Making Sense of Depressive Symptoms Associated With Stroke:

A Q Methodological Study

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ABSTRACT

This thesis aimed to investigate depressive symptoms associated with stroke. Depression related to stroke is highly prevalent, not easy to diagnose, with important consequences for prognosis. Specific beliefs patients hold about their physical illness are well known to be important predictors of outcome, and there is now a growing literature on the role of beliefs about mental illness as predictors of outcome. Much less is known about how patients who have had a stroke make sense of their mood symptoms. Research indicates that including depressed patients in decisions about their care results in better outcomes; however, little is known about what treatments depressed stroke patients most prefer, and how this relates to their beliefs about their mood symptoms. Therefore, the aims of the current study were to: 1) Investigate patients' beliefs about their depressive symptoms following a stroke to find out if there are similar patterns in the way they think about them, and 2) to assess stroke patients' preferences for treatment for their depressive symptoms and to see how this relates to their beliefs about their low mood.

Q methodology was used. Twenty stroke patients were recruited who had endorsed depressive symptoms on standardized measures of mood. Patients sorted a wide range of statements about low mood associated with stroke and revealed four distinctive viewpoints: 1) depression due to external, physical factors, an emphasis on physical symptoms and social consequences; 2) highly determined with less worry, the importance of positive social support, helpful environment and a belief that depression will be over quickly; 3) past depression, internal cause, out of control and lasting a long time; 4) strong need for independence and the meaning of physical aids. Frustration, anger and worry, but not out of control. These distinct viewpoints were also associated with quite distinct preferences for treatment. Clinical implications and future research directions were discussed.

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ABBREVIATIONS

AVM: Arteriovenous malformation

PSD: Post-stroke depression

HBM: Health Beliefs Model

SRM: Self-Regulation Model

HADs: Hospital Anxiety and Depression scale

BDI-FS: Beck Depression Inventory – Fast Screen

INTRODUCTION

Background

Depression associated with stroke is an extremely prevalent condition that is not easy to diagnose but has important consequences for prognosis. Despite much research in this area, there is considerably more work to be done to fully recognise it clinically and to fully understand it. One important area within the health psychology literature is the relationship between patients' beliefs about their physical illness and health outcomes. While it is a young literature, researchers are now beginning to understand the importance of patients' beliefs about their mental illness. Therefore, the main aim of this thesis was to gain an understanding of how people make sense of their low mood following a stroke. Also, with the growing emphasis on patient-centred care and the importance of patient involvement in decision-making, another aim of this study was to find out what treatment(s) patients would most prefer for their symptoms of low mood. This introduction will first examine stroke more generally, before discussing the wider literature around depression in chronic illness, depression specific to stroke, patient beliefs and treatment choice.

Stroke

Stroke has been defined by Hatano (1976) as "a focal (or at times global) neurological impairment of sudden onset, and lasting more than 24 hours (or leading to death) and of presumed vascular origin" (p. 3550). Within the Western world, strokes, or cerebrovascular accidents, are the third most common cause of death after heart disease and cancer. The principle predisposing factors typically targeted for treatment include hypertension, heart disease, diabetes, raised serum lipids and smoking (Lishman, 2005). A brief overview of the main subtypes of stroke will first be examined. The epidemiology of stroke, economic burden and other important factors will then be explored.

Stroke subtypes

Classification of the main stroke subtypes can be seen in Table 1. As Lishman (2005) submits, stroke is the common denominator between two main pathological processes leading to brain tissue starvation and death – haemorrhage, or bleed in the brain, and infarction, or disruption of normal blood flow. Small vessel disease associated with hypertension is the most common cause of brain haemorrhage, causing small lipohyalinotic aneurysms that eventually rupture (Donnan, Fisher, Macleod & Davis, 2008). Ruptures can also occur due to other abnormalities, such as arteriovenous malformations, tumour, or deficient coagulation (Lezak, Howieson, Loring, Hannay & Fischer, 2004).

Table 1. Classification of cerebrovascular disease (Robinson, 2006)

Haemorrhagic disorders
Intraparenchymal haemorrhage
Primary (hypertensive) intracerebral haemorrhage
Other causes: haemorrhagic disorders (e.g. thrombocytopenia and clotting disorders) and trauma
Subarachnoid or intraventricular haemorrhage
Ruptured saccular aneurysm or AVM
Other causes
Subdural or epidural haematoma
Ischaemic disorders
Infarction
Atherosclerotic thrombosis
Cerebral embolism
Lacunae
Other causes: arteritis (e.g., infectious or connective tissue disease), cerebral thrombophlebitis, fibromuscular dysplasia, and venous occlusions
Transient Ischemic Attacks

Approximately 10 percent of all strokes are due to intracerebral haemorrhage, which is associated with greater initial stroke severity, higher mortality and greater long-term neurological consequences compared to ischaemic strokes (Chiu, Peterson, Elkind, Rosand, Gerber & Silverstein, 2010). The other main type of haemorrhage occurs within the subarachnoid space and is typically caused by a ruptured intracracial aneurysm, rather than hypertensive small vessel disease (Lishman, 2005). Ischaemic strokes are much more common, accounting for approximately 80 percent of all cases (Donnan et al, 2008). These result from a temporary or permanent reduction in blood flow occurring within one of the main arteries of the brain. In most cases this is caused by an embolus or local thrombosis, leading to occlusion of a cerebral artery (Dirnagl, Iadecola & Moskowitz, 1999).

Morbidity

Morbidity refers to the incidence and prevalence of stroke. In their recent report, the British Heart Foundation (2009) estimated that there are approximately 111,000 cases of first-time strokes every year in the UK. Within those cases, approximately 98,000 are estimated to be ischaemic, and 8,500 are haemorrhagic strokes. Incidence increases rapidly with age with a fairly even gender split. There appears to be similar prevalence in England, Wales, Scotland and Northern Ireland, occurring in about two and three percent of men and women, with the prevalence increasing in older age groups of both genders (British Heart Foundation, 2009). In 2006 there were approximately 585,000 men and 555,000 women in the UK who had had a stroke. The 2004 Health Survey indicated that Black African and Chinese had a relatively low prevalence of one percent, whereas Black Caribbean and Irish were much higher (British Heart Foundation, 2009).

Mortality

About nine percent of deaths around the world are caused by stroke and it is the second most common cause of death after ischaemic heart disease (Donnan et al, 2008). In Western countries, approximately 10-12 percent of deaths are caused by stroke, with 12 percent of these occurring in those under the age of 65. Approximately 25 percent of stroke patients are dead within the first month, 33 percent by six months and 50 percent by one year (Donnan et al, 2008). The authors point out that these early mortality rates are mostly due to neurological deterioration, but also to secondary causes, such as infection. Later deaths are mainly due to cardiac disease or other complications.

Within the UK, stroke accounts for about 53,000 deaths per year, with stroke being the cause of death in five percent of those under the age of 75. Rates are approximately 50 percent higher in Scotland compared to London reflecting a north-south gradient. There is also a three-fold increase in the most socio-economically deprived areas compared to the least deprived, and in men born in Bangladesh compared to men born in England and Wales (British Heart Foundation, 2009).

Economic burden

With a consideration for diagnosis, inpatient and outpatient care, income loss and social benefit payments, Saka, McGuire and Wolfe (2009) estimated the UK societal cost of stroke to be £8.9 billion per year, with the burden on the NHS being approximately £2.8 billion per year (Department of Health, 2005).

Risk factors

The latest guidelines by the American Stroke Association for the primary prevention of stroke (2011) distinguish between non-modifiable and modifiable risk factors. For example, "The cumulative effects of aging on the cardiovascular system and progressive nature of stroke risk factors over a prolonged period substantially increase the risks of both ischemic stroke and intracerebral haemorrhage" (p. 519). The risk of stroke doubles each decade after the age of 55 (Guidelines for the Primary Prevention of Stroke, 2011). Other non-modifiable factors include low birth weight, race / ethnicity and genetic factors. The most evidenced modifiable risk factor is hypertension, with treatment of hypertension being one of the best strategies for stroke prevention. Other modifiable risk factors include smoking, diabetes, high cholesterol, sickle cell disease, poor diet / nutrition, lack of physical activity and drug abuse (Guidelines for the Primary Prevention of Stroke, 2011).

Diagnosis

With clear evidence that rapid treatment improves outcome after stroke, the NICE guidelines for stroke diagnosis and initial management (2008) stress that rapid recognition of symptoms is primary. The guidelines stipulate that outside of the hospital, the Face Arm Speech Test (FAST) should be used as a brief screen. Developed in 1998 by stroke physicians and paramedics, the FAST test was designed as a training tool for UK ambulance staff and has been found to achieve high levels of detection and diagnostic accuracy (Harbison, Hossain, Jenkinson, Davis, Louw & Ford, 2003). The NICE guidelines also stipulate that hypoglycaemia should be ruled out with sudden-onset symptoms and that

patients admitted to A&E should have the diagnosis established rapidly using a validated tool, such as the ROSIER (Recognition of Stroke in the Emergency Room).

Consequences

Physical symptoms following a stroke are diverse, and are useful in making diagnoses as they are dependent on the type, location and severity of the underlying damage (Bogousslavsky & Caplan, 2001). For example, strokes within the vascular distribution of the carotid / anterior circulation often cause contralateral paralysis or weakness, sensory loss and visual field loss. Disruption to the anterior cerebral arteries also has distinct symptoms, such as weakness in the opposite leg, incontinence, abulia, facial and proximal arm weakness, for some examples (Teasell, Bayona & Heitzner, 2008). Specific symptom profiles inform which of the anterior arteries are likely involved. Strokes involving the middle cerebral artery account for most of ischemic strokes and lead to much the same clinical consequences mentioned above, although facial / upper extremity dysfunction is more prevalent (Teasell et al, 2008).

Most of the consequences of stroke are lateralized, and so it is useful to consider the range of deficits that frequently occur with left / right lesions. For example, right hemisphere involvement typically leads to visuo-perceptual deficits including unilateral neglect, figure ground disorientation and constructional apraxia. Emotional disorders are also common, such as flat affect and emotional lability. Subtle communication difficulties, such as with turn-taking and the use and comprehension of jokes and irony can also occur with right-sided lesions (Teasell et al, 2008). Regarding left-sided lesions, Teasell and colleagues (2008) point out that 97 percent of people have language controlled primarily by the left hemisphere. Language disorders following stroke are termed *aphasia*, and Broca's aphasia, or difficulty with speech production, is the most common type in left hemisphere strokes (Teasell et al, 2008).

The World Health Organization (2008) classifies the impact of stroke within the following four dimensions: 1) the loss of bodily functions and structures such as many of those already discussed (e.g. hemiparesis, cognitive dysfunction), 2) activities limitations, such as difficulties with performing tasks of everyday living (e.g. telephone use), 3) participation restrictions, such as problems returning to work due to poor mobility or cognitive deficits and 4) contextual factors, which are unique to each individual, including internal attributes such as the person's gender, ethnicity, comorbid conditions, family support, etc. (Miller et al, 2010).

Acute Treatment

As Donnan and colleagues (2008) indicate, the most substantial recent advance in stroke care has been the creation of specialist stroke care units (SCU) which have been shown to reduce mortality and functional outcome by about 20 percent. Improved blood pressure control, early mobilisation and overall adherence to best practice are probable reasons for this (Donnan et al 2008). Within the acute stage following stroke, steroids can help in reducing cerebral oedema and there is good evidence for low dosage aspirin in reducing the chance of further strokes and death (Lishman, 2005).

Thrombolysis, or breakdown of blood clots, via tissue plasminogen activator (tPA) is the most biologically effective treatment of acute ischaemic stroke; however, the very short treatment window, shortage of expertise and funding means that most stroke units typically only use it with five percent of patients (Donnan et al, 2008). Finally, decompressive surgery has proven efficacy for the small number of acute ischaemic cases where it is warranted, such as in fatal brain oedema, for example (Donnan et al, 2008).

Rehabilitation

Recovery following stroke is often spontaneous and is typically a slow process. The mechanisms underlying gains in rehabilitation are not completely understood, but are thought to involve the transfer of functions to unaffected brain areas, brain reorganisation and the removal of inhibitory influences from intact regions (Lishman, 2005). As Miller and colleagues (2010) illustrate, successful rehabilitation must consider all of the dimensions affected and their interactions (i.e. the impact of cognitive deficits on social interaction), and that a multidisciplinary approach is paramount for appropriate care.

Stroke teams typically involve a range of professionals with particular expertise in the problems encountered. For example, neuropsychologists help with assessing and treating cognitive and neurobehavioural deficits. Occupational therapists help patients with skills of daily living, developing treatment programs, comprehensive home and employment assessments, adaptive equipment, etc (Miller et al, 2010). Apart from various other duties, specialist nurses act as treatment coordinators, liaising with other members of the team. Physiotherapists aim to treat neuromuscular problems that impact on mobility. Physicians manage the rehabilitation team and treat the medical conditions specific to the stroke as well as any comorbidities (Miller et al, 2010). Social workers help with identifying resources available to individuals and their families, prevent crises, counsel patients and families. Finally, speech and language therapists provide interventions to assess and treat various

speech disorders, as well as other cognitive functions (Miller et al, 2010). Now that some background on stroke has been explored, it is useful to discuss depression in chronic illness before focusing on depression specific to stroke.

Depression in chronic illness

Introduction

The term 'depression' refers to a wide range of mental health problems associated with an absence of a positive affect, low mood and a range of emotional, cognitive, physical and behavioural symptoms (NICE, 2009). The term can refer to diagnosable psychiatric disorders, as well as depressive symptoms found within the normal population (DOH, 2006). The identification of major depression is problematic as there is not a firm cut-point between 'clinically significant' and 'normal' depression and clinicians must include indications of severity, other symptomology, as well as functional impairments when making diagnoses (NICE, 2009). The epidemiology of depression in chronic illness will now be explored, along with a summary of its relationship to health outcomes.

Epidemiology

Katon (2003) reviewed the epidemiological literature with the major long-term health conditions including myocardial infarction, diabetes, HIV, cancer, stroke and Parkinson's disease, with several meta-analyses showing higher rates of depression amongst these patients compared to those without the illnesses. For example, diabetics were shown to be twice as likely to suffer with major depression compared to non-diabetics, and patients infected with HIV were found to have a two-fold higher rate compared to controls (Katon, 2003). Depression has been found to be three times higher in patients after an acute myocardial infarction compared to those in the general population, with estimates that 15-20 percent of these patients meeting the Diagnostic and Statistical Manual of Mental Disorders criteria for major depression (Lichtman et al, 2008).

Depression has also been found to be highly prevalent within neurological conditions. For example, it is estimated to be anywhere from 20-30 percent in Parkinson's disease, 16-30 percent in multiple sclerosis and between five and 54 percent in stroke (Katon, 2003). It has been argued that neurological illness may impact on neural circuitry involved with mood regulation and that ischaemic brain disease may be a risk factor for the

development of depression in aging populations (Katon, 2003). There is also evidence of a two-way relationship between depression and other chronic illnesses. For example, premorbid depression has been shown to be a risk factor for diabetes (Knol, Twisk, Beekman, Heine & Pouwer, 2006) and dementia (Saczynski, Beiser, Seshadri, Auerbach, Wolf & Au, 2010).

Reciprocal relationship

As mentioned, there is evidence for a two-way relationship, with many studies showing that chronic illness leads to depression, and that depression itself is an important risk factor for many illnesses (NICE, 2009). On the one hand, the widely cited Canadian study by Patton (2001) followed a group of 11,859 people over a two-year period showing physical illness to be a significant risk factor for major depression. The risk was found to be comparable in a range of conditions, including hypertension, asthma, arthritis, heart disease, etc. (NICE, 2009). Potential pathways for which physical illness may lead to depression include the additive effects of pain on emotional distress, the onset of disability in previously healthy individuals, and physical changes making it more difficult for the body to adapt to stress (NICE, 2009).

On the other hand, the NICE guidance for depression in adults with chronic physical health problems (2009) also cite several prospective studies showing that depression is a risk factor for many chronic illness, such as coronary heart disease, heart attack, stroke, colorectal cancer, back pain, irritable bowel syndrome, multiple sclerosis and diabetes. It also lists potential physical mechanisms such as an increase in inflammation, autonomic nervous system changes, electrocardiogram changes, immune system changes (NICE, 2009).

Consequences

There is some evidence that depression may lead to shorter life expectancy and lead to poorer quality of life (NICE, 2009). Furthermore, there is evidence showing higher rates of negative health-related behaviours, such as being sedentary, smoking and over-eating, as well as poor adherence to treatment regimes (Katon, 2003).

Depression following stroke is an extremely prevalent condition that has important consequences for prognosis. While extensively studied, there still appears to be much controversy within the literature regarding diagnosis, aetiology, risk factors and the overall pattern of the condition (Kouwenhoven, Kirkevold, Engedal & Hesook, 2011). The prevalence, diagnosis and factors associated with post-stroke depression (PSD) will now be explored.

Prevalence

As Robinson (2006) submits, the prevalence of post-stroke depression (PSD) has been assessed in numerous studies around the world, but reaching firm conclusions is problematic due to many factors. For example, within Whyte and Mulsant's (2002) review, the prevalence varied considerably between studies, with a much higher incidence found in hospital samples compared to patients being treated in the community. A more recent systematic review of 40 studies also showed a wide range of prevalence (5-54 percent), with much inconsistency of measurement tools used (Kouwenhoven, Kirkevold, Engedal & Kim, 2011). These authors also found evidence for continuation of PSD 12 months following stroke and a link between depression and mortality at 12 and 24 months. Also, using a cut-off score of ≥ 8 on the Hospital Anxiety and Depression (HAD) scale, a large multicentre study of 532 patients showed an incidence between 24 and 30 percent (De Wit et al, 2008).

Stroke as cause and consequence

As previously mentioned, there is a reciprocal role between depression and many chronic illnesses, where depression can be seen as a risk factor, as well as a consequence, of a chronic physical condition. One hypothesised mechanism within stroke is that depression caused by stressful life events leads to micro damage within the brain, such as inflammation, atrophy within the hippocampus and prefrontal cortex, a decrease in neurogenesis and an increase in apoptosis (markers of cell death). Normal repair mechanisms may fail if the depression and inflammation become chronic (Wager-Smith & Markou, 2011).

