# *A QUALITATIVE ANALAYSIS OF THE PHENOMENA STROKE SURVIVORS ASSOCIATE WITH POST-STROKE ANXIETY*

Thesis submitted for the degree of

Doctorate in Clinical Psychology at the University of Leicester

By

## Zoë Louise Lander

BSc (Lincoln), MA (Nottingham), MA/ DipSW (Hull),

BA (Westminster College, Oxford), PGCE (Bristol)

Department of

Faculty of Medicine & Biological Sciences,

School of Psychology in partial fulfilment

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# STRUCTURE AND WORD COUNT

**Section**

**A**      **Thesis Abstract**                             **(305 words)**

          **Literature Review Abstract**                 **(240 words)**

**B**      **Literature Review**                       **(5579 words)**

          **Research Report Abstract**                 **(160 words)**

**C**      **Research Report**                          **(12974 words)**

**D**      **Critical Appraisal**                      **(2374 words)**

**E**      **Appendices**

**F**      **Addendum - Interview Transcripts**

**Notes on style**

This literature review has been written with a view to submission to the Journal of Clinical Psychology and therefore follows the guidelines for contributors to this journal (see Appendix I).

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# SECTION A


# THESIS ABSTRACT

# THESIS ABSTRACT

**TITLE:** **A qualitative analysis of the phenomena stroke survivors associate with post-stroke anxiety .**

**AUTHOR:** **Zoë Louise Lander**

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## Aims:
The thesis had the broad aim of facilitating the development of theory that is grounded in the post-stroke context that begins to explain the phenomena of stroke-related anxiety. Specifically, it aimed to explore stroke survivors' views about factors they associated with their post-stroke anxiety.

## Literature Review:
A review of literature into the prevalence rates for post-stroke anxiety disorders and the factors significantly correlated with post-stroke anxiety, found that research in this area was in its infancy. Limitations in studies undermined the reliability and validity of some findings. No prevalence rate could be given with any confidence for post-traumatic stress disorder (PTSD). However, evidence suggested a prevalence rate for general anxiety disorder (GAD) of between 20-28%. There was little evidence relating to other anxiety disorders. A relatively small number of studies identified a few factors significantly correlated with post-stroke GAD or PTSD. The evidence was strongest for GAD being comorbid with: depression, pre-morbid psychiatric history, reduced quality of life, and reduced social support.

## Methodology:
The research adopted a qualitative approach, using semi-structured interviews to gather data from stroke survivors. The interview transcripts were analysed using Grounded Theory.

## Main findings:
Participants associated factors with their anxiety that could be grouped into three main categories: dependence, vulnerability and inability to meet expectations. Participants expectations appeared linked to pre-stroke beliefs and experiences of the self and were used to compare with and judge their post-stroke experiences and identity over a prolonged period post-stroke. The relationship of anxiety with these phenomena could be explained with cognitive behavioural psychological theory. Adjustment to stroke related changes may have been delayed by unclear prognosis, vague expectations and slow rehabilitation that seem to be part of the pathway of post-stroke rehabilitation.

# SECTION B


# LITERATURE REVIEW


**Prevalence and associated factors of post-stroke anxiety:**

**A review of the literature.**


Target journal – British Journal of Clinical Psychology (see Appendix I for 'Notes for

Contributors').

# 1. ABSTRACT

**Background**:

Stroke is a major cause of death and the biggest cause of severe disability in the UK. Research strongly suggests that mood disorders negatively impact on rehabilitation outcomes and life satisfaction.

**Aim**s:

The current paper aims to establish valid, reliable, evidence based prevalence rates for post-stroke anxiety disorder and to identify factors significantly correlated with post-stroke anxiety.

**Method**:

Structured literature searches of peer reviewed, English language papers were carried out on 08/12/08, using the databases PsychInfo, Scopus, Web of Science and Medline. Keywords searched included anxiety disorder, stroke and post-traumatic stress disorder. Related words and variations on these terms were also searched.

**Findings**:

Limitations in studies undermined the reliability and validity of some findings. No prevalence rate could be given with any confidence for post-traumatic stress disorder (PTSD), however evidence suggested a prevalence rate for general anxiety disorder (GAD) of between 20-28%. There was little evidence relating to other anxiety disorders. A relatively small number of studies identified a few factors significantly correlated with post-stroke GAD or PTSD. The evidence is strongest for GAD being associated with: depression, pre-morbid psychiatric history, reduced quality of life, and reduced social support.

**Conclusion**:

Research into post-stroke anxiety is clearly in its infancy and further research is required, especially into the full range of anxiety disorders and perhaps also into a mixed anxiety-depression disorder. Previous research limitations need to be addressed and different approaches may be more appropriate using qualitative methodology.

## 2. INTRODUCTION

In the UK, stroke is a major cause of death and the biggest cause of severe disability (DoH, 2001; BPS, 2002). The UK Stroke Association currently states that someone in the UK has a stroke every five minutes, which is over 150,000 people per year (The Stroke Association, 2009). They also report that stroke is the third most common cause of death and that 250,000 people in the UK live with disabilities caused by stroke. This gives rise to enormous resource implications. For example, in 2002 stroke survivors occupied 20% of all acute hospital beds and a further 25% of all longer-term beds (BPS, 2002). Strokes are experienced by people of all ages, including about 250 children per year, and10,000 people under retirement age (BPS, 2002). However, the largest population affected are older people (over 65 years of age) who experience half of all strokes (The Stroke Association, 2009).

Stroke involves a blockage or a haemorrhage of blood vessels in the brain that causes the death of brain cells and the effects last more than 24 hours (Colman, 2003). The consequences depend on which part of the brain is affected and can include physical paralysis, cognitive and sensory impairments, and mood/ emotional and personality changes (Carota et al.,2002; Chemerinski & Robinson,2000).

Anxiety is defined as involving feelings of distress, hyper-arousal to threat cues, with cognitive disruption, avoidance behaviours, and physiological arousal (e.g. increased heart rate) (Carota et al., 2002). There is much overlap between the symptomatology of specific anxiety disorders as defined in diagnostic criteria, see ICD-10 (International Classification of Disease published by the World Health Organisation, 2001) and DSM-IV (Diagnostic and Statistical Manual of mental disorders American Psychological Association, APA, 2000). For the purposes of this review, the DSM-IV criteria will be used.

## 2.1 Background

The occurrence of mental health problems following stroke is well recognised and post-stroke depression has received substantial attention (e.g. Anderson et al., 2007; Cole et al., 2001; Hackett et al, 2007; Hackett & Anderson, 2005; Hackett, Anderson et al., 2005; Hackett, Yappa et al., 2005; Robinson, 1997, 2002, 2006; Turner-Stokes & Hassan, 2002). Researchers have more recently recognised the impact of comorbid anxiety with depression on quality of life and long-term outcomes (Morrison et al., 2005). Evidence suggests that post-stroke depression and anxiety hinder all aspects of rehabilitation (see Robinson, 2006). In particular they combine with physical conditions of stroke to become chronic mental health problems and negatively impact on physical health, including increasing mortality rates (Chemerinski & Robinson, 2000; Deykin et al., 2001; Frühwald et al., 2001; Shimoda & Robinson, 1998; Surtees et al., 2003; Tedstone & Tarrier, 2003; van Zelst et al., 2006; Verdelho et al., 2004). Studies into depression have shown that there is a high comorbidity with anxiety disorders and that anxiety impairs the prognosis of major depression (Åström et al., 1993). Anxiety also tends to be worsened by comorbid depression. Anxiety alone can markedly affect quality of life, post-stroke, although this is worsened by comorbidity with depression (Frühwald et al., 2001; Kuroda et al., 2006; Olatunji et al., 2007; Sturm et al., 2004).

By contrast, many researchers who mention post-stroke anxiety disorders note that it has been relatively neglected by studies (e.g. Bruggimannn, 2006; Burvill, 1995; Johnson, 1991; Kanner & Barry, 2003; Leppävuori et al., 2002). Previous reviews in this area reflect this lack of research related to anxiety as none focus specifically on post-stroke anxiety and their aims are outlined in Appendix II.

To date, no review has been carried out that focuses on post-stroke anxiety. Reviews into general post-stroke psychiatric disorders have mentioned anxiety but have

not been systematic, nor have they investigated prevalence rates for anxiety disorders nor significantly correlated factors. As a result there is a need for a review specifically into post-stroke anxiety. The aim of this paper is to systematically review current literature pertaining to post-stroke anxiety to identify the prevalence of post-stroke anxiety disorders and significantly correlated factors. This will provide valuable information into a phenomenon that may undermine the well-being and rehabilitation of stroke survivors. As such, the findings may facilitate the provision of the care of stroke survivors.

## 3. METHODOLOGY

A systematic strategy was employed using the electronic databases Medline, Scopus, Web of Science, and Psych.INFO. Informative, well evidenced literature was sought to identify prevalence rates for post-stroke anxiety disorders and significantly correlated factors.

### 3.1 Search strategy and terms

Literature searches were carried out of English language, peer reviewed, papers for all years on 08/12/08, using the databases. A wide search was carried out using the key words stroke, cerebrovascular, ischemia, TIA, haemorrhage, and post-traumatic stress (and all derivations and spellings of these words), and anxiety, phobia, agoraphobia, panic and social phobia. Other papers were sought using the "snowball" method to identify further literature relevant to the search. Searches were also made using key authors' names.

### 3.2 Inclusion/ exclusion criteria

The current review focused on prevalence rates for, and factors associated with, post-stroke anxiety disorders in adulthood. Therefore any studies relating to children or

dementia were excluded. Studies involving 1-4 participants were also discounted because it was not possible to generalise their findings and they did not provide the statistical data necessary for the purposes of this study. Papers that focussed on subarachnoid haemorrhage (SAH) were also removed because the medical treatment involves surgery so the experience of these survivors was significantly different from other strokes (Berry, 1998).

## 4. RESULTS

### 4.1 Overview

Initial searches provided forty-one studies that met the review criteria (see Appendix III for numbers of papers identified by each database). Papers included in the current review are listed in Appendix IV. One paper was rejected (Kadojić et al., 2005) because the paper was very poorly translated and written undermining confidence in the quality of the study.

Eight reviews were identified that mentioned post-stroke anxiety and one that included post-stroke PTSD (see Appendix III). The paper into PTSD reviewed research relating to a number of physical illnesses including only one study on post-stroke PTSD. The other reviews were not systematic and looked at general psychiatric disorders post-stroke, focussing on depression, with little investigation into prevalence rates. Anxiety was mentioned briefly as a generic phenomenon (rather than identifying specific disorders) (e.g.Mukherjee et al., 2006).

Papers were identified that gave prevalence rates for post-stroke anxiety disorders and factors significantly correlated with post-stroke anxiety (see Table B1 and Appendix IV). The majority looked at GAD or PTSD and as a result these disorders

were the focus of the current review and have been summarised in Appendix V and

assessed against criteria for rigorous research in Appendix VI.

**Table B1:**
**Papers reviewed**

| Post-stroke anxiety disorders and factors significantly correlated with post-stroke anxiety | Number of papers |
| --- | --- |
| GAD | 8 |
| PTSD | 5 |
| Agoraphobia | 2 |
| Panic disorder | 1 |
| Simple phobia | 2 |
| Research into factors correlating with post-stroke anxiety | 4 |
| General research into anxiety identifying factors correlated to post-stroke anxiety | 11 |

## 4.2 Prevalence rates

Many studies provided prevalence rates for anxiety levels but only eight

identified rates for GAD (see Table B2 and Appendices V and VI). By contrast, only

four studies identified a prevalence rate for post-stroke PTSD (see Table B3).

Even fewer studies investigated other anxiety disorders. Three studies into

agoraphobia found prevalence rates of 2-9%, with rates being higher for women (Burvil

et al., 1995; House et al., 1991; O'Rourke et al., 1998). These researchers considered

their participants to be from populations that they believed to have lower rates of

anxiety disorders. Sharpe et al. (1990) was the only study to identify a prevalence rate

for Panic Disorder at 2%. This was one of two studies that looked at the prevalence rate

for phobias that found rates between 3-5% (House et al., 1991; Sharpe et al., 1990). The

population from which the participants were drawn were recognised by the researchers

as having low levels of anxiety, so these may be underestimates.

### 4.3 Associated factors

4.3.1   GAD and general anxiety

Only a limited range of variables have been studied and correlated with post-stroke anxiety (see Appendix VII). Evidence seems strongest for the association of depression with an increase in prevalence and severity of post-stroke anxiety, but impairments in social, physical and cognitive functioning also seemed to be negatively correlated with anxiety.

On the other hand, counter-intuitively, the severity of strokes and associated disabilities did not seem to be associated with post-stroke anxiety (e.g. Castillo et al., 1995; Morrison et al., 2000).

4.3.2   PTSD

Few studies have investigated factors associated with stroke-related PTSD and the results seem contradictory for a number of factors (see Appendices V and VIII). The greatest evidence seems to support links between higher prevalence rates of PTSD and high levels of general anxiety, severe depression and negative cognitive appraisals about the self and world.

**Table B2:**
**Summary of post-stroke GAD (and symptoms) prevalence at different assessment points**

| Study | Over 5 days | 1 month | 3 months | 4 months | 6 months | 1 year | 2 years | 3 years |
|---|---|---|---|---|---|---|---|---|
| House et al. (1991) | | GAD=1% Adjustment disorder = 4% | | | GAD= 1% Adjustment disorder = 3% | | | |
| Castillo et al. (1993) | GAD=26.9% | | | | | | | |
| Burvill et al. (1995) | | | | Anxiety disorders 5% of men 19% of women Agoraphobia= 4%, men 17% women | | Anxiety disorders alone = 21% 7 agoraphobia, 2 GAD Comorbid anxiety with depression 17% | | |
| Åström (1996) | | | GAD= 31% | | | GAD= 24% | GAD 25% | GAD= 19% |
| Schultz et al. (1997) | | | GAD less than 3 months 27% | | GAD 6 months or later 23% | | | |
| O'Rourke et al. (1998) | | | | | GAD 2% Any anxiety disorder 13% | | | |
| Shimoda & Robinson (1998) | | | GAD = 23% (10% anxiety alone, 13% pre-morbid with depression) | | | | | |

| Study | Over 5 days | 1 month | 3 months | 4 months | 6 months | 1 year | 2 years | 3 years |
|---|---|---|---|---|---|---|---|---|
| Tang et al. (2002) | | GAD = 0.6% | | | | | | |
| Leppävuori et al. (2003) | | | | GAD = 20.6% Primary GAD = 11.2% GAD due to stroke =9.4% | | | | |
| Barker-Collo (2007) | | | Moderate –severe anxiety = 21% Moderate anxiety with moderate depression = 6.8% Severe anxiety with severe depression = 5.5% | | | | | |

**Table B3:**
**Summary of post-stroke PTSD (and symptoms) prevalence at different assessment points**

| Study | 2 weeks | 6 weeks | 3 months | 6 months | 12 months | 18 months |
|---|---|---|---|---|---|---|
| Sembi et al. (1998) | | | | | | 21% 7% |
| Sampson et al. (2003) | (More than 5 days) 5.6% PTSD (Control group 6.1%) | | | | | |
| Bruggimann et al. (2006) | | | | | Possible PTSD (IES)= 31% | |
| Merriman et al (2007) | | | | | PTSD symptoms within 12 months post-stroke 30.7% | |

# 5. DISCUSSION

## 5.1 Prevalence rates

### 5.1.1 <u>General Anxiety Disorder</u>

The range of GAD prevalence rates is identified as being between 0.6% (Tang et al., 2002) and 31% (Åström, 1996). Both studies focussed on the stage post-stroke that was within 3 months of the stroke (often referred to as the 'acute' stage, during which many survivors experience some of their most acute difficulties). These two studies might have been expected to have different outcomes. Tang and colleagues' (2002) pilot study may have been expected to find a higher prevalence of anxiety because they also excluded TIAs and only accepted participants who had a stroke identifiable by CT scan. Hence it is likely such strokes resulted in larger areas of damage and consequently greater impairment (although there are no known links between levels of impairments and post-stroke anxiety). However, they did not state whether they used a hierarchic diagnostic system (used by DSM-IV diagnostic criteria) which prioritises the diagnosis of depression as the primary disorder over anxiety where they are both present. As depression is common and often comorbid with anxiety, a hierarchical system of diagnosis reduces the number of cases of GAD identified.

On the other hand, Åström (1996) may have been expected to find a lower prevalence rate as only 61% of the participants had lesions identifiable on a CT scan, suggesting a large proportion had smaller strokes, perhaps with more limited damage and impact on the participant's lives. He also used a non-hierarchical diagnostic approach, so everyone who experienced GAD was included.

The wide difference in the identified prevalence rates may be due to the socio-cultural differences between the Hong Kong Chinese participants of Tang and colleagues and the Swedish participants of Åström (1996). For example, social isolation

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was experienced by 38% of those in Åström's research, many of whom lived alone. Another finding of this study was that social isolation was correlated with increased levels of anxiety. It is not clear whether the Chinese participants were socially isolated, but cultural differences may have made this unlikely.

Three studies support Tang and colleagues, finding a prevalence rate for GAD that was little different from the general population (Burvill et al., 1995; House et al., 1991; O'Rourke et al, 1998). Anxiety disorders have been reported at a frequency of 10.2% in the general population aged between 55-85 years (Beekman et al.,1998).

The research of House et al. (1991) met rigorous standards in their methodology (see Appendix VI), although they did not use a clinician administered assessment, which may have affected the low prevalence rate. In addition, they used a hierarchical system of diagnosis that may have disregarded cases of anxiety where it was comorbid with depression. They investigated a wider range of anxiety disorders than most studies. The sample was community based, the participants had mild disabilities, had experienced their first stroke and were more independent and less likely to have been hospitalised. Consequently the prevalence of anxiety might be expected to be lower. In addition the participants were from a less socially deprived geographical area than most. The researchers believe this is reflected in other studies taken from the same population which showed low rates of psychiatric disorders (e.g. Feldman et al., 1987; Sharpe et al., 1990).

O'Rourke et al. (1998) found a prevalence rate of 2% at 6 months post-stroke, but the participants who refused to participate had higher rates of anxiety. Furthermore the aim of the study was not to ascertain prevalence rates. Similarly Burvill and colleague (1995) found low rates of GAD but were the only researchers to find high rates of agoraphobia. Their study was also the only one to use the Psychiatric

Assessment Schedule as a diagnostic tool. This may have influenced the results as their overall rate for all anxiety disorders was 21% which is similar to the second group of studies.

The current analysis suggests that low prevalence rates may be linked to demographic and cultural factors which reduce the relevance to their findings to similar population groups. As a result they may not be applied more generally.

On the other hand, six studies (Åström, 1996; Barker-Collo, 2007; Castillo et al., 1993; Leppävuori et al., 2003; Schultz et al., 1997; Shimoda & Robinson, 1998) have consistently found prevalence rates of 20-28%. Although there were a number of methodological issues this research generally appeared reliable and valid, with large sample sizes, longitudinal studies and a variety of assessment points post-stroke (see Appendices V & VI). The participants of the studies seemed more representative of general populations from which they were taken. As a result the prevalence rate of 20-28% appears the more reliable.

However, although the following studies support this prevalence rate they suggest that research into post-stroke anxiety may have been too simplistic, because anxiety may be a more complex issue than generally thought. For example, Castillo and colleagues (1995) explored GAD that begins in the acute stage post-stroke (prevalence rate 27%) and the onset of GAD over 3 months later (prevalence rate 23%). They suggest that, although similar in appearance, they may come from different pathophysiological mechanisms. Based on their findings they concluded that post-stroke anxiety, depression, and anxious depression may be separate disorders with differing aetiologies (Castillo et al., 1993).

In addition, Leppävuori and colleagues (2003) were the first to investigate two diagnostic subgroups of GAD: primary GAD (frequency 11.2%), and

GAD due to stroke (frequency 9.4%). They identified factors that were distinct between these groups 3-4 months post-stroke (discussed later). They indicated that GAD due to stroke had factors in common with depression, supporting Burvill and colleagues' (1995) view that the major post-stroke psychiatric disorder may be mixed anxiety-depression, not depression alone.

5.1.2   PTSD

In the general population the prevalence for PTSD is 1-2% (DSM-IV; APA, 1994). Sembi and colleagues (1998) carried out the first research specifically investigating post-stroke PTSD. Their 61 hospital patients were within 16 months of their first stroke or TIA. A prevalence rate of 9.8% was found, although the researchers recognise that this may be an underestimate because they were unable to follow-up four of the thirteen participants who appeared to be experiencing PTSD symptoms.

