Validation of Behavioural Outcomes of Anxiety (BOA) Questionnaire in Stroke Survivors with Aphasia

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Abstract

Aims: Anxiety disorders and aphasia are common following stroke. This study investigated the psychometric properties of the Behavioural Outcomes of Anxiety scale (BOA) in a sample of aphasic stroke survivors. The BOA relies upon the observations of a carer to rate the anxiety of the stroke survivor. The Generalised Anxiety Disorder-7 measure (GAD-7) is a brief screen for general anxiety which has not been investigated in stroke. A secondary aim of this study was to evaluate the performance of an observational version of the GAD-7 for aphasic stroke survivors.

Design: Cross-sectional questionnaires, with repeated measures and a relaxation intervention for a subsample. Correlational and ROC analysis to assess psychometric properties, repeated measures MANOVA to assess the outcome of the intervention.

Method: One hundred and eleven stroke survivor-carer dyads were recruited through voluntary sector organisations. All survivors completed a visual self-report anxiety screen, the Tension Rating Circles (TRCs), and the Frenchay Aphasia Severity Test (FAST). Carers completed the BOA and adapted versions of the anxiety subscale of the Hospital Anxiety and Depression Scale (HADS-A) and GAD-7. A sub-group of 29 survivor-carer dyads repeated the measures two weeks later to assess test-retest reliability. Within this sub-group, stroke survivors were randomly allocated to a relaxation training or control group.

Results: 41.4% of these aphasic stroke survivors were identified as anxious which is higher than prevalence rates in general stroke samples. The BOA and the GAD-7 correlated significantly with each other and with all the other measures of anxiety. When using the HADS-A (≥7) as a criterion standard against the BOA, the area under the ROC curve (AUC) was 0.90 (excellent range of accuracy). A cut-off score on the BOA >16 achieved recommended levels of sensitivity (0.85) and specificity (0.85).

For the GAD-7, using the same criterion standard, the AUC (0.94) also fell within the excellent range of accuracy, and was significantly greater than an AUC of 0.50.

Optimal cut-off for identifying anxiety was a score of >4 (sensitivity: 0.91, specificity: 0.83).

Significantly greater reductions in the BOA scores occurred in survivors who completed relaxation training than in the controls, providing evidence of construct validity. The BOA and the GAD-7 both showed good test-retest reliability of 0.91 and 0.67 respectively. Feedback from carers revealed that the BOA was easy and quick to use and prompted further reflection on the emotional status of the survivors.

Conclusions: The carer-completed BOA appears to be a valid and reliable screen for anxiety in stroke survivors with aphasia. Preliminary support for the validity of the GAD-7 is provided and further studies are warranted. Clinical and theoretical implications of the study findings are discussed and recommendations for future research are outlined.

CONTENTS

LIST OF TABLES

LIST OF FIGURES

LIST OF APPENDICES

Chapter One

Introduction

1.1 Focus of the thesis

A stroke is a life changing experience for most patients (Field *et al.,* 2008). Whilst improved survival rates have been observed (de Freitas *et al.,* 2005) stroke is the most frequent cause of 'complex disability' relative to any other chronic condition (Adamson *et al.,* 2004). Recovery can continue for many years following stroke (van der Gaag *et al.,* 2004). Mood disorders post stroke are highly prevalent (Ayerbe, Ayis, Wolfe *et al.*, 2013) and have important consequences for prognosis. Post stroke anxiety is associated with a range of adverse outcomes including lower quality of life (Jeong *et al.*, 2012); depression (Ayerbe, Ayis, Wolfe *et al.*, 2013); increased disability (Moser *et al.*, 2007); social isolation (Astrom, 1996); alcohol abuse (Castillo *et al.*, 1993); lowered functional ability (D'Alisa *et al.*, 2005) and impairment in activities of daily living in the short and long term (Schultz *et al.*, 1997). Furthermore, untreated mood disorders can lead to longer term hospitalisation and increased use of health care services (Cushman, 1988) and even a higher rate of morbidity and mortality (Reynolds, 1992).

Attention to anxiety after stroke has been endorsed in clinical guidance (Royal College of Physicians, 2012). However, the majority of the literature thus far has focused on post stroke depression, and relatively little attention has been paid to post stroke anxiety. This is particularly the case in the field of mood screening. There is a dearth of validated tools for screening post stroke anxiety. This debilitating condition often remains undetected, and thus untreated. This is especially the case among stroke survivors with aphasia who are unable to easily communicate their mood state. Traditional methods of assessment and screening that rely on verbal report are not appropriate for many stroke survivors.

The Behavioural Outcomes of Anxiety scale (BOA; Kneebone *et al.*, 2012) is an observational tool that has been developed to screen post stroke anxiety in survivors

with communication impairment. It contains a range of anxiety descriptors and is rated by a carer. The BOA has been validated in stroke survivors without communication difficulties (Linley-Adams *et al.*, 2014) but has yet to be evaluated in a sample of aphasic stroke survivors.

The primary objective of this thesis is to address this gap in the literature and to determine the psychometric properties of the BOA in stroke survivors with aphasia. Building on this, the study also aims to evaluate the performance of an observational version of the Generalised Anxiety Disorder-7 measure (GAD-7; Spitzer *et al.*, 2006). The GAD-7 has been shown to have good reliability, as well as criterion, construct, factorial, and procedural validity in non-stroke populations (Spitzer *et al.*, 2006). It has yet to be validated in a stroke population.

There is some evidence to support the use of group based relaxation techniques to treat tension (a common indicator of anxiety) post stroke (Kneebone & Jeffries, 2013). However, further research is needed to explore the potential utility of self-administered relaxation training among stroke survivors with aphasia. The present study aims to extend the finding that relaxation training can alleviate anxiety after stroke, whilst assessing construct validity of the BOA.

1.2 Definitions of key terminology

1.2.1 Stroke survivor

In this thesis the term 'stroke survivor' is used to refer to anyone who has experienced a diagnosis of stroke. The term is used to describe those who have had any type and any number of strokes. It is used inter-changeably with the term 'survivor'.

1.2.2 Carer

The term 'carer' refers in this thesis to family members, friends or professionals who provide care, help or support to an individual who has experienced a stroke (Welsh Assembly Government, 2012).

1.2.3 Aphasia

The term 'aphasia' in this thesis refers to an impairment of language, affecting the production or comprehension of speech and the ability to read or write (National

Aphasia Association, 2014). It refers to the full spectrum of severity from mild to severe. It also encompasses all forms, including the ability to retrieve the names of objects, the ability to put words together into sentences and the ability to read.

Global aphasia arises when all linguistic capacities are lost, making communication extremely limited. Broca's aphasia is characterized by difficulties clearly expressing language and can lead to problems being understood, which can interfere with social interaction (Parr *et al.*, 1997). Wernicke's aphasia results in difficulties, or inability, to understand language. Comprehension of what others are saying is impaired. This can lead to frustration and lack of insight into difficulties (Lazar *et al.*, 2000).

1.2.4 Screening

The term 'screening' refers to the brief assessment of mood, usually by a standard tool, the results of which may indicate the need for further assessment. Screening tools should be applicable to routine clinical practice in stroke.

1.3 Stroke and mood disorders

1.3.1 Stroke and its effects

Stroke is a condition which results from a disruption of cerebral blood flow leading to death of brain cells (Department of Health, DH, 2007). There are two main sub-types of stroke (Royal College of Physicians, 2008a). Ischemic stroke occurs when there is a blockage in the supply of blood to the brain, and this accounts for approximately 69% of total strokes (Wolfe *et al.*, 2002). Haemorrhagic stroke refers to the rupture of a major blood vessel and subsequent bleeding on the brain, and this accounts for approximately 13% of strokes (Wolfe *et al.*, 2002). This results in chronic neurological impairments. In the UK, approximately 152,000 people are diagnosed with stroke each year, resulting in 49,000 deaths (Townsend *et al.*, 2012). This equates to 1.5-2.1% of the total population (National Audit Office, 2005). However, it is projected that by 2020 there will be an additional 22,000 stroke-related deaths per year because of anticipated increases in population size, lifespan and the pervasiveness of lifestyle factors that increase the risk of a stroke, such as excessive alcohol consumption, poor diet and insufficient physical exercise (Houses of Parliament, Parliamentary Office of Science & Technology, 2014). Stroke is the third most common cause of death and primary cause of adult disability (DH, 2007) and

around 1.1 million people are living with the effects of stroke in the UK (Townsend *et al.*, 2012). Improvements in stroke rehabilitation have led to increased survival rate and therefore increasing numbers of people with chronic difficulties and disabilities. Stroke causes a greater range of disabilities than any other condition and is the principal cause of complex disability among adults (Adamson *et al.*, 2004). Specific physical difficulties often include general movement (80%; Royal College of Physicians, 2012), swallowing (40%; Royal College of Physicians and the Clinical Effectiveness & Evaluation Unit, 2008); bladder control (50%; Harwood *et al.*, 2010) and visual problems (up to 66%; MacIntosh, 2003).

1.3.2 Mood disorders after stroke

Mood disorders are a frequent complication following a stroke (Lincoln *et al.*, 2012, pp.283-284). Approximately 23% to 60% of stroke survivors are affected in the first year after stroke. The frequency varies depending on the diagnostic tools, criteria and sample populations used (Turner-Stokes & Hassan, 2002). The variation in rates may also be accounted for by the difference in performance of measures used (Schramke *et al.*, 1998). Post stroke depression has been found to have an average prevalence of 33% across studies (Hackett & Anderson., 2006). Around 55% experience anxiety at some point after stroke (Ayerbe *et al.*, 2011). Incidence of post stroke anxiety has been shown to be as high as 20% at one month post stroke, increasing to 23% within five months and reaching 24% at six months or more following stroke (Campbell Burton *et al.*, 2013). Anxiety is also a frequent problem affecting stroke survivors in the long term with prevalence rates of 32-38% up to ten years post stroke (Ayerbe *et al.*, 2014). Anxiety and depression are comorbid for 57–73% of patients (Ayerbe, Ayis, Crichton *et al.*, 2013). Clinical levels of depression and anxiety are experienced by an estimated 25–79% of stroke survivors (Kneebone & Dunmore, 2000). Elevated levels of psychological distress are associated with recurrent strokes (Iso *et al.*, 2002; May *et al.*, 2002). Many report general psychological distress, not severe enough to warrant a clinical diagnosis but that negatively impedes recovery and quality of life (Jaracz *et al.*, 2002).

1.3.3 Anxiety after stroke

Anxiety is the most prevalent mental health problem in the world (Lepine, 2002) and is commonly reported by stroke survivors (Campbell Burton *et al.*, 2013; Ferro *et al.*, 2009; Wolfe *et al.*, 2011). Despite this, post stroke anxiety has only relatively recently been subject to investigation (Castillo *et al.*, 1995; Chemerinski & Robinson, 2000; Dennis *et al.*, 2000; Robinson, 1997; Shimoda & Robinson, 1998).

There is some evidence that women (Morrison *et al.*, 2005; Schultz *et al.*, 1997) and younger stroke survivors (<59 years) may be more vulnerable to anxiety (Schultz *et al.*, 1997), although some studies have found no significant relationship (Dennis *et al.*, 2000). Anxiety can last through to the chronic stage of stroke recovery (Astrom, 1996; Langhorne *et al.*, 2005). Lincoln *et al.* (2013) found that 29% of stroke survivors were anxious five years post stroke. The incidence of anxiety up to ten years post stroke has been found to range from 17 to 24%, with a cumulative incidence of 57% and point prevalence range of 32–38% (Ayerbe, Ayis, Crichton *et al.*, 2013). Anxiety can cause symptoms including irritability, lowered energy, poor concentration, tension and sleep problems and it may also be linked with family and social difficulties (Campbell Burton *et al.*, 2013; Ferro *et al.*, 2009; Wolfe *et al.*, 2011). There is evidence that all types of anxiety disorders can follow stroke (House *et al.*, 1991; Max *et al.*, 2002).

1.3.4 Consequences of post stroke anxiety

A recent study found up to 75% of stroke survivors with anxiety had comorbid depression, which predicts mortality and disability (Ayerbe, Ayis, Crichton *et al.*, 2013). More than three quarters of those suffering with anxiety at three months post stroke continue to suffer one year later, compared to just 40% of those with post stroke depression (Astrom *et al.*, 1993). There is evidence that whilst depression decreases, anxiety remains stable for three years following a stroke (Morrison *et al.*, 2005). Post stroke anxiety is associated with a number of negative outcomes. These include lower quality of life (Ayerbe, Ayis, Crichton *et al.*, 2013; Jeong *et al.*, 2012), depression (Ayerbe, Ayis, Wolfe *et al.*, 2013); increased disability from health conditions (Moser & Dracup, 1996; Moser *et al.*, 2007); more social isolation (Astrom, 1996); increased frequency of alcohol abuse (Castillo *et al.*, 1993) and

lowered participation and functional ability (Astrom, 1996; D'Alisa *et al.*, 2005). Anxiety is linked to increased impairment in activities of daily living in the acute stage and up to three years post stroke (Schultz *et al.*, 1997). The severity and course of recovery from stroke has been shown to be adversely affected by anxiety disorders (Shimoda & Robinson, 1998).

Comorbidity of anxiety and depressive disorders has been shown to exacerbate numerous clinical aspects of these conditions, including onset, duration, response to treatment, and severity, relative to each condition alone (Coplan & Gorman, 1990; Coryell *et al.*, 1985; Liebowitz *et al.*, 1990; Shores *et al.*, 1992). The interaction of anxiety disorder and depression has been found to lead to greater impairment in activities of daily living and the progression of recovery in social functioning long term, compared with post stroke depression alone (Shimoda & Robinson, 1998). There is also evidence that stroke survivors with depression plus generalised anxiety disorder experience significantly lengthier and more severe depression than those without comorbid anxiety disorder (Shimoda & Robinson, 1998). Thus, the comorbidity of anxiety and depression seem to have serious implications for long term prognosis and response to intervention.

The impact of mood disturbance following stroke is not limited to the stroke survivor. Caring for someone who has suffered a stroke is challenging (Simon *et al.*, 2009). Carers report that anxiety and depression in the stroke survivor is among the most stressful difficulties they encounter (Haley *et al.*, 2009). Depression in stroke survivors can result in carers also experiencing depression (Binder, 1984; Spencer, 1992).

The early detection of post stroke mood problems, including anxiety, is therefore essential to enhance the rehabilitation and recovery of stroke survivors. Despite its frequency and impact, there has been relatively little investigation into the identification of anxiety after stroke (Campbell Burton *et al.*, 2013; Chemerinski & Levine, 2006; DeWit *et al.*, 2008) comparative to post stroke depression.

It is essential to attend to mood problems to afford stroke survivors with the maximum opportunity for therapeutic gains (Swindell & Hammons, 1991). The clinical and economic ramifications of mood disorders are numerous. Anxiety is associated with lower quality of life and depression, which is a predictor of poorer prognosis (Whyte & Mulsant, 2002). There is evidence that the prognosis for post

stroke anxiety is worse than for depression (Astrom, 1996; Astrom *et al.*, 1993).There is an association between mood disorders and poorer long term outcomes including increased morbidity and mortality (House *et al.*, 2001, May *et al.*, 2002; Pohjasvaara *et al.*, 2001). The emotional impact of stroke, if untreated can reduce the impact of rehabilitative interventions via low motivation and decreased participation in the rehabilitation program (Shoemaker, 2001). This can lead to poorer physical functioning, lengthier rehabilitation time, and adverse functional and rehabilitation outcomes (Anderson, 1997; King *et al.*, 2001; Nelson, Cicchetti *et al.*, 1994). There is evidence that unrecognized and untreated mood disorders can lead to increased long term hospitalisation, increased use of health care services and long term care, and higher rate of morbidity and mortality (Cushman, 1988; Reynolds, 1992). Estimates suggest that the care of unrehabilitated stroke survivors costs an additional £64,000 over the course of a lifetime relative to a rehabilitated patient (Ashburn, 1997).

1.4 Mood screening

1.4.1 Value of post stroke mood screening

In view of the consequences of anxiety after stroke it is important that it is recognised and treated. However, there is a paucity of psychologists and doctors who are qualified to identify clinical mood disorders including anxiety. Screening protocols can support all staff to identify stroke survivors with mood disturbance and thus enable more selective referrals for further assessment (Watkins, Daniels *et al.*, 2001). Screening therefore helps to identify those who require more detailed assessment to determine the severity of emotional distress (Gurr, 2011). Screening methods can identify individuals who may not be currently experiencing clinical levels of mood disturbance, but are nonetheless impacted by a high rate of symptoms and who may go on to develop a mood disorder in the future (Taylor *et al.*, 2011). Identification and monitoring of such individuals allows for timely intervention and support to be offered, if and when necessary. Hence, screening for anxiety and depression may increase the numbers of survivors who are diagnosed and treated appropriately.

Anxiety and depression are common comorbid conditions. Therefore, stroke survivors reporting symptoms of depression should be screened for anxiety as management of both anxiety and depression may improve the overall prognosis (Ayerbe, Ayis, Crichton *et al.*, 2013). However, anxiety frequently goes undetected and therefore treatment, if any, is often inadequate (Astrom, 1996; Barker-Collo, 2007; Hackett, Yapa *et al.*, 2005; Leppavuori *et al.*, 2003; Townend, Whyte *et al.*, 2007). Identification and diagnosis of mood disorders in individuals with any form of brain damage including stroke, is a complex process. Among stroke survivors, the distinction between adverse mood states as symptoms and as clinical disorders can be particularly challenging (Johnson *et al.*, 1995). Associated neurological effects, such as language and memory deficits or unawareness of emotional status can interfere with responses to mood assessments. These challenges cause difficulties for clinicians and researchers (Spencer *et al.*, 1997).

1.4.2 Policy on mood screening

There are now a multitude of policy, guidelines and standards that emphasise the need for a comprehensive approach to psychological care throughout the stroke journey, including the voluntary sector. These include: The National Clinical Guidelines for Stroke (Royal College of Physicians, 2008b, 2012); National Stroke Strategy (DH, 2007); National Stroke Sentinel Audit (Royal College of Physicians, 2008a); Psychology Concise Guide for Stroke (Royal College of Physicians, 2008c); National Service Framework for Older People (DH, 2001b) and the National Service Framework for Long Term Conditions (DH, 2005). A key aspect of these guidelines is that all stroke survivors should receive mood screening in order to identify those in need of appropriate treatment and support. In line with a stepped care model (Gillham & Clarke, 2011) all stroke survivors should have a mood screening within six weeks of stroke diagnosis using a validated tool (The National Clinical Guidelines for Stroke, Royal College of Physicians, 2012; NICE, 2013). Mood should then be assessed at three and six months post stroke (Gillham & Clarke, 2011).

Despite screening offering numerous benefits and it being recommended in many policies and guidelines, a quarter of patients are not screened for mood problems in hospital (Royal College of Physicians, 2014). Professionals report a number of

barriers to screening including lack of awareness of guidelines, limited knowledge, reduced perceived control, low belief in effectiveness and time constraints (Hart & Morris, 2008).

1.4.3 Benefits of mood screening

Mood disturbance is not an irremediable effect of stroke and there is much support that can be offered to stroke survivors experiencing anxiety or depression (Kneebone & Dunmore, 2000). Mood problems after stroke are usually treated with medication and/ or psychological therapy (Eriksson *et al.*, 2004). The essential requirement to develop appropriate assessment tools to identify and monitor anxiety following stroke is an increasing priority as treatments are researched and established for anxiety in the stroke population (Kneebone *et al.*, 2014; Kneebone & Jeffries, 2013; Waldron *et al.*, 2012). Thus, it is an important clinical and research goal to develop accurate screening for anxiety (Forkmann *et al.*, 2013) in order to identify patients needing treatment.

Screening permits effective treatment via early recognition of mood problems and access to intervention. It supports the identification of possible risks to survivors and enables steps to be taken to support them. Information and education about anxiety and other mood problems can then be provided. Early detection might help to alleviate the burden and suffering due to a compromised quality of life (Moon *et al.*, 2004; Sturm *et al.*, 2004) and has been found to improve rehabilitation outcomes (Gawronski & Reding, 2001; Gonzalez-Torrecillas *et al.*, 1995).

Screening is beneficial in hospital and community settings where staff are faced with multiple and competing demands and lengthy, specialist-led assessments may not be feasible (Lee, 2003). But stroke survivors may be compromised physically and cognitively such that they are not able to sustain concentration or do not have the cognitive capacity needed to answer often complex questionnaires.

1.4.4 Complexities of identifying post stroke mood disorders

Identification of post stroke mood disorders can be difficult (Gordon & Hibbard, 1997). The accuracy of various mood screening measures for use in stroke survivors

is documented in the literature. A number of factors complicate the diagnosis of depression or anxiety after a stroke. The availability of appropriate, validated tests can present a barrier to identification.

Problems in attention, cognition, language and the presence of stroke-related physical sequelae, such as fatigue and sensory impairments can create difficulties in focussing on, and processing, self-report questionnaires, or responding to interview items (Nelson, Mitrushina *et al.*, 1993; Talelli *et al.*, 2004; Williams *et al.*, 2007), consequently impeding detection. Moreover, stroke survivors are not always able to accurately report their emotional status, and have been found to have a propensity to minimise or overstate their physical, cognitive and affective difficulties (Lincoln *et al.*, 2003).

1.4.5 Limitations of clinical interview

The diagnosis of psychological disorders is ideally made by standardized clinical interview (Ramasubbu & Kennedy, 1994). The clinical interview is generally deemed to be the 'gold standard' in the diagnosis of mood disorder following stroke. It is usually centred on formal classification systems such as the DSM-IV (APA, 1994) and/or ICD-10 (WHO, 1993). These criteria are clearly defined and acknowledged, and so are commonly used for the diagnosis of mood disorders in clinical and research practice (Fedoroff *et al.,* 1991). While standardized psychiatric interview schedules offer enhanced diagnostic accuracy compared with unstructured assessment, these necessitate training to administer, and are generally restricted to use by psychiatrists, as most healthcare professionals do not receive appropriate training. They are also very time consuming and thus impracticable with the volume of stroke survivors entering the treatment pathway. Screening instruments offer a pragmatic alternative and benefit from the speed and ease with which they can be administered, as well as the potential to be used by a range of staff.

1.5 Self-report of post stroke mood

1.5.1 Self-report screening questionnaires

Self-report questionnaire assessments are often administered to assess mood post stroke. Self-report measures generally benefit from being relatively brief and simple

to administer. Thus, they offer a practical approach to screening large number of individuals (Sutcliffe & Lincoln, 1998). Self-report mood questionnaires frequently used with stroke survivors include the Beck Depression Inventory (BDI; Beck *et al.*, 1961); Center for Epidemiologic Studies- Depression Scale (CES-D; Radloff, 1977); Geriatric Depression Scale (GDS; Yesavage *et al.*, 1982, 1983); Hamilton Depression Rating Scale (HDRS; Hamilton, 1960); Structured Assessment for Depression in Brain Damaged Individuals (Gordon *et al.*, 1991); The Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) and Generalised Anxiety Disorder assessment (GAD-7; Spitzer *et al.*, 2006). There are numerous screening tools available to measure mood problems generally, consequently there is wide variability in those used by clinicians in stroke services (Bennett & Lincoln, 2006).

1.5.2 Desirable characteristics of a screening tool

1.5.2.1 Psychometric properties

It is essential that instruments are validated on stroke populations and that the optimum cut-offs for stroke survivors are known, rather than those appropriate for the general population. Many screening instruments used in medical and mental health settings have not been well validated in stroke populations. In order to be clinically relevant, screening measures must have an established cut-off point above which all those with a mood problem score, but few without a mood problem score (Bennett *et al.*, 2006). A screening tool must have been evaluated for the likelihood that those who screen positively are suffering with a mood problem (positive predictive value) and that those who screen negatively are not (negative predictive value; Watkins, Leathley *et al.*, 2001). It is important that sensitive and specific measures are used. The 'incremental gain' or advantage in diagnostic accuracy achieved from using the screening tool relative to clinical estimation, refers to the difference between positive and negative predictive values. This enables clinicians to appreciate how a test is likely to perform in a particular group (Griner *et al.*, 1981).