Diagnosis

With the high prevalence and impact on outcome, the National Clinical Guidelines for Stroke (2008) recommend that every patient entering rehabilitation be screened for depression using a validated simple screening test (Kneebone et al, 2010). While this practice is currently on the rise, many argue that a brief screen is simply not enough. For example, Hackett et al (2010) reviewed data from two prospective stroke studies totalling 1262 patients, 492 of which were from the Leeds and Bradford areas. In these studies, a standardized screen was utilized along with a single question – "do you often feel sad and depressed?" Interestingly, up to 28 percent of the people who did not meet the study criteria for depression reported important negative cognitions (i.e. hopelessness, worthlessness, suicidal thoughts). The authors conclude that screening is no replacement for a sensitive exploration of the psychological impact on each individual.

Paolucci (2008) submits that diagnosis of PSD is problematic as the presence of somatic symptoms caused by the medical illness can lead to over-diagnosis, while factors such as cognitive impairment or inadequate knowledge by physicians can lead to under-diagnosis. The author also points out that commonly-used rating scales, such as the Hamilton Depression Rating Scale or the Beck Depression Inventory, are not useful for differentiating the somatic symptoms of depression compared with the physical symptoms of stroke. For example, loss of appetite or sleep disturbance may be a side effect of stroke rather than a mood disorder (Paolucci, 2008). Interestingly, Ried, Jia, Cameon, Feng, Wang and Tueth (2010) investigated 790 older adult stroke patients and found that nearly 10 percent had depression before their stroke. Also, those patients with a premorbid diagnosis of depression were significantly more likely to receive a diagnosis of PSD and more likely to receive antidepressants. Similarly, within Williams' (2005) trial, 30 percent of stroke patients reported taking antidepressants at the time of their stroke. The author points out that many researchers apply the term 'post-stroke depression' to patients, regardless of whether their depression was actually present beforehand.

Further complicating the issue is the fact that many patients may under-report depressive symptoms. For example, Hunt, Auriemma & Cashaw (2003) devised a unique experiment to see if people would report more depressive symptoms on the Beck Depression Inventory when its purpose as a measure of depression was hidden. Within their sample of 238 participants, people significantly reported fewer symptoms in the overt condition. Furthermore, within the overt condition, only 13 percent scored above the cut-off threshold of 15 for depression, whereas in the covert condition, 34 percent were above cut-off. Bell

and colleagues (2011) investigated the reasons why people would under-report symptoms of depression within primary care. In their large telephone survey, reasons given included a fear of being referred to a psychiatrist, belief in symptom severity, perceived stigma and an absence of family history.

Consequences

Numerous studies have shown PSD to be associated with poorer outcomes, including longer hospital stays, reduced participation in rehabilitation, functional dependence (Schmid, Kroenke, Hendrie, Bakas, Sutherland & Williams, 2011) and even an increased risk of death (Ellis, Zhao & Egede, 2010). For example, in a longitudinal study of 444 patients assessed within 2-6 weeks following stroke and then again at 9, 13, 26 and 52 weeks, there was a strong association between persistent psychological symptoms and functional outcome at 52 weeks (West, Hill, Hewison, Knapp, House, 2010). The other important implication of this research was the conclusion that initial high scores on screening tools do not necessarily predict lasting high scores, and that the pattern of persistent depressive symptoms for each individual should be identified via interview and repeated observations (West, Hill, Hewison, Knapp, House, 2010).

Specific symptoms of stroke have been identified to be associated with PSD, such as functional impairment including poor mobility, although the direction of causation remains to be clarified (Salter, Bhogal, Teasell, Foley & Speechley, 2008). Likewise, cognitive impairment, particularly problems with memory, visual perception and language, has been shown to be much more common in PSD (Nys et al, 2005), although again, teasing out cause and effect is problematic. There is also some evidence to suggest that PSD leads to a reduction in, and satisfaction with, social contact. Social withdrawal can result if patients' sense of self-efficacy or self-image have been affected (Salter et al, 2008).

Stroke characteristics

Much research has tried to determine if the hemispheric location of the lesion is related to depression. Untangling this relationship remains problematic, however, due to the various classification systems used and the wide range of findings (Kouwenhoven et al, 2011). Other researchers have proposed that generalised vascular changes within the brain have a negative impact on mood regulation, while other research has stressed the importance of cognitive and functional impairment, rather than putting it down to purely physical processes (Kouwenhoven et al, 2011).

Treatment

Treatment of post-stroke depression typically involves medications and / or psychosocial interventions. Drug therapy is based on the assumption that there is an imbalance and under-activity of noradrenergic and seretonergic neurotransmitter systems (Salter et al, 2008). Hackett, Anderson and House (2005) conducted a systematic review of the literature and concluded that, while there is some evidence of improved mood with antidepressant use, it is not known if it is clinically significant. They also stated that there was insufficient evidence to justify antidepressant use in routine practice considering the potential side effects. Robinson and colleagues (2008) compared the antidepressant escitalopram with problem-solving therapy against a placebo and concluded that both treatments led to a significant reduction in depression incidence over a 12-month period; however, in a more conservative analysis the problem-solving treatment failed to reach significance over placebo (Robinson et al, 2008).

Salter and colleagues (2008) reviewed the literature on pharmacological treatment of PSD and concluded that there is strong evidence that antidepressants for PSD are positively associated with functional recovery and also have a prolonged, protective effect on survival rates. They also concluded that there was very little evidence for psychological therapies as solitary treatments for PSD, but that they have shown to be effective alongside antidepressants (Salter et al, 2008).

The Department of Health's National Stroke Strategy (2007) stipulates that both patients and carers struggling to adjust to the effects of illness require access to emotional support services, with referral to psychological or psychiatric services when needed. They recommend that these support services are part of a coordinated programme of care, beginning with support in the hospital, and then with longer-term support provided by the voluntary sector. The recent NICE Quality Standards for Depression in Adults (2011) also stipulate the need for coordinated care to treat depression in chronic illness, with strong links between primary and secondary services. Regarding psychological adjustment to illness, one widely studied area is the powerful role of health beliefs.

Health beliefs model

Initially developed by Rosenstock (1966), the Health Beliefs Model (HBM) predicts that health-related behaviour is a result of a specific set of core beliefs involving the following dimensions: 1) the patients' perceived susceptibility to the illness, 2) the perceived illness severity, 3) the potential costs or 4) benefits to carrying out health-related behaviours, and finally 5) any internal or external cues to action, such as feeling a symptom onset, or receiving external information in a health education leaflet (Ogden, 2007).

This model has been used in a wide range of illnesses and has shown some utility in predicting help-seeking behaviours. For example, Kivlahan, Sloan & Haselkorn (2007) found that a focus on the perceived benefits of treatment predicted adherence in patients with multiple sclerosis. Perceptions of greater illness severity, perceived benefits, fewer perceived barriers and greater cues for action predicted participation in cancer support groups (Sherman, 2008). It has also been used to predict adherence to screening for hypertension and cervical cancer, and to predict changes in alcohol use, diet and smoking (Ogden, 2007). Levinson and Druss (2005) reported that older adults with symptoms of depression were more likely to believe that they were susceptible to chronic conditions and that they were more severe.

While the HBM was devised to understand help-seeking behaviours related to physical illness, there has been a small amount of research showing its applicability within mental health. For example, Waite and Killian (2008) examined a focus group of 14 individuals who had received treatment for depression and found that their behaviours that led them to seek treatment could be usefully understood using the HBM. Much research has shown that men seek help for depression less often than women. Social norms about masculinity and inhibition of emotional expression impacting on symptom perception are two of the identified barriers (Möller-Leimkühler, 2005).

Self-regulation model

Leventhal and colleagues (e.g. Leventhal & Nerenz, 1985) developed the self-regulation model (SRM) in order to better explain adjustment to illness. Their model proposes that health behaviours are the result of complex illness representations that people actively construct when faced with a diagnosis (Sharpe & Curran, 2006). These representations encompass five main areas: the perceived identity, cause, consequences, cure / control and timeline of the illness. This model is referred to as *self-regulatory,* as patients facing a diagnosis are considered to be active 'problem solvers', with adjustment occurring through three main stages: interpretation, coping and appraisal (Ogden, 2007). As Sharpe and Curran (2006) indicate, these representations are believed to have two levels – the abstract and the concrete, and these also have two levels: cognitive and affective. For example, when a patient faces a new diagnosis, they may draw on health information as well as personal experience, which may lead them to have a large, negative emotional reaction, guiding the actions they take.

Illness representations have been shown to be good predictors of outcome in a range of conditions. For example, French, Cooper and Weinman (2006) found that cardiac patients with positive perceptions of identity, cure / control, consequences and coherence were more likely to access rehabilitation following myocardial infarction. Negative perceptions about time and consequences were predictors of poor adherence to fluid and salt intake in hemodialysis patients (Chilcot, Wellsted, & Farrington, 2010). Beliefs about the consequences of pain predicted outcome at six-month follow-up in 152 chronic oral pain patients, and were more powerful predictors than both pain and mood (Galli, Ettlin, Palla, Ehlert & Gaab, 2010). Furthermore, Frostholme et al (2007) found negative illness perceptions predicted worse prospective health at 12 and 24-month follow-up in 1785 primary care patients.

Regarding stroke, recent work by Twiddy, House and Jones (2012) indicated a discrepancy between the illness representations held by stroke patients and carers that was associated with higher carer distress. Also, depressed stroke patients who perceive their social support as adequate have been found to have a shorter duration of mood symptoms following stroke (Morris, Robinson, Raphael & Bishop, 1991), which ties into the known evidence-base confirming the powerful role of perceived social support in physical and psychological outcomes (e.g. Moak & Agrawal, 2010).

Illness representations as predictors of depression

As Sharp and Curran (2006) submit, illness representations have been found to be related to emotional adjustment and recovery within a wide range of illnesses. For example, Juergens, Seekatz, Moosdorf, Petrie & Rief (2010) found that patients' beliefs about their cardiac surgery predicted health-related outcomes including depression after three months. Health beliefs have also been found to be significant predictors of depressive symptoms in patients with coronary artery disease (Stafford, Berk & Jackson, 2009) and changes in health beliefs have been shown to predict changes in depression in oesophageal cancer (Dempster, McCorry, Brennan, Donnelly, Murray & Johnston, 2011). Ibrahim and Chiew-Tong (2011) demonstrated that end-stage renal patients who perceived more symptoms, more frequent cyclic illness, more consequences, higher emotional reactions and more causes were more depressed compared to those who had a greater sense of personal and treatment control. Most of these studies conclude with the implication that maladaptive beliefs should be targeted clinically.

Illness representation interventions

There is a growing literature on how targeting specific illness representations can have a positive effect on both psychological and health outcomes. The representational approach to patient education, first developed by Donovan and Ward (2001), is a process whereby the clinician identifies patients' beliefs according to the five dimensions of the SRM, including any gaps or confusions they may have, as well as their beliefs about how they came to those conclusions. Using a cognitive behavioural approach, they then encourage patients to think about problems and consequences associated with their beliefs, making direct links between maladaptive beliefs and negative consequences, for example. The clinician then fills the gaps by providing new, more adaptive information and discusses the likely positive consequences that would result. Donovan and colleagues (2007) indicate that this approach has been shown to reduce subjective pain in cancer, to help patients articulate and make decisions about their care, and to increase adaptive self-care behaviours in breast cancer patients.

Broadbent, Ellis, Thomas, Gamble and Petrie (2009) conducted a randomised-controlled trial demonstrating that a brief intervention with spouses of heart attack patients led to less anxiety about physical activity, about medications and less distress about physical symptoms. Similarly, a brief intervention targeting specific illness representations following heat attack led to a faster return to work and less reported symptoms of angina

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compared to controls (Petrie, Cameron, Ellis, Buick & Weinman, 2002). Watkins and colleagues (2011) assessed the effect of a brief motivational interviewing programme with 411 stroke patients and found a significant decrease in depression incidence and mortality at 12 months. Within this programme, clinicians elicited patients' perceived barriers to obtaining their recovery goals and supported their sense of self-efficacy in finding their own solutions.

As can be seen, most of the research to date has explored representations of *physical* illness using the SRM; however there is a growing body of evidence that the way patients think about their mental illness is also important.

Representations of mental illness

Lobban, Barrowclough and Jones (2003) reviewed the literature and assessed the validity of the SRM with reference to mental illness, concluding that the beliefs people hold about their mental illness are consistent with the model. A recent systematic review by Alderson , Glidewell, McLintock and House (2012) examined 38 qualitative and two mixed-methods studies looking at chronically ill patients' beliefs about their depression. Of these studies, 57 different topics were covered with 77 percent containing verbatim text. Topics covered typically fell within the five domains of the SRM - in other words, as with physical illness, when patients spoke about their depression, they typically spoke about it with relation to its identity, cause, consequences, cure / control and timeline.

Interestingly, 14 topics did not fit into the SRM and four new domains were uncovered: emotion, existential and self, depression cycle, stigma, and blame & responsibility (Alderson et al, 2012). Also, within four qualitative studies, patients were not always coherent in their descriptions of their depression. For example, some patients held conflicting beliefs, some changed their beliefs while discussing them, while others simply did not understand their depression and so had unfixed beliefs. Also, suicide was considered a consequence by some, but was thought of as a means of coping by others (Alderson et al, 2012).

As with physical illness, beliefs about depression can influence health-seeking behaviours, coping strategies, adherence to treatment, as well as the choice and effectiveness of treatments offered. For example, studies have shown that a belief in biological causes of depression can influence confidence in antidepressant treatment and help seeking, whereas a disagreement about biological causation can lead patients to not accept the diagnosis at all (Hansson, Chotai and Bodlund, 2010). Research has shown that depressed patients who

reported higher self-efficacy, or the belief that they had more control over their depression, attended to their mood symptoms more and are were more likely to take action to try and improve them. Furthermore, those who endorsed external causes for their depression (i.e. that it was due to something that happened to them) were also more likely to take action, whereas patients who attributed their depression to internal causes had more dysfunctional attitudes, worries, rumination, and were less likely to take action to try and elevate their mood (Manber, Chambers, McGahuey, Delgado & Allen, 2003).

In their review of 71 studies, Prins, Verhaak, Bensing and van der Meer (2008) found that patients gave multiple explanations for the cause of their depression and tended to believe psychological treatments were the best option. They were more likely to endorse biological causes compared to lay people, and compared to those with less severe depression. Interestingly, previous studies have shown that lay people tend to favour psychosocial causes for depression (e.g. Jorm, 2000), whereas clinicians are more likely to favour biological causes (Ogden, 1999).

 Srinivasan, Cohen and Parikh (2003) assessed beliefs about the cause of depression in 102 individuals and found that they most endorsed stress and negative life experiences to be the cause, and least endorsed spiritual or religious factors. They also found that women were more likely to endorse a biological abnormality as the cause compared to men and they also tended to endorse the notion that it was due to their cognitions more often than men. In their study of 303 depressed primary care patients, Hansson et al (2010) found that patients tended to favour psychosocial causes for their depression, which could be summarised into three main themes: current life stressors, past life events and constitutional factors.

Regarding consequences, Lobban, Barrowclough and Jones (2004) used the SRM as a guide to assess 124 patients' beliefs about their schizophrenia. They found that negative beliefs about consequences were significant predictors of poor outcomes, in both cross-sectional and longitudinal analyses. Most of the research to date has focused on perceived consequence of stigma related to mental illness. Livingston and Boyd (2010) conducted a systematic review and meta-analysis of this literature and found a robust, negative relationship between internal feelings of stigma and variables such as hope, self-esteem and empowerment. It was also related to poorer adherence to treatment and greater severity of mental illness symptoms. Roeloffs et al (2003) found that depressed primary care patients in America expected stigma to lead to negative consequences for their employment, health insurance and on their friendships. There is also some evidence that suggests people with a past history of depression rate interpersonal difficulties as more important compared to those

who were experiencing their first episode (Wernicke, Pearlman, Thorndike & Haaga, 2006). The authors also noted that people with more severe depression rated it as more distressing and debilitating compared to those with less severe mood symptoms.

Beliefs about depression in stroke

Surprisingly, there are very few published studies that specifically evaluate stroke patients' beliefs about their depression. Klinedinst (2008) utilised the SRM and found that stroke survivors tended to label depressive symptoms as 'upset', 'depressed' or 'angry'. Causes were conceptualised as due to 'stroke', 'stress' or 'worry' and that both patients and carers thought that the depressive symptoms were controllable with little consequences. Roger and Johnson-Greene (2008) found an age cohort effect in acute stroke patients' attitudes towards their depression, with older participants more likely to view depression as a personal failure requiring no treatment. While informative, these two studies were somewhat limited in scope in relation to patients' beliefs, with the former following the dimensions of the SRM, and the latter only utilising a very brief measure consisting of three statements. There is some evidence that stroke patients with significant levels of depressive symptoms recognise clusters of symptoms as potentially being depression (Klinedinst, Dunbar & Clark, 2012).

What this literature indicates is that there is a wide range of beliefs people may hold about their mental illness and, as in physical health, certain maladaptive beliefs can be conceptualised as risk factors for poor outcome. Another area that is also closely related to outcome is patients' involvement in decision-making, particularly their preferences for treatment. Integrating this into everyday practice, however, is not straightforward.

Morecroft (2006) points out the fact that most published clinical guidance is based upon evidence provided by systematic reviews and meta-analyses of randomised-controlled trials (RCT's). Guidelines such as those produced by the National Institute for Clinical Excellence and the National Service Framework make clear what clinical practice in the UK should look like. However, the authors rightly point out that integrating this into real-world practice is not always straightforward. For example, GP's may be reluctant to alter prescribing habits due to personal and professional experiences, and have voiced concern over the applicability of research data to individual patients (Morecroft, 2006). Patients and clinicians may simply have different ideas about which treatment is best. For example, Hodges and colleagues (2009) analysed treatment preferences for 100 depressed cancer patients and found significant differences between treatments that clinicians preferred versus what patients wanted. Patients most preferred talking treatments alone, whereas GP's preferred a combination of drug and talking treatments. Nevertheless, patients, including those who have had a stroke, value involvement in decision-making about their care (Slot & Berge, 2009).

So it can be seen that there is some tension between offering evidence-based practice and patient-centred care. The Department of Health (2001) submits that the expertise held by patients, if utilised, could greatly benefit the quality of their care and subsequently their quality of life. They emphasise that, given enough information to enable empowerment, patients can become key decision-makers in their treatment.

Patient choice and health outcomes

As Bryant, Bown, Bekker and House (2008) point out, within the 2006 government White Paper 'Our health, our care, our say' the word 'choice' appears a total of 95 times. Similarly, the 2008 White Paper, 'Choice matters, putting patients in control' emphasises that patients want more choice over their health care, they want the right for information to help them make informed choices and that they want services to be shaped around their needs. With this emphasis on patient choice, it is important to consider the impact of this on health outcomes.