Sampson and colleagues (2003) assessed in the acute stage post-stroke when people may be experiencing normal adjustment reactions. Their study may have been compromised by their massive sample (417 patients) being reduced by ¾ due to exclusion criteria (for physical and cognitive impairments) and attrition (60 people refused to participate). Their participants were also generally more elderly (range 64-78) than the other studies.

As with Sampson et al. (2003), Bruggimann and colleagues (2006) and Merriman et al. (2007) were likely to have overestimated the prevalence of PTSD because their participants did not meet all of the DSM diagnostic criteria (particularly the period of time symptoms should be experienced). Furthermore, the latter two studies used self-report measures, i.e. Impact of Events Scale-Revised (Horowitz,1979) and Posttraumatic Diagnostic Scale (Foa, 1995; Foa et al., 1997), that are screening tools to identify PTSD but were not designed to be diagnostic measures (Bruggimann et al.,

2006; Lapsoa & Alden, 2003; Merriman et al., 2007). Bruggimannn and colleagues (2006) also had sampling issues, with only 52% of the selected patients returning the self- report questionnaires.

**5.2 Factors significantly correlated with post-stroke anxiety and anxiety disorders**

5.2.1   GAD and post-stroke anxiety

The factors associated with anxiety seem to be many and complex. To date much of the research has focussed on single factors and not explored their interactions. Intuitively, one might expect the global impact of stroke on individuals and their families to result in a complex, fluid interaction of factors post-stroke that may not be explained by looking at a small number of variables. Few studies focussed specifically on GAD, but treated anxiety as a generic phenomenon. The following focuses on factors with the strongest evidence associating them with anxiety.

As depression has been extensively investigated, it is unsurprising that it provides extensive evidence for links with comorbid anxiety and the negative impact of this correlation on survivors. Depression has been highly correlated with anxiety post-stroke with as many as 85% of people who experience anxiety, also having comorbid depression 3 years post-stroke (e.g. Åström, 1996; Castillo et al., 1993,1995; Dennis et al., 2000; Leppävuori et al., 2003; Lewis et al., 2001; Masskulpan et al., 2008; Schultz et al., 1997). Indeed, as has already been mentioned, post-stroke anxiety and depression seem to share similar mechanisms, occur at approximately the same time, and may represent a single mixed anxiety-depression disorder (Burvill et al., 1995; Castillo et al., 1995; Paul, 1988; Schultz et al., 1997).

The comorbidity of depression with anxiety is important because they seem to have a significant influence on the severity, onset, response to treatment and chronicity of each disorder in a way that is different from the disorders when they occur separately

(Shimoda & Robinson, 1998). Furthermore, comorbidity has been found to increase the mortality rate and impair activities of daily living and recovery of social functioning (Burvill et al., 1995; Shimoda & Robinson, 1998).

The evidence for brain lesion location being linked to anxiety is relatively strong and is developing. Where anxiety has been linked to a lesion site, the evidence has been consistent (see Appendix VII). Social support is another area that has been strongly associated with anxiety. The relationship is two way i.e. decreases in social support or an increase in anxiety has a negative affect on the other.

Other populations appear to have an increase in anxiety where there is a history of mental health disorders (Bennett et al., 2002; McFarlane, 1989). In particular, Leppävuori and colleagues (2003) also found a higher level of anxiety as the primary diagnosis correlated with a previous history of insomnia, depressive disorder and comorbid depressive disorder.

5.2.2   Associated Factors with post-stroke PTSD

Appendix VIII shows the evidence for factors associated with PTSD. The strongest evidence for factors associated with strokes is replicated in a number of studies. Consequently, it may be suggested with some confidence that negative affect in some form of anxiety and severe depression is linked with PTSD. However, any causal relationship cannot be identified from the data because the studies are not longitudinal and have no pre-morbid measure of affect. Similarly a causal relationship cannot be established between negative cognitive appraisals on PTSD symptoms. However, participants with negative cognitive appraisals of themselves and the world were found to experience more severe PTSD symptoms in three studies (see Appendix VIII). This supports previous research by Foa and colleagues (1999) and Ehlers and Clark (2000)

whose cognitive model of PTSD indicates negative appraisals might explain variance in the severity of PTSD symptoms.

Many other factors may be associated with PTSD and interact with each other. For example, the study by Sampson and colleagues (2003) found no significant difference in the levels of depression, anxiety, PTSD-like symptoms and autobiographical memories between stroke and non-stroke hospitalised participants. This suggests that it may be something about the experience of being hospitalised that may be correlated with PTSD (and anxiety). Clearly more research is required in this area.

## 5.3 Limitations of Studies

### 5.3.1 Anxiety as a Generic Phenomenon

Most studies into anxiety have treated it as a generic concept (e.g. Angelelli et al., 2004; Dennis et al., 2000; Fure et al., 2006; Giaquinto et al., 2007; Kuptniratsaikul et al., 2009; Masskulpan et al., 2008). The research into specific anxiety disorders is very limited and focuses on PTSD or GAD.

### 5.3.2 Diagnostic Issues

Only a very few studies carried out clinical interviews that allowed specificity of diagnosis (e.g. Åström, 1996; Burvill et al., 1995; Castillo et al., 1993; Sembi et al., 1998; Tang et al., 2002). Most research explored the prevalence of anxiety symptoms by using a screening measure, predominantly the Hospital and Anxiety Depression Scale (HADS)(Zigmond & Snaith, 1983). Not only is this not a diagnostic tool but many studies used different cut off points for clinical caseness; from 11 points (D'Alisa et al., 2005), to 8 points (Dennis et al., 2000), or stated no cut-off point at all (e.g. Bennett et al., 2006; Bond et al., 1998; Lewis et al., 2001). Similarly, PTSD screening measures (such as the Impact of Events Scale, Horowitz, 1979) were used so diagnosis

could not be made. In particular the diagnostic criteria, of the time symptoms should be present, were waived by researchers (e.g. Bruggimann et al., 2006; Merriman et al., 2007). PTSD studies also use a variety of assessment tools that make comparisons between findings difficult.

The measures, e.g. HADS and IES, though validated for use with certain populations have been found to lack sensitivity and specificity (O'Rourke et al., 1998; Johnson et al., 1995). Thus the prevalence of disorders may have been overestimated and any significant correlations involving incorrectly diagnosed participants are undermined. It has also been suggested that anxiety disorders post-stroke may not be the same in aetiology or symptomology as described by DSM criteria (Burvill et al., 1995; Schramke et al., 1998).

The overlap of physical and psychiatric symptoms can also adversely affect the diagnosis of disorders – this makes the use of self report measures (such as HADS) less reliable because the symptoms can be hard to quantify (House et al., 1991). Consequently normal adjustment reactions, such as fear and distress, could be mistakenly pathologised. Such self-report measures also rely on the participants ability to communicate and judge their own symptoms accurately, which may be complicated by post-stroke impairments.

The use of different diagnostic models used in studies e.g. DSM-IV and ICD-10 may also have affected findings because they identified different types of anxiety disorders. For example, more people received diagnoses of anxiety disorders under DSM-III (APA, 1994; Barker-Collo, 2007; Leppävuori et al., 2003). In addition, DSM diagnostic criteria uses a hierarchical diagnostic model that biases diagnosis towards depression disorders, even if the participant meets the criteria for an anxiety disorder

(e.g. House, 1991; Tang et al., 2002). Consequently, where anxiety is comorbid with depression, it may be underestimated.

### 5.3.3    Types of Stroke

Studies did not always discriminate between the types of stroke they included and some strokes involve different experiences. For example, the study by Lewis et al (2001) was one of the few that specifically excluded SAH, which involves surgery and may involve a more traumatic experience, resulting in a higher prevalence rate of PTSD (e.g. Berry, 1998; Merriman et al., 2007). Furthermore every stroke is unique and no account is made for the highly individualised outcomes. Some researchers would only include participants with a brain lesion observable by CT or MRI scan (Åström, 1996; Barker-Collo, 2007; Schultz et al., 1997; Sharpe et al., 1990; Shimoda & Robinson, 1998). As a result people with minor strokes were excluded and their experiences, such as treatment, hospital admission, life events, rehabilitation, loss of independence etc may be entirely different from those with severe or moderate strokes. Consequently, the generalisability of the findings of studies that do not consider the impact of the severity of a stroke were undermined.

### 5.3.4    Medication

Most studies took no account of survivors' use of medication (e.g. Barker-Collo, 2007; Castillo et al., 1995; Merriman et al., 2007; O'Rourke et al., 1998). Drugs may have ameliorated anxiety or created side-effects that could have been mistaken for anxiety symptoms.

### 5.3.5    Study Design

Few studies used control groups, giving no comparisons to identify variables specific to stroke. The studies with controls suggested stroke survivors' experiences may not be specifically related to stroke because they were shared by others

experiencing life threatening physical health problems (e.g. Bond et al., 1998; Frühwald et al., 2001; Sampson et al., 2003 Sheldrick et al., 2006).

Most research into post-stroke anxiety was cross-sectional in design (e.g.Angelelli, et al., 2004; Dennis et al., 2000; Merriman et al., 2007; O'Rourke et al., 1998; Sembi et al., 1998; Sharpe et al., 1991; Tang et al., 2002), so did not always show the progression of anxieties, nor did they identify whether it was the same people having particular experiences over time. Cross-sectional design also limited the ability to predict PTSD from factors with which it was correlated because the direction of the relationships was unclear (Field et al., 2008). Where longitudinal methodology was used, often non-neurological comparison groups were not (Åström, 1996; Burvill et al., 1995; Castillo et al., 1995; Morrison et al., 2000; Schultz et al., 1997; Shimoda & Robinson, 1998).

5.3.6   <u>Participants</u>

Participant selection and exclusion varied widely in age, culture context (some were community based, others hospitalised), severity of stroke, type of stroke included, cognitive deficits excluded. Many studies excluded those with communication difficulties (e.g. D'Alisa et al., 2005; Barker-Collo, 2007; Sembi et al., 1998) which affects so many stroke survivors but often improves over time, further undermining generalisability of findings.

5.3.7   <u>Assessment point</u>

Assessment of symptoms has occurred at different points post-stroke e.g. during the acute phase anxiety (when PTSD appeared to be higher), and there may be distinct differences between early and late-onset anxiety (Castillo et al., 1995). Only a handful of studies assess beyond the acute stage (i.e. Åström, 1996; Burvill et al., 1995; Castillo et al., 1995; House et al., 1991; Leppävuori et al., 2003; Schultz et al., 1997).

5.3.8   <u>Comorbidity with other psychiatric disorders</u>

Approximately four fifths of stroke survivors experiencing anxiety disorders also have a depressive disorder (Åström,1996; Castillo et al., 1993, 1995; Leppävuori et al.,2003; Starkstein et al.,1990) resulting in a number of difficulties when investigating factors associated with post-stroke anxiety. For example, the disorders may not be separate but represent a mixed anxiety-depression disorder (Burvill et al., 1995).

There is a significant overlap of symptoms between anxiety and other disorders, and in particular with depression (Clark et al.,1994). For example, people who rate themselves highly on a scale for symptoms of anxiety tend to do the same on scales for depression, as do clinicians who treat them (Clark & Watson, 1991). Furthermore, the measures for anxiety and depression seem to tap into the same symptoms of negative affect, which includes affective states such as distress, anger, guilt, fear and worry (Clark & Watson, 1991, Clark et al.,1994). This makes differentiating the disorders difficult. The studies reviewed in the current paper do not mention these issues.

In addition, the symptoms of depression can influence post-stroke experiences that could influence factors identified by studies as being correlated with anxiety (Carson et al, 2002; Clark et al.,1994).  In particular, depression could also be correlated with: increased fatigue, slowed cognitive processing speed, difficulties coping with everyday life, poorer quality of life, negative cognitions, and anticipating the worst and pessimism about the future. The studies reviewed here do not address depression as a potential cause of these factors.

**5.4 Good quality studies**

Despite these limitations there were many examples of good quality research amongst the papers reviewed (see Appendix VI).  In particular the following papers reflected rigorous research standards: Barker-Collo (2007), House et al. (1991),

Leppävuori et al (2003), Sembi et al. (1998), Shimoda & Robinson (1998), Tang et al. (2002).

## 6. RECOMMENDATIONS FOR FUTURE RESEARCH

The dearth of research into post-stroke anxiety has resulted in a lack of knowledge of this area so any rigorous investigations are likely to produce useful findings. In addition replicating existing studies, especially if methodological problems were resolved, would allow their reliability to be validated.

Research is still required to clarify the prevalence rate for anxiety post-stroke, whilst avoiding the limitations of previous studies. Currently research also suggests factors correlated with post-stroke anxiety but there is a lack of information about causal variables. Furthermore, experimental designs are needed that identify factors that test which factors may be changed to increase or decrease anxiety.

Longitudinal designs may help to understand the nature and course of post-stroke anxiety and how variables interact to influence anxiety levels. Understanding the course of anxiety for individuals may shed light on how anxiety progresses. In particular, research that enables the understanding of processes underlying post-stroke anxiety would further the development of psychological theory in this field. Studies may also be helpful that explore the relationship between anxiety and depression and how they develop post-stroke.

Alternatively, a qualitative approach may allow the multivariate nature of the investigations to be studied in context. In addition, the experience of post-stroke anxiety has yet to be investigated from the stroke survivors' perspectives leaving a significant gap in current knowledge.

# 7. CLINICAL IMPLICATIONS

Much of the evidence to date has identified rather vague factors that are correlated with post-stroke anxiety, but does not provide concrete evidence of factors that directly influence post-stroke anxiety. This makes specific clinical recommendations difficult and the following are made on the basis of the limited research and 'clinical common sense'.

Clearly, the impact of post-stroke anxiety, especially comorbid with depression, is significant; it hinders rehabilitation, reduces quality of life and increases mortality rates. Consequently, survivors may benefit from screening for and treatment of post-stroke anxiety at different points after a stroke, including after people return home. An increase in the understanding of the aetiology, nature and course of the disorder would facilitate the development and targeting of interventions, health education, and service planning. Such information would also aid the identification of risk and protective factors and might indicate the optimum timing for assessments and interventions and help with teaching and preparing survivors for change. In the light of this interventions could be targeted at social support, developing coping skills and receiving support in adjusting to stroke related impairments.

# 8. CONCLUSION

Research into post-stroke anxiety is in its infancy, with GAD and PTSD being the focus of studies. Research suggests that the prevalence of post-stroke GAD may be between 20-28% (much higher than that found in the general population (Kessler et al., 1994). Prevalence rates may be higher in the acute stage post-stroke (around 29.5%) and may then fall, remaining relatively stable for at least 3 years post stroke (Åström, 1996).

However, it may not be the same individuals who have high levels of anxiety at each point (House et al., 1991).

Research raised questions about the nature of post-stroke anxiety, such as whether early and late-onset GAD are distinct and different disorders. A mixed depression-anxiety disorder might better represent the experiences of the majority of those who experience anxiety post-stroke.

The prevalence rate for PTSD cannot be stated with great confidence because of the small number of studies and their lack of consistency, with suggested rates of between 5.6-31%. The most reliable study seems to be that of Sembi and colleagues (1998) who found a rate of around 9.8%, which they considered to be an underestimate.

Potentially an extensive number of variables are associated with anxiety and these are only beginning to be investigated. To date key variables include post-stroke depression, social factors and stroke related impaired functioning. Studies suggest that the relationship between these variables may be dynamic and complex.

Studies into post-stroke anxiety disorders were undermined by many fundamental limitations, particularly the lack of accurate diagnosis of disorders. Examples of rigorous research were found and these need to be replicated to establish the reliability of their findings. Research designs were also limited and did not allow the exploration of multiple anxiety-related factors over time. Further research is required to develop the knowledge base in this area and inform clinical practice and service development.

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\* - indicates papers included in the review

\*\* - indicates papers rigorously reviewed

# SECTION C


# RESEARCH REPORT

# 1. ABSTRACT

**Objectives:** To explore phenomena that survivors of strokes associate with post-stroke anxiety.

**Design:** Qualitative study

**Method:** Fourteen participants were interviewed and the data recorded, transcribed and analysed using a Grounded Theory (Charmaz, 2006) approach.

**Results:** Anxiety was associated with the core categories of dependence, vulnerability and inability to meet expectations. Expectations appeared linked to pre-stroke beliefs and experiences of the self. Participants frequently used these expectations to compare with and judge their post-stroke experiences and identity.

**Conclusion:** Post-stroke anxiety may be explained by cognitive behavioural approaches, especially the discrepancies between actual self and how stroke survivors think that they "ought" to be that relates to their pre-stroke cognitions about the. This discrepancy may also give rise to feelings of anxiety as a result of prolonged cognitive disonance. Adjustment of cognitions may be delayed due to a prolonged period of unclear prognosis, vague expectations and slow rehabilitation that seem to be part of the pathway of post-stroke rehabilitation.

## 2. INTRODUCTION

### 2.1 Background

In the UK stroke is a major cause of death and the biggest cause of severe disability (DoH, 2001; BPS, 2002). The UK Stroke Association stated that someone in the UK has a stroke every five minutes, which is over 150,000 people per year (The Stroke Association, 2009). They also report that stroke is the third most common cause of death and that 250,000 people in the UK live with disabilities caused by stroke. This gives rise to enormous resource implications. For example, in 2002 stroke survivors occupied 20% of all acute hospital beds and a further 25% of all longer-term beds (BPS, 2002). Strokes are experienced by people of all ages, including about 250 children per year, and 10,000 people under retirement age (BPS, 2002). However, the largest population affected are older people (over 65 years of age) who experience half of all strokes (The Stroke Association, 2009).

Stroke involves a blockage or a haemorrhage of blood vessels in the brain that causes the death of brain cells and the effects last more than 24 hours (Colman, 2003). The consequences depend on which part of the brain is affected and can include physical paralysis, cognitive and sensory impairments, and mood/ emotional and personality changes (Carota et al., 2002;Chemerinski & Robinson, 2000).

Commonly anxiety disorders post-stroke affects between 0.6% (Tang et al., 2002) to 31% of stroke survivors (Åström, 1996). Although problematic to define due to a lack of a universally accepted definition, anxiety could be characterized by feelings of distress, hyper-arousal to threat cues, with cognitive disruption, avoidance behaviours, and physiological arousal (e.g. increased heart rate) (Carota et al., 2002; Rachman, 2002). The symptoms of anxiety identified in the current study are those found in the

DSM-IV (Diagnostic and statistical manual of mental disorders American Psychological Association, APA,, 2000) criteria.

## 2.2 A psychological understanding of anxiety – a cognitive behavioural approach

Research suggests that there is a generalized biological vulnerability involved in some experiences of high levels of anxiety e.g. GAD. For example it seems to be partially hereditary (Noyes et al., 1987; Noyes et al., 1992) and can be experienced by twins (Kendler et al.,1992, 1995). People who experience such anxiety appear to be chronically tense and appear to be highly sensitive to perceived threats, especially those that have personal relevance. As a result anxious people attend more readily to sources of threat (Aikins & Craske, 2001).

One in depth, research based, understanding of the aetiology of anxiety is that provided by cognitive-behavioural approaches (Brewin, 1996). These suggest that a heightened level of anxiety is the result of distorted perceptions of danger (Beck, 1976; Butler & Mathews, 1983; Clark, 1986; Martin et al., 1991). Anxious people overestimate danger (Butler & Matthews, 1983).

Cognitive-behavioural approaches hold that cognitions and behaviours are learned and reinforced by negative and/ or positive reinforcement. Behaviour is determined by the immediate context and the individual's interpretation of them (Kirk, 2003). The interpretations of threat may be the result of negative thinking that is central to the maintenance of anxiety (Beck, 1967).

Cognitive-behavioural theory assumes that cognitive processes mediate all emotional and behavioural responses (Beck & Clark, 1988) and are understood to maintain anxiety. A high sensitivity to threat is conditioned through earlier life experiences through which a person learns that specific things, or the world in general,

are dangerous (Beck, 1967). Once anxious cognitions have been acquired, these may be triggered by specific events or environmental factors.

Sometimes cognitive schemas become maladaptive and dominant over other functional schema. The schema dominant in clinical levels of anxiety seem to be those of perceived psychological or physical danger that are personally threatening as well as an exaggerated sense of vulnerability (Beck & Clark, 1988). Avoidance or escape behaviours prevent people learning that their negative predictions about situations are untrue and their attentional bias to potentially threatening stimuli further maintain overestimates of danger (Beck, 1976; Eysenck et al., 1987)

Cognitive content-specificity strategy (based on Beck, 1976) has been extensively supported by research (e.g. Beck et al., 1987, Beck et al., 2003; Clark et al., 1990; Jolly et al., 1994; Woody et al., 1998). This argues that high levels of anxiety are related to specific kinds of cognitions/ schema about self and the world that make people prone to interpret a wide range of situations in a threatening way (Beck, 1985). Most of the schemas are related to anxiety involve issues of acceptance, competence, control, responsibility and symptoms of anxiety (Clark, 2003).