Screening tools should have good sensitivity (detect all those who do have a mood problem), and specificity (correctly identify those who do not have a mood problem). It is important that no-one with a mood disorder is missed at screening and thus a higher sensitivity may be preferable (Lincoln *et al.*, 2003). However, raising the

sensitivity of a test means a larger proportion require additional assessment to clarify the presence or absence of a mood disorder (House *et al.*, 1989) and can result in lower specificity (Lincoln *et al.*, 2003). Consequently, a balance is necessary. Bennett and Lincoln (2006) suggest sensitivity values should be over 0.80 and specificity values should be over 0.60. Screening measures should be validated at various time phases throughout the rehabilitation and recovery pathway due to the often chronic impact of stroke necessitating long term management by stroke services (Turner *et al.*, 2012).

1.5.2.2 Screening practicalities

Screening tools should be brief and straightforward to administer and require minimal training in order to overcome the practical challenges of conducting mood screening in stroke services. Inpatient and community staff may lack the training or confidence to administer and interpret more complex tools, and time pressures may render training sessions unfeasible. Limited time of all professionals means mood screening must be quick to administer and easily incorporated into routine duties (Gurr, 2011). It is also important that the screening measure is acceptable to survivors, carers and staff.

1.5.2.3 Confounding variables

Somatic items should not be included as this can confuse the clinical picture in stroke survivors with physical problems. Older adults often reject the concepts of anxiety and depression, or somatise mood symptoms (Snowdon, 1994). Many mood screening measures that are frequently administered to stroke survivors, such as the Beck Depression Inventory II (BDI-II; Beck *et al.*, 1996) and Wakefield Depression Inventory (WDI; Snaith *et al.*, 1971), include physical symptom items, but which may be direct effects of the stroke, neurological impairment or a consequence of the environment (Lincoln *et al.*, 2003).

The format must be simple and utilise scales with consistent response categories to aid verbal administration. Measures should be valid (measure that which it is designed to measure) and reliable (produce similar results when administered repeatedly). Screening tools should be investigated for utility with stroke survivors.

Most self-report assessments assume that stroke survivors have good awareness of their condition and can accurately report and reflect upon their mood. However, this is not true for some individuals who may deny or exaggerate physical, cognitive and affective difficulties following stroke (Gordon *et al.*, 1991; Hibbard *et al.*, 1990). Almost three quarters of stroke survivors may be unable to reliably respond to verbal interviews concerning their mood (Nelson, Mitrushina *et al.*, 1993).

1.5.3 Limitations of self-report questionnaires

Most screening measures are in questionnaire form and are therefore inappropriate for many stroke survivors. It has been suggested that the items and possible responses may be read to the person by the administrator (Snaith, 2003), however, such an approach has not been subject to validation studies in stroke survivors. Accordingly, screening of mood problems in this patient group is a challenge (Bennett & Lincoln, 2006). Individuals with more than mild communication difficulty are at risk of being overlooked in clinical settings (Hackett, Anderson *et al.*, 2005). Whilst it has been purported that it is more desirable to assess aphasic stroke survivors for mood problems by clinical interview, this can be implausible for even the most experienced speech therapist, psychologists or doctor (Wahrborg, 1991). The Post Stroke Depression Rating Scale (PSDRS) was developed by Gainotti *et al.* (1997) and is completed by an examiner following an interview with the stroke survivor. Gainotti *et al.* (1997) found it correlated strongly with the HDRS (Hamilton, 1969) but no further detailed psychometric evaluation has been performed. Furthermore, a 'professional examiner' is required for the interview, limiting the accessibility of this approach.

Although several self-report measures have been developed for, or validated in, populations of stroke survivors, the self-report format is not suitable for use with those with aphasia (Aben *et al.*, 2002). Many screening tools that are validated with stroke survivors such as the General Health Questionnaire (GHQ-28; Goldberg & Williams, 1988) often necessitate the assistance of the assessor or another person. This is time-consuming and thus may restrict routine use in clinical practice (Anderson *et al.*, 2004). The practice of mood assessment by means of clinical interviews or self-report questionnaires is highly reliant upon verbal communication. Among stroke survivors with language, cognitive and perceptual problems, self-

report measures tend to have low specificities and predictive values (Goldberg, 1985).

1.6 Aphasia after stroke

1.6.1 Impact of post stroke aphasia

Alternative screening tools are needed for people with communication impairments. Aphasia is a common symptom after stroke affecting between 23–38% of stroke survivors (Dickey *et al.*, 2011; Engelter *et al.*, 2006; Flowers *et al.*, 2013; Kyrozis *et al.*, 2009; Pedersen *et al.*, 1995; Royal College of Physicians, 2012; Wade *et al.*, 1986). Indeed stroke is the largest cause of aphasia (Chapey, 2008). Aphasia can impact on all areas of communication including the ability to comprehend verbal and written language, producing spoken language, writing and numerical skills. Accordingly, aphasia can have a severe impact on personal relationships, employment and social participation (Kauhanen *et al.*, 2000; Wade *et al.*, 1986). Moreover, aphasia restricts full involvement in activities of daily living (Enderby & Emerson, 1995). Thus, additional adverse psychological and social consequences are experienced by stroke survivors with aphasia and their families (Le Dorze & Brassard, 1995).

Aphasia is typically associated with left hemisphere lesions (Davis, 2007). In comparison to individuals with right hemisphere lesions, individuals with left hemisphere damage may have greater preserved emotional awareness and exhibit observable emotional reactions (Davis, 2007). There is some evidence that the frequency of clinically significant mood problems is higher among individuals with damage to this area (Robinson *et al.*, 1984). Survivors with aphasia are therefore vulnerable to mood disorders (Kauhanen *et al.*, 2000). Individuals with more severe communication problems may experience greater emotional distress (Thomas & Lincoln, 2008). This highlights the important need to identify mood disorders in this vulnerable group.

1.6.2 Challenge of mood screening in aphasia

Whilst clearly a group susceptible to mood disorders (Lee *et al.*, 2007) detection is impeded by the difficulties in communicating and expressing subjective feelings.

Indeed, a communication difficulty is one of the primary reasons assessment of stroke survivors' emotional condition may prove particularly challenging and problematic (Rickards, 2005; Royal College of Physicians, 2008a).

Use of self-report measures have been shown to be difficult or impossible for many stroke survivors with communication impairments such as aphasia (Berg *et al.*, 2009). A large proportion of stroke survivors may be unable to, or have difficulty with reading comprehension and self-reporting their mood status as a consequence of language problems and other cognitive sequelae of stroke. Indeed, Toedter *et al.* (1995) found that even among those without substantial communication problems or frank aphasia, 60% experienced difficulty understanding the format, logic and consistency of self-report mood evaluation measures. A cognitive screening test such as the Neurobehavioural Cognitive Status Examination (NCSE, Kiernan *et al.*, 1987) to assess ability to complete mood screening has been proposed (Toedter *et al.*, 1995), however the additional time and expertise required is likely to undermine the utility of such a process.

In most research into post stroke emotional changes and mood screening, stroke survivors with aphasia are systematically excluded. This is likely to underestimate the prevalence of mood disorders post stroke. This limits the generalisability of findings and ultimately skews the literature and general understanding of post stroke emotional changes to patients who have had a stroke but do not present with aphasia (Nelson, Mitrushina *et al.*, 1993; Sinyor *et al.*, 1986). This emphasises the important need for an instrument that can measure anxiety in stroke survivors with communication difficulties for both clinical practice and future research studies.

The use of multi-modal assessment methods of mood disorders following stroke that includes clinical interview, self-rating measures and report from relatives or professionals is recommended by The British Psychological Society (2002). Clearly, there is a need to adapt conventional approaches to mood screening in this client group. The following section describes some of the methods that have been investigated.

1.7 Verbal approaches to mood screening in aphasic stroke survivors

1.7.1 Single item screening question

One measure that offers advantage due to its brevity and simplicity is the Yale, a single item screening question *'Do you often feel sad or depressed?'* taken from the Yale– Brown obsessive-compulsive scale (Mahoney *et al.*, 1994). It is suitable for patients who cannot read, write and who have speech problems as the response format is either 'yes' or 'no'. It offers a useful, sensitive and specific screening assessment of depression as long as there is a reliable 'yes/no' response (Eriksson *et al.*, 2004; Mahoney *et al.*, 1994; Watkins, Daniels *et al.*, 2001; Watkins *et al.*, 2007). However, other studies have found the Yale to have low specificity (Dickinson *et al.*, 1998) and almost a third of aphasic stroke survivors are unable to provide a reliable 'yes/no' answer (Laska *et al.*, 2007). This suggests the Yale is not an appropriate means of screening stroke survivors with cognitive and communication impairments. Furthermore, this single-item method may not be as straightforward as it initially appears as many stroke survivors feel sad, but not depressed following a stroke, and may answer 'yes' to this question (Royal College of Physicians, 2005).

1.7.2 Adapted questionnaires

Creative adaptations to standard questionnaire measures have been developed. Gordon *et al.* (1991) established the Structured Assessment for Depression in Brain Damaged individuals (SADBD) which has been evaluated with stroke survivors. The SADBD aimed to enhance validity with individuals with brain damage by employing a factual style of questioning, a yes/no response format, and permitting the repetition of questions as frequently as needed. The verbal assessment questions are supplemented by visual cue cards comprising simple key words. Acceptability, validity and reliability have been demonstrated (Gordon *et al.*, 1991; Hibbard *et al.*, 1993), however there are concerns surrounding the appropriateness of the cue cards for individuals with reading comprehension or visuo-perceptual deficits (Spencer *et al.*, 1997). Moreover, the SADBD is unsuitable for screening stroke survivors with severe communication problems and unreliable 'yes/ no' responses without external observer feedback (Gordon *et al.*, 1991).

The Brief Assessment Schedule Depression Cards (BASDEC; Adshead *et al.*, 1992) was designed for use with older people in a hospital ward environment. It is a set of 19 cards describing depression symptoms. The respondent is required to place the statement card next to either a 'True' or 'False' card according to their current mood. Healy *et al.* (2008) investigated the performance of the BASDEC in elderly stroke survivors and found it had acceptable reliability (0.77), test-retest reliability and excellent criterion validity (sensitivity: 1.0, specificity: 0.95) when identifying cases of major depression using the cut-off score of at least 7. The sensitivity (0.69) of the BASDEC reduced when identifying minor and major depression, although the BASDEC demonstrated better diagnostic accuracy than the BDI-FS (Beck *et al.*, 2000) and the depression subscale of the HADS (Zigmond & Snaith, 1983). Whilst the BASDEC offers a user friendly format and simple response categories, it is not appropriate for stroke survivors with more severe comprehension and reading difficulties.

1.8 Non-verbal approaches to mood screening

1.8.1 Visual analogue

Arguably, assessment of internal emotional states is most reliably made by asking the stroke survivor directly (Stern, 1999). However, clinical interviews or self-report measures are often not possible for those with more than mild communication difficulties. Research has recently focused on the development of non-verbal mood screening tools. Pictorial-based scales have been developed for use in patients with communication difficulties. They are quick to complete and do not rely on high level language ability. Thus they aim to circumvent communication and language difficulties through the use of pictorial material to screen mood (Brumfitt & Sheeran, 1999a; 1999b). However, many of them are limited by the lack of validation studies with aphasic stroke patients (Townend, Brady *et al.*, 2007). Nonetheless, visual analogue scales and other approaches to non-verbal assessment have been advocated to enable the reliable identification of mood problems post stroke (Turner-Stokes, 2003).

1.8.1.1 The VAMS and VASES

The Visual Analogue Mood Scale (VAMS; Stern, 1997) and the Visual Analogue Self-Esteem Scale (VASES; Brumfitt & Sheeran, 1999a) are non-verbal, picture-based scales which utilise schematic facial expressions to directly depict emotion and symbolise positive and negative mood states (Code & Herrmann, 2003). The VAMS (Stern, 1997) is a measure of mood that is suitable for aphasic stroke survivors. It contains eight cartoon faces depicting various moods (afraid, confused, sad, angry, energetic, tired, happy, tense) and is supplemented by verbal descriptions. Each face is presented at one end of a line with a neutral face at the other end. Individuals are required to point to the line that indicates how they feel in regards to that particular mood dimension.

The VAMS has been shown to correlate highly with the HADS (Bennett *et al.*, 2006) and the profile of mood states (POMS; McNair *et al.*, 1971) and has good discriminant validity among stroke survivors (Arruda *et al.*, 1999). The VAMS benefits from being short and screening a range of emotions, however, no clear cut-off scores have been identified for stroke survivors which limits its use as a screening tool as it does not make clear what score is indicative of further evaluation (Bennett *et al.*, 2006). Moreover, the reversal in polarity of the scales is suggested to be problematic for stroke survivors who may benefit from a consistent response format (Price *et al.*, 1999). It may be more useful as an indicator of severity of low mood than as a screen (Bennett *et al.*, 2006).

The VASES (Brumfitt & Sheeran, 1999a) was originally developed to measure self-esteem as a distinct concept in individuals with aphasia. Self-esteem is closely linked to mood as an indicator of psychosocial mal-adjustment (Brumfitt & Sheeran, 1999b). A poor self-perception may be directly associated to the development of anxiety and depression (Heatherton & Polivy, 1991). It consists of ten opposing pictures representing different self-perceptions. Individuals respond on a scale of one to five where higher scores are indicative of higher self-esteem.

The VASES has demonstrated good internal reliability among non-stroke aphasic individuals (Brumfitt & Sheeran, 1999a). In a stroke sample without significant communication problems, no clear cut-off scores were found which render it an unsuitable screening tool despite a strong correlation with the HADS (Bennett *et al.*, 2006). At a cut-off of 31/32, good sensitivity (0.81) but poor specificity (0.05) was

found (Bennett *et al.*, 2006). Like the VAMS, the VASES may be more useful as an indicator of severity of low mood (Bennett *et al.*, 2006). The VASES does not seem to be affected by potential confounding factors that may be present post stroke and therefore may offer a convenient means of detecting those at risk for developing low mood (Vickery, 2006). However, survivors with the most severe aphasia appeared to misunderstand the purpose of the task due to problems with comprehension compared to those with milder language impairment. Thus, care should be exercised when used with people with severe communication impairment (Vickery, 2006).

1.8.1.2 The DISCs

Another basic visual analogue scale is the Depression Intensity Scale Circles (DISCs; Turner-Stokes, Kalmus *et al.,* 2005) which is aimed at measuring sadness or depression in people with cognitive or communication problems. It consists of six shaded circles representing severity of sadness or depression. The circles are presented vertically, each with an increasing amount of dark shading, from the bottom to the top (Turner-Stokes, Kalmus *et al.*, 2005). The circle with no shading indicates the absence of depression or sadness (scored 0) and the one with the most shading depicts the most severe depression or sadness (scored 5). The DISCs was evaluated in a sample of younger adults with acquired brain injury and was found to have good sensitivity (0.60) and specificity (0.87) and test-retest reliability (0.84). Using a score of >2 highlighted 'cases' for depression in line with the DSM-IV criteria with improved accuracy over the Yale question.

The DISCs provides a graded response format which may be advantageous. Kneebone *et al.* (2010) suggest that the vertical arrangement of circles benefits from being a larger stimulus than the VAMS, which is an important consideration in the context of neglect and perceptual deficits sometimes experienced post stroke. However, only two thirds of the sample in the study that ascertained the acceptability, reliability and validity were stroke survivors, therefore further studies with stroke survivors is warranted. There is some evidence that among those unable to respond to any other questionnaire approach or visual analogue scale this intuitive visual scale is accessible (Jackson, 2004). However, further research is necessary with stroke survivors unable to participate in verbal and detailed visual screening measures (Turner-Stokes, Kalmus *et al.,* 2005).

1.8.1.3 The Smiley

Smiley faces have been explored as a substitute for visual analogue scales. Lee *et al.* (2008) investigated the validity of three diagrammatic faces with a smile, neutral or sad expression. Stroke survivors were asked to rate how often they had experienced the different facial expression in the preceding week using a 3-point scale from 0 (none at all), 1 (less than half the time in a week), and 2 (equal to or more than half the time). Endorsement of the sad face correlated with diagnosis of depression using the DSM-IV criteria and was also comparable with that of the GDS, compared to the happy and neutral face. However, sensitivity of each facial expression was low (0.76) and some depressed participants were missed. The GDS was found to be superior. Stroke survivors with moderate and severe aphasia were excluded, thus limiting the generalisability of the measure to this group.

1.8.1.4 Distress Thermometer

The Distress Thermometer (DT; Roth *et al.*, 1998) is an 11-point visual analogue scale, measuring distress from 0 (no distress) to 10 (extreme distress) initially developed to screen psychological distress among cancer patients. The accuracy of the DT among stroke survivors has been compared to DSM-IV criteria for major depression in a study by Turner *et al.* (2012). The standard cut-off score of at least 4 failed to meet recommended levels of sensitivity (0.69) and specificity (0.57). When a lower cut-off score of at least 2 was employed, all survivors with major depression were correctly detected (sensitivity: 1.0); but specificity was poor, incorrectly classifying a number of people with sub-clinical levels of depression as having major depression (specificity: 0.33). The DT measures global distress in a single item, therefore poor specificity may be due to the range of non-depressive states that are encapsulated by the DT (Turner *et al.*, 2012).

1.8.2 Limitations of visual analogue

Whilst offering a means of screening mood in stroke survivors with communication problems, there are a number of limitations inherent with visual analogue methods. Firstly, stroke survivors have been found to be less accurate in completing visual analogue relative to healthy controls (Price *et al.*, 1999). There are concerns

regarding response reliability especially among stroke survivors with severe impairments. Indeed, among the more severely impaired population, a quarter to one third of individuals have been found to experience difficulty completing visual analogue scales accurately (Turner-Stokes & Rusconi, 2003). Spencer *et al.* (1997) suggest checking the ability of stroke survivors to respond on similar scales in order to improve confidence in the results, however this complicates the process.

Secondly, visual analogue mood scales have also been shown to have low sensitivity when used with stroke survivors (Berg *et al.*, 2009). Although the aim of these measures is to gauge the individual's own view of their subjective low mood, no further understanding into what this means for the individual, or the effects of the symptoms is provided. Visual analogue measures are restricted in that they can depict pictorially only a limited range of mood symptoms (Herrmann & Wallesch, 1993). It is thus essential to follow up these simple questions with a more thorough assessment (Bula *et al.*, 2003) especially when intervention is implicated (Turner-Stokes, Kalmus *et al.*, 2005). Finally, some stroke survivors may perceive the presentation format of cartoon faces as patronising (Spencer *et al.*, 1997). Further validation studies with aphasic stroke survivors is required (Townend, Brady *et al.*, 2007).

1.8.3 Observer rated

In light of the limitations surrounding use of self-report measures to screen mood in stroke survivors, observer-rated measures offer an alternative. This approach gathers information or ratings about the emotional state of the stroke survivor from the observations of a third party significant other, usually a family caregiver, friend or carer (Kneebone & Dunmore, 2000; Turner-Stokes & Hassan, 2002). This is particularly relevant for aphasic stroke survivors who are often unable to partake in clinical interview or complete conventional self-report measures. Many stroke survivors are also unable to complete self-report visual analogue scales. Whilst judgements by carers offers an imperfect solution, there is currently a paucity of alternatives for those aphasic stroke survivors who cannot complete self-report measures (Sutcliffe & Lincoln, 1998). Thus, observational measures that rely on a secondary informant may inform screening of mood in those who are untestable by traditional means, including those with communication problems who are unable to

self-report their emotional status. Therefore, such approaches can potentially offer an alternative to the patient's self-report (Spencer *et al.*, 1997). A number of observational methods of screening mood have been investigated.

A small number of observer rated mood measures currently exist that are based on observable behaviour related to depression such as the Signs of Depression Scale (SoDS Watkins, Leathley *et al.*, 2001), the Stroke Aphasic Depression Questionnaire (SADQ; Sutcliffe & Lincoln, 1998) and Aphasic Depression Rating Scale (ADRS; Benaim *et al.*, 2004). There is evidence that including information from carers and nurses may improve screening of post stroke depression (Lightbody *et al.*, 2007). Several studies indicate that observer-rated measures can be valid, reliable, sensitive and specific screening tools for post stroke depression in individuals with aphasia.

1.8.3.1 The SADQ

The Stroke Aphasic Depression Questionnaire (SADQ-21; Sutcliffe & Lincoln, 1998) was developed to screen depression in stroke survivors with aphasia. It is a 21 item measure completed entirely by another person who rates observed behaviours. Sutcliffe and Lincoln (1998) investigated the construct validity of the SADQ-21 and found it had a poor correlation with the HADS depression subscale (Zigmond & Snaith, 1983). However it demonstrated an adequate correlation with the HADS anxiety subscale (Zigmond & Snaith, 1983) and with the Wakefield Depression Inventory (WDI; Snaith *et al.*, 1971). Test-retest analysis indicated the SADQ is reliable over a four-week interval (Sutcliffe & Lincoln, 1998).

A shortened version was developed, the SADQ-10 comprising the ten items which best differentiated between depressed and non-depressed stroke patients. Leeds *et al.* (2004) validated the SADQ-10 against the Geriatric Depression Scale-15 (GDS-15; Sheik & Yesavage, 1986) in non-aphasic stroke survivors. A cut-off of 14/15 was found to be most appropriate, with sensitivity of 0.70 and specificity of 0.77. However, only a modest correlation was found between SADQ-10 and GDS-15, limiting the validity of the SADQ-10 with those without significant aphasia. Among aphasic stroke survivors discharged from hospital, the SADQ-10 has shown an adequate correlation with the HADS depression subscale (Sutcliffe & Lincoln, 1998).

However, Lincoln *et al.* (2000) found a poor correlation between the SADQ-10 and HADS depression subscale but an adequate correlation with the HADS anxiety subscale. It has been found to have an excellent correlation with the WDI by Sutcliffe & Lincoln. (1998) but a poor correlation with the WDI by Lincoln *et al.* (2000). The SADQ-10 has been found to have adequate test-retest reliability over a four-week period (Sutcliffe & Lincoln, 1998).

A revised version, the Stroke Aphasic Depression Questionnaire- hospital version (SADQ-H; Lincoln *et al.*, 2000) was developed for patients in hospital. It contains the same 21 items as the SADQ, but the response options changed to become more quantifiable (from 'often', 'sometimes', 'rarely', 'never' to 'every day this week', 'on 4-6 days this week', 'not at all this week'). Satisfactory inter-rater reliability was demonstrated in 30 in-patients with stroke (Lincoln *et al.*, 2000). The SADQ-H was also found to be more highly correlated with the WDI than the original version (Lincoln *et al.*, 2000). In a validation study of the SADQ-H by Bennett *et al.* (2006) optimum cut-offs of 17/18 for depression on the SADQ-H offered a sensitivity of 1.0 and specificity of 0.81, and 9/10 for anxiety provided a sensitivity of 0.75 and specificity of 0.40.

A shortened version, the SADQ-H10 has been found to have an adequate correlation with the HADS depression subscale, a poor to adequate correlation with the HADS anxiety subscale, and an adequate correlation with the total HADS scale (Bennett *et al.*, 2006). For depression screening, a cut-off of 5/6 with a sensitivity of 1.0 and specificity of 0.78 was suggested to be optimum (Bennett *et al.*, 2006).

1.8.3.2 The SoDS

The Signs of Depression Scale (SoDS; Watkins, Leathley *et al.*, 2001) is a six item measure of observerable mood symptoms, initially developed for assessment of elderly patients in hospital. It has been validated in an acute stroke population against the Montgomery Asberg Depression Rating Scale (MADRS; Montgomery & Asberg, 1979) in a study by Watkins, Leathley *et al.* (2001). A cut-off score of 1/2 gave 0.70 sensitivity and 0.56 specificity. The SoDS has been shown to be effective in identifying depression (Bennett *et al.*, 2006; Lightbody *et al.*, 2007; Watkins, Leathley *et al.*, 2001) but not anxiety (Bennett *et al.*, 2006) in a sample of

hospitalised stroke survivors. For depression, Bennett *et al.* (2006) found a cut-off score of 1/2 resulted in a sensitivity of 0.86 and specificity of 0.62. However for anxiety, a cut-off score of 0/1 resulted in a sensitivity of 0.63 and specificity of 0.29. Whist benefiting from being quick and easy to administer, validation findings are mixed. Using the Structured Clinical Interview for DSM-IV (SCID), Lightbody *et al.* (2007) however, found low sensitivity (0.64) and low specificity (0.61) at a cut-off of 1/2 when completed by nurses. It has also been found to have low internal consistency (0.53) and poorer correlation with the HADS (0.22) compared to SADQ-H (0.45) and SADQ-H10 (0.51; Bennett *et al.*, 2006).

