participants were feeling annoyed or frustrated and some described feeling trapped or angry about their losses. These qualitative findings suggest that the dimension of anger may be relevant in distress following stroke and it would be interesting to follow this up with quantitative research.

18.6: Methodological issues-background variables:

Background measures consisted either of well-defined entities (gender and age) or scales for which good reliability and validity had been previously reported were used (please see Chapter 6, section 6.4). The only exception was the Nottingham index, for which reliability and validity data was not available. Nonetheless, some results were surprising and this raised certain methodological issues.

18.6i: Deprivation- Carstair's deprivation index

The very small numbers of participants classified with high deprivation scores is notable, but reflects the relative affluence of Edinburgh (Carstairs and Morris, 1991). Fifty-eight percent of participants' post-codes fell within the mid-range deprivation bracket. These tend to be areas of mixed material wealth/deprivation and so less accurate at identifying fine-grained material differences between individuals (Carstairs and Morris, 1991) and this reflected my observations while collecting the data. However, examination of the pattern of distress by deprivation scores (please see Appendix E, section E.5, E.7, E.9) suggests a wide range of variation in distress for most deprivation categories, not just those in the middle range. Therefore it is unlikely that the zero-order associations found between deprivation and distress would change with a larger sample.

18.6ii: Age

The distribution of age in this sample was normally distributed, and the reasons for this have been discussed (please see Chapter 10, section 10.1ii). There was not a statistically significant association between age and distress at either point in time, however examination of scatter-plots (please see Appendix E, section E.5, E.7, E.9), suggests that by follow-up distress levels were more spread out amongst younger as opposed to older participants. Certain issues specific to a few young participants were highlighted in the SCID and qualitative data, and theoretically interesting associations between age and the belief variables 'Why me?' and 'Found meaning?' were observed. These will be discussed in the next chapter. More rigorous investigation

regarding specific issues relevant to emotional distress and disorder amongst young and 'old old' stroke patients could benefit from age-stratified research.

18.6iii: Stroke severity and disability

As discussed, individuals with more severe strokes were probably under-represented in this sample due to exclusion of patients with severe cognitive impairment (please see Chapter 10, section 10.1iii). Participants also tended to have low levels of severe disability. For example, according to Barthel index scores, fifty-nine percent were fully independent at nine months; whereas forty-eighty percent were fully independent at six months in a study that used the same population but did not exclude patients with severe cognitive impairment (O'Rourke, 1996). The limited range of stroke severity and Barthel index scores puts these variables at a statistical disadvantage. However, this may have been somewhat offset by also measuring extended activities of daily living (Nottingham index).

The superior strength and statistical significance of associations between distress and the belief variables related to the effects of stroke compared to the stroke severity and disability measures is pleasing in view of the hypotheses. However, the belief measures may have benefited from certain aspects that the disability measures lacked. Similarly to past research (please see Chapter 2, section 2.4i), the qualitative results (please see Chapter 16, section 16.2i) suggests that patients miss not being able to do a more comprehensive range of daily activities, social and leisure pursuits than even the more 'extended' Nottingham index addresses. In contrast, the global and abstract nature of items within the self-evaluative belief variables makes them flexible measures (please see Appendix D, sections D.19 and D.21) that allowed individual participants to respond in relation to those activities they personally valued.

Qualitative research has emphasised that stroke patients tend to compare themselves and their abilities 'now' as opposed to 'before' the stroke (please see Chapter 2, section 2.3v). The self-evaluative belief measures, in particular the negative identity change measure, captured this sense of change.

However, the disability measures do not assess change in abilities from before to after stroke. By assessing disability statically rather than in relation to change following stroke, the Nottingham index contains a degree of redundancy. Some patients never drove, some never gardened, a few were unable to write letters and a few had never attempted to use a washing machine pre-stroke. However, not doing these things post-stroke would result in a points being deducted from the extended activities of daily living score (please see Appendix D, section D.13).

As disability was assessed by self-report its measurement was subject to self-report biases (please see section 18.4). Incontinence is a socially undesirable topic and possibly subject to under-reporting. Some participants actually discussed their embarrassment about incontinence (please see Chapter 16, section 16. 2iii), but I suspect others preferred not to even report it. One man's wife made a point of telling me her husband was actually severely incontinent when he was out the room. Two other men who had not reported incontinence went for a toilet break during the interview and I heard them shouting at their wives about finding trousers that looked the same to hide the fact they had needed to change.

It is possible that distress confounded the measurement of disability, because distressed participants may under-report ability. A lack of confidence could result in an unwillingness to test out and assess one's ongoing recovery. This possibility was suggested because a few participants were surprised at how well they were able to sign the consent form. Participants with agoraphobia would report that they do not walk outside but this does not mean that they were actually physically unable to (please see Chapter 15, section 15.4iii). Confounding between distress and self-reported disability would have worked against the hypotheses regarding association between distress and subjective beliefs about the effects of stroke.

18.6iv: Life events

A statistically significant association between life events and distress was only found at baseline, but not at follow-up. This is not that consistent with past research in which a more moderate sized statistically significant association was found at six months and one year respectively (Andersen et al., 1995; Bush, 1999). This may be because life events were measured differently in these studies. The overlap in the reporting of life events between the pre-stroke period, and the period of the study (please see Chapter 12, section 12.3iii) may represent a response or memory bias.

18.6v: Social support

The finding that social support was not statistically significantly associated with distress was surprising in view of past findings (please see Chapter 1, section 1.6iii). It may be that older participants tend to be very loyal and under-report a lack of support from others (Power, 2002, personal communication) or that they do not always feel entitled to it (Laidlaw et al., 2003). Most participants also emphasised how wonderful and caring their children, grandchildren and spouses were in qualitative interviews (please see Appendix H, section H.1i). Although as discussed, social support, or, more specifically a sense of loneliness, did appear to be a relevant factor to a small minority of depressed participants (please see Appendix H, section H.1ii).

It may be that social 'support' is not the most ideal choice of subjective social variable involved in emotional well-being amongst stroke patients. This may be particularly the case amongst samples consisting of mainly older British adults. This was suggested by spontaneous comments participants made about 'emotional support' items. Some suggested that they did not want someone to 'talk to', 'confide in' or 'understand' their problems and that they thought this was all a bit 'American'. The qualitative results suggested the need to give as much as receive support within the family and provided insights regarding other social aspects of participants' lives that seemed to be emotionally beneficial (please see Chapter 19, section 19.3).

18.5: Methodological issues-belief variables

A balance always has to be struck between using measures with well-established reliability and validity and the relevance of measures to the hypotheses and their acceptability to participants. The weakness of the single-item belief measures was recognised before conducting the study (please see Chapter 6, 6.9). However, on balance I decided it was better to choose measures with good face validity, than to abandon relevant hypotheses. Also, when a measure suited to stroke patients was not available, new ones were constructed and piloted.

18.5i: Casual controllability

As described (please see Chapter 6, section 6.6i), this was a complex variable that involved eliciting causal attributions before being able to question participants about their perceptions of future control. To maximise the reporting of causal attributions, a checklist of causes as well as probing open-ended questions were used. Different methods to elicit casual attributions can produce results will slightly different emphasis (French et al., 2002). Some participants were initially hesitant about reporting causal attributions (please see Appendix F, section F.2 for description). Therefore, it should be acknowledged that this measure may not be highly reliable. However, very similar proportions of different attributions and overall causal controllability scores were obtained at baseline and follow-up (please see Appendix F, section F.2, and Chapter 12, section 12.5ii), which provides an indication of consistency at the group level.

The causal controllability variable consisted of the mean of all causal controllability ratings made by an individual. This was fairly crude, because it did not account for varied relative responsibility ratings amongst causal attributions. Some causes, such as smoking and worry, (please see Appendix F, section F.2) tended to be rated as 'most responsible' more often than others, such as family history and cholesterol. Also some participants reported believing that the different risk factors they reported were acting in combination, for example, that worry was linked to smoking and both were

linked to high blood pressure. Finally, as discussed (please see Chapter 2, page 41), distinctions between agents of control and other control factors such as self-efficacy were not measured. Given the finding that higher causal controllability scores were predictive of distress across time, a measure that does at least weight relative perceived responsibility meaningfully and allow for synergistic causal thinking may be worthy of development in future.

The qualitative data indicated fatalistic and naïve attitudes about prevention. For example, that 'nothing' could be done to stop another stroke, or, that over-exertion may bring strokes on. This may seem incongruent with the finding that all but two participants had been able to report the types of causal factors described in the quantitative results. However, both sets of beliefs may operate simultaneously. One can be aware of distal risk factors and see these as being more or less controllable. Nonetheless, the actual moment in time in which a stroke occurs may still be seen as entirely unpredictable, or as triggered by something such as doing heavy housework. The checklist for causal attributions did not include an item such as 'no reason at all', but the qualitative results suggest that some participants may have endorsed it. Therefore, although mean causal controllability scores were low, they may have actually been an underestimation of some patients' sense that strokes are beyond control.

Some participants did not rate smoking as a risk factor until a later stage during the interview, for example when questioned about recurrence fear. This may be because smoking is a taboo subject. I was not convinced that two participants who reported having given up smoking really had. One had nicotine-stained fingers and when another told me he had stopped, his son shook his head to indicate this was not the case. A couple of participants said they were not convinced smoking was a risk factor at baseline but changed their mind at follow-up. A couple of participants who had initially managed to quit but relapsed during the course of the study reported the reverse. Although some bias (social desirability and the dynamics of addiction and denial), in the reporting of this attribution appeared evident, this in itself suggests that

smoking may be a particularly emotionally and cognitively demanding issue amongst stroke patients that is perhaps worthy of future investigation.

18.5ii: 'Why me?'/'Found meaning?'/Confidence in recovery

The variables 'Why me?', 'Found meaning?' and confidence in recovery were assessed with single items which is less ideal than the use of well standardised questionnaires. They have been used in past research with stroke patients (Larner and Sampson, 2000; Morrison and Johnston, 1999; Thompson, 1991) and so using them was therefore considered beneficial for comparative purposes. Also, alternative measures were not available. The variables 'Why me?' and 'Found meaning?' had a restricted range of scores and confidence in recovery was dichotomised because its distribution was so skewed. Therefore these variables were slightly disadvantaged in the multivariate analyses. It is possible that better, more reliable measures may have produced stronger results.

Some older participants commented that the ' 'Found meaning?' question was 'stupid' and the majority of participants reported that they had never asked 'Why me?'. Paradoxically, it seems that the question of meaning is only relevant subsequent to the question of 'Why me?' (please see section 18.6ii). This seems to be a pattern of thinking that is more typical of young patients or those with a pre-stroke history of depression. Therefore these belief variables may have been overwhelmed by these background variables in the multivariate analyses.

18.5iii: Negative identity change/ acceptance of disability

The variables negative identity change and acceptance of disability were assessed with multi-item questionnaires with reports of good reliability as well as some evidence of reasonable validity (please see Chapter 6, section 6.7i and 6.7ii). The flexible advantages of these variables at being able to tap perceptions of change and the comprehensive range of activities participants engaged in pre-stroke has already been discussed (please see section 18.6iii).

The negative identity change questionnaire contained a few items ('bored'. 'unhappy' and 'worried') and the acceptance of disability measure one item ('Because of the effects of my stroke, I miss the things I like to do most') that would have confounded the measurement of these beliefs with emotional distress. The extent to which this may have biased results is difficult to ascertain. However, as discussed the disability measures were also probably confounded with distress (please see section 18.6iii). Therefore, bias towards a type II versus a type I error due to confounding within the disability versus the self-evaluative measures was balanced out.

Strictly speaking it was not accurate to refer to the identity change measure as 'negative' identity change. For example ten participants reported no overall change and four even reported a slight positive overall change at baseline (please see Chapter 10, section 10.6ii). However, the majority of participants did report negative changes, and this title reflected the manner in which the measure was scored and indicated the direction of relationship with distress. The qualitative results (please see Append H, section H.2) and open-ended responses for the 'Found meaning?' item suggest that the content of the negative identity measure was not particularly conducive to accessing some possible positive changes. These were being less grudging, appreciative or committed to family members (please see Chapter 10, section 10.5iv), or more empathic to other disabled persons (please see Appendix H).

18.6iv: Shame

As discussed (please see Chapter 6, section 6.7iii), some participants complained about items in the first piloted scale. The stroke-specific shame scale we designed for this study was found to be reliable. It measured not just the experience of shame but also appreciation of others differential treatment (please see Chapter 10, section 10.6iii and Appendix C, sections C.1 and C.6). The positive items were simply reverse scored in this study but it would be interesting to develop this distinction further in future. The unusual distribution of shame by distress scores and its implications in statistical testing has been discussed previously (please see Chapter 11, section 11.2ii).

In itself this suggests that shame was an important problem but to just a minority of individuals. This concords with the results for social phobia (please see Chapter 15, sections 15. 4iv and 15.7iv) and the qualitative findings (please see Chapter 16, section 16.2iii).

18.6v: Recurrence fear

The adapted recurrence fear scale was found to be acceptable to patients and to have good re-test and internal reliability (Appendix C, section C.1 and Chapter 6, section 6.8iii). Compared to the very frightening and negative beliefs about recurrence reported in qualitative interviews (please see Chapter 16, section 16.4), the meaning of items in the recurrence fear questionnaire seem a bit diluted. Most of the questionnaire items address non-specific health concerns. Therefore its face validity as a fear of stroke recurrence measure is implicit not explicit. However, this was probably ideal because responses to the most direct item ('I worry about my stroke returning') seemed to be confounded by coping (please see Chapter 10, section 10.7iii). Also, participants reported such varying and idiosyncratic recurrence fears qualitatively (please see Chapter 16, section 16.4i) that a scale that included them all would run the risk of heightening participants' overall fear and of producing floor effects.

18.8: Summary of methodological issues

The main limitation of the study is considered to be the representative-ness of the sample. Unfortunately, the sample was biased towards those with less severe disability that is likely to be due to the exclusion of patients with aphasia and severe cognitive impairment. Methods that allow the psychological assessment of aphasic patients need to be developed. Ideally the interviewer would have been 'blinded' to the hypotheses, although I suspect hypotheses would be obvious to anyone trained to collect psychological data. Biases of social desirability and denial have been discussed and probably led to some slight inaccuracies regarding specific items of certain measures.

Methodological issues regarding the measurement of emotional distress and disorder have been highlighted. However, the general correspondence found between these measures strengthens the findings of the study. Issues of confounding between disability measures and self-evaluative belief measures have been discussed. However, because both the disability and the self-evaluative measures were somewhat confounded with distress, bias towards a type II versus a type I error regarding the main hypotheses is likely to be balanced out.

Chapter 19: Theoretical and empirical discussion

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19.1: Support for the main hypotheses in relation to cognitive theories

Cross sectional findings of independent associations between certain negative beliefs and distress offers support to the first main hypothesis that:

'A relationship between beliefs and emotional distress would be found at an initial point in time (baseline) and a later point in time (follow-up)'

This supports Beck's proposition that cognition has a primary place in emotional distress.

The results for the predictive analyses only weakly support the second main hypothesis that:

'Beliefs found at baseline would predict emotional distress at follow-up'

although alternative more supportive interpretations in light of multi-colinearity and the lack of variation in distress across time have been discussed (please see Chapter 14, section 14.6 and Chapter 18, section 18.2). The finding that acceptance of disability and causal controllability predicted follow-up distress suggests that they represent something with long-term rather than simply transient meaning to distress. The finding that causal controllability was predictive of variation in distress across time, goes some way to suggest that positive beliefs in the controllability of perceived cause plays a protective role against distress following stroke.

Although, Beck's (1987) theory does not claim causality (please see Chapter 1, section 1.7) it does suggest that underlying negative schemas of core beliefs contribute to the build-up and maintenance of emotional disorder via dysfunctional thinking processes. The weak support for the second main hypothesis could be cautiously interpreted as having relevance to this process. Ultimately, to test the role of cognition in the build-up and maintenance of emotional disorder, negative schemas rather than their products (negative beliefs), would need to be measured and tested in relation to the onset and variable course of emotional disorder (Haaga et al., 1991).

The operation of positive beliefs is not yet discussed in depth in cognitive theories of emotional disorder (Gillham and Seligman, 1999). The protective function of causal controllability reflected in this study actually provides a better theoretical match to Kelley's (1971) suggestion that well-adjusted individuals tend to bias their causal analysis to things perceived as controllable. However, the mean causal controllability score was low, suggesting that most un-distressed and distressed participants alike lacked this protective sense that their causal factors were being adequately controlled.

19.2: General comparison to past research

Past quantitative research (reviewed in Chapter 2), has provided support for associations between most of the belief variables and distress following stroke apart from causal controllability, acceptance of disability and recurrence fear, although mainly in univariate analyses (Ellis-Hill, 1998; Larner and Sampson, 2000; Morrison and Johnston, 1999; Morrison et al.; Thompson, 1991; Vine, 2003). Qualitative research has also highlighted the possibility that the self-evaluative belief variables and recurrence fear may be reported in stroke patients' descriptions of their experiences (please see Chapter 2, secions 2.3iii, 2.3v and 2.4vi). This study has extended previous findings by investigating the relative contributions of these variables to distress while controlling for key background factors. Also by combining the main quantitative study with simultaneous open-ended exploration of the beliefs amongst patients with emotional disorder.

The theoretical and empirical relevance of specific background and belief variables studied will be discussed in following sections. At a general level, the results support the general thesis that it is important to understand stroke patients' beliefs about 'the effects of stroke' as well as about the illness 'stroke' (please see Chapter 2, section 2.1). At present, the dominant theoretical and empirical models in health psychology focus on illness and illness concepts (Petrie and Weinman, 1997). Understanding of emotional distress amongst other disabled medical populations may also be furthered by clarification regarding the assessment of beliefs about the disabling aspects of the condition as well as about the underlying illness.

19.3: Theoretical and empirical discussion of background variables

Demographic variables- age, gender and deprivation

Examination of inter-correlative relationships (please see Appendix G, section G.1 and G.2), suggests that younger participants were less disabled and reported a greater sense of personal control regarding recovery, which may be explained by age-related potential for recovery. Younger participants were also more likely to report a pre-stroke history of depression. This makes sense in light of evidence suggesting depression may be a risk factor for stroke (please see Chapter 2, section 2.2iii). They were also more likely to ask 'Why me?' yet report having found a positive meaning in their experience. These results correspond with 'just world theory' and past research (Thompson, 1991). As discussed, the search for meaning may largely depend on perceptions of the injustice and unexpectedness of an event (please see Chapter 2, section 2.2ix and 2.2xi).

A minority of younger participants appeared more likely to experience certain rarer symptoms of distress. Younger participants were more likely to report trauma type symptoms of numbing or re-living (please see Chapter 15, section 15.7), and the belief that they were actually experiencing mini strokes (please see Chapter 16, section 16.4iii), than older participants. Tentatively, these findings complement the greater tendency to ask 'Why me?' amongst younger participants and reflects a sense of mental unprepared-ness. Major depression was more common amongst younger participants at follow-up. This may be explained by the experience of severe financial difficulties and broken relationships for those two younger participants who developed this disorder over time (please see Chapter 15, section 15.6). Overall, while some young stroke patients appear to do very well physically and mentally a few seem to fare particularly badly. These speculations regarding possible relationships between age and distress could benefit from age-stratified future research.

Female gender and emotional distress and disorders were found to associate. Interesting, a gender bias in the cognitive appraisal of 'stroke' and 'its effect' was not apparent. Similarly to past qualitative research (Anderson, 1992; Pound et al.,

1998), some female participants did report strong concern about their lost housewife roles; however equally some male participants emphasised lost roles such as driving just as much (please see Chapter 16, section 16.2i). Gender differences in distress may be partly attributable to mediation by lower levels of social support and ability to perform extended activities of daily living (please see Appendix G, sections G.1 and G.2); although gender overwhelmed the latter in the baseline 'univariate' regression analysis (please see Chapter 11, section 11.4iii). Female participants were twice as likely to live alone than male participants. Depressed female participants who lived alone quite often reported loneliness (please see Appendix H, section H.1ii). Tentatively, these interpersonal factors may be involved in the gender difference observed and this could be addressed more rigorously in future research.

The results of this study suggest that deprivation is unrelated to distress levels following stroke, which may seem surprising given the well-known lawfully graded relationships that exist between deprivation and both depressive symptoms and ill health (please see Stansfield et al., 2003 for a review). However, the strong level of association between ill health and depressive symptoms across levels of deprivation is not in itself much reduced by consideration of other factors associated with deprivation (Stansfeld et al., 2003). Caution is required in extrapolating from this epidemiological evidence that tends to be based on middle-aged rather than older population. At face value, this evidence supports the present finding that once the population of individuals who have actually had strokes is selected, material circumstances appear of little relevance to distress. However, an important exception to the rule may be younger patients with pressing financial commitments who appear to be very poorly served by insurance/ social security systems (please see Chapter 15, section 15.6).

Social support

The qualitative data did suggest that a few participants experienced degrees of loneliness, and so the concept of social support may have been relevant to their distress despite the lack of a statistically significant correlation for the whole group.

The social support variable essentially measures whether participants believe loved ones are supportive or whether they feel let down by them. The qualitative findings suggest that the reverse may be important; in other words, participants expressed concern not to let their loved ones down. They emphasised that they wanted to 'be there' for their children and grandchildren in emotional and practical ways. More distressed participants expressed concern that they were not, or may not be in future. Concern about being a burden to loved ones also associated with distress in the qualitative interviews.

Pre-stroke history of depression

The strong relationship between previous and subsequent episodes of depression is well-established and well-recognised amongst other populations (see for example, Coyne et al., 1999). Interestingly, perceptions of selective incidence ('Why me?') were fairly uncommon and inconsistently associated with levels of distress following stroke. However this sense of personal injustice was one of only two variables with which a pre-stroke history of depression was found to statistically significantly associate (the other being younger age). In qualitative interviews participants who reported a sense of injustice, also emphasised having been dealt quite profound difficulties in life (for example, a murdered husband, an abusive childhood, or multiple serious illnesses at a young age). In light of these considerations the relationship between a pre-stroke history of depression and distress following stroke does seem particularly unjust, but has practical implications (please see Chapter 20, section 20.3vi).

Stroke severity and disability

The findings of this study are fairly consistent with past research (please see Chapter 1, section 1.6iii), in that stroke severity and, or, disability were associated with distress in some analyses but not others. Overall, the results strongly support a relationship between subjective beliefs about stroke-related changed ability and self-evaluation but only weakly support a relationship between distress and disability as measured in this study.

19.4: Theoretical and empirical discussion of beliefs in distress following stroke

19.4i: Discussion of justice and meaning in having a stroke

The results provide support for the theory that a sense of injustice in one's fate ('Why me?) and conversely the finding of positive meaning are related to distress However the results for 'Why me?; and 'Found meaning?' were inconsistent. Only 'Found meaning?' at baseline remained in the regression models to suggest an independent relationship with distress. However, as discussed these variables may be particularly relevant to a subset of distressed patients- younger patients (please see section 19.3), those who believe they have already experienced a high level of misfortune in life (please see Appendix H, H.2i), or those with a pre-stroke history of depression (please see section 19.3). These results concur with just world theories and past research findings (please see Chapter 2, page 42 for the review).

19.4ii: Discussion of identity and acceptance of disability

The cross-sectional findings strongly support the relationship between these self-evaluative/subjective disability variables and distress. Particularly strong and independent associations between these variables and distress were found at follow-up and acceptance of disability was found to be predictive of distress across time. These findings were corroborated by the qualitative results (please see Chapter 17, section 17.8) and the structured clinical interview results for depressive disorder (please see Chapter 15, section 15.3). In contrast to the conclusions of past qualitative research (please see Chapter 2, section 2.3v) the results do not support a link between descriptions of 'body failure' and universal identity disruption.

A lot of variation in reports of identity change was found in both the quantitative and qualitative results. Negative identity change sometimes appeared to be painfully conscious and related to self-recriminating attitudes and concern about reliance on or burdening others in the qualitative interviews. These results for distressed participants concur with cognitive theory that emphasises negative self-evaluations in distress and the concept of 'spread' from Dembo et al.'s (1956) acceptance of disability theory (please see Chapter 2, section 2.3ii). The qualitative results also support acceptance of disability theory concepts and immunising theories of successful ageing as relevant to some participants who were not depressed or

anxious. These participants appeared to be able to stoically disregard, devalue or accept the effects of their stroke.

19.4iii: Discussion of social shame and fear of falling with reference to the results for 'agoraphobia' and 'social phobia'

The findings of this study support previous research (please see Chapter 2, section 2.3v) by demonstrating a univariate association between shame and distress. High levels of shame were only found amongst a minority of stroke patients. High levels of fear of falling were fairly common. Both shame and fears of falling were reported in the qualitative interviews, particularly by participants with 'agoraphobia' and 'social phobia'. Some participants emphasised that they were particularly concerned about their disability because their social circle was predominantly young; however, the findings are not entirely consistent with Pound et al. (1998) who suggest shame is not a problem to older adults.

Statistically the measures of shame and fear of falling were associated with diagnoses of 'agoraphobia' and 'social phobia'. The structured clinical interview results also highlighted that these stroke-specific fears resulted in avoidance. These findings support the theoretical concept of 'excess disability' (Laidlaw et al., 2003) as an explanation for how negative beliefs and distress can partially account for low levels of social participation amongst some stroke patients.

Opinions regarding the seriousness and/or the reasonableness of specific anxiety disorders and symptoms amongst stroke patients are conflicting (please see Chapter 1, section 1.4i). The exploratory results question any assumption that every patient who meets DSMIV criteria for agoraphobia has got a disabling psychological problem. A third of participants 'with' agoraphobia at baseline and half at follow-up reported that they did not mind staying in. This could be interpreted as passive acceptance, or, more positively, as successful adaptation as these participants seemed content to restrict their goals to their family and home. Criteria that include a corollary of related distress and dissatisfaction might be more appropriate for use with this population.

DSMIV excludes patients who fear the social impact of a medical condition from the diagnosis of social phobia Participants who were considered to have a significant problem with social shame/fear in this study were generally avoidant of the social situations they believed would cause embarrassment and yet dissatisfied with this. Some could not report whether they experienced physiological symptoms when facing these situations because they had been completely avoidant. They were also unlikely to recognise that their social fears as 'excessive or unreasonable'.

It is not possible to verify the social reality of reported experience, however as discussed (please see Chapter 15, section 15.4iv), the stroke-deficits participants found embarrassing were real. Therefore, 'shame' may be a more appropriate term than 'fear', because participants seemed to feel more or less 'marked out' rather than in danger of 'being found out'. It seems inappropriate that their negative social beliefs, feelings and avoidance are dismissed as not clinically significant in DSMIV. However, it also seems inappropriate to conclude that it is 'most judicious to apply the diagnosis of social phobia to these persons' as has been with spasmodic torticollis (Gundel et al., 2001) as this does not account for the stigmatising experience participants reported.

As discussed (please see Chapter 2, section 2.), stigma has to be perceived for it to become distressing. In addition to reports of negative experiences, participants who were considered to have a problem with stroke-related shame and avoidance also seemed to judge themselves harshly and highly value others actual negative reactions, or, be bias to perceiving others differential reactions as negative (i.e. as 'pity' not 'kindness'). Although the beliefs and avoidances of these patients did not seem entirely 'excessive or unreasonable' the negative bias involved in their thinking could be amenable to change and assertive strategies could be learnt to cope with actual stigma (Newell and Clark, 2000). Therefore it would seem useful to develop criteria based on modified DSMIV criteria in order to identify patients who may be described as having problematic stroke-related shame and social avoidance.

19.4iv: Discussion of beliefs in recovery from stroke

It was surprising that locus of control was only weakly and inconsistently associated with distress. Similarly, that although confidence in recovery was moderately associated with distress at the univariate level it was not in the multivariate analyses. These findings are inconsistent with past research that, at face value, suggests that these variables are actually predictive of distress across time (Morrison and Johnston, 1999; Morrison et al., 2000). However, as discussed, these results may have been confounded by the different timing of the measurement of distress and these belief variables (please see Chapter 2, section 2.4i and 2.4iii).

It is notable that recovery locus of control scores reported by patients in this study indicated a high level of internality, or personal sense of control regarding recovery. Also, the results suggest that participants felt highly confident about making a good recovery, particularly at baseline. Confidence in recovery scores were found to statistically significantly decrease across time. Bach-Y-Rita & Bach-Y-Rita (1990) suggest therapists are often taught to be conservative and avoid raising false expectation. However, it is argued that unrealistically high expectations are an important emotionally protective part of early adjustment (Holbrook, 1983). The results suggest the operation of the latter position amongst this sample of stroke patients. Despite the drop in confidence in recovery scores from high to less high levels across time, they remained inversely associated with distress at follow-up. This suggests that in most cases these patients' tendency towards high expectations initially were indeed emotionally beneficial.

Quite a few participants actually spontaneously suggested that their earlier optimism had been unrealistic, and that they 'really' knew this deep down all long but preferred to face it gradually, when they were responding to the confidence in recovery measure at follow-up They actually commented they were glad their therapists had not forced them to come to terms with the possibility of a limited recovery too soon. Therefore, the therapists involved with these patients may have been particularly encouraging in their orientation. Also, it has been shown that recovery locus of control is very amenable to modification (Johnston et al., 2000). It is plausible then that therapists working with these patients may have also been

particularly successful at nurturing internal orientation to recovery. If this is the case, then these positive clinical relationships may not be accounted for by the statistical findings.

19.4v: Discussion of fear of- and beliefs in control of- recurrent stroke with reference to the results for 'PTSD'

The results support and extend past findings that fear of recurrent stroke is emotionally involving (please see Chapter 2, section 2.4v). An independent statistically significant association between the recurrence fear measure and distress was found both initially and at follow-up. The qualitative results provided description of the nature (for example, fear of severe disability from a further stroke) and origins (for example, family history or observation of other patients), of recurrence fears. Theoretically these findings concur with cognitive theory predictions (Clark and Beck, 1988), that distress is heightened by-overestimation of severity, under-estimations of resources to deal with threat and over-estimation of probability.

With hindsight it would have been useful to systematically elicit patients' estimations of the likelihood of recurrence. One participant, who did spontaneously estimate his risk, thought he had a fifty-fifty chance and another thought it was 'more than likely'. In addition a few participants reported extreme fears of recurrence involving interpretation of physical symptoms. A couple reported sometimes getting very anxious because a headache may be the start of a stroke and a couple actually reported believing they had been experiencing multiple tiny strokes. Interestingly, these beliefs and anxious symptoms were generally reported in the PTSD interview and not in the panic disorder interview. Although the criteria for PTSD did not provide an ideal match with reported experience (primarily because distress was attached to future recurrence beliefs not the past event of the stroke they had already had), it did usefully help to identify these extreme cases.

As discussed (please see Chapter 18, section 18.7v) the fatalistic and naïve beliefs for example ('Nothing can be done', 'Should I be hovering?') reported in qualitative

interviews indicated an even more extreme sense of low controllability than the quantitative results regarding control over causal attributions. This may be because 'stroke' needs to be conceptualised as both underlying/distal causal factors ('smoking', 'blood pressure', 'worry') and triggers ('fate', 'no reason', 'over-exertion').

Causal controllability ratings were generally low. However, higher causal controllability scores at baseline were found to protective against distress across time and the theoretical orientation of this finding has been discussed (please see section 19.1). Sadly, the more detailed results for causal attributions highlights that often those factors rated as most responsible are also rated as least controllable (in particular smoking, worry and depressing experiences), please see Appendix F, section F.2 for further details. A few depressed participants did raise strong concerns about not being able to quit smoking in the qualitative interview and we know that enacting this behavioural change is very difficult (Irvin and Brandon, 2000).

The findings of this study raise questions about whether interventions can be devised to increase the majority of patients' sense of causal controllability. We know that information provision alone does not improve mood in stroke patients (Forster et al., 2001). However, interventions may need to address much more than knowledge to tackle complex addictive behaviours (physical dependency, and idiosyncratic control beliefs such as self-efficacy and locus of control). A greater sense of control may be encouraged by assessing and addressing some of the more naïve recurrence fear beliefs highlighted in this study, or, by nurturing the rare positive beliefs regarding medical treatment of blood pressure.