Lin and colleagues (2005) conducted a study with depressed primary care patients, offering them the choice between anti-depressants and / or counselling. Those participants who received the treatment of their choice showed more rapid improvement in their depression when measured at three and nine months. Interestingly, patients who preferred medication were older, in poorer physical health and were typically already taking anti-depressants. Other research has also shown that people who choose psychotherapy for depression do better compared to those who are assigned it (e.g. Chilvers et al, 2001). This is not to say that every patient will necessarily want to be involved in decision-making. Research has shown that mutual agreement between clinicians and patients in how much involvement they wish to have results in better outcomes, including greater levels of satisfaction with care (Jahng, Martin, Golin & DiMatteo, 2005).

One well-known factor affecting outcome is the level of patient adherence to treatment regimes. Totman (1976) conducted an interesting experiment utilising placebo sleeping pills. One group of patients were given the choice between two different looking pills, while the other were just given the one. While both groups of patients unknowingly took an inert substance, the ones who were given the decision benefitted more and voiced greater satisfaction (as cited in Salmon, 2001). Research such as this is backed up by countless social psychology studies showing that when people perceive that they have made a choice by their own volition, they are more committed to it and more willing to change their behaviour accordingly (Salmon, 2001).

Patients given a choice over tuberculosis drugs were more likely to complete treatment (Rennie, Bothamley, Engova & Bates, 2007) and adherence improved with choice in depressed patients being seen in primary care (Loh, Wills, Kriston, Niebling & Harter, 2007). In this latter study, patients who were involved in shared decision-making also reported greater satisfaction with their care. A large European survey of over 45,000 patients found that involvement in decision-making and being treated as equals predicted their adherence to medication (Stavropoulou, 2011).

Summary and aims

To sum up, stroke is a highly prevalent condition with significant consequences, both economically, as well as physically and psychosocially. Depression associated with stroke is also highly prevalent with important consequences upon outcomes. We know much about the impact of patients' beliefs about their physical condition, which is translating into treatments that identify and target maladaptive beliefs. There is also a growing literature on the impact of patients' beliefs about their mental illness upon outcomes. However, much less is known about how patients who have had a stroke make sense of their symptoms of low mood.

There is a growing emphasis for greater patient involvement in decisions about their care, including treatment choice. This has been shown to increase adherence to treatment regimes and improve patient satisfaction and health outcomes. We know that including depressed patients in decisions about their treatment results in better outcomes; however, little is known about what treatments depressed patients most prefer following a stroke, and how this relates to their beliefs about their mood symptoms. Therefore, the aims of the current study were to:

- Investigate patients' beliefs about their depressive symptoms following a stroke, to find out if there are similar patterns in the way they think about them.
- To assess stroke patients' preferences for treatment for their symptoms of low mood and to see how this relates to their beliefs about their mood symptoms.

The next section will introduce Q methodology as a means of investigating patients' beliefs and preferences for treatment, before going on to describe how it was used to implement the current investigation.

METHOD

Introduction to Q methodology

Background

Created by William Stephenson (1935), Q methodology aims to scientifically investigate human subjectivity (Mckeown & Thomas, 1988). Subjectivity, in this sense, means nothing more than someone's communication of their own point of view, their 'internal' frame of reference (Watts & Stenner, 2005). Psychological testing was widely adopted by positivistic psychology in the early part of the 20th century, giving rise to tools such as correlational R methodology and factor analysis. However, as Stainton Rogers (1995) indicates, there was an interesting paradox, as psychological tests seemed better suited to reveal commonalities between *tests* rather than between people. It was this notion – that there were fundamental limitations with the ability of psychometrics to tap into underlying mechanisms / traits - which led Stephenson to develop Q methodology (Stainton Rogers, 1995).

Within this method, participants, termed the P set, are presented with a sample of statements about a topic, called the Q set, and are asked to rank order them according to some preference, judgement or feeling (Van Exel & Graff, 2005). The statements are typically printed onto cards, handed to the participants, who then sort them according to how much they agree or disagree with them by placing the cards onto a quasi-normally distributed grid. By completing this sorting task, participants reveal their subjective point of view (Van Exel & Graff, 2005). It is important to note that the subjective point of view being sought is therefore not free or spontaneous, but is about where the participant stands in relation to comments made by others.

P set

Within Q methodology, it is the Q set, not the participants, that make up the sample. Nevertheless, the P set are typically selected on the basis that the topic under investigation has unique relevance to them – that they are likely to have interesting or pivotal opinions about a given subject (Watts & Stenner, 2012). The number of participants is much smaller compared to R methodological studies because the aim is to establish particular viewpoints,

and to be able to compare and contrast them, rather than to necessarily generalise to the wider population. Watts & Stenner (2005) submit that participant groups are likely most effective when they contain between 40-60 participants; however, the authors go on to explain that "this is only a rule-of-thumb, however, for highly effective Q studies can be carried out with far fewer participants" (p. 79). Also, selecting participants that adequately represent specific demographic variables may be useful, but only if there are theoretical reasons why they may have differing viewpoints. As Watts & Stenner (2005) explain, Q methodology is exploratory in nature, therefore the best procedure for selecting participants is to not have too many preconceptions, but to instead allow participants to categorise themselves.

The Q set

The statements which make up the Q set are developed from a concourse of all the possible viewpoints on a given subject. The development of the concourse and subsequent Q set has been described as more of an art than science, with the main aim of gathering a broadly representative sample of viewpoints of a given subject (Watts & Stenner, 2005). Whereas in R methodology the sample of participants is thought to be broadly representative of the wider population of interest, in Q methodology it is the sample of statements that make up the Q set that should broadly represent the wider population of viewpoints (Watts & Stenner, 2005). This can be achieved in numerous ways, such as consulting the academic literature, qualitative interviews, informal discussions, popular magazines, etc. Usual practice is to first organise the concourse into categories, themes or domains, and then derive the Q sort by sampling from each (similar to quota sampling). This is a way of ensuring all viewpoints are included and reduces the potential for bias within the Q set.

Figure 1. Example Q sort grid (Cross, 2005).

```
  -5   -4   -3   -2   -1    0    1    2    3    4    5
!----!----!----!----!----!----!----!----!----!----!----!
!    !    !    !    !    !    !    !    !    !    !    !    !
!----!----!----!----!----!----!----!----!----!----!----!
!    !    !    !    !    !    !    !    !    !    !    !    !
!----!----!----!----!----!----!----!----!----!----!----!
     !    !    !    !    !    !    !    !    !    !
     !----!----!----!----!----!----!----!----!----!
     !    !    !    !    !    !    !    !    !    !
     !----!----!----!----!----!----!----!----!----!
          !    !    !    !    !    !    !    !
          !----!----!----!----!----!----!----!
          !    !    !    !    !    !
          !----!----!----!----!----!----!
               !    !    !    !
               !----!----!----!
               !    !
               !----!
```
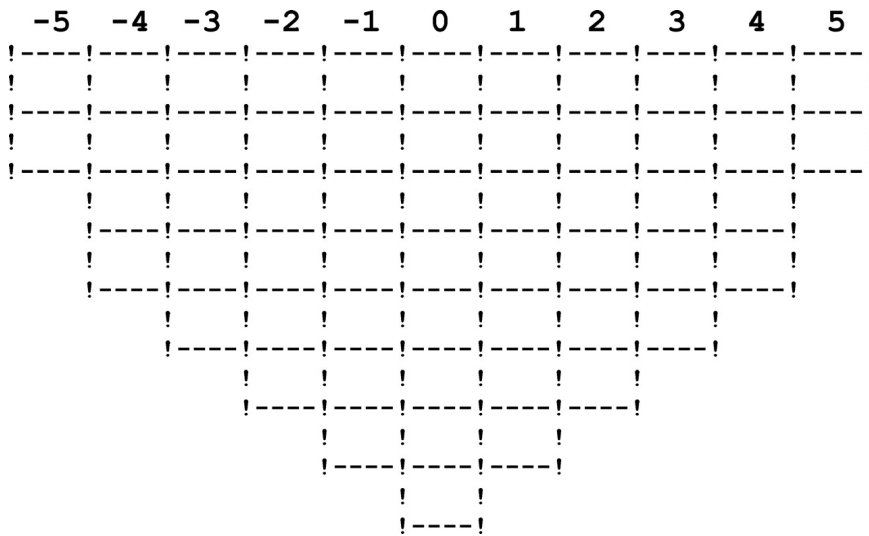
Sorting procedure

Figure 1 shows an example Q sort grid taken from Cross (2005). It can be seen that there are places for two statements at -5 (strongest disagreement), and two places at +5 (strongest agreement). The middle of the grid, at level 0, reflects those statements that participants feel more neutral about in comparison to the rest. As previously mentioned, participants are handed the cards and asked to sort them according to how much they agree or disagree with them. Of particular relevance to the current study, this task is often broken down into smaller sub-steps which makes the overall sorting task more straightforward and less taxing for participants (Watts & Stenner, 2012). For example, participants are commonly asked to first 'pre-sort' the cards into three separate piles according to 'agree', 'neutral' and 'disagree'. If necessary, further pre-sorting can be done by asking participants to then sort their 'agree' pile into three further subcategories, such as 'most agree, agree, somewhat agree', and then to do the same with their 'disagree' pile.

Once this is completed, participants are typically prompted to place the cards that they most agreed with on the far right-hand side of the grid (+5). For example, in Figure 1 they would need to choose two statements from their 'most agree' pile and place them onto the grid. This would continue until all of the statements they agreed with are placed onto the grid, working from right to left. This procedure is then repeated for the items participants disagreed with the most, working from the far left-hand side of the grid to the right. Finally, participants are prompted to place the cards from their neutral pile onto the centre section of

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the grid, with those items they might have agreed with more to the right-hand side, and those they disagreed with more, to the left.

Following the sorting procedure, participants are typically asked to provide additional information about items that they placed in the extremes, such as what meaning or significance those items hold for them. Participants are also typically asked to provide further information about those items placed in the centre of the grid, and about any additional items they might have included. This brief interview helps the researcher to interpret the factors that emerge as they are a good indication of what led them to sort the statements the way they did. It also provides much richer detail, shedding light on participants' wider understanding of the issue at hand (Watts & Stenner, 2012).

Factor analysis

As Watts and Stenner (2005) explain, Q methodology is unique from R methods in that it uses a by-person correlation and factor analysis. In other words, the initial correlation matrix consists of how each individual Q sort configuration relates to every other configuration, rather than the relationship of each item with every other item as in R methodology. The authors explain that participants who load onto a single factor will therefore have very similar configurations in how they sorted the statements. If one considers all of the possible ways someone might sort a large number of statements, the ability to detect statistically significant, holistic patterns of viewpoints that people share, is a real strength of this methodology.

Reasons for using Q methodology

Q Methodology was chosen over a questionnaire design as the sorting task enables a much more in-depth exploration of personal meanings, likes or dislikes, interpretations and overall understandings (Watts & Stenner, 2005). As Silverman (2000) points out, there are differing strengths and weaknesses with both quantitative and qualitative approaches, and the dichotomy is open to question. He argues that objectivity should be the common aim of all social science and that "…doing qualitative research should offer no protection from the rigorous, critical standards that should be applied to any enterprise concerned to sort 'fact' from 'fancy'" (p. 12). Bryant (2006) points out that, a real strength of Q methodology is

that all viewpoints are presented equally to participants so every viewpoint is considered with equal merit, not just the majority opinion.

This methodology was specifically chosen over other qualitative methods as it allows for the quantitative comparison of multiple *patterns* of viewpoints from multiple participants (Wright, 2009). As Watts and Stenner (2005) point out, rather than purely focusing on topics or themes that emerge from individuals, Q methodology is unique in its ability to explore combinations or configurations of themes within groups. Furthermore, these common themes, or factors, are generated from the participant's sorting rather than through the researchers ideas for categorising them, leading to less potential researcher bias; however, as Shinebourne (2009) rightly points out, the potential for bias merely happens somewhat earlier in Q methodology, when the researcher selects which statements should be included.

Cross (2005) outlined several arguments for the use of Q methodology in measuring attitudes compared to other methods. For example, while Likert Scales are useful in that they allow participants to express their agreement or disagreement with a large set of items in a relatively economical way, the forced-choice paradigm within Q methodology prompts participants to think about the individual items at a much deeper level, comparing and contrasting them, and placing their own meanings onto them. While Q methodology embraces the statistical analysis of complex data, it also places much emphasis on gathering qualitative statements from participants to aid the interpretation (Watts & Stenner, 2012).

Q methodology has been widely adopted by researchers wishing to better understand subjective viewpoints. For example, it has shed light on people's consumption behaviour whilst using their mobile phones, gaining insight into the relationship people have with their mobile phones and their consumption practices (Andrews, Drennan & Russell-Bennett, 2005). It has also recently been utilised to assess beliefs about organic food (Stanton & Guion, 2010) and consumers' views about food assurance schemes (Eden, Bear & Walker, 2008), to name a few.

It has also been used in a wide range of studies exploring patients' beliefs. For example, it has been used to assess understandings within chronic pain (Risdon, Eccleston, Crombez &McCracken, 2003), preferences for hypertension management (Morecroft, Cantrill & Tully, 2006), smokers' representations of their smoking (Collins, Maguire, & O'dell, 2002) perceptions of fatigue in rheumatoid arthritis (Nikolaus et al, 2010) and perception of post-partum depression (Jang, Kim, Kim, Kim & Choi, 1996).

Criticisms of Q methodology

One common criticism of Q methodology is that repeated sorts do not always yield similar results, leading some to question its reliability; however, as Cross (2005) points out, there is not necessarily an expectation that a participant *should* produce the same point-of-view at two time points. On the other hand, Brown (1980) argues that Q sorts can be replicated up to 12 months and still result in an 85 percent consistency, even when different Q sets are used for a given topic. Many also argue that only a limited number of accounts can ever be generated from a Q sort due to the constraints of the limited number of items making up the Q set; however, as previously stated, much emphasis is placed on gathering further qualitative information, either during or directly following the sorting procedure, to help in the interpretation and to uncover new information (Cross, 2005). As with all research methods involving self-report, Q methodology is inevitably susceptible to demand characteristics, meaning that participants may provide information that they believe to be more socially desirable, rather than what they truly believe (Cross, 2005).

Finally, a common criticism of Q methodology is the extent to which the results generalise to the wider population. As Amin (2000) indicates, generalisation is limited within Q studies because of the small number of participants included; however, he points out that generalisation is actually not intended – that Q methodology is exploratory in nature and the viewpoints uncovered can be followed up with larger surveys to examine their prevalence in the wider population.

The concourse

The previously mentioned systematic review of qualitative and quantitative studies by Alderson et al (2012) was used for the concourse for the current study. As discussed, this was a recent review of studies where depressed patients with chronic physical conditions verbalised their beliefs about their depression, and much verbatim text was provided.

Sampling the Q set

It was decided that a structured approach to sampling would be utilised, covering the five domains of the SRM, as well as some of the newly discovered categories of beliefs identified by Alderson et al (2012). While it was important for the final Q set to contain as much breadth as possible, after consulting with experts in the field who have carried out Q sorts with physically ill patients, it was decided that the total number of statements should not exceed 40, and that a number closer to 30 would be optimal so that the sorting task for patients was not overwhelming. With the help of supervisors and professionals working in stroke, statements were developed which appeared to capture patients' beliefs in each of the following categories:

- Coherence – their belief about whether they understood what the word depression means
- Identity or label – i.e. their beliefs about the appropriateness of the word depression for them
- Cause – their beliefs about what caused their depressive symptoms
- Cure and / or control – what treatment(s) they believed to be the best or most appropriate for their depressive symptoms
- Timeline – their beliefs about how long they felt their depressive symptoms would last
- Consequences – what were the most salient consequences for them?
- Existential and self – did they see themselves differently because of their depressive symptoms?

- Depression as a cycle – did they feel that they were in a cycle of depression? For example, did they feel that the consequences of depression led to more depression, such as in a feedback loop?
- Stigma, blame & shame – Did they perceive that there was stigma or shame associated with being depressed?

Through examining the results of Alderson et al's (2012) review, it was evident that beliefs about the cause, cure and consequences could also be further broken down into biological, psychological and social subcategories. For example, when patients spoke about the consequences of their low mood, some spoke about the physical impact of their depression while others spoke about more psychological aspects, such as anxiety, sadness, despair, anger, guilt and feeling out of control. Finally, some patients emphasised social consequences of their depression, such as feeling isolated and the impact on their family or partners.

Some patients also stressed the importance of religious aspects. For example, some felt that they were depressed because they were being punished by God or that there was some spiritual reason for it. Others felt that their religious and / or spiritual beliefs helped their depression (treatment). While the review did uncover unique views on suicide, after careful discussion, it was decided that for ethical reasons this topic would not be included as it may have been too upsetting for patients.

With all of the above categories and subcategories agreed upon, the author and her two supervisors worked separately and developed lists of potential statements that they felt best represented the concourse. The author also consulted international experts about how the statements should be worded (i.e. first or second person). Through comparing the separate lists, the number of statements was cut down from 51 to 34 statements which we all agreed still adequately captured the underlying ideas. Finally, this list was sent to two clinical psychologists and one assistant psychologist specialising in stroke to gain their opinion on the clarity and breadth of the statements. They felt that the statements were clear and that they would not be too upsetting for patients. Also, from their clinical experience they recommended that we include two new statements relating to potential causes of depression, one being due to worry about the future and the other to do with being physically dependent on others. The final list of statements and the main categories for which they represent are as follows:

Coherence

    1.   I understand what the word depression means

Identity

    2.   The word depression best describes my mood

Cause

Biological

    3.   My depression is due to a physical change in my brain

    4.   My depression is hereditary

    5.   My physical health problems have caused my depression

    6.   The stress of being physically unwell has caused my depression

Psychological

    7.   The way I think about things has caused my depression

    8.   I'm depressed because I've had too much to cope with

    9.   I am the sort of person who is prone to depression

    10. I'm depressed because I'm worried about my future

Social

    11. I'm depressed because I've had to cope with things on my own

    12. The thought of being physically dependent on others makes me depressed

Religious

    13. I think that there is a religious explanation for my depression

Cure / Control

Biological

    14. I think medication would help my depression

    15. Treating my physical health problems will help my depression

    16. The best thing for my depression is to see a health professional

Psychological

    17. I think talking to a therapist would help my depression

    18. I prefer to manage things myself if I get depressed

    19. Talking about my problems just makes me feel worse

    20. There's nothing I can do to cure my depression

Social

    21. My family and friends will help me get over my depression

    22. Being in my own surroundings will make my depression better

Religious

23. I find that my faith helps with my depression

Timeline

24. I'll get over this period of depression quite quickly

25. I think my depression is going to last a long time

Consequences

Biological

26. Being depressed will affect my general physical health

27. Depression will make the effects of my stroke worse

Psychological

28. My depression makes me feel out of control

Social

29. My depression makes me want to be on my own

30. It upsets my family or friends when I'm depressed

Depression as cycle

31. Being depressed tends to make me more depressed

Existential

32. Being depressed is part of who I am

33. I see myself differently now that I am depressed

Stigma / Shame / Blame

34. I feel it's a sign of weakness to be depressed

35. I feel ashamed that I'm depressed

36. People would blame me if they knew I was depressed

As can be seen, the final Q set consisted of 36 statements in total covering nine main categories. While using the bio-psycho-social subcategories was useful, it was still not certain which category some statements fall into. For example, we felt that statement 16: 'The best thing for my depression is to see a health professional', may reflect either a biological treatment preference, such as seeing a doctor or nurse, or may reflect a more psychological preference, such as talking to a therapist. If statements such as these were particularly salient for individuals, their particular beliefs would be clarified when interviewed following their Q sort.