1.8.3.3 The ADRS

The Aphasic Depression Rating Scale (ADRS; Benaim *et al.*, 2004) is a nine-item observer rated measure of depression developed to identify depression in the sub-acute stage of stroke. Benaim *et al.* (2004) performed initial psychometric evaluation with sub-acute stroke survivors and reported the test-retest reliability of the global ADRS score to be excellent (0.89). At a cut-off of 8/32, compared with the diagnosis made by a psychiatrist, an overall sensitivity of 0.83 and a specificity of 0.71 was reported. The ADRS correlates significantly with professional's ratings of depression and the HDRS (Benaim *et al.*, 2004). However, no further validation has been performed on this scale.

1.8.4 Summary

Whilst non-language based modified depression screening methods have been established, including observer rated tools and visual analogue scales, there is currently only a limited amount of evidence for the suitability of these with stroke survivors. It is important that the informant has regular contact with the stroke survivor in order to provide a valid report (Carota & Bogousslavsky, 2003). Stroke survivors with communication and cognitive difficulties are commonly excluded in research studies, despite the high frequency of these mood difficulties in this population. Up to 50% of stroke survivors may have been excluded from post stroke mood research as a consequence of difficulties in participating (Turner-Stokes, 2003). This means the screening tools are often not validated in aphasic stroke

survivors, and considerable uncertainty regarding the suitability of such tools in this population remains.

1.9 Screening for post stroke anxiety

1.9.1 The HADS

Most research has focussed on the development or validation of depression screening tools. Importantly, there is a dearth of screening measures for post stroke anxiety. Only one self-report measure of anxiety has been investigated for its utility among stroke survivors; the anxiety subscale of the Hospital Anxiety and Depression Scale (HADS-A; Zigmond & Snaith, 1983). The HADS is a 14-item self-report measure and was developed to detect both depression and anxiety whilst excluding the physical symptoms of emotional distress. Thus it is suitable for hospitalised or physically ill patients. It contains subscales for anxiety (HADS-A) and depression (HADS-D). The total score (HADS-T) can be used as a measurement of emotional distress (Herrmann, 1997). According to the test manual, a subscale score of 0-7 is regarded *normal*, scores of 8-10 are *mild*, scores of 11-14 are *moderate,* and scores between 15 -21 are *severe* (Zigmond & Snaith, 1983).

The HADS total score has also been used as a measure of psychological distress in stroke survivors for identification of depression and anxiety (Aben *et al.*, 2002; Johnston *et al.*, 2000; Sagan *et al.*, 2009). Studies have directly compared the HADS to other scales and demonstrated it is comparable to the GHQ-30 (O'Rouke *et al.*, 1998); BDI, HDRS and Symptom Check List 90 (Aben *et al.*, 2002), but is less suitable than the GDS-30, GHQ-28 (Johnson *et al.*, 1995); BASDEC (Healy *et al.*, 2008) and MADRS (Sagan *et al.*, 2009). At the recommended diagnostic threshold of 19 (definite cases) for the HADS-T, sensitivity was low (0.37) and specificity was high (0.96; Sagan *et al.*, 2009).

The HADS-A has been investigated for its utility among stroke survivors. Recommended cut-off points for anxiety in stroke survivors range from 4/5 (sensitivity of 0.83, specificity of 0.65; Sagen *et al.*, 2009), 5/6 (sensitivity of 0.80, specificity of 0.46; Johnson *et al.*, 1995) to 6/7 (sensitivity of 0.83, specificity of 0.68; O'Rourke *et al.*, 1998). The complexity of this scale renders it difficult to use with many stroke survivors, however, even those without cognitive and communication

difficulties (Kneebone *et al.*, 2014). Anxiety is therefore not well evaluated by means of standard screening tools and further assessment methods are required.

1.9.2 The BOA

To address the need for an anxiety screening tool for stroke survivors with communication and cognitive difficulties, a group of clinicians have developed the Behavioural Outcomes of Anxiety scale (BOA; Kneebone *et al.*, 2012). The BOA has a similar format to the SADQ measure of post stroke depression (Sutcliffe & Lincoln, 1998). The BOA consists of a series of descriptions of anxiety, based on relevant diagnostic criteria and clinical experience. It is rated by an observer who knows the stroke survivor well, usually a carer. The observational nature of the BOA was chosen as stroke survivors with severe communication difficulties may not be able to respond reliably to adapted or visual analogue measures (Turner-Stokes, Kalmus *et al.*, 2005). The BOA has been found to have acceptable psychometric properties and validity in stroke survivors without communication difficulties (Linley-Adams *et al.*, 2014). At a cut-off score of 13/14, sensitivity was 0.77 and specificity was 0.58 against the HADS-A. Further study is needed to establish its validity with survivors with aphasia.

1.9.3 Summary

There is currently a shortage of appropriate validated tools for screening anxiety in stroke survivors with aphasia. There is evidence for the validity of two screening measures of post stroke anxiety, the HADS-A and the BOA. As described above, the HADS-A has been found to have acceptable psychometric properties but is limited to use by stroke survivors who are able to self-report reliably. Thus, the HADS-A remains unsuitable for a sizeable group of individuals with severe aphasia who are unable to complete self-report assessments or to report their feelings (Sutcliffe & Lincoln, 1998). The BOA offers an alternative approach to screening stroke survivors who are unable to report their own mood state. It measures the observations of a carer of the behavioural signs of anxiety in the stroke survivor. Thus, it can be used to measure anxiety in even the most severely communication impaired survivors. Its validity has been demonstrated in non-aphasic stroke survivors (Linley-Adams *et al.*,

2014) but to date no studies have investigated its validity in stroke survivors with aphasia.

In the following section a systematic review was carried out to further understand the psychometric properties of post stroke mood screening tools.

1.10 Systematic review

1.10.1 Aims

The present study aims to investigate the psychometric properties of an observational screening measure of anxiety for stroke survivors with aphasia. Therefore, a systematic review has been undertaken to explore the findings and quality of existing research into post stroke mood screening.

An initial review of the literature was carried out to determine whether any studies had focused on the development of screening measures for mood in stroke survivors with aphasia. Given the relative dearth of research in this area the systematic literature search was expanded in order to answer the following the question: "What are the psychometric properties and clinical utility of self-report anxiety screening tools and observational mood screening tools in stroke survivors with and without aphasia".

1.10.2 Search methodology

On 14 December 2014 a review of the clinical research evidence, from 1990 to 2014, was conducted using the following databases: PsychINFO, Science Direct, Embase, Social Science Research Network, Medline, PsycARTICLES full text, Web of Science and Scopus. The following grey literature databases were also searched: GREYLIT, Proquest dissertations and theses database and OPENGREY in addition to Google and Google Scholar. The following professional bodies were also searched: The British Psychological Society, Royal College of Physicians and National Institute of Clinical Excellence. The Stroke Association and Different Strokes third sector organisations were also searched. All abstracts and titles identified during this process were reviewed (N= 422 after removal of duplicates).

Key search terms relating to mood in stroke survivors were: anxiety, depression, mood, mood disorder.

Key search terms relating to stroke survivors were: survivor, stroke survivor, post stroke.

Key search terms relating to assessment were: psychometric, measure, questionnaire, tool, screening tool, screening, instrument, scale, inventory.

Key search terms relating to test development were: development, validation, validity, reliability, ROC analysis, sensitivity, specificity, item analysis, psychometric.

Terms with similar meaning were combined using Boolean operator 'OR' (e.g. survivor* OR stroke survivor*) to give overall topic results for: Mood (Topic), Assessment (Topic), Test development (Topic), and Stroke survivors (Topic). Topics were then combined using Boolean operator 'AND' –

I.e. Mood (Topic) AND Assessment (Topic) AND Test development (Topic) AND Stroke survivor (Topic).

All titles and abstracts discovered via this process were reviewed. Full articles were reviewed where it was unclear whether the paper met inclusion criteria from the abstract alone. The reference lists of all articles that met the inclusion criteria, key review papers, book chapters and meta-analyses were examined for relevant studies.

The search was repeated on 27 April 2015 to capture any further studies published between December 2014 and April 2015.

1.10.3 Study criteria

1.10.3.1 Inclusion criteria

- Development (including items selection, studies of acceptability and feasibility) and/ or validation (including studies of factor structure, diagnostic accuracy) of screening measures of current anxiety and/ or depression in stroke survivors
- Original articles
- Quantitative or qualitative studies
- Peer reviewed papers
- Studies published in English, between 1990 – 2015

1.10.3.2 Exclusion criteria

- Studies of tools that were designed for assessment of mood or diagnosis rather than screening tool
- Studies of tools for the assessment of generic related constructs (e.g. quality of life)
- Development of assessments for mood in carers of stroke survivors
- Development of assessments for severe mental health problems
- Development of outcome measures of mood
- Studies of translations of existing measures in different countries
- Studies of protocols for test administration, recording or actioning results
- Review papers
- Papers that were not peer reviewed, such as dissertation
- Conference papers or abstracts where the data could not be accessed
- Inclusion of non-stroke survivors (e.g. TBI) or where less than 70% of the participants had suffered a stroke and where stroke data were not separately reported
- Studies of tools where the cut-off scores did not yield sensitivity values of ≥0.80 and specificity ≥0.60
- Studies published before 1990
- Studies with stroke survivors under 18 years old

Duplicates were discarded and further studies were identified via cross-referencing

1.10.4 Publication status

All available research on post stroke mood screening was searched for inclusion, including peer reviewed journals, book chapters and conference presentations. This

aimed to limit the potential of publication biases, whereby publication is influenced by the results of a study (Song *et al.*, 2000). The inclusion of published-only studies may over-estimate the psychometric properties of mood screening tools.

1.10.5 Results and quality framework

A total of nine studies were included in the systematic review. A diagram of search results is provided in Appendix 1.1. A summary of each tool and it's clinical utility is provided in Table 1.1. Study information is detailed in Table 1.2 below and a summary of the psychometric properties of each included screening tool is provided in Tables 1.4 and 1.5. Quantitative cross sectional survey studies were included within the review.

A quality framework developed by Cardiff University's Support Unit for Research Evidence (SURE) specifically for diagnostic test studies was applied to the studies (Cardiff University, 2012). Relevant studies were evaluated against the quality framework (see Table 1.3 below). A numerical scoring system was implemented in addition to the existing assessment guidance within the quality framework. Studies were rated and agreed with the researcher's supervisor to improve reliability of scores.

++ *(good) = score of 2*

\+ *(mixed) = score of 1*

\- *(poor) or nr (not reported) = score of 0*

Table 1.1 Brief description of each identified screening measure and clinical utility

Measure	Description of measure	Type of screening tool	Time to administer	Administration training required?	Initial costs	Recurring costs
ADRS (Benaim *et al.*, 2004)	A professional rates the individual's behaviour on the basis of observation and/or interview on nine items. Items are scored (0-6) and total score is totalled (maximum 32 points). Includes somatic symptom items.	Observational	Not reported	Yes	None	NA
BOA (Kneebone *et al.*, 2012)	A carer or someone who knows the survivor well rates the frequency with which the person has demonstrated behavioural signs of anxiety on 10 items. Items are scored (0-3). Maximum score = 30, higher scores indicate greater anxiety.	Observational	<5 minutes	No	None	NA
HADS (Zigmond & Snaith, 1983)	Individuals rate the degree to which they agree with seven anxiety and seven depression items over the previous week on a four-point scale (maximum score of 42 or 21 for each subscale). Excludes somatic symptoms.	Self-report	2-6 minutes	No	Must be purchased (£100 for complete kit)	Ongoing costs for record forms/digital administrations
SADQ-H (Lincoln *et al.*, 2000)	An observer rates the frequency of inpatients' behaviour on 21 items related to low mood on a scale of 0–3 (total of 63). Includes somatic symptoms.	Observational	<5 minutes	No	Freely available	NA
SADQ-H10 (Lincoln *et al.*, 2000)	An observer rates the frequency of inpatients' behaviour on 10 items associated with low mood on a scale of 0–3 (total of 30). Includes somatic symptoms.	Observational	<5 minutes	No	Freely available	NA
SoDS (Hammond *et al.*, 2000)	An observer rates the occurrence of six behaviours associated with low mood with a 'yes/no' response. Scores are totalled (score 0-6). Minimal somatic symptoms.	Observational	<5 minutes	No	Freely available	NA

VAMS 'sad item' (Stern, 1997)	Patients are presented with a vertical 10-cm line with a cartoon sad face with a verbal descriptor and a neutral face at opposite ends. The individual expresses the severity of their mood via the position on the line, which is measured. Excludes physical items.	Visually aided self-report	<5	No	Must be purchased: >£100 for kit (includes eight mood states)	Recurring costs for response booklets

ADRS, Aphasia Depression Rating Scale; BOA, Behavioural Outcomes of Anxiety Scale; HADS, Hospital Anxiety and Depression Scale; SADQ-H, Stroke Aphasic Depression Questionnaire – Hospital version; SADQ-H10, 10-item SADQ-H; SoDS, Signs of Depression Scale; VAMS, Visual Analogue Mood Scales.

Table 1.2 Summary of studies used for systematic review

Measure, Authors, Country	Design	Informant	Sample & recruitment location	Exclusions	n and Survivor and Carer details: gender, age, ethnicity & relationship to survivor	Data collection (timing, location, etc)	Key Findings	Key Limitations
BOA Linley-Adams *et al.* (2014) U.K	Cross-sectional longitudinal survey	Observer rated (carers)	Stroke survivor-carer dyads recruited in community stroke groups.	Stroke survivors with aphasia.	N= 89 Mean age of the stroke survivor: 68.7 years, mean age of the carer: 65.2 years. 62.5% of the stroke survivors were male, but only 28.2% of the carers were male. 78.2% of carers were the spouse of the stroke survivor and 7.7% were the offspring.	Data collected at time one (T1) and a subgroup (N= 27) repeated the measure one week later (T2).	Correlations between the carer BOA and the survivor HADS-A ($r = .55$, $p < .001$) and the survivor BOA ($r = .73$, $p < .001$) demonstrated construct validity. Cronbach's alpha for the carer BOA was .81; item statistics did not identify any items for exclusion. The test–retest coefficient at one week was 0.83. ROC analysis against the survivor HADS-A and BOA produced areas under the curve of 0.75 and 0.88, respectively. At a cut-off score of >13 sensitivity and specificity against the HADS-A were 0.77 and 0.58, respectively, and 0.86 and 0.68 against the survivor BOA. The impact of stroke on memory was associated with elevated anxiety. Scores for both BOA versions were independent of demographic variables.	Survivors with aphasia excluded.

GHQ-30 and HADS O'Rourke *et al.* (1998) U.K	Measures compared against DSM-IV diagnosis	Self-report	Stroke survivors living at home referred by hospital.	Stroke survivors with cognitive impairment and aphasia.	N= 145 Median age: 68 (range, 18 to 90 years), 51.7% subjects were male.	Questionnaire data collected at time one (T1) and interview data collected two weeks later (T2).	GHQ-30: ROC curve suggests the best cut-off point is 8/9 with a sensitivity of 0.80 and specificity of 0.76. HADS: A cut-off point of 6/7 on the depression subscale achieved a sensitivity of 0.8 and specificity of 0.79. On the anxiety subscale a cut-off point of 6/7 achieved a sensitivity of 0.83 and specificity of 0.68.	No confidence intervals reported. The HADS and GHQ were administered in different ways and at different times potentially biasing results.
BDI, HADS, SCL-90, HDRS Aben *et al.* (2002) Netherlands	Compared four screening tools against DSM-IV diagnosis	BDI, HADS and SCL-90: self-report HDRS: observer rated	Consecutive patients with a diagnosis of first hemispheric infarction were included.	Those with comorbid intracerebral disease, major psychiatric disorder other than affective disorder, those unable to communicate reliably on basis of MMSE and FAST.	N= 202 45.5% female Mean age: 68.5	Interview data collected at time one (T1) and questionnaire completed at home at time two (T2). Patients were assessed one month after first-ever stroke and completed questionnaires a median of five days later.	The optimum cut-off score for HADS-D was 8 (sensitivity: 73.1, specificity: 81.6). Use of the total HADS resulted in a sensitivity of no less than 91.7 (specificity: 65.3) at its optimum threshold score of 11. The optimum cut-off point for the SCL-90 depression subscale was a score of 25 (sensitivity: 88.5, specificity: 60.7); for the BDI it was a score of 10 (sensitivity: 0.80, specificity: 0.61); for the HDRS it was a score of 17 (sensitivity: 0.62, specificity: 0.91). Thus all scales found to be acceptable screening instruments for post stroke depression.	Clinical interview and HDRS administered by the same interviewer during the same session introducing possible bias. Survivors with severe aphasia excluded.
HADS, GDS, and GHQ-28	Compared three screening tools against	Self-report	All strokes that occurred in Perth were contacted as part of the Perth	No details of exclusion criteria provided.	N= 204 Mean age of patients: 71 years (median	Emotional outcome was assessed at four months in a two-stage procedure. First, all patients	The GHQ-28 and GDS but not the HADS-D, were shown to be satisfactory screening instruments for depression, with the GHQ-28 having an overall superiority. At a cut-off	No exclusion criteria or confidence limits reported.

Johnson *et al.* (1995) Australia	DSM-III diagnosis		community stroke study.		72, range 23-95 years) Male to female ratio was 1.27: 1.	completed either the HADS or the GDS. The former was completed by or for consecutive patients whose stroke occurred in the first half (nine months) of the study period and the latter for the remaining patients. The second stage involved an interview, as soon as possible after the first stage, by a psychiatrist who was blind to clinical information about the patient. Each patient completed the GHQ-28 immediately prior to the formal psychiatric interview.	of >6 the HADS-A had sensitivity of 0.57, specificity of 0.56. At a cut-off of >4 on the HADS-D sensitivity was 0.83 and specificity was 0.44. The GHQ-28 had sensitivity of 0.89 and specificity of 0.75 at a cut-off of >4 and the GDS has a sensitivity of 0.84 and specificity of 0.66 at a cut-off of >10.	
HADS and MADRS Sagen *et al.* (2009) Norway	Correlational design	Self-report	Stroke patients, consecutively admitted to a stroke unit, were assessed with HADS	Stroke survivors with TIA, insufficient competence in the Norwegian language,	N= 104 Mean age: 64.5 61 males (58.7%)	At follow-up four months after stroke, survivors were assessed with the MADRS, SCID and HADS successively.	For anxiety, the optimal screening cut-off was 4 for HADS-A and 6 for HADS-T; for depression, optimal cut-offs were 4 for HADS-D, 11 for HADS-T, and 8 for MADRS. At cut-offs commonly used in clinical practice for depression	No blinding implemented. Clinical interview and questionnaires administered by the same person and in the same

			and MADRS four months after stroke. Depression and anxiety disorders were diagnosed using the SCID.	cognitive impairment-score on MMSE of < 20, severe aphasia and terminal illness.			screening (HADS-D: 8, MADRS: 12), the MADRS performed marginally better than the HADS.	sequence, possibly biasing the results.
SADQ-H10 Hacker *et al.* (2010) U.K	Naturalistic audit. Cross-sectional design.	SADQ-H10: observer rated BASDEC: self-report	All patients from an acute in-patient stroke unit were routinely screened with the SADQ-H10 and BASDEC over a twelve month period.	Non-English speaking, blind, deaf and aphasic stroke survivors.	N= 125 58 women and 67 men aged between 31 and 100 (mean: 73, SD-13). Ethnicity not reported.	The SADQ-H10 was completed by nursing staff and the BASDEC was administered by an assistant psychologist. Both measures were completed within the same week on a single occasion.	The SADQ-H10 and BASDEC significantly correlated. ROC analysis showed that the SADQ- H10 discriminated between depressed and non-depressed acute stroke patients. At a cut-off score of >5, sensitivity: 0.70, specificity: 0.69.	Exclusion of aphasic stroke survivors. Did not use structured clinical interview as criterion standard.
VAMS, VASES, SADQ-H and SoDS Bennett *et al.* (2006) U.K	Correlation analysis between new questionnaire and established measures	VAMS and VASES: self-report. SADQ-H and SoDS: informant reported (either nurse or relative) HADS self-report (for	50 healthy older adults living in the community recruited from a range of sources (e.g. day centres, Age Concern, church groups).	Stroke survivors excluded if they had dementia, were blind or deaf, were non-English speaking, or did not give	N= 100 51 male, 49 female. Median age: 71.5. Ethnicity not reported.	All stroke survivors completed the VAMS and VASES, a nurse completed the SADQ-H and SoDS in relation to the survivor, and those without communication problems completed the	In stroke patients the internal consistency of the SADQ-H, VAMS, and VASES was high (Cronbach's alpha 0.71–0.84) but that of the SoDS was low (Cronbach's alpha 0.53). The HADS-D scale correlated significantly with all the scales (0.35–0.55) but only the SADQ-H10, VAMS, and VASES were significantly correlated with the HADS-A scale (0.40–0.52).	Low prevalence of depression (22%) thus sample lacks generalisability to stroke population. Stroke survivors were acute post stroke inpatients at time of study which may skew the mood ratings, and limits generalisability to

		those able to complete)	100 stroke patients recruited from two acute hospitals.	informed consent.		HADS 2-4 weeks following stroke.	Appropriate cut-offs were found for the SADQ-H (17/18; sensitivity: 1.0, specificity: 0.81), SADQ-H10 (5/6; sensitivity: 1.0, specificity: 0.78), SoDS (1/2; sensitivity: 0.86, specificity: 0.62), and VAMS 'sad' item (22/23; sensitivity: 0.88, specificity: 0.62) in comparison to depression on the HADS. No appropriate cut-offs were identified in comparison to anxiety on the HADS.	community dwelling survivors.
SoDS Lightbody *et al.* (2007) UK	Cross-sectional method-agreement study	Informant rated	Inpatient stroke survivors at an inner-city teaching hospital	Unconscious; medically unfit; unwilling to participate; unable to give informed consent and had no carer or relative to provide assent; or those discharged before assessment could be completed by the nurse or	N= 71 Median age: 70 (IQR: 59–76) and 40 (56.3%) males. Median score on the FAST was 25 (IQR: 18–28) and 36/71 patients (50.7%) had normal communication.	The nurse responsible for each survivor's care and a carer (when available) independently rated the stroke survivor's mood using the SoDS, generally within a day of each other. Clinical interview using the SCID was conducted by a psychiatrist.	Sensitivity of the SoDS at a cut-off >2 when rated by nurses was 0.64, and specificity 0.61. Carers achieved sensitivity of 0.90 and specificity of 0.35. The optimal cut-off point for carers was higher at >4. Inter-rater agreement between nurses and carers was fair.	Small proportion of carers (42%) included, limiting generalisability of results and conclusions. No clear optimal cut-point found for the SoDS when rated by nurses. Low sensitivity is not desirable.

				the psychiatrist.				
ADRS Benaim *et al.* (2004) France	Correlational design	Observer rated	Stroke rehabilitation in-patients were recruited.	None reported.	N= 49 Mean age: 64 (38-78) 31 (63%) males and 18 (37%) females).	Stroke survivors were evaluated twice at a one-month interval (+/- 5 days).	ADRS correlated highly with VAS and HDRS (r = 0.60 to 0.78). Against the psychiatrist diagnosis criterion standard sensitivity and specificity of ADRS were 0.83 and 0.71, respectively, with a cut-off >9.	No blinding, tests were completed independently however by different members of rehab team and psychiatrist. Only 48% of the sample were aphasic limiting generalisability of results.