Chapter 20: Conclusions and implications

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22.1: Forward

The thesis was inspired by the plausibility of cognitive therapy to facilitate emotional adjustment to distress following stroke. Cognitive theories of distress and emotional adaptation to illness and disability theories were used to develop this study. Associations between negative beliefs in 'stroke' and 'its effects' and emotional distress and disorder amongst stroke patients were investigated using a mainly quantitative but also qualitative approach. The first main hypothesis that:

- A relationship between beliefs and emotional distress would be found at an initial point in time (baseline) and at a later point in time (follow-up)

was strongly supported (please see Chapter 11, section 11.4 and Chapter 13, section 13.4). The second main hypothesis that:

- Beliefs found at baseline would predict emotional distress at follow-up

was also supported but less definitively (please see Chapter 14, section 14.6 and Chapter 18, section 18.2).

The main quantitative findings have been discussed in relation to the specific hypotheses (please see Chapter 11, section 11.5; Chapter 13, section 13.5; Chapter 14, section 14.6). The findings of the qualitative interviews have been summarised in relation to diagnoses of depression/GAD. The main findings of the quantitative, structured clinical interview and qualitative study have been summarised and compared. Methodological issues have been discussed (Chapter 18) and the results have been discussed in comparison to past research and relevant theory (Chapter 19). In this final chapter, I will highlight what I consider to be the most key findings and make suggestions regarding their potential implications for future research or interventions.

20.2: Key findings and their implications

20.2i: The nature of emotional distress following stroke

Descriptive results for emotional distress and disorder support the position that anxiety is important as well as depression following stroke (House 1996; Johnston, 1991). Anxiety disorder and symptoms were as common as depressive disorder and symptoms. There was much overlap between these measures, particularly generalised anxiety disorder, depressive disorder and the continuous measure of emotional distress. These results support the use of the distress construct as the main subject of study in this thesis.

Nonetheless in addition to worry, the nature of anxiety tended to be characterised by specific fear and avoidance (please see section 20.2iv) while panic symptoms were rare. This supports and extends previous findings from community studies of older adults and stroke patients (Burvill et al., Flint, 1994; Kay, 1988; Sharpe et al., 1991).

A mixed approach to the measurement of emotional distress that used both a continuous measure and criteria for emotional disorders highlighted the preceding issues. The qualitative finding that participants often felt 'frustrated' or 'annoyed' suggests another relevant emotional dimension to address in future research.

20.2ii: Beliefs in 'stroke' and 'its effects' and their association with- and prediction of- distress following stroke

I think it is fair to conclude that most beliefs in 'stroke' and 'its effects' studied were related to distress following stroke to some extent. The independence of associations found between distress and negative self-evaluation and recurrence fear suggests these are key beliefs relevant to stroke patients' distressed reactions. It seems fair to cautiously conclude that a lack of certain more stoical beliefs (acceptance of disability and causal controllability), appear meaningfully related to distress across time.

These quantitative findings were further supported and elaborated by the structured clinical interview and qualitative study.

20.2iii: Negative self-evaluations following stroke

Consistent with cognitive theory, all three methods of exploring distress emphasised associations with a negative view of self. The quantitative results suggested that negative self-evaluation, particularly an inability to accept reduced capacity and to see oneself in more negative terms was related to distress. Patients meeting criteria for depressive disorder often described themselves as 'useless' and their self-recriminating beliefs about what they 'should' be doing, and aversion to feelings of reliance on- or being a burden to- others was evident in the qualitative interview. In contrast, some participants who were not depressed or anxious appeared to stoically disregard, devalue or accept lost activities. These results concur with 'immunising' theories of successful ageing (Brandstanter, 1999) and acceptance of disability theory (Dembo et al., 1956). These beliefs appear to be tapping something fundamental to the person. Therefore, cognitive therapy that aims to address underlying negative assumptions and values and core beliefs maybe of benefit.

20.2iv: Self-confidence and confidence in recovery

Stroke patients often report a loss of confidence following stroke. More specifically convergent lines of investigation highlighted that fears of falling and shame were distressing to a sub-set of patients and involved phobic avoidance. These issues may be regarded as 'excess disability' (Laidlaw et al., 2003). If stroke rehabilitation is to meet its aim to promote social participation, these issues merit consideration. Rehabilitation patients are often reported to be unrealistically optimistic about recovery. These patients were very confident about their recovery initially, but this decreased over time. If anything their initial confidence appeared to be emotionally beneficial. Locus of control was inconsistently statistically associated with distress. However, patients reported notably high levels of internal control. It may be that the therapists involved with these patients had nurtured this and that the statistical results fail to reflect the benefit of their positive clinical approach.

20.2v: Fear of- and beliefs in control of- recurrent stroke

All patients in this sample knew that they may have another stroke and the recurrence fear measure was strongly related to distress. Varied types of recurrence fears were reported from concern about over-exertion, fear of severe dependency, and very occasionally catastrophic beliefs that multiple tiny strokes were regularly experienced. Further research is required to investigate whether there is a general tendency to over-estimate the likelihood of recurrence, and to what extent.

Belief in the controllability of risk factors tended to be low. Certain risk factors were regarded as more potent than others. A few particularly depressed and anxious participants reported distress about trying to control risk, particularly smoking. In contrast, a greater initial sense of causal controllability was shown to be independently protective against distress across time. This finding concurs with Kelley's (1971) attributional theory of control. Information provision, such as leaflets about stroke and risk factors, appears insufficient to reduce distress (Forster et al., 2001). However, interventions that actually address patients' idiosyncratic fears and misconceptions about recurrence and empower a sense of causal control may be beneficial.

20.2vi: Qualifications to a cognitive explanation for distress following stroke: A pre-history of depression and initial levels of distress

A history of depression in life prior to stroke associated with distress at baseline, at follow-up and was predictive of distress across time. These results are unsurprising in light of research with other populations (Coyne et al., 1999; Hammen, 1997). Inter-relationships between a pre-stroke history of depression and other factors (age and 'Why me?') have been discussed, are theoretically interesting and highlight the injustice of its association with subsequent distress (please see Chapter 19, section 19.3). Unfortunately, a pre-stroke history of depression is un-modifiable. Its pervasive influence, together with the influence of prior distress on subsequent distress, qualifies support for an explanation of distress following stroke in terms of the beliefs in 'stroke' and 'its effects' that were studied.

These sober findings have practical implications. The inclusion of- and the quality and reporting of assessments for- a pre-stroke history of emotional disorder has been inconsistent in stroke research to date (Spencer et al., 1997). The importance of controlling for this issue in future research is underlined, particularly because it may actually increase the risk of stroke occurrence (please see Chapter 2, section 2.2iii). Influences regarding an individual's emotional state immediately pre-stroke may well be ongoing after stroke. This could prove challenging to therapeutic efforts and should be particularly controlled for in intervention studies. In clinical practice, knowledge of pre-stroke history of depression may prove advantageous in the identification of patients most vulnerable to high levels of distress both initially and in subsequent months.

20.3: Concluding comments

A high prevalence of emotional distress and disorder was found at both an initial- and later-point in time following stroke. Given the reality of physical and functional losses following stroke, commonsense suggests that this is 'understandable'. Nonetheless, participants emotional responses showed much variation, that was only weakly associated with the variation in stroke severity and measures of disability. Stoical reasoning suggests that:

> "Lameness interferes with the limb, not with one's faculty of choice. Say this at each thing that happens to you, since you will find it interferes with something else, not with you."
>
> Epictetus, quoted p.453 in Moorey, 1996

and modern cognitive theory emphasises negative beliefs about the self, one's position in the world and one's future prospects in emotionally distressed states (Haaga et al., 1991). The results support a relationship between distress and beliefs about 'stroke' and 'its effects', qualified by the pervasive influence of a pre-stroke history of depression and initial distress levels across time. Particularly strong relationships between distress and self-devaluing beliefs regarding the effects of stroke, and fear of the possibility and nature of future strokes were found. A positive sense of control over causal factors appeared protective against distress across time. In conclusion, this study provides qualified support for cognitive explanations of distress amongst stroke patients. A cognitive therapeutic approach that addresses, the scope and precipitants of beliefs identified in this study may help promote emotional adaptation following stroke.

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LOTHIAN RESEARCH ETHICS COMMITTEE

APPLICATION FORM

For official LREC Use Only	*For official LREC Use Only*
1702/ / /	

INSTRUCTIONS: Please complete in type. Please place a circle around Yes/No options as appropriate. A version of this form is available on disc from the Secretary of the LREC.

It is essential that this form is completed fully and sent with relevant enclosures. **You should not simply refer to the protocol but complete the form with the information requested.** Please refer to the accompanying Guidance Notes when completing the form and complete the checklist before sending. Where a question is not applicable it is important to make this clear and not to leave it blank. **It is important that the language used in this application is clear and understandable to lay members**. All abbreviations should be explained.

Applicant's Checklist

Please indicate if the following have been enclosed by underlining or placing a circle round Yes/No/Not applicable options.

Application Form (**seventeen** copies)	Yes	
Full protocol (**seventeen** copies)	Yes	
Application Fee of £400		Not applicable
Research subject consent form (**seventeen** copies)	Yes	
Research subject information sheet (**seventeen** copies)	Yes	
Advertisement for research subjects (**seventeen** copies)		Not applicable
GP/consultant information sheet or letter (**seventeen** copies)	Yes	
Interview schedules for research subjects (**seventeen** copies)	Yes	
Letters of invitation to research subjects (**seventeen** copies)	Yes	
Questionnaire* Not yet finalised (**seventeen** copies)	Yes	
Researchers brochure or data sheet for all drugs (one copy only)		Not applicable
Statement on compensation arrangements (**seventeen** copies)		Not applicable
CTX/CTC/DDX (one copy only)		Not applicable
Annexe A** (**seventeen** copies)		Not applicable
Annexe B*** (**seventeen** copies)		Not applicable
Annexe C**** (**seventeen** copies)	Yes	

* *Please indicate whether or not this is the final version*

** *Required if the study involves the use of a new medicinal product or medical device, or the use of an existing product outside the terms of its product licence. Annexe A is attached to the Application Form.*

*** *Required if the study includes the diagnostic use of ionising, radiation (radioactive materials or X-Rays). Annexe B is attached to the Application Form.*

**** *Information concerning local researchers should always be given where possible at this stage. Annexe C is attached to the Application Form. Please make additional copies as necessary.*

SECTION 1 **Details of applicant(s)**

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1. Short title of project:

The psychological impact of stroke.

Full title:

Perceived health status and self concept change as predictors of emotional distress following stroke.

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2. Principal researcher (who will be responsible for dealing with the LREC and the local R&D Office)

Surname:

Townend

Forename:

Ellen

Title:

Miss

Present appointment of applicant:

Psychiatry MRC PhD student

Qualifications:

Psychology MA Hons & Health Psychology MSc

Address:

Work address:
Department of Psychiatry/ University of Edinburgh/ 2nd fl, Kennedy Tower/
Royal Edinburgh Hospital/ Morningside Park/ EDINBURGH/ EH10 5HF.

Tel:
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Address

Home address:
3F2, 27 Stewart terrace/ Georgie/ Edinburgh/ EH!! 1UW

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E.L.Townend@sms.ed.ac.uk

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3 Please give an approximate figure for the number of trials/studies in which the principal researcher has been involved over the past year

Two

---

4. Names, titles and qualifications of other local researchers working on this project

Supervisors:

Dr Michael Sharpe, MA,MB,MRCP,MRCPSYCH, Senior Lecturer in Psychological Medicine, University of Edinburgh. Honorary Consultant Psychiatrist LUHT and LPCT.

Dr Debbie Tinson, M.appSci,PhD (Consultant Clinical Psychologist), Lothian Primary Care NHS Trust.

Also:

Dr Martin Dennis, MBBS,FRCP,MD, Reader in Stroke Medicine and Consultant physician LUHT

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5. Who is sponsoring the study?

Contact name:

Organisation: Medical Research Council

Address:

20 Park Crescent,
London
W1N 4AL

Tel:

0171 636 5422

E-Mail:

students@headoffice.mrc.ac.uk

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6. Drug Company Reference Number

N/A

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7. Funding

Please give full details where applicable of:

a) Payment to subjects

N/A

b) Payment to Trust/practice/research funds, etc. *(specify institution(s))*

N/A

c) Personal payment or personal benefit to researcher

N/A

Is payment:

i) A block grant *Yes*

ii) Based on the number of research subjects recruited? *No*

If yes, how much per patient:

d) Details of other benefits, e.g. equipment

N/A

e) Details of NHS Trusts and hospitals/facilities to be used

None

f) Will the costs incurred by the institution be covered by the payment? *N/A*

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8. What other researchers are/do you intend to be involved in this project? (Details of researchers added subsequently must be notified to the LREC)
Please use the form attached at Annexe C

Professor Mick Power, BSc, D Phil, MSc, Professor of Clinical Psychology.

SECTION 2 Details of project

*This section must be completed fully. A copy of the protocol should be enclosed with the application form, but it is **not** sufficient to complete questions by referring to the protocol.*

9. Aims and objectives of project *(Maximum. 250 words)*

AIMS:

1) Study a cohort of stroke survivors with the aim of identifying **cognitions** relating to their **psychological understanding of stroke** and **self concept change related to the effects of stroke** (disability acceptance, interpersonal shame and identity change).

2) Investigate the relative contribution of these cognitions to **emotional distress** over time.

3) Combine data from interviews with depressed participants and previous questionnaires to develop a **stroke specific cognitions scale** addressing their 'psychological understanding of stroke' and 'self concept'.

In order to study the relative importance of these cognitive variables other potential predictors of depression (social support, social integration, life events, prior history of depression) will be controlled for.

HYPOTHESES:

1. Emotional distress is associated with

   - more negative psychological understanding of stroke (stroke representations)
   - more negative self concept related to the effects of stroke

2. Anxiety will be associated specifically with stroke fear and less perceived control

3. Depression will be associated specifically with negative self-concept

4. Psychological variables at 1 month will predict distress at 6 months

10. Scientific background of study *(Maximum. 250 words)*

1. Background

Patients often develop long term distress after stroke. Indeed a 20% prevalence was found amongst stroke patients in Lothian (O'Rourke, 1996). Understanding the causes of stroke patients' distress will aid development of helpful interventions.

Biological predictors of post stroke depression, such as lesion laterality have been revealed as poor predictors of post stroke depression (Carson et al, in press). Meanwhile there has been little research investigating psychosocial predictors of depression. As stroke survivors are faced with significant loss, life threat and residual disabilities, it does seem likely that negative thinking may produce subsequent distress.

Some promising results have been found. Changes in stroke survivors sense of identity and perceptions of social devaluation were found to associate with distress by Ellis-Hill (1998) and Vine (2000) respectively. Stroke survivors who self-blamed or who asked 'Why me?' were found to be more depressed than others (Thompson, 1991). However, attributions of physical causes and confidence in recovery have been found to negatively correlate with distress (Thompson, 1991, Morrison, 1999).

However these studies have generally been conducted with small samples. There is now a need for more rigorous and wide ranging studies in which various psychological factors are set against other known predictors of depression in order to assess their relative importance

11. Brief outline of project including outcome measures *(Maximum. 250 words)*

Participants

150 consecutive stroke admissions to the Western General who meet the inclusion criteria.

The first 15 participants who are found to have major depression, and similarly aged non-depressed participants will also be given a semi-structured interview. This qualitative data will undergo content analysis and be used to develop a 'stroke specific cognitions questionnaire'. This questionnaire will be administered by post.

Measures

Structured interviews will consist of verbal administration of various scales which measure the following variables (please see protocol for further information)

Emotional distress (as a total score and separate anxiety and depression sub-scores)
Anxiety and depression as clinical diagnoses.

Psychological Understanding of stroke (beliefs in causes, acceptance of stroke, control and confidence over recovery and fear of recurrence).

Self-concept (identity change, disability acceptance and interpersonal shame).

Non-psychological factors (disability, prior depressive episodes, recent life events: and social support).

The semi-structured interviews will be used to elicit depressed patients key cognitions relating to everyday problems, understanding of stroke and beliefs in self concept change due to the effects of stroke.

Procedure

Once consent obtained, participants will receive two structured interviews. The first in hospital and the second at home six months later. They will be carried out in private and last approximately 1 ½ hours.

12. Proposed start date and duration of project

Start: July 2000

Duration: 2 years

13. Study design (e.g. Randomised Controlled Trial, cohort, case control, epidemiological analysis)

Prospective cohort study

14. Size of the study (including controls)

150

Will the study involve:

(a) Human Subjects *Yes*

i) How many patients will be recruited?

150

ii) How many controls will be recruited?

N/A

iii) What is the primary end point?

Prediction of emotional distress by cognitive factors

iv) How was the size of the study determined?

A precise power calculation proved difficult to make. However, previous work with stroke patients in Lothian and Bristol suggests that a sample of this size is sufficient for the questions being addressed.

v) What is the statistical power of the study?

Given results of previous research, this study should give medium effect sizes.

(b) Patient Records *Yes*

i) How many records will be examined?

150

ii) How many control records will be examined?

N/A

iii) What is the primary end point?

As before

iv) How was the size of the study determined?

As before

v) What is the statistical power of the study?

As before

---

15. Scientific critique

Has the protocol been subject to scientific critique? If so, please give the following information:

If the critique formed part of the process of obtaining funding, please give the name and address of the funding organisation:

Medical Research Council/ 20 Park Crescent/ LONDON/ W1N 4AL

If the critique took place as part of an internal process, please give brief details:

If you are in possession of any referees' or other scientific critique reports relevant to your proposed research, please forward copies with your application form.

SECTION 3 — Recruitment of subjects

16. Local Recruitment of Subjects

a) How many subjects are being studied within Lothian?

150

b) Are any of these subjects involved in existing research or have been involved in any recent research in the last six months? *Yes*

If yes, please justify their use in this project

Some patients may be participating in the Lothian FOOD trial

This study addresses different research questions and entails only interviews.

c) Will any of the subjects involved be in a dependent relationship with the researcher? *No*

If yes, please ensure you comply with local recruitment arrangements

d) Will any of the subjects involved be medical students? *No*

If yes, please obtain signed agreement of the Dean of the Faculty of Medicine:

Signature the of Dean of the Faculty of Medicine
or equivalent if medical students are research subjects:
.....*N/A*.....

17. How will the subjects in the study be:

a) selected?

All consecutive admissions to the Western General Hospital, with a confirmed stroke, who meet the inclusion criteria will be approached until the number of required participants is met.

b) recruited?

Once the permission of the responsible medical consultant has been obtained patients will be asked by ward staff if they are interested in hearing more about the study. Those interested will then be introduced to the researcher by the ward staff and given the information sheet. They will be given a day or so to consider their participation. Interviewing will only proceed if written consent is obtained

c) what inclusion criteria will be used?

Participants must be aged over 16 years old, be able to give consent and understand and respond to the questions.

Only patients who: have already survived three weeks after their stroke, who are judged medically stable and likely to survive throughout the duration of the study will be considered.

d) what exclusion criteria will be used?

The medical staffs' clinical judgement will be used to assess whether patients' are too unwell because of their stroke or any other life threatening disease to take part.

Severe cognitive impairment. This will be operationalised by a cut-off score on the Mini Mental State Exam (MMSE) which forms part of patients' routine neurological assessment.

Aphasia. This will be operationalised as a below cut-off score on the Frenchay Aphasia Screening Test (FAST) which is a standard screening device for verbal comprehension and production.

---

18. How will the control subjects group (if used) be: *(Type N/A if no controls)*

a) selected?

N/A

b) recruited?

N/A

c) what inclusion criteria will be used?

N/A

d) what exclusion criteria will be used?

N/A

SECTION 4 **Consent**

19. Is *written* consent to be obtained? *Yes*

If yes, please attach a copy of the consent form to be used.

If no written consent is to be obtained, please justify.

20. How long will the subject have to decide whether to take part in the study?

If less than 24 hours please justify.

At least 24 hours

21. Please attach a copy of the written information sheet or letter to be given to the subject.

(See Guidelines page 3 and Appendix A.)

If no Information Sheet is to be given, please justify.

22. Have any special arrangements been made for subjects for whom English is not a first language? *No*

If yes, give details.

If no, please justify.

Participants must be able to understand the consent giving procedure, and understand and respond to the questions. Participants do not need to have English as their first language. However, it is impractical to translate all the questionnaires, and so those with a poor command of English will be excluded.

23. Will any of the subjects or controls be from one of the following vulnerable groups?

Children under 16

People with learning difficulties

Unconscious or severely ill

Other vulnerable groups e.g. mental illness, dementia

No

If yes, please specify and justify:

---

24. What special arrangements have been made to deal with the issues of consent for the subjects above? *(Please see Guidelines.)*

N/A

SECTION 5 — Details of interventions

25. Does the study involve the use of a new medicinal product or medical device, or the use of an existing product outside the terms of its product licence? *(Please see Guidelines.)* *No*

If yes, please complete Annexe A of the Application Form.

26. Will any additional diagnostic tests using ionising radiation (radioactive materials or x-rays be administered? *No*

(NB Please ensure information in Question 17 includes exclusion criteria with regard to ionising radiation if appropriate.)

If yes, please complete Annexe B of the Application Form.

27. Please list those procedures in the study to which subjects will be exposed indicating those which will be part of normal care and those that will be additional (e.g. taking more samples than would otherwise be necessary). Please also indicate where treatment is withheld as a result of taking part in the project.

SECTION 6 Risks and ethical problems

28. Are there any potential hazards? *No*

If yes, please give details, and give the likelihood and details of precautions taken to meet them, and arrangements to deal with adverse events.

29. Is this study likely to cause any discomfort or distress? *No*

If yes, please give details and justify.

If interviews become burdensome or tiring the patient will have the opportunity to defer completion or to terminate.

30. Safety Requirements

a) Medical support and other facilities available:

b) Local emergency contact details:

Supervisors of project:

Dr Michael Sharpe and Dr Debbie Tinson, who are a consultant psychiatrist and a consultant clinical psychologist respectively.

c) Local independent adviser details:

Dr Anne Tait, consultant psychiatrist at the Western General Hospital.

d) If you are going to administer drugs what arrangements have you made to store, code and administer them? *(See Annexe A)*

Signature of Hospital Pharmaceutical Officer: .....

e) Are you going to administer radioactive materials? ***(See Annexe B)*** *No*

i) If yes, do you have an ARSAC certificate for this particular research study? *NA*

ii) Have you informed the Radiation Protection Adviser? *NA*

Signature of Radiation Protection Adviser:

.....

31. What particular ethical problems or considerations do you consider to be important or difficult with the proposed study?

Please give details.

It is recognised that stroke patients are often highly emotional and so care will be taken to ensure their emotional comfort during interviews. Any patient who seems to be getting distressed and/ or tired during participation will be asked of he/ she would like a break or would like to re-schedule the interview.

Dr Michael Sharpe and/ or Dr Debbie Tinson will be available on the telephone during all interviews in the unlikely event that a participant may react with great distress to being questioned.

32. Will information be given to the patient's General Practitioner? *Yes*

Please note: permission should always be sought from research subjects before doing this.

If yes, please enclose an information sheet/letter for the GP.

If no, please justify:

33. If the study is on hospital patients, will permission of all consultants whose patients are involved in this research be sought? *Yes*

If no, please justify:

SECTION 7 Compensation and confidentiality

Product liability and consumer protection legislation make the supplier and producer (manufacturer) or any person changing the nature of a substance, e.g. by dilution, strictly liable for any harm resulting from a consumer's (subject or patient) use of a licensed product.

---

34. Have arrangements been made to provide indemnity and/or compensation in the event of a claim by, or on behalf of, a subject for non negligent harm?
(Please indicate N/A if not applicable)

N/A

If yes, please give details of compensation arrangements with this application.

N/A

For pharmaceutical company sponsored research, the company should confirm that it will abide by the most recent ABPI guidelines *(Manual V.14.1.1)*

---

35. In cases of equipment or medical devices, have appropriate arrangements been made with the manufacturer to provide indemnity?

(Please indicate N/A if not applicable) *N/A*

If yes, please give details and enclose a copy of the relevant correspondence with this application.

NA

---

36. Will the study include the use of any of the following?

Audio/video recording *Yes*

Observation of patients *No*

If yes to either:

i) How are confidentiality and anonymity to be ensured?

Tapes will be labelled with a code and not with patients' names.
Tapes will be transported in locked briefcase and stored in locked filling cabinet in The Kennedy Tower at The Royal Edinburgh Hospital.
Transcription of tapes will proceed ASAP after interview. Tapes will be destroyed by blanking out labels and cutting tape.

ii) What arrangements have been made to obtain consent for these procedures?

Item four of the consent form specifies consent to interview being tape recorded. Additionally participants verbal consent will be checked before switching on tape recorder immediately prior to interview and their wishes will be strictly abided.

---

37. Will medical records be examined by research worker(s) outside the employment of the NHS? *No*

(In addition to contract with the MRC, I have honorary contracts with The Lothian University Hospitals NHS Trust and Lothian Primary Care NHS trust).

If yes, please see Guidelines.

---

38. What steps will be taken to safeguard confidentiality of personal records?

All personal records will be labelled with a code and not with patients' names, these will be re-coded on entry to computer.
Interview records will be transported in locked briefcase and stored in locked filling cabinet in The Kennedy Tower at the Royal Edinburgh Hospital.
Data entry will proceed ASAP after interview and then interview manuscripts will have labels blanked out.

---

39. What steps will be taken to safeguard the information relating to specimens and the specimens themselves?

NA

SECTION 8 — Management Details

40. Confidentiality

a) Can this project be included in the NRR — *Yes*

b) If NO Should the Project remain confidential to the host Trust until after its completion Date ? — *Yes* *No*

---

41. Is this research carried out as part of a: **Undergraduate Degree?**

Postgraduate Degree? *Yes*

If **YES** which one?

PhD

---

42. Is the host Trust the Lead Institution for this project ? *No*

If **No,** please indicate Lead Institute

University of Edinburgh

---

43. Will the proposed project involve support departments, *No*

(Please indicate with whom you have discussed this in the space provided)

Biochemistry			Medical Physics		
Biomedical Engineering			Medical Statistics		
Clinical Genetics			Mechanical		
Cytogenetics			Microbiology		
Dental Technology			Midwifery Services		
Dieticians			Nuclear Medicine		
DNA			Nursing		
ECG			Occupational Therapy		
EEG			Pathology		
Haematology			Pharmacy		
Health Education/ Promotion			Physiotherapy		
Histopathology			Psychology		
Imaging			Speech Therapy		
Immunology			Virology		
Medical Illustration/ Photography			GP		

---

44. Who has vetted the contract?

	Commercial Development Unit (CDU)
	University equivalent(UnivEd)

[X] Not Applicable

SECTION 9 NHS Resource Implications/Costs

45. Time Resources

a) Host Trust Staff involved in execution of project

Name	Grade of Staff	Hours on project per week	Funded by projects	
		Please estimate as accurately as possible, you should include hours outside your contracted hours	Yes	No
1.				
2.				
3.				
4.				
5.				
6.				
7.				

b) Additional time invested in project

Category	Details	Hours per month
Grant Applications		
Writing reports/manuscripts		
Publication		

46. Service Costs

a) Is your study likely to incur excess treatment costs *No*

b) Additional Hospital Costs

Location of research	Additional resource implication per patient Please tick all that apply	Quantity per patient
Wards	additional days	
Theatres	additional hours/procedure	
Outpatients	additional visit	
Acute receiving Unit	additional hours	
Clinical Laboratories		
Day care		
Primary care		
Patient's Home		
Office		
Other		

c) Could this activity be carried out within a Clinical Research Facility, with centralised research nursing, tracking and administration. ? *No*

47. What additional Investigations are involved per patient ? (Please discuss the NHS resources needed with the relevant departments and obtain their agreement)

None

NOTE FOR SIGNATORIES

IF YOU ARE UNSURE AS TO WHETHER THIS WILL BE ACCEPTABLE TO YOUR CLINICAL DIRECTOR/ HEAD OF DEPARTMENT, THEN PLEASE DISCUSS WITH THEM BEFORE SIGNING.

(a) Nursing
Grade of staff & Hours involved

Description of activities involved

Additional no. of contracts

Funded from grant **Yes** **No**

Agreed by Director of Nursing/Deputy or Department contact (as per local arrangements):

Signature: ..... Designation:.....

Date: .....

(b) PROFESSIONS ALLIED TO MEDICINE (PAMS e.g. Occupational Therapists, Speech Therapists, Physiotherapists, Dieticians, Chiropodists)
Grade of staff & Hours involved

Description of activities involved

Additional no. of contracts

Funded from grant **Yes** **No**

Agreed by Head of Department/Deputy or Department contact (as per local arrangements):

Signature: ..... Designation:.....

Date.....

(c) Pharmaceutical Implications

Name of investigation drugs

Summary of dosing protocol

Additional cost of drug therapy

Additional dispensing requirements and storage & costs

Agreed by Chief Pharmacist/ Deputy or Department contact (as per local arrangements):

Signature: ..... Designation:.....

Date: .....

(d) Laboratory Investigations

Name of test	
Name of laboratory	
Number per patient	
Funded from grant	**Yes** **No**

Agreed by Clinical Director/Deputy or Department contact (as per local arrangements):

Signature: ..... Designation:.....

Date: .....

(e) Radiology/Imaging Procedures

Name of test

Number per patient

Funded from grant **Yes** **No**

Agreed by Clinical Director/Deputy or Department contact (as per local arrangements):

Signature: ..... Designation:.....

Date: .....

(f) High cost consumables
e.g. Hickman lines - number per patient
platinum coils - number per patient

Agreed by Clinical Director/Business Manager or Deputy:

Signature: ..... Designation:.....

Date: .....

(g) ECG/ Exercise Testing/ Lung Function Test
Number per patient

Agreed by Clinical Director/Deputy or Department contact (as per local arrangements):

Signature: ..... Designation:.....

Date: .....

(h) Anaesthetics/Theatres

Agreed by Clinical Director/Business Manager or Deputy:

Signature: ..... Designation:.....

Date: .....

48. Additional Equipment

Purchased specifically for study	**Description**	**Cost**
Additional use of existing equipment		
	frequency of additional use	

49. What Space is Used

Location/room no	**% R&D**	**Externally funded**	
Ad hoc use of rooms on ward as avaiable for interviews		**Yes**	**No**

50. What Administration support is involved

Secretarial (Grade of Staff) None	**Hours per week on R&D**
Medical Records **Please state the number of case notes to be retrieved as part of this study?**	**No. of case notes** These will be reviewed but it is anticipated most will be available on the ward when required. A few may need to be retrieved from records

PLEASE ENSURE THAT YOU COMPLETE THE CHECKLIST ON THE FRONT COVER OF THE APPLICATION FORM AND ENCLOSE ALL RELEVANT ADDITIONAL DOCUMENTS.

SECTION 10	Declaration

DECLARATION

The information in this form is accurate to the best of my knowledge and belief and I take full responsibility for it.

I understand it is my responsibility to obtain management approval where appropriate from the relevant NHS body before the project takes place.

I agree to supply interim and final reports on the pro forma provided, and to advise my sponsor, the LREC from which approval was granted for this proposal and any other researchers taking part in the project of any adverse or unexpected events that may occur during this project.

Signature of Principal Researcher: .....

Date:.....

Annexe C 1	Local Researchers

OTHER RESEARCHERS INVOLVED IN THIS STUDY

Please provide the name and contact details of other researchers involved in this study. Please include your own name and centre if you are also a local researcher.

(Please copy and complete this page for each researcher. You must inform the LREC Administrator by means of a copy of this form as each new researcher is recruited.)

LREC Reference Number:

Name

Miss Ellen Townend

Contact Address:

2nd floor, Kennedy tower,
Royal Edinburgh Hospital,
Morningside Park,
EDINBURGH,
EH10 5HF.

Location of research
(if different):

Western General Hospital

Telephone:

0131 537 6507

Fax:

0131 447 6860

E-Mail:

E.L.Townend@sms.ed.ac.uk

Please retain a blank copy of this form, complete it and send to the LREC Administrator whenever other local researchers become involved in the future.

Annexe C 2 **Local Researchers**

OTHER RESEARCHERS INVOLVED IN THIS STUDY

Please provide the name and contact details of other researchers involved in this study. Please include your own name and centre if you are also a local researcher.

(Please copy and complete this page for each researcher. You must inform the LREC Administrator by means of a copy of this form as each new researcher is recruited.)

LREC Reference Number:

Name

Dr Michael Sharpe

Contact Address:

2nd floor, Kennedy tower,
Royal Edinburgh Hospital,
Morningside Park,
EDINBURGH,
EH10 5HF.

Location of research
(if different):

Western General Hospital.