Ethical clearance

An application for this project was initially made to the Sheffield Research Ethics Committee (REC) on the 17th of October 2011 and was reviewed by the committee on the 7th of November 2011 for which the author attended. Unfortunately, this application was not successful and ethical clearance was not granted at this time. After consulting with University supervisors, the author contacted the REC co-ordinator to see if the recommended amendments and clarifications could be reviewed at sub-committee level to save time. Unfortunately the co-ordinator confirmed that it was part of the Sheffield REC's standard procedure that if a study were rejected, a new application must be made and re-reviewed by the full committee. Therefore, a new application stipulating all of the requested amendments and clarifications was made to the Sheffield REC on 24th December 2011 and reviewed by the committee on the 6th of February 2012 for which the author and Professor Allan House attended. This application was granted provisional ethical approval. After making the further stipulated amendments, the current study was given full REC approval on 21st February 2012 (see Appendix 1). Research and Development approval was then obtained from the Leeds Teaching Hospitals NHS Trust and the Leeds Community Healthcare NHS Trust in March 2012 (see Appendix 2).

Participants

The plan was to recruit patients who were over 18 who had a confirmed diagnosis of a stroke and had completed a recent mood screen with a member of staff. The inclusion criteria were purposely open to enable a more diverse sample of patients and therefore to hopefully capture a more diverse range of viewpoints. Patients were to be recruited from inpatient wards and community stroke teams in Leeds where mood screening was being routinely undertaken. Only those patients who had been communicated the outcome of their mood screen and therefore knew that they had endorsed items that are regarded as symptoms of depression were to be recruited. The following exclusion criteria were utilised:

Exclusion criteria

- If not proficient with the English language (the statements on the cards for the Q sort were in English and derived from qualitative research studies which were conducted in the English language).

- If unable to consent to participating due to cognitive or communicative difficulties.

- Presence of any neurological impairment which would prevent them from carrying out the Q sort (e.g. acute sensory deficit, paralysis, etc). Suitability of inclusion was decided by appropriate staff involved with their care, which was most often clinical psychologists specialising in the neuropsychology of stroke.

Recruitment

The aim was to recruit a sample of 40 patients. It was a stipulation of the REC that a clinician involved in their care must make the first approach to patients regarding participation. Therefore, the current study was aligned with the programme of routine mood screening being undertaken on the stroke inpatient wards in Leeds. This programme of screening was conducted by an assistant psychologist, two days per week. The procedure for this psychologist was to administer face-to-face mood screens with only those patients with a confirmed diagnosis of a stroke who had no significant confusion, verbal or visual deficits as determined by ward staff (typically nurses and junior doctors); therefore, those patients given a routine face-to-face mood screen by this psychologist were likely to meet the inclusion criteria for this study. Data from this screening programme was compiled into a secure database by the psychologist and, through consultation with field supervisors, it was decided that the author would review this database on a regular basis to see if any patients screened were suitable for inclusion.

The recruitment procedure for the first 12 participants was:

1. Clinician identified patient who was likely suitable
2. Author liaised with clinician to ensure that they met the inclusion criteria, and, if so, that clinician provided the patient with an information sheet about the study.
3. A minimum of 24 hours later, the author approached the patient and informed consent was sought.

It was decided that recruitment would initially consist of inpatients, but that patients seen by the community stroke teams and outpatients could also be recruited if necessary. Unfortunately, recruitment was extremely slow due to the fact that minimal face-to-face mood screening was being undertaken on the inpatient wards. During the four-month recruitment period for this project, just 33 face-to-face mood screens were administered, with only five meeting the inclusion criteria for this study. Furthermore, no routine mood screening was being undertaken by the community stroke teams or during any of the stroke outpatient clinics.

Because of these difficulties, in June 2012 the author contacted the Sheffield REC to request an amendment to enable her to conduct the mood screening and initially approach patients herself. Response from the Chair can be seen in Appendix 3. The Chair stipulated that the only way this would be possible is if the author were a member of the stroke clinical care team. In light of this, and after consulting with supervisors, from July 2012 onwards the author worked on secondment as part of the Leeds clinical neuropsychology stroke team, conducting mood screening with stroke inpatients and outpatients as part of her clinical role and recruiting patients who met the inclusion criteria. This was done alongside a specialist stroke nurse. Therefore, the recruitment procedure for the final eight participants was:

1. Author or specialist nurse conducted clinical mood screening.
2. Those meeting the inclusion criteria were given an information sheet by the specialist nurse.
3. A minimum of 24 hours later, the author contacted the patient and informed consent was sought.

Materials

- The 36 statements making up the Q set were printed in font size 14. This size was chosen as a minimum after consulting with professionals working with stroke patients. They were numbered, cut into 50mm x 50mm cards and laminated so that they could be sanitised between uses.
- The sorting grid (Appendix 4) was printed onto an A2 size poster board and was laminated.

- Self-adhesive Velcro loop and hook coins were placed on the back of each of the cards and each of the spaces on the grid so that the cards would firmly adhere to the grid for ease of use with inpatients.

- Copies of the sorting grid were also printed in A4 size for the researcher to record the results of each participant's sorting.

- Ten 168 x 116 x 40mm plastic containers were used to hold the cards during the sorting procedure. Nine of these had one of the following printed on them in large, bold text: 'Agree', 'Neutral', 'Disagree', 'Strongly Agree', 'Agree', 'Slightly Agree', 'Strongly Disagree', 'Disagree', 'Slightly Disagree'. It was decided to use these after piloting the Q sort with colleagues.

- Demographics and background proforma (Appendix 5)

- Patient information sheet (Appendix 6)

- Patient consent form (Appendix 7)

Mood screens

As mentioned, data from mood screens being used in routine clinical practice was used; therefore, these were not administered explicitly for the purposes of this research. The ultimate goal was to identify patients who reported a state of distress that could reasonably be described as "depression" in routine practice. Mood screens and cut-off points used were:

- Hospital Anxiety and Depression (HAD) scale (score of >=6)

- Wimbledon self-report scale (score of >=11)

- Beck Depression Inventory-Fast Screen (score of >=4)

The HAD scale (Zigmond & Snaith, 1983) comprises 14 items from which separate anxiety and depression scores are derived. Scores range between 0 and 21 for each subscale. Scores of at least 8 were cited in the original publication as possible depression. There is evidence within the literature for its use as a successful screening tool for depression in stroke (e.g. Aben, Verhey, Lousberg, Lodder & Honig, 2002). Researchers have identified that a score of 6/7 produces good sensitivity (0.8) and specificity (0.79) for identifying cases within stroke (O'Rourke, MacHale, Signorini & Dennis,1998).

The Wimbledon self-report scale (Coughlan and Storey, 1988) is a 30-item scale developed to detect mood disturbance with neurological patients and has been found to have good reliability, sensitivity and specificity. Scores >=11 are considered to reflect clinically significant mood disturbance. This scale is scored uni-dimensionally, and, as with many other mood scales, its factor structure is unclear. Nevertheless, as with the clinical neuropsychologists who developed the mood screening programme for stroke patients in Leeds, we felt that a score of >=11 would adequately detect a level of distress that could be reasonably described as 'depression' in routine practice.

The Beck Depression Inventory Fast Screen (Beck, Steer & Brown, 2000) is a 7-item self-report measure for the detection of depressive symptoms in medical patients. A score of >=4 was found to have a sensitivity (71) and specificity (74) with stroke patients (Healey, Kneebone, Carroll & Anderson, 2008). While this is relatively low, only one patient was recruited who had completed this scale, scoring three-fold higher than this cut-off.

Procedure

1. Participants were seated at a table.
2. Informed, signed consent was obtained and any questions were answered. Participants were reminded why they were recruited and of the mood questionnaire they recently completed that showed some symptoms of low mood.
3. Demographic and background information was collected using the proforma (this information was later verified and expanded upon using their medical records wherever possible).
4. The 36 statements making up the Q set were placed in the un-labelled plastic container and placed in front of them.
5. The author stated, "In here I have 36 statements about low mood or depression. I've used the word 'depression' on many of the cards to make it easier, but feel free to substitute that word with whatever you feel fits you best". "I'd like you to think about your mood symptoms after your stroke and sort these cards according to how much you agree or disagree with them".
6. The three plastic containers labelled 'Agree', 'Neutral', 'Disagree' were placed in front of the participants, from right to left, and participants were prompted to read each statement, one at a time, and place them into one of the three containers.

7. The filled 'Agree' container was then placed in front of the participants, along with the empty 'Strongly Agree', 'Agree' and 'Slightly Agree' containers. Participants were prompted to sort through their agree items, one by one, into the three containers. This procedure was repeated for the disagree items.

8. The sorting grid was then placed in front of the participants. The author stated: "I know this might look rather complicated, but we'll go through it step-by-step". "We're going to fill this grid with the statements that you've sorted".

9. The 'Strongly Agree' container was then placed in front of participant and they were prompted to look through them and choose one statement that they agreed with the most. This was then placed on the far right side of the sorting grid. They were then prompted to choose the next two items that they agreed with the most, and so on, filling the grid from right to left. Once all of the items from the 'Strongly Agree' container were placed onto the grid, the 'Agree' and 'Slightly Agree' items followed; again, filling the grid from right to left. The author left the participants to do each of these sub-sorting tasks on their own, unless they had any questions or required support.

10. This procedure was then repeated for the all of the disagree items, starting with the 'Strongly Disagree' container, etc., filling the sorting grid from left to right.

11. The participants were then prompted to sort through the neutral items, placing the ones that they most agreed with to the right of the board, and the ones they most disagreed with to the left.

12. During the sorting, the author made a note of which items the participants strongly agreed or disagreed with, which items were agreed or disagreed with in total, as well as which items were neutral.

13. Once the sorting was completed and the grid filled, participants were asked about items they strongly agreed with – i.e. starting with the item on the far right of the grid, they were asked "Why did you agree with this one the most?" "Why was it important for you?" Qualitative statements were recorded by hand for all items that the participant strongly agreed with. This was repeated for the items the participants strongly disagreed with.

14. They were then asked to look through the items in the middle of the grid and prompted to comment on any items that were important to them.

15. Finally, all participants were asked if there was anything else that they felt was important that was not covered. To further clarify, participants were asked "If I

handed you a blank card and asked you to write down a statement about your mood that was important to you, what do you think you would write?"

Ethical considerations

As previously mentioned, this study was granted ethical and R&D approval. All participants meeting the inclusion criteria were given an information sheet about the study by a clinician involved with their care a minimum of 24 hours before they were recruited. As agreed by the ethics panel, after the author joined the clinical care team she too became involved with recruitment. For the eight participants recruited in this way, the author worked alongside a specialist stroke nurse, conducting the mood screening jointly and stressing that their participation in this research was completely voluntary, separate from their clinical care, and that it would not affect their treatment in any way. Informed, signed consent was obtained and the participant's GP's were notified of their participation.

Participants were made aware via the information sheet that they would be asked to think about their mood symptoms in some depth and that this may be emotionally upsetting. Participant's emotional state was carefully assessed by the author throughout the procedure using her clinical judgement. If a participant did become upset or fatigued, they were encouraged to take a break and reminded that they could discontinue at any time. As per the information sheet, participant confidentiality was strictly upheld at all times, but that the author was aware of the limitations of this when any risk issues should become apparent. If this were the case, the author intended to inform the professionals involved with their care to ensure their safety or the safety of others. Fortunately this issue never arose. All information gathered was anonymised and kept in a secure filing cabinet in-line with the Data Protection Act (1998).

The next section will outline the factor analysis that was conducted, including a detailed account of the results.

RESULTS

Participant background information

Demographic data

      Demographic information for the participants is displayed in Table 2. As the table shows, there was a fairly even gender split and the most common age group was 51-60 (mean of 59.3). All participants were white British. Most had suffered ischemic strokes approximately 2-3 months before taking part in this research. Most reported that they were in a relationship, and most, but not all, rated their level of social support as good. Nine out of twenty stated that they had suffered with depression at some point in the past, although only one stated that they were experiencing depressive symptoms at the time of their stroke. Six participants had chronic co-morbid medical conditions, such as heart disease, chronic obstructive pulmonary disease, urological disorders and arthritis.

Table 2. Participant demographic information (n=20)

		Number	Percentage
Gender	Male	11	55
	Female	9	45
Age Group	51-60	9	45
	61-70	4	20
	71-80	3	15
	41-50	2	10
	21-30	1	5
	81-90	1	5
Ethnicity	White British	20	100
Stroke Type	Right ischemic	9	45

	Left ischemic	6	30
	Left hemorrhagic	2	10
	Ischemic (area unknown)	2	10
	SAH	1	5
Months Since Stroke	2-3	7	35
	4-7	5	25
	12-24	4	20
	<1	3	15
	48	1	5
Relationship Status	In relationship	14	70
	Not in relationship	6	30
Perceived Social Support	Good	14	70
	Fair	4	20
	Poor	2	10
Past mental health history	Depression	9	45
Other chronic conditions		6	30

Mood screen data

All participants scored above cut-off on the mood scales. Fourteen completed the HAD scale, with a mean depression score of 10.4 (range 7-14, above cut-off for depression) and a mean anxiety score of 9.5 (range 3-13). Three participants completed the Wimbledon scale, with a mean score of 19.7 (range 14-30, above cut-off for mood disorder), and one completed the BDI-FS, with a score of >20 (above cut-off for mood disorder).

The Q sort data was entered into PQMethod software. The two most common methods of analysing Q data are Principal Components Analysis (PCA) and Centroid factor analysis. Some Q methodologists prefer Centroid analysis used with theoretical rotation as this allows for greater researcher input and judgment, whereas PCA with Varimax rotation "maximises the amount of variance explained by the extracted factors and…automatically seeks the best mathematical solution" (Watts & Stenner, 2005, P. 81). However, both approaches are used widely and Watts and Stenner (2012) have reported that they produce similar results. For pragmatic reasons PCA with Varimax rotation was chosen for this study as support for this method was available within the researcher's Institute.

In order to decide the optimal number of factors to rotate, two criteria were used as described by Watts and Stenner (2005). The first requirement is that each unrotated factor should have an eigenvalue greater than 1.00, as a means of safeguarding factor reliabilities. As Table 3 shows, within the current analysis there were six factors meeting this requirement, which explained 75 percent of the study variance.

Table 3. Eigenvalues and percentage variance explained by Factors 1-6

Factor no.	Eigenvalue	% Variance explained
1	7.3	37
2	1.9	9
3	1.7	9
4	1.5	8
5	1.3	7
6	1.1	5

The second criterion typically used is to choose factors that have at least two or more Q sorts that significantly load onto them. For the current study, a conservative ($p <$ 0.01) significance level for loading was chosen using the following equation provided by Watts and Stenner (2005): $2.58(1/\sqrt{x})$, where x equals the number of statements in the Q set (in this study $x = 36$). Using this equation, only three factors had two or more Q sorts loading significantly at $p < 0.01$ (a loading of 0.43 or above) on one factor only. However,

it was decided that one participant would be flagged as a 'negative' exemplar of factor 3 as their views were decidedly unique from all others in the study, warranting further consideration. Therefore, a fourth factor was generated with this single participant loading onto it.

Table 4 shows the results of the rotated factor loadings provided by PQ Method software. An X is placed next to participants who exemplify that factor (i.e. they significantly load onto one factor and not the others).

Table 4. Factor loadings of participants onto Factors 1-4

Q Sort	Factors			
	1	2	3	4
1	0.6869X	0.2278	-0.0039	0.0039
2	0.5751	0.5055	0.0397	-0.0397
3	0.8024X	0.0827	0.2493	-0.2493
4	0.4389	0.5900X	0.0992	-0.0992
5	0.2112	0.1899	0.7216X	-0.7216
6	0.7788X	0.1380	0.0210	-0.0210
7	0.7433X	0.2844	-0.0234	0.0234
8	0.6524X	0.3752	0.0548	-0.0548
9	0.3998	0.6252X	-0.1039	-0.1039
10	0.2364	0.3853	0.0651	-0.0651
11	0.7971X	0.2720	-0.1174	0.1174
12	0.2351	0.6626X	-0.1626	0.1626
13	0.1741	0.5725X	-0.0432	0.0432
14	0.3661	0.3778	-0.4603	0.4603X
15	0.1471	-0.1607	0.6581X	-0.6581
16	-0.0592	0.5241	0.5594	-0.5594
17	0.7020X	0.095	0.0886	-0.0886
18	-0.0519	0.7863X	0.2012	-0.2102
19	0.5805X	0.1062	0.3950	-0.3950
20	0.7033X	0.1502	0.1055	-0.1055

PQMethod software uses these exemplifying sorts to calculate a factor estimate using a weighted formula developed by Spearman (1927) whereby sorts which have higher factor loadings contribute more to the factor estimate compared to those with lower loadings. Once these weightings are calculated, the factor loadings are converted to standard (Z) scores so that cross-factor comparisons can be made, and these in turn are converted into a factor array. For example, for Factor 1, statement number three had the highest Z-score and so was awarded the highest ranking in the factor array for Factor 1 (5). The factor arrays for factors 1-4 are displayed in Table 5. Distinguishing statements that are significant at $p < 0.05$ are in bold print, and those at $p < 0.01$ are shown in red.