## 2.3 The impact of anxiety on rehabilitation

Research suggests that anxiety alone can markedly affect quality of life post-stroke, although this is worsened by comorbidity with depression (Frühwald et al., 2001; Kuroda et al., 2006; Olatunji et al., 2007; Sturm et al., 2004). Comorbid anxiety with depression can have long term consequences for: quality of life (Morrison et al., 2005), increasing the likelihood of chronic mental health problems, and negatively impacting on physical health (including increasing mortality rates)(Shimoda & Robinson, 1998; Chemerinski & Robinson, 2000; Deykin et al., 2001; Frühwald et al.,

2001; Surtees et al., 2003; Tedstone & Tarrier, 2003; van Zelst et al., 2006; Verdelho et al., 2004).

## 2.4 Aim of research

The current research is particularly important to undertake because of the potential number of people experiencing post-stroke anxiety and difficulties many of these people experience. Furthermore, there is a lack of research into post-stroke anxiety in general, as noted by other researchers ((e.g. Bruggimannn, 2006; Burvill, 1995; Johnson, 1991; Kanner & Barry, 2003; Leppävuori et al., 2002). In addition, there is an absence of the views of the survivors and of qualitative research in this area. There also appears to be a need to develop theory to apply to post-stroke anxiety. Consequently research that increases understanding of post-stroke anxiety is needed and has the potential of improving patient care and increasing the rate of rehabilitation, whilst also impacting on the cost of stroke care.

The aim of this study is to facilitate the development of theory that is grounded in the post-stroke context that begins to explain the phenomena of stroke-related anxiety. This research is to investigate post-stroke anxiety by seeking stroke survivors' views about what they associate with their anxiety.

## 3. METHOD

## 3.1  Research Design

Investigating subjective views of post-stroke anxiety involves potentially unstructured and contradictory data. Qualitative research methods have been found to be appropriate for analysing such data (Kempster, 2006; Strauss & Corbin, 1998; Willig, 2001). In particular a qualitative approach known as Grounded Theory has often been used where there is little or no previous research, and also to develop new theories

(Pidgeon, 1996; Willig, 2001). A rationale for using grounded theory is provided in Appendix IX.

Many variables may be associated with post-stroke anxiety and very few have undergone focussed investigation. Qualitative methodology enables a wide number of variables to be investigated in real-life contexts without losing their complexity and depth, unlike quantitative methodology. This involves not controlling variables and not having standardised measures, which could be argued as evidence that such approaches are unscientific (Charmaz, 2006). However, researchers have challenged such ideas and sought to provide systematic, rigorous strategies for qualitative research practice (e.g. Glaser, 1992; Glaser and Strauss, 1967; Meryick, 2006; Strauss & Corbin, 1998). Such strategies have been utilised in the current study (see Appendix XII).

Grounded Theory can also be utilised from a number of different philosophical and theoretical stances. The Principle Investigators approach is critical-realist and is described in Appendix XI.

## 3.2 Ethical considerations

3.2.1   Ethical/ Research Governance Approval

This research received ethical approval from the Trent Region NHS Local Research Ethics Committee (see Appendix XIII for approval letter).

3.2.2.   Informed consent

Strokes often cause cognitive impairments that could have affected ability to give informed consent to participate in the study. Consequently, participants were only recruited where they were able to complete a demographic survey and anxiety and depression self-report measures. After this they were required to give informed consent. Written consent was obtained after the participants received verbal and written

information about the study (copies of participant and interview information and consent forms can be found in Appendices XIV-XVI).

### 3.2.3 Confidentiality

To protect the confidentiality of the participants, on receipt of their surveys, any identifying data was removed and the data was coded. All data was kept in accordance with NHS and university data protection guidelines. Any data used in the study was anonymised and pseudonyms used to refer to participants in the text.

### 3.2.4 Participant Distress

Participants were forewarned that interviews could cause them distress. The researcher had some experience working in a professional capacity with people who experienced distress; she was also supervised by a qualified clinical psychologist with extensive experience with this client group.

### 3.2.5 Participants

Participants were recruited from Stroke Association stroke clubs in the Trent Region (see Figure C1 for a summary of the recruitment procedure). Consequently, they had all experienced a stroke, but they were not entirely representative of all those who have survived strokes because they were not so impaired or anxious that they were unable to attend stroke clubs. The club leaders spoke of having limited club membership because they were unable to cope with people who needed one-to-one care and could not offer help with using the toilet.

The inclusion criteria of this study was that participants were able to give informed consent and able to answer the interview questions. Thus people with severe speech impediments were unable to participate if they had no means by which to communicate. Fifteen people returned the envelopes with completed information (see Appendix XVII for demographic data and Table C1 for a summary of key data). One

participant was excluded from the study because at the beginning of our interview it became apparent that she was unable to give informed consent due to cognitive impairment assessed by her inability to answer the research questions coherently.

**Table C1:**
**Summary of key demographic data**

| | |
|---|---|
| Number of strokes experienced per participant | 6 participants experienced 1 |
| | 6 participants experienced 2 |
| | 2 participants experienced multiple |
| Gender | 7 male |
| | 7 female |
| Age range | 40-87 years |
| | 10 of working age at time of stroke |
| Cultural background | 1 Asian |
| | 1 Black |
| | 12 White |
| Recency of stroke at interview | Range = 6 months to 10 years |
| Living alone | 3 |
| Marital status | 1 single |
| | 1 long term partner |
| | 1 widow |
| | 2 divorced |
| | 9 married |
| | |
| Number experiencing anxiety levels | HADS anxiety scoring> 8 = 8 (high) |
| | BAI scoring $\leq$ 10 = 4 (low) |
| | BAI scoring $\geq$ 30 = 7 (high) |

### 3.3.Procedure

Procedural steps are summarised in Figure C1. The researcher approached a number of stroke club leaders and was given permission to deliver a small presentation to each club (see Appendix XVIII). Information was given about the nature of the research, what would be required of participants and envelopes (stamped and addressed

to the University of Leicester) were distributed to all who were interested in contributing to the study. The documents provided in the participants' envelopes can be found in Appendices XIV and XIX and includes: an invitation to participate, a list of sources of help should they be needed, initial information about the study, a demographic survey, a Hospital Anxiety and Depression Scale (HADS)(Zigmond & Snaith, 1983) and a Beck's Anxiety Inventory (BAI)(Beck, 1993). Participants were asked for their name and telephone number which was then used to make contact and arrange an interview.

On return of the envelopes, each participant's data was given a numerical code and identifiable information detached. Surveys were then scored and collated. The Principal Investigator contacted participants by telephone. She reminded them that participation was entirely voluntary and that they could withdraw at any point. Meetings were then arranged to carry out interviews at participants' homes. A letter was sent to confirm this meeting with an information letter (see Appendices XX and XV).

**Figure C1:**
**Recruitment and research procedure undertaken by the Principle Researcher**

Stroke Association for Trent Region was asked for permission to approach Stroke Clubs associated with them for the purposes of this research

↓

Stroke Club leaders were approached to arrange presentations to their members

↓

Presentation given to Stroke Clubs in the Trent Region

Participation invited and packs left with the group for anyone wishing to volunteer

↓

Volunteers returned questionnaires which were anonymised and given an identification code and data recorded

↓

Volunteers were telephoned to confirm their willingness to participate & agree arrangements for a face-to-face interview date, time & place

↓

Interview information leaflet posted to the volunteer with a letter confirming interview meeting

↓

At least one week later the Principle Researcher met the volunteer, verbally went through the interview information leaflet, answered any questions from the volunteer & both signed the consent form, then the interview took place

↓

The interview recordings were transcribed and analysed

3.3.1   <u>Data Collection</u>

Around a week after the participant had received the appointment letter, the Principal Investigator met with the participants. She recapped the contents of the information letter, including the confidential and voluntary nature of the study. Every participant was given the opportunity to ask any questions and then asked to sign a participant consent form (Appendix XVI).

An initial interview schedule was compiled that included a definition of anxiety (taken from the DSM-IV criteria for GAD)(Appendix XXI and XXII). Questions focused on anxiety but also addressed negative affect in order to aid participant responses about this difficult area. Questions were added to the schedule as evidence emerged. Interviews were semi-structured and audio-recorded. The grounded theory approach required data collection and analysis to be ongoing, so the interviews followed similar topics but were flexible to include any new themes as they emerged. The interviews followed Charmaz's (1990, 2006) interview structure that included building a rapport with the participant. The initial topics included:

- Changes in life post-stroke

- Difficulties and frustrations experienced post-stroke

- Factors they could easily identify as being associated with anxiety

After the interviews the participants were debriefed to ensure that they were not distressed and they had an opportunity to ask any further questions.

The recorded data lasted 1- 1 ½ hours per interview and was transcribed verbatim. Time limitations made it impossible for the Principle Researcher to transcribe all of the interviews personally but she checked transcripts for accuracy where they were transcribed by a colleague. See the Addendum for copies of transcriptions. Quotes

are referred to using a code such as 15:408, indicating that this was participant number 15, line number 408. Words in capital letters indicate the interviewer is speaking.

**3.4 Analysis**

3.4.1   Initial Coding

Initially interviews were analysed line by line, with the Chief Investigator making a brief note at the end of each line to summarise what was being said by the interviewee, using language that stayed close to the original words of each participant. Examples of coding are given in Table C2 and Appendix XXIII. Peers also coded sections of data in order to help identify bias.

3.4.2   Memo-writing

The Principal Researcher wrote and made mental notes about her thoughts and impressions following each interview (see Table C2 and Appendix XXIV for examples of memos and research journal entries). These raised issues to be explored in the following interview. Memos were an ongoing part of the process and enabled the researcher to develop themes and ideas (Charmaz, 2006).

3.4.3   Constant Comparative Method

Grounded theory involves the analysis of data using the constant comparison method (Glaser & Strauss, 1967). This involves the ongoing comparisons for similarities and differences of: codes, themes, emerging concepts and theories. Codes were grouped to form more focussed codes and categories grouped to form increasingly abstract concepts and theories. The codes for each interview were laid out in a table that enabled them to be grouped into similar ideas. The groupings were refined and revised after each interview. Comparisons at these different levels continued until a core concept emerged that connected the codes and categories (Carlsson et al., 2004). Ideally

this process would continue until no new data could be found that added to the theory.

The time limitations meant that this study was unable to reach this point of saturation.

**Table C2:**
**Example of coding using the constant comparative method**

| Interview number | Evidence | Initial codes | Revised code | Further revised code |
|---|---|---|---|---|
| 1 | "…I used to remember everything." (2:12) | Previously remembering everything | Inability to get body to work as it used to | |
| 3 | "…I always thought…that if I ever lost my job you come to rock bottom, you could always ride a bike.  That's one of the things I always thought but when you can't ride even a bike you know you have gone past rock bottom…" (3:70-74) | Not expecting to be so bad | Inability to get body to work as it used to. | |
| 12 | "Well, that that's an example of what things I can't do. Like I used to /YES/ I mean like I can't do any gardening either at all. So you know that's right out of things." (11:13-15) | Comparing ability with pre-stroke standards | | Comparing/ judging ability against pre-stroke self |
| | **Memo** | | | |
| | Participants use their pre-stroke self as a reference point by which to judge their post-stroke self and find they don't meet expectations – they are doing this years after their stroke. | | | |

### 3.4.4 Themes and categories

As interviews progressed the number of focussed codes grew and constant comparison enabled these to be merged into higher codes. Potential themes and categories were written onto cards to explore potential relationships between them to help to identify higher order categories. These were used to recode all fourteen interviews. In this way, a process model was developed that showed how the categories and themes were linked. Supervisors and peers facilitated this process through discussion.

### 3.4.5 Theoretical Sampling

Grounded theory involves theoretical sampling, which is the process of testing developing theories through the selection of participants depending on the experiences of those interviewees (Charmaz, 2006). Once the demographic data had been collated (see Appendix XVII) it provided basic information that indicated the potential experiences of the participants. The order in which participants were interviewed depended on issues raised by the previous interviewee and demographic data that facilitated the exploration of difference and the development of emerging themes. For example, the second participant was chosen because he was single, of working age, and had high levels of anxiety, so his experiences were likely to be very different from those of the interviewee before who was female, married, of retirement age, with low levels of anxiety. Further examples are given in Table C3.

**Table C3:**
**Examples of theoretical sampling**

| Interview Number | Interviewee Number | Process | Comment | Resultant evidence |
|---|---|---|---|---|
| 11 | 9 | Expecting to be 'normal' | Participant selected because he was from a minority cultural background and his views of 'normality' and values may have been different from previous interviewees | "I've seen so many people. In one time I was ah um leader of the community." (9:505) "…I want to be back to normal where I was. I want to go back to the community, talk to them…"(9:539-540) "I want that role back." (9:652) |
| 12 | 11 | What is normal? Pre-stroke state is the socially defined norm? | Participant selected because he was older, retired and may have had fewer social expectations but more of his own. | "Well same as anybody, yourself … if you toss something on the floor you just pick it up and don't even think about keeping your balance or gripping it with your hand err that ..SO YOU MEAN NORMAL FOR SOMEONE WHO HASN'T HAD A STROKE? Yeah, tha that that's it." (11:133-135) |
| 13 | 8 | What is normal and does everyone compare? | Participant was selected because he was of a similar age as the previous participant, but the previous participant was more active pre-stroke than expected and had not reduced his activities on retirement. This participant also had longer to adjust as it was twice as long since his stroke than the previous interviewee. | The participant made no reference to wanting to return to a pre-stroke state and when asked why he felt people were motivated to try to return to their previous level of ability he said: "I suppose they don't realise what a serious thing a stroke is." (8:443). He added "In some ways a stroke can be worse than a heart attack. They can do a certain amount with the heart nowadays. They can't do anything with a stroke." (8:446-448). |

# 4. RESULTS

Fifteen participants returned surveys and fourteen interviews were completed lasting 1-1 ½  hours each (see Appendix XVII for demographic data). These provided a diversity of rich data that reflected survivor's experiences of post-stroke anxiety. On interview it became apparent that three participants also experienced multiple physical problems that were unrelated to their stroke and which they believed had a greater impact on their lives than their stroke. Several interviewees were speech impaired, three felt they had difficulties with comprehension (although they did not feel that this interfered with their interviews and declined additional assistance). Most considered they had memory difficulties, for example difficulty word finding and short term memory problems. Predominantly they could only speak with confidence about their current experiences. The majority of interviewees also seemed to struggle to articulate complex ideas, raising the issue of how much higher processes might have been impaired.

These issues made it more difficult for participants to articulate their thoughts in a way that could be understood. Where necessary the investigator endeavoured to repeat what she thought the participant had said in order to check she had understood correctly and so that data could be clearly recorded by the dictaphone.

Participants were asked specifically about anxiety, but also about negative emotional states related to anxiety in order to help them give responses. Research has found that there is a significant conceptual and empirical overlap between anxiety and depression (Watson et al., 1988). Depression and anxiety appear to share increased levels of negative emotional states that can confound self-report symptomatology measures (Beck et al.,2001) and may have caused some data to be captured that related to depression.

In the light of this, a further important factor that is highly likely to have impacted on results was the high number of people (8) identified as suffering from depression/ low positive affect. The symptoms of depression may have interfered with interviewing and been reflected in responses. In particular, the following symptoms may have been reflected in this study: low energy levels or fatigue, low self-esteem, poor concentration and difficulty making decisions, feelings of hopelessness and slowed motor and cognitive functions. However, the experience of the Principle Investigator was that the participants interviewed were fully engaged and did not appear to be depressed. There was also no evidence of anhedonia that may be a marker of depression (for review see Borkovec et al., 1998).

**4.1 Categories and themes**

Data was coded and the codes were grouped, with others of similar content, into themes and then again into higher order categories. Categories with examples of themes used to develop them are shown in Table C4. The theoretical links between these categories are summarised in Figure C2.

**Table C4:**
**Summary of higher order categories and themes**

| Main categories | Higher level categories | First level categories | Examples of themes |
|---|---|---|---|
| Inability to meet expectations/ values | Comparing/ judging against pre-stroke self | Inability to make body work as expected | Limbs not working as wanted/ as they should<br>Embarrassing behaviour<br>Tiring quickly/ Low energy levels<br>Memory not working (Not remembering people, faces, names, words, connections between things) |
| | | Loss of adult status/ autonomy | Feeling childlike in competence<br>Being told what to do by others<br>Not being able to go and do what I want when I want<br>Difficulty expressing views<br>Not involved in decision making |
| | | Role loss | No longer feeling able to perform role (spouse, man, mother, carer) |
| | | Not performing as normal in social settings | Not able to mix/ mingle in groups normally<br>Communications difficulties (speaking slowly/ unclearly/ forgetting words)<br>Feeling too tired to engage socially |
| | | Perceived negative appraisals by others | Not being treated as equal<br>Not being treated as competent |

| Main categories | Higher level categories | First level categories | Examples of themes |
|---|---|---|---|
| Dependence | | Carers | Getting carers to do what I want when I want it<br>Needing help |
| | | Autonomy | Not being involved in decision making |
| | | Mobility/freedom | Not being able to go out or where I want<br>Not being able to drive |
| Vulnerability | | To others | Not being able to get away from threats<br>Fear of being taken advantage of because less able |
| | | Physical harm | Fearing another stroke<br>Fearing death/ further disability<br>Fearing harm because less able to self-care |
| | | | Not knowing (what is wrong, what will happen next, why stroke happened) |
| | | Discrimination | Architectural inaccessibility<br>Being ignored/avoided |
| Resources | | Information | Getting information<br>Understanding what has happened and what is wrong |
| | | Social support | Going to stroke club (talking to people who understand)<br>Social activities |

| Main Categories | Higher level categories | First level categories | Examples of themes |
|---|---|---|---|
| | | Carers | Having people to call on for help |
| | | Material/ financial | Having adaptations to compensate for impairments<br>Finances<br>Accessible services (transport etc)<br>Time |
| | | Personal | Problem solving skills<br>Personality (sense of humour, motivation, determination)<br>Knowledge<br>Skills |

**Figure C2:**
**Model of themes associated with anxiety**
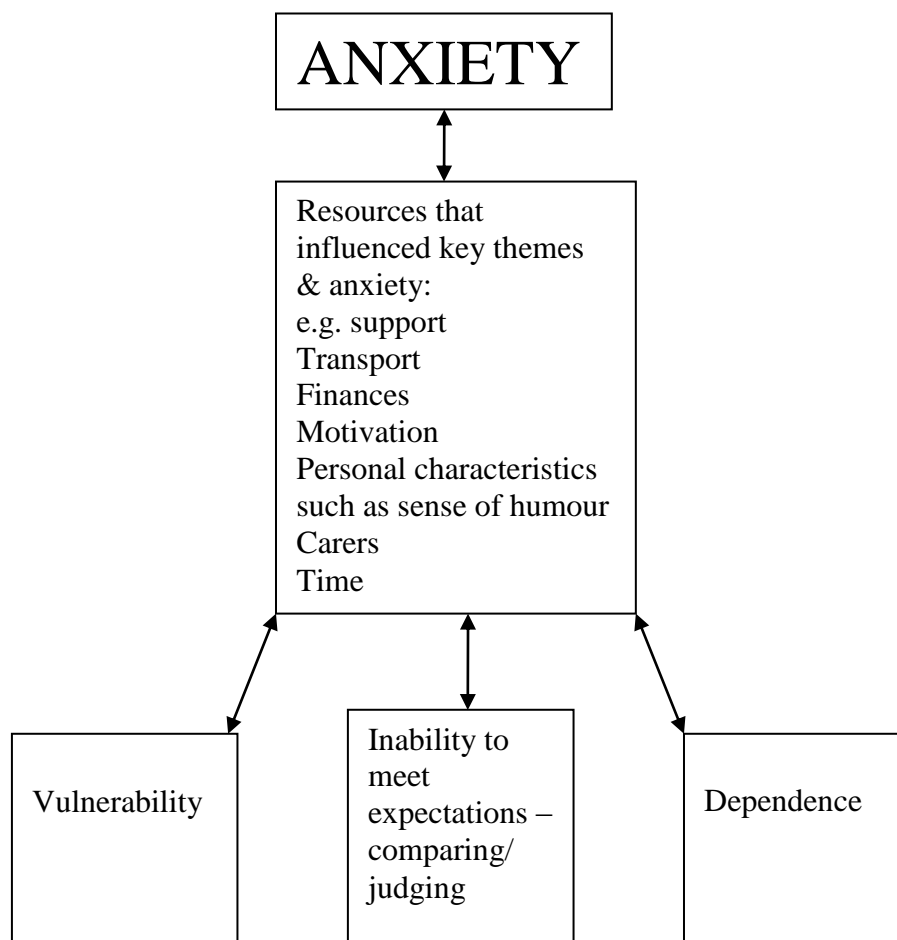
**4.2 Themes associated with anxiety**

Figure C2 is a model of themes associated with anxiety as outlined in Table C4. The main categories that seem to be associated by survivors with anxiety were vulnerability, dependence and failing to meet expectations based on pre-stroke beliefs about the self. Each of these seemed to overlap and require a degree of adjustment. Most survivors also mentioned a number of factors that helped or hindered them and influenced the themes they raised and levels of anxiety they experienced. The results for the categories will now be discussed more fully.