Telephone:

0131 537 6672

Fax:

0131 537 6641

E-Mail:

Michael.Sharpe@ed.ac.uk

Please retain a blank copy of this form, complete it and send to the LREC Administrator whenever other local researchers become involved in the future.

Annexe C 3	Local Researchers

OTHER RESEARCHERS INVOLVED IN THIS STUDY

Please provide the name and contact details of other researchers involved in this study. Please include your own name and centre if you are also a local researcher.

(Please copy and complete this page for each researcher. You must inform the LREC Administrator by means of a copy of this form as each new researcher is recruited.)

LREC Reference Number:

Name

Dr Debbie Tinson

Contact Address:

Clinical Psychology department,
Astley Ainslie Hospital,
133 Grange Loan,
EDINBURGH
EH9 2HL

Location of research
(if different):

Telephone:

0131 537 9124

Fax:

0131 537 9000

E-Mail:

NA

Please retain a blank copy of this form, complete it and send to the LREC Administrator whenever other local researchers become involved in the future.

Annexe C 4	**Local Researchers**

OTHER RESEARCHERS INVOLVED IN THIS STUDY

Please provide the name and contact details of other researchers involved in this study. Please include your own name and centre if you are also a local researcher.

(Please copy and complete this page for each researcher. You must inform the LREC Administrator by means of a copy of this form as each new researcher is recruited.)

LREC Reference Number:

Name

Dr Martin Dennis

Contact Address:

Department of Clinical Neurosciences,
The Bramwell Dott building,
Western General Hospital,
Crewe Road,
EDINBURGH,
EH4 2XU.

Location of research
(if different):

Telephone:

0131 5371719 or 5375505

Fax:

0131 3325150

Email:

msd@skull.dcn.ed.ac.uk

Please retain a blank copy of this form, complete it and send to the LREC Administrator whenever other local researchers become involved in the future.

Annexe C 5	Local Researchers

OTHER RESEARCHERS INVOLVED IN THIS STUDY

Please provide the name and contact details of other researchers involved in this study. Please include your own name and centre if you are also a local researcher.

(Please copy and complete this page for each researcher. You must inform the LREC Administrator by means of a copy of this form as each new researcher is recruited.)

LREC Reference Number:

Name

Professor Mike Power

Contact Address:

4th floor, Kennedy tower,
Royal Edinburgh Hospital,
Morningside Park,
EDINBURGH,
EH10 5HF.

Location of research
(if different):

Western General Hospital

Telephone:

0131 537 6507

Fax:

0131 447 6860

E-Mail:

M.J.Power@ed.ac.uk

Please retain a blank copy of this form, complete it and send to the LREC Administrator whenever other local researchers become involved in the future.

Appendix B

Information sheets, consent form and letters

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B.1	Consultant information sheet	xxxii
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B.6	Patient invitation to second interview	xxxviii

B.1: Consultant information sheet

CONSULTANT INFORMATION SHEET FOR THE IMPACT OF STROKE STUDY

About the researcher

My name is Ellen Townend and I am a PhD student, supervised by Dr Michael Sharpe (Consultant psychiatrist) and Dr Debbie Tinson (Clinical psychologist). My research is funded by the UK Medical Research Council.

About the research

The research is concerned with psychological prediction of distress following stroke. Understanding of this should inform the development of psychological interventions. The study aims to assess the impact factors concerning: how patients understand their stroke (stroke representations) and how they see themselves (self- concept) in light of the effects of their stroke.

What is required of participants

Participants will be invited to take part in an interview at 1 month (in hospital or at home) and at 6 months (at home). These interviews will consist of verbal administration of scales relating to their emotional distress, psychological understanding of stroke and self concept. Interviews should last about 1 ½ hours; however if a patient is finding the interview tiring or burdensome another appointment can be made to finish it. The first 15 participants who have major depressive disorder on the SCID will also be interviewed in a more open ended manner about their recent stroke experiences. Finally participants will be mailed a questionnaire developed from data collected during these interviews.

Ethical considerations

Strict adherence to patient confidentiality and anonymity will be followed at all times. Lothian's Psychiatry and Clinical Psychology Research Ethics Sub-Committee have reviewed this study.

I will enquire whether you have any reservations about patients' suitability before I ask a member of ward staff to introduce me to patients to ask if they would be willing to take part.

If I encounter a patient who is extremely distressed I will inform the relevant clinical staff.

Please feel free to contact me if you have any queries about the research:

Tel: 0131 6507 email: E.L.Townend@sms.ed.ac.uk

B.2: Patient information sheet

INFORMATION SHEET FOR: THE IMPACT OF STROKE STUDY

0131 447 6860

E.L.Townend@sms.ed.ac.uk

0131 537 6507

Invitation paragraph
You are being invited to take part in a research study. It is important for you to understand why the research is being done and what it will involve before you decide whether to take part. Please take time to read the following information carefully. Please ask if there is anything you are not clear about, and feel free to discuss it with family and friends.

Why are we asking for your help?
We know a great deal about the physical impact of stroke, however much less is known about the psychological impact. A better understanding of this should lead to better ways of helping people who have had a stroke. This study will involve interviewing people who have had a stroke soon after the stroke and again 6 months later.

Why have I been chosen?
Everybody coming into this hospital with a stroke who is well enough is being asked to take part. We intend to interview about a hundred patients.

Do I have to take part?
It is up to you to decide whether you want to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are free to withdraw at any time and without giving a reason. This will not affect the treatment you receive.

Who is involved with the study?
Ellen Townend, a research psychologist, is carrying out the research interviews. She is supervised by Dr Michael Sharpe who is a consultant psychiatrist and Dr Debbie Tinson who is a consultant clinical psychologist. The UK Medical Research Council funds the study.

What is involved for me if I take part?
Ellen will visit you in hospital at a time that is good for you, and interview you in private about your experience of stroke. We are particularly interested in your thoughts about your health, how you feel about yourself and how your life has

changed because of the stroke. This interview should take between one and two hours. If you are finding the interview tiring she will stop, and make another appointment to finish it.

Ellen would then like to contact you again in 6 months time to invite you to participate in a second interview. This time it would take place in your own home. Taking part in the first interview does not mean that you have to take part in the second interview.

Who will have access to the information that I provide?
All information, which is collected, about you during the course of the research will be kept strictly confidential and will be stored with your name and address removed so that you cannot be recognised from it. We need to inform your GP that you are taking part in the study. Access to information you give is limited to Ellen Townend, and her supervisors. The only exception to this is if the interviews reveal information that is important to your medical care. In that case we need to ensure that the doctor looking after you is aware of this.

Who has reviewed the study?
Lothian's Psychiatry and Clinical Psychology Research Ethics Sub-Committee have reviewed this study.

Who to contact for further information
Please feel free to contact Ellen Townend for information about this study at any time during your participation by phoning 0131 5376507. A brief summary of the overall results will be made available by the summer of 2002. You are very welcome to contact Ellen to obtain a copy at this time.

If you would like impartial advice about whether to take part in this research from a doctor who is not involved with this study you may contact Dr Anne Tait, consultant psychiatrist at the Western General Hospital, Edinburgh (Tel: 0131 537 2855).

What do I do now?
You may like to discuss the project with others. Ellen will visit again in the next couple of days to see if you would like to take part.

Thank you for your time and consideration.

B.3: Consent Form

Study Number_____

CONSENT FORM

Title of Project: Impact of stroke study

Name of Researcher: Ellen Townend

0131 447 6860

E.L.Townend@sms.ed.ac.uk

0131 537 6507

Please initial each box:

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my medical care or legal rights being affected. ☐

3. I understand that sections of my medical notes relevant to the project may be looked at by the researcher and I give permission for her to have access to these notes. ☐

4. I consent to my interview being tape recorded. ☐

5. I give permission for Ellen Townend to phone me in seven months time to enquire whether I would like to be interviewed a second time, and I understand that taking part in the first interview does NOT mean I have to take part in the second. ☐

6. I agree to take part in the above study. ☐

_____	_____	_____
Name of Patient	Date	Signature
_____	_____	_____
Researcher	Date	Signature

B.4: G.P. introduction letter

Date: --/ --/ --

Ellen Townend
2nd Floor, Kennedy Tower
Royal Edinburgh Hospital
Morningside Park
Edinburgh
EH10 5HF

Dear Dr _____

Impact of stroke study

I would like to let you know that your patient:

Mr / Mrs _____ (DOB:)

took part in an interview for the above study on: _____

I am conducting this study as a PhD student at the University of Edinburgh. While we know a great deal about the physical impact of stroke, much less is known about the psychological impact. A better understanding of psychological predictors of emotional distress should provide valuable information regarding the development of future interventions.

Participants will be invited for a further interview at six-month follow-up. Your patient has agreed that I may contact him/ her at this time to invite him/ her for a further interview. However, I will write to you nearer the time, so that you may decline his/ her consent if you believe it is inappropriate. Meanwhile, I would like to thank you for your time and if you require any further information please do not hesitate to contact me.

Yours sincerely,

_____
Ellen Townend (MRC PhD student)

ENC: Patient information sheet for the impact of stroke study

B.5: GP letter about second interview

Date: --/ --/ --

Ellen Townend
2nd Floor, Kennedy Tower
Royal Edinburgh Hospital
Morningside Park
Edinburgh
EH10 5HF

Dear Dr _____

Re: Patient's name and DOB

Your patient took part in an interview for 'The Impact of Stroke' study in ___ last year. S/he also consented to contact to discuss arranging a follow-up visit. I appreciate that you are very busy and so please only reply if it is **inappropriate** to contact your patient about participating, because she has died, or, is too severely physically ill to take part at the moment. If I do not hear from you within the next 2 weeks, I will assume that there is not a problem like this at present. I've enclosed a copy of the information sheet for the study and please do not hesitate to contact me if you would like more information.
Thank you very much for your time and consideration,

Yours sincerely,

_____
Ellen Townend (PhD student)

Reply slip (only needed if your patient cannot participate)

My patient:

_____ (patients name) _____
(D.O.B)

can not participate in his/ her follow-up interview for "The impact of stroke study" because:

Please explain reason:

_____

_____

_____

B.6: Patient invitation to second interview

Date: --/ --/ --

Ellen Townend
2nd Floor, Kennedy Tower
Royal Edinburgh Hospital
Morningside Park
Edinburgh
EH10 5HF

Dear

Thank you once again for the time you gave to be interviewed for the 'Impact of stroke' study last _____.

It is now time for your follow-up interview and I would like to come and see you at a time that is suitable for you. I'll give you a ring shortly so we can discuss whether you would like to make an appointment.

Meanwhile thank you for your invaluable contribution so far,

All best wishes,

_____
Ellen Townend (PhD student)

Appendix C

Development of measures

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C.1: Development of measures during piloting

Table C1: Shame pilot data

Piloted item	Association with HADs distress (N = 15)	Test-retest score (N = 8)	Comments about suitability of item(s)
1. Since my stroke, I think others sometimes see me as inadequate as a person.	.44*	.87**	Compared to 'Other as Shamer' scale, all items appeared acceptable
2. Since my stroke, I sometimes feel that others see me as not measuring up to them.	.09	.89**	
3. Since my stroke, I get embarrassed that others must think I've lost control over my feelings.	.22	.94**	Brought up emotionalism issues but this was not considered to invalidate item
4. Since my stroke I sometimes feel useless because others have to make allowances for me.	.22	.73**	Appeared particularly pertinent to depressed participants
5. Since my stroke, the way others fuss about me sometimes gets irritating.	.15	.62**	
6. Since my stroke, I sometimes get embarrassed about the way I must appear to others.	.39	.75**	
7. Since my stroke, I sometimes get upset because others treat me as if I'm less intelligent.	.31	.96**	
8. Since my stroke, I find it comforting that others are protective towards me. [1]	.23	.94**	This does not seem to be evaluated positively by anyone
9. Since my stroke, I've found it nice that others make allowances for me. [1]	.47*	.96**	
10. Since my stroke, people have acted as if I'm just as intelligent as I was before. [1]	.46*	1.0**	

* $p<.05$ **$p<.01$

[1] Reverse scored items

Table C2: Recurrence fear pilot data

Piloted item	Association with HADs distress (N = 27)	Test-retest score (N = 15)	Comments about suitability of item	Decision to retain item
1. I think about my health often.	.23	.85 *	Often comments like 'Wouldn't you?' or 'Wouldn't you at my age?' made – appears too self-evident to be discriminatory.	
2. I am bothered by the uncertainty of my health.	.48*	.71*	Good association and retest	YES
3. I think about my health now more than before I had my stroke.	.51*	.42	Good association, Test-retest score low but one of the few stroke-specific items.	YES
4. I worry no more about my health than other people worry about their health.	.21	-.76 *	Often had to explain meaning of 'no more' and low association with HADs	
5. I feel that there is no need to worry about my future health.	.32	.10	Ambiguous wording – does 'no need to worry' mean one believes there is not any call for concern or worry is pointless. Also low retest score	
6. I always take my health into consideration when making future plans.	.36 *	.57 *	Good association and retest score	YES
7. Compared to other persons who have had a stroke, I feel that I worry less than they do about health concerns.	.44 *	.77 *	Good association and retest score	YES
8. I sometimes find myself preoccupied with my physical condition.	.32	.47	Maybe confused with disability/ recovery and mediocre association and retest scores	

9. Just prior to having tests like blood pressure done, I become uneasy.	.23		.63	*	Some agree but some commented that they are uneasy because they haven't had tests or find tests reassuring, so would produce ambiguous data	
10. I think no more about my health presently than I did before I had my stroke.	.16		-.65		Often had to explain meaning – seemed confused by double negative and low association HADs	
11. I would like to feel more certain about my health.	.003		.74	*	Often made comment 'Of course – wouldn't everyone like to feel more certain about their health' and low association HADs	
12. Because of my physical health, my future is of concern to me.	.42	*	.83	*	Good association and retest score	YES
13. I do not worry about my stroke returning.	.28		-.30		Good validity could maybe improve reliability by rewording without a double negative.	YES But change to 'I worry about my stroke returning'
14. When I think about my future health, I feel some uneasiness.	.70	*	.83	*	Good association and retest score	YES
15. I get symptoms that remind me of having my stroke.	.30		.12		Caused a lot of confusion – did 'symptoms' refer to present difficulties or the experience of having a stroke, also very low retest score	
16. I do not feel anxious when I read articles about strokes.	.38	*	.67	*	Good association and retest scores. However, often had to rephrase as '…when I hear information about strokes' for those who could not read or who had not been offered articles.	YES But change to: 'I do not feel anxious when I hear information about strokes'

* $p < .05$

C.2: Exploratory factor analysis for main study

Table C3: Factor structure for the acceptance of disability measure at baseline [1]

	Factors		Suggested name of factor
	I	II	
Item 1: I have a hard time adjusting to the limitations of my stroke.	**.86**		Unhappy about limitations and dependency
Item 2: Because of the effects of my stroke, I miss the things I like to do most.	**.82**		
Item 3: The effects of my stroke make me feel useless at times.	**.80**		
Item 4: The effects of my stroke make me more dependent on others than I want to be.	**.67**		
Item 6: The effects of my stroke make me feel inadequate.	**.68**	.48	
Item 5: The effects of my stroke make me a burden on my family and friends.		**.63**	Feeling burdensome and inadequate
Item 7: I will never be self-sufficient enough to make me happy.		**.75**	
Item 8: I think people are often uncomfortable being around me because of the effects of my stroke.		**.81**	
Percentage of variance explained by each factor	35	15	

[1] Only values above .40 are reported

Table C4: Factor structure of the '<u>Before</u> I had my stroke' items from the negative identity change measure at baseline [1]

	Factors					Suggested name of factor
	I	II	III	IV	V	
Item 3: In control	**.60**	.45				Ability
Item 8: Confident	**.54**	.44				
Item 14: Independent	**.76**					
Item 15: Capable	**.83**					
Item 16: Active	**.58**					
Item 17: Co-operative	**.49**					
Item 1: Bored	.41	**.61**				Feeling down
Item 2: Unhappy		**.64**				
Item 4: Worried		**.56**				
Item 5: Dissatisfied		**.66**				
Item 10: Worthless		**.66**				
Item 18: Withdrawn		**.52**		.42		
Item 11: Aggressive			**.77**			Grumpy/ patient
Item 12: Irritable			**.71**			
Item 20: Patient			**.69**	.44		
Item 13: Caring				**.73**		Congeniality
Item 19: Friendly				**.53**		
Item 6: Attractive					**.62**	Positive outlook
Item 7: Hopeful					**.47**	
Item 9: Stable					**-.62**	
Percentage of variance explained by each factor	27	10	9	7	6	

[1] Only values above .40 are reported

Table C5: Factor structure of the 'Now I've had my stroke' items from the negative identity change measure at baseline [1]

	Factors						Suggested name of factor
	I	II	III	IV	V	VI	
Item 1: Bored	**.63**						Ability/ Negative emotional reaction to disability
Item 2: Unhappy	**.62**	.45					
Item 3: In control	**.70**						
Item 8: Confident	**.63**		.51				
Item 14: Independent	**.79**						
Item 15: Capable	**.82**						
Item 16: Active	**.64**						
Item 7: Hopeful		**.52**					Sense of worth
Item 9: Stable		**.52**					
Item 10: Worthless		**.56**					
Item 17: Co-operative		**.70**					
Item 19: Friendly		**.69**					
Item 4: Worried			**.72**				Fed up
Item 5: Dissatisfied			**.49**				
Item 18: Withdrawn		.53	**.61**				
Item 11: Aggressive				**.84**			Grumpy
Item 12: Irritable				**.73**			
Item 13: Caring					**.85**		Nice
Item 20: Patient				.46	**.54**		
Item 6: Attractive						**.81**	Looks
Percentage of variance explained by each factor	29	10	8	6	6	5	

[1] Only values above .40 are reported

Table C6: Factor structure of the shame measure at baseline [1, 2]

	Factors			Suggested name of factor
	I	II	III	
Item 3: I get embarrassed that others must think I've lost control over my feelings	**.74**			Considered feeble and in need of protection
Item 4: I sometimes feel useless because others have to make allowances for me	**.72**			
Item 5: the way others fuss about me sometimes gets irritating	**.61**			
Item 6: I sometimes get embarrassed about the way I must appear to others	**.73**			
Item 1: I think others sometimes see me as inadequate as a person	.46	**.61**		Considered relatively incompetent
Item 2: I sometimes feel that others see me as not measuring up to them		**.74**		
Item 7: I sometimes get upset because others treat me as if I'm unintelligent		**.84**		
Item 10: people have acted as if I'm just as intelligent as I was before		**.68**		
Item 8: I find it comforting that others are protective towards me			**.89**	Given welcome consideration
Item 9: I've found it nice that others make allowances for me			**.90**	
Percentage of variance explained by each factor	37	17	10	

[1] Only values above .40 are reported
[2] All items begin 'Since my stroke,…'

Table C7: Factor structure of the fear of recurrence measure at baseline [1]

	Factors		Suggested name of factor
	I	II	
Item 1: I am bothered by the uncertainty of my health	**.63**		Increased health worry following stroke
Item 4: Compared to other persons who have had a stroke, I feel that I worry less than they do about health concerns	**.59**		
Item 5: Because of my physical health, my future is of concern to me	**.72**		
Item 6: I worry about my stroke returning	**.72**	.40	
Item 7: When I think about my future health, I feel some uneasiness	**.68**		
Item 2: I think about my health now more than before I had my stroke		**.67**	Increased health consideration following stroke
Item 3: I always take my health into consideration when making future plans		**.67**	
Item 8: I do not feel anxious when I hear information about strokes		**.66**	
Percentage of variance explained by each factor	35	15	

[1] Only values above .40 are reported

Table C8: Factor structure of the 'Before I had my stroke' items from the negative identity change measure at follow-up

	Factors						Suggested name of factor
	I	II	III	IV	V	VI	
Item 3: In control	**.58**						Ability
Item 8: Confident	**.62**						
Item 13: Caring	**.56**						
Item 14: Independent	**.77**						
Item 15: Capable	**.74**						
Item 16: Active	**.61**						
Item 1: Bored		**.57**					Grumpy/ patient
Item 11: Aggressive		**.63**					
Item 12: Irritable		**.75**					
Item 20: Patient		**.72**					
Item 4: Worried			**.78**				Fed up
Item 5: Dissatisfied			**.72**				
Item 18: Withdrawn			**.68**				
Item 6: Attractive				**.82**			Self-like or hate
Item 10: Worthless				**.63**			
Item 2: Unhappy					**-.48**		Steady or sad
Item 9: Stable					**.64**		
Item 17: Co-operative					**.70**		
Item 7: Hopeful						**.82**	Cheerful
Item 19: Friendly						**.40**	
Percentage of variance explained by each factor	23	11	8	7	6	6	

Table C9: Factor structure of the 'Now I've had my stroke' items from the negative identity change measure at follow-up

	Factors						Suggested name of factor
	I	II	III	IV	V	VI	
Item 1: Bored	**.56**	.48					Feeling down/ or not
Item 2: Unhappy	**.81**						
Item 4: Worried	**.64**						
Item 5: Dissatisfied	**.75**						
Item 7: Hopeful	**.53**						
Item 8: Confident	**.63**	.44					
Item 10: Worthless	**.60**						
Item 3: In control		**.77**					Ability
Item 14: Independent		**.83**					
Item 15: Capable		**.82**					
Item 16: Active		**.71**					
Item 11: Aggressive			**.84**				Grumpy/ or patient
Item 12: Irritable			**.69**				
Item 18: Withdrawn			**.48**				
Item 20: Patient			**.58**				
Item 13: Caring				**.79**			Helpful
Item 17: Co-operative				**.62**			
Item 6: Attractive					**.85**		Dependability
Item 9: Stable					**-.50**	.48	
Item 19: Friendly						**.85**	Friendly
Percentage of variance explained by each factor	31	10	8	6	6	5	

Table C10: Factor structure of the shame measure at follow-up [1, 2]

	Factors		Suggested names of factor
	I	II	
Item 1: I think others sometimes see me as inadequate as a person	**.78**		Considered weak and less able
Item 2: I sometimes feel that others see me as not measuring up to them	**.76**		
Item 3: I get embarrassed that others must think I've lost control over my feelings	**.78**		
Item 4: I sometimes feel useless because others have to make allowances for me	**.78**		
Item 5: the way others fuss about me sometimes gets irritating	**.67**		
Item 6: I sometimes get embarrassed about the way I must appear to others	**.88**		
Item 7: I sometimes get upset because others treat me as if I'm unintelligent	**.80**		
Item 10: people have acted as if I'm just as intelligent as I was before	**.52**	.46	
Item 8: I find it comforting that others are protective towards me		**.85**	Given welcome consideration
Item 9: I've found it nice that others make allowances for me		**.85**	
Percentage of variance explained by each factor	46	17	

[1] Only values above .40 are reported
[2] All items begin 'Since my stroke,…'

Table C11: Factor structure of the fear of recurrence measure at follow-up [1]

	Factors		Suggested name of factor
	I	II	
Item 1: I am bothered by the uncertainty of my health	**.61**	.51	Concern about health, for now and the future
Item 2: I think about my health now more than before I had my stroke	**.62**		
Item 3: I always take my health into consideration when making future plans	**.72**		
Item 5: Because of my physical health, my future is of concern to me	**.84**		
Item 4: Compared to other persons who have had a stroke, I feel that I worry less than they do about health concerns		**.69**	Worried feelings about health and the possibility of stroke
Item 6: I worry about my stroke returning		**.57**	
Item 7: When I think about my future health, I feel some uneasiness	.51	**.66**	
Item 8: I do not feel anxious when I hear information about strokes		**.76**	
Percentage of variance explained by each factor	41	17	

[1] Only values above .40 are reported

Appendix D

Interview schedule

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D.1: Background/screening information

Study code:_____

DOB:_____ Gender:_____ GP details:_____

Post Code:_____ Living situation/relationships:_____

Stroke severity score:_____ Previous history of stroke:_____

Hodkinson Mental Test

Age of patient.....

Time (to nearest hour).....

42 West street.....

Name of hospital.....

Year.....

Date of birth of patient.....

Month.....

Dates of world war II.....

Name of monarch.....

Count down from 20 to 1.....

FAST scoring

1) Riverside comprehension /5

2) Shapes comprehension /5

3) Expression regarding scene /5

4) Naming /5

5) Reading /5

6) Writing /5

D.2: Definition of 'stroke'

First of all, could you describe to me what you understand a stroke is?
(If need probe) What is it that you think happened inside your body when you had your stroke?

_____

_____

_____

_____

D.3: Causal attributions/Causal controllability

Have you spent time thinking about a cause of your stroke?
(If Yes) Can you tell me about these?
(Double-check) Sometimes people do have their own ideas or theories but they're not sure because they're not doctors. I wonder if you're like that as I'm interested in what you think.

Yes/No *(circle one from open-ended questioning)*

Checklist
I'm just going to show you a list of causes other people who have had strokes have mentioned. Could you have a look/As I read them out could you tell me whether you think any apply to yourself?

_____

_____

_____

_____

_____

_____

_____

If you had to choose the most important reason why you had your stroke out of _____ what would you choose?
And what would you say is the next most important reason out of _____?

Causes other people who have had strokes have mentioned…

Overwork

Smoking

Worry

Lack of exercise

Stress

Lifestyle

Overweight

Diet

Drinking

Family history

Anxiety

Frustration/anger

Tension

Other illness

Over-involvement

Cholesterol

Situational factors

Age

High blood pressure

Over-excitement

Diabetes

For each cause:
How controllable would you say your _____ is?

(future probe) OK, from now on/given that ____ now, how controllable would you say your ____ is?
(funnelling probes) Overall is ___ something that is controllable or is not controllable?/ Would you say that is something easy or moderate to control?/ Would you say that was easy or just fairly easy?

1.
_____

_____

2.

_____

_____

3.
_____

_____

D.4: Definition of 'the effects of stroke'
Stroke causes different effects for different people, what are the effects of your stroke that you have now?
(If need probe) Sometimes one side of the body is paralysed; sometimes it is just the leg, or a feeling of weakness. Some people have speech or vision problems, or difficulties with their memory or concentration. What sort of effects do you have now?

_____

_____

_____

_____

_____

_____

D.5: Recurrence fear

Now I would like to ask you about your concerns for your health, now that you have had a stroke, please could you tell me how much you agree or disagree using the options at the bottom of the page (*Give cue card & check understanding)*
If necessary use funnel questions to establish how much respondent agrees or disagrees.)

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
1. I am bothered by the uncertainty of my health.	0	1	2	3	4
2. I think about my health now more than before I had my stroke.	0	1	2	3	4
3. I always take my health into consideration when making future plans.	0	1	2	3	4
4. Compared to other persons who have had a stroke, I feel that I worry less than they do about health concerns.	4	3	2	1	0
5. Because of my physical health, my future is of concern to me.	0	1	2	3	4
6. I worry about my stroke returning.	0	1	2	3	4
7. When I think about my future health, I feel some uneasiness.	0	1	2	3	4
8. I do not feel anxious when I hear information about strokes.	4	3	2	1	0

D.6: Fear of falling

Have you had a fall since your stroke?
(If yes) can you tell me a bit about it?

Yes/ No *(circle as appropriate)*

_____

_____

Now I would like to ask you some questions about falls and would like you to tell me how much you agree or disagree with them as we did before

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
1. If I had a fall I think I'd lose a lot of confidence.	0	1	2	3	4
2. I am not bothered by fears of falling.	4	3	2	1	0
3. I believe a fall would seriously affect my recovery.	0	1	2	3	4
4. I believe I could cope with a minor fall.	4	3	2	1	0

D.7: 'Why me?'
Have you ever asked yourself 'Why me? Why did I have a stroke?'

Yes/No *(circle as appropriate)*

If so, how often do you find yourself asking Why me?

Never	Rarely	Sometimes	Often	Nearly all the time	(circle as appropriate)
0	1	2	3	4	

D.8: 'Found meaning?'
Have you found any meaning in your experience of having had a stroke?
(If need probe) Is there anything good that has come out of the whole experience of having a stroke for you?

Yes/No *(circle as appropriate)*

_____

_____

_____

_____

D.9: Confidence in recovery

For the next three questions I would like you to give your answer as a number between zero and ten using the line shown

Establish that can see both ends of line on response cue

First of all, on a scale of 0 – 10, how confident are you that you will make a full recovery from the effects of your stroke?

(If need probe) If you could let me know how confident you are by giving it as a mark out of ten, a bit like as if you were giving a mark out of ten for a test of some sort?

0… ..1… …2… ..3 …..4……5……6…. .7… ..8 ….9……10

Not at all Confident — Extremely Confident

D.10: Recovery locus of control

Now I would like to ask you about your beliefs in recovery and would like you to tell me how much you agree or disagree with the statements as we did before

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
1. How I manage in the future depends on me, not on what other people do for me.	0	1	2	3	4
2. It's often best to just wait and see what happens.	4	3	2	1	0
3. It's what I do to help myself that's really going to make all the difference.	0	1	2	3	4
4. My own efforts are not that important, my recovery really depends on others.	4	3	2	1	0
5. It's up to me to make sure I make the best recovery possible under the circumstances.	0	1	2	3	4
6. My own contribution to my recovery doesn't amount to much.	4	3	2	1	0
7. Getting better now is a matter of my own determination rather than anything else.	0	1	2	3	4
8. I have little or no control over my progress from now on.	4	3	2	1	0
9. It doesn't matter how much help you get – in the end it's your own efforts that count.	0	1	2	3	4

D.11: Qualitative 'Concerns' questions

What I'd like to do now is spend a bit of time getting your side of the story

I've asked a lot of questions but now hearing about your own point of view. What would you say are the main things in life that are concerning to you just now?

Probes to establish main concerns:
We all have things that concern us sometimes, what would you say are the things which are most bothersome, or a bit concerning to you now?
(If necessary) Some people are concerned about things like health or money, others are concerned about work or family or things in the news. It can be anything really I'm just interested in what sort of things in life are an issue to you.

Probes to explore concerns, feelings and beliefs:
So _____ *is a concern c*an you tell me a bit more about that?

That's interesting what is it about _____that makes it a prime concern at the moment?

What kind of feelings do you have about_____?
How do you feel about _____ ?

What sort of emotional word would you use to describe how_____ makes you feel?

When you're feeling _____ about _____ what goes through your mind about it?

If you could imagine you're in a situation when you're feeling _____
what sort of things do you think about/what comes to mind?

So what does that do/ What does that make you think? What does that mean?

Summarise and check accuracy of main concerns emphasising them as main concerns in life and then move on to stroke concerns:
OK, so _____ are your main concerns/issues/things that bother you (a bit) in life at the moment, but now I'd like to ask a different question, what would you say were your main stroke concerns?

Probes to establish main stroke concerns
When it comes to the stroke and its effects what is the thing that worries you/bothers you/concerns you the most?
Or if there was one thing about stroke or its effects that you'd say was an issue, or something that you'd change if you could, what would that be?

Explore main stroke concerns using the similar probes as for main concerns

D.12: Barthel index

Now if its' OK with you, could I run through the things that you may need some help with now you've had your stroke

Use questions such as A lot of people have problems with a weak bladder or accidents after their stroke, is this sort of thing a problem for you?

Barthel index

1.	Feeding	2=Independent 1=Needs some help 0=Needs to be fed
2.	Bathing	1=Able to wash all over in bath/shower 0=Needs help
3.	Grooming	1=Totally independent 0=Needs help with personal care
4.	Dressing	2=Independent 1=Needs help with some items 0=Unable to do anything without help
5.	Bowels	2=No accidents 1=Occasional accidents/help with enema 0=Incontinent
6.	Bladder	2=No accidents 1=Occasional accidents (max, once per24 hrs) 0=Incontinent/catheterised
7.	Toilet	2=Independent (on/off dressing and wiping) 1=Needs some help, but can do something alone 0=Dependent/unable to use
8.	Transfer bed/chair	3=Totally independent 2=Minor help (verbal or physical but can walk) 1=Major help (one or two people/wheelchair independent) 0=Unable, no sitting balance
9.	Mobility	3=Independent 2=Walks with the help of one person verbal or physical) 1=Wheelchair independent (including corners) 0=Unable
10.	Stairs	2=Independent 1=Needs help (verbal, physical, carry aid) 0=Unable

D.13: Nottingham index

	Not at all/ With help	Alone with difficulty/ Alone easily
Do you…		
Walk around outside?		
Climb stairs?		
Get in and out of the car?		
Walk over uneven ground?		
Cross roads?		
Travel on public transport?		
Manage to feed yourself?		
Manage to make yourself a hot drink?		
Take hot drinks from one room to another?		
Do the washing up?		
Make yourself a hot snack?		
Manage your own money when you are out?		
Wash small items of clothing?		
Do your own shopping?		
Do a full clothes wash?		
Read newspapers or books?		
Use the telephone?		
Write letters?		
Go out socially?		
Manage your own garden?		
Drive a car?		