Table 5. Factor arrays for factors 1-4. Distinguishing statements at p<0.05 are in bold. Distinguishing statements at p<0.01 are printed in red ink.

No.	Statement	F1	F2	F3	F4
1	I understand what the word depression means	2	4	4	**-1**
2	The word depression best describes my mood	**-2**	1	1	2
3	My depression is due to a physical change in my brain	5	3	-2	-1
4	My depression is hereditary	**-5**	-1	**0**	-3
5	My physical health problems have caused my depression	3	1	1	4
6	The way I think about things has caused my depression	-1	-1	-2	**3**
7	I'm the sort of person who is prone to depression	-3	-2	**1**	-2
8	I'm depressed because I've had too much to cope with	-1	0	0	0
9	The stress of being physically unwell has caused my depression	**4**	1	-2	0
10	I'm depressed because I've had to cope with things on my own	-1	-1	-1	-1
11	I think that there's a religious explanation for my depression	-4	-2	-5	0
12	I think medication would help my depression	0	0	3	**-3**
13	Treating my physical health problems will help my depression	2	0	2	2
14	The best thing for my depression is to see a health professional	1	2	2	1
15	I think talking to a therapist would help my depression	3	2	-1	1
16	I prefer to manage things myself if I get depressed	1	1	1	2
17	Talking about my problems just makes me feel worse	-2	-3	-2	**1**
18	There's nothing I can do to cure my depression	**-3**	**-5**	2	0
19	My family and friends will help me get over my depression	0	5	0	3

20	Being in my own surroundings will make my depression better	**0**	4	**-3**	4
21	I find that my faith helps me with my depression	-3	**0**	-4	-3
22	I'll get over this period of depression quite quickly	**-1**	3	**-4**	2
23	I think my depression is going to last a long time	-1	-1	**4**	-1
24	Being depressed will affect my general physical health	3	2	1	0
25	My depression will make the effects of my stroke worse	1	0	-1	0
26	My depression makes me feel out of control	1	**-1**	3	**-4**
27	My depression makes me want to be on my own	**0**	2	3	**-4**
28	It upsets my family or friends when I'm depressed	2	0	**4**	1
29	Being depressed tends to make me more depressed	0	1	1	1
30	Being depressed is part of who I am	**-4**	**-4**	0	-1
31	I see myself differently now that I'm depressed	1	-3	0	-2
32	I feel it's a sign of weakness to be depressed	**0**	-2	-3	-2
33	I feel ashamed that I'm depressed	-2	-2	0	-2
34	People would blame me if they knew I was depressed	-2	-4	-3	-5
35	I'm depressed because I'm worried about my future	4	**-3**	**-1**	5
36	The thought of being physically dependent on others make	2	3	**-1**	3

Consensus items

Although these factors represent four discreet viewpoints, it can be seen that there were some items of agreement or consensus – that is there were no significant differences at p <0.01 in scores across the factors for six statements. For example, the following items were placed in the centre (0), or just to the left (-1) or right (+1) on the Q sort grid across all four factors, suggesting these were not generally strongly held beliefs:

- (8) I'm depressed because I've had too much to cope with
- (10) I'm depressed because I've had to cope with things on my own
- (25) My depression will make the effects of my stroke worse
- (29) Being depressed tends to make me more depressed

There was agreement (+1 or +2) with these statements across all four factors:

- (14) The best thing for my depression is to see a health professional
- (16) I prefer to manage things myself if I get depressed

There was shared disagreement (-2 to -5) with this statement at $p < 0.05$

- (34) People would blame me if they knew I was depressed

Responses to the open question – was there anything else you would have included?

Nine participants provided further information when asked this question. Two stated that their depression was in part due to the fact that they looked well and so others did not understand how they were feeling. For example:

- *"It's about how others react to you. Because I look well, people don't understand how I feel"*

Two people indicated that their mood symptoms were partly due to the treatment they received by professionals. For example:

- *"I don't think it was the stroke. It was the treatment I had and the pain. I was treated as an inconvenience by the doctor who first saw me"*

One person stated that they were very frightened after watching their husband go through a stroke. Two people spoke about it being related to their physical symptoms, such as their impact on work. One person stated that they struggled with mood swings between feeling quite angry and then crying.

Factor 1: depression due to external, physical factors, an emphasis on physical symptoms and social consequences

Demographic data

Factor 1 explained 28 percent of the study variance. Nine participants were significantly associated with this factor – five males and four females with a mean age of 58.3 years. The mean number of months since their stroke was 14, although this ranged from 3-48. Four participants were in relationships and five were not. Four participants rated their social support as good, three rated it as fair and two rated it as being poor. Of the four who were in a relationship, two rated their social support as good, while two rated it as fair. Of the five who were not in a relationship, only two participants felt supported, one rated it as fair, and two stated that they had poor social support.

Regarding mood, one participant completed the Wimbledon scale, scoring in the range for a mood disorder (>11). Eight completed the HAD scale, with an average depression score of 9.4 and an average anxiety score of 9.6. Furthermore, four participants stated that they had suffered with depression in the past, one of whom was experiencing depression at the time of their stroke.

Eight out of nine of the participants had ischaemic strokes, three occurring in the left hemisphere, four on the right, and one occurring in both hemispheres. One participant had a subarachnoid haemorrhage. Regarding co-morbid chronic medical conditions, six participants had no other significant conditions, two participants had between 1-2 co-morbid conditions, while one person had five. Finally, one participant was an inpatient, while the rest were living at home.

As Table 5 shows, four statements distinguished factor 1 at a significance level of $p < 0.01$, and five were significant at $p < 0.05$. In order to aid interpretation, the following crib sheet was created. Distinguishing statements are shown in bold:

Items ranked at +5 and +4

  3.   My depression is due to a physical change in my brain (+5)

  9.   **The stress of being physically unwell has caused my depression (+4)**

  35.   I'm depressed because I'm worried about my future (+4)

Items ranked at -5 and -4

  4.   My depression is hereditary (-5)

  11.   I think that there's a religious explanation for my depression (-4)

  30.   Being depressed is part of who I am (-4)

Items ranked significantly higher in Factor 1 than in any other factor

  32.   I feel it's a sign of weakness to be depressed (0)

Items ranked significantly lower in Factor 1 array than in any other factor

  2.   The word depression best describes my mood (-2)

Items that were significantly more neutral compared to the other factors

  27.   My depression makes me want to be on my own (0)

  20.   Being in my own surroundings will make my depression better (0)

  22.   I'll get over this period of depression quite quickly (-1)

Additional distinguishing statements for factor 1

  18.   There's nothing I can do to cure my depression (-3)

Identity

One statement that distinguished factor 1 was that exemplifiers disagreed that the word depression best described their mood (-2). As the crib sheet shows, this item was ranked lower in Factor 1 compared to the others. For example:

- *"I don't get depressed. Sometimes I get fed up, but I wouldn't say that I'm deeply depressed"*

Cause

One highly significant distinguishing statement was their agreement that the stress of being physically unwell had caused their depression (+4). People gave a range of reasons for why they strongly agreed with this statement. For example, some indicated that physical pain made them feel low, that physical symptoms made them more apprehensive about having another stroke, that they had negative implications for work and that they served as a reminder of the traumatic experience of having a stroke. For example:

- *"When you have pain all the time that won't go away it gets you down. If I didn't have that, I wouldn't be depressed."*
- *"The stroke caused my depression but my physical symptoms keep it going. They make me more apprehensive about having another stroke."*
- *"I fear being useless at work. I'm nervous in meetings as I don't want to sound less than 100 percent."*
- *"I'm physically less able and it's hard to come to terms with on a day-to-day basis – even little things like walking and picking things up and down. Every time I wake up I'm aware of what's happened, because of the physical symptoms."*

Similarly, they strongly agreed that their depression was due to a physical change in their brain (+5), stating that it was because they felt it was due to the stroke, which they knew had occurred in their brain. For example:

- *"It's obvious because that's where the damage has been. There was a blood clot in my brain due to my smoking."*

As the crib sheet shows, exemplifiers of Factor 1 also strongly agreed that they were depressed because they were worried about their future (+4). For this item, people simply listed worries about their future, which were mainly about stroke recurrence and about being able to cope, both at work and financially. They also agreed that their physical health problems had caused their depression (+3), with one participant indicating that their stroke worsened their pre-existing physical pain. Finally, they agreed that the thought of being physically dependent on others made them depressed (+2). Qualitative statements revealed that this was due to a loss of independence, a change in role from caregiver to having to accept care from others, and not wanting to burden others. For example:

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- *"I've always been really independent. I've always been the one doing the sorting! It's awful to have to ask for help. I'm her Mom, she's not mine."*
- *"Mom had a stroke about six months ago and Dad became quite depressed about having to look after her."*

One other distinguishing causal statement was their strong rejection of the notion that their depression was hereditary (-5). For this statement, most participants indicated that it was because they knew it did not run in their family, but also because they believed their depression was caused by their stroke. They also strongly rejected the notion that there was a religious explanation (-4), providing reasons such as the fact that they were not religious, that religion had nothing to do with it, and again, that they believed that their stroke was the cause. Another cause that they somewhat rejected was the notion that they were the sort of people who were prone to depression (-3). This idea was rejected more within Factor 1 than the other three factors. Reasons for this were they that they felt occasional low mood was normal and also the fact that they had not been depressed in the past for a prolonged period.

Cure

One highly significant distinguishing statement was their neutrality about the idea that being in their own surroundings would make their depression better (0). A hypothesis is that this may be related to their situation at home, considering that many rated their level of social support as fair or poor. Unfortunately no qualitative data was obtained for this statement. Similarly, they were also neutral with regards to their family and friends helping them get over their depression (0).

The treatment most preferred by participants was seeing a therapist (+3), which was in-line with their rejection of the notion that talking about their problems would make them feel worse (-2). Qualitative statements revealed that this was due to people having a preference for talking to others, having a high opinion of psychologists, and having had past experience of therapy. Participants also somewhat agreed that treating their physical health problems would help (+2), which in in line with their belief that their physical symptoms were causal.

One distinguishing statement about cure was their rejection that there was nothing they could do to cure their depression (-3). They instead listed things that they could do, such as seeking and using help, doing more things such as going on holiday, talking to someone or taking tablets. People rejected the notion that faith helped them with their

depression (-3) for the same reasons they did not believe in a religious cause – mainly because they were not religious themselves.

Timeline

One distinguishing statement was that they were unsure that they would get over their period of depression quite quickly (-1). Similarly, they were also unsure about whether it would last a long time (-1). Only one person commented on this topic, highlighting the importance of physical symptoms for these people. For example:

- *"It depends on how long my physical symptoms last. They make me more apprehensive about having another stroke. I feel that my mood symptoms are temporary."*

Consequences

The only distinguishing statement relating to consequences was their neutrality with regards to their depression making them want to be on their own (0). Participants most agreed that their depression would affect their general physical health (+3) because of the association between their mood and their physical symptoms. For example, one person merely described their depression as having a 'knock-on' effect, while another explained that merely thinking about their stroke made them anxious, which led to the negative physical symptoms associated with anxiety, such as sweating.

Exemplifiers of Factor 1 also felt that their depression upset their family or friends (+2). One person stated that family members sometimes became annoyed with them, particularly when they (the participant) were irritable. The impact on family members also led to feelings of guilt. For example, one participant powerfully communicated this point:

- *"I see my family upset and it makes me upset, makes me feel guilty. I feel guilty for surviving sometimes, by having others have to focus on me. Sometimes my family think my low mood is their fault."*

Again, this may be related to their level of social support at home, but it may also be due to the fact that they had a strong preference for independence and not relying on others as described earlier.

Existential

One highly significant distinguishing statement was their strong disagreement that their depression was part of who they were (-4). In fact, most viewed being depressed as the opposite to how they were before. For example:

- *"Being depressed is opposite to who I am. Friends would say this isn't me."*
- *"I've always been a happy go-lucky person. It's not me."*

They also rejected that depression was part of who they were because it was due to something that happened to them (stroke), and because they had not been depressed in the past. However, there was some indication that they saw themselves differently (+1), more so than those within the other factors.

Stigma

One distinguishing statement was their neutrality over whether depression was a sign of weakness (0) – all other viewpoints rejected this notion. Only one person commented on this topic, stating:

- *"You do feel weak. I don't like people to see me weak. I was the one who took care of others and now I can't take care of myself. I'm not as involved with things now and I don't feel part of the group. People don't put me in the loop. It's somebody else taking over."*

However, exemplifiers disagreed that they felt ashamed to be depressed (-2) or that people would blame them (-2). One person commented that you should not be ashamed because it is not your fault – that the depression is due to something that happened to you.

Factor 2: highly determined with less worry, positive social support, helpful environment and a belief that depression will be over quickly

Demographic data

Factor 2 explained 17 percent of the study variance. Five participants were significantly associated with this factor – four males and one female, with a mean age of 63.2 years. The mean number of months since their stroke was six, although this ranged from less than one month to 24 months. All five were in a relationship and all five stated that they had good social support.

Regarding mood, one person completed the Wimbledon scale, scoring in the range for a mood disorder (>11). Four completed the HAD scale, with an average depression rating of 10 and an average anxiety score of 9.25. None reported to have suffered with depression in the past.

All five participants had suffered ischemic strokes, two in the left hemisphere, two in the right, and for one person the location was unknown as their medical records were not available and the clinician who recruited her did not have this information. No participants had co-morbid medical conditions, although one person had suffered a stroke in the past, and another had suffered a previous heart attack. Finally, one person was an inpatient at the time they were recruited, while the other four were living at home.

Looking back at the factor array in Table 5, it can be seen that within Factor 2, there was one distinguishing statement that reached a significance level of $p < 0.01$, and four that were significant at $p < 0.5$. In order to aid interpretation, the following crib sheet was created. Distinguishing statements are shown in bold:

Items ranked at +5 and +4

19.   My family and friends will help me get over my depression (+5)

20.   Being in my own surroundings will make my depression better (+4)

1.   I understand what the word depression means (+4)

Items ranked at -5 and -4

18.   There's nothing I can do to cure my depression (-5)

34.   People would blame me if they knew I was depressed (-4)

30.   Being depressed is part of who I am (-4)

Items ranked significantly higher in Factor 2 than in any other factor

21.   I find that my faith helps me with my depression (0)

Items ranked significantly lower in Factor 2 than in any other factor

35.   I'm depressed because I'm worried about my future (-3)

Additional distinguishing statements for factor 2

26.   My depression makes me feel out of control (-1)

Identity

While neither of the statements about the depression identity or label statistically distinguished Factor 2; nevertheless, exemplifiers of this viewpoint strongly agreed that they understood what the word depression meant (+4).

Cause

What was missing from the initial set of statements considered was a clear sense of what they believed to be the cause of their depression. As Table 5 shows, only one statement regarding cause statistically distinguished Factor 2 – the fact that they fairly strongly disagreed with the notion that it was because they were worried about their future (-3). Qualitative statements revealed the idea that they did not worry about the future because they felt that they had no control over it. For example:

- *"Whatever's gonna be is gonna be. If it's gonna happen, it's gonna happen. I can't change it."*
- *"The future is just what happens. I'm not worried about it."*

The other statements regarding cause and their rankings by exemplifiers for Factor 2 are shown below:

- My depression is due to a physical change in my brain (+3)
- The thought of being physical dependent on others makes me depressed (+3)
- I'm depressed because I'm worried about the future (-3)

It can be seen that they most agreed with the cause being a physical change in their brain and that the thought of being physically dependent on others was also an important factor. A good example of the latter is:

- *"I don't like others doing things for me. I don't want them to look after me. If I can't do it myself it's no good. I don't want to be a burden and I also want independence. When the roles are reversed I feel like I'm failing."*

So, like those exemplifying Factor 1, there was a need for independence and a reluctance to rely upon or burden others. Participants also somewhat agreed that their physical health symptoms and the stress of being physically unwell were causal.

However, in line with their strong disagreement that depression was part of who they were, they also rejected the notion that they were the sort of people who were prone to depression. Like Factor 1, these people were similar in that they felt that the cause of their depression was something external that happened to them (stroke), rather than it coming from them. For example,

- *"Up to having a stroke I wasn't depressed. I've always been a happy go-lucky person, a joker."*
- *"I know this (that stroke can cause depression) from my past medical training"*

Cure

Regarding cure, they felt strongly that there was something they could do to cure their depression (highly significant distinguishing statement) and that they felt that their social support (+5) and being in their own surroundings (+4) would be most helpful. They also somewhat agreed that seeing a health professional (+2) or therapist (+2) might help, whereas they were equally unsure about medication (0) or faith (0) helping. They were unique in that they were more neutral about the possibility of faith helping, whereas those within the other factors rejected this. Unfortunately, no qualitative statements were obtained regarding this topic. Regarding being in their own surroundings, qualitative statements revealed that people were comparing being in hospital to being at home. For example,

- *"Being with things and people you know goes a long way to bringing you back. I felt much worse in hospital"*
- *"It's better than being in hospital. You're not woken up at 6:30. There's no privacy and the ward is noisy."*

Furthermore, many people gave much praise for their friends and family, speaking about how supportive they were. One exemplifier also stated:

- *"Being isolated has caused me to feel this way. No decent form of communication because of my speech problems."*

Qualitative statements revealed an inner sense of determination to overcome depression, reflecting the idea that the best method for overcoming it was from within. For example:

- *"There are things you can do to cure it. It's down to yourself, not tablets, but time and your own self-will."*
- *"There are things you can do to make yourself feel better. You've got to have hope – finding that one thing that you can do for yourself."*
- *"I can do anything to help and cheer myself up"*

Timeline

No statements regarding the perceived duration of their depression distinguished factor 2. However, they did agree that they would get over it quite quickly (+3), which was ranked higher than exemplifiers of the other three factors. They somewhat disagreed that it would last a long time (-1). One exemplifier stated that they felt that they would get over their depression quickly because they were currently an inpatient and were soon due to be discharged home.

Consequences

A distinguishing statement was the fact that, unlike people within the other factors, they somewhat disagreed that their depression made them feel out of control (-1). However, they somewhat agreed that it would affect their physical health (+2) and that their depression made them want to be on their own (+2). They felt neutral about the notion of it making the effects of their stroke worse (0), or that it would upset their friends or families (0). This latter statement was unique to Factor 2, in that the others all agreed that it did upset their friends or families.