Table 1.3 Quality framework for diagnostic test studies, Support Unit for Research Evidence (SURE), Cardiff University, 2012

	Scoring guidance: 2 = good, 1 = mixed, 0 = poor, nr = not reported, na = not applicable **Quality framework criteria**										
	1. Was there a clear question for the study to address?	**2. Was there a comparison with an appropriate reference standard?**	**3. Did all patients get the diagnostic test and reference standard?**	**4. Could the results of the test have been influenced by the results of the reference standard?**	**5. Is the disease status of the tested population clearly described?**	**6. Were the methods for performing the test described in sufficient detail?**	**7. What are the results?**	**8. How sure are we about the results? consequences and cost of alternatives performed?**	**9 &10. Can the results/test be applied to your patients/ the population of interest?**	**11. Were all outcomes important to the individual or population considered?**	**12. What would be the impact of using this test on your patients/ population?**
Linley-Adams *et al.* (2014)	To validate the BOA in stroke survivors	HADS-A used as reference standard	Yes, all survivors completed the HADS-A	na, no blinding as not feasible	Anxiety prevalence 25.41%	Participants completed carer and survivor versions of the BOA and HADS-A.	At a cut-off score of 13/14 on the carer completed BOA, sensitivity and specificity against the HADS-A were 0.77 and 0.58, respectively, and 0.86 and 0.68 against the survivor BOA.	Confidence intervals provided.	Sample is representative of the population in south Wales. However, aphasic stroke survivors excluded.	Yes	The BOA has the potential to enable anxiety among stroke survivors with aphasia to be identified. The BOA is highly applicable to clinical practice. It can be completed by a carer,

											no formal training required to administer or interpret the results.
	2	**2**	**2**	**na**	**2**	**2**	**2**	**2**	**1**	**2**	**2**
Bennett *et al.* (2006)	Compare the SADQ-H, SoDS, VAMS, and VASES in screening for mood problems after stroke	HADS used as criterion standard	Yes, for all survivors who could complete the HADS	na All participants completed all the measures	20% were depressed and 22% were anxious as measured using the HADS.	All participants completed the VAMS, VASES, and a close relative/friend or a nurse if survivor in hospital completed the SADQ-H and SoDS in relation to the participant. Those without communication problems completed the HADS.	In stroke patients, the HADS-D scale correlated significantly with all the scales (0.35–0.55) but only the SADQ-H10, VAMS, and VASES were significantly correlated with the HADS-A scale (0.40–0.52). Appropriate cut-offs were found for the SADQ-H (17/18), SADQ-H10 (5/6), SODS (1/2), and VAMS 'sad' item (22/23)	No confidence limits reported.	Sample included aphasic stroke survivors and is therefore highly relevant to the current study.	Yes	Results relevant to aphasic stroke survivors. The SADQ-H, SADQ-H10 and SoDS were all appropriate for screening for possible depression after stroke but not for screening for possible anxiety. The SADQ-H10 was recommended as the most appropriate for screening purposes.

							in comparison to depression on the HADS. No appropriate cut-offs were identified in comparison to anxiety on the HADS.				The VAMS and VASES were suggested as suitable for assessing severity of low mood rather than for screening purposes.
	2	**2**	**2**	**na**	**2**	**2**	**2**	**1**	**1**	**2**	**1**

Hacker *et al.* (2010)	To validate the SADQ-H10, an observer-rated measure of depression against the BASDEC in acute stroke.	BASDEC used as criterion standard.	Yes, all survivors completed the BASDEC	Blinding was implemented at the data collection stage. Different professionals administered the BASDEC and SADQ-H10	32% of the patients were classified as depressed by the BASDEC	All participants completed the BASDEC and nursing staff completed the SADQ-H10	The SADQ-H10 and BASDEC significantly correlated. ROC analysis showed that the SADQ-H10 discriminated between depressed and non-depressed acute stroke patients. A cut-off score of >5 gave sensitivity of 0.70 and specificity of 0.69.	Confidence intervals provided.	Demographics of sample are generalisable except the reliance on self-report necessitated communication ability.	Yes	SADQ-H10 and BASDEC are brief and simple to complete but the BASDEC requires survivors to have verbal understanding. No ongoing costs or formal training required for SADQ-H10 but this information is not available for the BASDEC.
	2	**2**	**2**	**2**	**2**	**2**	**2**	**2**	**1**	**2**	**2**

Benaim *et al.* (2004)	To construct a new behavioural depression rating scale for aphasic stroke patients and assess the validity in patients with severe aphasia	Psychiatrist diagnosis of depression	Yes all stroke survivors assessed by psychiatrist	Members of the team who completed the ADRS and VAS were unaware of the psychiatrist's rating.	Depression was diagnosed in 58% by the psychiatrist and in 68% by the HDRS.	Each stroke survivor was assessed by a psychiatrist, who graded the severity of depression symptoms from 0 (no symptom of depression) to 100 (extremely severe depression) Rehabilitation staff completed the VAS and ADRS in respect to each survivor.	ADRS correlated highly with VAS and HDRS (r= 0.60 to 0.78). With respect to the psychiatrist's diagnosis, the sensitivity and specificity of ADRS were 0.83 and 0.71, respectively, when the threshold was set at 9/32.	ROC analysis not performed, confidence intervals not reported.	Only a proportion of the sample were aphasic thus findings may be influenced by the communicative ability of the rest of the sample. The ADRS was found to be a valid, reliable, sensitive, and specific rating scale for the evaluation of depression in aphasic post stroke inpatients.	Yes	Study offers preliminary support for the ADRS as a valid, reliable, sensitive, and specific tool for the screening of depression in aphasic patients during the stroke sub-acute phase. Training required however which may limit the clinical utility.
	2	**2**	**2**	**2**	**2**	**2**	**2**	**1**	**1**	**2**	**1**

Lightbody *et al.* (2007)	To determine the accuracy and utility of an observational screening tool (SoDS), when rated by nurses and carers for detecting depression in patients who have recently had a stroke	Clinical diagnosis of depression by a psychiatrist	Yes	Nurses responsible for each patient's care and a carer (whenever available) independently rated the survivor's mood using the SoDS, which was presented to them by the research nurse. The nurse and the carer generally completed the SoDS within a day of each other. A psychiatrist blind to the ratings on the SoDS conducted the clinical interview.	The psychiatrist classified 35.2% of survivors as depressed.	SoDS completed by a nurse and clinical interview completed by a psychiatrist.	Using the recommended cut-off point of >2 on the SoDS, the nurse and carer respectively rated 38% and 60% survivors as potentially depressed. Sensitivity when rated by nurses was 0.64, and specificity was 0.61, whereas carers achieved sensitivity of 0.90 and specificity of 0.35. The optimal cut-off point for carers was higher at 4 or more. Inter-rater reliability between nurses and carers was fair.	Confidence intervals provided.	Sample included aphasic stroke survivors, other demographics are generalisable to current study, except the sample were inpatients.	Yes	SoDS is brief, freely available and does not require specialist training to administer or interpret the results.

	2	2	2	2	2	2	2	2	1	1	2
O'Rourke *et al.* (1998)	Compare the accuracy of the GHQ-30 and the HADS in detecting psychiatric morbidity after stroke and to determine the most suitable cut-off points for different purposes	DSM-IV psychiatric interview used as criterion standard	Yes	Blinding performed, psychiatrist unaware of the patient's scores on HADS and GHQ	Psychiatric evaluations identified 28.6% with 40 psychiatric diagnoses. 27.5% had depressive disorders, 7.5% had anxiety.	Stroke survivors completed both the GHQ-30 and HADS six months post stroke before a blinded psychiatric clinical interview.	No significant differences were found between the GHQ-30 and the HADS in identifying those patients with any DSM-IV diagnosis, grouped depression, or anxiety disorders. The ROC curve suggests the best cut-off point is 8/9 with a sensitivity of 0.8 and specificity of 0.76.	No confidence intervals given. The HADS and GHQ were administered in different ways and at different times potentially confounding the results. Cost ratios calculated but sensitivity and specificity values do not reveal an appropriate cut-off.	Sample demographics generalisable, however reliance on verbal self-report excluded aphasic survivors.	Yes	Results are applicable only to stroke survivors able to self-report.
	2	2	2	2	2	2	2	1	1	2	1

Johnson *et al.* (1995)	Evaluation of the relative efficacy of the HADS, the GHQ-28-item version in screening stroke survivors four months after stroke for depressive and anxiety disorders	DSM- III criteria used as criterion standard	Yes	Blinding performed, psychiatrist unaware of the patient's scores on HADS, GDS and GHQ	26% of sample diagnosed with depression and 24% diagnosed with anxiety according to DSM-III criteria.	Stroke survivors assessed at four months with either HADS or GDS. Clinical interview performed as soon as possible by psychiatrist and GHQ-28 administered.	The GHQ-28 and GDS but not the HADS depression, were shown to be satisfactory screening instruments for depression, with the GHQ-28 having an overall superiority. The performance of all three scales for screening post stroke anxiety disorders was less satisfactory. The HADS-A had the best level of sensitivity, but the specificity and positive predictive values were low and the misclassifica	No confidence limits reported.	Demographics of sample are generalisable except the reliance on self-report necessitated communication ability.	Yes	The GHQ-28 and GDS demonstrated acceptable psychometric properties for depression screening and the HADS had the best sensitivity for detecting anxiety. Findings relevant to stroke survivors without aphasia, however, cannot be applied to aphasic survivors.

							tion rate high.				
	2	**2**	**2**	**2**	**2**	**2**	**2**	**1**	**1**	**2**	**1**
Aben *et al.* (2002)	To evaluate the depression screening abilities of the BDI, HADS, SCL-20 and HDRS in 202 consecutive patients one month after first-ever ischemic stroke.	DSM-IV diagnosis of major and minor depressive disorder.	Yes	Yes Clinical interview and HDRS administered by the same interviewer during the same session	15.8% met DSM-IV criteria for major depressive disorder, and 9.4% met criteria for minor depressive disorder for an overall prevalence of 25.2%.	All survivors were interviewed with both the SCID and the HDRS. Survivors completed the BDI, HADS and SCL-90 questionnaires at home after the interview.	At the optimum cut-off values, the sensitivity of the self-rated scales varied between 0.80 and 0.90, while the specificity was about 0.60. For the observer rated HDRS sensitivity was 0.78 and specificity was 0.74.	No confidence intervals reported.	Sample included aphasic stroke survivors, other demographics are generalisable to current study.	Yes	The study recommends the use of self-report BDI, HADS and SCL-90 and observer report HDRS for screening depression. However, the unknown cost of the BDI and the reliance on verbal self-report of both the BDI and HADS reduce their clinical utility.
	2	**2**	**2**	**0**	**2**	**2**	**2**	**1**	**2**	**2**	**1**

Sagen *et al.* (2009)	Compare the performance of the HADS and MADRS as screening instruments for anxiety and depression disorders four months after stroke.	DSM- IV criteria used as criterion standard.	Yes	No blinding. Clinical interview and questionnaires administered by the same person and in the same sequence. It is possible that the responses to the clinical interview were influenced by the responses to the MADRS.	Clinical interview revealed 23.1% with anxiety and 19.2% with depression. 13.5% subjects had comorbid depression and anxiety disorders. 70% of the depressed patients had at least one significant anxiety disorder and 58% of the patients with anxiety suffered from depression.	At follow-up four months after stroke, participants were assessed with MADRS, SCID, and HADS, successively.	For anxiety, the optimal screening cut-off was 4 for HADS-A and 6 for HADS-T; for depression, optimal cut-offs were 4 for HADS-D, 11 for HADS-T, and 8 for MADRS. At cut-offs commonly used in clinical practice for depression screening (HADS-D: 8, MADRS: 12), the MADRS performed marginally better than the HADS.	Confidence intervals reported.	Norwegian sample, but otherwise generalisable. Severe aphasic survivors excluded.	Yes	The HADS and MARS are brief self-report measures that require survivors to have verbal understanding. HADS incurs ongoing costs.
	2	**2**	**2**	**0**	**2**	**2**	**2**	**2**	**1**	**2**	**1**

Table 1.4 Sensitivity and specificity of screening tools for post stroke anxiety for those with and without aphasia

Screening tool	Cut-off score for depression	Study	Sensitivity	Specificity
HADS-Total	>5	Sagen *et al.* (2009)	0.83	0.60
HADS-Anxiety subscale	>3	Sagen *et al.* (2009	0.83	0.65
	>4	Aben *et al.* (2002)	0.89	0.72
	>6	Johnson *et al.* (1995)	0.57	0.56
		O'Rourke *et al.* (1998)	0.83	0.68
		Sagen *et al.* (2009)	0.70	0.83
BOA	>13	Linley-Adams *et al.* (2014)	0.77	0.58

Table 1.5 Sensitivity and specificity of screening tools for post stroke depression for those with aphasia

Screening tool	Cut-off score for depression	Study	Sensitivity	Specificity
ADRS	>8	Benaim *et al.* (2004)	0.83	0.71
SADQ-H	>17	Bennett *et al.* (2006)	1.0	0.81
SADQ-H10	>5	Bennett *et al.* (2006)	1.0	0.78
		Hacker *et al.* (2010)	0.70	0.69
SoDS	>1	Bennett *et al.* (2006)	0.86	0.62
		Lightbody *et al.* (2007)	0.64	0.61
VAMS 'sad item'	>22	Bennett *et al.* (2006)	0.88	0.62

1.10.6 Synthesis of studies

The studies included in the systematic review will be synthesised and the findings and methodological limitations will be discussed.

1.10.6.1 Screening for anxiety

Two screening tools were identified that had been investigated for their ability to detect post stroke anxiety. The BOA and the HADS anxiety subscale were the only measures specifically aimed at screening anxiety and were the only tools that generated adequate sensitivity and specificity values at any cut-off (Table 1.4).

1.10.6.2 Clinical utility

The HADS has been found to have mixed clinical utility (Table 1.1). Administration time is brief (less than five minutes) and only minimal staff training is required. However, it incurs initial and continuing costs which limit the clinical utility. The BOA on the other hand is quick to complete and is freely available, which offers an advantage in terms of clinical utility.

1.10.6.3 Screening for depression

Non-verbal response self-report screening measures of depression

The VAMS 'sad item' was found to have effective cut-off scores, although no discrepancy between depression severity is possible.

1.10.6.4 Observational screening measures of depression

Four observational depression screening measures were identified from four papers: SADQ-H, SADQ-H10, ADRS and SoDS. All of the measures except for the SoDS contain physical symptoms related to mood.

1.10.6.5 Optimal cut-off scores for depression screens

The systematic review included only those papers where the validity results of the screening tools were adequate. Optimal cut-off scores for the detection of major depression or any depressive disorder were explored (Table 1.5). Suitable cut-offs were found for the ADRS, SADQ-H and VAMS 'sad item', however severity of low mood could not be ascertained. For all depression screens, the papers reviewed included multiple cut-off scores, but due to design variability, heterogeneity of participants across the papers, and differing sensitivity and specificity values found, lack of clarity regarding ideal cut-off scores exists.

1.10.6.6 Clinical utility

The clinical utility of the four selected non-verbal depression screening instruments was examined (Table 1.1). Administration time for all the measures was appropriate for a screening tool (under 10 minutes), although this data could not be found for the ADRS. Training in the use of the ADRS, but not for the other screening tools, is required. Many of the included tools are freely available (ADRS, SADQ-H, SADQ-H10, SoDS), however there are initial and ongoing costs for the VAMS, reducing its clinical utility.

All of the observational depression screens, with the exception of the SoDS include physical mood-related symptoms. This is a contentious issue as questions that focus on fatigue, concentration and memory difficulties or change in sleeping patterns may reflect the normal and common consequences of being in hospital which may be unrelated to emotional disturbance. It is feasible that such items may contribute to a higher score on a screening tool and thus lead to inaccurate clinical or research inferences. Some mood screens have omitted somatic items, in order to address the potential confounding impact of them. However, it is not clear what the effect of excluding such items is, and there is some support that physical symptoms are among the most useful discriminants of depression among stroke survivors (de Coster *et al.*, 2005). Adjustment of the cut-off scores so that they take account of the increase in prevalence of somatic symptoms in the stroke population may offer a useful comprise (Burton & Tyson, 2014).

1.10.6.7 Discussion

The systematic search identified a range of measures to screen for post stroke mood disorders. From the observational tools examined, only the BOA, SADQ-H and SoDS met recommended psychometric criteria and demonstrated good clinical utility. Among anxiety screening tools, the HADS-A has acceptable validity but is limited to use with survivors who are able to reliably communicate, and has initial and recurring costs.

The VAMS 'sad item' and ADRS were found to have adequate psychometric value for screening depression indicating that they can accurately ascertain survivors who may require further assessment. However, the VAMS relies on ability to comprehend instructions and incurs costs, and the ADRS requires training, thus limiting their clinical value.

To summarise, whilst a number of valid screens to detect post stroke depression in aphasic and non-aphasic survivors are available, there is a clear lack of tools to detect anxiety among aphasic survivors. Moreover, the quality of the studies as outlined in Table 1.3 effects the confidence with which conclusions can be drawn. This issue is explored in further detail below.

1.10.7 Methodological issues

1.10.7.1 Samples and populations

The nine studies recruited stroke survivors at a range of time points and from a range settings. Many of the selected papers recruited participants at the acute admission to hospital stage (Bennett *et al.*, 2006; Hacker *et al.*, 2010; Lightbody *et al.*, 2007; Sagen *et al.*, 2009). Consecutive admissions were sampled in three of the studies (Aben *et al.*, 2002; Benaim *et al.*, 2004; Sagen *et al.*, 2009). In two studies survivors were also participating in a clinical trial (Johnson *et al.*, 1995; O'Rourke *et al.*, 1998). Five studies recruited community dwelling stroke survivors (Aben *et al.*, 2002; Johnson *et al.*, 1995; Linley-Adams *et al.*, 2014; O'Rourke *et al.*, 1998; Sagen *et al.*, 2009).

Most studies assessed stroke survivors in the acute (within 1 month) (Aben *et al.*, 2002; Bennett *et al.*, 2006; Hacker *et al.*, 2010; Lightbody *et al.*, 2007) or sub-acute (between one and six months) post stroke phase (Benaim *et al.*, 2004; Bennett *et al.*, 2006; Johnson *et al.*, 1995; O'Rourke *et al.*, 1998; Sagen *et al.*, 2009). Only one study recruited stroke survivors many years post stroke (Linley-Adams *et al.*, 2014).

A range of criterion measures were employed as the reference gold standard. The majority of studies used the opinion of a psychiatrist established following a semi-structured interview or assessment instrument (Aben *et al.*, 2002; Benaim *et al.*, 2004; Johnson *et al.*, 1995; Lightbody *et al.*, 2007; O'Rourke *et al.*, 1998; Sagen *et al.*, 2009). The DSM criteria were used in most of the studies in the classification of mood disorders (Aben *et al.*, 2002; Johnson *et al.*, 1995; Lightbody *et al.*, 2007; O'Rourke *et al.*, 1998; Sagen *et al.*, 2009). Three studies used an alternative screening or assessment tool as the criterion standard (Bennett *et al.*, 2006; Hacker *et al.*, 2010; Linley-Adams *et al.*, 2014).

Most studies recruited stroke survivors only (Aben *et al.*, 2002; Benaim *et al.*, 2010; Hacker *et al.*, 2010; Johnson *et al.*, 1995; Sagen *et al.*, 2009). One study stipulated that the stroke survivors had a diagnosis of first stroke at time of recruitment (Aben *et al.*, 2002) but the majority of papers did not explicitly specify if participants had one or more strokes (Benaim *et al.*, 2010; Bennett *et al.*, 2006; Hacker *et al.*, 2010; Johnson *et al.*, 1995; Lightbody *et al.*, 2007; Linley-Adams *et al.*, 2014; O'Rourke *et al.*, 1998; Sagen *et al.*, 2009).

Four studies excluded stroke survivors with cognitive impairment (Aben *et al.*, 2002; O'Rourke *et al.*, 1998; Sagen *et al.*, 2009) and dementia (Bennett *et al.,* 2006). One study included individuals with cognitive impairment (Benaim *et al.*, 2010). It is not clear if the other studies included survivors with cognitive impairment or not (Hacker *et al.*, 2010; Johnson *et al.*, 1995; Lightbody *et al.*, 2007; Linley-Adams *et al.*, 2014).

Most studies excluded stroke survivors with aphasia (Aben *et al.*, 2002; Hacker *et al.*, 2010; Linley-Adams *et al.*, 2014; O'Rourke *et al.*, 1998; Sagen *et al.*, 2009). Three studies included aphasic survivors (Benaim *et al.*, 2010; Bennett *et al.,* 2006; Lightbody *et al.,* 2007) and one did not state if aphasia was an inclusion or exclusion criteria (Johnson *et al.*, 1995).

1.10.7.2 Country/ ethnicity

The studies were completed in a range of countries but mostly Westernised developed countries. Most studies did not report the ethnicity of the participants. One study provided ethnicity information in the inclusion criteria: that participants must have competence in the Norwegian language (Sagen *et al.*, 2009). The other twelve studies did not report any information concerning ethnicity.

1.10.7.3 Type of stroke

In terms of types of stroke, two studies included survivors of ischemic stroke (Aben *et al.*, 2002; Sagen *et al.*, 2009). The majority of studies reported a range of types of strokes suffered by participants (Benaim *et al.*, 2010; Hacker *et al.*, 2010; Linley-Adams *et al.*, 2014) and four studies did not clarify type of stroke (Bennett *et al.*, 2006; Johnson *et al.*, 1995; Lightbody *et al.*, 2007; O'Rourke *et al.*, 1998).

1.10.7.4 Age

The age of stroke survivors included in the studies was reported in all the studies and were, for the most part, in the older adult age group (mean age- 68.5, Aben *et al.*, 2002; 64, Benaim *et al.*, 2010; 71.5, Bennett *et al.*, 2006; 73, Hacker *et al.*, 2010; 71, Johnson *et al.*, 1995; median- 70, Lightbody *et al.*, 2007; mean- 68.7, Linley-Adams *et al.*, 2014; median- 68, O'Rourke *et al.*, 1998; mean- 66.4, Sagen *et al.*, 2009).

1.10.7.5 Gender

In terms of gender most of the studies sampled a male majority (Aben *et al.*, 2002; Benaim *et al.*, 2010; Bennett *et al.*, 2006; Hacker *et al.*, 2010; Johnson *et al.*, 1995; Lightbody *et al.*, 2007; Linley-Adams *et al.*, 2014; Sagen *et al.*, 2009) and one study had approximately equal males and females (O'Rourke *et al.*, 1998).

1.10.7.6 Design and recruitment

All the studies included details of when participation took place relative to the stroke. This ranged from one week (Hacker *et al.*, 2010) to up to six years post stroke (Linley-Adams *et al.*, 2014).

A correlational design was used in three studies (Benaim *et al.*, 2010; Bennett *et al.*, 2006; Sagen *et al.*, 2009). The remaining studies utilised a cross-sectional design (Aben *et al.*, 2002; Hacker *et al.*, 2010; Johnson *et al.*, 1995; Lightbody *et al.*, 2007; Linley-Adams *et al.*, 2014; O'Rourke *et al.*, 1998).

1.10.7.7 Sampling setting and technique

Almost all the studies specified the setting where the research took place and where the participants were sourced from. Six studies recruited their clinical samples exclusively though inpatient settings (Aben *et al.*, 2002; Benaim *et al.*, 2010; Bennett *et al.*, 2006; Hacker *et al.*, 2010; Lightbody *et al.*, 2007; Sagen *et al.*, 2009). One study recruited a combination of participants known to inpatient and/or outpatient services (Johnson *et al.*, 1995). Three studies recruited community dwelling stroke survivors (Linley-Adams *et al.*, 2014; O'Rourke *et al.*, 1998). As such the majority of studies took place within clinical settings.

Five studies employed a systematic sampling method whereby consecutive admissions were recruited (Aben *et al.*, 2002; Benaim *et al.*, 2010; Hacker *et al.*, 2010; Johnson *et al.*, 1995; Sagen *et al.*, 2009). Two studies specified the unit(s) or service(s) from where the sample came from, but did not specify the selection strategy (Bennett *et al.*, 2006; O'Rourke *et al.*, 1998). Opportunistic sampling was employed by two studies (Lightbody *et al.*, 2007; Linley-Adams *et al.*, 2014).

Four studies reported the number of participants who refused consent or who were excluded (Aben *et al.*, 2002; Benaim *et al.*, 2010; Johnson *et al.*, 1995; Lightbody *et al.*, 2007). Three studies provided approximate figures of those whom refused or were excluded from participating as no formal recordings were made (Hacker *et al.*, 2010; O'Rourke *et al.*, 1998; Sagen *et al.*, 2009). The remaining studies did not report the number of participants who refused consent or who were excluded (Bennett *et al.*, 2006; Linley-Adams *et al.*, 2014).

1.10.7.8 Sample size

It is essential to examine sample size and statistical power when appraising the validity and reliability of studies. There was considerable variation in sample sizes across the included studies (see Table 1.1). The one study specifically focussing on anxiety by Linley-Adams *et al.* (2014) employed a moderate sample size (N= 89). With the exception of the Bennett *et al.* (2006) study focussed on depression screens, the studies that included aphasic stroke survivors had comparatively smaller overall sample sizes, and only a minority of participants with aphasia (Benaim *et al.*, 2010; Lightbody *et al.*, 2007).