**4.3 Vulnerability**

4.3.1   <u>To others</u>

Survivors spoke of feeling anxiety because of the way their impairments made them feel more vulnerable to others. For example, participant 2 spoke of being afraid of walking home at night because she felt unable to get away from threats quickly: "I'm (heavy sigh) more afraid of going out at night … I never used to bother … because I can't walk so quickly." (2:214,243,245).

Similarly, a woman was afraid of getting lost when out at night because she was afraid of having to ask a stranger for directions: "Because if I'm going to get lost I've got to stop in the dark and try and read the map or, worse still, I've got to stop and ask somebody in the dark." (1:439-440).

Experiencing such vulnerability increased participants' anxiety about the future. One woman gave an example of how she had learned how vulnerable she had become:

"…I now know the hard way that I can be talked into doing something that I don't really want to do.  I had the porch double glazed just after the stroke. Um. I had the company out. I only wanted a wood-grained front door and they talked

me into having the door, the sill, the side windows. The whole of the porch is wood grain which is more expensive than white. Um which I didn't want and I still don't like but they talked me into doing it, so I know I can be talked into having work done or having something done that I don't want."(1:454-460)

### 4.3.2 Physical harm

Increased risks of physical harm created by impairments were also associated with fear and anxiety both because of the fear of getting hurt and the limitations it imposed on their lives:

"I could, 99 times out of a hundred I could be alright and just walk down the street as calm as anything. Once I could walk straight under a car, a bus or anything …And you think 'that's not right.' (3:49-51)

One lady had been burned and dare not use her cooker again:

"And the thing that annoyed me most of all was that I couldn't finish the job. I had done the apples … I daren't for the life of me finish the job because it would mean messing with heating and electrics and so on." (7:368-370)

Most participants expressed anxiety related to a fear of further strokes resulting in death or greater impairment (2:719; 5:723; 6:137; 7:162; 10:93; 11:65; 14:773).

### 4.3.3 Discrimination

Participants referred to difficulties created by discrimination that they associated with anxiety. For example, one participant expressed his sense of lack of protection: "I

feel vulnerable because there isn't a voice out there for me. I've got to do it myself."(4:294-295).

Other interviewees had experienced discrimination through being ignored or avoided by people (participants 1, 9, 12, 15), or had difficulty accessing facilities because of ramps and steps (participants 1,3,4,7,).

Participant 12 experienced anxiety at being ignored and was not alone in feeling that people believed that she was mentally deficient:

"No, no, no. He doesn't want to speak to me because there is something wrong about me… That's why he don't want to speak…. There is nothing wrong with me. I understood what being said to me but other people don't feel the same way." (12:213-216)

Only one participant expressed no such sense of vulnerability (participant 8). Through the interview it became clear that his wife and daughter did everything for him, so he did not expose himself to situations where he felt vulnerable.

**4.4 Dependence**

4.4.1  Autonomy

Most participants seemed unhappy with being dependent, but it appeared to cause more anxiety earlier post-stroke. Some comments suggested a degree of acceptance of dependence was necessary, for example:

"I don't like to be dependent on others… I like to do everything myself, but there is some times when you have got to bite the bullet and say 'well, I'll accept it'." (4:203-205).

Participant 8 was a noticeable exception and he seemed quite unaffected by having his wife do everything for him. He spoke of having accepted this because there was nothing he could do about it. His perspective seemed to be one of resigned hopelessness and helplessness. He said: "In some ways a stroke can be worse than a heart attack. They can do a certain amount with the heart nowadays. They can't do anything with a stroke." (8:447-448).

For most participants, dependence seemed to conflict with their sense of autonomy and expectations about themselves. One man said that it was not so bad being dependent now, but "I always been my own man…I always make decisions." (15:526-529). He felt that he was being left out of family decision making and that family members did not tell him simple things like where they were going when they went out (15:532-538). Similarly, another man stated: "…it was things that we would discuss and I would have my input and H would help. But now a lot of it (*clears throat)* excuse me, I haven't got any input at all." (11:389-391)

4.4.2   Carers

Dependence also raised a number of issues associated with anxiety, including getting and trusting carers to do what was wanted. As one woman explained:

"My partner, as much as I love him, he doesn't always know what's best for me and (*pause*) I couldn't trust him to run the house, and I couldn't trust him to take care of my needs I don't think." (6:155-157)

The three participants who lived alone also spoke of anxiety produced by uncooperative hired carers and the limitations of help provided by someone outside of the home. Participant 12 described how one of her carers did not do as she asked and

treated her with a lack of respect. In particular, one carer seemed to show no understanding of her difficulties and was doing things in a hygienic way that caused a lot of anxiety (12:367-394). She added that she did not like the loss of privacy she experienced as a result of having a stranger in her home: "…if I tell somebody something…in the short space of time they will all know about it and I don't like them things." (12:126-128).

Participant 5 lived alone and said that telling someone that he needed help was hard because he was a proud man. Similarly, participant 1 spoke of having to wait for a carer to come and help her when she had difficulty with a task – such as cracking an egg or reading her post. Some tasks that required help could not wait and the consequences were distressing and created anxiety about the future: "I called someone and they said they'd be there in a minute. And I wet myself. And that was really embarrassing." (2:306-307).

### 4.4.3   Mobility/ freedom

Loss of mobility was often equated with a loss of freedom and normality. Several male participants felt particularly strongly about their loss of ability to drive:

"I'd say it's worse than a heart attack because an heart attack you can get your independence again, you can get some normality back to life and that. With a stroke you can't cause your vision's affected, your reactions are not right and very few people are allowed to drive again after a stroke." (3:123-126)

"…losing the power to drive, um, that is independence. Losing that independence and having to rely on everybody for almost everything, it's a shock to the system."  (5:575-577)

## 4.5 Inability to meet expectations

As previous comments showed participants compared and judged themselves against their pre-stroke identity, ability and expectations. Anxiety seemed to be associated with these evaluations being negative and interviewees being unable to meet their pre-stroke expectations. Many participants had a strong drive to rehabilitate and their goal was to return to normal. For example one man stated: "What is in my mind is that I want to be a proper person like I was before…I was a fighter and I want to be back normal where I was." (9:439,539).

Only 2 participants did not compare themselves with a pre-stroke normality (8 & 15) and a further woman did not identify any sources of anxiety (14). Participant 14 was a 72 year old woman who experienced her stroke 10 years ago and spoke of having adjusted, having everything she needs and having resolved most of the things that she perceived as difficulties since her stroke. In particular her husband took care of all her care needs. Participant 8 was a 77 year old woman who experienced her stroke 6 years ago and participant 10 was an 86 year old man whose stroke was 2 ½ years ago, but he had suffered from ill health for many years prior to his stroke. It was noticeable that these participants were amongst the oldest and with some of the longest periods since their strokes or they had previously experienced significant health problems. They spoke of having had anxieties or still having anxiety, but seemed to accept difficulties as a natural part of aging.

Changing these expectations may be difficult. Participant 15 said that he thought people found change more difficult as they get older (15:925-926). Whereas participant 8 said that he believed people who worked hard to recover did not understand their stroke: "I suppose they don't realise what a serious thing a stroke is." (8:443). He added "They can't do anything with a stroke." (8:446-448).

4.5.1   <u>Body failing to work as expected</u>

Impairments that stopped survivors behaving 'normally' were most associated with anxiety. Having their bodies fail to work as they expected was the most frequently mentioned source of anxiety. The extensive impact of the stroke on bodily functioning and the subsequent anxiety evoked is underlined by one participant: "Everything causes me anxiety. Just walking out into the street, walking out into my garden. Everything. Because of my eyesight and hearing… I have trouble dealing with things…"(5:662-665).

Most participants appeared to have the expectation that they wanted and should be able to behave in a more 'normal' way, for example a woman said of her household chores: "I still think I should get it done." (6: 383-384). Similarly, a man spoke of needing others to push him in his wheelchair: "I felt like it shouldn't be happening. I shouldn't be like this." (4:128-129). Another noted: "…not being able to do things as I aught to do. Err err that that that's annoys me." (11:126-127).

Interviewees didn't seem to expect this sort of behaviour from themselves. One participant noted her jobs should take a lot less time and effort: "I think it's unacceptable. I think it is an unacceptably long time to not just because of the length of time its taken me to do that." (1:214-216). Another was amazed at her own experience:

 "Because it's unbelievable…to me … that this would happen and tha' you could actually, you know, go to pick a cup up and want to drink it that way but tip it… into your lap instead." (6: 320-331)

For many, the feeling was one of embarrassment, stupidity and incomprehension at not being able to do something that they think they should (e.g. 2:65-71). Sometimes low

energy levels were also related to not being able to function as normal and as interviewees wanted:

"I'm too tired to do the things that I used to do, you know, like I feel that I can't manage to do like visiting friends after work...and that is not me." (6:454-460)

An interviewee spoke of his frustration at not finding a way to do tasks and still trying even when he realises he will fail. He said, "…I know that something I will never be able to do it and I know that, but I try … I get frustrated but there should be some other way."(15: 950-951,960).

Survivors did not seem to accept their current impaired state as being who they 'really are' and did not feel that they were their 'normal selves'.

"Well just that this feeling of … not being able to do it err… compared with what I was normally do, not just getting up and going about things like dressing."                                                                                                  (11: 117-119)

When asked what he meant by 'normal' an interviewee said:

"Well same as anybody, yourself … if you toss something on the floor you just pick it up and don't even think about keeping your balance or gripping it with your hand err that ..SO YOU MEAN NORMAL FOR SOMEONE WHO HASN'T HAD A STROKE?  Yeah, tha that that's it." (11:133-135)

### 4.5.2 Loss of adult status/ autonomy

Impairments also appeared to evoke anxiety where they reduced a sense of status or autonomy that participants expected. For example, one participant identified the way he felt his wife had taken away his autonomy as a source of anxiety:

"… put it this way, I'm not allowed out on my own and that apparently the wife says is for my safety... the wife stops me.… I am like Number 6. I am a prisoner… I'm a prisoner in my own house… you just lose your independence and everything." (3: 46-48,157-159)

Another interviewee noticed feeling less since her stroke and that it had discouraged her from attending her pre-stroke art group. She said: "… I do still feel a bit inferior shall we say…I feel I can't do simple things they expect me to do." (7: 268,273).

The majority of participants used childlike terms to describe how they reacted to feeling less than adult in status and ability, for example, this participant spoke about how she felt she was treated by others: "I feel like it (*breathes in*) somebody's had their bottom smacked and a clean nappy put on." (7:304-305). These are other typical examples:

"I found a book to follow recipes on there with my finger down running down to make sure I haven't forgotten something or make process like an 11 year old at school learning to cook again." (1:169:171)

"It comes like a little boy the age of 2 or 3 writing so I know that is a problem." (9:428-429)

"It's like learning to walk all over again from when you was a baby." (14:335)

On people watching her health and telling her what to do a woman said:

"I do find that my partner tries to make me sit down and rest when I really feel like I need to get on with stuff but it would just wind up in an argument if I carry on. And I feel, and then I'm like, you know, frustrated … very frustrated… It's horrible…. Frustratingly horrible, the fact that I'm an adult.  You know, I know what's good for me, I know it's like, you know, an' just I feel like people are judging…" (6:405-407,419-424)

Comments about loss of autonomy often related to having the freedom to do what interviewees wanted and expected to be able to do. Expressing his frustration, an interviewee said: "I knew what I wanted – to get out and do things. And I couldn't – I was stuck here" (4:594-595).

4.5.3   Role loss

Similarly participants felt a range of emotions, including anxiety, frustration and guilt related to their loss of role such as spouse, man, mother, father, leader, carer. Several spouses spoke of being frustrated at not being able to undertake the responsibilities and tasks that had been theirs pre-stroke:

"Well, it's awful because it's not my share of our married life. That's what I feel I've lost…. I'm not doing my share of married life." (11:254-256).

"I don't feel, I feel like she shouldn't be doing it. I should be doing more, some of it." (4:219-220)

The male interviewees also linked their role as husband with being a man and commented that being reliant on others stopped them feeling like a man (e.g. 15:823, 828) and that they had to leave their role to their families and carers (e.g. 10:179).

The only mother with younger children living at home described how she felt:

"I felt guilty. I felt guilty that I had had a stroke and you know all their friends' Mums were carrying on as normal as normal – normal. But I couldn't do that for them. I had a, I felt a huge amount of guilt. But it wasn't about me thinking that I brought it on myself. I didn't blame myself for it happening. But it was just the fact that I couldn't do for them." (6: 347-351)

Similarly a daughter spoke of her feelings of responsibility towards her elderly mother: "I get worried because I can't help my mother as much as I should do."(1:725).

Although most participants were working at the time of their stroke most were of retirement age at the time of interview. However, several still felt their loss of social role as a result of their stroke. For example: "I was the unofficial receiver of everybody's secrets, yeah. They all used to come to my house with their grievances… but they think I'm not capable now." (7:598-602).

A participant who had been a leader in his community spoke clearly:

"I've seen so many people. In one time I was ah um leader of the community…I want to be back to normal where I was. I want to go back to the community, talk to them…I want that role back." (9:505, 539-540, 652)

A nurse who had been doing voluntary work before her stroke felt that she had lost her role as carer when she had back problems, but now she can't even communicate with people (12:274-276,282).

However, a loss of role was not always linked with anxiety, for example where a participant was not keen on his jobs (8:102), or where they had become used to having things done for them over years (e.g. participants 10:179 and 14:174).

4.5.4  Not performing as normal in social settings

Most of the social experiences that people mentioned were those within their immediate family. However, encountering the world outside of their homes appeared daunting and to heighten interviewee's sense of anxiety. Most difficulties were expressed in relation to controlling their bodies, which may be due to Western societal expectations. Anxiety sometimes seemed very general for example one man stated: "I'm frightened of the outside world in a great to a great degree, which I think is general across the board." (5:755-756). On the other hand, anxiety was often keenly felt related to specific tasks. One lady expressed views, echoed by others, in feeling embarrassed about making a mess when eating and that had stopped her going out for social meals:

"I refuse to go out on their 'days out at meals' for a long time 'til they impressed on me that we are all in the same boat. She said 'What is the matter? Why won't you go? I said 'I make such a mess, you know, dropping things'. She says, 'we all do. She says, 'we all dribble', you know. And I thought, you know what, yes.

I suppose I do, yeah. So next time I went I kinda looked around and saw that the hesitation in the way they fed themselves and everything and people were actually dribbling a bit…" (7:220-228)

An inability to meet social demands was a problem that caused anxiety for most participants, especially where interviewees felt that they weren't able to be the sociable person that they expected themselves to be. For example, a woman said that social situations made her feel quite anxious and she started thinking, "is it worth going to whatever it is I'm going to?" (1:432-433). Another woman explained, "Just trying to remember somebody's name can also make you anxious." (5:60-61). For example participants commented:

"I'm thinking 'who the hell is this', where the hell, you know. Where do I know, do I know them from here, do I know them from somewhere else. I'm completely floundering, I'm drowning." (1:385-387)

"I can't go out like I did before … I had to sit in the chair, I couldn't socialise…I couldn't mingle, I couldn't talk to people. And the people I wanted to talk to were over there, and I was sat here. I had to wait for people to come to me basically…"(4:412-417)

At times the anxiety became so great that interviewees spoke of withdrawing from social interactions adding to their social isolation: "I used to go out no end. But I don't go out on my own now … I have no friends that come." (2:95-97). Another man

said: "I don't get a lot of response [from people generally] because I don't have a lot to do with people any more." (5:751-752).

Speech impairments exacerbated difficulties. A man with a speech impairment described social situations (such as at the pub and with family) where people talked in front of him as if he was not there (15:673-674). His friends did not sit and talk with him anymore (15:678). He believed that they did not understand what he said (15:695) – he thought that they felt embarrassed about that (15:701).

Low energy levels also interfered with participant's social lives, as one woman explained:

"I see fewer people because … a lot of my friends are working now, so evening time would be the time that we do the most catching up… sometimes being tired I've turned invites down because I don't want people seeing me tired…" (6:470-472,483-484)

## 4.5.5   Perceived negative appraisals by others

The perception that others appraised them negatively interacted with their sense of not being able to meet social expectations. Some of the comments in the previous section have already alluded to this. For example, the comments about feeling discomfort about eating in public and having people judge them negatively because of their impairments. The following comments are representative of the views of the majority of the participants about perceived negative appraisals from others:

"It causes me embarrassment when I go out because I feel out of place.
IN WHAT WAY, OUT OF PLACE?

Just, you just, um. Because you feel changed and I make a mess. I can't eat properly. I know I'm not alone in that. Sometimes this freezes up – left hand - … and when your abilities are cut short in the middle of having meal, when embarrassing things start to happen and it's hard just to think nothing of it, you feel more and more embarrassed and especially if people start pointing things out. 'Look at him, he's spilt his peas'. ….If I'm eating my nose runs and its really embarrassing. I just sss (*sniffs*) now. But I have run out of tissues. …. People think it's disgusting." (5:762-780)

"It's just a vision people there's a lot of people got the vision that when you've had a stroke you become a moron. … Can I say it categorically here and now it's not true." (7:653-655)

Participants who were speech impaired appeared to encounter the attitude that they were mentally deficient more often. One man who was speech impaired said that people in shops sometimes thought he could not understand them and would speak slowly to him: "And then I say I I stroke, not loony." (15:279). Another lady found these experiences more anxiety provoking, especially as she believed her neighbour was ignoring her because she was mentally deficient:

"He doesn't want to speak to me because there is something wrong about me. … That's why he don't want to speak. …There is nothing wrong with me. I understood what being said to me …" (12: 209-210, 213-216)

Her response to this treatment was: "I want to close the door and not communicate with anybody." (12:240).

Some interviewees had impairments that were not immediately evident and perhaps this encouraged those without understanding of strokes to expect them to be more able. One gentleman was troubled by the way he was unable to help his wife carry their shopping to the car at the supermarket. He commented: "I feel that people outside the family think that I should be doing more" (11:307-308). Similarly, a woman said:

"Um, now I have got a little bit of worry with one of my daughter-in-laws. Now she thinks I'm putting it on. Now it's only because she um knows somebody that is got going and got back to work and got herself all going. I said, 'yes, but she might – her stroke might be a different stroke to me'." (14:323-326)

Others felt that family members were frustrated with them because they were not doing more and trying harder to be normal. One man said of his son:

"… He's 23 and he calls me all the names under the sun 'cause he's frustrated….I have to sit here and just take it, and that. Sometimes I go upstairs out of the way but when he starts ranting and raving I can't do anything about it and I don't think he can see that. You know he said you're sat there when I get up, you're sat there when I go to bed, you're sat there … and I said, well I can't do anything else, you know." (4:464-471)

## 4.6 Resources

Participants mentioned resources that appeared to influence their anxiety. Often a lack of these resources, or difficulties accessing them, seemed to increase anxiety levels. On the other hand some interviewees who were asked about these resources

expressed no anxiety associated to them because they had good access to them or had found an alternative means to cope. The following are the categories of resources identified by interviewees.

### 4.6.1  Carers

Interviewees who had carers who solved problems for them and compensated for their impairments often spoke of appreciating this for example one woman said she had "… tremendous help from my family." (7:137). Another well-supported man stated "You need support…. This desperate situation people need help from the family, from his friends or like…" (9:77,771).

As has already been noted a number of interviewees spoke of difficulties that they associated with anxiety related to getting the care they wanted or needed. In addition there were reports of survivors losing partners as a result of the pressures of caring and this is likely to have severely increased anxiety levels (4:441-447; 5:427-430).

### 4.6.2  Material/ financial

Material resources, especially finances, were associated with anxiety for a variety of reasons, such as getting benefits because "…it's just too much of a nightmare, you know, trying to fill all this paper work in. " (6:588-589). The need for help was identified by another participant: "I couldn't have managed [finances] without help" (7:465).