D.14: Structured interview for depression (Present status and pre-stroke history)

Five or more of the following criteria must: have been present during the same 2 week period; represent a change from previous functioning; and be coded three.
At least one must be or 2.

Scoring: ? = unsure, 1 = no, 2 = Borderline, 3 = definitely yes.

N.B. First conduct interview for how participant has been feeling over last two weeks (**Now**) then repeat for any time in life (**Before**).

		Scoring			
1. Depressed most of the day nearly every day.	N	?	1	2	3
o Have you been feeling down or low over the last two weeks?	B	?	1	2	3
o Has that been most of the time or just some of the time?					
2. Markedly diminished interest or pleasure in all, or almost all activities of the day, nearly every day.	N	?	1	2	3
	B	?	1	2	3
o Right and has there been a change in the things you enjoy doing or activities you take pleasure in? (Well, for example, quite a lot of people enjoy watching sport or soap operas on T.V.).					
o And is that because you can't do that now or is it because you feel you just can't be bothered?					
o What about stuff that you can still do but just don't?					
3. Feelings of worthlessness or excessive or inappropriate guilt (may be delusional) nearly every day, not merely self-reproach about being sick. N.B. code 1 or 2 if only Low self Esteem.	N	?	1	2	3
	B	?	1	2	3
o And how have you been feeling about yourself as a person lately?					
o How's your self-esteem been?					
o When you're feeling bad about yourself would you say that you feel worthless?					
4. Recurrent thoughts of death (not just fear of dying).	N	?	1	2	3
Recurrent suicidal ideation without a specific plan, or a suicide attempt or a specific plan for committing suicide. N.B. code 1 for self-mutilation without suicidal intent.	B	?	1	2	3
o I can see you've had a difficult time, have things ever seemed so bad you've thought you would be better off dead?					
o Have you been thinking about death a lot?					
o Has that ever gone further than a thought?					
o So have things been so bad that you've thought about ending it all?					

5. Insomnia or hypersomnia nearly every day (particularly look for early awakening). N ? 1 2 3

B ? 1 2 3

- Have you experienced a change in your sleeping patterns?
- Can you tell me a bit about that?

6. a) Psychomotor agitation or retardation nearly every day (observable by others not merely subjective feelings of restlessness/being slowed down). N ? 1 2 3

B ? 1 2 3

- Have you ever been particularly fidgety or feeling extremely restless? or,
- Have you ever been feeling extremely slowed down to such an extent it's difficult to make yourself move?

b) Was there psychomotor agitation/retardation during the interview? N ? 1 2 3

B ? 1 2 3

7. Fatigue or loss of energy nearly every day.

N ? 1 2 3

- And how have your energy levels been lately?

B ? 1 2 3

- Has that been most of the time or just some of the time?

8. Significant weight loss when not dieting, or weight gain (a change of more than 5% in 1 month) or Decrease/Increase in appetite nearly every day. N ? 1 2 3

B ? 1 2 3

- How has your appetite been compared to normal?

9. Diminished ability to think or concentrate or indecisiveness nearly every day. N ? 1 2 3

- Have you been having any difficulties thinking or concentrating lately? B ? 1 2 3

(just about small every day things)

- Again has that been just some of the time or all of the time?

Note: I changed ordering of questions to avoid ending with suicide questions

Do you receive any medication from the doctor like anti-depressants or sleeping pills?

D.15: Screening for Anxiety disorders and specific structured interviews

Explore any 'Yes' response with appropriate further questioning (I used loose sheets for' pages 4 to10' which were used as appropriate)

	Yes	No
Panic Disorder Have you ever had a panic attack, suddenly felt extremely frightened or anxious or suddenly developed a lot of physical symptoms? If Yes, Have these attacks ever come on completely out of the blue/in situations when you didn't expect to be nervous or uncomfortable? If unclear, How many of these kinds of attacks have you had? (At least two?)	PAGES 4 & 5	
Agoraphobia without panic disorder Were you ever afraid of going out of the house alone, being alone, being in a crowd, queuing up or travelling on buses or trains?	PAGE 6	
Social phobia Is there anything that you have been afraid to do, or felt uncomfortable doing in front of other people, like speaking, eating or writing?	PAGE 7	
PTSD Sometimes people find having a stroke extremely upsetting and memories keep coming back in nightmares, flashbacks or thoughts that you can't get rid of. Has this been happening to you? If no, What about being very upset when you are in a situation that reminds you of having the stroke?	PAGES 8 & 9	
GAD In the last six months have you been particularly nervous or anxious?	PAGE 10	

PAGE 4

Panic disorder without agoraphobia

To meet criteria for panic disorder all items must be answered 'Yes' unless otherwise specified

- **So you've experienced a panic attack....**
    - **Evidence of worrying about its implications, or another episode?**

Did you **worry** that there might be something **terribly wrong** with you, like you were getting very ill again or going crazy?

Did you **worry** a lot about **having another** panic attack? (How long did you worry? (At least a month?)

Did you do anything differently because of the attacks
(like avoiding certain places?/going out alone?/certain activities like exercise?)
(What about things like always making sure you are near a bathroom or exit?).

- **Abrupt onset & less than 10 mins to peak?**

When was the last one? **What** did you notice first? **Then what?**

Did the symptoms come on **all of a sudden?**

How long did it take from when it began to when it got really bad?

- **4 of these....**

Heart racing, pounding or skipping?

Sweating?

Trembling or shaking?

Difficulty catching breath?

Feelings of choking?

Chest pain or pressure?

Feeling nauseous, as if stomach upset or as if going to have diarrhoea?

Dizziness, feel unsteady, or like fainting?

Feeling that things around were unreal or you were detached from things around or from part of your body?

Fear of going crazy or losing control?

Fear of dying?

Tingling or numbness in parts of your body?

Flushes or chills?

MUST ANSWER 'No'

- **Just before you have a panic attack have you ever taken any drugs, caffeine, diet pills, or other medicines**

Panic disorder with Agoraphobia

See previous page for panic disorder symptoms
Maybe fairly obvious from prior questioning that agoraphobia accompanies panic disorder, but must answer 'Yes' to these questions

- **Are there situations that make you nervous because you are afraid that you might have a panic attack?**

E.G. Outside home?/In crowds?/In public transport?

- **Avoidance/Marked distress/Need for a companion**

Do you **avoid** these situations?

When you are in one of these situations do you feel **very uncomfortable** or like you might have a panic attack?

Do you **need someone** you know to be with you?

N.B. ONSET QUESTIONS

When did your fear of, discomfort with ... ...begin?

How long did it last for?

PAGE 6

Agoraphobia without Panic Disorder

To meet criteria for agoraphobia without panic disorder must answer 'Yes' to both questions…

- **So you've been afraid of …** going out of the house alone, being alone, being in a crowd, queuing up or travelling on buses or trains …

What were you afraid would happen?

  - **Do you avoid these situations?**

If no, When you are in one of these situations, do you feel **very uncomfortable** or like you might have a panic attack

Do you **need someone** you know to be with you?

  - **Just before you begun having these fears, were you taking any drugs, caffeine, diet pills, or other medicine?**

N.B. ONSET QUESTIONS

When did your fear of, discomfort with … …begin?

How long did it last for?

PAGE 7

Social Phobia

To meet criteria for Social Phobia must answer 'Yes' to all items...

- **So you have been afraid or, have felt uncomfortable** ... speaking, eating or writing .... **in front of other people?**

Tell me about it?

What were you afraid would happen when _____?

- **Do you always feel anxious when you are confronted with** ...phobic stimulus...**?**

- **Did you think that you were more afraid of** ...phobic stimulus... **than you should have been (or than made sense)?**

- **Do you go out of your way to avoid** ...phobic stimulus...**?**

If no, How hard is it for you to _____?

DISTRESS/IMPAIRMENT (must be judged significant)

- **How much does having this fear interfere with your life?**

ALSO,

- **How much has the fact that you have this fear bother you?**

- **Just before you begun having these fears, were you taking any drugs, caffeine, diet pills, or other medicine?**

N.B. ONSET QUESTIONS

When did your fear of, discomfort with ... ...begin?

How long did it last for?

PAGE 8

PTSD

To meet criteria for PTSD some aspects of each item must be answered 'Yes'

- **So you've been extremely upset by the stroke by...**
memories that keep coming back in nightmares, flashbacks or thoughts that you can't get rid of ...

- **Or, you get very upset** when you are in a situation
that **reminds** you of having the stroke...

  - **ONE or more of the following specific ways that this may have had an affect**

Did you think about having your stroke when you didn't want to or did thoughts about it come to you suddenly when you didn't want them to?

What about having dreams about having your stroke?

What about finding yourself acting or feeling as if you were back in the situation?

What about getting very upset when something reminded you of having the stroke?

What about having physical symptoms like breaking out in a sweat, breathing heavily or irregularly, or your heart pounding or racing?

  - **THREE or more of the following avoidances**
Have you made a special effort to avoid thinking about or talking about what happened?

Do you try and avoid thinking about it, or having conversations about it.

Have you stayed away from things or people that reminded you of it?

Have you been unable to remember some important part of what happened?

Have you been much less interested in doing things that used to be important to you, like seeing friends, reading books, or watching T.V?

Have you felt distant or cut of from others?

Have you felt 'numb' or like you no longer have strong feelings about anything or loving feelings for anyone?

Have you noticed a change in the way you think about or plan for the future?

- **TWO of the following arousal items**

Have you had trouble sleeping?

Have you been unusually irritable? What about outbursts of anger?

Have you had trouble concentrating?

Have you been watchful or on guard even when there was no reason to be?

Have you been jumpy or easily startled, like by sudden noises?

DISTRESS/IMPAIRMENT (must be judged significant)

- **How much do these experiences interfere with your life?**

ALSO,

- **How much does it bother you that you have these experiences bother you?**

N.B. ONSET QUESTIONS (Symptoms must have lasted longer than one month)

When did your fear of, discomfort with ... ...begin?

How long did it last for?

PAGE 10

Generalised Anxiety Disorder

To meet criteria for GAD, all items must be answered 'Yes'

- So you've been feeling particularly nervous or anxious over the last six months?

  - **What do you worry about?** (a number of events or activities)

How much do you worry about_____?

  - **During the last six months would you say that you've been worrying more days than not?**

  - **Do you find it hard to stop yourself worrying?**

  - THREE **of following symptoms…**

Thinking about those times over the last six months when you've been really anxious…

Do you often feel physically restless – like you can't sit still?

Do you feel keyed up or on edge?

Do you often tire easily?

Do you have trouble concentrating or does your mind go blank?

Are you often irritable?

Are your muscles often tense?

Do you have trouble falling or staying asleep?

DISTRESS/IMPAIRMENT (must be judged significant)

  - **How much does it bother you that you worry so much, find it hard to stop or get these symptoms?**

  - **Just before you begun having these fears, were you taking any drugs, caffeine, diet pills, or other medicine?**

N.B. ONSET QUESTIONS (Symptoms must have lasted longer than one month)

When did your fear of, discomfort with … …begin?

How long did it last for?

D.16: Hospital Anxiety Depression scale

Instructions: Doctors are aware that emotions play an important part in most illnesses. If your doctor knows about these feelings he or she will be able to help you more. This questionnaire is designed to help your doctor know how you feel. Read each item and place a firm tick in the box opposite the reply which comes closest to how you have been feeling in the past week. Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought-out response.

I feel tense or 'wound up':	
Most of the time	3
A lot of the time	2
Time to time, occasionally	1
Not at all	0

I still enjoy the things I used to enjoy:	
Definitely as much	0
Not quite so much	1
Only a little	2
Not at all	3

I get a sort of frightened feeling like something awful is about to happen:	
Very definitely and quite badly	3
Yes, but not too badly	2
A little, but it doesn't worry me	1
Not at all	0

I can laugh and see the funny side of things:	
As much as I always could	0
Not quite so much now	1
Definitely not so much now	2
Not at all	3

Worrying thoughts go through my mind:	
A great deal of the time	3
A lot of the time	2
From time to time but not too often	1
Only occasionally	0

I feel cheerful:	
Not at all	3
Not often	2
Sometimes	1
Most of the time	0

I can sit as ease and feel relaxed:	
Definitely	0
Usually	1
Not often	2
Not at all	3

I feel as if I am slowed down:	
Nearly all of the time	3
Very often	2
Sometimes	1
Not at all	0

I get a sort of frightened feeling like 'butterflies in the stomach':	
Not at all	0
Occasionally	1
Quite often	2
Very often	3

I have lost interest in my appearance:	
Definitely	3
I don't take as much care as I should	2
I may not take quite as much care	1
I take just as much care as ever	0

I feel restless as if I have to be on the move:	
Very much indeed	3
Quite a lot	2
Not very much	1
Not at all	0

I look forward with enjoyment to things:	
A much as I every did	0
Rather less than I used to	1
Definitely less than I used to	2
Hardly at all	3

I get sudden feelings of panic:	
Very often indeed	3
Quite often	2
Not very often	1
Not at all	0

I can enjoy a good book or radio or TV programme:	
Often	0
Sometimes	1
Not often	2
Very seldom	3

D.17: Life Events

Have any of the following events or problems happened to you during the last 6 months? Please tick the box corresponding to the month in which any event happened or began.

Use cues such as before Christmas or after Easter

	Months (label as appropriate)					
You yourself suffered a serious illness, injury or an assault.						
A serious illness, injury or assault happened to a close relative .						
Your parent, child or spouse died .						
A close family friend or another relative (aunt, cousin, grandparent) died.						
You had a separation due to marital difficulties.						
You broke off a steady relationship.						
You had a serious problem with a close friend, neighbour or relative.						
You became unemployed or you were seeking work unsuccessfully for more than one month.						
You were sacked from your job.						
You had a major financial crisis.						
You had problems with the police and a court appearance.						
Something you valued was lost or stolen.						

D.18: Social support

People sometimes look to others for companionship, assistance, or other types of support. How often is each of the following kinds of support available to you if you need it?

Please let me know how often each type of support is available to you

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
1. Someone to help you if you were confined to bed	0	1	2	3	4
2. Someone you can count on to listen to you when you need to talk	0	1	2	3	4
3. Someone to give you good advice about a crisis.	0	1	2	3	4
4. Someone to take you to the doctor if you needed it.	0	1	2	3	4
5. Someone who shows you love and affection.	0	1	2	3	4
6. Someone to have a good time with.	0	1	2	3	4
7. Someone to give you information to help you understand a situation.	0	1	2	3	4
8. Someone to confide in or talk to about yourself or your problems	0	1	2	3	4
9. Someone who hugs you.	0	1	2	3	4
10. Someone to get together with for relaxation.	0	1	2	3	4
11. Someone to prepare your meals if you were unable to do it yourself.	0	1	2	3	4
12. Someone whose advice you really want.	0	1	2	3	4
13. Someone to do things with to help you get your mind off things.	0	1	2	3	4
14. Someone to help with daily chores if you were sick.	0	1	2	3	4

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
15. Someone to share your most private worries and fears with.	0	1	2	3	4
16. Someone to turn to for suggestions about how to deal with a personal problem.	0	1	2	3	4
17. Someone to do something enjoyable with.	0	1	2	3	4
18. Someone who understands your problems.	0	1	2	3	4
19. Someone to love and make you feel wanted.	0	1	2	3	4

D.19: Acceptance of disability

Now I'd like to read some statements about whether having had a stroke has changed the way you think about life. I'll read them as if I'm you. Please would you tell me how much you agree or disagree with the statements as we did before

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
1. I have had a hard time adjusting to the limitations of my stroke.	4	3	2	1	0
2. Because of the effects of my stroke, I miss the things I like to do most.	4	3	2	1	0
3. The effects of my stroke make me feel useless at times.	4	3	2	1	0
4. The effects of my stroke make me more dependent on others than I want to be.	4	3	2	1	0
5. The effects of my stroke make me a burden on my family and friends.	4	3	2	1	0
6. The effects of my stroke make me feel inadequate.	4	3	2	1	0
7. I will never be self-sufficient enough to make me happy.	4	3	2	1	0
8. I think people are often uncomfortable being around me because of the effects of my stroke	4	3	2	1	0

D.20: Shame

These next statements are about how you think other people see you now

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
1. Since my stroke, I think others sometimes see me as inadequate as a person.	0	1	2	3	4
2. Since my stroke, I sometimes feel that others see me as not measuring up to them.	0	1	2	3	4
3. Since my stroke, I get embarrassed that others must think I've lost control over my feelings.	0	1	2	3	4

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
4. Since my stroke I sometimes feel useless because others have to make allowances for me.	0	1	2	3	4
5. Since my stroke, the way others fuss about me sometimes gets irritating.	0	1	2	3	4
6. Since my stroke, I sometimes get embarrassed about the way I must appear to others.	0	1	2	3	4
7. Since my stroke, I sometimes get upset because others treat me as if I'm less intelligent.	0	1	2	3	4
8. Since my stroke, I find it comforting that others are protective towards me.	4	3	2	1	0
9. Since my stroke, I've found it nice that others make allowances for me.	4	3	2	1	0
10. Since my stroke, people have acted as if I'm just as intelligent as I was before.	4	3	2	1	0

D.21: Negative identity change

Now I would like to ask you about the way you would describe yourself before you had your stroke as compared to now. So I'm going use to use a list of adjectives and with each one we'll work how much you'd agree for before and then how much you'd agree now.

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
1a. Before my stroke, I would describe myself as bored.	4	3	2	1	0
1b. Now I have had my stroke, I would describe myself as bored.	4	3	2	1	0
2a. Before my stroke, I would describe myself as unhappy.	4	3	2	1	0
2b. Now I have had my stroke, I would describe myself as unhappy.	4	3	2	1	0

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
3a. Before my stroke, I would describe myself as in control.	0	1	2	3	4
3b. Now I have had my stroke, I would describe myself as in control.	0	1	2	3	4
4a. Before my stroke, I would describe myself as worried.	4	3	2	1	0
4b. Now I have had my stroke, I would describe myself as worried.	4	3	2	1	0
5a. Before my stroke, I would describe myself as dissatisfied.	4	3	2	1	0
5b. Now I have had my stroke, I would describe myself as dissatisfied.	4	3	2	1	0
6a. Before my stroke, I would describe myself as attractive.	0	3	2	1	0
6b. Now I have had my stroke, I would describe myself as attractive.	0	3	2	1	0
7a. Before my stroke, I would describe myself as hopeful.	0	3	2	1	0
7b. Now I have had my stroke, I would describe myself as hopeful.	0	3	2	1	0
8a. Before my stroke, I would describe myself as confident.	0	1	2	3	4
8b. Now I have had my stroke, I would describe myself as confident.	0	1	2	3	4
9a. Before my stroke, I would describe myself as stable.	0	1	2	3	4
9b. Now I have had my stroke, I would describe myself as stable.	0	1	2	3	4
10a. Before my stroke, I would describe myself as worthless.	4	3	2	1	0

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
10b. Now I have had my stroke, I would describe myself as worthless.	4	3	2	1	0
11a. Before my stroke, I would describe myself as aggressive.	4	3	2	1	0
11b. Now I have had my stroke, I would describe myself as aggressive.	4	3	2	1	0
12a. Before my stroke, I would describe myself as irritable.	4	3	2	1	0
12b. Now I have had my stroke, I would describe myself as irritable.	4	3	2	1	0
13a. Before my stroke, I would describe myself as caring.	0	1	2	3	4
13b. Now I have had my stroke, I would describe myself as caring.	0	1	2	3	4
14a. Before my stroke, I would describe myself as independent.	0	1	2	3	4
14b. Now I have had my stroke, I would describe myself as independent.	0	1	2	3	4
15a. Before my stroke, I would describe myself as capable.	0	1	2	3	4
15b. Now I have had my stroke, I would describe myself as capable.	0	1	2	3	4
16a. Before I had my stroke, I would describe myself as active.	0	1	2	3	4
16b. Now I have had my stroke, I would describe myself as active.	0	1	2	3	4
17a. Before I had my stroke, I would describe myself as co-operative.	0	1	2	3	4
17b. Now I have had my stroke, I would describe myself as co-operative.	0	1	2	3	4

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
18a. Before I had my stroke, I would describe myself as withdrawn.	4	3	2	1	0
18b. Now I have had my stroke, I would describe myself as withdrawn.	4	3	2	1	0
19a. Before I had my stroke, I would describe myself as friendly.	0	1	2	3	4
19b. Now I have had my stroke, I would describe myself as friendly	0	1	2	3	4
20a. Before I had my stroke, I would describe myself as patient.	0	1	2	3	4
20a. Before I had my stroke, I would describe myself as patient.	0	1	2	3	4

D.22: Qualitative 'important areas' questions

Finally I'd like to ask for your own opinion one last time I'm interested in the things or areas of your life before the stroke that were most important to you?
(Probe) Sometimes the most important things people mention are the things they care about most, sometimes they mention what they enjoy most or what they are most proud of....

Which is the most important to you?/ Which is the least important of the three?

For each important thing/area:

Has your role as ___ /your enjoyment of ____ /your relationship with _____ changed since the stroke?.....How? Can you tell me about that?

How do you feel now knowing that _____ is limited/can't do _____?

What does that do?/ What goes through your mind when you think about_____?

Summarise what participant has said, check accuracy, emphasise something positive or how helpful it has been to hear about problems

Final check whether would like to ask questions and thank for participation

D.23: Example response cue sheet (used for acceptance of disability)

These statements are about the way you think having had a stroke has changed your life…

1. I have had a hard time adjusting to the limitations of my stroke.

2. Because of the effects of my stroke, I miss the things I like to do most.

3. The effects of my stroke make me feel useless at times.

4. The effects of my stroke make me more dependent on others than I want to be.

5. The effects of my stroke make me a burden on my family and friends.

6. The effects of my stroke make me feel inadequate.

7. I will never be self-sufficient enough to make me happy.

8. I think people are often uncomfortable being around me because of the effects of my stroke.

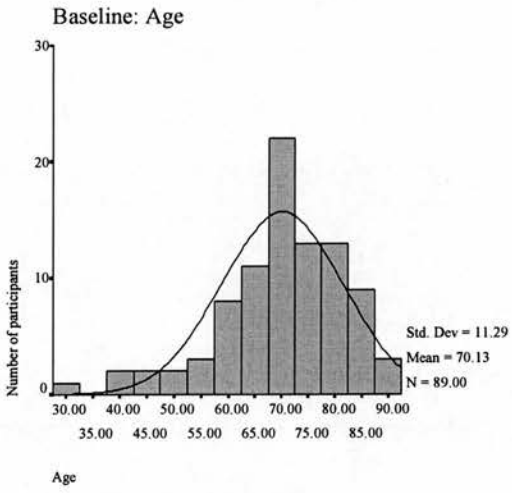
Strongly disagree	Disagree	Neutral	Agree	Strongly Agree

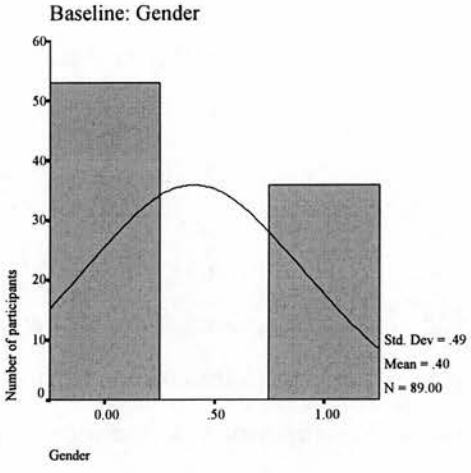
Appendix E

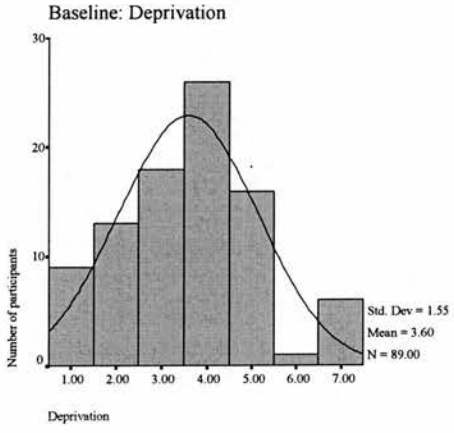
Histograms of background and belief variables and scatter-grams of their relationship with distress

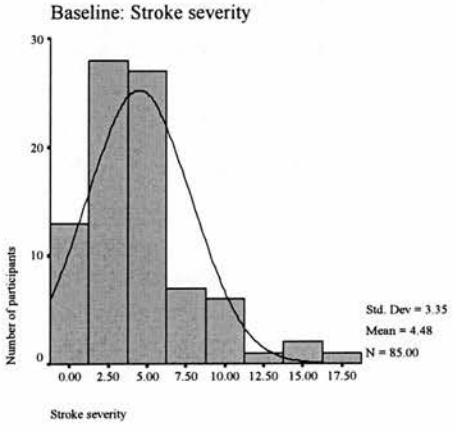
Section		Page
E1	Histograms of background variables at baseline	lxxxvi
E2	Histograms of belief variables at baseline	lxxxviii
E3	Histograms of background variables at follow-up	xc
E4	Histograms of belief variables at follow-up	xcii
E5	Scatter-plots of distress by background variables at baseline	xciv
E6	Scatter-plots of distress by belief variables at baseline	xcvi
E7	Scatter-plots of distress by background variables at follow-up	xcviii
E8	Scatter-plots of distress by belief variables at follow-up	c
E9	Scatter-plots of follow-up distress by baseline background variables	cii
E10	Scatter-plots of follow-up distress by baseline belief variables	civ

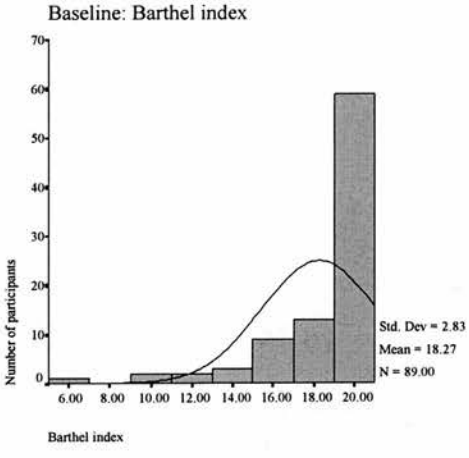
E1: Histograms of background variables at baseline

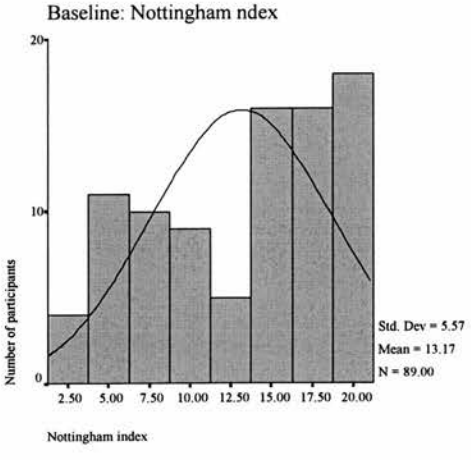


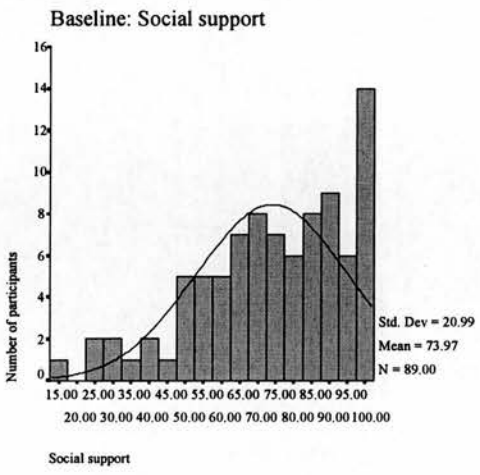


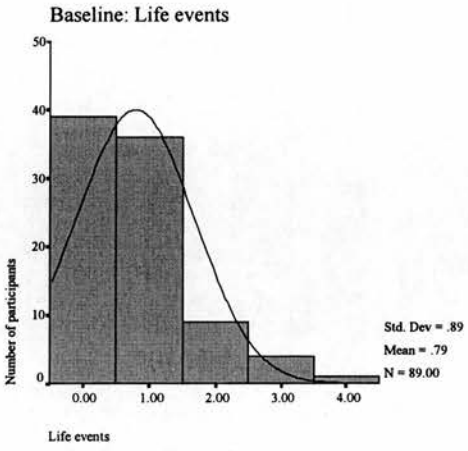


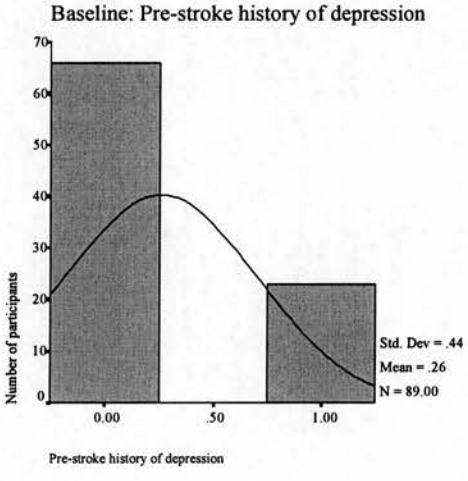








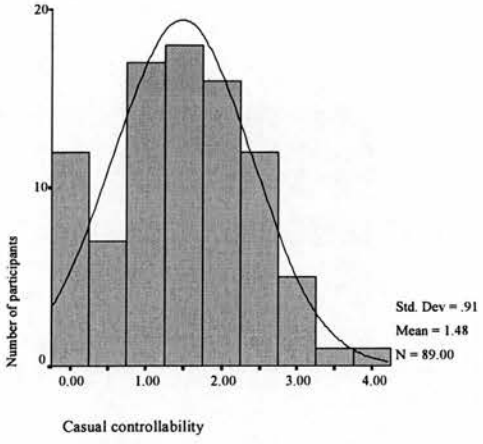




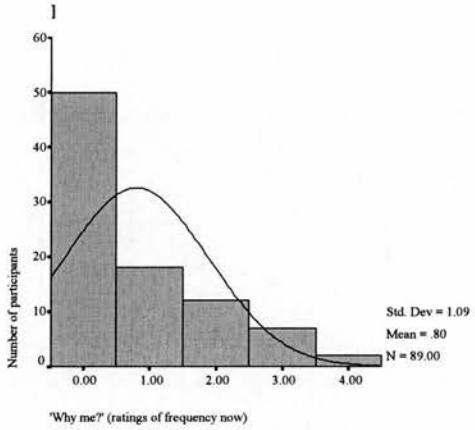
Appendix E: Histograms of background and belief variables and scatter-grams of their relationship with distress

E2: Histograms of belief variables at baseline

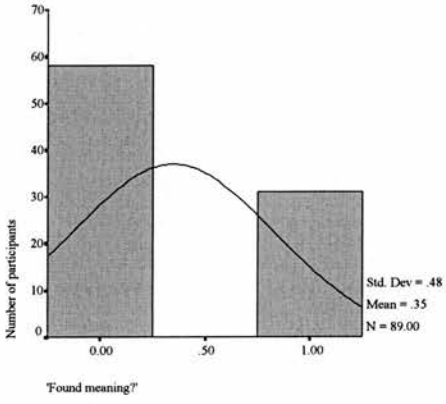
Baseline: Causal controllability



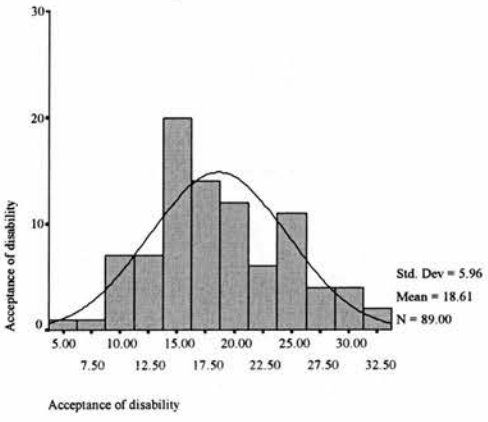
Baseline: 'Why me?' (ratings of frequency now)



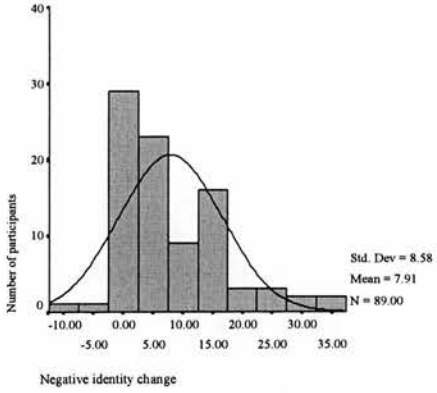
Baseline: 'Found meaning?'