1.10.7.9 Treatment of confounding variables

All the studies gave some account of the treatment of confounding variables and the potential impact of these. Most of the studies specifically described strategies employed to decrease bias (Aben *et al.*, 2002; Benaim *et al.*, 2010; Hacker *et al.*, 2010; Johnson *et al.*, 1995; Linley-Adams *et al.*, 2014; O'Rourke *et al.*, 1998; Sagen *et al.*, 2009).

The screening tools were administered at different times in four studies (Aben *et al.*, 2002; Hacker *et al.*, 2010; Johnson *et al.*, 1995; O'Rouke *et al.*, 1998). Moreover, for a number of studies the mode of administration differed across the different measures (e.g. self-report, staff reported) when this was not the aim (Aben *et al.*, 2002; Hacker *et al.*, 2010; O'Rouke *et al.*, 1998). The timing and mode of administration was not clear in two studies (Benaim *et al.*, 2010; Sagen *et al.*, 2009). These factors increase the potential variance within the sample and may have confounded the results.

Stroke survivors with a history of severe mental health problems were excluded in two studies (Aben *et al.*, 2002; Sagen *et al.*, 2009). Patients with comorbid physical conditions/ diseases were excluded in five studies (Aben *et al.*, 2002; Bennett *et al.*, 2006; Lightbody *et al.*, 2007; O'Rouke *et al.*, 1998; Sagen *et al.*, 2009).

The studies varied in terms of time since the stroke. Results from many of the studies may be confounded by physical difficulties negatively impacting on mood due to assessment during the acute post stroke period. Two studies assessed mood after

a longer period to limit the potential bias of somatic symptoms (six months- O'Rouke *et al.*, 1998; at least six months, mean 6.1 years- Linley-Adams *et al.*, 2014). One study assessed mood at more than one time point to limit the confounding effects of physical symptoms and to assess test-retest reliability (four and twelve months post stroke- Johnson *et al.*, 1995).

Somatic symptoms and stroke severity have potential confounding effects on results. The studies varied in their management of this. One study utilised the Barthel Index (Mahoney & Barthel, 1965) to encompass physical disability (Hacker *et al.*, 2010). One study used the Barthel ADL Index and the Modified Rankin Scale (van Swieten *et al.*, 1988; Aben *et al.*, 2002). The Scandinavian Stroke Scale (Lindenstrom *et al.*, 1991) and Barthel Index was employed by Sagen *et al.* (2009). The influence of stroke severity was not evaluated in six studies (Benaim *et al.*, 2010; Bennett *et al.*, 2006; Johnson *et al.*, 1995; Lightbody *et al.*, 2007; Linley-Adams *et al.*, 2014; O'Rouke *et al.*, 1998).

Four studies specified whether participants had previous strokes or whether this was the first (Aben *et al.*, 2002; Johnson *et al.*, 1995; Linley-Adams *et al.*, 2014; Sagen *et al.*, 2009). However the majority of studies did not include this information (Benaim *et al.*, 2010; Bennett *et al.*, 2006; Hacker *et al.*, 2010; Lightbody *et al.*, 2007; O'Rouke *et al.*, 1998). This has a potential confounding effect on results.

Most studies included descriptive details of age but did not investigate in relation to the results (Aben *et al.*, 2002; Benaim *et al.*, 2010; Bennett *et al.*, 2006; Hacker *et al.*, 2010; Johnson *et al.*, 1995; Lightbody *et al.*, 2007; Linley-Adams *et al.*, 2014; O'Rouke *et al.*, 1998). One study gathered information about educational attainment (Aben *et al.*, 2002) which allow the results to be understood in a wider context. Most studies did not report such details however (Benaim *et al.*, 2010; Bennett *et al.*, 2006; Hacker *et al.*, 2010; Johnson *et al.*, 1995; Lightbody *et al.*, 2007; Linley-Adams *et al.*, 2014; O'Rouke *et al.*, 1998; Sagen *et al.*, 2009).

Only two studies included data regarding participant's employment status (Linley-Adams *et al.*, 2014; Sagen *et al.*, 2009). Employment status was not included in most of the studies (Aben *et al.*, 2002; Benaim *et al.*, 2010; Bennett *et al.*, 2006; Hacker *et al.*, 2010; Johnson *et al.*, 1995; Lightbody *et al.*, 2007; O'Rouke *et al.*, 1998).

Social support is another important influence on mood which may affect results. Three studies reported the marital status of participants, or whether they had a carer or lived alone (Aben *et al.*, 2002; Linley-Adams *et al.*, 2014; Sagen *et al.*, 2009). No such information was reported in the majority of studies however (Benaim *et al.*, 2010; Bennett *et al.*, 2006; Hacker *et al.*, 2010; Johnson *et al.*, 1995; Lightbody *et al.*, 2007; O'Rouke *et al.*, 1998).

Living arrangements (independent living or in placement) were reported in only two studies (Linley-Adams *et al.*, 2014; Sagen *et al.*, 2009). The remaining studies did not report this information which is another source of potential bias (Aben *et al.*, 2002; Benaim *et al.*, 2010; Bennett *et al.*, 2006; Hacker *et al.*, 2010; Johnson *et al.*, 1995; Lightbody *et al.*, 2007; O'Rouke *et al.*, 1998).

1.10.7.10 Criterion measures

The studies adopted various approaches to evaluating the performance of the mood screen. The DSM-IV structured clinical interview for depression (SCID) was administered in four studies to compare screening tool accuracy (Aben *et al.*, 2002; Lightbody *et al.*, 2007; O'Rourke *et al.*, 1998; Sagen *et al.*, 2009). Two studies compared the screening tool to a psychiatrist's clinical interview (Benaim *et al.*, 2010; Johnson *et al.*, 1995). Scores on another tool were used as the criterion standard in three studies (Bennett *et al.*, 2006; Hacker *et al.*, 2010; Linley-Adams *et al.*, 2014). Inclusion of other measures of mood is valuable in that it allows the issue of domain specificity in mood to be addressed. It also improves the construct validity of the findings where measures that assess equivalent difficulties to the target measure are utilised.

1.10.7.11 Quality of written reports

All the included papers gave quality abstracts and introductions with a description of the rationale for the research based on existing scientific knowledge. Hypotheses were clearly stated in the Linley-Adams *et al.* (2014) study but the remainder did not clearly state the hypotheses.

Only three studies reported the dates across which the data were collected (Aben *et al.*, 2002; Johnson *et al.*, 1995; Sagen *et al.*, 2009). All studies clearly detailed inclusion and exclusion criteria except for Johnson *et al.* (1995). The majority of studies indicated how the study sample size was calculated or arrived at (Aben *et al.*, 2002; Benaim *et al.*, 2010; Hacker *et al.*, 2010; Johnson *et al.*, 1995; Linley-Adams *et al.*, 2014; O'Rourke *et al.*, 1998; Sagen *et al.*, 2009).

In terms of statistical analysis of data, all the studies provided clear descriptions of the approaches used and presented the findings. Summaries of the key findings were provided in all the paper's discussion. Each study provided at least some discourse regarding the limitations of the study. All the studies gave some interpretation of the findings and consideration to the generalisability of the findings. Only three studies indicated the funding source for the research (Johnson *et al.*, 1995; O'Rourke *et al.*, 1998; Sagen *et al.*, 2009).

1.10.8 Implications for clinical practice

National stroke guidelines (Royal College of Physicians, 2008; The National Clinical Guidelines for Stroke, Royal College of Physicians, 2012; NICE, 2013) promote the crucial requirement of mood screening. They do not, however, stipulate which screening tool should be used to achieve this. This systematic review has outlined the dearth of screening tools validated for detecting anxiety, and the difficulties in selecting screening measures for depression due to methodological variation across studies, such as different sample sizes, criterion standards, and sample characteristics. Moreover, some of the screening tools were initially developed to screen for distress among non-stroke populations. Accordingly, different cut-off scores were found, likely reflecting the diversity of mood symptoms following stroke. Services must select tools and cut-off values that have been validated with the clinical population concerned. For screening anxiety among aphasic survivors, there is currently an absence of tools where the validity has been established.

The utility of screening measures is also of clinical importance. When screening survivors on busy wards or within the context of short out-patient appointments, brief and simple validated tools are required (Lincoln *et al.*, 2012). Whilst highly brief measures such as the VAMS 'sad item' may be quick to use, it lacks detail regarding

the nature of the low mood and may be inappropriate for severely aphasic survivors. In contrast, lengthier tools, such as the HADS can screen for anxiety and depression and provide increased information but take longer to administer (Vodermaier *et al.*, 2009). Again, the self-report format is not feasible for those with aphasia. Among the observer rated measures, there was little difference in terms of time to administer, however, the ADRS requires training which may prove a barrier to implementation in the current climate of funding cutbacks.

The generalisation of many of the findings to those survivors with aphasia is limited as five of the studies included in the review excluded survivors with moderate to severe communication difficulties. Aphasic stroke survivors are considered to have a greater risk of developing clinical levels of distress (Barker-Collo, 2007). Observational methods of screening mood have been developed to address this issue. In the current review the ADRS, SADQ, SADQ-H10, SoDS observational measures of depression, and the BOA observational screen for anxiety, were found to meet recommended levels of accuracy. However, the BOA was validated in a non-aphasic stroke sample thus limiting generalisability of findings.

1.10.9 Limitations of the systematic review

It was beyond the remit of this systematic review to compare and discuss the positive and negative predictive values of each tool. As the prevalence rates of anxiety or depression increase, the PPV value will also increase (Baldessarini *et al.*, 1983). Thus, services should calculate positive and negative predictive values according to the rates of anxiety and depression in each specific service.

A limitation of this study is that the quality is dependent on the papers identified. There is the possibility of selection bias in the studies where only stroke survivors with an available carer were included (Lightbody *et al.*, 2007; Linley-Adams *et al.*, 2014). Moreover, in all studies only consenting survivors were included which may have influenced the prevalence of anxiety and depression in the sample thus impacting on the PPV and NPV. Studies were conducted in a range of countries and it is conceivable that the construct of anxiety and depression might differ across various cultures, thus influencing prevalence and screening properties.

None of the screening tools included in this review sought to incorporate the views of stroke survivors' and this limits understanding of content validity. Service users' views should be included in all levels of research in order to influence patient centred health care (Darzi, 2008).

1.10.10 Summary

Taken together these studies provide evidence that there are a number of valid depression screening tools for aphasic stroke survivors but there is a dearth of instruments to screen for the presence of anxiety in stroke survivors that have been subject to validity and reliability checks. Those that have are limited by the small sample sizes, confounding variables that have the potential to bias results, and the exclusion of those with communication problems. The most relevant study by Linley-Adams *et al.* (2014) involved a preliminary validation of the Behavioural Outcomes of Anxiety scale (BOA; Kneebone *et al.*, 2012). The BOA was developed to identify anxiety in stroke survivors with aphasia and has been demonstrated to have acceptable psychometric properties in a sample of non-aphasic stroke survivors, although further study is needed to establish its validity with survivors with aphasia.

1.10.11 Rationale for this thesis and hypotheses

The aim of this project is to validate the 10-item BOA questionnaire, an informant-completed measure, developed for use with aphasic patients (Kneebone *et al.*, 2012). The BOA underwent an initial validation with communicative stroke survivors (Lindley Adams *et al.*, 2014), but as yet it has not been subject to validation with aphasic stroke survivors.

The Generalised Anxiety Disorder- 7 measure (GAD-7; Spitzer *et al.*, 2006) is a simple screening tool for assessing generalised anxiety. The GAD-7 has been shown to have good reliability, as well as criterion, construct, factorial, and procedural validity in non-stroke populations. Increasing scores on the scale are strongly associated with multiple domains of functional impairment. It has yet to be validated in stroke population.

In order to address the fact that the BOA requires validation with stroke survivors with aphasia, the current research will evaluate the construct validity of the BOA and an observational version of the GAD-7 against an observational version of the anxiety measure of the HADS and an aphasia adapted anxiety test, the Tension Rating Circles (TRCs), in stroke survivors with aphasia. The TRCs was adapted from the Depression Intensity Scale Circles (Turner-Stokes, Kalmus *et al.*, 2005) by Kneebone *et al.* (2013) and is suitable for use with many people with aphasia as it requires individuals to point to the circle that represents the degree of tension they experience. Muscle tension is a common occurrence in people with anxiety (APA, 1994; Hazlett *et al.*, 1994) and is thus a correlate of anxiety. Therefore the TRCs will provide a measure of anxiety among those with communication problems.

A qualitative aspect of the study will be undertaken to determine carer's experience of using the BOA and the face validity. Relaxation training will be used to ascertain construct validity of the BOA. Prior studies have demonstrated the effectiveness of relaxation training in reducing anxiety among non-aphasic stroke survivors (Carin-Levy *et al.*, 2009; Mead, 2007). It seems reasonable to assume that aphasic stroke survivors would also find relaxation training beneficial. Thus, the BOA scores should reduce following relaxation training.

1.10.11.1 Aims

In summary, this study aims to promote the timely detection of anxiety in aphasic stroke survivors to allow them to receive appropriate support and treatment for anxiety. It aims to:

- Evaluate the construct validity of the carer completed BOA against an observational version of the anxiety measure of the HADS and an aphasia adapted anxiety test, the Tension Rating Circles (TRCs), and to assess test-retest reliability of the BOA.
- Explore carer's experience of using the BOA and the face validity.
- Assess construct validity of the BOA through re-administration following relaxation training.

• A secondary aim of this study was to evaluate the performance of an observational version of the GAD-7 against the HADS-A and TRCs.

1.10.11.2 Hypotheses

Based on the aims of the study and the literature to date, the following hypotheses will be tested:

1. There will be a strong correlation between the carer completed BOA and the carer completed HADS-A.

2. There will be a strong correlation between the carer completed GAD-7 and the carer completed HADS-A.

3. There will be a strong correlation between the carer completed HADS-A and survivor completed TRCs.

4. Carer completed BOA will correlate highly with the survivor completed TRCs.

5. There will be a high correlation between BOA scores at time one and two (good test-retest reliability)

6. ROC analysis on the carer completed BOA, GAD-7 and survivor completed TRCs against the carer completed HADS-A will reveal a large area under the curve (>0.75) and specificity and selectivity cut-offs will exceed the minimum recommended by Bennett and Lincoln (2006).

7. Self-administered relaxation training will result in significant reductions in the carer completed BOA, HADS-A, GAD-7 and survivor completed TRCs compared to the control group as revealed by repeated measures MANOVA and follow-up analyses.

8. Due to the exploratory nature of the carer's qualitative feedback on their experiences of using the BOA, no firm hypotheses can be made, although it is anticipated that the themes will reveal generally positive responses.

Chapter Two

Methodology

2.1 Design

A correlational design was implemented to assess the test-retest reliability, construct validity, sensitivity and specificity of the carer BOA and GAD-7 against the HADS-A scores and an aphasia adapted anxiety test, the TRCs. For a subset of the sample a two-group quasi-experimental design (intervention and control groups) employing a relaxation intervention that reduced anxiety was used to further establish the construct validity of the BOA. The qualitative feedback from carers on their experience of completing the BOA was analysed by inductive thematic analysis (Patton, 1990).

2.2 Participants

2.2.1 Power analysis

The sample size was based on that used in a similar validation study of an aphasic depression screening tool (77 stroke survivors; Sutcliff & Lincoln, 1998) and the validation of other stroke-specific questionnaires (between 40 and 93 participants: Howells *et al.*, 2012; Linley-Adams *et al.*, 2014; Simon *et al.*, 2003). The Pearson correlation used for validity and reliability gives a non-linear index of relationship strength, and confidence ranges depend on sample size and the size of the coefficient. The ranges are also asymmetrical about the correlation's value; 100 participants would give a 95% confidence interval from 0.58 to 0.78 for a typical moderate correlation of 0.70, and with 78 participants a correlation as low as 0.36 at a power of 0.95 and alpha set at 0.05, one tailed, could be detected. ROC analysis would require a sample of 22 to distinguish a typical area under the curve of 0.8 from an area of 0.5 (no prediction) at power = 0.80 and alpha set at 0.05.

A sub-group of 50 stroke survivors and carer dyads formed the test-retest group. Half were randomly allocated to relaxation training and the remaining formed the control group (no intervention). G Power was used to calculate that a total sample size of 20 is required to perform a between factors repeated measures MANOVA with a medium effect size (f = .25), alpha error probability of 0.05 and power of 0.95.

The final overall sample was made up of 111 stroke survivors and their carers.

2.2.2 Inclusion and exclusion criteria

2.2.2.1 Inclusion criteria

Participants were recruited if they met the following inclusion criteria:

1. Male and female stroke survivors where stroke occurred more than two months ago but less than 20 years ago.
2. Stroke survivor has communication difficulties (aphasia) as measured using the FAST.
3. Stroke survivor has a carer who spends at least three hours a week with them.
4. Stroke survivor is able to point to the circle that corresponds to their level of tension on the TRCs and complete tick boxes on the demographic information sheet (with assistance if necessary).

2.2.2.2 Exclusion criteria

Participants were excluded under the following circumstances:

1. Survivor or carer under 18 years of age.
2. Survivor does not have a carer who spends three hours or more per week with them.
3. Stroke in the past two months (whose symptoms do not classify as chronic, Penta *et al.*, 2001) or more than 20 years ago.
4. Stroke survivor is unable to point to respond on the TRCs or complete tick boxes on the demographic information sheet with assistance.
5. Stroke survivor does not have mild to moderate degree of aphasia.

2.3 Procedure

The stages of the study are set out in Figure 2.1 and described in detail below:

2.3.1 Participant recruitment

Stroke survivors with communication difficulties and carers were recruited from third sector voluntary stroke clubs in south Wales. The voluntary stroke clubs offer peer-support and communication support for stroke survivors and their carers. Many are independent and are affiliated to a larger body (e.g. the Stroke Association) for legal, marketing and training purposes. The Stroke Association website contains the following descriptions:

"Stroke Clubs are local groups for those affected by stroke, including stroke survivors and carers. They aim to provide a regular meeting place for people to come together and share their experiences as well as opportunities to take part in a programme of activities. Communication Groups are groups that are run by trained volunteers that help teach communication skills to those people who have a stroke and who suffer from communication problems. The group is often facilitated by a paid member of staff from the Stroke Association. Carers either attend the group or are known to facilitators through their work with the person who has had a stroke" (Stroke Association, 2014).

The sampling was opportunistic, with volunteers meeting the inclusion/exclusion criteria being proposed by the coordinator or being asked to volunteer at a group session.

2.3.2 Consent

Potential participants were informed of the study via the researcher visiting stroke group meetings or via group facilitators through communication of the participant information sheet (see Appendix 2.1). Potential participants indicated interest in the study by contacting the researcher directly, by return of the reply slip (see Appendix 2.2) or by informing group facilitators. Arrangements were made with participants

who met inclusion criteria (see section 2.7.2 below) to complete the questionnaires either within group sessions or at participant's homes.

Participants were asked to complete a consent form (see Appendix 2.3 and 2.4) before taking part in the project. In signing the consent form, participants were also asked to confirm they had read the participant information sheet.

The stroke survivors all had a degree of communication difficulty and some required support to facilitate their understanding and communication of consent decisions. In such cases, the researcher provided additional information verbally to help support the participant's ability to consent, or otherwise. Participants were informed that their decision to participate may be withdrawn at any time until the data were anonymised.

2.3.3 Data collection and storage

Data collection took place between February 2014 and March 2015. Stroke survivors and carers completed the measures in a private room in the stroke group venues or at home.

Prior to administering the questionnaires, the researcher informed participants about confidentiality and the boundaries of this, as detailed in the study information sheets (see Appendix 2.1).

Survivors completed the consent form, demographic questionnaire (see Appendix 2.5), TRCs (see Appendix 2.7) and the Frenchay Aphasia Severity Test (FAST) (see Appendix 2.8). Supported communication was used to aid survivors in giving their responses. Carers completed the consent form, demographic questionnaire (see Appendix 2.6), BOA (see Appendix 2.9), and adapted versions of the HADS-A (see Appendix 2.10) and GAD-7 (see Appendix 2.11). Carers also completed a short feedback questionnaire on their experience of using the BOA measure (see Appendix 2.12).

The researcher was present throughout the process and answered all questions raised by the participants. Data collection typically took around 45 minutes.

A sub-group of 50 carers chosen at random (using a random number table during recruitment) repeated the same measures fourteen days later to assess test-retest

reliability. Within this sub-group, stroke survivors were randomly allocated to a relaxation training or control group. The participants in the relaxation training group were given a relaxation CD that consisted of progressive muscular relaxation exercises (White, 2006) (see Appendix 2.13) and an instruction schedule (see Appendix 2.14) to follow for the subsequent two weeks. Weekly telephone contact was made to those in the relaxation training group to prompt completion of the relaxation exercises. The control group were only required to repeat the BOA, HADS-A and GAD-7 measures at the end of the fourteen days. A pre-paid envelope was provided to the sub-group of participants to return their questionnaires by post. Participants were provided with a debrief letter once the study was completed (see Appendix 2.15).

All data, including completed questionnaires, were stored using anonymised participant identifiers. Information connecting these identifiers to participant names was documented and logged in a password-protected file accessible only to the researcher. Identifying data were destroyed upon the conclusion of participant involvement in the study.

2.3.4 Ethical considerations

2.3.4.1 Ethical approval

The study was approved by the Psychology Research Ethics Committee, Cardiff University (see Appendix 2.16). Approval was also sought from the regional director of the Stroke Association and all group facilitators. An application was not made to an NHS ethics committee as access to stroke survivors and carers was achieved through the third sector. Patient records and NHS staff time were not required. The study therefore did not fulfil NHS National Research Ethics Service (NRES) criteria for determining that a study needs ethical approval from a NRES research ethics committee (http://www.hradecisiontools.org.uk/ethics/).

2.3.4.2 Inducement

Potential participants were first notified of the study via the researcher or group facilitator presenting the study aims during group sessions. Only participants who had shown interest in the study were then contacted by the researcher. It was also emphasised that participation was entirely voluntary. At debrief all those in the control group were offered a copy of the relaxation training CD and instructions, in the interest of fairness. These processes aimed to safeguard against undue pressure to participate.

2.3.4.3 Confidentiality

Questionnaires were coded and participants were requested not to write any personal identifiable information. Consent forms were kept separately from questionnaires in a locked cabinet. Participants were informed of these confidentiality arrangements verbally, and via the consent form (see Appendix 2.3 and 2.4) and debriefing letter (see Appendix 2.15).

2.3.4.4 Demands on participants

The FAST is designed for use with people with communication difficulties and is thus deemed to be a realistic level of requirement. The TRCs is a very brief tool that requires minimal effort on the part of the stroke survivor. Each measure and questionnaire was reviewed by the Regional Manager for Stroke Association Cymru and deemed to be an acceptable level of demand to place on stroke survivors and their carers.

There was a small risk that the questionnaires would increase participant's awareness of their anxiety and possibly their lack of support or treatment. As a precaution, participants were notified that they could omit items or stop the questionnaires at any time and that their participation was entirely voluntary (see Participant Information sheet, Appendix 2.1). Participants were also advised to contact their stroke club facilitator and/or their GP if they became distressed or required further support.

2.4 Measures

The questionnaires consisted of a demographic questionnaire (see Appendix 2.5 and 2.6) and a battery of questionnaires (see Appendix 2.9, 2.10, 2.11).

2.4.1 Demographic survey

Stroke survivors and carers completed a demographic questionnaire about themselves (e.g. gender, age, occupation) and concerning the impact of the stroke on the survivors from the survivor's and carer's perspective (see Appendix 2.5 and 2.6). Items provided a sample overview and an indication of impact of the stroke. Items were identified through consultation with research supervisor, who has expertise in stroke. Demographic details enabled the researcher to situate the sample in order to explore the generalisability of the research and to provide background information.

2.4.2 Behavioural Outcomes of Anxiety

The Behavioural Outcomes of Anxiety scale (BOA; Kneebone *et al.*, 2012) (see Appendix 2.9) is an observational tool that includes a set of anxiety descriptors which are rated by someone who knows the patient well, usually a carer. The descriptors were developed based on relevant diagnostic criteria and clinical experience. An observational instrument was developed rather than a simplified self-report measure since even adapted questionnaires may not permit reliable or meaningful responses by those with severe communication or cognitive impairment (Turner-Stokes, Kalmus *et al.*, 2005).