For others, debt had become a source of anxiety for example:

"Yeah, because I'm back at work, but I'm only back part time so I do worry. But I've tended to like bury my own head a bit where finances are concerned 'cause nothing – and I have run up a very large credit card." (6:217-219)

"Well you've seen the 'For Sale' sign, didn't you? That's how worrying it's getting you know." (5:474-475)

### 4.6.3   Information

Information seemed to be important to participants. Many wanted to know what had happened to them, what functional damage had been done and how this might affect them. They voiced frustration at not getting information (e.g.2:224). This participant reflected the views of many when he said: "Now I want to know what happened to me." (15:1036). Participant 5 explained:

"... it might just be the fact that you don't understand and that can be a very big thing… I need to know why but nobody can explain to me why because they don't know… Explanation can be a great thing. And if someone takes time to explain something to you and gives you a reason why, that helps. It might not help you stand up, but it squares things away in your mind."

(5:81-82, 101-102, 118-120)

Interviewees also wanted information to help them manage their impairments, for example, participant 4 spoke at length about needing information, such as the accessibility to premises, in order to plan outings (4:146-147).

### 4.6.4   Personal

Interviewees mentioned humour and the ability to laugh at things was a positive thing, one lady felt strongly that it had kept her going (7:181-182, 7:189, 7:717). Almost half of the participants mentioned having a sense of humour and being able to laugh at

things as something they valued and enjoyed (e.g. 1:759,828-830; 4:570; 12:37; 15:574). Humour was something that some people mentioned as a personal quality they possessed that enabled them to think in a positive way about their situation. Whereas others spoke of people with whom they shared humorous interactions.

### 4.6.5  Stroke Club

Humour was also identified as a valuable aspect of Stroke Club which one man said was the "best day of the week…we can laugh and joke ourselves" (15:572-573, 574). Stroke Clubs were unanimously described as a positive resource by all participants. Interviewees found a source of support that could only be offered by others who had experienced strokes. One woman reflected the views of many when she said:

> "It's great how sitting there and having a natter with people who have got the same problems…when you failed something and it's brilliant to be able to share it… Understanding because it's happened to them as well…it's great to share disappointments as well as achievements."(1:880-881, 892, 897, 902 )

# 5. DISCUSSION

## 5.1 Summary of results

The current study explored phenomena participants associated with their anxiety. All but one participant had experienced their stroke over two years prior to interview. They had completed rehabilitation treatment and returned home to the activities of daily living. Not every participant was experiencing anxiety at the time of interview, as other research shows: "…a large proportion of stroke survivors adjusts well and reports few, if any, emotional problems." (Gangstad et al., 2009).

The participants described things they found anxiety inducing, which seemed to fall into one of three categories:

1.) comparing and judging themselves negatively compared to their pre-stroke selves and failing to meet their expectations

2.) vulnerability

3.) dependence

Related to these themes were a number of resources that interviewees mentioned as being important to them because these factors could increase or decrease anxiety levels. Amongst the themes was: access to care, finances, personal qualities, information and support from Stroke Clubs. Having a sense of humour and being able to laugh with others was also felt by participants to be important. This may provide evidence that participants were less likely to be exhibiting depression as anhedonia has been identified as a marker of depression (Beck et al., 2003; Watson et al., 1988).

## 5.2 Vulnerability and dependence

Participants indicated that they experienced anxiety associated with issues of vulnerability and dependence. These results have been supported by research into anxiety and disabilities, chronic illness and acquired brain injuries, although the issues

have not been categorised in the same way. Research suggests that people who experience impairments often experience stressors more than those without disabilities (Bramston & Fogerty, 2000) and the stress tends to be disability related and chronic (Noonan et al., 2004; Turk & Monarch, 2002; Yorkston et al., 2003). In particular, anxiety is multifaceted and related to factors that fall into the categories of: physical (Jarama & Belgrave, 2002), social (Bramston & Fogerty, 2000), psychological (e.g. self-esteem; Janssen et al., 2002), economic (Ward, 2003) and discrimination (Noonan et al., 2004). Research concurs that reduced levels of independence and coping with 'usual' daily living activities appears to be linked with increased anxiety levels (Barker-Collo, 2007; Leppävuori et al., 2003; Masskulpan et al., 2008; Schröder et al., 2007; Shimoda & Robinson, 1998).

In particular, qualitative research by Iwasaki & Mactavish (2005) into stress amongst people with disabilities found very similar results to the current study, perhaps because they also looked at an aspect of negative affect. They suggest that stress is a cumulative phenomenon relating to aspects of daily life. They described causes of stress that included living with the added daily demands and complications of disability (effort, time, care required etc), health, interpersonal relationships, and the inability to meet expectations. Furthermore, environmental causes of stress included: exclusionary social systems and structures, physical accessibility, and economic marginality.

Specific issues raised by the current study were identified by other studies, although not in relation to anxiety. For example, difficulty getting financial help, limited physical accessibility of places/ things, getting carers to do things as and when wanted, and not being able to drive or go out where and when they want, and being able to engage in everyday activities how and when they wanted (e.g. Ch'Ng et al., 2008; Kuroda et al., 2006).

## 5.3 Not meeting expectations

Participants in the current study frequently associated their anxiety with their inability to meet expectations (sometimes their own and sometimes more general social expectations). These expectations seem to have been based in pre-morbid identity and experiences. Similar findings have been identified by research into the experiences of people with impairments, acquired brain injury and stroke survivors (Becker, 1993; Ch'Ng et al., 2008; Ellis-Hill et al., 2000; Iwasaki & Mactavish, 2005; Kirekevold, 2002; Mumma, 1986; White & Johnstone, 2000).

For example, Iwasaki & Mactavish (2005) found that people with disabilities commonly described the inability to fulfil perceived social expectations as a source of anxiety (Iwasaki & Mactavish, 2005). Furthermore, they noted that people who have acquired brain injuries and impairments have disability related difficulties that frequently led to "…the perceived inability to meet expectations, which in turn, became another source of stress in the participant's lives." (Iwasaki & Mactavish, 2005,p.201). These expectations seemed to be based on their pre-morbid experiences and beliefs. Indeed research into quality of life has shown that both anxiety and 'comparing' have been more closely linked with quality of life post-stroke than physical ability (Frühwald et al., 2001; Masskulpan et al., 2008; Olatunji et al., 2007; Wyller & Kirkevold, 1999).

## 5.4 Adjusting

Research claims that most stroke survivors adjust to discontinuity and failure over the first year post-stroke, and redefine themselves and develop a new concept of 'normal' (Becker & Kaufman, 1988-1995). However, results from the current, and previous studies (such as Ch'Ng et al, 2008; Ellis-Hill & Horn, 2000; Ellis-Hill et al., 2000; Kirkevold, 2002), show that survivors continue to compare themselves and hold

expectations related to their pre-stroke self over a prolonged period. The current study suggests this 'comparing' may be associated with anxiety.

Adjusting may have been important to participants in the current study because those interviewees who claimed to experience little anxiety spoke of having had more anxiety in the past and having come to accept their limitations over time for example: "I realise I can't do these things and just come to accept things more… You accept things and that's it." (8:343,458).

Similarly, Ch'Ng and colleagues (2008) found a number of their participants emphasized that reaching a sense of acceptance of their stroke and impairments meant moving beyond the struggle with and dominant thought of 'I need to get back to normal'. They felt that the realisation that hope and determination were not sufficient to achieve a full recovery, and that they had to accept a lack of control over their lives and a greater sense of mortality, was needed to adjust. Kirkevold (2002) also noted that adjusting to a new 'normal' self, and addressing discrepancies between rehabilitation outcomes and recovery expectations, were critical issues. These adjustments appear to be slow, with a gradual realisation of the extent of the change faced and difficulties of daily living (Ch'Ng et al., 2008).

### 5.5 Cognitive-behavioural approaches

Cognitive-behavioural approaches have a well established history in facilitating the understanding and effective treatment of anxiety (Brewin, 1996; Chambless, & Gillis 1993, Dobson, 1989; Hollon et al., 1993). The three themes identified in the current study (i.e. expectations about themselves, dependence, and vulnerability) provide evidence of cognitions that have been implicated in increased anxiety levels by cognitive-behavioural researchers (e.g. Brewin, 1996; Beck & Clark, 1988).

From a cognitive-behavioural perspective, post-stroke anxiety could be understood as being the result of stroke survivor learning that they are more vulnerable than they had previously thought through the life-threatening experience of stroke. As a result, survivors may be more sensitive to perceiving physical and psychological threats to the self as well as having an exaggerated sense of vulnerability (Beck & Clark, 1988).

Furthermore, schema post-stroke seem to include thoughts such as "I ought to be the way I was before my stroke" and "If I try hard enough I will return to my pre-stroke state". Once these have been acquired then situations that remind people of their stroke-related negative changes may feel threatening and trigger negative emotions. Attention may be focused on these events and behaviours then maintain them (Clark, 2003). In Figure C3 Clark's (1986) model has been adapted to present such a cognitive-behavioural pattern.

Cognitive-behavioural research shows that anxiety may be related to discrepancies between the "actual self" and the "ought self", whereas depression may be related to discrepancies between "actual self" and "ideal self" (Brewin, 1996; Higgins et al., 1985). The current study suggests that the experience of stroke challenges the sense of self-identity because survivors are often no longer able to be the person they had always believed they were (e.g. able-bodied, capable, socially acceptable, independent etc). Survivors described ideas that they "ought" or expected to be the person they were pre-stroke or to behave in a way that others expected but could not achieve this on many occasions. Consequently, there was a change in their "actual self" that was predominantly negative and required adjustment. There was often a significant deficit between their new "actual self" and pre-stroke "ought self". In addition, they were likely to have been further from being their ideal self, leaving them vulnerable to cognitions that have been related to depression.

In summary, stroke survivors may be more vulnerable to both anxiety and depression post-stroke for a number of reasons. Firstly, they experience serious threats to their physical and psychological self. Secondly, they have to adjust concepts of self, often to a more negative self concept (Ellis-Hill & Horn, 2000; Field et al., 2008). Thirdly, they are likely to have significant discrepancies between their pre-stroke sense of self, how they used to feel they "ought" to be, and their post-stroke experience of themselves. Finally, post-stroke experiences of self are likely to fall short of how they would ideally like to be based their pre-stroke cognitions and expectations.

The need to process and work through cognitive and emotional disturbances created by distressing or traumatic experiences has long been understood (Brewin, 1996; Parkes, 1971; Rachman, 1990). Working through the experiences of trauma and distress has been found to heighten arousal in itself, resulting in initial denial, then alternating between acceptance of changes and attempts to block them out (Brewin, 1996). Eventually, a person integrates their new information into their cognitive models. Delayed adjustment and prolonged comparing with pre-stroke self may be affected by unique aspects of the pathway of post-stroke rehabilitation that usually involves an unclear prognosis, resulting in vague expectations given by professionals and slow and gradual  rehabilitation (Becker, 1993; Becker & Kaufman, 1995; Ch'Ng et al., 2008; Kirkevold, 2002). Ch'Ng and colleagues (2008) found that this lack of prognosis has been a major contributor to anxiety and distress. Survivors are left with a sense that they can rehabilitate and are not told that they will not return to their pre-stroke state (Ch'Ng et al., 2008; Kirkevold, 2002). Whilst treatment is being given, survivors may still have hope that things will improve and so not adjust their cognitions. After treatment has ended and they return to their daily lives, they find that they cannot return to their previous lives because of impairments.

**Figure C3:**
**Cognitive-behavioural model of post-stroke anxiety**

Pre-stroke experiences/ beliefs:
Role, ability, competence, self-efficacy, invulnerability, autonomy, adult status,
freedom

↓

Stroke:
Impairment of physical self, changes in cognitions, perceptions

↓

Post-stroke experiences:
Change/ loss of role, socially less conforming, loss of self, social isolation, increased
vulnerability

↓

Triggers:
When others do things for me• When I fail / don't do as I think I should

Behaviours:
Try harder to behave
like pre-stroke self
but failing
•Avoidance of
situation•
Withdrawing from
others

Feelings:
Anxiety/ cognitive
dissonance/ Fear
(experiencing threat
to self), frustration,
anger, embarrassment

Thoughts:
•I failed  •I should /
ought to do better • I
don't understand why
I cannot do this • This
is not me

Perceived views of others: •I am embarrassing • I am mentally incapable •There is

nothing wrong with me because I look normal so I should be doing more

Some survivors may continue to undertake rehabilitation on their own for some time and hope ability will improve, resulting in a number of people experiencing anger, frustration and anxiety, and struggling to accept not being able to 'get back to normal' for years after their stroke (Ch'Ng et al., 2008). Exacerbating this situation may be a survivor's and carer's often unrealistic expectations of a speedy and full recovery, and a poor acceptance of having had a stroke (Ch'Ng et al., 2008; White & Johnstone, 2000). As a result research indicates that people often leave treatment seeking a way to function as they did before and consequently are unable to incorporate their stroke disability into their future lives (White & Johnstone, 2000).

Adjustment may be further delayed and anxiety induced because of memory difficulties. Most of the interviewees in the current study experienced memory problems and this is supported by other research (Hanger et al., 1998; Lincoln & Tyson, 1989). The reference point for memory of the self may be in pre-stroke memories if acquiring post-stroke memory is poor. Thus, the process of creating new memories on which to build a new self-concept and more adaptive schema may be hindered, leaving a discrepancy between pre- and post- impairment self-image. Such difficulties have been noted in relation to impairments caused by brain injuries and encephalitis (Bachna et al., 1998; Conway, 2005; Dewar & Gracey, 2007; Nochi, 1998).

A further reason to avoid adjustment is that it involves an acceptance that one may not be able to return to a pre-stroke life. This involves letting go of the two components that have been theorised as constituting hope (Kennedy et al., 2009). These components being: the positive perception that one has the ability to initiate and maintain actions necessary to achieve a goal, and a belief in one's ability to generate paths to one's goals (Kennedy et al., 2009). Together they are thought to provide a positive motivational state that is associated with better rehabilitation outcomes (e.g. for

burn survivors; Barnum et al., 1998; and fibromyalgia; Affleck & Tennen, 1996). Thus to relinquish the belief that one is not able to attain the goal of pre-stroke normality, nor is there a way for one to do so, is to reduce hope and undermine motivation for rehabilitation. Therefore, adjustment may increase survivors vulnerability to depression.

**5.6 Depression**

A large number of the participants (8) were identified as experiencing high levels of depression, consequently, it is possible that this may have influenced the data. This may have been encouraged by the interview schedule that, whilst focussing on anxiety, included questions about more general negative affect. However, the Principle Researcher did not assess these accounts as being the result of depression, nor did she witness anhedonia but saw great determination, and sense of humour in participants.

Similarly, participant accounts of feeling lower in status seemed a realistic description of their experiences, rather than a depressive symptom of lowered self-esteem. Despite this, depression may have influenced participant low energy levels, slowed physical and cognitive functioning, forgetfulness and reduced mobility.

**5.7 Adaptive anxiety**

Having proposed models to explain why people may experience anxiety post-stroke it is worth noting that anxiety can be a positive influence, which can help a person protect themselves from harm. It also helps to identify where a person is being treated in a way that is less than they merit as an adult. It can act as a warning that change is necessary because emotions and internal or external demands are becoming overwhelming (Watson & Sinha,2008). Furthermore comparing self with others can be a helpful strategy as it may encourage normalising. Several participants noted that there were those who are worse affected by stroke or younger than them which made them feel more fortunate for example one woman said:

"I can't complain about my stroke. There's other people that have had them before… There's a lot younger than me as well… A lot of people can't talk. And I think that's a terrible…" (2:304-305,336, 391)

## 5.8 Strengths and limitations of the study

A key strength of this study is that it seeks the views of stroke survivors about their anxiety. As such it makes an important and unique contribution to this area of research. The use of grounded theory methodology has facilitated the creative analysis of data and use of psychological theory to propose a new way of understanding post-stroke anxiety. This is also a rigorous qualitative study with multiple quality checks based on the principles of transparency and systematicity and other techniques to establish rigour at each stage of the research (Meyrick, 2006; Appendix XII).

The sample is small which inevitably reduces the potential to generalise the results. The participants may also not be representative of all people who have strokes as they were recruited from Stroke Clubs. Some people especially those with minor strokes, may not have joined the clubs as they may not have wanted support. Others may have been unable to attend clubs due to the severity of their impairments or high levels of anxiety.

The exclusion criteria were minimal, participants self-selected, with 15 of the 50 participant packs being returned. People with greater cognitive impairments may have found the questionnaires and the thought of being interviewed too daunting to engage with the study, or may have forgotten to return the packs. Cognitive difficulties may also have hindered the interviewees from giving responses on a more abstract level. Furthermore some of the participants spoke of finding the questionnaires difficult to read and tiring to complete, so others may have been discouraged from, or unable to, complete the forms.

Finally anxiety is difficult to conceptualise, define and identify. This necessitated the taking of a critical-realist stance in which anxiety was assumed to exist as an objective reality and defined to the participants to give them an approximation of the meaning of the concept. In order to support participant attempts to conceptualise "anxiety", both aspects that characterise anxiety, as well as more general ideas relating to negative affect, were included. This increased the likelihood of data being influenced by experiences other than anxiety and especially depression.

It was also difficult to ascertain how much participants understood the definition of anxiety given to them at the beginning of the interview (see Appendix XXII). Regardless of participant understanding of the aims of the study, it is possible that they used the interviews as an opportunity to talk to someone about their experiences rather than to answer the interviewer's questions. Further exploration of the participants' understanding of the meaning of 'anxiety' may have been useful. In addition, a focus on negative affect may have reduced a potentially artificial distinction between anxiety and depression.

## 6. CLINICAL IMPLICATIONS

The wide prevalence and negative impact of post-stroke anxiety necessitates its identification and treatment. The experience of anxiety over a prolonged period post-stroke suggests that ongoing access to interventions is needed and not only in the early stages of rehabilitation.

Importantly, the impact of impairments needs to be considered and treated in context because it is not the impairment in itself that is associated with anxiety. For example, people with speech impairments may not need speech and language therapy alone, but also support to maintain social networks and encouragement to engage with

others. The tendency seems to be for many to become reluctant to go outside of the home (Ellis-Hill et al., 2000; Pringle et al., 2008). Furthermore, meanings about the body may be socially defined and impairments need to be related to their meaning in the context of individual survivors (Ellis-Hill, et al., 2000).

The interviewees mentioned the need to target specific difficulties that continue to negatively impact on them years after their strokes. For example managing lower energy levels, accessing funds and information about their impairments and how they might continue to rehabilitate after treatment has ended. As coping with everyday living was associated with anxiety, survivors' mental health may benefit from a functional assessment. Further help may come from cognitive as well as physical rehabilitation, encouragement, ongoing support, pacing, managing lower energy levels, help with problem solving, support in adjustment, and information about their limitations to help them understand and explain to others.

On a practical level coping skills such as relaxation and a sense of humour and the ability to laugh at things may also be beneficial (Ch'Ng et al., 2008). In addition ameliorating transport difficulties may decrease the sense of loss of freedom and increase a sense of independence. Where possible a return to driving may be most helpful (Ch'Ng et al., 2008). This would facilitate any interventions that support activity. Financial difficulties may also be eased by ensuring survivors know sources of help and have an advocate available to address problems as they arise.

Socially, anxiety in relationship conflict was an issue raised by some participants. These may need addressing; especially where there is a high level of dependency on a carer, there are communication difficulties or a need to build a new social network.

Initially survivors may benefit from help with managing prognostic uncertainty and maintaining rehabilitation motivation. However, unrealistic expectations and delaying the realisation of the long-term nature of some impairments may be a protective factor that sustains hope, preventing an individual becoming overwhelmed by anxieties and maintains motivation to rehabilitate (Kirkevold, 2002). Therefore it may be destructive to undertake this cognitive work too soon. Survivors may benefit from periodical assessments to establish whether rehabilitation has continued and whether ability levels have stabilised. Over time people may find it more helpful to receive support with cognitive positive reinterpretation (which has been linked with positive mood states), problem solving (especially building on strengths to compensate for weaknesses) and help with bereavement (Ch'Ng et al., 2008).

Adjustment could be facilitated by supporting survivors with the challenge of developing a new daily structure, adjusting to changing valued activities and generally integrating the stroke into the life of the individual. This is likely to involve reflecting on life, finding new meanings for oneself and ones life, and finding a new sense of 'normality' than was held pre-stroke (Kirkevold, 2002).

Ultimately post-stroke adjustment seems to require adapting self-concepts, incorporating stroke and its consequences into post-stroke identity, making life changes, accepting lost abilities, and managing emotional distress. A multifaceted approach such as those used in therapies using cognitive-behavioural approaches seem most appropriate to begin to address such a wide range of issues, especially to facilitate cognitive adjustment.

# 7. FUTURE RESEARCH

As there is so little research in the area of post-stroke anxiety and this is the first study of this kind known to the author, there is a great deal of scope for further research. For example, future research could explore the participants not included in this study, particularly those not attending Stroke clubs.