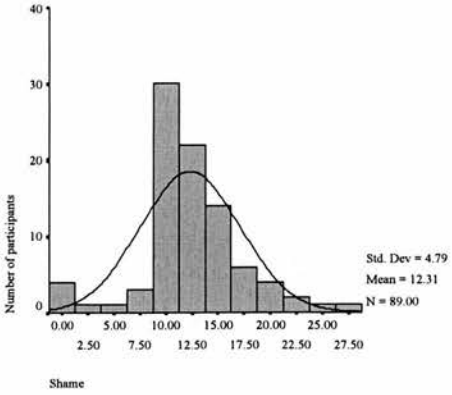
Baseline: Acceptance of disability

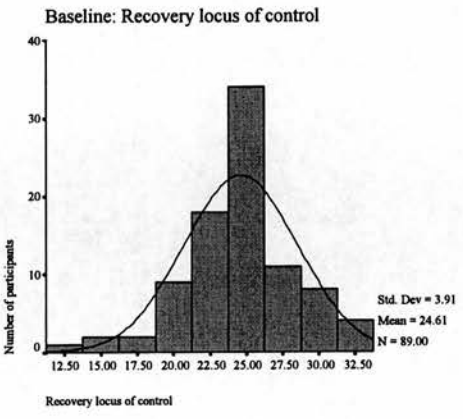


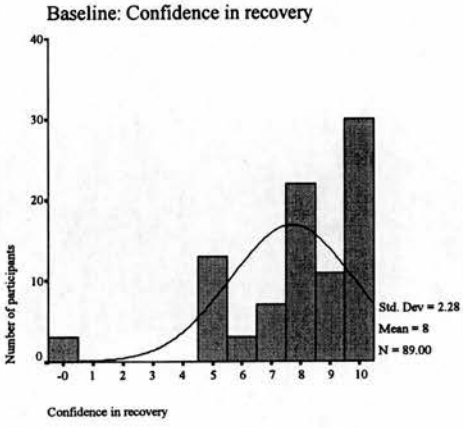
Baseline: Negative identity change

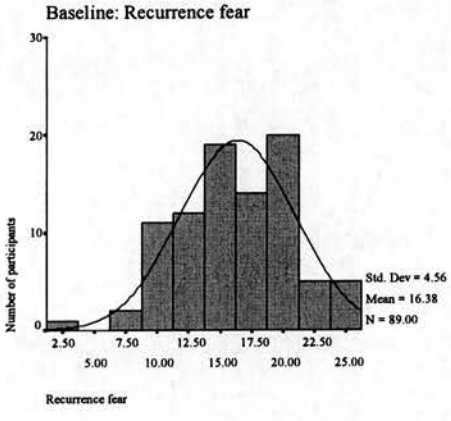


Baseline: Shame



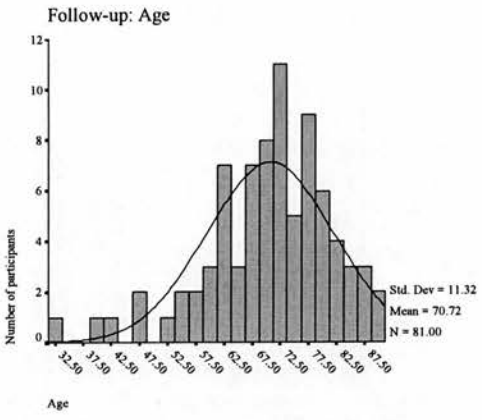


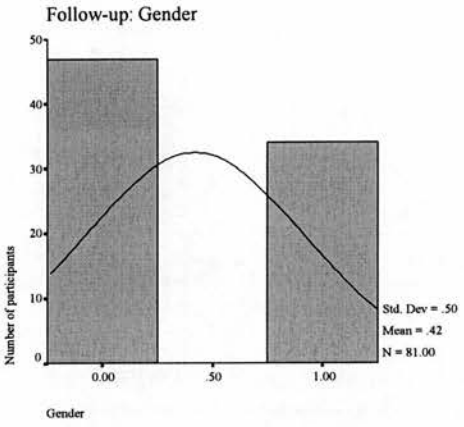


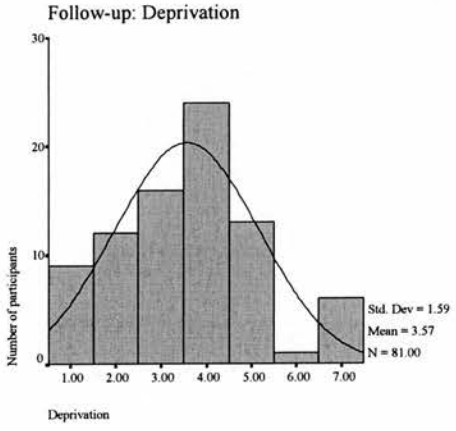


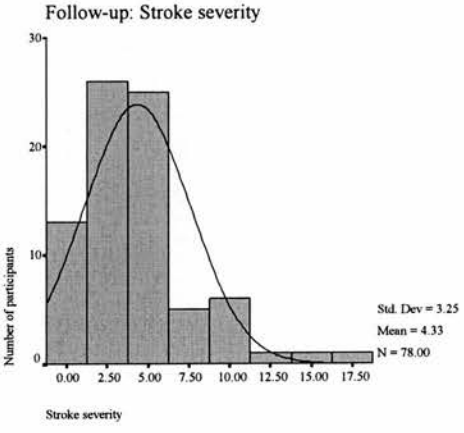
Appendix E: Histograms of background and belief variables and scatter-grams of their relationship with distress

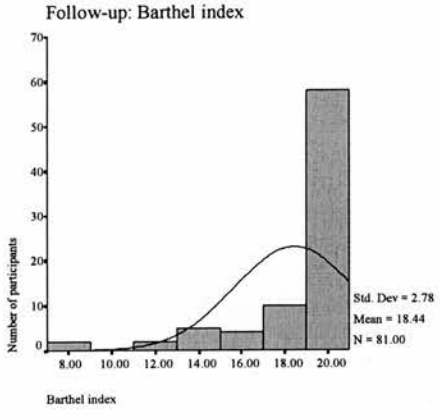
E3: Histograms of background variables at follow-up

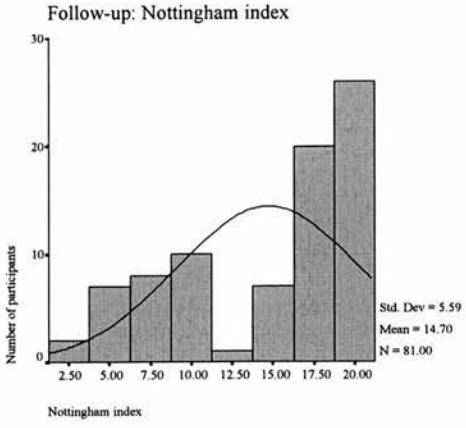


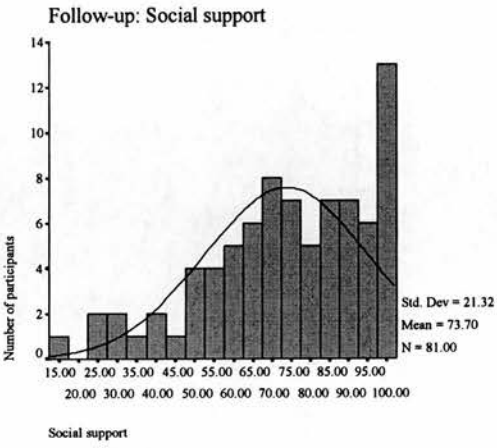


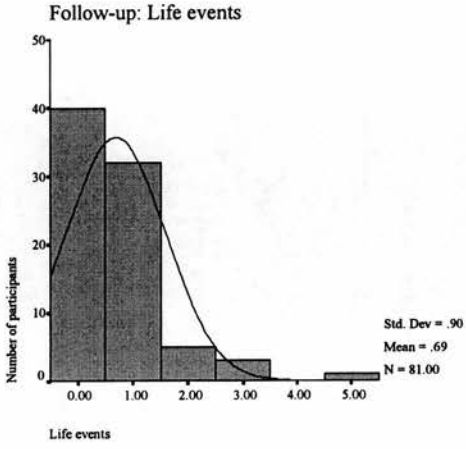


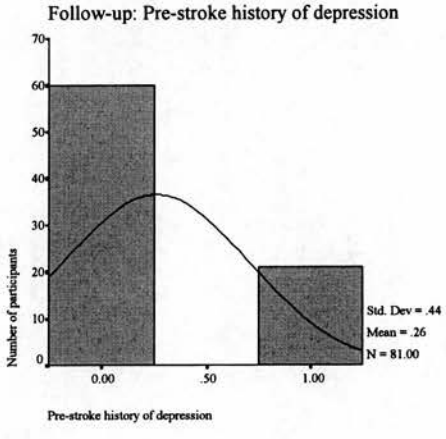








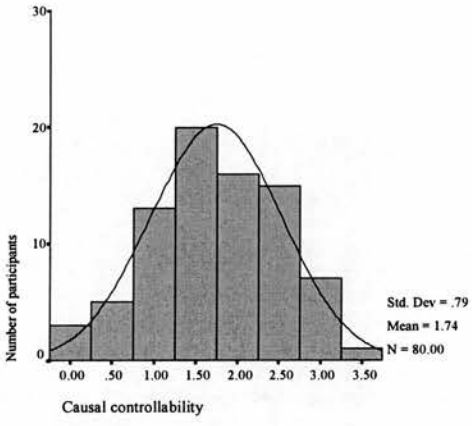




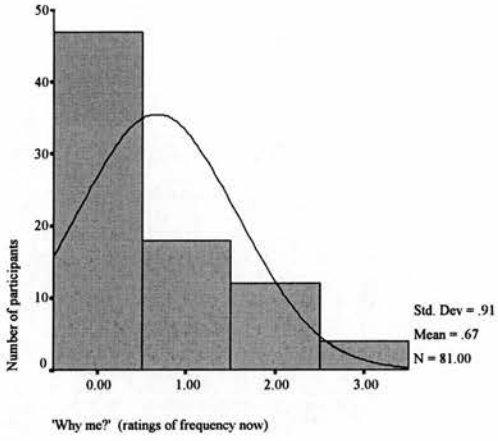
Appendix E: Histograms of background and belief variables and scatter-grams of their relationship with distress

E4: Histograms of belief variables at follow-up

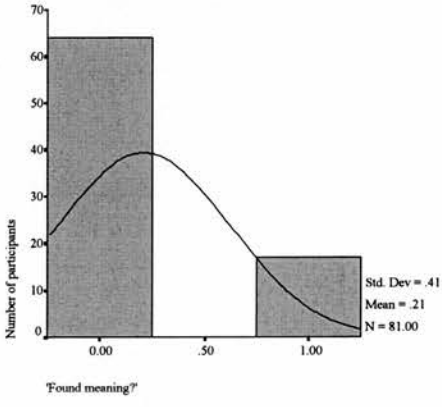
Follow-up: Causal controllability



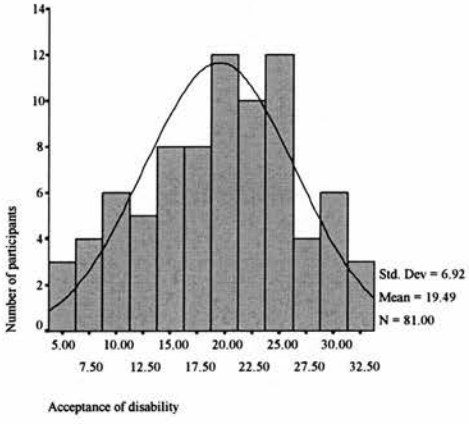
Follow-up: 'Why me?' (ratings of frequency now)



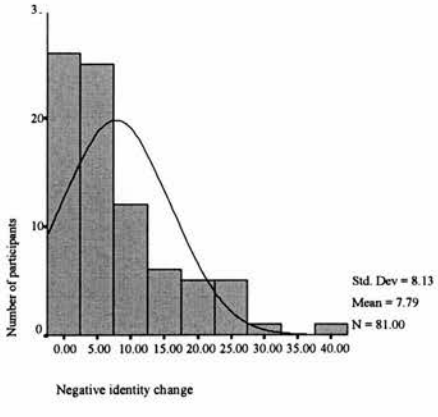
Follow-up: 'Found meaning?'



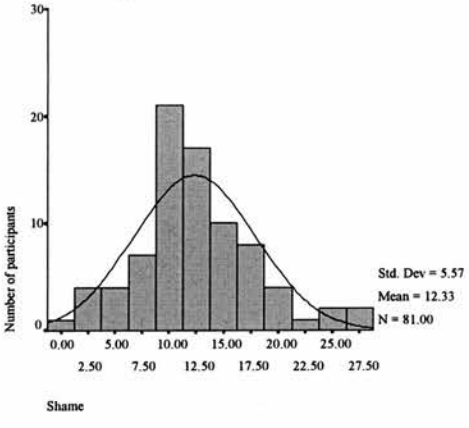
Follow-up: Acceptance of disability

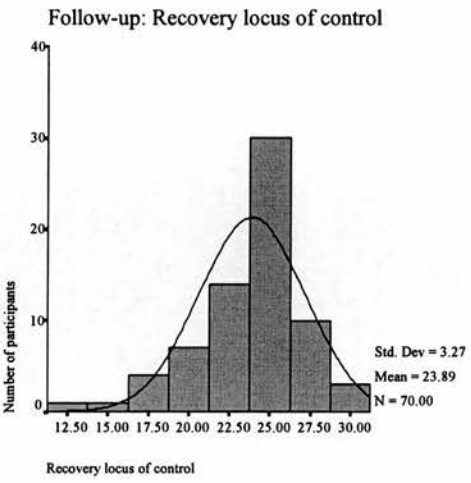


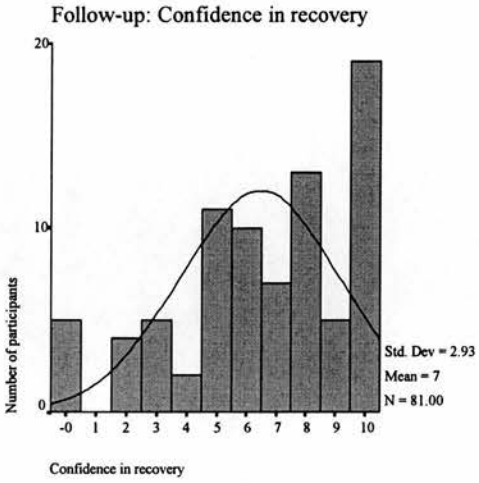
Follow-up: Negative identity change

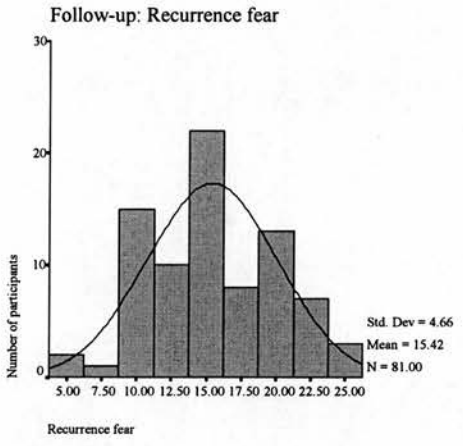


Follow-up: Shame



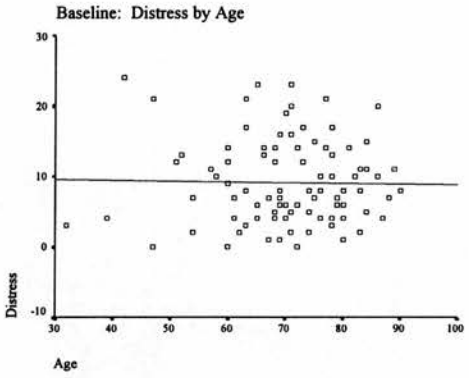


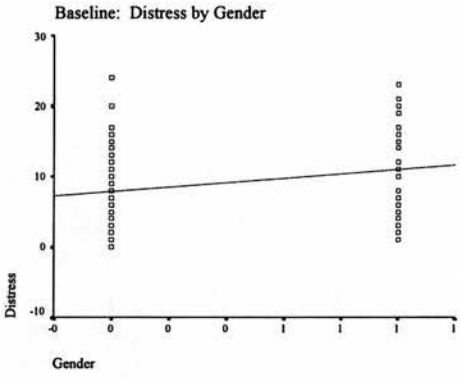


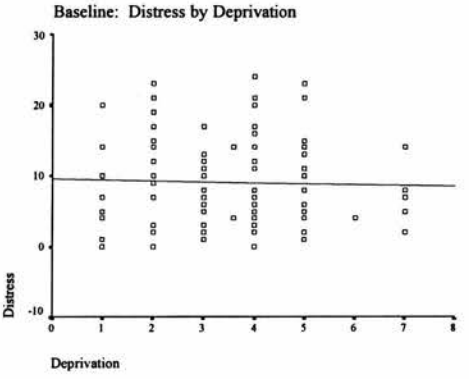


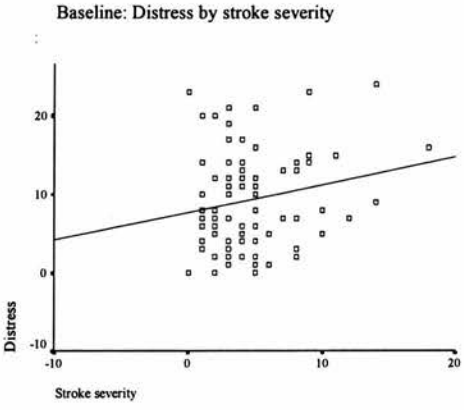
Appendix E: Histograms of background and belief variables and scatter-grams of their relationship with distress

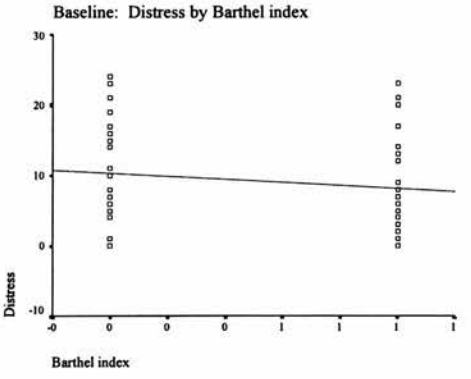
E5: Scatter-plots of distress by background variables at baseline

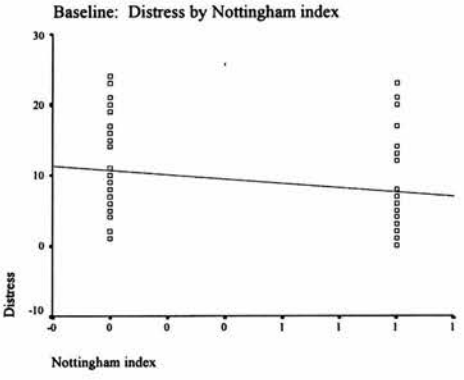


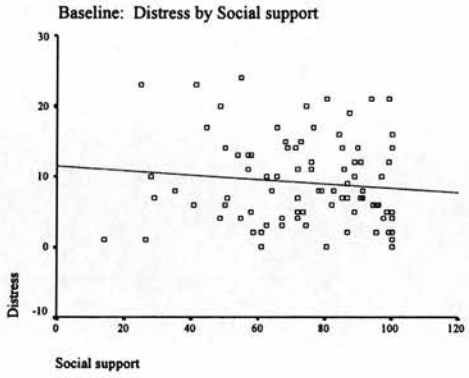


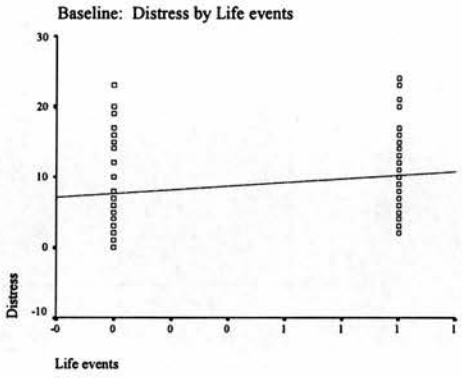


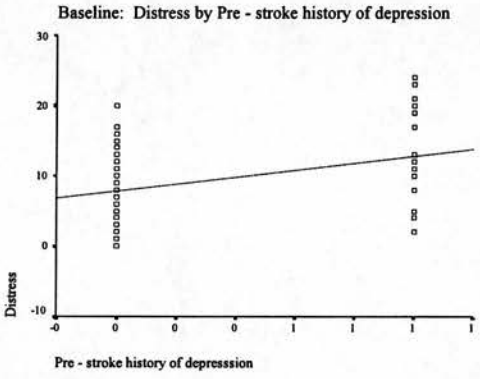








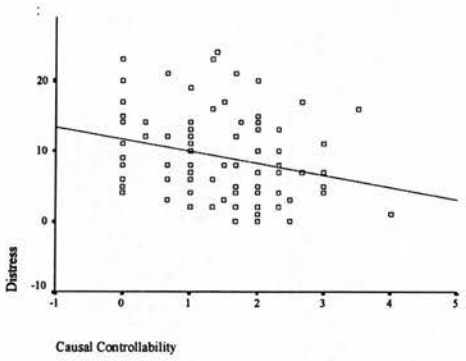




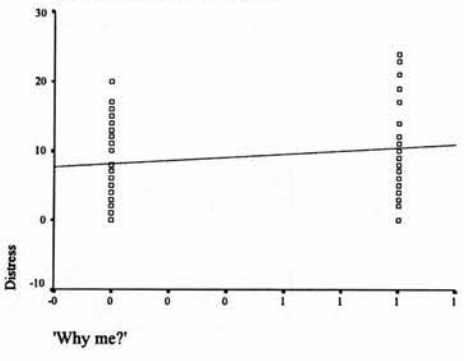
Appendix E: Histograms of background and belief variables and scatter-grams of their relationship with distress

E6: Scatter-plots of distress by belief variables at baseline

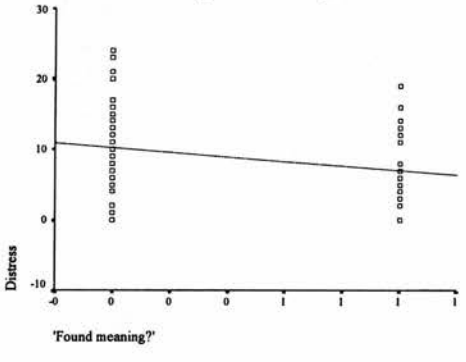
Baseline: Distress by Causal controllability



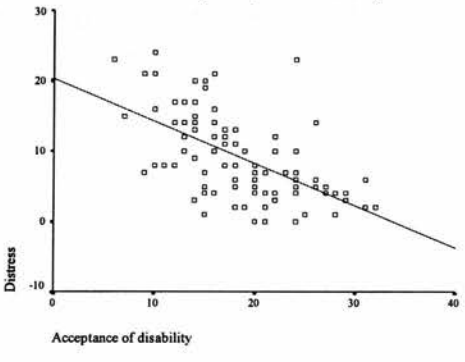
Baseline: Distress by 'Why me?'



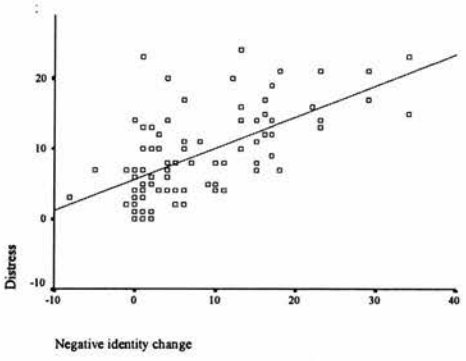
Baseline: Distress by 'Found meaning?'



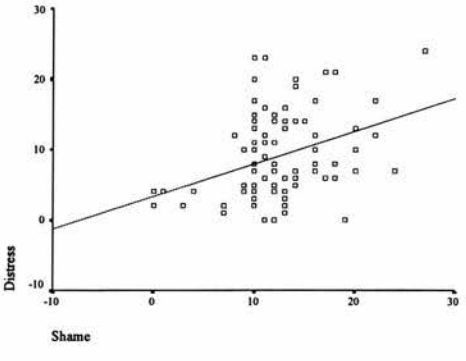
Baseline: Distress by Acceptance of disability

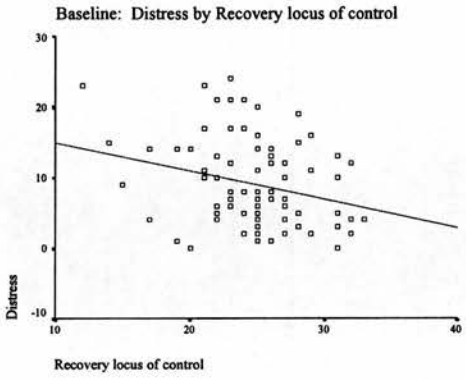


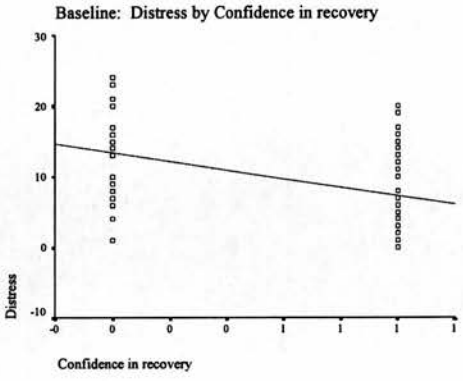
Baseline: Distress by Negative identity change

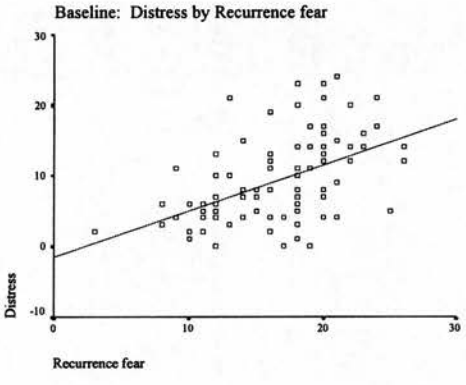


Baseline: Distress by Shame



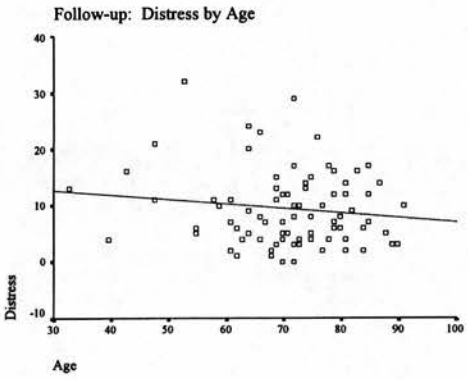


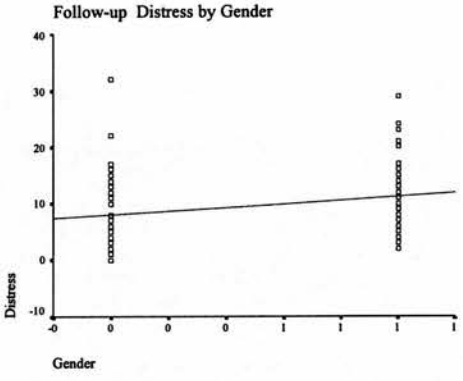


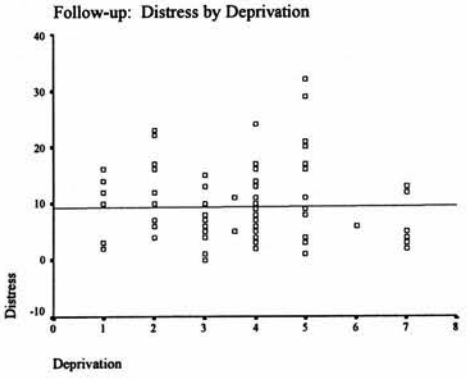


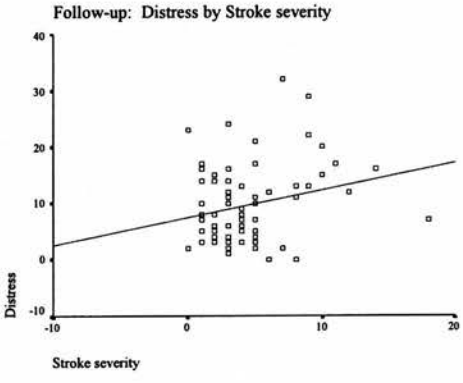
Appendix E: Histograms of background and belief variables and scatter-grams of their relationship with distress

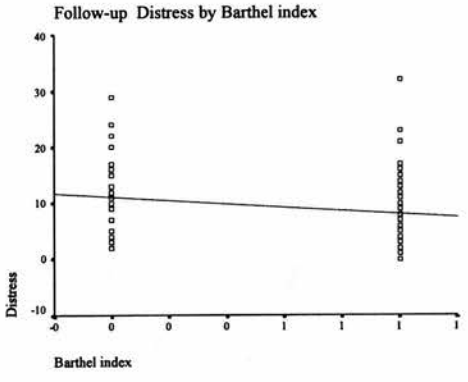
E7: Scatter-plots of distress by background variables at follow-up

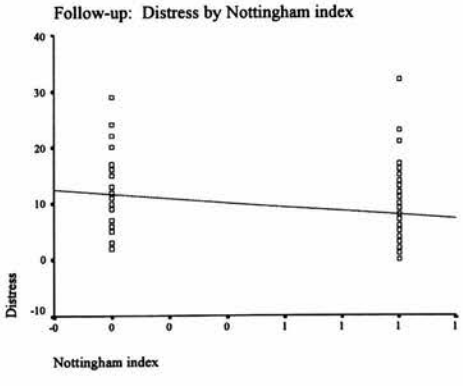


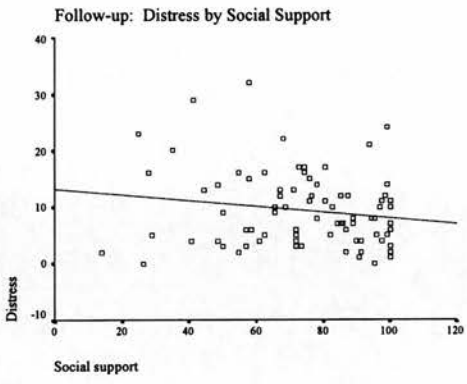


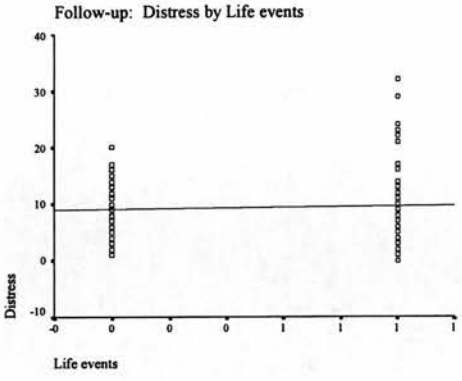


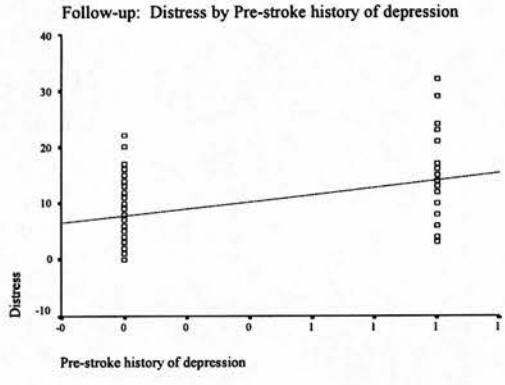












Appendix E: Histograms of background and belief variables and scatter-grams of their relationship with distress