While they felt strongly that their social support and being in their own surroundings would help their depression, they also felt that it made them want to be on their own. For example, one person stated:

- *"When you're feeling depressed you don't want to see anybody."*

Existential

A distinguishing statement for Factor 2 is that exemplifiers strongly rejected the notion that depression was part of who they were (-4). They also fairly strongly rejected the idea that they saw themselves differently because of their depression (-3). For example:

- *"It wasn't me before. I'm determined not to be (depressed)."*
- *"It's not part of who I am. It's due to the illness (stroke). Even depression in general is just an illness."*

The former statement again reflects an inner sense of determination to overcome depression and the latter also lends further support that they most agreed with the stroke being the cause of their depression.

Stigma

While there were no statements relating to stigma which distinguished Factor 2, exemplifiers strongly rejected the idea that people would blame them (-4). They also rejected the notion that they were ashamed (-2) or felt that it was a sign of weakness to be depressed (-2). One person explained that it was not a weakness because it was from something that had happened to them. For example:

- *"You've had a stroke, so it's not a weakness. It's part of the illness."*

Factor 3: past depression, internal cause, out of control and lasting a long time

Demographic data

Factor 3 explained 9 percent of the study variance. Two participants exemplified this factor – one male and one female. One participant was in their twenties, while the other was in their fifties. The number of months since stroke was 16 for one person, and only two for the other. While one person was in a relationship, the other was currently going through a divorce. Both felt that they had good social support.

Regarding mood, one person completed the Wimbledon mood scale, scoring within the range for a mood disorder (>11). The other person completed the HAD scale, scoring in the range for moderate depression and above cut-off for anxiety (mild range). Both had suffered ischemic strokes, one within the left hemisphere and the other within the right. One person suffered with chronic heart problems while the other had no other chronic conditions. They both had a significant history of depression. Finally, one person was living at home while the other was an inpatient. Both participants had recently been assessed by a Clinical Psychologist.

Looking back at Table 5, there were eight distinguishing statements for Factor 3, three at a significance level of $p < 0.01$, and five reaching significance at $p < 0.05$. In order to aid interpretation, the following crib sheet was created. Distinguishing statements are shown in bold:

Items ranked at +5 and +4

    1.   I understand what the word depression means (+4)

    23.   **I think my depression is going to last a long time (+4)**

    28.   **It upsets my family or friends when I'm depressed (+4)**

Items ranked at -5 and -4

    11.   I think that there's a religious explanation for my depression (-5)

    21.   I find that my faith helps me with my depression (-4)

    22.   **I'll get over this period of depression quite quickly (-4)**

Items ranked significantly higher in Factor 3 than in any other factors

    7.   **I'm the sort of person who is prone to depression (+1)**

Items ranked significantly lower in Factor 3 than in any other factors

    20.   **Being in my own surroundings will make my depression better (-3)**

    36.   **The thought of being physically dependent on others makes me depressed (-1)**

Items that were significantly more neutral in Factor 3 compared to the other factors

    4.   **My depression is hereditary (0)**

    35.   **I'm depressed because I'm worried about my future (-1)**

Identity

There were no distinguishing statements related to identity. Both exemplifiers of Factor 3 felt that they understood what the word depression meant (+4), but were much less certain that that label best described their mood (+1).

Cause

Three statements related to cause distinguished Factor 3. Unlike the other three factors, these people somewhat agreed that they were prone to depression (+1). They were also more neutral about their depression being hereditary (0), whereas the others all disagreed with this statement. They were also unique in their neutrality about their depression being due to worry about the future (-1).

Both participants indicated that they felt their past depression was the cause of their current depression, with one indicating that their stroke had made it worse. They also rejected the notion of a religious cause (-5), more so than any other factor. As with many others, they simply stated that they did not think religion had anything to do with their mood symptoms.

Cure

The only distinguishing factor related to cure was their fairly strong rejection that being in their own surroundings would make their depression better (-3). One person merely stated that being in their own surroundings did not affect their mood - that it did not make them feel any better. Factor 3 exemplifiers were unique in that they were the only ones who felt that medication would help (+3), which they ranked higher than all the other statements regarding cure. They also felt that there was nothing they could do themselves to help (+2). They rejected the notion of faith helping more than all the others (-4) and also disagreed with the notion of a therapist helping more than the other factors (-1). Finally, exemplifiers of Factor 3 were neutral about their family and friends helping (0), with one person indicating that they did help, just not with their mood.

Timeline

Both of the statements regarding the duration of their depression were highly significant distinguishers. They were the only ones who felt that their depression would last a long time (+4), and similarly, they were the only ones to reject the notion that it would be over quickly (-4). One person indicated that it was due to their past mood difficulties. The other exemplifier commented:

- *"It just feels like a black hole, like I'm going to struggle to get out of. I don't smile very often or laugh out loud. Things don't excite me. It's been amplified since the stroke, though I had low mood before my stroke."*

Consequences

One statement related to consequences distinguished Factor 3 – their strong agreement that their depression would upset their family or friends (+4). They also agreed more with the statements regarding feeling out of control (+3) and wanting to be on their own (+3) compared to the other factors. One person stated:

- *"I distance myself from people when something goes wrong. I don't trust people so find it hard to confide in others."*

Existential

There were no distinguishing statements within this category. However, they were unique in that they ranked being depressed as being part of who they were (0) higher compared to the other three factors.

Stigma

There were no distinguishing statements relating to stigma. While they ranked that they felt ashamed higher compared to those on the other factors (0), they were more similar to others in their rejection that it was a sign of weakness to be depressed (-3).

Factor 4: strong need for independence and the meaning of physical aids. Frustration, anger and worry, but not out of control

Demographic data

Factor 4 explained 9 percent of the study variance. As previously mentioned, this is a bipolar factor, with only one exemplifier whose views differed from the rest in a number of ways. This was a female in her mid 70's who had had a left-sided haemorrhage three months previous. She scored above cut-off for depression (>6) on the HAD scale (mild range), and scored in the moderate range for anxiety (>11). She had suffered with pre-existing low mood since the passing of her husband and had previously undertaken counselling for this. She had no other mental health history or any co-morbid conditions. She stated that she was not in a relationship and rated her social support as fair. She was living at home at the time of recruitment. She stated that watching her husband suffer a 'terrible' stroke had left her with much anxiety about her illness.

Looking at Table 5, it can be seen that six statements distinguished factor 4, three of which reached a significance level of $p < 0.01$, and three at $p < 0.05$. In order to aid the interpretation, the following crib sheet was created. Distinguishing statements are shown in bold:

Items ranked at +5 and +4

5.   My physical health problems have caused my depression (+4)
20.   Being in my own surroundings will make my depression better (+4)
35.   I'm depressed because I'm worried about my future (+5)

Items ranked at -5 and -4

26.   **My depression makes me feel out of control (-4)**
27.   **My depression makes me want to be on my own (-4)**
34.   People would blame me if they knew I was depressed (-5)

Items ranked significantly higher in Factor 4 than in any other factors

6.   **The way I think about things has caused my depression (+3)**
17.   **Talking about my problems just makes me feel worse (+1)**

Items ranked significantly lower in Factor 4 array than in any other factors

1. **I understand what the word depression means (-1)**

12. **I think medication would help my depression (-3)**

Identity

   This person was unique in that they were the only one to disagree that they understood what the word depression meant (-1). They were also most in agreement that the word depression best described their mood (+2).

Cause

   One causal statement distinguished Factor 4 from the other factors – this person was the only one to endorse the notion that the way they thought about things was a cause of their depression (+3). For example,

- *"When I see my stick and my bath hoist, I'm reminded of what happened and it makes me angry and frustrated. I refuse to go in a wheelchair. That (wheelchair) is a sign of getting old."*

As with others, the above statement indicates that physical health problems can serve as an upsetting reminder of the stroke. Rather than just feeling low, however, this person indicated feelings of anger and frustration, and not wanting to use certain aids because of the negative meaning they associated with them (getting older).

Looking at the crib sheet, they also strongly agreed that their physical health problems (+4) and worries about their future (+5) were causal. For example:

- *"Because I can't do what I want. It's taken away my independence and it's not nice relying on other people."*

This need for independence and not relying on others is similar to the other factors. Also, they indicated that their worries about the future were about stroke recurrence, which others had also mentioned.

This exemplifier was the only person who did not disagree with a possible religious cause (0). They stated that they were raised to be religious, but were not currently practicing.

Cure

Two statements related to cure distinguished Factor 4. For example, this person was the only one to disagree that medication would help (-3) and they were the only person to agree that talking about their problems would make them feel worse (+1). As in Factor 2, they felt strongly that being in their own surroundings would help (+4), with indication that they associated it with independence. For example:

- *"I like my home. I can do what I want, get a bit of independence back."*

Similarly, they ranked that they preferred to manage things their self higher than those within the other factors (+2). This person also felt that their family and friends would help them get over their depression (+3). In-line with their previous statement about physical aids, they somewhat endorsed the notion that treating their physical health problems would help (+2).

Timeline

There were no distinguishing statements related to this domain. However, there was some indication that they felt they would get over it quite quickly (+2), and slight disagreement that it would last a long time (-1).

Consequences

There were two distinguishing statements for this domain. For example, this was the only person to strongly disagree that their depression made them feel out of control (-4) or that it made them want to be on their own (-4). Regarding control, they indicated that they did not feel out of control unless things happened which caused them to lose their temper, such as frustration due to difficulties with activities of daily living. Also, they stated that being in their own surroundings helped because they liked their own company and were quite happy to be on their own.

Existential

There were no distinguishing statements within this domain. They disagreed that they saw themselves differently (-2) or that depression was part of who they were (-1).

Stigma

There were no distinguishing statements within this domain. However, they strongly disagreed that people would blame them for their depression (-5), ranking it lower than everyone else. They indicated that people they knew would not blame them and that their depression was understandable considering how much they had been through.

Summary of factors 1-4

Table 6. Summary of Factors 1-4. Distinguishing statements in bold

	Factor 1	Factor 2	Factor 3	Factor 4
Label	**Depression label does not fit**, understand what word means	Depression label might fit, Understand what word means	Depression label might fit, Understand what the word means	Depression label fits, somewhat unsure of what the word means
Cause	**Due to being physically unwell**, stroke, worried about future, being dependent on others, not prone to it, **not hereditary**	**Not worried about future**, stroke, being dependent on others, not prone to it	**May be prone to it**, **may be hereditary**, **May be worry about future**, past depression	**The way I think about things**, physical health problems, worried about future, being dependent on others
Cure	**Unsure own surroundings**	**Feelings of self-efficacy &**	**Own surroundi**	**Medication will not help**,

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	will help, prefer therapy, treating physical health problems, **feelings of self-efficacy**	**determination**, social support, being in own surroundings	**ng won't help**, medication, low self-efficacy	**talking won't help,** own surroundings, family and friends
Timeline	**Unsure of duration**	Over quite quickly	Will last long time	Over quite quickly
Consequences	Will affect physical health, will upset friends & family, **unsure it will make me want to be on my own**	Will affect physical health **Not out of control**, want to be on own	**Will upset family & friends**, feel out of control, want to be on own	**Do not feel out of control**, **do not want to be on own,**
Existential	**Not part of who I am**, somewhat see self differently	Not part of who I am, do not see self differently	Unsure if part of who I am	Unsure if part of who I am, do not see self differently
Stigma	**Unsure if it's a weakness**, not ashamed	Others won't blame, not ashamed	Not a sign of weakness, unsure if ashamed	Others won't blame

Table 6 is a brief summary of the main points that distinguish the four factors. Factor 1 describes people who were fairly certain that they were not depressed, but instead had strong physical attributions for the cause of their low mood. They most preferred therapy and treating their physical health problems. They also felt that there were things they could do to elevate their mood. They were unsure how long their low mood symptoms would last because they were linked with their physical symptoms. They felt that their depressive symptoms upset their friends and family. They strongly felt that depression was from something that happened to them, rather than coming from them.

Factor 2 describes people who potentially agreed that they were depressed and also felt that it was due to their stroke. However, what set them apart was their strong sense of self-efficacy, determination, and their emphasis on the helpfulness of their social support and home environment. They felt that their mood symptoms would improve quite quickly. They were unique in that they somewhat rejected the notion of depression making them feel out of control and they uniquely felt more neutral about it upsetting their friends and family, compared to those within the other factors who were more certain it would. Finally, they were unique in how strongly they rejected that depression was part of who they were.

Factor 3 describes people who were much less sure of the cause within the Q sort, but qualitative statements revealed this was because they felt that their pre-existing depression was the cause. They were also unsure of what would help, with some agreement that medication might, but that being in their own surroundings would definitely not help. They were also fairly certain that their low mood upsets their friends and family and that it would last a long time. While they rated their social support as good, their Q sort revealed that they did not believe this would be helpful for their mood and that it made them want to be on their own. They were the only ones to agree that they might be prone to depression.

Finally, Factor 4 describes someone who was unsure of what the word depression meant, yet they felt that the word depression fit their mood symptoms. They were the only person to attribute their low mood to internal psychological reasons, describing thoughts fuelled by anger and frustration with physical symptoms and refusing to use mobility aids because of what they represented. They had watched their husband suffer what they described as a 'terrible' stroke, which left them quite anxious about their own illness. While they felt that their depression would be over quite quickly, they did not think that medication or talking would help. They were unique in that they disagreed quite strongly that their depression made them want to be on their own, but in fact they preferred to be on their own, associating it with independence. They were also the only person to strongly disagree that their depression made them feel out of control.

Summary of treatment preferences

While not all of participants' beliefs about potential treatments featured in the statistics of each factor, considering the overall shape of each factor the following differences can be seen:

- Distinguishers of Factor 1 were positive about seeing a therapist and neutral about everything else including being at home.
- Distinguishers of Factor 2 were extremely positive about being home and help from family, and mildly positive about seeing a health professional including a therapist.
- Distinguishers of Factor 3 were the only ones who were positive about medication, and were very negative about being at home as a potential cure.
- The distinguisher of Factor 4 reflected the only person to voice negativity about medication as a treatment.

DISCUSSION

This study has shed light on how patients understand their depressive symptoms associated with stroke. Four distinct viewpoints were uncovered. One perspective represented depression as being due to external, physical causes, closely linked with physical symptoms. Because they linked their mood with the physical impact of the stroke, they were unsure how long their mood symptoms might last. They did not agree that they were depressed and felt the most helpful thing to elevate their mood would come from them, rather than from their own environment or social contacts. A second perspective emphasised the beneficial impact of very positively-perceived social support and home environment, and this was linked with a strong sense of determination and self-efficacy. While they potentially agreed that they were depressed, they believed there was plenty that they could do to help elevate their mood and thought it would subside quite quickly. A third perspective emphasised the unique viewpoint of two patients with a significant history of depression. While they felt that their stroke worsened their mood, they saw the cause as coming from them. They were much less certain what might help to elevate their mood and felt that it would last a long time. While they claimed to have good social support, they saw little benefit from this for their mood. Finally, a fourth perspective represented an individual who had witnessed her husband pass away from what she described as a 'terrible' stroke. There was a strong need for independence in the context of anger and frustration associated with the meaning she ascribed to using mobility aids.

Discussion of Factors 1-4

Factor 1: depression due to external, physical factors, an emphasis on physical symptoms and social consequences

The emphasis with this viewpoint is the link between physical symptoms and low mood. Participants spoke about physical symptoms, such as pain and fatigue, but also about their psychological reaction to them. For example, many spoke about the impact of their symptoms on their daily lives, such as not having the energy to function as well, or frustrations with their physical limitations. They also indicated that their physical symptoms made them apprehensive about stroke recurrence and that there were social consequences related to their physical symptoms.

There is a wealth of literature linking depression and physical symptoms. Regarding pain, Kroenke (2003) stressed that over half of depressed patients suffer from pain, while more than a quarter of patients with pain report significant depression. Pain is a risk factor for poor treatment response in depression, and the severity of pain accurately predicts the severity of depression. As already discussed, functional impairment, including poor mobility, has been found to be linked with PSD, although the direction of causation is unclear (Salter et al, 2008). Appelros (2006) followed a large sample of stroke patients over a 12-month period and found that symptoms such as pain and paresis, which were not present before the stroke, predicted depression. They also noted that fatigue was closely linked with physical disability. Similarly, even though four participants had suffered depression in the past, most felt that their stroke caused their depression and their physical symptoms served to maintain it.

Physical symptoms causing distress and worry about stroke recurrence can be conceptualised in terms of the health anxiety model (Warwick & Salkovskis, 1990). The cognitive model of health anxiety states that anxiety is created and maintained by the catastrophic misinterpretation of normal bodily symptoms. For example, the experience of having a stroke may have caused the formation of dysfunctional schemas, such as a real fear of death, and those schemas can become reactivated during some critical event, such as the experience of severe physical symptoms. Indeed, one distinguisher of this factor described feeling an increase in physical symptoms after he was prompted to think about his stroke. For example:

- *"Even talking to you about it I can start to feel more physical symptoms – sweating, tingling, anxiety."*

Wells (1997) explains that the result of these misinterpretations is typically anxiety; however, depression is also a common secondary feature. Behaviours that typically contribute to the maintenance of health anxiety are checking, avoidance, safety behaviours and reassurance seeking.

Participants who distinguished this factor also spoke about their physical symptoms leading to a loss of independence, as well as a role-reversal from someone who took care of others, to someone having to rely on others. Robinson-Smith, Johnston and Allen (2000) assessed 63 stroke patients at one month and then six months later. They found that, as functional independence increased, depression rates decreased, and this was closely linked with participants' sense of self-efficacy, or their confidence in their ability to do things to manage their mood symptoms. Loss of independence has been found to be particularly relevant to younger stroke patients, such as those who distinguished this factor. Jerome and colleagues (2009) noted that patients under the age of 75 reported their primary concern was related to their independence, leisure activities and financial resources. Indeed, distinguishers of this factor were under 60 years of age. They had strong agreement that they were worried about their future, and some of the reasons provided were:

- *"Because I'm worried about being able to pay bills including rent"*
- *"not having enough money, being able to keep working so I can support myself."*
- *"worried it might happen again and how I'd cope at work"*

Related to this role-reversal was the perception that they did not wish to burden others and that their depression made them feel socially excluded. This is consistent with the observation that stroke survivors tend to experience a decline in their social networks and that quality of life following a stroke is strongly linked with the level and quality of patients' social interaction (Scott, Phillips, Johnston, Whyte & MacLeod, 2012). Many of the participants within this factor perceived the quality of their social support to be sub-optimal. They were also unsure that being in their own surroundings would help their mood and they voiced feelings of guilt for upsetting others.