Given difficulties with the complexity of the concept of anxiety, further qualitative studies may be useful from a more social constructionist perspective that explores participants' views and understanding of anxiety. Research could also focus more narrowly on anxiety or look at combined depression and anxiety.

Survivors in the current study also indicated that there were a number of resources that had an impact on their levels of anxiety. These factors could be explored directly and further. It may be particularly interesting to test whether changing aspects of the post-stroke rehabilitation pathway could reduce the prolonged difficulties in adjusting.

# 8. CONCLUSION

The current study represents qualitative research that utilised a grounded theory methodology to ascertain the phenomena that stroke survivors associated with their post-stroke anxiety. The findings suggest that issues of vulnerability, dependence and not meeting expectations, alongside difficulties in adjusting post-stroke self-concepts, are associated with post-stroke anxiety. The findings of the current study are supported by research into strokes, chronic illness, and acquired brain injury.

A cognitive-behavioural approach could be applied to the current results to explain post-stroke anxiety as a consequence of discrepancies between cognitions about the self based on pre-stroke experiences and post-stroke experiences and the difficulties being the person they believe they "ought" to be. These cognitions may be particularly difficult to adjust due to the unique nature of the post-stroke rehabilitation pathway. In particular the way it usually involves an unclear prognosis, resulting in vague expectations given by professionals, and slow and gradual rehabilitation. As a result survivors may be left with an unresolved sense of identity post-stroke that may be combined with a hope of returning to a pre-stroke state.

The clinical implications include the need for long-term periodic assessments of physical and psychological changes that understand the meanings survivors attribute to factors in their own contexts. When survivors are ready to accept support they may benefit from help with cognitive reinterpretation, especially adjusting self-concepts and their meaning of 'normality'.

As this is an exploratory study, and the first of its kind in this area, these proposals are made with caution. The Principle Researcher hopes that this work will promote further research in this area and facilitate understanding of stroke survivors an improvement in their care.

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# SECTION D


# CRITICAL APPRAISAL

## 1. Choice of research topic

Clinical psychology was not my first career as I had previously been a teacher and social worker. In the latter profession I worked for a time with older people, many of whom were stroke survivors. I was surprised how little treatment was available to them and how a few had worked very hard to regain ability. One lady made a particular impact on me. She spoke of having taught herself to talk again over the five years since her stroke. I had not realised that recovery could continue over such a long period. I was also struck by how many people had to go into care and lost their homes and independence following a stroke. Unsurprisingly, I encountered many people experiencing low mood and having a sense of hopelessness.

In training I met a tutor who had also worked with stroke survivors, which was sufficient to encourage me to undertake this study. On investigating the research into post-stroke mood disorders I found a large amount of research into post-stroke depression, but very little into post-stroke anxiety. This appeared a substantial gap in knowledge and a worthwhile area for research.

## 2. Choice of methodology

Firstly, the lack of research in this area suggested that an exploratory investigation would be appropriate. In addition, no research had asked survivors what they associated with their anxiety, suggesting a qualitative methodology based on clients actual experiences would be a good place to start. Grounded theory was chosen because it is a proven method for abstracting theory from experience (Glaser & Strauss, 1967) and provides a richer understanding of data than a quantitative measure (Henwood & Pidgeon, 1992).

Secondly, I was keen to learn qualitative research skills as part of my clinical training because I had never used such an approach to research before.

## 3. Epistemological Stance

Identifying my epistemological stance was a process that necessitated a degree of pragmatism as I saw the merits of each position, from positivism to constructivism. Initially I thought that I would take a constructionist approach, considering that reality is socially constructed. However, the subject of anxiety is difficult to define and the study could easily have become an exploration of what participants considered anxiety to be. This may be a useful exercise but my aim was to explore what survivors associated with their anxiety. In addition the measure that clinicians currently use is an objective, diagnostic measure (DSM-IV, APA, 2000) for anxiety that was also used by quantitative research. If I wanted to explore factors associated with anxiety and engage with existing research, then it seemed pragmatic to take the definition of anxiety as one given in the DSM-IV. Consequently, I found myself taking a post-positivist stance known as critical realism that recognised that complete objectivity is unattainable because of the impact of the views of the researcher and interviewees on the study. However, this approach seeks to identify influences on the research in order to achieve a degree of partial objectivity. Thus the study is a product of participants' views, my views and biases, and my interpretation of the data.

## 4. Ethics, Research Governance and Participants

Ethical and Research Governance approval was straightforward because the participants were not patients and were not recruited through the NHS.

Stroke Clubs and their members were welcoming and very willing to support the study. People in the Clubs were keen to talk to me on my initial visit to introduce myself and the study. The questionnaires may have discouraged some from participating, especially if they had difficulty reading and had low energy levels.

Fifteen people volunteered, which made theoretical sampling more difficult as I did not have a large bank of volunteers to choose between. However, I was able to arrange interviews as I went along in an order that enabled me to begin to explore some ideas. The number of interviews was more than I originally intended and thought I had time to analyse, but I interviewed them all out of respect for the volunteers. Once I had the data I managed to find time to analyse it all. On reflection, this was too much data to analyse in the time available in addition to the other demands of clinical training (such as placements and lectures). The data was particularly rich because of the relatively wide range of differences between participants for example in ages, marital status, cultural background and impairments experienced.

## 5. Interviewing

I followed Charmaz's (2006) interview schedule format that began with a few easy structured questions to help people become more comfortable and put them at ease before giving open unstructured questions. Initially I sought to give interviewees the opportunity to speak freely about their experiences but quickly found that they struggled for a combination of reasons. Often an interviewee would forget what they were saying, or wanted to say, due to memory impairments. I also noticed most participants seeming to struggle to talk about more abstract thoughts.

Using the interview schedule I was able to keep track of whether we had addressed the main areas I wanted to explore, whilst participants spoke about things of interest to them. I added questions to the interview schedule and to my journal to remind myself about things I wished to explore further with the next interviewee. The process was therefore one of evolving enquiry.

At times participants expressed concerns or distress which I wanted to respond to in a therapeutic way. Mostly I resisted doing this, but occasionally I offered words of

encouragement or information that I realised were not part of the interviewing process. I realised that I am not naturally an interviewer because I struggle not to respond to the distress of individuals when it is unnecessary and I can help to alleviate it. I stayed with most of the participants after the interview to check that they were alright.

The majority of interviewees said that they had not thought through these issues before and expressed thanks for having the opportunity to talk about them. I also had the chance to give a little information or encouragement that might have been helpful.

I realised that it was only at the end of my interviews that I understood what I wanted to know about the subject and would have liked a further fifteen interviews to continue to develop ideas. This was not possible in the time available. In addition, I think that completing more interviews than I had intended was at the cost of having less time to analyse data and write up the report.

On reflection, I also considered the perspective that anxiety may serve a positive purpose and that this had not been explored by this study. For example, anxiety may have motivated participants to rehabilitate, challenge oppression and seek help.

## 6. Analysis and write up

I endeavoured to analyse data as I went along. Where I felt that a transcript needed further analysis before the next interview, but I lacked time, then I always listened to and made notes on the previous interview again before the next. It quickly became apparent that I needed some help with transcribing, but I completed the majority myself. As part of quality control measures, peers coded sections of data to check the reliability of my coding. Peers and supervisors also looked at examples of coding in order to check for bias.

I was aware that the first interviews had a greater impact on me than many subsequent. I was careful to keep checking all transcripts for evidence of themes and categories as they developed.

I was not accustomed to a grounded theory approach and learned the methodology for this study. It was a steep learning curve in which I made many mistakes that required me to frequently return to data and recode and re-analyse it.

I have found that data analysis is a process in which one needs to be immersed and distractions are extremely unhelpful. This process was hindered by a serious illness that I experienced in the middle of analysis which was a significant distraction.

Grounded theory also demands a great deal of time to code and recode data. I realised that this is not possible to do as extensively as possible in the time available in addition to other training demands. I felt that data analysis would be done best in a team to generate more ideas and reduce the influence of individual bias.

## 7. Supervision

Supervision was essential because insight can be hard to gain when immersed in the data. Supervision also kept me motivated through the long and extensive process of coding, comparing and recoding data. In addition I received supervision from a person experienced in the use of grounded theory, who taught me about the methodology and helped me to be consistent in my use of the model.

Supervision prompted me to think ideas through more thoroughly and challenged my theories, encouraging me to reflect further on my analysis. It was a process that helped me to better understand myself and my strengths and weaknesses as I reflected on the process I was undergoing and received feedback on my reflections. For example, I had previously thought myself more of a quantitative researcher because I appreciate and enjoy the clarity of statistical findings. However, in supervision I found

myself being extremely enthusiastic about the creative opportunities afforded by qualitative research.

## 8. Progress and time-scale

My research had to be rescheduled due to unforeseen problems (see chronology Appendix XXV). I was encouraged by gaining ethical permission to proceed with the study in good time. This allowed me to begin the research early in my training, allowing plenty of time to analyse transcripts between interviews. Unfortunately time was lost trying to make transcribing more manageable by having to wait to acquire equipment to facilitate typing. I also lost over a month through illness and health worries that took priority over my training.

Despite this, through being able to dedicate large chunks of time to research, much of this time was reclaimed, but the pressures may have negatively influenced how I perceived the research experience.

## 9. Reflexivity

On reflection, I cannot decide whether this was a research method that suits my temperament. I valued the rich data that allowed creativity and exploration of ideas. I felt positive about enabling the participants' voices to be heard and develop theories that seemed relevant to them. On the other hand, I struggled with the time consuming coding and recoding and returning continually to previously analysed transcripts.

Practical issues also impinged on the research process as limited working and storage space required transcripts to be laid out and put away so they didn't interfere with my family life. These matters reduced my enjoyment of the research, whereas quantitative methodology allows data to be reduced to statistical data that can be relatively quickly analysed and then reflected on.

Although reflective practice has been an important part of training and all of my professions, this study has demanded more patience and reflection than I believed myself capable of. I think that I developed my capacity to be reflective through this study. My most productive periods of reflection were a result of supervision meetings. In some ways the amount of absorption in the data and repeated reflection on it felt too luxurious to spend so much time in this necessary activity when there is so much else which also requires reflection during training, for example placement matters. As a result I felt that this methodological approach could be intrusive into other areas of life. I would want to carefully choose the timing of such research when I undertake it again in the light of limited human, time and finance resources.

## 10. Development of research knowledge and practice

I was surprised by the outcome of the study. I had expected ideas about loss and grief and this was supported by some of the data. I stuck with this theory quite a long time because of my expectations. It was only about half way through my participants that I realised that most of the interviewees were highly motivated and still working to live the life that they wanted without a sense of loss.

The later interviews became more focussed and I asked more questions to explore theories. The final interviews gave me some opportunities to test theories with interviewees, with some unexpected outcomes. For example, interviewee eight was asked why he thought some survivors were very motivated to rehabilitate. I had thought of such drive and motivation as being a positive thing and had admired it. He responded that they were behaving in this way because they did not understand the real consequences of stroke – his was a negative view. This reinforced for me what a powerful methodology I was using as it gave participants the opportunity to bring completely fresh ideas to the data.

Only after analysing the data did I look at qualitative studies related to post-stroke experiences. I was encouraged to read quotes from participants in other studies similar to those in this one. It also gave me an opportunity to reflect on other ideas and return to my own with fresh ideas of theories that might be relevant to my results.

I have learned participant interviewing skills for research which I found different from interviewing clients. I had never undertaken qualitative research before and learned a great deal about the methodology. I have more confidence to use it again in the future and think that this will be as useful as quantitative methodology in my professional life and I am more aware of what to use it for.

## 11. Summary

In summary, I learned a great deal from participants, not just about post-stroke experiences and anxiety, but also about my prior assumptions. I gained greater respect and understanding for stroke survivors. I developed my skills in research interviewing and qualitative approaches. I learned about my limitations in how much work I can accommodate and how I have greater capacity to reflect than I had anticipated.

I am encouraged to engage in further research as I have found this a rewarding experience, but would do so with a greater awareness of how this needs to be managed within the limited human, time and financial resources.

# 12. REFERENCES

American Psychiatric Association (APA)(2000). *Diagnostic and statistical manual of mental disorders* (4th rev. ed.). Washington, DC: American Psychiatric Press.

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Glaser, B.G., & Strauss, A.L. (1967). *The discovery of grounded theory*. Chicago: Aldine.

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# SECTION E


# APPENDICES

# Appendix I

## BPS Journal requirements

The British Psychological Society gives submission guidelines for authors at: http://www.bps.org.uk/publications/submission-guuidelines/submission-guidelines_home.cfm. There are two publication submission guidelines. The first is for the submission of research journals that requires APA format and authors are referred to APA manuals for further guidelines.

The second guidelines are for all other publications and are published in a 70 page handbook available at the above website.

**Table E1:**
**Summary of previous reviews**

| Reviews | Aims | Conclusions |
|---|---|---|
| House, 1987 | Review of general mood disorders following a stroke. Focused on issues that had been the subject of recent research into psychiatric disorders post-stroke. Little mention was made of anxiety and mainly discussed depression.<br>The aim was not to review prevalence data. | Not applicable |
| Johnson, 1991 | Review of general psychiatric disorders post-stroke. Focus on post-stroke depression. Mentions anxiety and the lack of research.<br>The aim was not to review prevalence data. | |
| Bishop & Pet, 1995 | Review of general psychiatric symptoms, syndromes, psychosocial and behavioural problems post-stroke other than depression. It considers the functional impact on survivors of these issues along with diagnostic and treatment issues. The aim was not to review prevalence data. | Not applicable |
| Ghika-Schmid & Bogousslavsky, 1997 | Review of general affective disorders post-stroke. Aimed to identify studies into lesion location as a cause of post-stroke affective disorders.<br>The focus was psychiatric and described affective symptoms and how they might effect neurological recovery.<br>The aim was not to review prevalence data. | Not applicable |
| Chemerinski & Robinson, 2000 | Aimed to consider the neuropsychiatry of stroke. It looked at the clinical and pathological correlates and epidemiology of affective disorders.<br>The aim was not to review prevalence data. | Psychiatric disorders inhibit recovery and limit quality of life. |

| Robinson, 1997 | Describes general post-stroke emotional and behavioural disorders.<br>Not aiming to rigorously review prevalence data. | Identified 2 papers to provide prevalence data (Castillo et al., 1993,1995) |
|---|---|---|
| Robinson 2002 | Provides information for the psychiatric management of stroke. Focuses on depression.<br>Not aiming to rigorously review prevalence data. | Identified 2 papers to provide prevalence data (Castillo et al., 1993 & Åström, 1996). |
| Robinson 2006 | Aimed to describe general post-stroke psychiatric symptoms in order to facilitate the diagnosis and treatment of affective disorders. The aim was not to review the prevalence data. | |
| Tedstone & Tarrier, 2003 | Aimed to review PTSD as a result of physical illness and its treatment. Stroke-related PTSD formed part of this review.<br>Aimed to identify prevalence rates for PTSD, intrusive and avoidance symptoms, predictive and associated factors and consequences of PTSD on healthcare utilization and outcome. | Prevalence rates were highest for patients treated in intensive care units and those with HIV infection. Post-traumatic symptomatology was more common than PTSD caseness across all physical illnesses.<br><br>Only one study (Sembi et al., 1998) was reviewed in relation to post-stroke PTSD. |

**Table E2:**
**Databases, search criteria and number of results**

| Search words | PsychINFO | Scopus | Medline | Web of Science |
|---|---|---|---|---|
| Anxiety disorder, PTSD, post-traumatic stress, GAD, panic, phobia, agoraphobia, and stroke, Cerebrovascular, ischemia, TIA, brain haemorrhage, Not dementia | 296 | 711 | 205 | 980 |

**Table E3:**
**Papers identified for review**

| Type of study | Number of studies | References |
|---|---|---|
| Reviews | 9 reviews | House, 1987; Johnson, 1991; Bishop & Pet, 1995; Ghika-Schmid & Bogousslavsky, 1997; Chemerinski & Robinson, 2000; Robinson, 1997, 2002, 2006; Tedstone & Tarrier, 2003 |
| GAD | 8 | Castillo et al., 1993,1995; Åström, 1996; Schultz et al., 1997; Shimoda & Robinson, 1998; Tang et al., 2002; Leppävuori et al., 2003; Barker-Collo, 2007 |
| Psychiatric disorders/ generic anxiety | 11 | Sharpe et al., 1990; Gillespie, 1997; Schramke et al., 1998; Dennis et al., 2000; Carota et al., 2002; Angelelli et al., 2004; Aybek et al., 2005; Fure et al., 2006; Giaquinto et al., 2007; Masskulpan et al., 2008; Kuptniratsaikul et al., 2009 |
| PTSD | 5 | Sembi et al., 1998; Sampson et al., 2003; Bruggimannn et al., 2006; Merriman et al., 2007; Field et al., 2008 |
| Anxiety disorders | 4 (all looked at a range of anxiety disorders including GAD) | Burvill et al., 1995; O'Rourke, 1998; Tang et al., 2002; House et al. 1991 |
| Associated factors | 4 | Knapp & Hewison, 1998; Morrison et al, 2000, 2005; Lewis et al., 2001 |

**Appendix V**

**Table E4:**
**Summary of studies into GAD and PTSD  (Key at foot of table)**

| Study | Design | Sample | Assessment Tool | Timing of Assessment | Prevalence of Anxiety disorder and number of participants out of the total sample | Main Findings |
|---|---|---|---|---|---|---|
| House et al. (1991) | Consecutive referrals | N=128 + control group Mean age = 71.2 (18-96 years) Community sample English | Barthel index ADL,PSE, BDI, MMSE | 1 month 6 month 12 month | ICD-9 1 month GAD=1% (1/89) Adjustment disorder = 4% (4/89) 6 months GAD= 1% (1/119) Adjustment disorder = 3% (4/119) 12 months GAD =0% (0/112) Adjustment disorder = 4% (5/112) | Higher levels of mood disorder in stroke survivors than controls, but this difference mostly disappeared after 1 year |
| Castillo et al. (1993) | Crossectional Prospective Participant selection from consecutive inpatient admissions to stroke unit | N=309 Mean age=58.9 Sex data omitted Inpatients USA | Clinical  Interview | Acute phase | GAD=26.9% | Comorbid anxiety and depression were associated with left cortical lesions. Anxiety alone was associated with right hemisphere lesions. Worry was associated with posterior right hemisphere lesions. GAD was associated with posterior right hemisphere lesions |

| Study | Design | Sample | Assessment Tool | Timing of Assessment | Prevalence of Anxiety disorder and number of participants out of the total sample | Main Findings |
|---|---|---|---|---|---|---|
| Burvill et al. (1995) | Consecutive referrals from community stroke and depression study | N=294 + control group Age = elderly (no other age data given) Sex data unclear Australian | PAS | 4 months 12 months | At 4 months Anxiety disorders= 5% of men 19% of women (only 9% in women over 80 years)(All GAD occurred in those over 70 years) Agoraphobia= 4%, 15 men 17%, 34 of women (only 9% in women over 80 years of age) Community control anxiety disorders=5% At 12 months Anxiety disorders alone = 21% (9/42) (7 agoraphobia, 2 GAD) Comorbid anxiety with depression = 17% (7/42) | A higher rate of agoraphobia was found than GAD. At 12 months 51% of those with agoraphobia had recovered. A higher rate of mortality found in participants with comorbid anxiety & depression. |

| Study | Design | Sample | Assessment Tool | Timing of Assessment | Prevalence of Anxiety disorder and number of participants out of the total sample | Main Findings |
|-------|--------|--------|-----------------|---------------------|---------------------------------------------------------------------------------|---------------|
| Åström (1996) | Prospective Longitudinal study Participant selection from consecutive inpatient admissions to stroke unit | N=80 No control group Mean age = 73 years (44-100 years) Men=49 Inpatients at recruitment. Swedish | Clinical interview, CT scans | Immediate post-stroke, 3 months, 1 year, 2 years, 3 years | GAD= 28% in acute phase No significant change over 3 years. 3 months GAD= 31% (22/70) 12 months GAD=24% (16/66) 2 years GAD=25% (16/66) 3 years GAD=19% (9/48) | GAD after stroke is common and long-lasting and interferes considerably with social life and functional recovery. GAD alone associated with right hemisphere lesions. Fewer social contacts correlated with GAD Dysphasia correlated with GAD |
| Schultz et al. (1997) | Longitudinal, consecutive series of inpatients recruited | N=42 57% male 66% black Mean age 58.1 | Clinical interview, PSE, Ham-D, MMSE, STC, SFE, JHFI, CT scan DSM-IV criteria modified from symptoms present for 6 months to a period of at least 2 weeks | Post stroke, 3months, 6 months, 12 months, 24 months | **27%** Early onset **23%** Late onset | ¾ of anxious patients had comorbid major & minor depression. Early onset associated with previous psychiatric history. Late onset at median of 3 months. Onset of depression occurred approximately the same time as anxiety Possible correlations between more anxiety symptoms and younger age and female gender |

| Study | Design | Sample | Assessment Tool | Timing of Assessment | Prevalence of Anxiety disorder and number of participants out of the total sample | Main Findings |
|---|---|---|---|---|---|---|
| O'Rourke et al. (1998) | Study testing validity and reliability of GHQ-30. Participants selected from a previous randomized trial | N=105 Median age 66 (range 18 to 90 years) | HADS (cut offs at 6/7, 8/9, 10/11), GHQ-30, SADS, & clinical interview | Assessed 6 months of stroke onset | **13 %** any anxiety disorder **2%** GAD | GHQ-30 & HADS exhibited similar levels of sensitivity and specificity in detecting psychiatric morbidity in stroke survivors |
| Shimoda & Robinson (1998) | Longitudinal study, participants consecutively admitted hospital patients | N=142 Inpatients Mean age of those with GAD=56.9±14 33.3% female 60% black 60% married 18 participants also had comorbid depression | MMSE, JHFI, SFE, CT scan, PSE, clinical interview, HAM-D, DSM-IV criteria modified (excluding presence of worry or anxious foreboding and duration criteria) | Assessed 3 months post-stroke | **23%** (10% anxiety only + 13% comorbid with depression) | Anxiety disorder significantly correlated with depression, impairment in activities of daily living and social functioning. An increase in anxiety levels associated with the severity and course of depression. Anxiety did not affect cognitive impairments. Anxiety disorders seem to be important in the post-stroke prognosis of depression, but they may have different mechanisms |

| Study | Design | Sample | Assessment Tool | Timing of Assessment | Prevalence of Anxiety disorder and number of participants out of the total sample | Main Findings |
|---|---|---|---|---|---|---|
| Tang et al. (2002) | Patients consecutively admitted to hospital recruited | N=157 Participants Hong Kong inpatients 45% male Mean age = 71±10 years | MMSE (Chinese version), SCID, DSM-III-R, CT scan, AMT, clinical interview | Assessed within 1 month post-stroke | 0.6% | Post-stroke, low morbidity of affective disorders with a relatively favourable short-term outcome |
| Leppävuori et al. (2003) | Prospective study Cross-sectional Participant selection from consecutive series of patients involved in Helsinki Stroke Aging Memory Study & patients of a neurology department | N=277 + control group Mean age = 70.7±7.5 (55-85 years) Comparing survivors with primary GAD with survivors with GAD due to stroke Hospital patients Finnish | MMSE, Bartel Index, SCAN by psychiatrist, PSE-10, ZSRS, GAF, MADRS, SSS | 3 – 4 months | GAD = 20.6% (57/277) Primary GAD = 11.2% (31/277) GAD due to stroke = 9.4% (26/277) | GAD is common in ischemic stroke and hampers rehabilitation.