While the BOA has been published as part of a community protocol to screen for mood disorders after stroke, as yet it has been only partially validated with a non-aphasic sample (Linley-Adams *et al.*, 2014). The original authors provided a rationale for the inclusion of each question, but did not undertake any validation or evaluation of the instrument. It is a 10 item measure scored on a four point categorical scale of 'often', 'sometimes', 'rarely', 'never'. Total scores range from 0-30, with higher score indicating greater observed anxiety.

2.4.3 Hospital Anxiety and Depression Scale-Anxiety subscale

The Hospital Anxiety and Depression Scale-Anxiety subscale (HADS-A; Zigmond & Snaith, 1983) (see Appendix 2.10) was used as the reference instrument because it is the only anxiety scale validated with stroke survivors (Kneebone *et al.*, 2012). It is a clinically reliable, sensitive and valid screening tool that is predictive of psychosocial outcome (Herrmann, 1997). The HADS-A is scored on a four-point scale with categories dependant on item content.

Sensitivity of the HADS among stroke survivors has been found to range from 0.80 to 0.92 and specificity range from 0.46 to 0.79, in three separate studies (Aben *et al.*, 2002; Johnson *et al.*, 1995; O'Rourke *et al.*, 1998). The construct validity and utility of the HADS in stroke survivors has been demonstrated in addition to its capacity to differentiate anxiety and depression and its ease of use in populations with serious physical illness (Johnston *et al.*, 2000). The HADS-A has been recommended for anxiety screening in stroke survivors with a cut-off of >6 (Bennett & Lincoln, 2006) or >4 (Sagen *et al.*, 2009). It is not suggested for patients with communications difficulties (Bennett & Lincoln, 2006). Specificity concerns were highlighted by Bennett & Lincoln (2006) and Johnson *et al.* (1995). However, Sagen *et al.* (2009) found that a HADS-A cut-off of >4 provides an acceptable level of sensitivity and specificity values in excess of the values (0.80 and 0.60, respectively) recommended by Bennett and Lincoln (2006). Despite these exceptionally low thresholds, Linley-Adams *et al.* (2014) found that the traditional cut-off of 7/8 gave the best properties and produced prevalence rates consistent with other similar studies.

2.4.4 Generalised Anxiety Disorder-7

The Generalised Anxiety Disorder-7 measure (GAD-7; Spitzer *et al.*, 2006) (see Appendix 2.11) is a simple screening tool for assessing generalised anxiety disorder. The GAD-7 has been shown to have good reliability, as well as criterion, construct, factorial, and procedural validity in non-stroke populations. Increasing scores on the scale are strongly associated with multiple domains of functional impairment. It has yet to be validated in a stroke population.

The GAD-7 has a sensitivity of 0.89 and a specificity of 0.82 for generalised anxiety disorder using a cut-off score of 10 (Spitzer *et al.*, 2006). It is moderately good at screening three other common anxiety disorders – panic disorder (sensitivity 0.74, specificity 0.81), social anxiety disorder (sensitivity 0.72, specificity 0.80), and post-traumatic stress disorder (sensitivity 0.66, specificity 0.81; Spitzer *et al.*, 2006).

2.4.5 Tension Rating Circles

The Tension Rating Circles (TRCs) (see Appendix 2.7) was adapted from the Depression Intensity Scale Circles (Turner-Stokes, Kalmus *et al.,* 2005) by Kneebone *et al.* (2012) and is suitable for use with many people with aphasia as it simply requires individuals to point to the circle that represents the degree of tension they experience. Muscle tension is a common occurrence in people with anxiety (APA, 1994; Hazlett *et al.*, 1994) therefore the TRCs offers a measure of anxiety among those with communication problems.

2.4.6 Frenchay Aphasia Severity Test

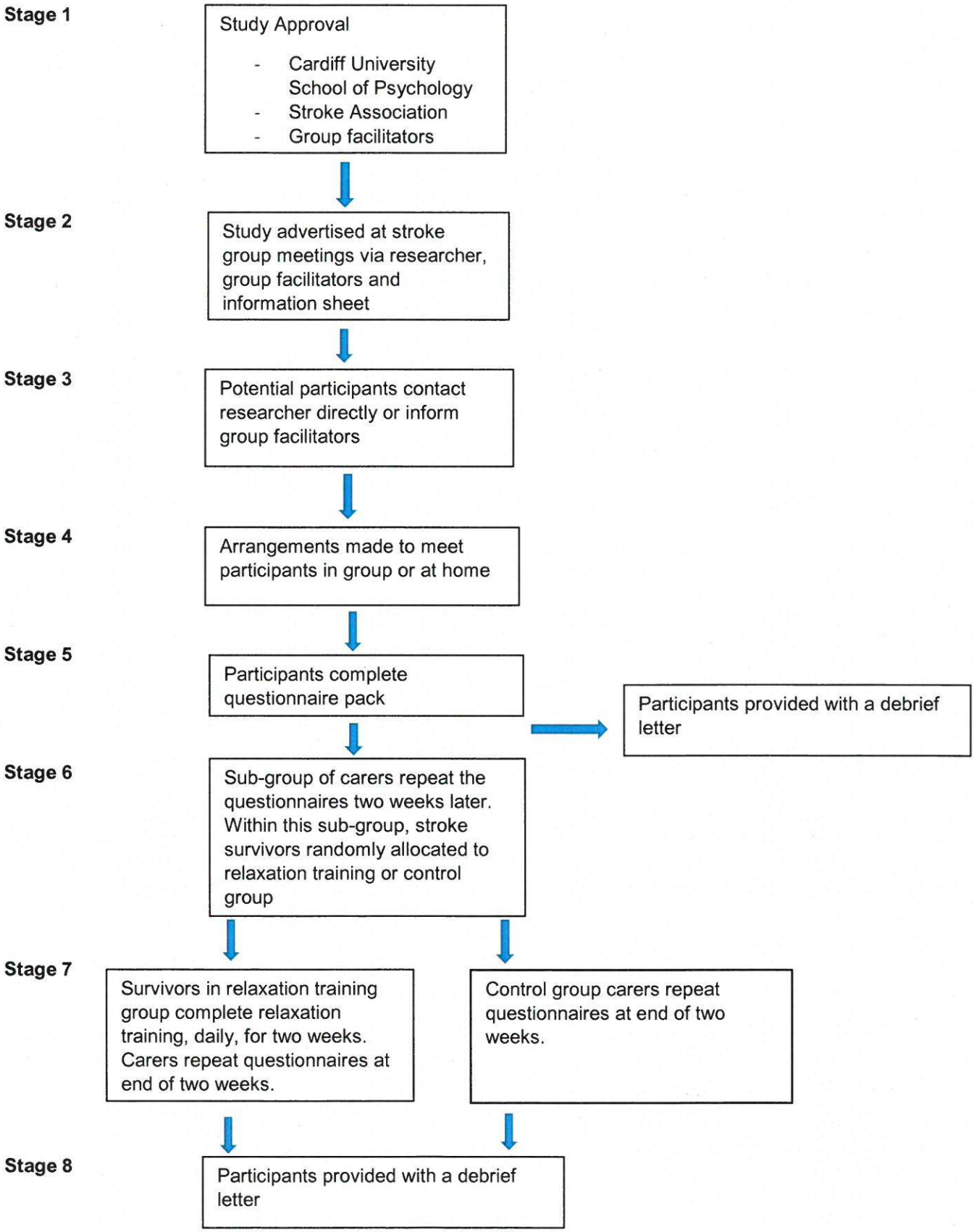
The Frenchay Aphasia Severity Test (FAST; Enderby *et al.*, 1987) (see Appendix 2.8) provided a measure of the degree of aphasia experienced by each stroke survivor. The brief test examines comprehension, verbal expression, reading, writing and automatic speech. It has been found to have moderate sensitivity (0.87) and specificity (0.80; Al Khawaja *et al.*, 1996). The FAST has also been found to have high intra-rater reliability (Kappa = 1, Philip *et al.*, 2002) and high inter-rater reliability (0.95; Sweeney *et al.*, 1993). The FAST was developed for use by non-specialists, to assist in identifying patients who have difficulties understanding, using spoken language, reading or writing.

2.4.7 Experience of using the BOA

This questionnaire sought to establish the acceptability and ease of completion of the BOA. The four items were scored on a five point Likert scale (1- strongly disagree to 5- strongly agree). There was space for carers to add their comments

and reasons if they responded that they had found the BOA difficult to complete (see Appendix 2.12).

Figure 2.1 Research procedure



2.5 Data analysis

2.5.1 Correlational analysis

Data analysis was completed using SPSS version 20 (IBM Corporation, 2011). All continuously distributed data were screened to confirm they met the assumptions for parametric testing. Specifically, they were inspected to identify outliers and spurious data points, tested for deviation from a normal distribution and checked to ensure equality of variance in the relaxation and control groups (see section 3.2). Correlational analyses using Pearson's Product-moment correlation were conducted to test hypothesised associations between scores on the BOA, HADS-A and GAD-7, at time one and time two, in addition to exploring relationships with demographic variables.

Bonferroni Correction was employed as the probability of finding significant outcomes, and therefore making a type I error, is artificially increased when repeated tests are conducted on a single sample (Morgan, 2007).

2.5.2 Multivariate analyses

A repeated measures multivariate analysis of variance (MANOVA) was used to test whether relaxation training resulted in significant reductions in the BOA, HADS-A and GAD-7, compared to the control group. The sensitivity, specificity and positive and negative predictive values for the BOA, GAD-7 and TRCs against the HADS-A was assessed using ROC analysis by MedCalc version 12.7.4.0 (Medcalc Software bvba, Ostend, Belgium).

2.5.3 Qualitative analysis

Inductive thematic analysis (Patton, 1990) was used to analyse the qualitative information generated by the open question asking carers to describe their experience of using the BOA.

Chapter Three

Results

3.1 Chapter outline

In this chapter the results of the present study will be outlined. The chapter describes preliminary data analysis carried out to confirm that the quality of the data were sufficiently satisfactory to conduct the statistical tests used; the descriptive statistics for the sample and measures used; the statistical analysis and qualitative analysis. The results of the statistical analysis will be reported in accordance with the stated hypotheses. Data analysis was carried out via the Statistical Package for the Social Sciences (SPSS, Version 20; IBM Corporation, Armonk, NY, USA) with the exception of the ROC analyses which were performed with MedCalc version 12.7.4.0 (MedCalc Software bvba, Ostend, Belgium).

3.2 Preliminary data analysis

3.2.1 Error analysis

Minimum and maximum values for each categorical and continuous variable were screened in order to test whether data fell within the possible range on an item. All questionnaire total scores were checked to ensure the sums had been totalled correctly. Two data points were identified as incorrect using this method and were consequently corrected after referring back to the raw data[1].

[1] One item on the survivor ability to remember was incorrectly entered as '3' instead of '2' and one item on survivor ability to walk was incorrectly entered as '3' instead of '2'.

3.2.2 Missing data

Missing data for continuous variables were relatively low (12 item scores) and was randomly distributed. On visual inspection, missing data for nominal and ordinal variables were also found to be evenly spread through the data set with the exception of two stroke survivors and their carers who did not complete the demographic information forms. Missing data for test scores were replaced using the mean of all responses for that participant. There were only four missing test scores.

3.2.3 Assumptions for parametric statistics

For parametric correlation to be used a number of assumptions should be met (Field, 2013). These include, normal sampling distribution, a linear relationship between variables, homoscedasticity and an absence of outliers. These are considered in turn below.

3.2.3.1 Normality

Correlational analyses were conducted to examine associations between the different variables. Parametric correlations require normally distributed scores on variables (Field, 2013). Normality was assessed via the Kolmogorov-Smirnov test for each variable (see Appendix 3.1). Only survivor age and post BOA scores were found to be non-significant and therefore normally distributed ($D(110) = 0.073$, $p = 0.20$; $D(29) = 0.146$, $p = 0.116$, respectively). Scores from all other variables (years since stroke, carer age, pre BOA score, pre HADS-A score, pre GAD-7 score, FAST score, post HADS-A score, post GAD-7 score) were found to deviate from the normal distribution. These results in conjunction with the histograms, Q-Q plots and the values of skewness and kurtosis suggest the scores are significantly different to a normal distribution.

3.2.3.2 Linearity

Parametric correlations require a linear relationship between variables (Field, 2013). Scatter plots of BOA scores against each variable (see Appendix 3.2) were visually inspected to check for linearity. Scatter plots showed a linear distribution for all the variables.

3.2.3.3 Homoscedasticity

The assumption of homoscedasticity (or equal scatter) necessitates similar variance at each level of the predictor variable (Field, 2013). Scatter plots of BOA scores against each variable (Appendix 3.2) were visually inspected and appeared homoscedastic.

3.2.3.4 Outliers

Parametric tests assume that there are no extreme scores or outliers, and Pearson's correlation is especially susceptible to outliers. Outlier analysis was carried out to identify extreme data points that might exert disproportionate influence in consequent statistical analyses. Inspection of the frequency distributions and the corresponding box plots identified one outlier on the FAST variable. This outlier was changed to the lowest quartile of the distribution of FAST scores as recommended by Thomas and Ward (2006), prior to the normality test outlined above.

3.2.3.5 Conclusion

Field (2013) suggests that data be normally distributed in order to determine the significance of parametric tests, including Pearson's correlation coefficient (*r*). When the data has violated parametric assumptions, Kendall's tau should be used (Field, 2013). There is evidence that Kendall's tau statistic is a more accurate estimation of the correlation in the population than Spearman's rho, so is preferred (Howell, 1997). However, Pearson's correlation coefficient (*r*) is a robust measure and probability statements for *r* have been found to be accurate even when there is extreme deviation from normality as long as there are no outliers (Havlicek & Peterson, 1977). Thus, Pearson's correlations will be reported. As a check these results are also compared with non–parametric analysis (i.e. Kendall's tau) in Appendix 3.3 and show very little difference.

3.3. Descriptives

3.3.1 Response rate

Out of 123 questionnaires completed by stroke survivors, ten were excluded as the carer completed questionnaires were either not completed or were not returned. A further two sets of data were excluded as the stroke occurred within the previous two months or more than 20 years ago (see exclusion criteria, section 2.2.2.2). The final sample therefore consisted of 111 stroke survivors and carers. A sub-group of 50 survivors and carer pairs were chosen at random to repeat the measures 14 days later to assess test-retest reliability. Twenty five stroke survivors in this sub-group were randomly allocated to the relaxation training group and 25 were randomly allocated to the control group. Out of this sub-group, 21 sets of post data were excluded as the questionnaires were either not completed or were not returned. Out of the 29 questionnaires that were returned there were 12 survivor-carer dyads in the relaxation training group and 17 in the control group.

3.3.2 Demographics of stroke survivor

Demographic data for the stroke survivors are presented in Tables 3.1 and 3.2. The age of survivors ranged from 30 to 93, with a mean age of 69.7, and standard deviation (*SD*) of 10.7 (see Table 3.1 below). This indicates that at least one survivor was as young as 30 years of age and that the majority of stroke survivors were aged between 58 and 80 years old. The mean number of years since stroke was 6.2 years as rated by survivors (*SD* = 5.21), ranging from two months to 20 years. Seven participants were under six months post stroke, ranging between two to six months, and were coded as 0.5 years since stroke.

Table 3.1 Stroke survivor age and years since stroke[a]

	N[a]	M	*SD*	Range
Age	110	69.7	10.7	30- 93
Years since stroke	107	6.2	5.21	0.5- 20

[a] *N*= number of stroke survivors

There was a disproportionate number of male survivors (69.1%) compared to females (30.9%). The majority of survivors were retired (91.0%) and living either with a carer (52.3%) or living with someone else not classified as a carer (32.4%). The vast majority of stroke survivors were white British (98.9%) (see Table 3.2 below).

Less than half of the stroke survivors reported on the type of stroke they had experienced. Haemorrhagic strokes were reported by 16.2% and ischemic strokes were reported by 29.7%. The majority of survivors had experienced one stroke (58.6%) and reported experiencing no anxiety or depression in the two years prior to the stroke (82.9%) (see Table 3.2 below). Although the demographic questionnaire also contained a question regarding current/prior job title, the data obtained were not codable, and are therefore not reported.

Table 3.2 Stroke survivor demographics [a]

		N[a]	%[a]
Gender	Male	76	69.1
	Female	34	30.9
Ethnicity	White British	110	98.9
	Other (Chinese)	1	1.1
Type of stroke	Haemorrhage	18	16.2
	Ischemic	33	29.7
	Missing/Don't know	60	54.1
Number of strokes	One only	65	58.6
	More than 1	42	37.8
	Missing/Don't know	4	3.6
Pre-stroke anxiety/depression	Yes	17	15.3
	No	92	82.9
	Missing	2	1.8
Living circumstances	Living with carer	58	52.3
	Living with non-carer	36	32.4
	Living alone	15	13.5
	Missing	2	1.8
Occupational status	Retired	101	91.0
	In employment	8	7.2
	Missing	2	1.8

[a] *N*= number of stroke survivors; %=percentage of total sample.

3.3.3 Demographics of carer

Demographic data for carers is presented in Table 3.3 and 3.4. The age of carers ranged from 20 to 86, with a mean age of 64.7 and standard deviation (*SD)* of 12.2 (see Table 3.3 below). This indicates that at least one carer was as young as 20 years of age and that the majority of carers were aged between 52 and 77 years old. The mean number of years since stroke as rated by carers was 6.1 years (*SD* = 5.2), range from 2 months to 20 years. A good level of agreement between survivor and carer's report of years since stroke was therefore found.

Table 3.3 Carer age and years since stroke

	N[a]	Mean	*SD*	Range
Age	108	64.7	12.19	20-86
Years since stroke	107	6.1	5.25	0.5- 20

[a] *N*= number of carers

The majority of carers were female (72.1%) relative to male (24.3%) and were retired (69.4%). Most of the carers were married to the survivor (72.1%) and 11.7% were offspring. Four (3.6%) carers identified themselves as professional carers. The majority of carers lived with the survivor (75.7%) and therefore most reported spending every day with the survivor (79.3%). The vast majority of carers were white British (98.9%) (see Table 3.4 below).

Table 3.4 Carer demographics[a]

		N[a]	%[a]
Gender	Male	27	24.3
	Female	80	72.1
	Missing	4	3.6
Ethnicity	White British	110	98.9
	Other (Chinese)	1	1.1
Relationship to survivor	Spouse	80	72.1
	Offspring	13	11.7
	Professional carer	4	3.6
	Other	10	9.0
	Missing	4	3.6
Living circumstances	Living with survivor	84	75.7
	Not living with survivor	23	20.7
	Missing	4	3.6
Time spent with survivor	Everyday	88	79.3
	Most days	2	1.8
	Few days	9	8.1
	Few hours	7	6.3
	Missing	5	4.5
Occupational status	Retired	77	69.4
	In employment	30	27.0
	Missing	4	3.6

[a]*N*= number of carers; %=percentage of total sample.

3.3.4 Impact of stroke

Nearly 80% of stroke survivors and 84.6% of carers reported the stroke had affected the survivor's ability to remember either 'a little' or 'a lot'. The majority of stroke survivors (64.9%) and carers (59.5%) reported that the stroke had impacted 'a lot' on the survivors' ability to do things. Most also felt that the stroke had affected their/ survivors' ability to walk 'a lot' (51.4% of survivors and 49.5% of carers). Ability to communicate was rated as being affected either 'a little' or 'a lot' by almost all survivors (97.3%) and carers (90.9%) (see Table 3.5).

Table 3.5 Impact of stroke[a]

		Survivor		Carer	
Variable	Rating	*N*[a]	%[a]	*N*[a]	%[a]
Ability to remember	Not at all	21	18.9	11	9.9
	A Little	41	36.9	45	40.5
	A Lot	47	42.3	49	44.1
	Missing	2	1.8	6	5.4
Ability to do things	Not at all	13	11.7	4	3.6
	A Little	24	21.6	36	32.4
	A Lot	72	64.9	66	59.5
	Missing	2	1.8	5	4.5
Ability to walk	Not at all	23	20.7	19	17.1
	A Little	29	26.1	32	28.8
	A Lot	57	51.4	55	49.5
	Missing	2	1.8	5	4.5
Ability to communicate	Not at all	1	0.9	5	4.5
	A Little	49	44.1	48	43.2
	A Lot	59	53.2	53	47.7
	Missing	2	1.8	5	4.5

[a]*N*= number of survivors/carers; % = percentage of total sample.

Survivors and carers were highly congruent in all estimates of the impact of stroke as measured by Kendall's tau-b. There was a high level of agreement between carer and stroke survivor on the impact of stroke on memory (.38), ability to do things (.46), ability to walk (.44) and ability to communicate (.41), which were all significant at $p < .000$ (see Table 3.6) as evaluated using Kendall's tau-b.

Table 3.6 Kendall's tau-b correlation of carer and survivor ratings of impact of stroke

Ability to remember		Carer			
		Not at all	A little	A lot	Association
Survivor	Not at all	9	1	1	.380
	A little	7	23	15	
	A lot	4	17	28	
Ability to do things		Carer			Association
		Not at all	A little	A lot	.458
Survivor	Not at all	2	2	0	
	A little	7	14	15	
	A lot	4	7	55	
Ability to walk		Carer			Association
		Not at all	A little	A lot	.440
Survivor	Not at all	12	2	5	
	A little	8	12	12	
	A lot	2	14	39	
Ability to communicate		Carer			Association
		Not at all	A little	A lot	.406
Survivor	Not at all	1	3	1	
	A little	0	31	17	
	A lot	0	14	39	

3.3.4.1 Aphasia

All but one of the survivors met the cut-off point for the presence of aphasia determined using the FAST. The presence of aphasia is indicated if the patient scores below the following cut-off points: age up to 60, 27/30 points; age 61+, 25/30 points (Enderby *et al.*, 1987).

The mean score on the FAST was 19.0 (*SD* = 5.9). Only one person scored above this cut-off at 28, suggesting the presence of milder communication difficulty.

3.3.4.2 Anxiety scores

The mean score overall on the BOA at time one was 15.1 (*SD* = 6.2) which is above the cut-off of 13/14 recommended by Linley-Adams *et al.* (2014), as was the mean BOA score in the relaxation sub-group (*M* = 17.2, *SD* = 4.4). The test scores on the BOA, HADS-A, GAD-7 and TRCs are outlined in Table 3.7.

Table 3.7 Test scores overall[a]

Test	*N*[a]	Mean	Standard Deviation	Median	Range
TRCs	111	2.0	1.4	2.0	0-5
Pre BOA	111	15.1	6.2	15.0	1-28
Post BOA	29	12.9	7.6	14.0	1-28
Pre GAD-7	111	5.4	5.4	4.0	0-19
Post GAD-7	29	5.5	6.1	3.0	0-19
Pre HADS-A	111	6.9	4.4	7.0	0-20
Post HADS-A	29	5.2	5.2	4.0	0-19

[a]*N*= number of questionnaires completed by carers, with the exception of TRCs completed by survivors.

3.3.4.3 Equivalence of relaxation and control groups

T- tests were conducted to check the relaxation and control groups were equivalent on demographic variables. The relaxation training group and control group did not differ significantly in terms of age of survivor or carer and years since stroke.

Pearson's chi-square was conducted on the categorical variables. There was a significant association between survivor's rating of ability to do things and post measures of anxiety ($\chi^2(4) = 7.19$, $p < .05$). Survivors in the relaxation group were statistically more impaired in ability to do things than those in the control group. No other categorical variables were found to be significantly associated with anxiety scores.

A between groups multivariate analysis of variance (MANOVA) was conducted to compare the relaxation group and control group across the different measures of pre intervention anxiety (see Table 3.8 below). A statistically significant MANOVA effect was obtained using Pillai's trace ($V = 0.32$, $F(4, 24) = 2.87$, $p < .05$). However, separate univariate ANOVA's on the anxiety scores revealed non-significant differences between the relaxation and control groups on pre BOA scores, ($F(1, 27) = 0.33$, $p = .570$), pre HADS-A scores, ($F(1, 27) = 3.14$, $p = .088$), pre GAD-7 scores ($F(1, 27) = 3.76$, $p = .063$), although a significant difference between pre TRCs scores was found ($F(1, 27) = 6.97$, $p = .014$).