Another salient element within this factor was the strong perception of their depression being due to *external* reasons, rather than coming from internal factors. As discussed, Manber and colleagues (2003) found that external attributions for the cause of depression was associated with self-efficacy, where patients were more likely to take action to try and elevate their mood. Similarly, distinguishers for this factor strongly disagreed that there was nothing they could do to cure their depression, but instead listed several things they could do. This appeared to be related to the fact that participants disagreed that the depression label best described their mood. Qualitative statements revealed that participants did not agree with the depression label because they did not see themselves that way, and that their current mood symptoms were in fact strongly at odds with how they viewed themselves. For example,

- *"Being depressed is opposite to who I am. Friends would say this isn't me."*
- *"I've always been a happy go-lucky person. It's not me."*
- *"It's just not who I am"*

So it can be seen that the unique viewpoint underpinning this factor supports the well-known association between mood and physical symptoms, but it also shed much light on participant' understandings of why their physical symptoms were so distressing. It emphasises that there are possible biological (i.e. pain, fatigue), psychological and social aspects at play. It also emphasises the protective role of strong feelings of self-efficacy, particularly within the context of a somewhat negative social experience. While the level of actual physical symptoms was not measured, it is of note that three of the participants had considerable co-morbid chronic conditions which may have made their physical symptoms worse. Finally, this factor shed light on a possible association being physical attribution for low mood, and the perception of the likely duration of mood symptoms.

Factor 2: highly determined with less worry, positive social support, helpful environment and a belief that depression will be over quickly

This unique viewpoint is consistent with the well-known, protective benefit when social support is perceived in a strong, positive light. It is thought that social support may buffer the consequences of chronic illness by promoting adherence to treatment advice, aiding recovery and supporting psychological adjustment (e.g. Bisschop, Kriegsman, Beekman & Deeg, 2004). As previously discussed, findings by Morris and colleagues (1991) indicated that perception of social support from a spouse was significantly linked with the presence and severity of depression following stroke. The authors also found that patients' depression lasted longer when their perception of their social support was poor.

While participants who distinguished this factor felt that the depression label might fit, the cure they most endorsed was their positive social support and being in their own surroundings. It is interesting to note that their strokes had occurred on average six months previously. This may explain why they were making more comparisons between hospital and home. For example:

- *"Being with things and people you know goes a long way to bringing you back. I felt much worse in hospital"*
- *"It's better than being in hospital. You're not woken up at 6:30. There's no privacy and the ward is noisy."*

As in the former statement above, it makes sense that if one perceives their social support as being quite beneficial, they will not wish to be in hospital away from family and friends. However, while it was not statistically significant, there was some agreement that their depression made participants want to be on their own, which is somewhat contradictory.

It is also interesting to note that, while their level of depression, anxiety, stroke type and location was similar to those in the previous factor, they were unique in that they had no co-morbid medical conditions, which may explain why there was much less focus on physical symptoms. It is also of note that four out of five of distinguishers for this factor were male. There are well established gender differences in depression, including findings such as that of Hänninen and Aro (1996) that males tend to distract themselves from their mood with physical or other activities, while females are more likely to ruminate about their mood symptoms (as cited in Piccinelli and Wilkinson 2000). Indeed, the male distinguishers of this factor stated:

- *"Whatever's gonna be is gonna be. If it's gonna happen, it's gonna happen. I can't change it."*

- *"The future is just what happens. I'm not worried about it."*

Finally, within this factor there was an even stronger indication of self-efficacy and externalisation of their depression compared to the previous factor, and this was linked with a belief in a short duration of their mood symptoms. While little research has been done on the area of beliefs about duration in depression associated with chronic illness, Alderson et al (2012) noted that, while depressed patients held a range of views about the likely duration of their mood symptoms, those who viewed the cause as external tended to also believe in a shorter duration. This makes sense if one also strongly believes that they have control over their mood symptoms, as these participants did.

Factor 3: past depression, internal cause, out of control and lasting a long time

It is interesting that the two participants who distinguished this factor are quite different demographically. They are different genders, with a large difference in age, time since stroke and stroke location. However, the one thing they both shared was a significant history of depression and more severe current mood symptoms. Unlike the previous two factors, these participants somewhat attributed their depression to internal causes, and, because their depression was pre-existing, they felt that it was going to last a long time, which is consistent with findings by Alderson et al (2012). Other research has indicated that people with depression, as well as those without, tend to view it as a chronic condition (Vollmann, Scharloo, Salewski, Dienst, Schonauer & Renner, 2010).

These participants also strongly endorsed social consequences, such as upsetting their friends or family, even though they rated their social support as good. While they felt that medication might help more than those on any other factor, overall they were unsure what would best help to elevate their mood. It is not known if they had previously taken anti-depressants.

What is apparent from the overall shape of this factor, and from some of the qualitative statements, is a feeling of hopelessness. For example:

- *"It just feels like a black hole, like I'm going to struggle to get out of. I don't smile very often or laugh out loud. Things don't excite me. It's been amplified since the stroke, though I had low mood before my stroke."*

Some theorise that particular cognitive styles, such as the tendency to attribute negative events to stable and global causes, can make individuals more vulnerable to depression and hopelessness (O'Connor, Connery & Cheyne, 2000). Bennett, Adams & Ricks (2012) note that a pessimistic attributional style has been found to be linked with poor health, immune functioning and even mortality in a range of illnesses, and is typically linked with greater self-reported disability. Interestingly, the authors found that positive beliefs about self-efficacy acted as a buffer between pessimistic attributional style and the experience of cardiac symptoms, which again reflects the clinical importance of perceptions of self-efficacy (Bennett, Adams & Ricks, 2012). However, the participants within this factor were unsure about their ability to control their mood symptoms, so did not benefit from this important buffer.

Factor 4: strong need for independence and the meaning of physical aids. Frustration, anger and worry, but not out of control

This factor represents someone who was likely still in the early stages of adjusting to having a stroke, having only suffered it three months prior. She was unique from those within the other factors because she was older, had more severe anxiety, and was the only person to indicate that their mood was related, at least in part, to a past bereavement. As Hacket, Yapa, Parag and Anderson (2005) explain, stroke patients are typically older, female, and are more likely to have experienced a bereavement or other significant life event.

What was also apparent from her Q sort was her strong emotional reaction to having to rely on mobility aids, voicing much anger and frustration, because she associated them with a loss of independence and getting older. According to the SRM, powerful past experiences, such as this woman's bereavement, can lead to strong emotional reactions to their illness, which serve to over-ride cognitive representations and guide action. People

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may also form 'if-then' rules in order to try and maintain their self representation (e.g. independence), in the face of adjusting to disability (Sharpe & Curran, 2006). This may explain her refusal to use some mobility aids. This woman's viewpoint was also unique in her strong rejection that her mood symptoms made her want to be on her own. She instead preferred to be on her own, which was also closely related to her strong need to maintain independence. Her emotional reaction is consistent with research showing that disability is one of the strongest predictors of low mood in older adults (Prince, Harwood, Thomas, & Mann, 1998) and that negative reactions to mobility aids are common (Resnik, Isenstadt, Wasserman and Iezzoni, 2009; Yardley, Donovan-Hall, Francis, Todd (2006). It has also been shown that, while stroke patients can often see the usefulness of mobility aids, they do serve as a constant reminder of their disability (Pettersson, Berndtsson, Appelros & Ahlström, 2005).

Consensus items

There were six statements that were not significantly different across the four factors, four of which were placed in the centre of the Q sort, suggesting they were not strongly held beliefs. This may have simply been because the statements were more general compared to the others, or just not as relevant to participants. During data collection it became evident that participants found the statement 'being depressed tends to make me more depressed' confusing, which may explain their neutrality about it.

There was shared agreement with two statements related to cure: 'the best thing for my depression is to see a health professional' and 'I prefer to manage things myself if I get depressed', although these statements were not given high ratings of agreement. The latter statement makes sense in the context of Factors 1 and 2 where participants voiced strong agreement that there were things they could do to cure their depression. It also makes sense in the context of Factor 4 where it may have been related to this participant's strong desire for independence.

There was also a highly significant shared disagreement with the notion that people would blame them if they knew they were depressed. Looking at the distinguishing statements for each factor, only one factor included a statement regarding stigma, blame or shame. For example, distinguishers in Factor 1 were more neutral about the possibility of their depression being a sign of weakness, whereas people within all of the other factors

disagreed with this statement. Qualitative statements revealed that this was due to social factors – not wanting to rely on others and feeling excluded by others. Given the overall shape of Factor 1, this may have been associated with their perceptions of their social network, rather than a general world view, but this is merely a hypothesis.

Implications for practice

- Clinicians working with depressed stroke patients should enter into a conversation with them about their mood symptoms, rather than relying solely on mood screens. Depression following stroke is difficult to detect. This study found that stroke patients, even those with mild symptoms, hold a wide range of views about their depressive symptoms which do not feature on commonly-used mood screens. Some of those beliefs, such as the perceived helpfulness of social support or being at home, may be strongly held and linked with patients' preferences for treatment.

- Clinicians treating stroke patients should include a careful consideration of systemic information when assessing and treating people for depression following a stroke. This should include not just the presence or absence of patients' social support networks, but also their perception of the helpfulness of their social support.

- Clinicians should ask patients what treatments they would most prefer. The four factors identified within this study included four distinct opinions about what treatments patients thought were best, and only one factor reflected positive beliefs about medication.

- Clinicians should be on the lookout for self-efficacy, or the lack there of, in patients. If present, this should be utilised in a careful way so that patients can best help themselves to elevate their mood, in a way that does not undermine their physical rehabilitation.

- Clinicians should be aware of the range of impact from physical symptoms – that patients may closely link them with their mood, that they may lead not only to physical consequences, but they can also have a psychological and social impact as

well. The presence of physical symptoms may also affect patients' beliefs about the
likely duration of their depression.

Future research

- This study could be replicated without some of the limitations that may have
  impacted upon it. For example, it could be repeated with a larger set of participants
  and the Q set could be further refined through the use of focus groups. A larger P
  set may have clarified whether or not Factor 4 was a common view as it only had
  one exemplifier. It could also be replicated with an older participant group who
  reflect the more common stroke demographic.

- Also, the participants who distinguished the four factors in the current investigation
  could be interviewed to see if they agreed or disagreed with the findings, which
  would provide a means of further assessing the validation of the interpretation. As
  Robins and Krueger (2000) write, *"A truly hermeneutic Q approach therefore
  emphasizes the final step outlined above, in which the researcher returns to the
  researched with the conclusions of the survey and, sharing these results, evaluates
  the analysis together with the subject"* (p. 645).

- A questionnaire could be developed based upon the current findings, similar to the
  Illness Perception Questionnaire, but specifically related to depression associated
  with stroke. This questionnaire could be administered to a large sample of stroke
  patients to see whether the views expressed within this study are also found in the
  wider population. This questionnaire could also be used to assess beliefs about
  depression in stroke longitudinally, to look for beliefs that are risk factors for poor
  outcome.

- A tool could be developed for use by clinical psychologists working in stroke to
  enhance the assessments they undertake. For example, the current Q sort was
  demonstrated to a team of clinical psychologists who work in stroke who agreed
  that it could be a very useful tool to quickly get at the heart of what was most
  important for patients in relation to their mood. What was most striking while

carrying out the Q sorts was how quickly it facilitated a conversation about issues that patients found most salient. A shortened form of a Q sort has been shown to be effective in assessing and facilitating pain acceptance (la Cour, 2012)

• A study could be designed to investigate the utility of this Q sort as a possible means of assessing belief change in stroke patients before and after therapy. This is something that may be particularly relevant to therapies such as cognitive behavioural therapy or motivational interviewing, where specific maladaptive beliefs are targeted.

Critical appraisal of the study

A strength of the current study was that it investigated stroke patients' beliefs about their depressive symptoms across the five categories of the SRM, but also included the categories of coherence, existential and stigma. Participants' perception of their social support was also obtained. This was also the first study to investigate these domains in relation to treatment preference to look for relationships. It was unique in that, rather than simply filling in a questionnaire or being interviewed, patients' actively compared and contrasted statements within those domains, and in doing so, revealed their unique points-of-view. Another strength lies in the use of Q methodology itself. There was scientific rigour through the statistical analysis of the Q sort data and the methods chosen for the factor analysis were mathematically robust. Factor interpretation was guided by statistically significant statements, as well as qualitative verbal reports by participants, thus helping to reduce the chance of bias, while hopefully strengthening the validity of the interpretations.

P set

The current study also had several limitations. Due to the severe time constraints due to difficulties in gaining ethical approval, the sample size was relatively small. This small, entirely white British, P set means that the results do not necessarily generalise to the wider population. Furthermore, the participants were relatively young compared to the more common stroke demographic, and thus may have had important differences, such as fewer stressful life experiences (e.g. bereavements) or fewer co-morbid conditions. Due to their

young demographic they may also have had more living relatives, including partners, to provide social support. All of these factors may have affected the way they sorted the cards.

Also, because it was necessary to exclude those with significant physical or neurological impairments, those with more significant symptoms were not studied. Given the close relationship between mood and physical symptoms, this has implications for the generalisability of the findings to the wider stroke population. Related to this, it would have been beneficial to have gathered more information about their physical health, including level of disability, to see if it correlated with their perceptions. While professionals working in stroke were consulted to find patients who were suitable, an objective measure of their neuropsychological skills would have provided more evidence for their ability to successfully carry out the sorting task, which does require intact cognitive ability.

The participants included had a wide range of severity of their reported mood symptoms, and three out of the four factors were mostly distinguished by those with mild symptoms. Therefore, it is not known how the results would extrapolate to those with more severe depressive symptoms, or to those who had been communicated a diagnosis of depression. Also, some of the participants had been recently assessed by a clinical psychologist, which may have influenced their opinions, such as what treatment(s) they preferred.

Concourse

The concourse used for this study was based upon another researcher's review of studies evaluating beliefs about depression in chronic illness more generally. Therefore, there is potential for unknown bias or error with the studies that researcher chose to include, how they chose to report them, or within the studies themselves. We also do not know if those with stroke think about their depression in the same way compared to those with chronic illnesses more generally. Conducting focus groups with stroke patients and including that information within the concourse would have strengthened the validity of the final Q set. Unfortunately this was not possible due to the strict time constraints for this study.

Q set

Even though the Q set was piloted with colleagues of the author, it would have been better to have also piloted it with stroke patients. For example, as discussed earlier, during administration it became clear that the statement 'my depression tends to make me more depressed', which was intended to represent the notion of depression as a cycle or feedback loop, was confusing for participants as they repeatedly asked what it meant. It is not known if there was similar, unvoiced, confusion about other items, although participants were actively encouraged to ask questions. Furthermore, the author, her two supervisors and the professionals working in stroke who were consulted on the Q set, were all mental health professionals. This may have caused them to view the suitability of the statements in a certain light. The potential for this latter bias was hopefully somewhat reduced by the systematic process by which the Q set was developed.

The final Q set was relatively small compared to many Q studies, which was necessary so that the sorting task was achievable for stroke patients; however, this means that it might not have been completely representative of the concourse. Indeed, some participants stated that they would have included new topics, such as poor satisfaction with their treatment, for example. Furthermore, as with any investigation relying on self-report, the extent to which participants behaved according to social desirability (i.e. demand characteristics) is not known.

Data collection

Data was collected in a range of settings – outpatient clinic rooms, inpatient wards, and in patients' homes. The impact of these various settings on the Q sorts is unknown. For example, inpatients on busy wards may have been more concerned with confidentiality which might have impacted on what they were willing or able to say. To attempt to reduce this, inpatients were seen in a private room on the ward if possible; however, for one patient all that could be done was to pull the bedside curtain around. Related to this, some participants' families were nearby (i.e. down a corridor) while they were doing the sorting, which may have impacted on their sorting.

The author is also a psychologist in clinical training, with experience in carrying out therapy. When patients became emotionally upset, it was sometimes difficult not to switch into 'therapy mode', to give them adequate time and space to express themselves and feel listened to. However, this did not feel like real or adequate therapy, as I knew I was only with them for a brief, one-off session. Nevertheless, these informal conversations inevitably

involved my using therapeutic skills such as active listening and paraphrasing, which may have impacted upon their subsequent card sorting. During these occasions, it was stressed to participants that they did not have to continue.

Also, the author greatly values behaviourism and places particular emphasis on behavioural activation whilst working clinically with depressed patients. While I did not consciously encourage patients who reported that there were things that they could do to help their mood, for example, this was nevertheless a possibility – I may have said things or changed my body language in some way that influenced how they sorted the cards. The fact that most of the conversations took place *after* participants sorted the cards and were focused around items that they had already endorsed as important, helped to reduce this possibility.

Factor interpretation

As mentioned previously, within Q methodology there is the potential for bias to impact upon factor interpretation. For example, the author is from a different cultural background to all of the participants, which may have coloured her interpretations in some unknown way. The author's preference for behavioural activation in her own clinical work may have influenced how she interpreted the factors. However, the factors were interpreted on the basis of statistically significant distinguishing statements, as well as participants' verbal reports, so hopefully this was somewhat minimised. One strength of Q methodology is that factor arrays are there in black and white for all to see, so any inconsistencies in how they are interpreted can be easily seen by others, leading to more rigour in their interpretation.

Final summary and conclusions

This study aimed to shed light on how people make sense of depressive symptoms associated with stroke. Four distinct viewpoints were uncovered. One viewpoint reflected those who closely linked their mood symptoms with their physical symptoms, and thus endorsed an external cause for their depression. They described a range of reasons why their physical symptoms were difficult to cope with, and these spanned from the physical effects of pain and fatigue, to psychological and social consequences as well. Because they were unsure of the likely duration of their physical symptoms, they were similarly also unsure about the likely duration of their mood symptoms. They did not agree that the depression label fit them and endorsed a strong, external attribution for the cause of their mood symptoms. They felt they had a good sense of control over their mood symptoms, even though they were unsure of the helpfulness of their social support or home environment.

The second viewpoint emphasised the powerful role social support plays in buffering the consequences of physical illness. This was linked with a very high sense of self-efficacy, a strong external attribution for the cause of depression, less worry about the future and a belief that mood symptoms would be over quite quickly.

The third viewpoint reflected the perspectives of those with a significant history of depression, as well as more severe current mood symptoms. While they rated their social support as good, they did not believe it would help their mood and were unsure about any of the potential treatments, although they were the only ones that thought medication might help. They attributed their depression to internal causes and felt that it was going to last a long time.