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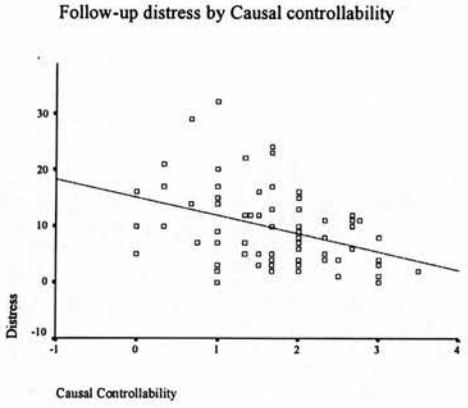
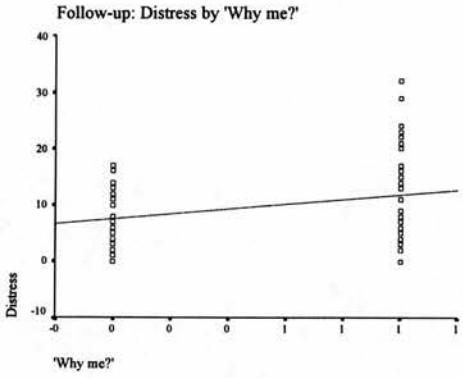
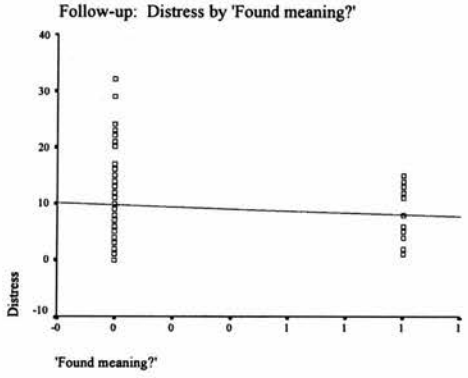
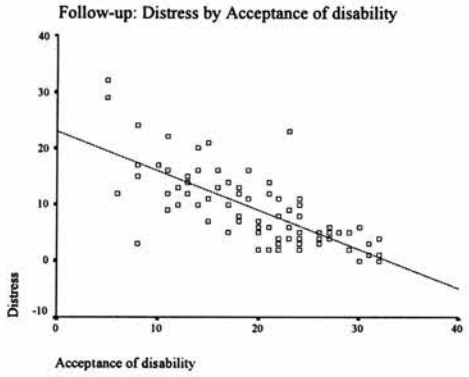
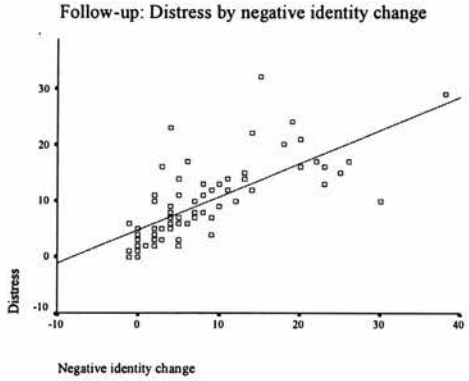
E8: Scatter-plots of distress by belief variables at follow-up

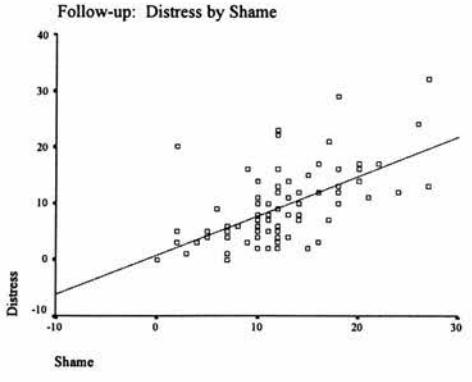


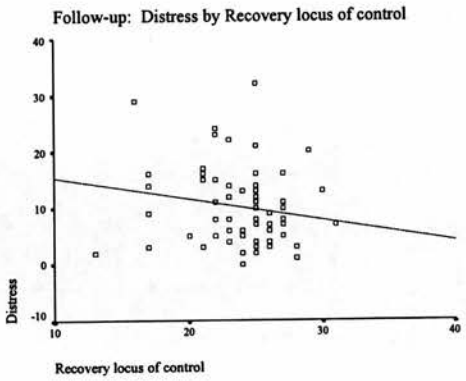


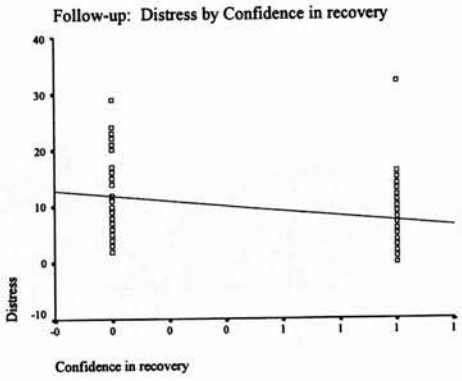


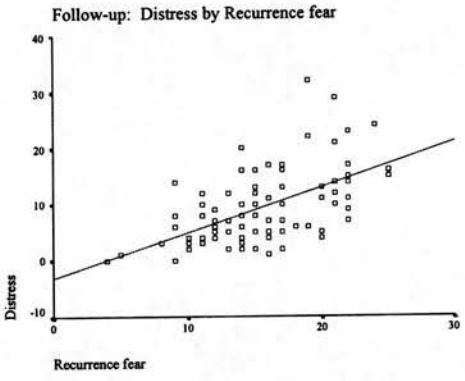








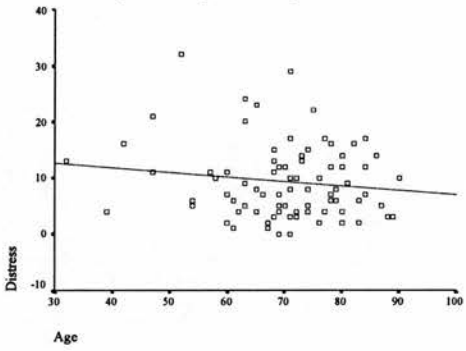




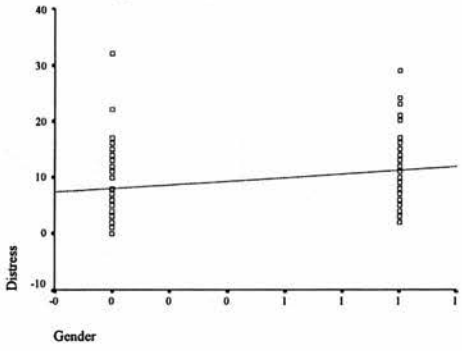
Appendix E: Histograms of background and belief variables and scatter-grams of their relationship with distress

E9: Scatter-plots of follow-up distress by baseline background variables

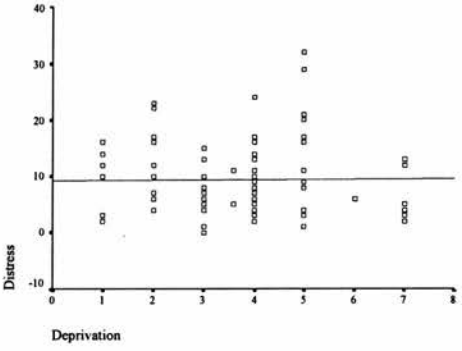
Follow-up Distress by baseline Age



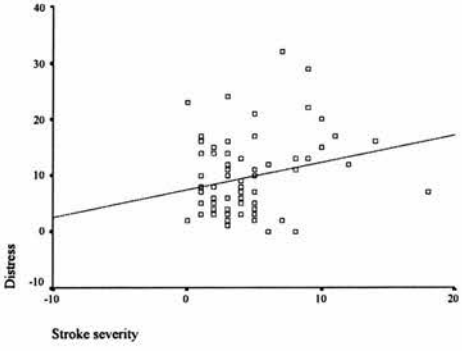
Follow-up Distress by baseline Gender



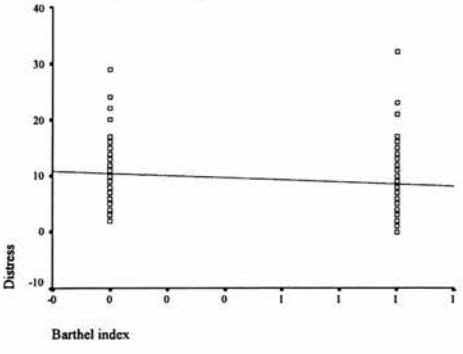
Follow-up Distress by baseline Deprivation



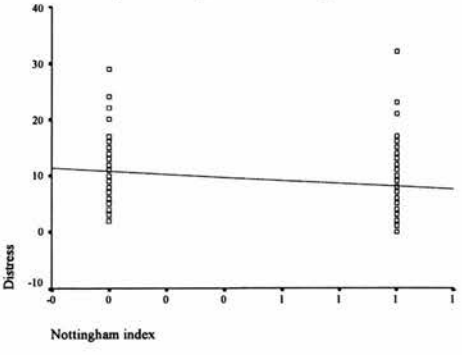
Follow-up Distress by baseline Stroke severity



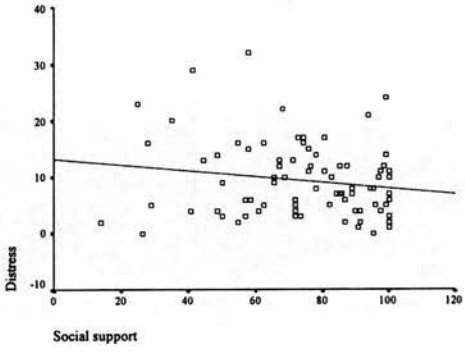
Follow-up Distress by baseline Barthel index



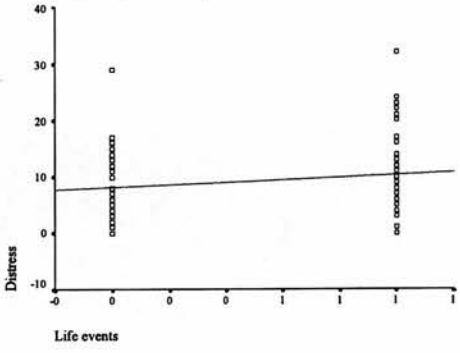
Follow-up Distress by baseline Nottingham index



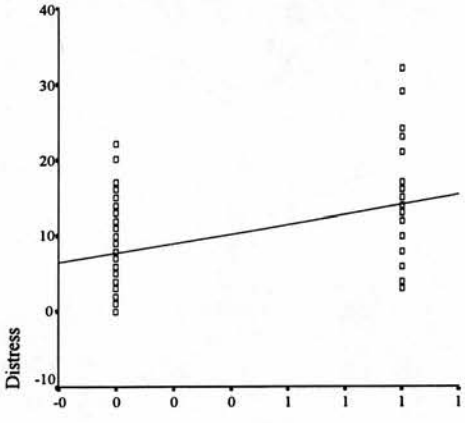
Follow-up Distress by baseline Social Support



Follow-up Distress by baseline Life events

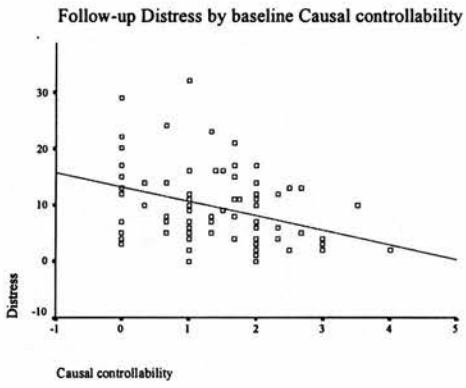


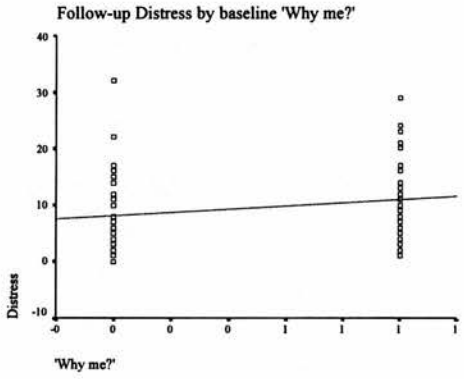
Follow-up: Distress by pre-stroke history of depression

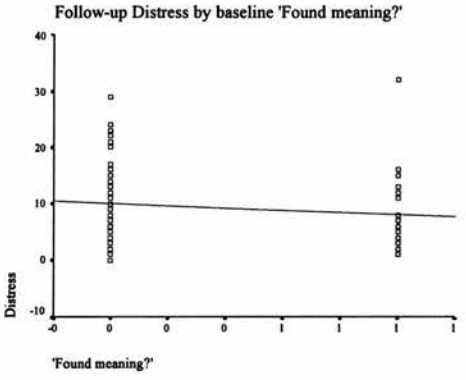


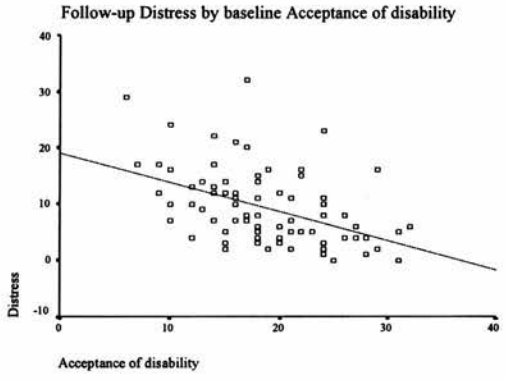
Appendix E: Histograms of background and belief variables and scatter-grams of their relationship with distress

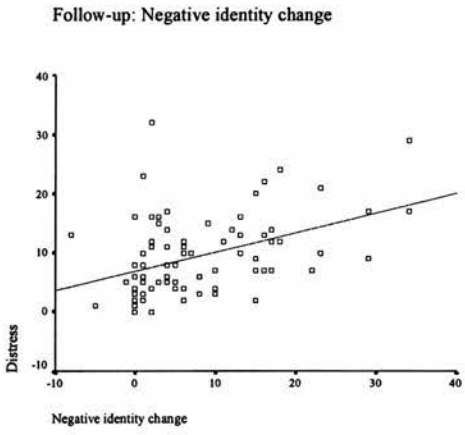
E10: Scatter-plots of follow-up distress by baseline belief variables

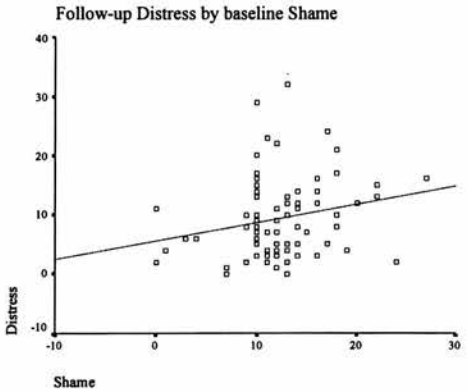


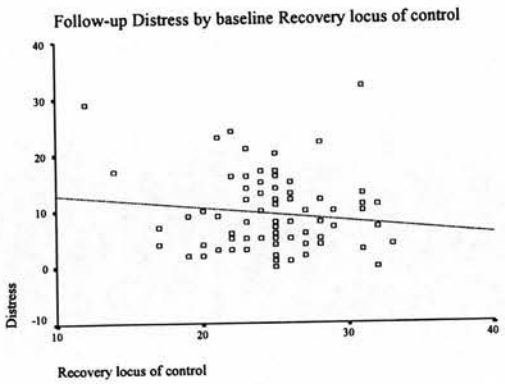


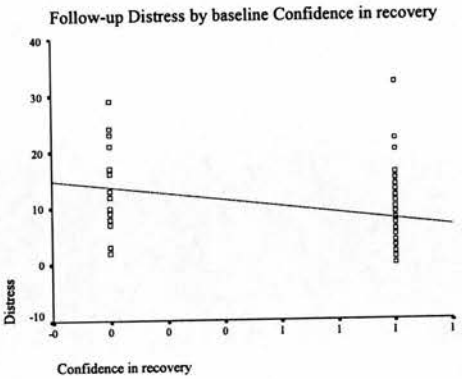


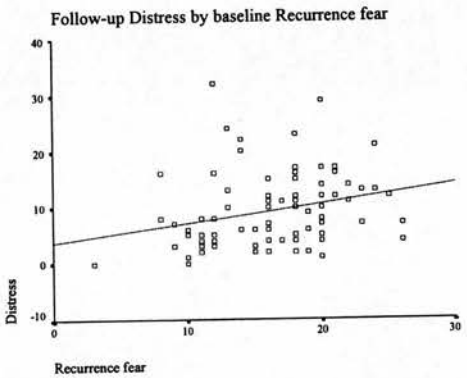












Appendix E: Histograms of background and belief variables and scatter-grams of their relationship with distress

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Appendix F

Additional descriptive data

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F.1: The difference between 'stroke' and 'its' effects'

Participants were asked to report their understanding of the terms 'stroke' and 'its' effects' to further investigate the importance of this distinction for theory development and questionnaire design in stroke. As expected from piloting this distinction was confirmed. The following more detailed report is provided for readers intrinsically interested in the way participants used these terms and the issues they raised.

F.1i: 'Stroke'

When first asked to describe 'stroke' at **baseline** participants sometimes said they were not sure or they described symptoms experienced at onset, or, gave contextual information surrounding the event of their stroke. A few participants' descriptions were emotive, for example 'frightening'. A seventy-seven year old female participants' account illustrates elements of symptoms, context and fear for the future:

'Dounnae ken, I've no idea, you just go useless. It came on awful sudden in the toilet. I just hope I don't get anymore'

Even, with prompting to describe what they thought was going on inside, eleven participants (11/ 89; 12%) did not.

However the majority of participants (77/ 89; 87%) gave a medical definition of 'stroke', usually with reference to the brain. The accuracy of accounts varied. Over half of participants (48/ 89; 54%) gave a fairly clean-cut accurate medical definition of a stroke, for example, a ninety-year old male participant said:

'It's a stoppage of blood to the brain which causes paralysis in certain regions'

Other participants (33/89; 33%) tended to define their stroke medically but with less confidence or accuracy, for example, a seventy-four year old man said:

'I haven't the foggiest... It must be something to do with the brain. It's been explained it's like a motorway, the right of the brain controls the left. Actually to be

honest I'm not sure if the left controls the right but I know the left side of the body is affected.'

When I interviewed participants at **follow-up** I had a transcript of their descriptions of stroke at baseline with me. I found that I recorded very little further information at follow-up as their explanations were nearly always the same. However, while the proportion of participants offering a clear accurate medical description of stroke was similar (43/ 81; 53%) a slightly lower proportion offered a 'patchy' medical account (21/ 81; 26%) and the proportion of people who were unable to describe what had gone on inside was higher (17/ 89; 21%).

It is possible that participants in this study tended to have more medical knowledge of stroke than is typical. They were cared for in a University specialist stroke unit and the approximately two thirds were interviewed for a clinical registrars' project regarding diagnosis of stroke. They may well have been provided with more information than other patients treated elsewhere.

F.1ii: 'The effects of stroke'

At **baseline,** six participants (6/ 89; 7%) reported they no longer felt they had any real effects of their stroke remaining. Other participants described effects that could be broadly classified into as physical, memory, visual or emotional.

Most participants (74/ 89; 83%) reported at least one physical effect of stroke. Paralysis or weakness of limbs, or functional effects, for example difficulty walking, dressing and eating, were mentioned often. General tiredness or finding one tired more easily was mentioned fairly often, and this may have an emotional element as well as a physical one. Problems with weaker speech or bladder control were both mentioned by three participants respectively. Other disabling physical effects such as hearing loss, pain, swallowing difficulty and breathlessness were mentioned once or twice.

About a third of participants reported memory problems (30/ 89; 34%). Most commonly participants reported that they were more forgetful or found their

everyday memory less 'sharp' or 'clear'. Problems with finding words or with concentration were mentioned fairly often and one participant reported finding it harder to make decisions. Memory problems were not emphasised in the standard disability measures used in the main study. However, the finding that they were often spontaneously mentioned suggests that they were issues that participants themselves considered important.

Quite a few participants (12/ 89; 14%) reported visual problems or related functional consequences such as reading or walking outside. Most commonly these participants reported difficulty seeing to one side. Other visual problems included less clear vision, seeing double, judging distance, sense of direction and seeing 2D. Similarly to memory problems, visual difficulties following stroke are rarely emphasised as stroke outcomes in the literature. However, the finding that they were often spontaneously mentioned suggests that they were issues that participants themselves considered important.

A quarter of participants (22/ 89; 25%) reported emotional effects. Participants most often described a loss of 'confidence' of varying degrees from 'a bit' to feeling 'overwhelmed'. They often mentioned being unconfident to go out and about. A few participants reported a loss of control over their emotions, for example being weepy or having mood swings. A few reported frustration regarding their situation and a few worry or concern for the future. One participant actually reported a positive emotional effect of pride in having coped. The spontaneous reporting of emotional problems supports the contention that these are important issues to many patients following stroke. Also the common use of the term 'lack of confidence' suggests that this would be a meaningful term to use when discussing emotional issues with stroke patients.

Compared to baseline, at **follow-up**, a higher number of participants reported they felt they no longer experienced any effects of stroke (11/ 81; 14%). However, similar proportions of participants reported physical effects (66/ 81; 82%) and visual problems (12/ 81; 15%) as had at baseline. Memory difficulties were now spontaneously reported as 'effects of stroke' less often (16/ 81; 20%) as were

emotional effects (16/ 81; 20%). The content of participants' descriptions of effects were similar at follow-up.

F.2: Additional information for causal attributions and causal controllability

As discussed previously (please see Chapter 6, section 6.6i) causal attributions are not always spontaneously reported with ease during piloting. This was similar during the main data collection, for example, when first asked about causes at **baseline**, about one in five participants (20/ 89; 22%) started off by saying they had 'no idea'. Some participants (15/ 89; 17%) commented that they felt they should not have had a stroke because they were too healthy and a few (7/ 89; 8%) that they were surprised because they too happy, or not stressed. However, once the checklist was used, the majority of participants (84/ 89; 94%) did make at least one causal attribution.

To be able to estimate causal controllability, participants were asked to report all their causal attributions, their perceptions of control over each, and to rate them in order from 'most' to 'least' responsible for their stroke. The mean number of causes reported at **baseline** was 2.46 (SD=.91) with a median of three and range from 0-5. Similar results were found at **follow-up:** on average 2.68 (SD=.79) causes were reported, and the median and range was the same.

Causes reported by participants were collapsed into fifteen types, in four groups, based on divisions related to objective modifiability discussed in Chapter 2, section 2.2iii. Participants were about twice as likely to report a modifiable medical risk factor (65 at baseline and follow-up) than unmodifiable medical, behavioural or

psycho-social risk factors (between 29 and 38 at baseline and between 35 and 38 at follow-up).

Given that ratings could range from 0-4, with 2 being the midpoint, participants' concurred with established opinion in that un-modifiable medical risk factors (old age and family history) were rated as particularly difficult to control (Mean=.44 $(SD=.74)_{baseline}$ and Mean=.50 $(SD=.74)_{follow\text{-}up}$). It was typically moderate for modifiable medical risk factors (Mean=.1.98 $(SD=.92)_{baseline}$ and Mean=2.19 $(SD=.93)_{follow\text{-}up}$) and just below moderate for behavioural risk factors (Mean=1.60 $(SD=1.17)_{baseline}$ and Mean=1.82 $(SD=1.17)_{follow\text{-}up}$). Participants diverged from the established opinion by reporting psycho-social risk factors and they tended to report believing this to be just less than moderately controllable (Mean=1.69 $(SD=.97)_{baseline}$ and Mean= 1.86 $(SD=1.05)_{follow\text{-}up}$). So the general picture for perceived controllability is negative overall, with little variation between the types of risk factors.

Most interesting differences were found by looking at individual risk factors and correspondent causal controllability. Frequency with which specific causes were reported, relative frequency with which each was rated as being the 'most' responsible cause for stroke and specific rates of controllability are reported in Table F.1 for **baseline** and in Table F.2 for **follow-up.**

Table F.1: Frequency with which risk factors were reported at baseline, relative frequency of 'Most responsible' ratings and average controllability scores for each type of risk factor

	Frequency [1]		Relative frequency of 'Most responsible' ratings[2]		Controllability scores [3] (Possible range of 0 –4)	
	Number	Percent	Number	Percent	Mean	SD
Unmodifiable Medical risk factors						
Old age	18	20%	7	39%	.17	.38
Family History	13	15%	1	8%	.77	.93
Modifiable Medical risk factors						
High blood pressure	39	44%	18	46%	2.18	.82
Other illness [4]	21	24%	8	38%	1.48	.98
Medical treatment [5]	15	17%	6	40%	1.47	1.19
Cholesterol	10	11%	1	10%	2.00	.94
Diabetes	6	7%	1	17%	2.50	.55
Behavioural risk factors						
Smoking	23	26%	14	61%	1.35	1.27
Under exercise	8	9%	2	25%	1.56	.93
Overweight	7	8%	4	57%	1.86	1.34
Reckless lifestyle in youth [6]	5	6%	1	20%	2.40	.55
Psycho-social risk factors						
Depressing experience [7]	15	17%	9	60%	1.53	.92
Worry [8]	11	12%	6	55%	1.15	.60
Overdoing it [9]	11	12%	3	27%	2.36	.81
Hard life [10]	5	6%	2	40%	1.40	1.52

[1] Frequency percentages were based on the total sample (N = 89)

[2] Frequency ratings of 'Most responsible' were calculated using the number of participants who reported the appropriate risk factor

[3] Controllability mean scores were calculated using the number of participants who reported the appropriate risk factor

[4] 'Other illness' consisted of heart disease, heart attacks, prior strokes and migraine

[5] 'Medical treatment' consisted of general anaesthetic, angina medication, deep vein thrombosis medication. warfarin, the contraceptive pill and a change in tablets

[6] A few participants clearly stated that they had lived healthy lifestyles just prior to the stroke but held smoking and heavy drinking in their youth and middle age as a cause of their present stroke

[7] Participants who reported bereavement, sadness or depression, may have used the 'stress' response on the checklist, but I felt their open-ended responses were better captured by 'Depressing experience'

[8] Checklist responses of 'Tension', 'Anxiety' and 'Worry' were collapsed into ''Worry'

[9] A few participants used the 'Overwork' response, but those not in employment sometimes used the checklist 'Stress' or 'Over-involvement' response, so these were collapsed into 'Overdoing it' which I felt better reflected their open-ended responses

[10] A few participants clearly stated that they held difficulties long in the past, such as a difficult childhood or marriage to be a cause of their present stroke

On the positive side, at **baseline** and **follow-up**, high blood pressure was the most frequently recognised risk factor. Approximately half of participants understood that high blood pressure was a risk factor and tended to rate this as moderately controllable. Also a few extra participants reported cholesterol as a risk factor by follow-up and a higher controllability rating was found. Also, although ratings for depressing experiences and worry tended to be on the difficult side, participants often felt that overdoing it was something that they could more easily control.

Smoking was the second most frequently cited risk factor. Most participants who recognised that smoking was a risk rated it as most responsible at both points in time. Depressing experience and worry were also often reported as most responsible. After, unmodifiable medical risk factors, smoking and worry at **baseline**, and smoking and depressing experience at **follow-up** were the risk factors rated as least controllable. These results do not concur with established opinion (please see section 2.2iii). However they parallel the qualitative interview findings in which some of the most anxious and depressed participants reported concern about smoking, and difficulties with support for cessation (please see Chapter 16, section 16.4iv).

Table F.2: Frequency with which risk factors were reported at follow-up, relative frequency of 'Most responsible' ratings and average controllability scores for each type of risk factor

	Frequency [1]		Relative frequency of 'Most responsible' ratings[2]		Controllability scores [3] (Possible range of 0 –4)	
	Number	Percent	Number	Percent	Mean	SD
Unmodifiable Medical risk factors						
Old age	23	28%	7	32%	.39	.78
Family History	15	16%	4	27%	.60	.63
Modifiable Medical risk factors						
High blood pressure	42	52%	20	48%	2.29	.83
Other illness [4]	17	21%	8	47%	1.88	.93
Medical treatment [5]	9	11%	4	40%	2.11	1.36
Cholesterol	15	19%	2	13%	2.27	.88
Diabetes	9	11%	0	-	2.44	1.13
Behavioural risk factors						
Smoking	21	26%	13	62%	1.48	1.17
Under exercise	7	8%	1	14%	2.00	1.15
Overweight	10	12%	3	30%	1.90	1.29
Reckless lifestyle in youth [6]	3	4%	2	67%	2.67	1.15
Psycho-social risk factors						
Depressing experience [7]	8	10%	4	50%	1.00	.93
Worry [8]	14	17%	4	29%	1.57	.64
Overdoing it [9]	15	19%	7	47%	2.73	.59
Hard life [10]	6	7%	0	-	1.50	1.22

[1] Frequency percentages were based on the total sample (N = 89)

[2] Frequency ratings of 'Most responsible' were calculated using the number of participants who reported the appropriate risk factor

[3] Controllability mean scores were calculated using the number of participants who reported the appropriate risk factor

[4] 'Other illness' consisted of heart disease, heart attacks, prior strokes and migraine

[5] 'Medical treatment' consisted of general anaesthetic, angina medication, deep vein thrombosis medication. warfarin, the contraceptive pill and a change in tablets

[6] A few participants clearly stated that they had lived healthy lifestyles just prior to the stroke but held smoking and heavy drinking in their youth and middle age as a cause of their present stroke

[7] Participants who reported bereavement, sadness or depression, may have used the 'stress' response on the checklist, but I felt their open-ended responses were better captured by 'Depressing experience'

[8] Checklist responses of 'Tension', 'Anxiety' and 'Worry' were collapsed into ''Worry'

[9] A few participants used the 'Overwork' response, but those not in employment sometimes used the checklist 'Stress' or 'Over-involvement' response, so these were collapsed into 'Overdoing it' which I felt better reflected their open-ended responses

[10] A few participants clearly stated that they held difficulties long in the past, such as a difficult childhood or marriage to be a cause of their present stroke

Table F.3: Demographic and cognitive ability data for the eighty-one participants at follow-up

	Number and percent, or Mean and SD as indicated	Median	Range
Gender			
Female [1]	34 (42%)		
Age			
Age in years[2]	72.87 (11.32)	72	32 - 91
≤ 52 years [1]	5 (6%)		
51 – 62 years [1]	8 (12%)		
61 – 72 years [1]	25 (31%)		
71 – 82 years [1]	31 (38%)		
81 – 92 years [1]	12 (15%)		
≥ 85 years [1]	5 (6%)		
'Younger' participants < 65 years [1]	21 (25%)		
'Older' participants ≥ 65 years [1]	62 (75%)		
Social economic status			
Carstairs index scores [2]	3.57 (1.59)		
Deprivation category 1 or 2 [1]	17 (26%)		
Deprivation category 3 or 4 or 5 [1]	53 (65%)		
Deprivation category 6 or 7 [1]	7 (9%)		
Owns home [1]	54 (67%)		
Living situation			
Living alone [1]	32 (37%)		
Living with spouse [1]	42 (52%)		
Living with son, daughter or sibling [1]	9 (13%)		
Cognitive status			
Hodkinson scores [2]	9.53 (.65)	12	8 -12

[1] Number and percentage of participants [2] Mean and standard deviation of scores

Table F.4: Demographic and disability status, emotional disorders and symptoms for participants in the qualitative analysis and the total sample

	Participants in the qualitative analysis (N = 60)		Total sample of participants (N = 89)	
Gender [1]	27 females	(45%)	36 females	(40%)
Age in years [2]	70.97	(10.01)	70.13	(11.29)
Carstairs (1991) deprivation category scores [2]	3.49	(1.58)	3.59	(1.54)
Previous history of stroke	15	(25%)	20	(23%)
Barthel scores [2]	18.17	(2.55)	18.27	(2.83)
SCID diagnosis of depression[1]	21	(35%)	29	(33%)
SCID diagnosis of Major depression [1]	12	(20%)	14	(16%)
SCID diagnosis of Minor depression [1]	9	(15%)	15	(17%)
SCID diagnosis of an anxiety disorder [1]	22	(37%)	31	(35%)
SCID diagnosis of Generalised anxiety disorder [1]	7	(12%)	12	(14%)
SCID diagnosis of Agoraphobia [1]	12	(20%)	19	(21%)
SCID diagnosis of Social Phobia [1]	7	(12%)	10	(11%)
HADS total scores [2]	9.08	(6.35)	9.13	(6.16)
HADS depression scores [2]	4.53	(3.19)	4.54	(3.60)
HADS anxiety scores [2]	4.52	(3.19)	4.57	(3.18)

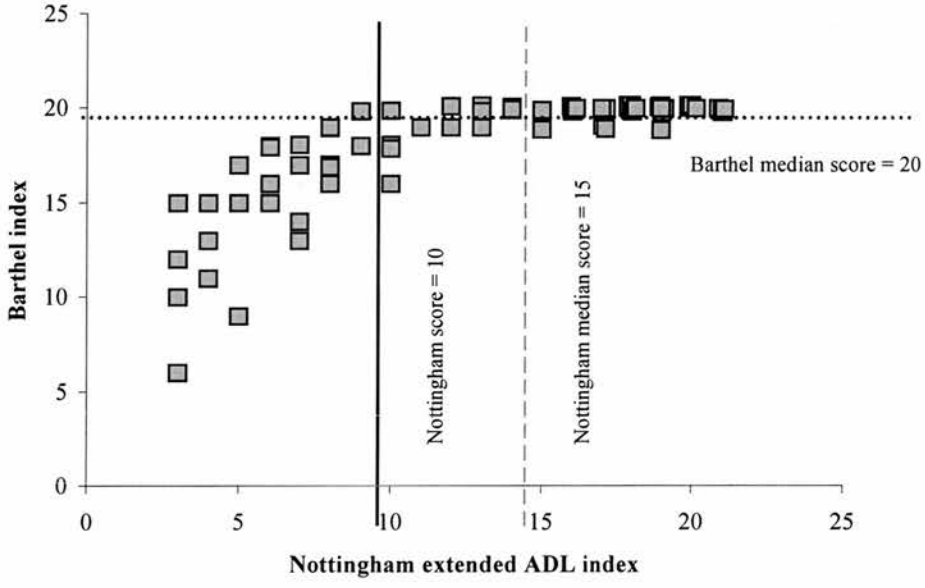
[1] Number and percentage of participants

[2] Mean and standard deviation of scores

F.4: Dichotomising participants into groups of 'higher' and 'lower' levels of disability

I wanted to be able to split participants into groups of higher and lower levels of disability for the purpose of exploratory non-parametric comparisons between those with and without diagnoses of emotional disorder. Ideally I wanted to be able to avoid making all these comparisons twice with groups based on both a Barthel index and a Nottingham index cut-off. I considered combining both measures and using the median score as a cut-off, however I was advised against this as the resultant distribution was bimodal (Graham, 2002; personal communication). Therefore the distributions of both were examined simultaneously for a single cut-off point that represented a good compromise between the information they provided.