Table 3.8 Sub-group test-retest scores

	N[a]		Mean		*SD*	
Test	Relaxation	Control	Relaxation	Control	Relaxation	Control
Pre BOA	12	17	17.2	15.9	4.4	7.3
Post BOA	12	17	8.6	16.0	6.7	6.7
Pre GAD-7	12	17	10.5	6.0	5.0	6.7
Post GAD-7	12	17	3.5	7.0	4.5	6.7
Pre HADS-A	12	17	10.7	7.3	3.8	5.9
Post HADS-A	12	17	3.0	6.7	3.7	6.2

[a]*N*= number of questionnaires completed by carers.

3.4 Statistical Analyses

3.4.1 Between-group repeated measures comparisons of means

A repeated measures MANOVA was used to compare pre and post scores on the BOA, HADS-A and GAD-7 in those survivors who completed relaxation training and those in the control group, thus testing H7.

Assumptions

Levene's test for homogeneity of variance verified equality of variances in the relaxation and control groups. Sphericity tests were not applicable as there were only two groups and at least three conditions are necessary for sphericity to be an issue (Field, 2013).

Results

H7: Self-administered relaxation training will result in significant reductions in the BOA, HADS-A and GAD-7, compared to the control group.

A repeated measures MANOVA found (using Pillai's trace), that there was a significantly greater multivariate reduction in anxiety levels following relaxation training than in the control condition, as evidenced by the Groups x Time interaction, (V = 0.662, F (3, 25) = 16.31, p < .001). This confirms hypothesis 7 and it therefore appears that relaxation training was effective in reducing stroke survivors' anxiety levels, as measured by the BOA, GAD-7 and HADS-A.

Follow-up univariate tests for the Group x Time interaction found significant differences between relaxation training and control group across all anxiety measures. Relaxation training resulted in significantly reduced anxiety scores compared to the control group as measured by the BOA (F (1, 27) = 22.159, p < .001); HADS-A (F (1, 27) = 64.615, p < .001) and GAD-7 (F (1, 27) = 26.316, p < .001) (Figures 3.1, 3.2 and 3.3 below).

Figure 3.1 Pre and post BOA scores for relaxation and control group

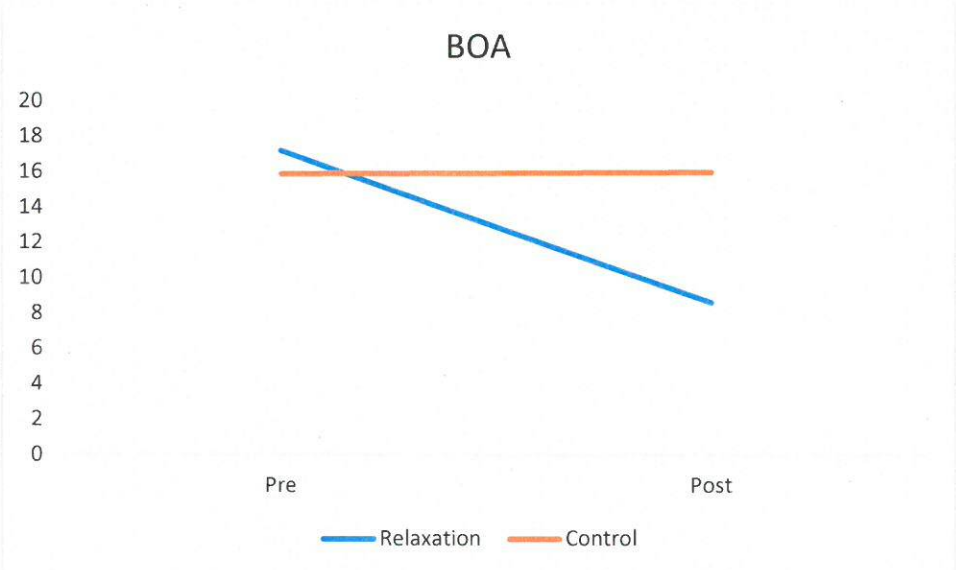


Figure 3.2 Pre and post HADS-A scores for relaxation and control group

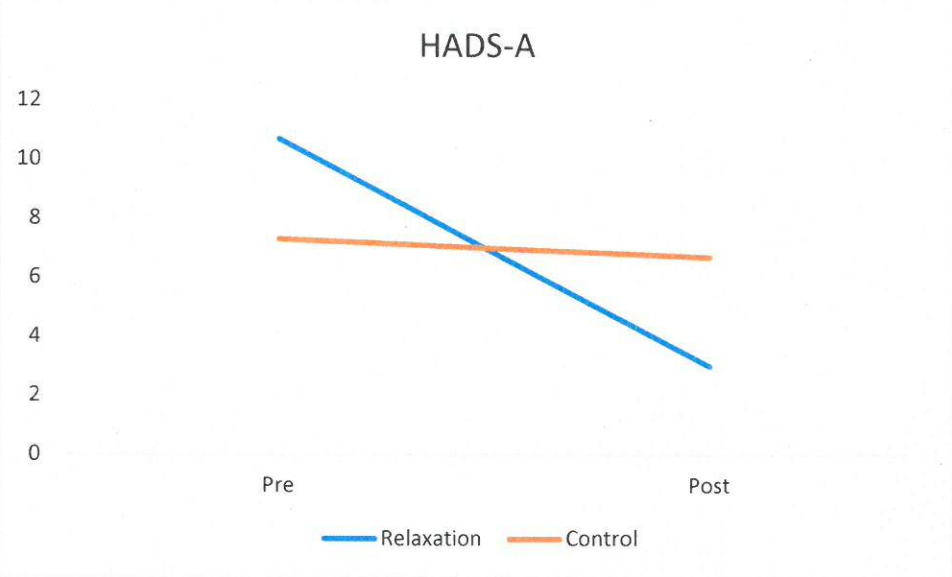
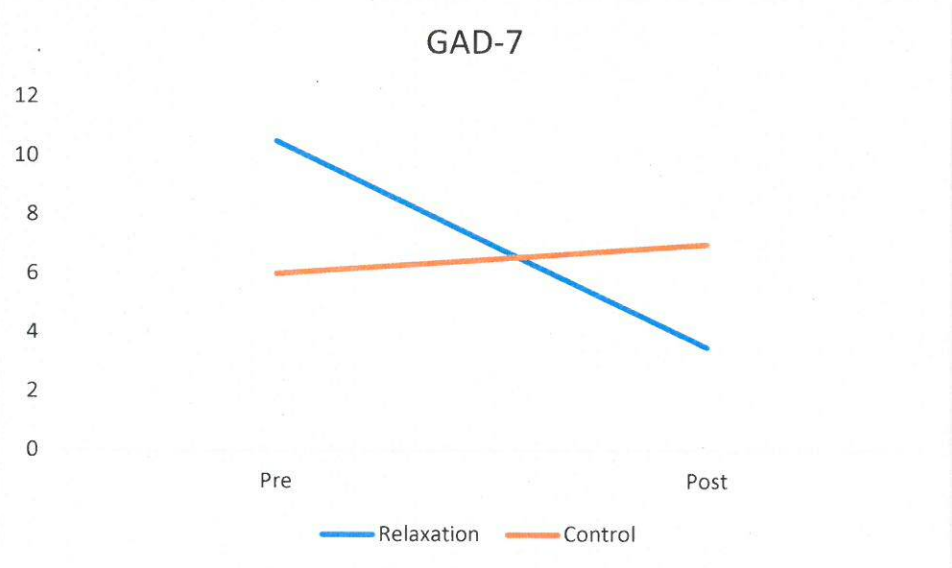


Figure 3.3 Pre and post GAD-7 scores for relaxation and control group



3.4.2 Correlational analyses

Correlational analyses using Pearson's Product-moment correlation were conducted to test hypothesised associations between scores on the BOA, HADS-A, GAD-7 and TRCs at time one and time two, in addition to exploring relationships with demographic variables (see H1 to H5, section 1.10.11.2). The results of the correlational analyses are shown in Table 3.9 below. All these correlations are given in terms of Pearson's correlation coefficient (*r*), for which significance was tested at the one-tailed level.

Table 3.9 Pearson correlation matrix of continuous variables

		1	2	3	4	5	6	7	8	9	10	11	12
1. Survivor Age		-											
2. Years since Stroke	*r*	.089											
	p	.183	-										
	N[a]	106											
3. Carer Age	*r*	.582**	.097										
	p	.000	.162	-									
	N	108	105										
4. Carer years since Stroke	*r*	.071	.915**	.052									
	p	.236	.000	.301	-								
	N	106	106	104									
5. Total Pre BOA Score	*r*	-.267**	-.070	-.200*	-.077								
	p	.002	.235	.019	.215	-							
	N	110	107	108	107								
6. Total Pre HADS-A Score	*r*	-.283**	-.091	-.147	-.098	.771**							
	p	.001	.176	.065	.158	.000	-						
	N	110	107	108	107	111							
7. Total Pre GAD-7 Score	*r*	-.216*	-.169*	-.102	-.138	.711**	.817**						
	p	.012	.041	.146	.077	.000	.000	-					
	N	110	107	108	107	111	111						
8. FAST Score	*r*	-.192*	-.149	-.079	-.199*	.204*	.198*	.154					
	p	.022	.062	.209	.020	.016	.019	.053	-				
	N	110	107	108	107	111	111	111					
9. Total Post BOA Score	*r*	-.047	-.123	-.155	-.091	.578**	.326*	.350*	-.007				
	p	.406	.270	.220	.323	.001	.042	.031	.486	-			
	N	28	27	27	28	29	29	29	29				
10. Total Post HADS-A Score	*r*	-.173	-.182	-.201	-.204	.651**	.660**	.584**	.153	.792**			
	p	.189	.182	.157	.149	.000	.000	.000	.213	.000	-		
	N	28	27	27	28	29	29	29	29	29			
11. Total Post GAD-7 Score	*r*	-.132	-.209	-.187	-.202	.714**	.669**	.673**	.201	.817**	.941**		
	p	.252	.147	.175	.151	.000	.000	.000	.148	.000	.000	-	
	N	28	27	27	28	29	29	29	29	29	29		
12. TRC Score	*r*	-.126	-.020	-.032	-.034	.314**	.312**	.300**	.076	-.058	.171	.140	-
	p	.095	.417	.371	.363	.000	.000	.001	.215	.382	.186	.234	
	N	110	107	108	107	111	111	111	111	29	29	29	

[a]*N*= number of survivors/carers; *p<0.05; **p<0.01 (one-tailed)

H1 *There will be a strong correlation between the carer completed BOA and the carer completed HADS-A.*

The scores on the BOA and HADS-A were positively correlated ($r = .77$, $p < .001$).

H2 *There will be a strong correlation between the carer completed GAD-7 and the carer completed HADS-A.*

The scores on the GAD-7 and HADS-A were positively correlated ($r = .82$, $p < .001$).

H3 *There will be a strong correlation between the carer completed HADS-A and survivor completed TRCs.*

The scores on the HADS-A and TRCs were positively correlated ($r = .31$, $p < .001$).

H4 *Carer completed BOA will correlate highly with the survivor completed TRCs.*

There was a positive correlation between the BOA and TRCs scores ($r = .31$, $p < .001$).

H5 *There will be a high correlation between BOA scores at time one and two (good test- re-test reliability).*

There was a positive correlation between the BOA scores at time one and two ($r = .91$, n = 17; $p < .001$).

These findings therefore confirm hypotheses H1, H2, H3, H4 and H5.

There was also a significant negative correlation between survivor age and all of the anxiety measures: BOA ($r = -.267$, $p < .002$); HADS-A ($r = -.283$, $p < .001$) and GAD-7 ($r = -.216$, $p < .012$).

3.4.2.1 Bonferroni correction

When repeated tests are carried out on a study sample, the probability of finding significant outcomes is artificially increased and the possibility of making a type I

error increases (Morgan, 2007). A type I error is when the null hypotheses is rejected when it is, in fact, true (Field, 2013). As a result it is now routine to utilise some method of adjusting the analysis to take account of this effect. There are a number of ways of achieving this. One is to change the significance threshold from < 0.05 to < 0.01, another is to study consistent patterns of similar findings rather than isolated findings. A third method is to apply a statistical correction technique called the Bonferroni correction (Morgan, 2007). The Bonferroni correction is highly conservative, dividing the level of significance by the number of correlations conducted (Field, 2013). The cost of applying Bonferroni correction is a loss in power and the increased risk of a making a type II error (not rejecting the null hypothesis when it is false, thus missing significant relationships; Field, 2013; Garamszegi, 2006), and consequently Bonferroni corrections are not conventionally applied to correlation matrices.

However, Bonferroni Correction was applied to each correlation involved in a hypothesis (alpha level of $0.05 \div 66$ correlational tests) and resulted in a significance level set at $p < 0.001$. All correlations remained significant at $p < 0.001$, thus confirming all hypotheses.

3.4.3 ROC analysis

Receiver Operating Characteristic (ROC) analysis was used to measure the predictive utility of the BOA, GAD-7 and TRCs to distinguish between survivors meeting HADS-A caseness and those who did not. The HADS-A cut-off of more than 8 proposed by Zigmond and Snaith (1983) and recommended in a paper by Bjelland *et al.* (2002) was chosen as it produced 46 (41.4%) positive cases and this is closest to the proportion typically found in surveys of stroke survivors (32-38%; Ayerbe, Ayis, Crichton *et al.*, 2013; 20-24%; Campbell Burton *et al.*, 2013), although it is considerably higher than in non-aphasic populations.

Different cut-off scores have been suggested for stroke, however no consensus has been reached: 4/5 (Sagen *et al.*, 2009), 5/6 (Aben *et al.*, 2002; Johnson *et al.*, 1995) and 6/7 (O'Rourke *et al.*, 1998). The variation may be associated with the use of markedly different specificity and sensitivity criteria, different length of time since

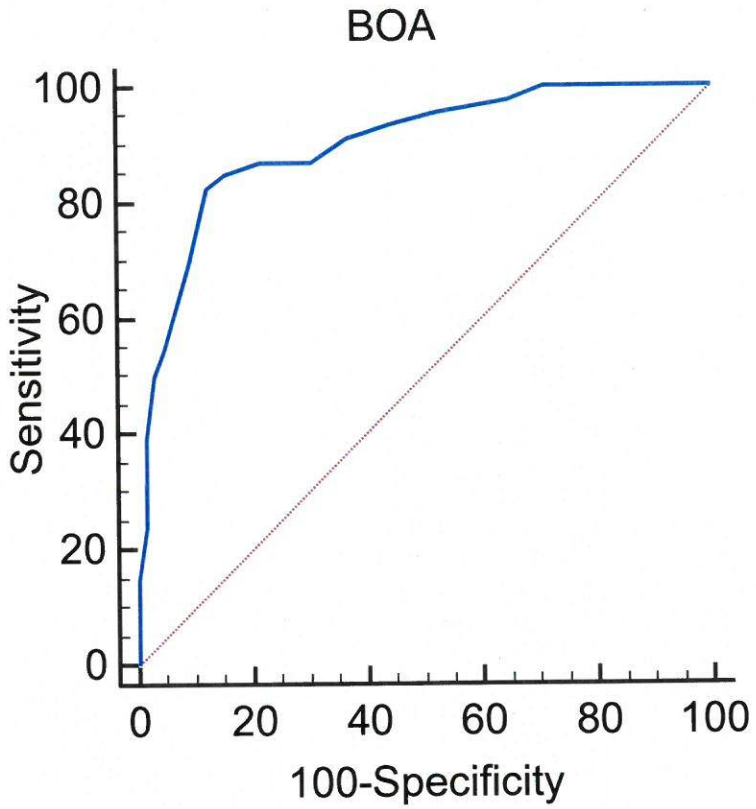
stroke and different tools for standard comparisons. The current analysis used the standard cut-off score of 7/8 in line with the preliminary BOA investigation (Linley-Adams *et al.*, 2014) and because this study recruited a community sample where a cut-off score of 7/8 is generally optimum (Bjelland *et al.*, 2002).

The rate of true-positive predictions at differing risk levels (the sensitivity) was plotted against the rate of false-positive predictions (1 - specificity) in order to construct a ROC curve. An area of 1.0 under the ROC curve signifies a perfect model, and an area of 0.5, which is beneath the diagonal line, represents a prediction made by chance.

H6 *ROC analysis on the HADS-A against TRCs, BOA and GAD-7 will reveal a large area under the curve (>0.75) and specificity and selectivity cut-offs will exceed the minimum recommended by Bennett and Lincoln (2006). Sensitivity values should be over 0.80 and specificity values should be over 0.60.*

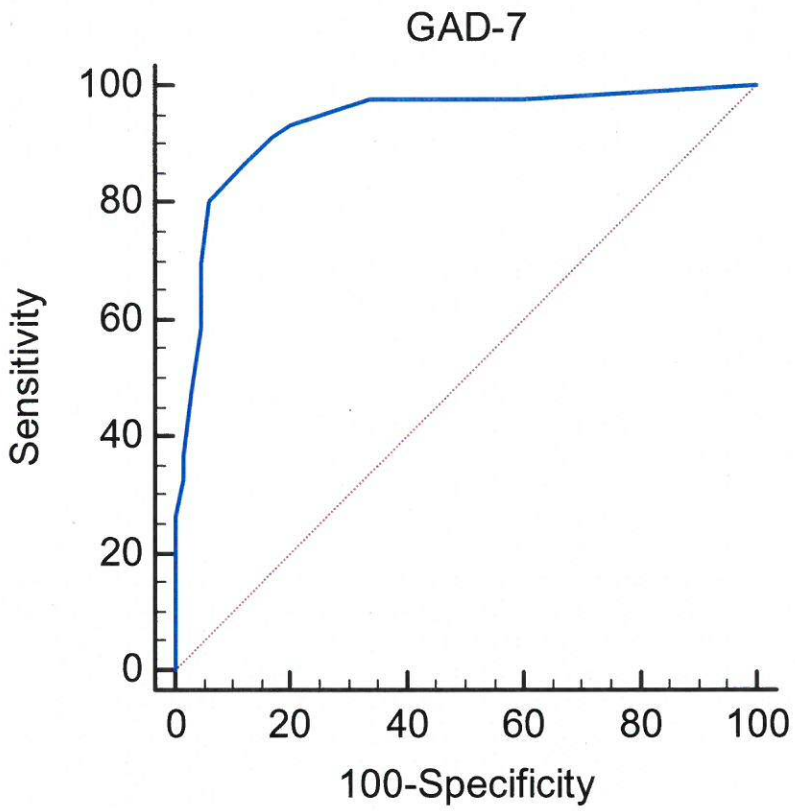
The ROC curve for the BOA against the HADS-A (Figure 3.4) had an area under the curve of 0.90 (95% CI, 0.83-0.95; z = 13.43, $p < .0001$). The results of the ROC analysis (see Appendix 3.4) indicated that the optimal cut-off on the BOA for identifying anxiety was a score >16. At a cut-off score of 16/17 sensitivity was 0.85 (95% CI, 0.71-0.94) and specificity was 0.85 (95% CI, 0.73-0.92), and the positive and negative predictive values were 0.38 and 0.98 respectively. This confirms hypothesis six.

Figure 3.4 ROC curve for BOA against HADS-A



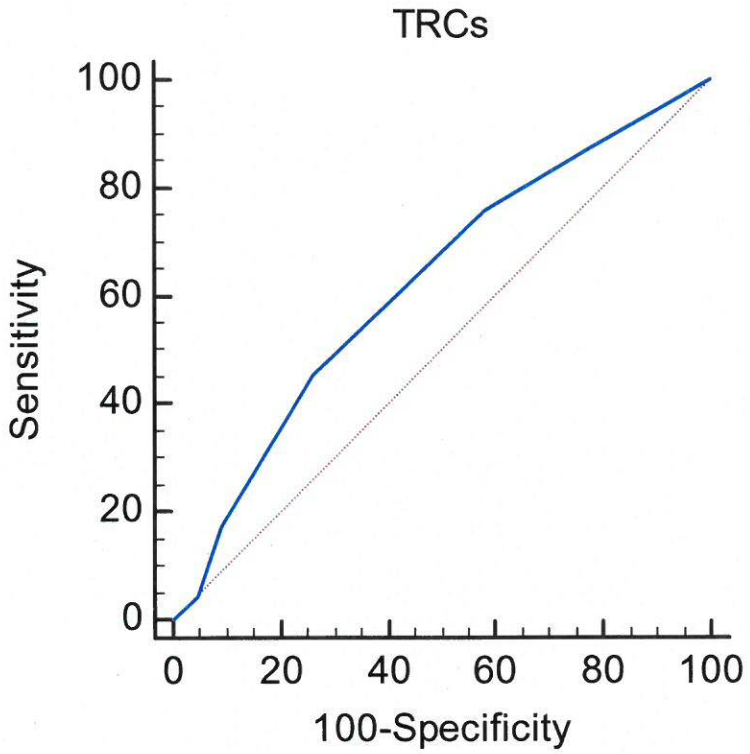
The ROC curve for the GAD-7 against the HADS-A (Figure 3.5) had an area under the curve of 0.94 (95% CI, 0.87-0.97; z = 17.78, $p < .0001$). The results of the ROC analysis (see Appendix 3.5) indicated that the optimal cut-off on the GAD-7 for identifying anxiety was a score >4. At a cut-off score of 4/5 sensitivity was 0.91 (95% CI, 0.79-0.98) and specificity was 0.83 (95% CI, 0.72-0.91), and the positive and negative predictive values were 0.37 and 0.99 respectively. This confirms hypothesis six.

Figure 3.5 ROC curve for GAD-7 against HADS-A



The ROC curve for the TRCs against the HADS-A (Figure 3.6) had an area under the curve of 0.62 (95% CI, 0.52-0.71; z = 2.32, $p < .05$). The results of the ROC analysis (see Appendix 3.6) indicated that the optimal cut-off on the TRCs for identifying anxiety was a score >1. At a cut-off score of 1/2 sensitivity was 0.76 (95% CI, 0.61-0.87) and specificity was 0.41 (95% CI, 0.29-0.54), and the positive and negative predictive values were 0.13 and 0.94 respectively. This finding does not confirm hypothesis six.

Figure 3.6 ROC curve for TRCs against HADS-A



All the measures had higher negative predictive values (the proportion of those who test negative who are not anxiety 'cases') than positive predictive values (the proportion of people with a positive test who are anxiety 'cases'). Thus, most cases are detected, which is appropriate for a screening instrument.

3.5 Experience of using the BOA

3.5.1 Descriptives

One hundred and nine carers completed the experience of using the BOA questionnaire (108 completed all four questions). Each statement was rated on a five point scale from one (strongly disagree) to five (strongly agree). As can be seen in Table 3.10, the mean response for the positively valenced questions was four which suggests on average carers agreed with the statements. The mean response for the negatively valenced statement was 1.85, indicating that on average carers disagreed that the BOA was difficult to complete. As outlined in Table 3.11 and Figures 3.7, 3.8, 3.9 and 3.10, 95% of carers agreed or strongly agreed with the statement *'I felt confident completing the BOA'.* Ninety seven carers reported that the questions made sense to them and 94% agreed or strongly agreed that the '*questionnaire was easy to complete'*. Only 2.8% of carers thought the BOA was difficult to complete, 94% disagreed or strongly disagreed with this statement. Overall, these results suggest the BOA was generally acceptable to carers.