GAD as a consequence of stroke was correlated with worse psychosocial functioning, a history of migraine, & anterior circulation stroke localisaion Primary GAD was correlated with a history of insomnia |

| Study | Design | Sample | Assessment Tool | Timing of Assessment | Prevalence of Anxiety disorder and number of participants out of the total sample | Main Findings |
|---|---|---|---|---|---|---|
| Barker-Collo (2007) | Consecutive referrals to inpatient rehabilitation unit. Correlational study | Recruited as hospital inpatients. N=73 54.8% male Mean age=51.7 years 28.8% married, 6.8% single 13.7% European, 12.3% Asian, 20.5% Maori | BDI-II, BAI, FIM, CVLT II, VPA, Digit and spatial spans, IVACPT, Victoria Stroop | 3 months post-stroke | 21% moderate-severe anxiety 6.8% comorbid moderate anxiety with moderate depression 5.5% severe anxiety with severe depression (Measure = BAI) | Reduced cognitive speed and left hemisphere lesion associated with anxiety. Strongest symptoms being fear of dying, fear of the worst and wobbliness |
| Sembi et al. (1998) | Cross-sectional Partially retrospective Screening by self-report questionnaires and diagnosis by clinical interview | N=61 Mean age = 66.4 years (SD 9.8, all over 18 years) Sex data omitted Inpatient and community English | Self-report questionnaires. Face-to-face interviews IES, Penn, CAPS, Barthel ADL Index, EPQ, GHQ-28, HADS | Up to 18 months post-stroke. | CAPS=9.8% (conservative figure) IES= 21% $\geq$ 30 Penn= 7% $\geq$ 35 | PTSD not related to age, gender, post-stroke disability or time since stroke. High comorbidity with anxiety and depression scores on HADS |

| Study | Design | Sample | Assessment Tool | Timing of Assessment | Prevalence of Anxiety disorder and number of participants out of the total sample | Main Findings |
|-------|--------|--------|-----------------|---------------------|-------------------------------------------------------------------------------|---------------|
| Sampson et al. (2003) | Prospective study – methodology data incomplete | N=103 (54 stroke, 49 non-stroke all hospital inpatients) Mean age=72.5 Inpatients English | HADS, GHQ, PCL-S, IES, MMSE, verbal fluency test, Digit Span Test, NART, LEI, Barthel ADL Index | More than 5 days post-stroke | 5.6% PTSD (Control group of non-stroke inpatients with other medical conditions 6.1%) | Levels of depression, anxiety, PTSD-like symptoms and autobiographical memories were not significantly different between stroke and non-stroke hospitalised participants |
| Bruggimannn et al. (2006) | Self-report surveys, Partially retrospective HDRS applied by psychiatrist Small qualitative section | N=49 Mean age = 51.4±16.2 33 men Community based Swiss | HADS, HDRS, IES, IESA, TEQ, MRI , Barthel Index, RAVLT, other questionnaire devised for the study (French versions of all measures) | 1 year after stroke | IES= 31% (15/ 49) (IES > 30) | PTSD symptoms were common in non-severe stroke and often accompanied by depression or anxiety. PTSD was more common in women, less educated patients and the subjective intensity of the of the stroke experience. Intrusions were more increased after basal ganglia strokes. Correlations were not found between PTSD symptoms and neurologic impairment, long term memory impairment, and physical pain during hospitalisation |

| Study | Design | Sample | Assessment Tool | Timing of Assessment | Prevalence of Anxiety disorder and number of participants out of the total sample | Main Findings |
|---|---|---|---|---|---|---|
| Merriman, Norman & Barton (2007) | Cross-sectional | N=47 Recruited via hospital records from current or previous post-stroke admissions. Mean age = 73.78 (range 46-93) 55.9% male 51.6% married or cohabiting | Posttraumatic Diagnostic Scale Barthel Activities of Daily Living Index, HADS, PANAS, Cognitive Appraisal Questionnaire | Within 1 year post-stroke | 30.7% (prevalence of those with PTSD symptoms not prevalence of those with a clinical diagnosis) | Time since stroke correlates with PTSD severity – the longer time elapsed since stroke the less severe the symptoms. The number of previous strokes correlates with the greater severity of symptoms Hemisphere of stroke, post-stroke disability, age, gender, marital are unrelated to severity or number of PTSD symptoms. Negative affect and cognitive appraisals correlated with severity of symptoms |
| Field, Norman & Barton (2008) | Cross-sectional & prospective associations between cognitive appraisals & PTSD post-stroke | Inpatients at recruitment Mean age 71.23 (range 39-94 years) | Posttraumatic Cognitions Inventory HADS, Posttraumatic Diagnostic Scale | Assessed on hospital admission & 3 months later | N=70 | Negative cognitions about the self and the world were found to correlate with severity of PTSD symptoms |

**Table E5:**
**Key of assessment tools for summary of studies into GAD and PTSD**

| | |
|---|---|
| ADL = Activities of Daily Living | MMSE = Mini Mental State Examination |
| AMT = Abbreviated Mental Test | MRI = Magnetic Resonance Imaging |
| BAI = Beck's Anxiety Inventory | N = number of study participants in sample |
| BDI, BDI-II = Beck's Depression Inventory | NART= National Adult Reading Test |
| BICRO-39 = Brain Injury Community Rehabilitation Outcome – 39 | PANAS = Positive and negative Affect Schedule |
| CAPS = Clinician-Administered PTSD Scale | PAS = Psychiatric Assessment Schedule |
| CAQ = Cognitive Appraisal Questionnaire | PCL-S = Post Traumatic Stress Disorder Checklist |
| COWAT = Controlled Oral Word Association Test | PDS = Posttraumatic Diagnostic Scale |
| CT scan = Computed Tomography | Penn = Penn Inventory of PTSD |
| CVLT II = California Verbal Learning Test II | PSE-10 = Present State Examination |
| DSM-III-R = Diagnostic and Statistical Manual of Mental Disorders Revised version | RAVLT = Rey Auditory Verbal Learning Test |
| DTS = Davidson Trauma Scale | RLCQ = Revised Life Changes Questionnaire |
| EPQ = Eysenck Personality Questionnaire | RIES = Revised Impact of Event Scale |
| FIM = Functional Index Measure | RLCQ = Revised Life Changes Questionnaire |
| GAF = Global Assessment of Functioning scale | SADS = Schedule for Affective Disorders & Schizophrenia |
| GHQ-28 = General Health Questionnaire | SCAN = Schedules for Clinical Assessment in Neuropsychiatry |
| GHQ-30 = General Health Questionnaire | SCID = Structured Clinical Interview for DSM |
| IES = Impact of Event Scale | SD = Standard Deviation |
| IVACPT = Integrated Visual Auditory Continuous Performance Test | SFE = Social Functioning Exam |
| HADS = Hospital Anxiety and Depression Scale | SSS = Scandinavian Stroke Scale |
| HDRS = Hamilton Depression Rating Scale | STC = Social Ties Checklist |
| ICD-9 = International Classification of Diseases | TEQ = Trauma Experience Questionnaire |
| IVACPT = Integrated Visual Auditory Continuous Performance Test | VPA = Visual Paired Associates |
| IPQ-R= Illness Perception Questionnaire-Revised | ZSRS = Zung Self Rating Scale |
| JHFI = John Hopkins Functional Inventory | |
| LCS = Life Change Scale | |
| LEI = Life Events Interview | |
| MADRS = Montgomery-Åsberg Rating Scale | |

**Table E6:**
**Papers measured against criteria for rigorous theory in research (Ellis et al.,1996)**

| Study | Evidence of theory base | Unambiguous hypotheses | Validity/ reliability controls | Psychometrically sound measures | Minimises statistical threats |
|---|---|---|---|---|---|
| House et al. (1991) | Yes | Yes | Yes<br>Control group<br>Yes validity/ reliability controls on clinical interview | Yes – PSE clinical interview<br>Rater reliability and validity checks | Yes |
| Castillo et al. (1993) | No | Yes | Control group<br>No checks | Yes – clinical interview | Yes |
| Burvill et al. (1995) | Yes | No | No<br>No control group | Yes – PAS clinical interview | Yes, conservative tests used |
| Åström (1996) | No | No (prospective study) | Yes, diagnostic assessor assessed "blind"<br>Avoided sampling bias by studying a consecutive series of participants.<br>No validity/ reliability controls on clinical interview<br>All assessments by the same psychiatrist for consistency | Yes – clinical interview | Sample sizes small |

| Study | Evidence of theory base | Unambiguous hypotheses | Validity/ reliability controls | Psychometrically sound measures | Minimises statistical threats |
|---|---|---|---|---|---|
| Schultz et al. (1997) | No | Yes | Yes, clinical interview blind to ratings on other measures and semi-structured. Steps taken to reduce the impact of physical impairments post stroke on measures for mental disorders | Yes – clinical interview | Large sample size but a large number of statistical analyses carried out |
| Shimoda & Robinson (1998) | Yes | Yes | Control group used. Clinical interview semi-structured | Yes, clinical interview | Large sample size |
| Tang et al. (2002) | Yes (but prevalence study) | Yes | Diagnoses from clinical interviews were checked to establish inter-relater reliability by a computer selecting assessments at random and reassessing them by another psychiatrist who was blind to the first assessment | Yes, clinical interview | Large sample, small number of statistical tests carried out |
| Leppävuori et al. (2003) | Yes | Yes | Yes, comparison group and control. No validity/ reliability controls on clinical interview | Yes – an extensive battery of tests, structured clinical interview and measures that have been validated with older people and neuropsychological problems | Yes |

| Study | Evidence of theory base | Unambiguous hypotheses | Validity/ reliability controls | Psychometrically sound measures | Minimises statistical threats |
|---|---|---|---|---|---|
| Barker-Collo (2007) | Yes | Yes | Yes, attempts were made to determine the overlap of physical outcomes of stroke and mental disorders | Yes – extensive battery of tests, but these are less reliable as diagnostic tools | Yes, a number of factors were excluded to reduce the number of contrasts performed. Due to the large number of correlations, only those where $p<0.01$ were considered significant |
| Sembi et al. (1998) | Yes | Yes | Yes<br>Control group<br>No validity/ reliability controls for clinical interview | Yes – clinical interview, PTSD specific measure and screening tool | Yes |

| Study | Evidence of theory base | Unambiguous hypotheses | Validity/ reliability controls | Psychometrically sound measures | Minimises statistical threats |
|---|---|---|---|---|---|
| Sampson et al. (2003) | Yes | Yes | Yes<br>Control group<br>No validity/ reliability controls for assessment measures | Yes – PTSD specific measure and screening tool | Large sample size but only 25% of original sample tested, 59% of those screened included in study |
| Bruggimann et al. (2006) | Yes, a little | Yes | Yes, but small sample was not representative of population from which they were taken. | Yes, PTSD specific measure used, but retrospective measures are less reliable and self-report questionnaires that are returned by post may create a self-selection bias | No evidence |
| Merriman et al. (2007) | Yes | Yes | Small sample. | Battery of tests including PDS, although these are screening tools | Small sample and a large number of correlations considered |

| Study | Evidence of theory base | Unambiguous hypotheses | Validity/ reliability controls | Psychometrically sound measures | Minimises statistical threats |
|---|---|---|---|---|---|
| Field et al. (2008) | Yes | Yes | Small sample size. | Battery of tests including PTSD specific measures | A number of comparisons were carried out with a small sample which may have reduced the power of the regression analyses |

**Table E7:**

**Factors associated with post-stroke general anxiety and GAD**

| Factor | Association | Evidence suggesting link with anxiety | Evidence suggesting no link with anxiety |
|---|---|---|---|
| **Depression** | High rate of comorbid depression | e.g. Åström,1996; Castillo et al., 1993,1995; Dennis et al.,2000; Leppävuori et al.,2003; Lewis et al., 2001; Masskulpan et al.,2008; Schultz et al.,1997 | |
| | Comorbidity increases severity of & chronicity of both, makes their onset earlier with a poorer response to treatment | Shimoda & Robinson,1998 | |
| | Comorbidity increases morbidity rate and impairs activities of daily living & recovery of social functioning | Burvill et al.,1995 Shimoda & Robinson,1998 | |
| **Brain Lesion Location** | Comorbid with depression linked with left-hemispheric lesions | e.g. Castillo et al.,1993 Barker-Collo, 2007 | Castillo et al.,1995 Dennis et al.,2000 Morrison et al.,2000 Schramke et al.,1998 Schultz et al.,1997 Sharpe et al.,1990 |
| | Anxiety alone linked with right-hemispheric lesions | e.g. Castillo et al.,1993 Åström,1996 | |
| **Gender** | Anxiety more prevalent amongst: women & | Barker-Collo,2007 Burvill et al.,1995 Castillo et al.,1993 | Åström,1996 Dennis et al.,2000 Frühwald et al.,2001; Masskulpan et al. 2009 |
| **Age** | younger survivors (<59 years) | Castillo et al.,1995 Morrison et al.,2000 Schultx et al.,1997 | |
| **Social support** | GAD linked with reduced social life | Åström,1996 | |
| | Reduced social life such as fewer social contacts linked with increased GAD | Bond et al.,1998; Knapp & Hewison 1998 Schultz et al.,1997 | |
| | Single marital status linked to increased likelihood of anxiety | Fure et al.,2006 | |

| Factor | Association | Evidence suggesting link with anxiety | Evidence suggesting no link with anxiety |
|---|---|---|---|
| **Physical factors (impairment, general health, independence, coping)** | Greater impairment linked to increased anxiety | Bond et al.,1998 Dennis et al.,2000 Schultz et al.,1997 | Castillo et al.,1995 Morrison et al.,2000 |
| | Poor general health linked to increased anxiety | Lewis et al.,2001 | |
| | Medical complications linked to an increase in anxiety | Kuptniratsaikul et al., 2009 | |
| | Reduced levels of independence & coping with activities of daily living significantly increases anxiety levels | Barker-Collo,2007; Leppävuori et al.,2003; Masskulpan et al.,2008; Schröder et al.,2007; Shimoda & Robinson, 1998 | |
| | Avoidant coping strategies linked to increased anxiety levels | Gillespie,1997 | |
| **Cognitive impairment** | Dysphasia linked to increase in anxiety levels | Åström,1996 Fure et al.,2006 | Castillo et al.,1995 Morrison et al.,2000 |
| | Impaired processing speed & verbal memory linked to increased anxiety levels | Barker-Collo,2007 | |
| **Cognitions (negativity, confidence in recovery, satisfaction with treatment)** | High levels of negative thoughts linked to increased anxiety (anxious preoccupation, hopelessness, helplessness) | Lewis et al.,2001. | |
| | Fear of dying/ the worst happening are linked with increased anxiety levels | Barker-Collo,2007 Burvill et al.,1995 | |
| | Associations with increased anxiety related to confidence about future recovery | Morrison et al.,2000 | |
| **Pre-morbid psychiatric history** | Pre-morbid history linked with increased levels & rates of post-stroke anxiety & early onset | Leppävuori et al.,2003 Castillo et al.,1995 Starkstein et al.,1990 Leppävuori et al.,2003 | |

| Factor | Association | Evidence suggesting link with anxiety | Evidence suggesting no link with anxiety |
|---|---|---|---|
| **Premorbid life events** | Greater number of severe life events linked with higher levels of anxiety | Bond et al.,1998 | |
| **Quality of life** | Poorer quality of life linked with higher levels of anxiety | Olatunji et al.,2007 Masskulpan et al.,2008 | |
| | even for mildly impaired survivors | Frühwald et al.,2001 | |
| | Women have been identified as having poorer post-stroke quality of life than men, suggesting that they may experience higher levels of anxiety | Kuroda et al.,2006 | |

**Table E8:**
**Factors associated with PTSD**

| Factor | Association | Evidence suggesting link with PTSD | Evidence suggesting no link with PTSD |
|---|---|---|---|
| **Negative affect** | Linked with an increase in PTSD severity | Merriman et al., 2007 | |
| **Anxiety** | Greater anxiety with more severe PTSD | Sembi et al., 1998<br>Sampson et al., 2003<br>Bruggimann et al., 2006 | |
| **Severe Depression** | Linked with more severe PTSD | Sembi et al., 1998<br>Sampson et al., 2003<br>Bruggimann et al., 2006 | |
| **Cognitive appraisals (about self, the world)** | Negative appraisals linked with more severe PTSD | Bruggimann et al., 2006<br>Field et al., 2008<br>Merriman et al., 2007 | |
| **Factor** | **Association** | **Evidence suggesting link with PTSD** | **Evidence suggesting no link with PTSD** |
| **Subjective intensity of stroke** | Linked with more severe PTSD | Bruggimann et al., 2006 | |
| **Social Dysfunction** | Greater social dysfunction more severe PTSD | Sembi et al., 1998 | |
| **Marital status** | | | Merriman et al.,2007 |
| **Insomnia** | Linked with higher rates of PTSD | Sembi et al., 1998 | |
| **Gender** | PTSD more common in females | Bruggimann et al.,2006 | Sembi et al., 1998<br>Merriman et al.,2007 |
| **Education** | Less educated people experience more PTSD | Bruggimann et al., 2006 | |
| **Number of strokes** | More previous strokes linked with more severe PTSD | Merriman et al., 2007 | |
| **Fear of recurring strokes** | | | Bruggimann et al., 2006 |
| **Post-stroke ability/ severity of stroke** | PTSD common in non-severe stroke | Bruggimann et al., 2006 | Sembi et al., 1998 |
| **Cognitive/ long-term memory** | Impairments not linked | | Bruggimann et al., 2006 |
| **Time since stroke** | The longer time since stroke the less severe PTSD | Merriman et al., 2007 | Sembi et al., 1998 |

| | | | |
|---|---|---|---|
| **Age** | | | Sembi et al., 1998<br>Merriman et al.,2007 |
| **Stroke location** | Basal ganglia strokes linked with more intrusions<br>Stroke hemisphere not linked | Bruggimann et al., 2006 | Merriman et al.,2007 |
| **Physical pain during hospitalisation** | | | Bruggimann et al., 2006 |

**Appendix IX**

**<u>Rationale for choice of Grounded Theory (GT) Methodology</u>**

1.) Qualitative methodology was chosen rather than quantitative in order to explore the phenomenon of post-stroke anxiety without losing the richness and breadth of data available.