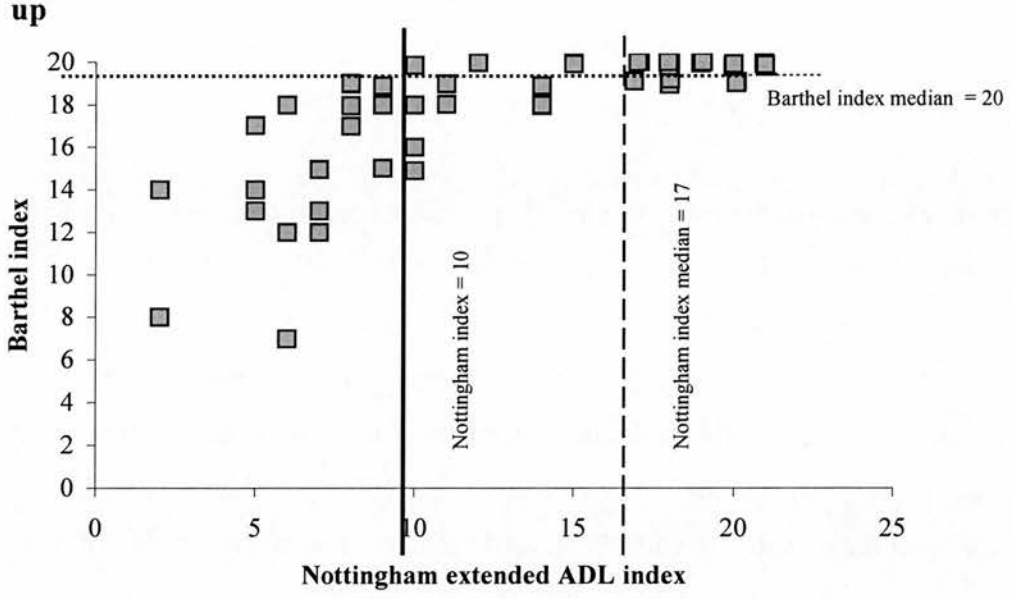
Figure F.1: Scatterplot of disability indices at baseline



As shown in Figure F.1, at **baseline** the Nottingham index median score of fifteen was less than ideal as a cut-off as it clumped a group of participants with full Barthel scores in with those with low Barthel scores. The Barthel median score of twenty was considered less than ideal as a cut-off as it clumped some participants with high Nottingham scores and fairly high Barthel scores in with those who had both low Nottingham and Barthel scores.

As can be seen, a cut-off point of 10 on the Nottingham index seemed to produce a fairly good compromise for this baseline data. All participants who scored above this cut-off on the Nottingham index also scored highly on the Barthel index. Whereas participants who scored less than this on the Nottingham index tended to achieve less than average scores on the Barthel index. Using this cut-off point, fifty-six participants (63%) were classed as having 'lower' levels of disability and thirty-three participants (37%) were classed as having 'higher' levels of disability.

Figure F.2: Scatterplot of disability indices at follow-up



As can be seen in Figure F.2, at **follow-up**, both Barthel and Nottingham median scores were again unsuitable as cut-off points for categorisation of 'lower' and 'higher' disability levels for the same reasons as before. A score of ten on the Nottingham index again appeared to provide a reasonable cut-off point. This categorised participants into those with high Barthel and moderate to high Nottingham scores ('lower' disability) and into those with variable Barthel scores and relatively lower Nottingham scores ('higher' disability).

Therefore participants were divided into groups of higher and lower levels of disability using a cut-off of ten on the Nottingham index for the purpose of exploratory non-parametric comparisons between those with and without diagnoses of emotional disorder in Chapter 9.

F.5: Description of fear of falling

At **baseline** the mean fear of falling score was 6.92 (SD = 2.89, Median = 7, Range = 0-13). Given a mid-point of eight out of sixteen, these statistics indicate that participants tended not to be highly afraid of falling. However, over a quarter of participants scores (25/ 89; 28%) were between nine and thirteen indicating above moderate to high fear. Very few participants gave very low scores, suggesting that most participants could not be regarded as lacking any fear.

Sometimes participants made 'Where?' type queries regarding item 1, because apparently, a fall outside would be more likely to set confidence levels back. Likewise, item 3, led to 'How bad?' type queries because a 'serious' fall, particularly one involving an injury, would be more likely to affect recovery. These comments cast some doubt on the interpretation of these items amongst participants and suggest ways of making improvements to the validity and hopefully the reliability of the measure in future. Nevertheless, the internal reliability of this measure at baseline was high (α = .79). Factor analysis produced a solution of just one factor that accounted for 61% of the variance in scores, and loadings between .63 and .86 for each item.

Participants were also asked to report on actual experiences of falls and just over a third (31/ 89; 35%) indicated they had fallen. Some participants described the experience as frightening and something that had caused a lack of confidence. Often they said they had felt foolish or embarrassed by the fall, and a couple described feeling angry at finding themselves helpless. Not being properly dressed, needing help to rise, or the idea of falling outside were often talked about as particularly embarrassing.

However, some participants seemed to discount their fall by blaming it on something easily avoidable (lush grass, a bad pavement, wine or being too 'pig-headed' to accept a wheelchair). Others reported they had simply learnt to be more careful. For one man, the manner his nurse dealt with the situation suggests a relationship between being able to rise and confidence:

'I turned around quickly to catch the nurse's attention and fell on the bed. The nurse made me get up myself, which was good. She just told me what to do and so gave me my confidence back'

Also some participants who hadn't fallen, still reported the fear that they may. Often these participants reported having been frightened by a stumble, or a near miss. A couple of participants who were still in hospital reported feeling dependent on the staff for confidence and that they would be devastated if they ever did fall. Participants at home reported a similar pre-empting of a confidence loss, for example a sixty-year old man said:

'If I fell I think I'd be going backwards not forwards with confidence'

Overall, slightly higher mean fears of falling scores were found for participants who had experienced a fall (Mean = 7.48, SD = 2.92) than for those who had not (Mean = 6.62, SD = 2.86). However, this difference was not found to be significant, $t = -1.35$, $p<.10$.

Descriptive statistics for fears of falling at **follow-up** were very similar to baseline: Mean = 6.52 (SD = 2.79) Median = 6, Range = 4 –14, and the slight decrease in the mean score across time was not significant, $t = 1.11$, n.s. However, in contrast to baseline, the distribution of scores was now slightly positively skewed, suggesting a tendency to the lower end of the spectrum. In line with this shift, scores above the mid point were only found for eleven participants (11/ 81; 14%) equally half the proportion found at baseline.

The proportion of participants (34/ 81; 44%) who reported that they had experienced a fall was higher now than it had been at baseline (31/ 89; 35%). However, only just

over half of participants who reported a fall at baseline (18/ 34; 53%) also reported a fall at follow-up. This suggests that some participants no longer remembered having a fall or now discounted them. In itself this lack of consistency in reporting across time suggests that the actual experience of a fall may not always result in fear development. A comparison between participants who said they had fallen at follow-up (Mean = 6.62, SD = 2.72) and those who did not (Mean = 6.45, SD = 2.72) found no significant difference in scores, t = -.27, n.s.

Appendix G

Supplementary quantitative results

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Table G1: Pearson correlations between the independent variables at baseline

	Age (in years)	Gender	Carstairs deprivation scores	NIH Stroke severity scores	Barthel scores	Nottingham extended ADL scores	MOS social support total scores	Life events total	Pre-stroke history of depression
Age	-	.03	-.17	-.18	-.19	-.34***	-.03	-.07	-.25*
Gender		-	.15	.05	-.14	-.26*	-.29**	-.06	.19
Deprivation			-	.23	.07	-.05	.05	.09	.00
Stroke severity				-	-.62***	-.51***	-.05	.08	-.05
Barthel scores					-	.71***	-.15	.02	.02
Nottingham index						-	.11	.05	.06
Social support							-	.02	-.01
Life events								-	.16
Pre-stroke history of depression									-
Causal controllability									
'Why me?'									
'Found meaning?'									
Acceptance of disability									
Identity change									
Shame									
Recovery locus of control									
Confidence in recovery									
Recurrence fear									

... Table G1: Pearson correlations between the independent variables at baseline continued

	Causal controllability	Why me?	Found meaning	Acceptance of disability	Identity change	Shame	Recovery locus of control	Confidence in recovery	Recurrence fear
Age	-.03	-.46***	-.40***	-.09	.07	.05	.35**	-.11	-.10
Gender	.17	.20	-.07	-.10	.14	-.04	-.19	-.18	-.01
Deprivation	-.08	-.05	-.03	.07	-.02	-.20	-.02	.04	-.01
Stroke severity	-.12	.01	-.03	-.38***	.42***	.09	.01	-.25*	.10
Barthel index	.02	.19	.19	.34***	-.18	-.19	.26*	.26*	.03
Nottingham index	.02	. 22*	.19	.44***	-.30**	-.18	.24*	.32**	-.08
Social support	-.11	-.02	.22*	.04	.05	-.09	.20	.32**	.08
Life events	-.10	.23*	-.02	-.04	.10	-.01	.07	-.07	.08
Pre-stroke history of depression	-.07	.36***	.16	-.02	.12	-.03	.10	-.13	.10
Causal controllability	-	-.08	.14	.14	-.21	-.00	.15	.09	-.10
'Why me?'		-	.12	.14	.19	-.01	.07	-.03	.23*
'Found meaning?'			-	.22*	-.16	-.19	.41***	.37***	-.04
Acceptance of disability				-	-.69***	-.44***	.32**	.39***	-.50***
Identity change					-	.24*	-.32**	-.37***	.44***
Shame						-	.24*	-.30**	.16
Recovery locus of control							-	.43***	.23*
Confidence in recovery								-	-.25*
Recurrence fear									-

Table G2: Pearson correlations between the independent variables at follow-up

	Age (in years)	Gender	Carstairs deprivation scores	NIH Stroke severity scores	Barthel scores	Nottingham extended ADL scores	MOS social support total scores	Life events total	Pre-stroke history of depression
Age	-	.01	.17	-.18	-.41***	-.46***	-.02	-.05	-.22*
Gender		-	.15	.05	-.16	-.26*	-.28**	.09	.24*
Deprivation			-	.23 *	.11	-.02	.05	-.04	.00
Stroke severity				-	-.25*	-.32**	-.05	.01	-.05
Barthel index					-	.74***	.22*	-.02	.09
Nottingham index						-	.16	-.02	.00
Social support							-	.08	-.06
Life events								-	-.02
Pre-stroke history of depression									-
Causal controllability									
'Why me?'									
'Found meaning?'									
Acceptance of disability									
Identity change									
Shame									
Recovery locus of control									
Confidence in recovery									
Recurrence fear									

... Table G2: Pearson correlations between the independent variables at follow-up continued

	Causal controllability	Why me?	Found meaning	Acceptance of disability	Identity change	Shame	Recovery locus of control	Confidence in recovery	Recurrence fear
Age	-.24	-.18	-.28*	-.13	-.02	-.13	-.35**	-.24*	-.08
Gender	-.27	.19	.18	-.14	.21*	.18	-.13	-.12	.16
Deprivation	-.01	.16	-.05	.07	.06	-.05	.06	.17	-.04
Stroke severity	-.05	.06	-.09	-.33**	.38**	.17	.07	.01	.18
Barthel index	.27*	.04	.24*	.43***	-.35***	-.19	.22	.15	-.07
Nottingham index	.27*	.05	.22*	.49***	.44***	-.25*	.25*	.25*	-.13
Social support	.13	-.09	.09	.09	-.11	-.05	.31**	.14	-.04
Life events	-.03	.14	.02	.04	-.00	.04	.04	.19	.08
Pre-stroke history of depression	-.15	.47***	-.03	-.10	.20	.24*	-.15	-.14	.27
Causal controllability	-	-.12	.40***	.37***	-.26*	-.13	.21	.36***	-.27*
'Why me?'		-	-.19	-.10	.13	.03	.03	-.07	.27
'Found meaning?'			-	.00	-.09	.16	.27*	.23*	-.06
Acceptance of disability				-	-.75***	-.75***	.24*	.41***	-.46***
Identity change					-	.54***	-.14	-.25*	.44***
Shame						-	-.16	-.18	.33**
Recovery locus of control							-	.40***	-.14
Confidence in recovery								-	-.27*
Recurrence fear									-

G.3: Spearman correlations between independent variables and distress

G.3i: Spearman correlations between baseline variables and baseline distress

As can be seen, these non-parametric results for the belief variables were extremely similar, in terms of the size and significance of correlations to those obtained using Pearson correlations (Chapter 13, section 11.3i, Table 11.1).

Table G.3: Univariate correlations between baseline belief variables and distress relating to specific hypotheses 1, 2, and 3 using Spearman correlations (N = 89)

	Distress (Global HADs scores)	**p value**
Specific hypothesis 1: Negative attributions		
Causal controllability	-.27	.012*
'Why me?'	.17	.117
'Found meaning?'	-.24	.024*
Specific hypothesis 2: Negative self-evaluations		
Acceptance of disability	-.62	.0001***
Identity change	.61	.0001***
Shame	.31	.003**
Hypotheses 3: Beliefs in recovery and recurrence		
Recovery locus of control	-.22	.037*
Confidence in recovery	- .41	.0001***
Recurrence fear	.51	.0001***

Table G.4: Univariate correlations between baseline background variables and distress and using Spearman correlations (N = 89 unless indicated otherwise)

	Distress (Global HADs scores)	p value
Demographic data		
Age (in years)	.03	..812
Gender	.23	.028*
Deprivation: Carstairs index	.003	.981
Other background variables		
Stroke severity [1]	.13	.239
Disability: Barthel index	-.30	.032*
Disability: Nottingham index	-.38	.006**
Social support	-.12	.253
Life events	.14	.030*
Pre-stroke history of depression	.29	.005**

[1] Stroke severity data was missing for four participants; therefore this whole analysis is based on eighty-five rather than eighty-nine participants

As seen in Table G.4, the pattern of results for the background variables using Spearman's Rho was generally similar to those found using Pearson correlation (Chapter 11, section 11.3ii, Table 11.3). However, a drop in the size and significance of the association between a pre-stroke history of depression and distress was seen. The trend towards statistical significance for an association between stroke severity scores and distress was lost. Also a statistically significant, if low, association with Barthel index disability was found with the non-parametric method.

G.3ii: Spearman correlations between follow-up variables and follow-up distress

Table G.5: Associations between follow-up belief variables and distress relating to specific hypotheses 1, 2, and 3 using Spearman correlations (N = 81, unless indicated otherwise)

	Distress (Global HADs scores)	p value
Specific hypothesis 1: Negative attributions		
Causal controllability	-.37	.001***
'Why me?'	.25	.024*
'Found meaning?'	-.06	.580
Specific hypothesis 2: Negative self-evaluations		
Acceptance of disability	-.74	.0001***
Negative identity change	.78	.0001***
Shame	.58	.0001***
Hypotheses 3: Negative beliefs in recovery and recurrence		
Recovery locus of control [1]	-.23	.058
Confidence in recovery [1]	-.36	.001***
Recurrence fear	.58	.0001***

[1] Eleven participants believed they had now fully recovered. They could not be assessed for locus of control so this correlation was based on just seventy participants. They were scored as fully confident in recovery and included in this correlation calculation.

These non-parametric results were extremely similar, in terms of the size and significance of correlations to those obtained with the Pearson method (Chapter 13, Table 13.1). However, the association between recovery locus of control and distress did begin to approach a statistically significant level using Spearman's (rho = .23, p = .058).

Table G.6: Associations between follow-up background variables and distress using Spearman correlations (N = 81, unless indicated otherwise)

	Distress (Global HADs scores)	p value
Demographic data		
Age (in years)	-.03	.780
Gender	.27	.017*
Deprivation: Carstairs index	-.01	.933
Other background variables		
Stroke severity [1]	.15	.190
Disability: Barthel index	-.23	.041*
Disability: Nottingham index	-.30	.008**
Social support	-.13	.249
Life events	-.07	.564
Pre-stroke history of depression	.36	.001***

[1] Stroke severity scores were missing for three of the participants seen at follow-up, and so this correlation was based on just seventy-eight participants

As seen in Table G.6, the pattern of results for the background variables using Spearman's Rho was generally similar to those found using Pearson correlation (Chapter 13, section 13.3ii, Table 13.3) However, a smaller and statistically non-significant correlation between stroke severity and distress was found. Conversely, a larger and statistically significant correlation between basic disability measured by the Barthel index and distress was found with this non-parametric method.

G.3iii Spearman correlations between baseline variables and follow-up distress

Table G.7: Associations between baseline belief variables and follow-up distress relating to specific hypotheses 1, 2, and 3 using Spearman correlations (N = 81)

	Distress (Global HADs scores)	p value
Specific hypothesis 1: Negative attributions		
Causal controllability	-.35	.001***
'Why me?'	.24	.034*
'Found meaning?'	-.14	.220
Specific hypothesis 2: Negative self-evaluations		
Acceptance of disability	-.48	<.0001***
Negative identity change	.44	<.0001***
Shame	.20	.077
Specific hypothesis 3: Negative beliefs in recovery and recurrence		
Recovery locus of control	-.08	.467
Confidence in recovery	-.38	.001***
Recurrence fear	.34	.002**

As can shown in Table G.7, results for baseline beliefs and follow-up distress found with the non-parametric method were extremely similar in terms of size and significance as results found with Pearson correlations (please see Chapter 14, Table 14.1). However, a slightly larger and more statistically significant correlation between follow-up distress and baseline fear of recurrence was found with this non-parametric method.

As seen in Table G.8, a statistically significant association between stroke severity and distress was not found with the non-parametric method whereas, a statistically significant association for the Nottingham index was. These results are the reverse of findings with the Pearson correlation method (please see Chapter 14, Table 14.3). Correlations of very similar size and significance were found for the other variables using Spearman's Rho.

Table G.8: Associations between baseline background variables and follow-up distress using Spearman correlations (N = 81 unless indicated otherwise)

	Distress (Global HADs scores)	p value
Demographic variables		
Age (in years)	-.03	.780
Gender	.27	.017*
Deprivation: Carstairs index	.01	.933
Other background variables		
Stroke severity [1]	.15	.190
Disability: Barthel index	-.16	.148
Disability: Nottingham index	-.24	.032*
Social support	-.13	.249
Life events	.17	.120
Pre-stroke history of depression	.36	.001***

[1] Stroke severity scores were only available for seventy-eight participants seen at follow-up

G.4: Comparison between HADs scores and SCID diagnostic categories

G.4: Supplementary purpose of the SCID and comparison between HADs scores and SCID categories

The relationship between categorical diagnoses of emotional disorder SCID categories) and the continuous measure of distress (HADs scores) was considered a useful supplement to this study. The main study investigated relationships between continuous measures of beliefs and the HADs continuous measure of distress. However, the structured clinical interview study involved the exploration of beliefs within diagnostic categories of emotional disorder, and the qualitative study compared patients' own reported concerns on the basis of having being found to have depression or GAD according to the SCID. Therefore study of concurrent validity between HADs scores and SCID diagnostic categories provides a useful link between the three studies, and informs the validity of comparisons between results across the different sets of data.

In addition, the HADs is often used as a screening tool in clinical practice and other academics and clinicians had expressed interest in comparison between the HADs and SCID at presentations during my studentship.

In stroke, there are certain issues that have been suggested as possible confounders in the assessment of depression. Expert opinion generally suggests that emotionalism or aprosody should not bias self-report but may lead to over-estimations by the observed method (Spencer et al., 1997). However, Gordon et al (1997) suggest aprosody could lead to an underestimation if regarded as nonchalance or indifference. As discussed (please see Chapter 1, section 1.4; Chapter 18, section 18.4) some experts suggest that some stroke patients may deny or be unaware of their emotional state, and this may lead to under-estimation in self-report assessment (Spencer et al., 1997).

The structured interview method may overcome issues of awareness/denial better than self-report questionnaires. Kishi et al (1996) used observed as well as acknowledged low mood to assess depression, one in five considered to have major and one in four considered to have minor depression denied low mood. Ten of eighty-five stroke patients who denied low mood could still be diagnosed as

depressed using a standard clinical interview for DSMIII (Fedoroff et al., 1991). The authors concluded that denial was rare and partial as symptoms such as worthlessness were more readily acknowledged. By conducting the SCID and using the HADs I could develop my own ideas regarding this issue of emotional awareness.

G.4ii: Comparison between HADs scores and SCID diagnostic categories at baseline

Mean HADs depression scores were related to SCID diagnoses of depression in a 'dose-dependent' theoretically meaningful fashion, please see Table G9. A similar pattern of results were also found for mean anxiety and distress scores. A MANOVA analysis of HADs scores by depression diagnoses produced statistically significant main effects:

HADs depression by SCID depression diagnoses: $F(86, 2) = 66.03$, $p<.0001$
HADs anxiety by SCID depression diagnoses: $F(86, 2) = 28.13$, $p<.0001$
HADs distress by SCID depression diagnoses: $F(86, 2) = 66.15$, $p<.0001$

Post hoc Tukey testing found all pair-wise comparisons to be highly significant. So overall a good correspondence between categorical diagnoses of depression and. the continuous measure was found.

Table G9: HADs scores for participant groups based on diagnosed emotional disorder at baseline (N = 89)

	Major depression (N = 14)	Minor depression (N = 15)	Not depressed (N = 60)	GAD (N = 12)	No GAD (N = 77)	Agoraphobia (N = 19)	No agoraphobia (N = 70)	Social phobia (N = 10)	No social phobia (N = 79)
HADs depression[1]	10.07 (2.43)	6.33 (2.47)	2.75 (2.15)	8.60 (2.70)	3.96 (3.35)	6.63 (3.73)	3.93 (3.29)	5.50 (2.55)	4.38 (3.64)
HADs anxiety[1]	8.71 (3.27)	5.80 (2.68)	3.32 (2.28)	9.42 (3.12)	3.83 (2.49)	6.26 (3.74)	4.13 (2.91)	6.40 (3.09)	4.35 (3.09)
HADs distress[1]	18.71 (4.01)	13.00 (4.21)	6.10 (3.74)	17.33 (4.67)	7.82 (5.23)	12.84 (6.71)	8.09 (5.52)	11.80 (5.29)	8.76 (6.12)

1: Mean and standard deviation of scores, HADs depression and anxiety scores can potentially range from 0 –21, HADs distress scores from 0 – 42)

As shown in Table G9, mean HADs scores amongst participants with GAD were relatively high. Mean HADs anxiety, depression and distress scores were all found to be statistically higher amongst participants diagnosed with GAD using MANOVA:

HADs depression by SCID diagnosis of GAD: $F(87, 1) = 66.03$, $p<.0001$
HADs anxiety by SCID diagnosis of GAD: $F(87, 1) = 28.13$, $p<.0001$
HADs distress by SCID diagnosis of GAD: $F(87, 1) = 66.15$, $p<.0001$

HADs scores for those with agoraphobia and social phobia tended to be lower than those found for GAD. However, they were higher than HADs scores for participants without agoraphobia or social phobia (please see Table G9). This actually makes good theoretical sense as these diagnoses are specific to certain domains, while GAD involves persistently high anxiety. Mean HADs scores were found to be statistically higher amongst participants with agoraphobia in a MANOVA:

HADs depression by SCID diagnosis of agoraphobia: $F(87, 1) = 9.55$, $p<.005$
HADs anxiety by SCID diagnosis of agoraphobia: $F(87, 1) = 7.09$, $p<.01$
HADs distress by SCID diagnosis of agoraphobia: $F(87, 1) = 10.09$, $p<.005$

The analyses of HADs scores by social phobia produced weaker results. Only mean anxiety scores were found to be higher amongst participants with social phobia at a statistically significant level.

HADs depression by SCID diagnosis of social phobia: $F(87, 1) = .887$, n.s.
HADs anxiety by SCID diagnosis of social phobia: $F(87, 1) = 3.73$, $p<.05$
HADs distress by SCID diagnosis of social phobia: $F(87, 1) = 2.25$, $p<.10$

Table G10: HADs scores for participant groups based on diagnosed emotional disorder at follow-up (N = 81)

	Major depression (N = 12)	Minor depression (N = 12)	Not depressed (N = 57)	GAD (N = 15)	No GAD (N = 66)	Agoraphobia (N = 18)	No agoraphobia (N = 63)	Social phobia (N = 7)	No social phobia (N = 74)
HADs depression[1]	10.07 (3.08)	6.50 (2.15)	2.95 (1.74)	8.47 (3.98)	3.74 (2.69)	7.33 (4.37)	3.84 (2.75)	8.00 (3.96)	4.61 (3.47)
HADs anxiety[1]	9.91 (3.45)	6.58 (2.27)	3.31 (2.93)	9.73 (3.17)	3.65 (2.91)	7.89 (4.66)	3.89 (2.98)	9.96 (3.53)	4.28 (3.46)
HADs distress[1]	20.50 (5.78)	13.08 (2.31)	6.26 (3.95)	18.13 (6.65)	7.39 (4.78)	15.17 (8.13)	7.73 (5.11)	17.71 (7.06)	8.59 (6.07)

1: Mean and standard deviation of scores, HADs depression and anxiety scores can potentially range from 0 –21, HADs distress scores from 0 – 42)

G.4iii: Comparison between HADs scores and SCID diagnostic categories at follow-up

As at baseline mean HADs depression, anxiety and distress scores were related to SCID diagnoses of depression in a theoretically meaningful way (please see Table G2). MANOVA analysis of HADs scores by depression diagnoses produced highly statistically significant main effects, and all pair-wise comparisons were statistically significant with Tukey tests.

HADs depression by SCID depression diagnoses: $F(78, 2) = 76.99$, $p<.0001$
HADs anxiety by SCID depression diagnoses: $F(78, 2) = 27.89$, $p<.0001$
HADs distress by SCID depression diagnoses: $F(78, 2) = 65.31$, $p<.0001$

As shown in Table G2, HADs mean scores (depression, anxiety and distress) were approximately twice as high for participants with anxiety diagnoses (GAD, agoraphobia or social phobia). All these differences were found to be highly significant using MANOVA, and the F values for these analyses are illustrated in Table G11. Overall, the correspondence between anxiety diagnoses and HADs scores was very good and even stronger than that found at baseline.

Table G11: F values and statistical significance levels for the MANOVA results for anxiety diagnoses by HADs scores at follow-up [1]

	HADs depression		HADs anxiety		HADs distress	
GAD	31.13	***	51.47	***	52. 84	***
Agoraphobia	16.98	***	19.19	***	22. 30	***
Social Phobia	7.89	*	16.44	***	14.03	***

[1] Please see Table G10 for mean scores and numbers of participants meeting these diagnoses

* significant at $p<.01$ *** significant at $p<.0001$

G.4iv: Comment on the comparison between HADs scores and SCID diagnostic categories

In general HADs scores reported in this study were notably low. Most participants with major depression and/or GAD would have been captured using standard published cut-offs for 'possible caseness' (7/8) for the HADs. However, participants with minor depression, agoraphobia and social phobia reported lower scores and so a lower cut-off point would be required for them. This echoes O'Rourke et al.'s (1998) finding that a cut-off of 6/7 may be appropriate with this population. But, as the HADs was not intended as a tool for categorisation it does not affect its validity as the continuous measure.

A 'dose-dependent' relationship was found between mean HADs across depression subtypes, and across participants with GAD, participants with a specific anxiety disorder, and participants not diagnosed with an anxiety disorder. These findings make good theoretical and statistical sense. Overall, a good correspondence between HADs scores and SCID diagnoses of anxiety and depression was found, particularly at follow-up. These findings serve to cross-validate the HADs and the SCID diagnoses. Results using the HADs can be taken to reasonably capture the essence of the emotional disorders, and vice versa.

Appendix H

Supplementary qualitative results

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H.1: Main theme 4- <u>They're OK, I'm OK or not.</u>

Codes relating to 'They're OK, I'm OK or not' are outlined on the following page. These are organised into a sub-theme concerning family (to the left of the page) and into a sub-theme concerning partners and social others (to the right). Separate codes for children and grandchildren (family) as compared to partners seemed justified as family was relevant to most participants, but partners to only approximately half and community to a smaller subset again. However, there was much crossover between codes for partners and the family in general. Therefore, the groupings of codes into broad sub-themes within this main theme are less strong than in previous sections.

H.1i: They OK, I'm OK, or not sub-theme 1- <u>Family concerns</u>

An overwhelming majority of participants (48/ 60; 80%) reported that they're family was an important area in their lives. Over half of participants (35/ 60; 58%) reported that they're main concern in life was their family, making this the most commonly reported main concern throughout the qualitative interviews. However, actual specific family problems were only reported by some. It was as if most participants concern was pre-emptive, and could be described as parental love better than concern or worry. For example, a female participant said:

'My concern just is that nothing ever happens to them.' **f75,** 68yrs

<u>Twenty – four participants made statements like</u>:

<u>'As long as they're alright, I'm alright'</u> **m37,** 71yrs; **m55,** 66yrs

or similar statements echoing the sentiment that they needed to know their children and grandchildren were 'OK' 'happy' 'well' or problem free, and that by doing so they were too. The link between participants families emotional well-being and their own was often so intrinsic that it defied further explanation, for example one man said:

'Why are they important? They are my wife and family, my sons and daughters.'
m64, 74yrs

Main theme 4: They're OK, I'm OK, or not

Family concerns

HT Having Them
The importance of simply having them and of keeping in touch, particularly with Grandchildren, and the positive feeling which flow from this.

TOK They're OK (so I'm OK)
Comments about the need to know they're OK and feeling peace of mind or happiness from knowing family is alright, happy, and problem free.

TG They're great
Evaluations of one's family as great, that they're law-abiding, interesting, fun, or successful and positive feelings of happiness, feeling good, pride, enjoyment or amusement which this provides.

WC We're close
Ideas of feeling close to one's family, in terms of having loving feelings and a close understanding, or being close knit as they live close and there's a lot of contact.

TC They're caring
Feeling good about caring and helpfulness of children or spouse. They may have shown this more since the stroke and being cared for may be viewed as having a nice/ comforting aspect.

STS Still the same
Sense of continuity through unchanged interest in or comfort from family

BT Being there
Being able to give loved ones encouragement, companionship, a listening ear or practical help. May involve positive feelings or concern if can't or worries about not being able to in the future.

FC Family concerns
Concern or sadness, about a child/ grandchild or sibling who may be ill, unsafe, have a problem or have died.

FI Family irritations
Irritation from family members being overprotective, uncaring, disappointing or inconsiderate.