The final viewpoint emphasised the impact of a past bereavement causing much anxiety and a strong need for independence in a woman who associated mobility aids with physical limitations and getting older. These associations caused much anger and frustration leading her to refuse to use some of them. She was unique in that she rejected the notion that medication would help her mood symptoms, but instead just preferred to be on her own. However, she clarified that being on her own was preferable because she linked it with her independence and she liked her own company.

Four distinct views on treatment preference were also uncovered, and these were related to other strongly held beliefs. For example, one viewpoint was positive about seeing a therapist while being neutral about everything else including being at home. This was in the context of somewhat negative views about their social support. On the other hand, one viewpoint was extremely positive about their social support and so thought that being at home and gaining help from friends and family would be the best help. They also thought that seeing a therapist might be helpful. Those with a significant history of depression were the only ones to have positive views about medication and were also very negative about being at home. Finally, one factor represented someone who voiced negativity about medication as a treatment and this was associated with an internal causal attribution for their depression.

These findings have important implications for clinical practice. It was uncovered that stroke patients hold a wide range of views about their depression and that some of these were linked with their preferences for treatment. Therefore, clinicians should enter into conversations with patients about their mood symptoms, rather than relying solely on quick mood screens that may have much less relevance to some individuals. There is also a real need for clinicians to consider systemic factors while assessing and treating depressed stroke patients. It has been shown that involving patients in decisions about their care, including preferences for treatment, has an impact on outcome. In the current study, there were four distinct viewpoints about treatment preference, only one of which endorsed the usefulness of medication. Therefore, again, clinicians should be aware of the likely range of views on this and actively discuss treatment preferences with patients. Clinicians should also be aware of the presence or absence of perceived self-efficacy in depressed patients. If properly utilised, patients could be taught how best to help themselves to elevate their mood. Finally, clinicians should be aware of the potential underlying reasons patients struggle with physical symptoms, that they can have not just physical implications, but also psychological and social implications as well. It was also shown that physical symptoms may be closely related to beliefs about the duration of depression.

The current study also brought to light new avenues for future research. For example, this study could be replicated with a further refined set of Q sort statements and a larger set of participants to further clarify the findings. Interviewing those who took part about the results would help to assess the validity of the findings. A questionnaire could be developed to test whether or not the unique views uncovered in this study are also found in the wider population. This tool could also be used to uncover maladaptive beliefs that may be risk factors for poor outcome in these patients. Finally, the Q sort used in this study may potentially be adapted for use as an assessment tool, quickly getting to issues patients' find most salient, or as a way of assessing change in psychotherapy.

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APPENDIX 1: Ethical approval

NHS
Health Research Authority

NRES Committee Yorkshire & The Humber - Sheffield

Yorkshire and the Humber REC Office
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Meanwood
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Telephone: 0113 30 50126
Facsimile: 0113 855 6191

21 February 2012

Mrs Carrie Rowbottom
Psychologist in Clinical Training
Leeds Teaching Hospital NHS Trust
Charles Thackrah Building
101 Clarendon Road
Leeds
L2 9LJ

Dear Mrs Rowbottom

Study title: MAKING SENSE OF DEPRESSIVE SYMPTOMS
                  ASSOCIATED WITH STROKE:A Q METHODOLOGICAL
                  STUDY
REC reference: 11/YH/0460

Thank you for your letter of 16 February 2012, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

for participants. You confirmed that if a participant were to become distressed you would pause the interview. The Committee advised that this information should be included within the Participant Information Sheet.

You confirmed that there are mechanisms in place for those instances where a participant can inform you of a potential risk or safety issue.

The Committee advised that the Information Sheet needs to explain that the participants GP will be informed and also needs to include who the participants can complain to. You explained that your supervisor had advised you to cut the Information Sheet down but you are happy to include any further information that is required. The Committee queried which Information Sheet and Consent Form is correct as 2 have been submitted within the application. You advised that the correct documentation is included in the appendices and the other documents were submitted in error. The Committee suggested adding an executive summary to the Information Sheet as stroke patients may have difficulty reading through several pages of documents.

You advised that you had given a naive estimation of the length of time needed for the participants to ask questions and agree to consent to take part in the study. The Committee advised that at least 24 hours should be given to the participant.

The Committee advised that there are inconsistencies throughout the application for the timings for the participant to complete the Q-cards. The Committee suggested that once you had completed the Q-cards you should then decide a consistent time for the participants to complete them.

The Committee felt that a specific stoke group of patients needs to be chosen for this study. If you decide to look at all forms of stoke, then the sample size would need to be sufficiently increased.

The Committee was therefore unable to give the study a favourable opinion as a significant part of the study had been omitted from the original application for ethical review.

I regret to inform you therefore that the application is not approved.

If you would find it helpful to discuss any of the matters raised above or seek further clarification from a member of the Committee, you are welcome to contact the Co-ordinator.

Options for further ethical review

You may submit a new application for ethical review, taking into account the Committee's concerns. You should enter details of this application on the application form and include a copy of this letter, together with a covering letter explaining what changes have been made from the previous application. We strongly recommend that you submit the new application to this REC. However, you may submit the application to a different REC if you prefer.

Alternatively, you may appeal against the decision of the Committee by seeking a second opinion on this application from another Research Ethics Committee. The appeal would be based on the application form and supporting documentation reviewed by this Committee, without amendment. If you wish to appeal, you should notify the relevant Research Ethics Service manager (see below) in writing within 90 days of the date of this letter. If the appeal is allowed, another REC will be appointed to give a second opinion within 60 days and the second REC will be provided with a copy of the application, together with this letter and other relevant correspondence on the application. You will be notified of the arrangements for the

APPENDIX 2: R&D approval

The Leeds Teaching Hospitals **NHS**
NHS Trust

Ref: Ciona Mclennan

14/03/2012

Mrs Carrie Rowbottom

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Dear Mrs Rowbottom

Re: NHS Permission at LTHT for: MAKING SENSE OF DEPRESSIVE
SYMPTOMS ASSOCIATED WITH STROKE:A Q METHODOLOGICAL
STUDY
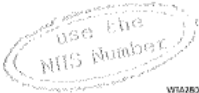LTHT R&D Number: PY12/10200
REC: 11/YH/0460

I confirm that *NHS Permission for research* has been granted for this project at The Leeds Teaching Hospitals NHS Trust (LTHT). NHS Permission is granted based on the information provided in the documents listed below. All amendments (including changes to the research team) must be submitted in accordance with guidance in IRAS. Any change to the status of the project must be notified to the R&D Department.

Permission is granted on the understanding that the study is conducted in accordance with the *Research Governance Framework for Health and Social Care*, ICH GCP (if applicable) and NHS Trust policies and procedures available at http://www.leedsth.nhs.uk/sites/research_and_development/.

This permission is granted only on the understanding that you comply with the requirements of the *Framework* as listed in the attached sheet "Conditions of Approval".

If you have any queries about this approval please do not hesitate to contact the R&D Department on telephone 0113 392 2878.

Chairman Mike Collier CBE Chief Executive Maggie Boyle

The Leeds Teaching Hospitals incorporating:
Chapel Allerton Hospital   Leeds Dental Institute   Seacroft Hospital
St James's University Hospital   The General Infirmary at Leeds   Wharfedale Hospital

use the
NHS Number

WTA260

Indemnity Arrangements

The Leeds Teaching Hospitals NHS Trust participates in the NHS risk pooling scheme administered by the NHS Litigation Authority 'Clinical Negligence Scheme for NHS Trusts' for: (i) medical professional and/or medical malpractice liability; and (ii) general liability. NHS Indemnity for negligent harm is extended to researchers with an employment contract (substantive or honorary) with the Trust. The Trust only accepts liability for research activity that has been managerially approved by the R&D Department.

The Trust therefore accepts liability for the above research project and extends indemnity for negligent harm to cover you as investigator and the researchers listed on the Site Specific Information form. Should there be any changes to the research team please ensure that you inform the R&D Department and that s/he obtains an appropriate contract, or letter of access, with the Trust if required.

Yours sincerely

Dr D R Norfolk
Associate Director of R&D

Approved documents
The documents reviewed and approved are listed as follows

Document	Version	Date of document
NHS R&D Form	3.3	09.03.12
SSI Form	3.3	13.03.12
Directorate Approval		13.03.12
REC Letter confirming favourable opinion		21.02.12
Protocol	1.2	21.02.12
Patient information sheet (REC approved)	1.2	16.02.12
Consent form (REC approved)	1.1	24.12.11
GP/Consultant information sheets (REC approved)	1.0	30.08.11

Leeds Community Healthcare **NHS**

NHS Trust

Telephone enquiries, please contact Linda Dobrzanska
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27th March 2012

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Selby
North Yorkshire
YO8 5ZU

Stockdale House
Headingley Business Park
Victoria Road
LS6 1PF

PCT Ref: NP/0106

Dear Mrs Rowbottom

Re: Making sense of depressive symptoms associated with stroke: A Q methodological study

Thank you for your recent submission requesting NHS permission for research to be conducted in Leeds Community Healthcare NHS Trust for the above study.

I am pleased to confirm that LCHT permission for the above research has been granted on the basis described in the application form, protocol and supporting documentaion.

Conditions of approval

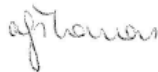You should be aware that approval is granted subject to the conditions specified below:

- In undertaking this research you must comply with the requirements of the Research Governance Framework for Health and Social Care (2nd edition 2005) which is mandatory for all NHS employees.

- Consent for Leeds Community Healthcare NHS Trust to audit your project, which is implicit in your acceptance of approval.

- Where any amendments, substantial or non substantial are made throughout the course of the study these should be notified to Leeds Community Healthcare NHS Trust.

- A copy of the final study report should be forwarded to Leeds Community Healthcare NHS Trust.

- Should any serious adverse event(s) occur throughout the course of the study these should be notified to Leeds Community Healthcare NHS Trust using the contact details set out above.

- You comply with Leeds Community Healthcare NHS Trust Policies on the handling of data. These policies are available from the research manager.

Should you require any clarification regarding any of the points raised above, or have any further queries in relation to approvals and post approval study management process then please do not hesitate to contact me on 0113 2033473.

Finally, may I take this opportunity to wish you well with your study and look forward to hearing about your progress in due course.

Yours sincerely

Dr. Amanda Thomas
Medical Director

Approved documents

The documents reviewed were:

Document	Version	Date of Document
REC Form	3.3	-
SSI Form	3.3	-
Participant Information Sheet	1.2	16th February 2012
Consent Form	1.1	24th December 2011
Protocol	1.2	21st February 2012
Letter to GP	1.0	30th August 2011
CV of researcher	-	reviewed
CV of academic researcher (if appicable)	-	reviewed
Sponsor identified	-	University of Leeds
Indemnity identified	-	University of Leeds

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Covering Letter		24 December 2011
Evidence of insurance or indemnity		28 September 2011
GP/Consultant Information Sheets	1.0	30 August 2011
Interview Schedules/Topic Guides	1.0	24 December 2011
Investigator CV		24 December 2011
Letter from Sponsor		24 December 2011
Other: Interview Safety Protocol for Home Visits	1.0	20 October 2011
Other: REC Feedback Letter	1.0	17 November 2011
Participant Consent Form	1.1	24 December 2011
Participant Information Sheet	1.2	16 February 2012
Protocol	1.2	21 February 2012
REC application	1.0	23 December 2011
Referees or other scientific critique report		23 May 2011
Response to Request for Further Information		16 February 2012

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

11/YH/0460	Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely

Anne Ward

Dr Basil Sharrack
Chair

Email: anne.ward7@nhs.net

Enclosures:	"After ethical review – guidance for researchers" *[SL-AR2]*
Copy to:	*Mrs Rachel E de Souza, University of Leeds*
	Dr Derek Norfolk, Leeds Teaching Hospitals Trust

-----Original Message----- From: Basil.Sharrack@sth.nhs.uk
[mailto:Basil.Sharrack@sth.nhs.uk] Sent: 21 June 2012 13:31 To: Ward Anne
(LEEDS AND YORK PARTNERSHIP NHS FOUNDATION TRUST);
b.sharrack@sheffield.ac.uk

Subject: RE: telephone conversation REC Ref: 11/YH/0460

Dear Anne I think it would be perfectly acceptable for her, if she is part of direct
clinical care team, to do these assessment provided these are required clinically
(which I think they are). If patients are found to be depressed, she, or someone
else from that team, can talk to the patient about the study. Hope this is
helpful. R BS

-----Original Message----- From: Ward Anne (LEEDS AND YORK PARTNERSHIP
NHS FOUNDATION TRUST) [mailto:anne.ward7@nhs.net] Sent: 21 June 2012
11:57 To: Sharrack, Basil (Neurology); Basil Sharrack

Subject: FW: telephone conversation REC Ref: 11/YH/0460 Dear Basil Study
MAKING SENSE OF DEPRESSIVE SYMPTOMS ASSOCIATED WITH STROKE:A
Q METHODOLOGICAL STUDY for Clinical Psychology doctorate

Carrie Rowbottom has telephoned as she is having very poor recruitment for her
study. She told the Committee at review that ' a neuro-psychologist would complete
the Mood screening and then based on the criteria and capacity would introduce the
study to the patient. You confirmed that you would be informed about participants
that meet the criteria and are interested.' She is finding that the care team are
not performing the mood screening to produce the criteria to decide whether to
introduce the study to the patients. I think her status in the care team is unclear,
see below, and thought if she was a member of the care team the Committee may
agree for her to make the initial approach to patients. What do you think? Is it
worth her pursuing this?   Kind regards Anne

APPENDIX 4: Q sort grid

(Actual size = A2 poster board)

Strongly Disagree   Neutral   Strongly Agree

APPENDIX 5: Proforma

1. Participant number_____

2. Age_____

3. Gender_____

4. Ethnicity_____

5. Relationship status_____

6. Stroke date & type_____

7. Mood Scale Used_____

8. Date of Mood Screen_____

9. Mood Score_____

10. Mental Health
    history_____
    _____
    _____
    _____
    _____

11. Medical
    history_____
    _____
    _____
    _____
    _____

12. Current
    conditions_____
    _____
    _____
    _____

APPENDIX 6: Patient information sheet

Patient Information Sheet

16th February 2012
Version 1.2

Faculty of Medicine and Health
Doctorate in Clinical Psychology Programme

Beliefs about low mood following stroke

You are invited to take part in a research study about low mood
related to stroke, conducted by Carrie Rowbottom, a Psychologist in
Clinical Training. Before making a decision about whether you would
like to take part in this research, please read the following information
carefully.

Brief summary of the main points:

- I'm interested in finding out how people make sense of low
  mood following a stroke

- I'm contacting patients who have recently completed a mood
  questionnaire with a member of staff that showed some
  symptoms of low mood or depression

- Taking part involves sorting a stack of cards according to how
  much you agree or disagree with the statements written on
  them

- Taking part will take no more than two hours in total

- Your personal information will be kept confidential

- You are under no obligation to take part in this study and you
  are free to withdraw at any time, for any reason. This will not
  affect your treatment in any way.

What is the purpose of the study?

We know that low mood is common after stroke. I am interested in finding out about how people make sense of low mood following a stroke, such as what they think might have caused it, and what they think the best treatment might be.

Why have I been asked to take part?

I am contacting patients who have had a stroke and have recently completed a mood questionnaire with a member of staff that showed symptoms of low mood or depression. If you take part in this study it will not affect your treatment in any way.

What will happen if I take part?

I will ask you to think about statements printed on cards - for example, "My physical health problems have caused my depression". I would like you to indicate how strongly you agree or disagree with these statements by sorting the cards into piles. Once you have sorted all the cards, I will ask you a few questions about how you've sorted them. I will ask you to tell me a little bit about yourself and any past experiences you've had with low mood.

Do I have to take part?

It is up to you to decide if you would like to take part. If you do want to take part, I will ask you to sign a consent form to show you have agreed to take part. You are free to withdraw at any time, without giving a reason. If you decide not to take part this will have no effect on your treatment.

Will my taking part in the study be kept confidential?

All information about you will be kept confidential. At no time will you be identified by name. If you do decide to take part, we will let your GP know by sending them a brief letter.

For the purposes of this study the researcher will access your medical records but your information will be kept strictly confidential.

The only time confidentiality would need to be broken is if we began to worry about your safety or someone else's safety. If this were the case, we would alert a member of staff to ensure your safety.

Please turn over....

What if I decide I no longer want to continue?

This study will prompt you to think about your mood in some detail. If you feel that participating is upsetting for any reason, please be reassured that you can say you don't want to take part, and I will not ask why. You can also say you don't want to continue at any point in the study and this decision will be respected.

If you should become upset for any reason, we will pause the research process until you are happy to continue. We would only continue if you were happy to.

You are under no obligation at all to complete the consent form or sorting procedure. You have the right to withdraw from the research at any time and without giving me a reason.

After completing this study, will I be contacted again?

No. However, if you would like to see a summary of my findings from this study, please let us know and we will send you a copy.

Who can I make a complaint to?

If you would like to make a complaint, feel free to telephone or write to:

Professor Stephen Morley, Director
University of Leeds Doctorate in Clinical Psychology Programme
Leeds Institute of Health Sciences
Charles Thackrah Building
Clarendon Road
Leeds, LS2 9LJ
Telephone: 0113 343 2732

Thank you,

Carrie Rowbottom
Doctorate in Clinical Psychology Programme
email: umclr@leeds.ac.uk

Patient Consent form
Version 1.1 24.12.11

Faculty of Medicine and Health
Doctorate in Clinical Psychology Programme

Making Sense of Low Mood Associated with Stroke
Name of Researcher: Carrie Rowbottom

Please
initial box

1.   I confirm that I have read and understand the information sheet dated _____ for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2.   I understand that I have been asked to participate in a research study about low mood associated with stroke.

3.   I have been fully informed of the purpose of the research by the researcher undertaking the work and it has been explained to me that my participation is entirely voluntary. I understand that I am entitled to withdraw from the study at any time without prejudice.

4.   I give permission for the researcher to have access to my records.

5.   I give permission for the researcher to inform my GP of my participation

6.   I also understand that any information I offer will be treated anonymously and all material arising out of the study will be dealt with on a confidential basis by the researcher involved. The research complies with the Data Protection Act (1998).

7.   I have read and understood the above information and agree to participate in the named study.

_____ _____ _____
Name of Participant   Date   Signature

_____ _____ _____
Name of Researcher   Date   Signature