2.) GT is a 'bottom up' approach that begins with the research data and at every point it grounds theory development in this data (the main components are outlined in Appendix X). This offered the Principle Researcher a methodology that could facilitate the identification of factors that stroke survivors believed had the greatest impact on their levels of anxiety in context thus incorporating the views of participants

3.) Whilst IPA would have allowed a thematic exploration of the perspectives of survivors, it is not grounded in the views of the participants. Rather, the researcher imposes themes on the data. By contrast, GT rigorously seeks to ground all developing theory in the data, facilitating the results to represent the views of the participants as much as possible. To date, survivors have not given their views about their anxiety and preserving these as faithfully as possible was deemed by the researcher as an empowering and respectful thing to do. In addition, this preserved the perspective of the participants throughout the theory development.

4.) Unlike other qualitative methods, such as Interpretative Phenomenological Analysis, GT is less focussed on subjective experience and depth of analysis so can be used to develop more general theories (Charmaz, 2006).

5.) The ongoing comparisons of similarities and differences and continuous analysis also facilitate the development of a theory that can have greater explanatory power because it tries to explain as many aspects of the data as possible (Charmaz, 2006; Glaser, 1978,1992; Glaser & Strauss, 1967).

6.) In theories developed using GT have been found to be more flexible because they are open to modification and to have increased durability over time (Charmaz, 2006; Glaser, 1978,1992; Glaser & Strauss, 1967).

7.) GT provided a means to begin to develop theory related to post-stroke anxiety, which seemed significantly lacking in current research.

8.) GT methodology provides insight into process and factors involved in post-stroke anxiety that could subsequently be researched using quantitative methodology in order to further test and establish how generally these theories might be applied.

9.) GT is appropriate to be used from a critical realist perspective, which was the epistemological stance taken for this study.  Although more recently it has been utilised by researchers from a constructionist perspective, it was originally designed to provide a methodology as rigorous as quantitative objectivist approaches.  As such GT also provides a bridge between qualitative and quantitative studies allowing quantitative findings to be held alongside and utilised in a qualitative study.

10.) GT provided a means to process data from a group that was not homogenous (whereas IPA requires a more homogenous group as it seeks themes that are similar for

all participants). GT seeks participants with different experiences in order to test and develop theories. As such this was ideal for a group of stroke survivors who came from widely different backgrounds and experiences. Often the survivors had little in common pre-stroke and their post-stroke experiences also differed widely.

11.) The aim of GT is focussed on the facilitation of the well-being of a disempowered group, starting with their perspective and needs and is deemed to be satisfactory if the theory developed explains the data and helps people (Charmaz, 2006; Galser & Strauss, 1967). As such, these aims were compatible with the philosophical and personal interests of the Researcher (see Appendix XI).

**Appendix X**
The following quote summarises the components of grounded theory practice:

- "Simultaneous involvement in data collection and analysis

- Constructing analytic codes and categories from data, not from preconceived logically deduced hypotheses

- Using the constant comparative method, which involves making comparisons during each stage of the analysis

- Advancing theory development during each step of data collection and analysis

- Memo-writing to elaborate categories, specify their properties, define relationships between categories, and identify gaps

- Sampling aimed toward theory construction, not for population representativeness

- Conducting the literature review *after* developing an independent analysis"

(Charmaz, 2006 pp5-6)

**Appendix XI**
**<u>Epistemological and philosophical stance</u>**

Four general paradigms of ontological and epistemological position can be taken (see Table E9). The epistemological stance taken in this study is the post-positivist stance known as critical realism. The ontological position is one in which there is a recognition that reality and complete objectivity exists but our understanding of it is influenced by subjective factors so our understanding is an approximation. This approach recognises that complete objectivity is unattainable because of the impact of the views of the researcher and interviewees on the study.

The many different forms of Grounded Theory allow researchers to take different philosophical stances. The question addressed by this study assumes that there is an objective phenomena we call "anxiety" and that 'real' theoretical categories exist, that emerge through research, thus the epistemological position taken is post-positivist (Glaser & Strauss, 1967).

Grounded Theory was initially developed to use from a critical realist perspective although it is now more commonly used from a social constructionist approach (Glaser & Strauss, 1967; Kempster, 2006; Strauss & Corbin, 1998). A critical realist approach is also pragmatic for the purposes of this study because of the usefulness of defining the concept of anxiety for participants rather than either spending the interviews investigating their view of the nature of anxiety or risking misunderstanding of a concept that is difficult to define. Furthermore, in order to relate findings to other research it was helpful to use the same definition, which suggested that an objective reality called 'anxiety' exists.

From this perspective, the epistemological stance of the researcher is one in which she seeks to be objective but subjective values and beliefs influence research. Thus, she attempts to identify influences on the research in order to achieve a degree of

partial objectivity. As a result, the study is a product of participant's views, the researcher's views and biases, and the investigators interpretation of the data.

The Principal Investigator recognised that subjective factors would influence the research process, such as the researcher's expectations, values and assumptions. However, due to resource limitations, especially that of time, a critical realist perspective was felt to be the most expedient. This perspective encourages the use of appropriate methods to facilitate the identification of relevant causal influences in a particular incidence (Sayer, 1992; Kempster, 2006). The Principal Investigator took steps to minimise the impact of her biases on the study, such as having others analyse parts of transcriptions to see whether they would reveal any bias in the original interpretation.

In order for the reader to be able to assess whether potential biases were created by the background of the Principal Investigator it is important to be transparent about them. This research was carried out as part of training for a doctorate in clinical psychology. Consequently, the process was time limited and the academic requirements took priority over the methodology of grounded theory. For example, a literature review had to be drawn up prior to the data being collected, resulting in the author having an awareness of current research in this area that may have influenced the research question, the questions asked at interview as well as the analysis of the data. The Principal Investigator is influenced by her cultural background as a white-British, female from a working class background and has also worked as a Social Worker with people who have experienced strokes. However, grounded theory constantly grounds analysis and evolving theory in the participants' accounts, which helps to mitigate some of these biases.

In order to be transparent the Principle Researcher is explicit about her own background and prior assumptions that will influence this research (see Table E7). The author is white, female and has held the professional positions of teacher and social worker prior to clinical psychology training.

**Table E9:**
**Ontological and epistemological positions**

| Paradigm | Positivism | Post-positivism | Critical Theory | Constructivism |
|---|---|---|---|---|
| **Ontology** | **There is one reality and this can be known and understood** | **There is one reality but our understanding is limited and inexact** | **Reality is defined by its historical, political, and cultural context** | **Reality is constructed through social interactions and changes as it is socially constructed** |
| **Epistemology** | **The researchers is objective and does not influence the research with their own values and perspectives** | **The researcher attempts to be objective but recognises that the researchers own values and perspectives have an influence on the research and findings** | **Research is subjective, the researchers values and context are inextricably linked with the research and objectivity is not possible** | **The researcher is an active part of the creative process of social construction, results are entirely subjective** |

**Table E10:**
**Researcher's epistemological influences**

| Philosophical influences | Personal interests |
|---|---|
| Feminism | Social welfare<br>Oppression |
| Community, social and critical psychology | Marginalised people groups<br>Service user involvement |
| Clinical Psychology | Mental well-being<br>Reflective practice |

**<u>Quality Measures</u>**

Meyrick (2006) made recommendations for ensuring rigorous qualitative research that are based on the principles of transparency and systematic methodology and offer techniques to establish rigour at each stage of the research. The Principle Researcher provided means to accomplish this based on Meyrick's (2006) quality framework.

The Principle Researcher defined the exact nature of her proximity to the data through the use of reflexivity (see Appendix XI). For example, she is explicit about her background and prior assumptions and these were further challenged in supervision and in peer support groups. Some guarantors of objectivity are also introduced through the use of a naïve researcher to code transcript extracts and theories were tested by asking participants about their views of them at the end of interviews.

At the methodological stage the study has clear aims/ objectives and explains why the methods used are appropriate for this research question. The sampling and data collection processes are described in detail and limitations stated in order to provide transparency and to offer an explicit analytical framework.

The transparency of data analysis is enhanced by providing examples of decision making processes and grounding theoretical concepts in data, with examples provided.

All cases were considered for each concept and some data was examined that contradicted the emerging theory. Further transparency was incorporated through the use of an audit trail of notes, journal and memos that account for decision making processes.

A degree of objectivity was also sought through the use of multiple and independent coding by peers and supervisor to confirm analysis of interviews. This was

facilitated by a peer qualitative support group. Furthermore, other research provided a means for triangulation in the discussion.

# APPENDIX

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# XVII

**Table E11:**
**Participant demographic data**

| Participant Number | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 14 | 15 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Order seen | 5 | 1 | 3 | 6 | 2 | 4 | 8 | 13 | 11 | 7 | 12 | 10 | 15 | 14 |
| Sex | F | F | M | M | M | F | F | M | M | M | M | F | F | M |
| Age | 56yr 1m | 62yr 5m | 60yr 8m | 62yr 6m | 57yr 1m | 40yr 3m | 84yr 3m | 77yr 3m | 56yr | 86yr 11m | 79yr 2m | 64yr 5m | 72yr 4m | 61yr 11m |
| Marital status | S | M | M | M | D | LT P | W | M | M | M | M | D | M | M |
| Alone | Y | N | N | N | Y | N | N | N | N | N | N | Y | N | N |
| Culture | C of E | C of E | C of E | Christian | N/A | White British | C of E | C of E | Blank | Christian | Methodist | Adventist/ afro-Caribbean | C of E | C of E |
| Supported | OK | Y | Y | Y | N | Y | Y | Y | Blank | Y | Y | N | Y | Some-times |
| No. of Strokes | 2 | 1 | 1 | ≥3 | 2 | 2 | 1 | 2 | 1 | 2 | 1 | 2 | ≥3 | 1 |
| Recency | 2yr 9m | 5yr 5m | 5yr 2m | 2yr 6m | 1yr 8m | 5m | 3yr 5m | 6yr | 6yr | 2yr 5m | 2yr 9m | 8yr 10m | 10yrs | 1yr 9m |
| Time in hospital | 2 wks | 19wks | 10 wks | 6m | 2m | 5m | wks | 12 weeks | 5m | 2wks | 3m | 6m | 9wks | Wks |
| Time at club | 1yr | 3yr | 6m | 6m | 4m | 2m | 3yr | 4yr 6m | 19m | 4yr 5m | 2yr | 8yr | 6m | 11m |
| Pre-stroke M.H. problem | Y Bad back, neck | N | N | N | Y PTSD | N | Y migraines/ headaches | N | N | N | N | N | N | N |
| Treated | | | | | | | N | N/A | | | | | | N/A |
| Post-stroke MH Problem | Y | N | Y | N | Y | Y | N | N | Y | N | N | Y | N | Y |
| Treated | N | | Anti-depressants | | N | Fluoxetine | | | | | | Y | | |

| Participant Number | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 14 | 15 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Problem | | | D | | | D | | | | | | D | | D |
| Anxiety BAI | 30 | 7 | 2 | 51 | 34 | 41 | 31 | 5 | 10 | 5 | 22 | 39 | 12 | 36 |
| HADS Anxiety | 9 | 6 | 6 | 11 | 17 | 18 | 9 | 2 | 9 | 2 | 7 | 14 | 5 | 18 |
| HADS Depression | 15 | 3 | 4 | 7 | 18 | 2 | 7 | 5 | 8 | 6 | 7 | 11 | 10 | 16 |
| Post-stroke problems | Aphasia | | Confusion, aphasia, attention, perception, loss of vision | | Balance | Left-eye, co-ordination | Loss of vision both eyes | loss of balance | Balance, vision | | | Walking | balance problems | |
| Weakness side | Right | Right | Right | Left | Left | Both | Left | Left | Left | Left | Right | Right | Left | Right |
| Memory | | | | | | | | N | | | | Y | Y | |
| Speech | | Y | Y | Y, comprehension | Y | Comprehension | | | Y Comprehension | Y | Y | Y | | Y |

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**Stroke Club Presentation Contents:**

The Stroke Club members will be thanked for giving their time.

The researcher will introduce herself as Zoë Lander and explain that she is a second year trainee studying to become a doctor of Clinical Psychology at Leicester University. She will also explain that she is employed by the Leicestershire NHS Partnership Trust while she trains.

The researcher will describe her research as being part of her training and something that will provide valuable information to improve stroke care. She will also say that her study is looking at stroke experiences and specifically post-stroke anxiety.

The researcher will explain that very little research that has been carried out to date that looks at post-stroke anxiety. Furthermore, those researchers have not asked people who have experienced a stroke about the things that may have increased their levels of anxiety following their stroke. The researcher will recognise the Stroke Club members' expertise in this area as they all know about what it feels like to live after a stroke and that this is why she is approaching them for help.

The researcher will explain that she is asking people to consider participating, but that they will be free to withdraw from the study at any time without discrimination. She will outline what will be required of participants, including the completion of 3 questionnaires about their thoughts, feelings and giving some general information about themselves. The researcher will state that 10-12 people will be invited to meet with her to tell her about their experiences. An interview would take place at a time and place that will suit the participant.

The researcher will emphasise that whatever information is given to her, it will be treated with the utmost respect and participants' information will be anonymised to protect their identities. They will be informed that any sensitive data will be kept in a locked cabinet in locked premises and will only be seen by the researcher and her supervisor.

The researcher will end by inviting any questions from the Stroke Club members and, if anyone is interested in finding out more they will be asked to take a self-addressed envelope containing: the Letter Requesting Help, the Research Information Sheet, the Sources of Help Leaflet, the Demographic Questionnaire, the Hospital Anxiety and Depression Scale, and the Becks Anxiety Inventory. They will be asked to read the information carefully before completing the surveys. If they chose not to participate, then a request will be made to return the questionnaires to reduce the costs of the study.

The researcher will thank the Stroke Club members for their time and interest.

# APPENDIX

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# XXI

## Appendix XXII

**<u>Definition of anxiety</u>**

The definition of anxiety was drawn from DSM-IV and National Institute for Health and Clinical Excellence clinical guidance 22 (amended)(National Collaborating Centre for Primary Care, 2007).

Interviewees were told that anxiety was the focus of the study and that anxiety was defined as experiences of several of the following:

"Restlessness, sense of dread, feeling on edge, worry, impatience, easily distracted, difficulty concentrating. Physical symptoms of excessive sweating, heart racing, dizziness, shortness of breath, stomach ache, tension in the muscles."

# APPENDIX

# XXIII

**Appendix XXIV**

**Journal Excerpts:**

**27<sup>th</sup> August**

I chose this interviewee because his questionnaire responses contained comments from him that he was keen to participate and his level of anxiety was high, but he had a low level of depression, and he seemed to have fewer ongoing problems. He was also single – and quantitative research suggested that this is the major cause of anxiety for many survivors.

Once again, I found that my questionnaires were not able to identify the breadth of difficulties stroke survivors may be left with. This interview was also shocking because this interviewee really wanted to talk and I felt his need to talk about his experiences was overwhelming. He lives alone and appears to have no one to talk to. I expected his need to talk to be potentially greater so made additional time for this interview in case it was needed. I stayed longer to give him space to talk a bit before and after the interview and I think he could have talked for hours! The use of questions to lift mood at the end of the interview seemed particularly important for him.

I wonder if other health issues are also impacting on anxiety levels. This interviewee seems to have had a number of health issues and it is hard to identify those that may be related to stroke and those to other issues. In addition, the lack of understanding and explanation for his symptoms seems to have been causing him great anxiety.

This interviewee had experiences that were significant to him related to perception, memory and communication. He also felt his loss of independence deeply. I wonder if there are gender related issues involved. He stressed the significant impact of no longer being able to drive or work. He missed being able to go where he wanted.

This may also have related to his previous profession as a lorry driver and he described his childhood as one in which independence was prized and prioritised.

Finances was a key issue – poverty and difficulties getting money to live on.

It seems that this participant's difficulties were less about being single, but more about not knowing how to get help and there being no advocate available to help him. He found sorting out help for himself as deeply stressful. He also struggled to express himself and to get answers regarding his health. He needed an understanding of his problems and felt that this would give him a sense of control.

He also felt his loss of social life, which appears to have been more casual and have depended on his ability to get to work or the pub and on his having money. Perhaps this would be different for women as they may build more of a support network. This interviewee also had no family to provide any support. His partner left him early after his stroke because she could not cope with his difficulties.

These first two interviewees seem so different, I'm wondering whether there are many similarities to explore and to be able to link together to build a coherent story. I also need to be more focussed with my questions, because the interviews are lasting too long and feeling too therapeutic in nature. People seem to want to talk about what actually happened when they had a stroke. Both of these interviewees also said that they had never thought about some of these things before. As a result, I felt responsible to give them a little space to express their feelings. However, I think I need to find a way at the beginning of interviews to focus on my area of research.

These interviews are lasting too long.

**28th August**

I chose this interviewee because he had a high level of anxiety, low depression, and is married. Once again, the carer seemed to have, and wanted to, bring additional information to the interview. She was clearly anxious. The interviewee described his wife as being so anxious that she had mental health difficulties. There is definitely more to be researched regarding the relationship between carer and stroke survivor.

This interviewee had less depression – perhaps due to medication. He also spoke of being protected from worrying things by his wife. Some time after his stroke he learned about some of the problems affecting him and his wife. He was aware of the financial difficulties and spoke of their situation as being desperate. They didn't know where to go for help. The anxiety was therefore present, but carried by the carer.

Gender issues may also have contributed to his anxiety due to his loss of independence and inability to go where he wanted – he was the only driver in his household so he and his wife both lost their mobility.

There were added issues of his wife clearly being very afraid of losing her husband and being very protective, limiting her husband's activities where possible. This interviewee also had physical perceptual difficulties that stopped him engaging in things.

I wonder whether defining anxiety to participants would help the interview to be more focussed and help to encourage the participant to focus on the same things as the interviewer.

**12ᵗʰ November**

I listened to the previous interview twice before this one to adjust my questions and begin to develop my theories.

Fifth interview. A single woman with anxiety – the first single woman I have interviewed – also of working age. She was in a more distant town, so it was quite tiring travelling at the end of a working day. It was surprising how resourceful this interviewee had been. Before her stroke she was skilled, resourceful and had worked in settings that gave her a great deal of information about sources of help. After her first stroke she returned to work. After the second stroke she used her knowledge and skills to solve her own problems as far as possible. She raised the issues of difficulty adapting due to difficulties learning new information.

She spoke of wishing she had a partner to talk to and share things with, which she had not felt before her stroke. However, she had maintained her independence and was taking steps to improve her rehabilitation. She struck me as someone who had a determined and resilient personality that had enabled her to work for her own rehabilitation. She had some memory problems, but these did not seem as extensive as others. She also had a little support from a voluntary agency.

She had a higher level of anxiety, but seems to be much as she was before her stroke. She appeared to be quite a driven person and this may have added to her frustration – she had high expectations of herself that frustrated her when she failed to meet them.

**13th November**

I listened to the fifth interview before meeting this interviewee. This sixth interview was another married man with high levels of anxiety. He was unusual because of his lack of financial difficulties. When asked about them he didn't seem to be aware of them.

His wife seemed to be the main carer and was carrying the bulk of their difficulties. The anxiety seems to be held by the couple and family, not just the survivor. It is a pity that I can't explore this relationship further and interview carers.

He had a son living at home with him who was having great difficulty adapting to his father's stroke. He seems to expect his father to be 'normal' and is treating him badly for not behaving normally.

He used a wheelchair more than the previous interviewees, although he was able to mobilise without the chair. He felt very keenly that he was not listened to and treated as a lesser person for being disabled. He became quite frustrated when he talked about different situations he had felt disempowered and badly treated in.

His anger and anxiety seemed partly justified but he seemed to think that he was entitled to everything that he had access to before no matter what the cost because it wasn't his fault that he was disabled.

**Appendix XXV**

**<u>Chronology</u>**

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|---|---|
| May 2007 | Thesis proposal made |

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| January 2008 | Permission received from local NHS Research Ethics Committee to undertake research |

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| September 2008 | Interviewing began alongside analysis |

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| Mid-December-Mid-January | Delay due to hospital treatment and waiting for results |

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| January 2009 | Interviewing completed |

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| May | Thesis submission |