BB Being a burden
Guilty feelings (including mild ones) about the emotional or practical strains providing care, or just being caring, entails for loved ones, now, in the past or for the future.

Partners and social contacts

SC Spouse as companion
Admiration for partner, appreciation of companionship, their shared life and shared interests. May involve overlap with less positive aspects, (see 'Can't dos': theme 1) if feels he/ she is holding partner back.

SH Spouses health
Concern about spouses emotional or physical health. Stroke may have refocused this concern, or may have created concern about him/ her coping or having to do more

GF Good friends
Appreciation and/ or realisation of friends caring, understanding and being there in practical or morale boosting ways.

SL Social life
The importance of being able to keep up with friends, share interests and enjoy their company. May feel this area of life is presently lacking depending on ability (see theme 1) or feelings of isolation, (see below)

SI Social isolation
Feelings of being socially isolated or enclosed, because in hospital, housebound, or not physically able. Lonely comments about having little family who care, or could care, or feeling more alone following a loved one's death.

GPl Going places, or not
Importance and enjoyment in being able to get away from weekend outings to holidays and visiting family who live far away, or disappointment if an no longer manage to get away

NNg Nasty Neighbours
Issues with frightening inconsiderate behaviour from neighbours, local kids, may be exacerbated by stroke problems

Many participants appeared proud simply because they had children and grandchildren. Often they would demonstrate this by listing the number and order of sons and daughters, by describing the ages and gender of grandchildren and great grand children, or by using photographs. Some explicitly stated their pride for example one great grandfather said:

'I have three great grandchildren, eight years, six years and four years that I keep in touch with and love and respect…that I have them that please me enormously. I am proud to say that I have great grandchildren.' **m35,** 84yrs

Many participants described their children and grandchildren in glowing terms such as 'Great' or 'Wonderful'. Often they reported pride in off - springs achievements. A few expressed feeling pleased that their children had happy marriages or that they were good moral people, for example:

'I couldnnae get a better family. They've never been in trouble and don't drink and don't bother with drugs, which is a great thing these days.' **m41,** 69yrs

Others reported pride in children and grandchildren who had been to University or who were successful in their careers. A few participants appeared taken with how interesting their grandchildren were, for example:

'My granddaughters are just another generation. They use the internet and videos. I just think it's amazing to see how evolution is evolving. When I was there age there was no such thing as a computer' **m66,** 65yrs

Often participants appeared to be charmed by the 'cheekiness' or 'mischievousness' of young grandchildren. For example a female participant described her grandson as a 'beautiful terror' and one man said:

'If I couldn't get anything else, as long as I can get the two little menaces running in the door I'm OK' **m66,** 62yrs.

Often they reported grandchildren provided 'fun' 'happiness' or 'joy'.

Twenty-six participants reported how caring their family was and often that this made them feel positive. Often they emphasised the effort their family had made to visit them in hospital especially when they had busy lives or long distances to travel.

Children were particularly mentioned in this context, while the youngest male participant reported being pleased his twelve brothers and sisters had hired a mini bus to visit from Glasgow. A few older participants reported pleasure from caring young grandchildren, for example, one man's grandson had brought a jigsaw to hospital because he understood his Granddad couldn't play football. A female participant described feeling 'nice' because her grandchildren no longer fought in her company, that her granddaughter had been helping in the house and said:

'They're watching their Grandma now' **f74,** 64yrs

Many reported appreciating a child or daughter in law helping in practical ways by doing the shopping either for themselves or for their spouses when they were in hospital. Often participants expressed feeling pleased that their family were there for them emotionally. For example one female participant said:

'It makes you realise how much they do love you – you see it open. I've always know that deep down but you can actually see it…It makes me feel good' **f52,** 57yrs

Twenty - eight participants reported that their experience with their family was unchanged or had become even closer since their stroke. Of the few who reported that they had been brought closer together, one man reported:

'If anything the stroke has brought us closer together through their concern. Everyone was concerned and interested in my welfare…It makes me feel good and have nice thoughts.' **m70,** 65yrs

The security some felt in their families' care was evident, as they had always expected they would rally round in such an event. But the clearest message seemed to be that for most the direction of positive aspects of family was about participants' own continued concern for, or interest or pleasure in, their children and grandchildren. For example, in reference to her grandson, a female participant said:

'Nothing has changed, he's still just as caring as before and still makes me feel great'

f77, 73yrs

In general when asked about change in concerns for, or the importance of family, participants expressed lack of change very briefly by saying 'nothing' had changed or that 'everything was still the same or 'just the same'.

Seventeen participants reported various specific problems or losses within the family. Often participants were concerned about a parent, sibling, child or grandchild who was ill, had died, or suffered a particular difficulty. A few participants concerns about others with deteriorating health, seemed exacerbated because they were far away or the stroke prevented visiting. However one female participant actually reported that the stroke had made her Fathers' death in london 'lighter' as she was 'forced to let go'. In contrast, another participant was very depressed and his grief for his sister challenged his normal orientation to being able to help others:

'When you're the oldest and you see your young sister die you think "What's going on here?" The world seems unfair, some get nothing and some get everything. It takes all types to make this world, it's a big bad world' **m55,** 66yrs

A few participants began by reporting concern about a child's who had been ill, for example with cancer but went on to report that at present they felt relief or pride as they had recovered. Others explained that they had some concern for a grandchild with a mild disability for example one man described his feelings for his grandson who needed retalin for hyperactivity as 'not a worry but a wee concern'. A couple of others described feeling 'helpless' about grandchildren who were very seriously ill, for example with a heart condition, and about the strain on their own children. A couple of participants' concerns for their sons' well-being were tinged with disappointment in their lifestyles. One mans' only concern in life was that one of his sons took hash, didn't look after himself and was in a rocky relationship. Another participants' alcoholic son caused her great anxiety and disappointment:

'I think about how he travelled to Hong Kong, got degrees and used to earn thousands…He should have a lovely job and now I've got him back an alcoholic and living on the dole.' **f74,** 64yrs

Ten participants expressed more direct irritation or hurt about a family members' behaviour. A few participants expressed annoyance at their families'

overprotection: either their nagging to stop smoking or eat more healthily, or not allowing them to over exert themselves or go out. This was expressed humouredly by an eighty year old lady whose Doctor had given her sons permission to protect her for a month:

'I could throw something at them…all my life I've told them what to do and now they're allowed to do it' **f27,** 80yrs

Two participants reported being annoyed and hurt by a daughter who was 'Not bothered'. For one, this was balanced as his sons who did care but for the other this seemed to compound her fear of loneliness. Other problems mentioned were being patronised by relatives since the stroke, borrowing money that couldn't be repaid, and a 'drama queen' granddaughter who brought a lot of agro into the household.

Concern to be able to 'Be there' for others, especially the family was expressed by twenty-six participants. Some expressed this positively as they felt able to offer practical or emotional support or both. For example, when talking about his children, an eighty-year-old man said:

'If they need anything, for example advice or money, we would feel only too happy to help. It's all really around the family, especially in your twilight years.' **m58,** 80yrs

Another participant reported holding his grandchildren 's confidences in him as very dear and demonstrated this by describing their various travels around the world, career decisions and relationships in depth. A female participant reported that the most important thing in her life was to be able make her family laugh and that she was still 'as funny as ever'. Another participant believed that teaching children to love nature would ensure they became good people. She described experiencing a 'lovely feeling of déjà vu' by taking her grandchildren to the Botanic gardens and the seaside, like she had with her own. A female participant who had been wheelchair bound for years before the stroke described feeling 'useful' because her husband still depended on her for some things, like memory:

'I'm his walking diary- well, not walking, I sit in the chair and say "What time you meeting so and so?"…' **f39,** 76yrs

However, some participants expressed negative feelings about not being able to 'Be there' for loved ones or worry about not being able to in future. As discussed earlier (please see chapter 16, section 16.2) the inability to carry out roles such as driving others concerned some, particularly depressed participants. A depressed female participant strong fear of not being there for her family if she died has also been described (please see Chapter 16, section 16.4).

A few other participants reported some concern about a family member who was dependent on them in some way. For example, a female participant reported having become concerned about the future living situation of her 'retarded' brother since her stroke.

A couple of depressed females' concerns about being there for others since their stroke were quite complex. The youngest female participant was single but had close friends whose children she child minded while they were at work. Although she still managed this successfully and had even informally taken on another girl in her street who seemed neglected by her own mother, she was self depreciative. She described herself as 'putting on a brave face' to prevent her friends worrying and kept comparing herself negatively to the past when she also ran a boys' brigade and Sunday school too:

'I just never used to be like this' **f21.** 47yrs

Another relatively young depressed participant's comments indicated some contradiction within her love for her family. On the positive side, she described herself and her home as having been the 'central pin' since her Mother's premature death and that she 'got that love back' particularly since her stroke. However, she was the only participant to describe having some emotional difficulty in her relationship with her grandchildren:

'I feel that I put out all the love out on my grandchildren and they weren't coming to see me. My son hadn't told them and so they've been up every Saturday since. I feel that I just can't be bothered but love them just as much.' **f52,** 57yrs

Against this she appeared to be extremely bothered about her practical responsibility towards her families livelihoods due to her important role in the family business (please see Section H.2iii).

Twenty-one participants expressed some level of concern over burdening their family. A few reported having felt sorry about causing their children or spouse's to worry while they were ill in hospital, for example one participant said:

' When I saw all their anxious faces I thought what a shame' **f75,** 68yrs

The bereaved depressed man described earlier was particularly concerned about causing any further emotional upheaval to his already suffering older sister and so had kept his stroke from her:

'I didn't want her to know I'd had one because our younger sister had just died and a few months ago her daughter took an overdose. I didn't want her to be worried about me as it may have made her go backwards about her own stroke.' **m55,** 66yrs

Others reported feeling some guilt about the practical help they received. This ranged from shopping, housework, and cooking to administering medicine and helping with bathing. A couple of participants worried about the strain on their husbands (please see later). A few felt it was 'unfair' that children should have to be involved in their personal care and one lady described feeling embarrassed.

A few participants voiced concern about becoming a burden in future and two older participants had decided to seek residential care to avoid this. One participant wanted to stop inconveniencing her daughter in law whenever she had a crisis and the other wanted to:

'Relieve my son and daughter from worrying about me, I just don't want them to worry.' **m68,** 88yrs

A participant who had looked after his aphasic wife for years reported concern not to similarly burden his son

:

'She used to hit you when she couldn't say what she wanted. I used to say to myself "If she dies now I'd be quite pleased". I was very tied down. I couldn't imagine C___ [son] doing it, to have to do it.' **m76,** 72yrs

Depressed participants seemed to be particularly averse to being a burden and seemed to think that they should care rather than be cared for. This was reflected by the strong concern of a depressed man in hospital who thought he would need help from his five children when discharged:

I'd hate to think their life was looking after their old man…It's me who should be looking after them' **m64,** 74yrs

In contrast, another participant who was not at all depressed, whose daughter's only relationship seemed to be as her companion and carer, reported relatively less concern:

'I do think about leaving her on her own as she doesnnae get out anywhere but she seems quite content the now' **f47,** 82yrs

Other depressed participants talked in terms of burden without evidence that they were actually causing any imposition. For example, one depressed man seemed to fear being a burden because he himself was no longer able to help:

' I'm concerned not to be a burden to the family in connection to the car' **m34,** 76yrs

The concerns of depressed participants not to burden others was very similar to the sort of self reproach reflected in their concerns about not being able to carry out family roles discussed previously (please see Chapter 16, section 16.2i).

H.1ii: They OK, I'm OK, or not sub-theme 2- <u>Partners and social contacts</u>

<u>Over half of participants who were in a relationship (17/ 29; 56%) indicated some level of appreciation of the companionship they gained.</u> The extent to which life was shared by many couples was reflected by the plural ('we', 'our' or 'us') when

asked about personal concerns. Many emphasised the importance of the length of their marriages as a worthwhile achievement, although a few mentioned they had had their 'ups and Downs'. Often marriages seemed to provide familiarity and comfort, for example:

'We've been married fifty years: you kind of get used to each other' **f39,** 76yrs

Others described themselves as entirely compatible, used terms such as being 'like hand and glove' and reported making each other happy. A few expressed outright admiration for their partner as a husband or wife, for their attributes as a parent, or person generally, for example one lady described her husband as:

'Excellent, he's my world' **f22,** 68yrs

A seventy-two male participant described having recently become involved in a courtship and one of the oldest participants had got engaged to his live in partner while in hospital:

'I've known C____ for eleven years now, so decided to make an honest woman of her!' **m35,** 84yrs

Appreciation for a partner was often reported as something that remained positive.

However, approximately half of participants who were in a relationship (14/ 29; 48%) reported concern for their spouse's health. Often health appeared to be a shared preoccupation, for example:

'I worry about him and he worries about me' **f42,** 70yrs

Some participants appeared more concerned about a spouses' health than their own, particularly when they were seriously disabled or chronically ill. Despite being wheelchair bound and hospitalised himself, one participant cited his wife's suffering from various chronic illnesses and a severe stroke as his main concerns in life:

'It makes me feel helpless, I try and do what I can but nothing will take away the pain'

m41, 69yrs

Another man described his wife's health as 'my worry for the last twenty years' and one reported sadness in relation to his wife who was in long term hospital care.

Various participants reported having developed concern for their spouse's welfare as a result of stroke. One female participant, who was cared for by her husband, was concerned he might hurt himself lifting her, and another that her husband would fall asleep at the wheel through tiredness. Some spouses were concerned their wives could experience something similar to stroke although a few went on to report that at least they could be thankful they had good health for now. Concern about whether partners could cope practically if something even more serious happened to them was also reported, for example:

'The worry is if I died before my wife, would she be able to look after herself?'
m58, 80yrs

Two female participants reported fearing how they themselves would cope if their husbands died or had a stroke, for example:

'If he had one, how would it affect my quality of life, mine as well as his?'
f52, 57yrs

Finally, concern for the emotional well-being of a spouse was brought up by a few participants. One wife was concerned about her husband because he had Meniere's disease and was afraid to go out, and two husbands voiced concern that their stroke may exacerbate their wives tendency to worry or get depression, for example:

'She's a bit of a worrier. I always have to try and not give her things to worry about, I try and hide things so she doesn't invent reasons to send me to hospital.'
m33, 66yrs

<u>The importance of friendship was emphasised in various ways by some participants.</u> Its' centrality in life was more often explicitly emphasised by female participants, for example:

'I suppose it's been what my life is all about…I like a personal relationship, I prefer relationships which are close and personal' **f49,** 60yrs

while a housebound participant described gaining satisfaction from being able 'to lift' troubled friends by listening to their problems on the phone. Meanwhile other participants often described having friendships as 'nice'.

The way some participants talked about their social circle seemed to reflect an important aspect to their own esteem or identity. A few participants pointed out that they felt popular because they had a lot of friends. Others reported membership of a rotary club or the Masons as important to them. A couple of men still attended golf or rugby clubs although they no longer played. Others maintained contact with their Second World War army corps either by official membership or personal contacts. An eighty-three-year old man was pleased that his poem had just been published that was called 'Reflections' and remembered 'with pride' his friends who had died 'Across a vale of years'.

A few participants reported the importance of their social lives. A wide range of leisure activities (please see Chapter 16, section 16.2i) were reported and these were often shared pursuits with partners. Social pursuits were described as enjoyable or fun and as providing happiness. This was still positive for participants able to socialise as before. For example, one participant emphasised the importance of her weekly taxi ride to bridge:

'I've jolly good friends and love bridge, otherwise life would be awful…I enjoy the game and the social side…It makes me feel fine' **f40,** 80yrs

Some participants reported a change in their social lives following stroke. Often they reported being pleased that friends cared enough to come and see them but that they hoped to get back to socialising. Some participants reported sadness because they missed going out and socialising through leisure pursuits while others social lives were hindered by feelings of shame as much as by their physical disability (please see Chapter 16, section 16.2i).

Fifteen participants' accounts portrayed feelings of social isolation or loneliness, or both. Participants who reported a sense of 'isolation' or being 'stuck here' tended to

do so in relation to the restriction imposed by stroke or another disability, and they were often depressed. Depressed participants tended to provide starker descriptions of feeling cut off from the outside world. For example, a participant who was not depressed explained:

'The friendship hasn't changed, but I don't enjoy the phone as much' **m43,** 60yrs

Whereas a depressed man described being housebound as making him feel:

'Confined, enclosed, frustrated, I just want to get up and get out' **m34,** 76yrs

A couple of depressed participants reported finding temporary separation from loved ones difficult. One described feeling lonely when her husband was at work. A participant in hospital reported missing seeing his family to know they were OK 'at all times' and used a poignant metaphor to describe trying not to think about it:

'If you thought about them all the time you'd be a cripple' **m64,** 74yrs

Some participants' reports of loneliness portrayed a sense that they had few people to socialise with, or who cared for them. The root and subsequent meaning of loneliness varied. One depressed married participant reported that her only enjoyment in life was occasional trips to the bingo with one sister. Her main concern in life was bereavement for her other sister and mother whom she used to go to Bingo with more regularly and she missed them 'terribly'. Another depressed married participant was very concerned that her husband was the only person she had to physically look after her because she felt the rest of her family 'wouldn't be bothered'. A divorced man, reported concern to be able to keep being able to appreciate 'nice looking lassies' and have company on nights out as:

'Sometimes you have loneliness, when you come in and there's naebody to talk to, I'm like a couch potatoe. I mean that I like their company and say I'm too old but still like looking and that's that' **m54** 62yrs

Other lonely participants tended to be depressed and female and either unmarried or widowed. A young participant reported being unmarried because she had looked after her Grandmother. Since her death she had developed depression been put on

anti-depressants and now felt she had no real family who could care for her the same. A couple of unmarried older participants reported feeling they had no one more since they were 'stuck' in doors. Meanwhile a couple of recently widowed participants reported missing having someone to talk to, for example one said she felt 'a bit out' during the day and:

'When I'm sitting at night and have no one to talk to I just feel like greeting. He had no family and I've no family either…' **f50,** 71yrs

Within a broader social horizon, getting away to other places on outings or on holiday was brought up as an issue by some participants. In contrast to how being unable to do more regular day to day activities were generally reported as immediate concerns (please see Chapter 16 section 16.2i), 'Going places' tended to come up in the important areas of life part of interviews. Some participants described the benefits of foreign weather and relaxation as enjoyable. Often outings or holidays were valued as family pursuits, especially if they involved visiting family who had emigrated to Ireland, England or Canada. For two men annual holidays without their wives were so they could spend time with a close male friend.

The meanings of stroke varied in relation to going places. Although no one had been far afield since the stroke participants generally still talked confidently about themselves as people who did these things, or even reported 'no change' when realistically they would not be able to at present. Some did speak about how the stroke may affect their ability to travel abroad in future either due to physical difficulties or 'sky high' insurance and a few participants reported holidays were something they would miss if they were not able to go again. Only three participants expressed disappointment at not being able to go places at present, two of whom were depressed. A depressed participant's stroke had confirmed his inability to go caravanning and he described this as something he missed. A depressed female participant described feeling 'terrible' and desperate to get home due to leg pain on a weekend drive with her husband.

Of everybody, travel was an over-riding interest of one man who was housebound following stroke, but who was remarkably upbeat rather than depressed:

'I feel that I could still travel but not far: Germany but not Australia. Twenty-two hours on the plane may be against Doctors orders, Ha,Ha!…I didn't let the first stroke bother me and think this one will go the same way' **m35,** 84yrs

His main concerns in life were cancellation of his family holiday to Thailand and frustration at not being able to fulfil his 'fresh air fiend' weekend outings. However, he appeared both confident in recovery and able to maintain his esteem as a 'great traveller' by his enthusiasm for what he had done previously as he talked very positively and in depth about his travels (including five trips to Russia).

Finally negative issues concerning their neighbourhood were brought up by six participants. Inconsiderate neighbours were mentioned by a few, for example, one man's only family concern was his sister had cut short her visit from Canada as she was 'sickened' by his drunk swearing neighbours. Other participants brought up the issue of crime in their neighbourhood. Teenage children playing football threatened two participants. One reported strong annoyance and worry that the 'little darlings' might smash her window. The other feared getting knocked at the bottom of her stairwell herself. She had had a close miss and they had already smashed the glass door countless times. Both expressed annoyance that teenagers weren't supervised to go and play out of harms way and expressed worry about the consequences.

H.2: Main theme 5- <u>Maintaining way of living or thinking, or making changes</u>

Codes related to this last main theme are illustrated on the following page. This was a complex theme that addressed either meaning in life issues or life transitions that were very relevant to a minority of participants, or more general issues in life such as retirement, non-stroke health concerns, or money. Broadly this theme qualifies the more stroke related first three main themes because it demonstrates concerns or pre-occupations outside the stroke domain. However, the first sub-theme was the exception to the rule.

H.2i: Maintaining way of living or thinking, or making changes sub-theme 1- <u>It's a bad world but it's nice to be nice</u>

<u>For five participants a strong obsession or religious/moral orientation permeated their responses throughout the qualitative interviews</u>. One female participant's work had dominated her life prior to stroke. She had depression/GAD and her conflicts about work will be discussed later. A relatively young man appeared to be obsessed with the lottery. Although he was unable to work and quite dysarthric with a slight limp, the concerns he reported were related to his feelings when his numbers don't come up. He reported his dreams of what he plans to do with the money as the most important area of his life. One female participant emphasised the importance of cleanliness in the home and of the body, and her feelings were so strong that it was like a religion. She did not have depression/GAD but her house was spotless. Her concern about the possibility of a severe stroke was centred around ideas of a 'frail body' and 'disgusting' house and she gave this description of her feelings:

'It's an inner feeling, just seeing myself in that condition and the house like that'
f51, 69yrs

One man, who was not at all depressed, explained that he was a son of a missionary and that his Christian role was the most important part of his life, for example:

'Faith means everything to me' **m38,** 60yrs

Main theme 5: Maintaining way of living or thinking, or making changes

It's a bad world....but it's nice to be nice

LO Life orientation
Emphasis on having a religious faith, or general orientation to people and doing good, or some other strong theme that colours everything, like a strong belief in cleanliness.

WM? Why me?
Wanting to be able to understand why the stroke happened in terms of justice, or feelings that it is undeserved and so pitying oneself.

EP Empathy/ pity
How one's own experience has given insight into or lead to thinking about someone else's experience, or, pity for those worse off, particularly young stroke victims

Keeping healthy

BH Being healthy
General comments about the importance of having one's health.

WS Warning sign
Stroke as a warning that need to take care, slow down, beneficial reassessment of self and health

HC Health Concerns
Restrictions from or concerns about other, non-stroke problems like arthritis.
(Also, 3 females have other serious health issues: f25 has breast cancer, f39 mobility issues from a spinal tumour, f46 acquired blindness)

Work

MJ My job
The different meanings of work for those who worked up until their stroke from a livelihood, to companionship, occupation (versus boredom) pride and sense of normalcy.

R Retiring
Regrets, or concerns about having retired, or having to, versus, positive feelings. Or just comments that life has changed now he/she isn't working.

IW I worked
Comments that emphasise the importance of having worked for a living, feelings of pride in their career , or comments suggesting the idea of 'work' or 'working' has continued into other pursuits.

Money helps

MW Money worries
Financial insecurity: dissatisfaction with income, desire for more, debts, annoyance at council tax rates

BC Being comfortable
Importance of being able to feel financially able to meet needs and wants

PFF Provided for family
Comfort in the knowledge he/ she will have provided for those he/ she will leave behind

Getting/ staying at home

GH Getting home
Hospital as a state of limbo, a different world, concerns about getting out and coping when does

MH Moving house
Suitability/ manageability of home in relation to self following stroke and family needs

GC Going into care
Feelings about leaving one's home, lifelong possessions and area. The thought of going into a home and fears of neglect and loss of self.

Getting old and to the end of life

GO Growing old
A realisation or a refocused awareness of ideas of growing old, thoughts about old age and the eventuality of death

DF Dependency in future
Fears about increasing dependency in future and feelings about what this would be like

WLD Wanting to live or die
Positive versus negative motivations for living longer

Another man explained his more secular philosophy in equal depth. His mother had been an orphan but her life changed for the better when she was adopted. From this he reasoned that it is 'nice to be nice' and that it was important to care about the less fortunate in life. In contrast he was depressed and had GAD. The difference between these two men was striking. The very religious man believed he was able to fulfil his Christian role in life. He described his academic talent and career as a 'gift' from God and believed he had contributed very positively to the world. He felt that his very mild stroke had given him 'insight' and allowed him to further develop his 'sympathy' for the more disabled.

In contrast, the other man reported that his stroke had frustrated his ability to fulfil what he described as his 'chicken-heartedness'. His main occupation had been fishing and he enjoyed the pleasure of surprising passer-bys by giving them his catch, but he could no longer do this. He talked with empathy but also sadness about the young and very disabled patients he had seen in hospital:

'I feel sorry for them, especially if they don't drink…I won't like anyone to have a stroke, not even my worst enemy' **m55,** 66yrs

Three other participants reported developing empathy for the more disabled, and of these two others were depressed. Therefore, while a positive value, empathy was more common amongst those who were depressed than amongst those who were not. Having a strong life orientation was not associated with depression/GAD, but feeling that one was no longer able to fulfil such beliefs gave them did seem to be.

Eight participants questioned 'Why me?' during qualitative interviews and they were all participants with depression/GAD. Their sense of injustice for some seemed to stem from the feeling that they had already suffered a disproportionate degree of misfortune in life. For example one participant felt it was unjust because she was already blind, another because her husband had been murdered, and another because she had had to cope with first one then her second husband dying from a devastating illness. The youngest male participant's sense of injustice has already been described (please see Chapter 15, section 15.4v).

H.2ii: Maintaining way of living or thinking, or making changes: sub-theme 2- Keeping healthy

Six participants emphasised their appreciation of good health following mild strokes. None of these participants had depression/GAD. Four participants talked about their stroke as a warning sign to take better care of their health for example:

I've looked around and seen worse problems. I feel quite lucky-I've had a little yellow card' **m38,** 60yrs

Similarly none of these participants had depression/GAD. In contrast, almost a third of participants overall reported additional health problems other than stroke, amongst which were cancer, arthritis, heart attacks, angina and gout. Eight out of eighteen participants who reported concern about addition health problems had depression/GAD.

H.2iii: Maintaining way of living or thinking, or making changes sub-theme 3- Work

Work was a very complex theme. As may be expected younger participants were typically concerned about not working. For one participant work seemed to represent her main orientation in life and was now her main over-riding. She ran her family business and reported feeling desperate to get back to work. She was very upset about friends who had criticised her determination to get back to work, for not putting her family first or spending time with her grandchildren. However, she said:

'They'd say your health and then you're your family and then work. But your family goes into your work. It quite annoys me that they just seem to think I'm more concerned about work than my family but there is the livelihood of five in our family and I run the financial side!' **f52,** 57yrs

At other times she reported feeling her husband always wanted more of her time than she could give. She appeared to be overwhelmed by her different roles and by others expectations of her and she was depressed. The two youngest male participants were not so concerned about their jobs per se. but one described thinking that getting back to work may help him feel more normal. The other had

been in a 'therapeutic' job designed to help rehabilitate people who had serious mental health problems. He described this as a 'wee hope' for the future, which he wanted to get back to. In contrast, a few participants who were about sixty-years-old actually welcomed the freedom that may come with the possibility of early retirement, although one was slightly concerned he may be bored.

Some retired participants had contributed in voluntary work, which they had enjoyed and now missed. Others reported that they had not wanted to retire. A few depressed older participants reported that they had really loved their jobs and missed them despite having been retired for quite a few years. A couple of these participants blamed their bad health on retirement, for example:

'I was never right since I stopped working. Maybe it was my chest or maybe the smoking. It makes me sad that I stopped working but I had to at seventy-one'
f77, 73yrs

A couple of participants also emphasised that they only stopped working because they had to. Two depressed participants reported that it was the 'fact that it has been taken out my control' about their retirement either due to this stroke or from reaching retirement age years before. Others reported feeling very proud of the careers they'd had and still being able to gain a sense of satisfaction from knowing how hard they worked or what they achieved. Some emphasised the positive side of retirement and the opportunities it gave for a well deserved rest from work and the freedom to enjoy pleasure and leisure pursuits:

'After forty-odd years of hard work I felt I deserved to take things easy and just do things I wanted when I wanted to' **f73,** 74yrs

Therefore work and retirement were complex issues with a range of different positive and negative meanings. Work issues did not discriminate between participants with/without depression/GAD, but its central importance to certain participants with depression/GAD has been highlighted.

H.2iv: Maintaining way of living or thinking, or making changes sub-theme 4- Money helps

Altogether twenty-five participants reported either positive or negative money issues, such as feeling comfortable financially, or, that they were 'OK but' could do with more to help find a bit left after paying bills. Some emphasised feeling secure that they had provided for their children and were not going to leave any debts behind. A few were concerned about paying for their own care if they became very frail and had to go into a home. It was quite sad that these participants all seemed quite well-off but that their awareness that people are now asked to make a contribution to residential care had lead them to believe they would not be allowed to retain any wealth.

However, although money was frequently mentioned it was rarely mentioned as a strong concern and did not associate with diagnoses of depression/GAD. The exception was one participant who had depression/GAD who had paid for a big family holiday after one of her daughter's husband died. She had done this on credit and was struggling with keeping up payments and in a dilemma about confiding in her family. She also emphasised concern about this debt during the GAD interview. Other serious financial problems developed for two young participants during the course of the study (please see Chapter 15, section 15.6).

H.2v: Maintaining way of living or thinking, or making changes sub-theme 5- Getting/ staying at home

Seven participants reported finding/having found hospital aversive and four of them had depression/GAD. Three who were still in hospital were concerned that that they would improve sufficiently to get home. Four who had got home emphasised not wanting to have to go back. Different negative aspects of hospital life were emphasised from missing the family to feelings of being trapped or the monotony of the daily routine.

Two participants who had recently moved into smaller homes both reported some regret. One had moved from a 'beautiful big Victorian house' because he thought it

may become burdensome as he got older, but he missed it. The other had moved from a two-bed to a one-bed council flat because he felt it was greedy to keep a spare room, but he was now worried that his son may split with his girlfriend and regretted letting it go. In contrast, another man wished he had sold his massive property years before. He was quite stressed about the up-keep of it and reported not having the energy to clear everything out and find somewhere smaller.

Seven participants reported having given the possibility of residential care some consideration. Interestingly only one of them had depression/GAD. She was one of two who were seriously considering residential care. They reported 'regret' about leaving their sheltered housing accommodation but feeling that the move into more supported care would relieve them from worrying about burdening their children. For one participant the concern was partly about what would happen if her money ran out, but also the fact that she wished to die before she became that dependent (please see Chapter 15, section 15.3). For the others their concern was to fight their disability and prevent having to give in to residential care.

H.2vi: Maintaining way of living or thinking, or making changes sub-theme 6-
Getting old and to the end of life

Ten participants reported that the experience of stroke had enforced upon them a sense of mortality and the realisation that they were growing old and would one day die. One man spoke about getting ready to go with 'regret' but feeling ready for it:

'I lost my last friend this year, it's almost as if a bit of myself died…I'm winding up my life but realise that the time has come to do that' **m68,** 88yrs

Another older man reported that things 'get watered down' in old age. Other participants who talked about fearing old age tended to be in their sixties and early seventies. All but one did not have depression/GAD. They reported still having some quality of life; however, they had begun to have concerns about what life may be like given 'future deterioration'. Twelve participants particularly emphasised that they would not like to be entirely dependent in future and this theme overlapped with fear of a severe stroke (please see Chapter 16, section 16.4i).

Altogether, across all these themes and the fear of recurrent stroke first sub-theme, seven participants, four of whom had depression/GAD, spoke explicitly about their motivation for wanting to live or die. As described previously one female participant reported being 'happy to go'. In contrast, as described in Chapter 16 section 16.4ii, one very depressed young participant reported that at least if she died she would be released from her extreme fears of recurrent stroke. As described in Chapter 16, section 16.4i, one participant reported the fear of death from a recurrent stroke because she felt her family could not cope without her. The depressed participant described in section H.2i as wanting to help others, reported a similar position. He was worried about no longer 'being there' to see that his grandchildren were 'OK'. Finally another two participants reported wanting to be able to see their grandchildren grow up a bit. Therefore grandchildren seemed to represent a prime motivation to stay alive. However, participants with depression/GAD tended to emphasise worry about their grandchildren's well-being in the event of their own deaths. In contrast, participants without depression/GAD wanted to live to be able to enjoy their grandchildren.