Table 3.10 Experience of using the BOA feedback

	(*N*) [a]	Mean	*SD*	Range
I felt confident completing the BOA	108	4.14	0.57	2-5
The questions made sense to me	109	4.24	0.52	2-5
The questionnaire was easy to complete	109	4.17	0.61	2-5
It was difficult to complete the questionnaire	109	1.85	0.72	1-5

Table 3.11 Frequency of responses to each item

Item	Rating	*Frequency*	%[a]
I felt confident completing the BOA	Strongly Disagree	0	0
	Disagree	3	2.8
	Neither agree nor disagree	2	1.9
	Agree	80	74.1
	Strongly Agree	23	21.3
The questions made sense to me	Strongly Disagree	0	0
	Disagree	1	0.9
	Neither agree nor disagree	2	1.8
	Agree	76	69.7
	Strongly Agree	30	27.5
The questionnaire was easy to complete	Strongly Disagree	0	0
	Disagree	3	2.8
	Neither agree nor disagree	3	2.8
	Agree	75	68.8
	Strongly Agree	28	25.7
It was difficult to complete the questionnaire	Strongly Disagree	28	25.7
	Disagree	75	68.8
	Neither agree nor disagree	3	2.8
	Agree	0	0
	Strongly Agree	3	2.8

[a]% = Valid percent

Figure 3.7 Frequency of carers' responses to the item: '*I felt confident completing the BOA*'

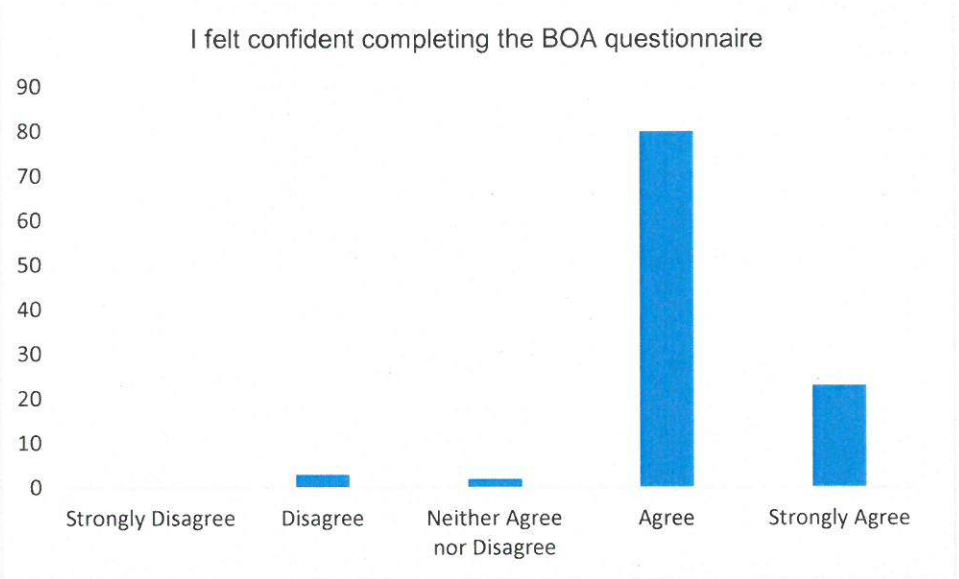


Figure 3.8 Frequency of carers' responses to the item: '*The questions made sense to me*'

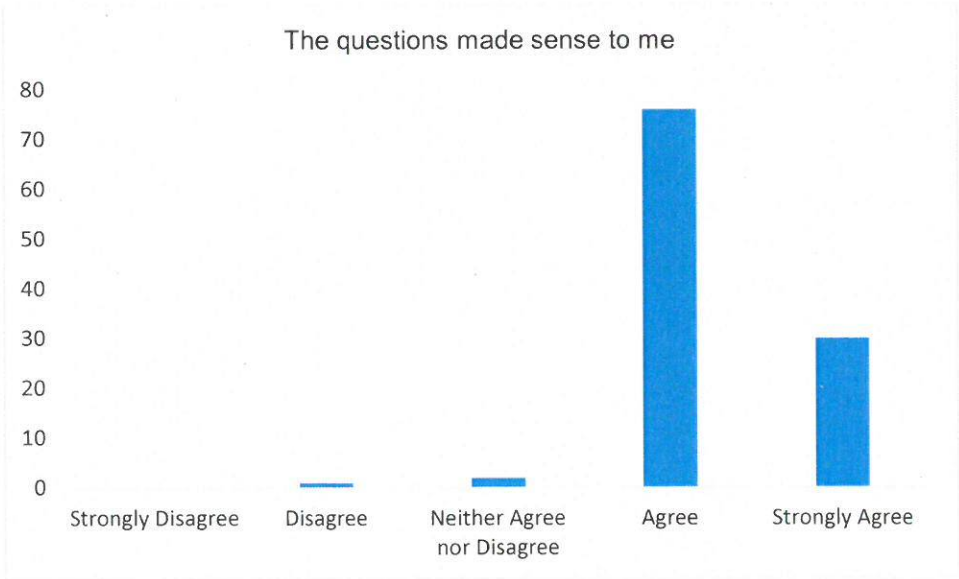


Figure 3.9 Frequency of carers' responses to the item: '*The questionnaire was easy to complete*'

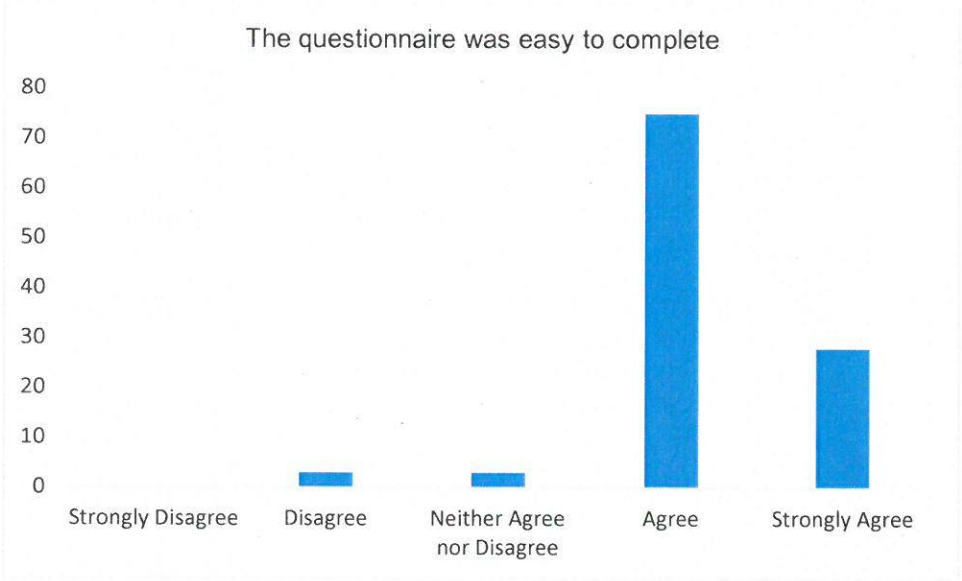
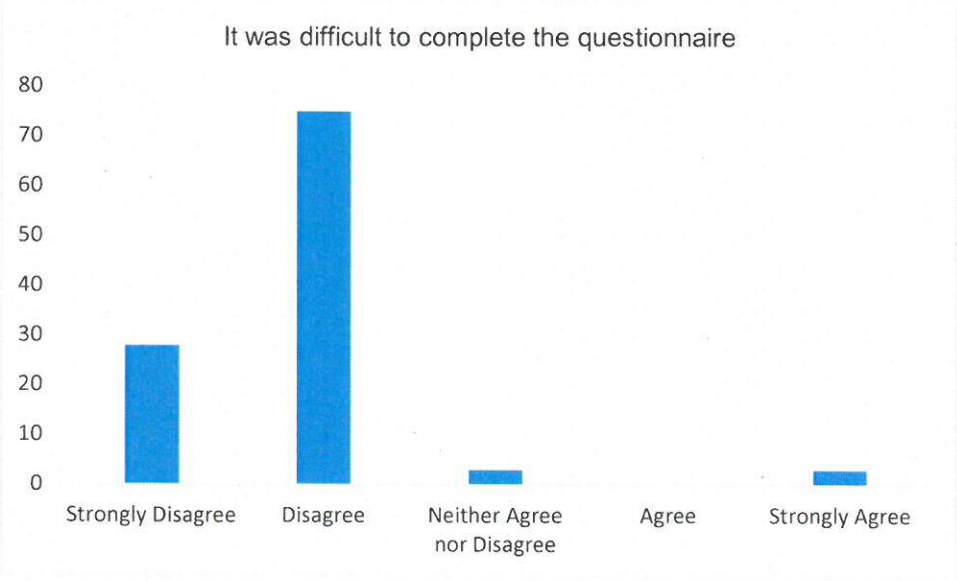


Figure 3.10 Frequency of carers' responses to the item: '*It was difficult to complete the questionnaire*'



3.5.2 Qualitative analysis

Twenty seven carers (24.32%) answered the open question which required them to describe their experiences of using the BOA. The qualitative information generated by the open question was analysed using inductive thematic analysis (Patton, 1990).

Key themes were identified by the researcher, which were then reviewed by the researcher's supervisor. A summary of the key themes from the experience of using the BOA feedback questionnaire are presented below and a sample of quotes are outlined in Table 3.12. Full details of all the quotes can be found in Appendix 3.7.

H8. Due to the exploratory nature of the carer's qualitative feedback on their experiences of using the BOA, no firm hypotheses can be made although it is anticipated that the themes will reveal generally positive responses.

3.5.2.1 Main theme 1: Acceptability of the BOA

One main theme emerged regarding the acceptability of the BOA.

3.5.2.1.1 Subtheme 1: Easy to understand and complete

The majority of respondents (18 out of 27) described their experience of completing the BOA in terms of ease of understanding and completion.

3.5.2.2 Main theme 2: Difficulties of the BOA

A second main theme relating to the difficulties carers had completing the BOA emerged and are discussed under two subthemes: difficulty interpreting survivor's mood and lack of relevance.

3.5.2.2.1 Subtheme 1: Difficulty interpreting survivor's mood

Five carers expressed concern regarding their ability to accurately interpret the mood of the stroke survivor.

3.5.2.2.2 Subtheme 2: Lack of relevance

A minority of carers reported that the questions were not applicable or lacked relevance to the stroke survivor.

3.5.2.3 Main theme 3: Additional benefits of using the BOA

One subtheme emerged under the main theme of additional benefits of using the BOA.

3.5.2.3.1 Subtheme 1: Prompted reflection

Two carers described experiencing additional benefits from completing the BOA in terms of prompting reflection on the stroke survivor's mood and behaviour further.

Table 3.12 Sample of responses under each main and subtheme

Main theme	Subtheme	Sample responses
1. Acceptability of the BOA	1. Easy to understand and complete	*"The questionnaire was clearly explained and easy to complete" x 6* *"No problem at all" x 6* *"It was easy to fill in the questionnaire as each question was clear and concise" x 2* *"Not difficult, the questions were quite clear and straight forward" x 4*
2. Difficulties of the BOA	1. Difficulty interpreting survivor's mood	*"It's hard to figure out what [husband] is thinking sometimes" x 4* *"Professional carer- only spend a few hours a week with [survivor]"*
	2. Lack of relevance	*"If questions related to last six months, some answers may have been slightly different (e.g. fear of another stroke, or being unable to answer the phone- lack of confidence)"* *"Some questions did not really apply to my husband"*
3. Additional benefits of using the BOA	1. Prompted reflection	*"One or two questions made me really think about my mother's behaviour/anxiety because I am not with her all the time at her home environment e.g. she has been restless or constantly on the move/ being so restless that it's hard to sit still. I do not think that her restlessness causes a physical response in her, but that her response is more mental/ thinking anxiety. But when she is alone I am, of course, unsure of her behaviour"* *"It made me think of how my husband has been affected by his stroke"*

3.5.2.4 Summary of qualitative analysis

The BOA appears to have been experienced positively by the majority of carers. Thus, confirming H8. The acceptability of the BOA emerged as a main theme and was described in terms of its ease of completion by 18 out of 27 respondents. Difficulties with the BOA emerged as a second main theme, with subthemes of difficulties interpreting the survivor's mood and the lack of relevance of some of the questions, although the latter was only raised by two carers. A third main theme emerged regarding additional benefits of the BOA. Two carers described the BOA

questionnaire as prompting further reflection of the impact of the stroke on the stroke survivor.

3.6 Results summary

The BOA was significantly positively correlated with all measures of anxiety (HADS-A, GAD-7 and TRCs). The HADS-A and TRCs were positively correlated, although the correlation was less strong than for the other measures, and the correlations remained significant after bonferroni correction was applied. The BOA showed good test-retest reliability over a two week period. Significant reductions in the BOA, HADS-A and GAD-7, following relaxation training were found. ROC analysis revealed a large area under the curve for BOA against the HADS-A (0.90). At a cut-off score of >16, sensitivity was 0.85 and specificity was 0.85. The ROC curve for the GAD-7 against the HADS-A also revealed a large area under the curve of 0.94. At a cut-off score of >4 sensitivity was 0.91 and specificity was 0.83. ROC analysis of the TRCs against the HADS-A revealed an area under the curve of 0.62. At a cut-off score of >1, sensitivity (0.76) and specificity (0.41) values did not the meet minimum standards set by Bennett and Lincoln (2006).

Feedback from carers revealed that the majority of respondents experienced the BOA positively. Qualitative analysis found a small minority of carers highlighted difficulties in interpreting the stroke survivor's mood and some suggested the questions were not relevant to their partner/ family member. The key themes derived from the feedback were the acceptability of the BOA, difficulties using the BOA and additional benefits of using the BOA.

Therefore, it can be concluded that, with the exception of the performance of the TRCs, all stated hypotheses were confirmed.

Chapter Four

Discussion

4.1 Summary of the main study findings

The study investigated the accuracy of two observational anxiety screening measures with a heterogeneous sample of aphasic stroke survivors. Screening of post stroke mood disorders is essential in order to employ the most suitable and timely interventions, and to avert secondary functional problems in the long term. The validation of an accurate measure of post stroke anxiety is essential for effective holistic rehabilitation planning for aphasic stroke survivors.

The primary aim of the study was to evaluate the test-retest reliability and construct validity of the BOA screening tool. Concurrent validity was evaluated by comparison against two criterion standards, the HADS-A and TRCs, and the construct validity by comparison of scores before and after an intervention known to reduce anxiety (relaxation training). This is the first study to investigate the psychometric properties of a screening tool specifically developed to measure anxiety using a sample of stroke survivors with aphasia. A secondary aim of this study was to investigate the validity of the GAD-7, a commonly used screening measure of anxiety which has to date not been validated with stroke survivors.

As hypothesised, the BOA correlated positively and significantly with the carer completed HADS-A and the survivor completed TRCs. The BOA was stable over time with good test-retest reliability observed. This suggests the BOA is an effective observational screening tool in this group. The construct validity of the BOA was investigated with relaxation training, which demonstrated significantly reduced anxiety scores over a two week period, compared to the control group as measured by the BOA, HADS-A and GAD-7. This finding also demonstrated that the BOA was sensitive to change. ROC analysis on the BOA against the HADS-A revealed a large area under the curve and cut-offs were identified that gave specificity and sensitivity

values exceeding the minimum recommended by Bennett and Lincoln (2006). Qualitative feedback indicated that the BOA was perceived as an acceptable and user-friendly tool for the majority of carers. Thus, all hypotheses regarding the BOA were confirmed.

In this study the GAD-7 and HADS-A were positively correlated. There was a strong positive correlation between GAD-7 scores at time one and two, suggesting good test-retest reliability. ROC analysis against the HADS-A criterion revealed a large area under the curve and acceptable specificity and selectivity cut-offs.

The performance of the TRCs did not meet hypothesised standards. Whilst a significant and positive correlation was found between the TRCs and the HADS-A and BOA, this accounted for only 31% of the variance. It is possible that this reflects the difficulties the aphasic stroke survivors experienced self-reporting their tension.

4.1.1 Prevalence of post stroke anxiety

When using a cut-off score of at least 7 on the HADS-A (Snaith & Zigmond, 1994) the overall prevalence rates for anxiety (41.4%) was higher than the base rates reported within the stroke literature (around 33%; De Wit., 2008; Hackett, Yapa *et al.*, 2005). Participants in the current sample all had aphasia, which may explain the higher rate of anxiety levels. All stroke survivors were community dwelling and were assessed at an average of six years post stroke. Therefore, these findings support the need to screen for anxiety disorders throughout all stages of the stroke care pathway (Royal College of Physicians, Intercollegiate Stroke Working Party, 2012).

All the anxiety scales showed a significant negative correlation with age of stroke survivor. This is in line with research that highlights the increased vulnerability of younger stroke survivors to developing anxiety (Schultz *et al.*, 1997), although was not consistent with findings from the preliminary BOA investigation with non-aphasic stroke survivors (Linley-Adams *et al.*, 2014).

4.1.2 Concurrent validity of the BOA

At the commencement of this study, the BOA had not been validated among stroke survivors with aphasia, despite being used in clinical practice. The BOA correlated significantly with all the measures and accounted for between 77% and 82% of the variance. However, the correlation only accounted for 31% of the variance when using the TRCs as a criterion standard.

The total area under the ROC curve is an evaluation of the overall performance of a diagnostic test, the larger the area, the more superior the performance (Westin, 2001). For the BOA, when using the HADS-A (≥ 7) as a criterion standard, the area under the ROC curve (AUC) was 0.90 which fell within the excellent range of accuracy (Fischer *et al.*, 2003) and was significantly greater than an AUC of 0.50 (no prediction). Others recommend that the accuracy of tests with AUC between 0.50 and 0.70 is low; an accuracy between 0.70 and 0.90 is moderate, while an AUC over 0.90 indicates high accuracy (Streiner & Cairney, 2007). According to this classification, the BOA achieved high accuracy.

A cut-off score on the BOA of at least 16 met recommended levels of sensitivity (0.85) and specificity (0.85; Bennett & Lincoln, 2006). This finding suggests a higher cut-off score than that of at least 13 recommended by Linley-Adams *et al.* (2014) in their study with non-aphasic stroke survivors. The ability to make a diagnosis or screen for a condition is determined by the discriminatory value of the test and on the prevalence of the condition in the population of concern (Lalkhen & McCluskey, 2008). In general, lower prevalence rates of the screened condition results in poorer sensitivity and specificity values (Goldberg, 1972).

There was a higher proportion of survivors with anxiety in the present study, compared to that found in the preliminary study with a non-aphasic stroke sample (Linley-Adams *et al.*, 2014). The positive predictive value increases as the incidence of anxiety increases. This may explain the higher cut-off score found in this study.

The detrimental impact of anxiety following stroke means the consequences of missing a case can be substantial; whereas, the effect of further mood assessment are less severe. Therefore, for screening purposes, it is preferable to have high sensitivity as lower (false negatives) specificity is not as important. Consequently,

this thesis provides evidence in support of the BOA, as an accurate yet brief and accessible screening measure for anxiety in survivors with aphasia, which has thus far been lacking. The findings need to be replicated with a larger sample in order to enhance generalisability to clinical practice.

Prior studies of mood screening tools among stroke survivors have found good internal consistencies (Berg *et al.*, 2009; Sagen *et al.*, 2009), high AUCs (Aben *et al.*, 2002; Berg *et al.*, 2009) and levels of sensitivity (Aben *et al.*, 2002; Johnson *et al.*, 1995), but poorer specificity levels (Aben *et al.*, 2002; Johnson *et al.*, 1995; Lincoln *et al.*, 2003) (see Table 4.1 below). The current evaluation of the BOA is thus comparable with the previous literature, with the exception of the specificity level which was found to parallel sensitivity level. This represents a strength of the BOA.

Table 4.1 Studies of psychometric properties of post stroke mood screening tools

	Study	Tool	Criterion measure	Cut-off score	Sensitivity	Specificity	PPV	NPV
Observer rated Anxiety	**Current**	**BOA**	**Carer completed HADS-A >7**	**>16**	**0.85**	**0.85**	**0.38**	**0.98**
	Linley-Adams *et al.* (2014)	BOA	Survivor completed HADS-A	>13	0.77	0.58	0.42	0.86
Depression	Bennett *et al.* (2006)	SADQ-H10	HADS-D >7	>5	1.0	0.78	*Not reported*	*Not reported*
	Hacker *et al.* (2010)		BASDEC >6	>5	0.70	0.69	*Not reported*	*Not reported*
	Benaim *et al.* (2004)	ADRS	Psychiatrist diagnosis of depression	>8	0.83	0.71	*Not reported*	*Not reported*
	Watkins, Leathley *et al.* (2001b)	SoDS	MADRS >6	>1	0.70	0.56	0.65	0.62
	Lightbody *et al.* (2007)		SCID DSM-IV depression	>1	0.64	0.61	*Not reported*	*Not reported*
Self-report Verbal	Aben *et al.* (2002)	HADS-A	SCID DSM-IV major and	>4	0.89	0.72	0.64	0.92

			minor depression					
		HADS-T		>10	0.87	0.70	0.45	0.95
	O'Rourke *et al.* (1998)	HADS-A	SADS DSM-IV any anxiety disorder	>6	0.83	0.68	*Not reported*	*Not reported*
	Sagen *et al.* (2009)	HADS-T	SCID DSM-IV any depressive disorder	>9 >10	0.90 0.90	0.83 0.83	0.55 0.55	0.97 0.97
		HADS-D		>2 >3	0.84 0.84	0.66 0.73	0.36 0.42	0.95 0.95
	Crabtree *et al.* (2012)	HADS-D	MINI major depression	>5	1.0	1.0	0.42	0.83
	Healy *et al.* (2008)	HADS-D	SCID DSM-IV major and minor depression	>7	0.62	0.69	0.42	0.83
	Johnson *et al.* (1995)	HADS-D	PAS DSM-III any depressive disorder	>3 >4	0.94 0.83	0.32 0.44	0.25 0.26	0.96 0.92

	Kang *et al.* (2013)	HADS-D	MINI DSM-IV major Depression	>6	0.83	0.76	*Not reported*	*Not reported*
	O'Rouke *et al.* (1998)	HADS-D	SADS DSM-IV any depressive disorder	>6	0.80	0.79	*Not reported*	*Not reported*
	Healey *et al.* (2008)	BASDEC	SCID DSM-IV major depression	>6	1.0	0.95	0.78	1.0
	de Man-van Ginkel *et al.* (2012a)	PHQ-9	GDS-15 >5 (major depression)	>9	1.0	0.86	0.50	1.0
		PHQ-2		>1	1.0	0.77	0.38	1.0
	Turner *et al.* (2012)	PHQ-9	SCID DSM-IV major depressive episode	>6	0.85	0.63	0.33	0.95
		PHQ-2		>1	0.77	0.63	0.31	0.93
	Williams *et al.* (2005)	PHQ-9	SCID DSM-IV major depressive episode	>9	0.91	0.89	0.80	0.95
		PHQ-2		>2	0.83	0.84	0.72	0.91

	Watkins Daniels *et al.* (2001a)	Yale question	MADRS >6	>0	0.86	0.78	0.82	0.82
	Watkins *et al.* (2007)			>0	0.86	0.84	0.86	0.84
Self-report Non-verbal	Bennett *et al.* (2006)	VAMS 'sad item'	HADS-D >7	>22	0.88	0.62	*Not reported*	*Not reported*

4.1.3 Construct validity of the BOA

Relaxation training was used to explore the construct validity of the BOA. It was hypothesised that if relaxation is effective in reducing stroke survivors' anxiety, by lowering tension levels, then corresponding reduction in scores on the BOA should follow. Significantly greater reductions in the BOA scores of those who completed the relaxation training were indeed found, therefore providing support that the BOA does truly measure anxiety. Furthermore, significantly greater reductions in anxiety as depicted by scores on the HADS-A and GAD-7 following relaxation training were found. In contrast, no such reductions in anxiety measure scores was demonstrated by the control group. These findings suggest that the BOA has good construct validity. It should be noted that valid carer ratings of anxiety are assumed and it is possible that carers' reports reflected the demand characteristics of the study.

The use of relaxation training in this study to explore the construct validity of the BOA, addresses some of the limitations of previous post stroke mood screening validation studies that have merely investigated convergent and discriminant validity. For example the convergent validity of the SADQ has been explored by examining correlations with other mood measures, and is well established (Bennett *et al.*, 2006; Lincoln *et al.,* 2000; Sutcliffe & Lincoln, 1998). Similarly Benaim *et al.* (2004) demonstrated the convergent validity of the ADRS through the correlations with the HDRS. The construct validity and utility of the HADS in stroke survivors has been demonstrated through its ability to discriminate anxiety and depression, and by its ease of use with those with serious physical illness (Johnston *et al.*, 2000). Thus, construct validity has been somewhat neglected in validation studies of post stroke mood screening measures. The current study therefore offers a more complete psychometric understanding of the BOA, relative to other mood screens.

Discriminant validity was not examined due to considerations concerning test burden. This could be studied in future BOA validation research. Priority was afforded to investigating construct validity in the present study.

4.1.4 Concurrent validity of the GAD-7

The GAD-7 had not previously been investigated for its validity among stroke survivors. The GAD-7 correlated significantly with all the anxiety measures. The correlation with the HADS-A and BOA accounted for between 71% and 82% of the variance.

When using the HADS-A (≥ 7) as a criterion standard, the AUC (0.94) fell within the excellent/ high range of accuracy (Fischer *et al.*, 2003; Streiner & Cairney, 2007). This was significantly greater than an AUC of 0.50. The ROC analysis indicated that the optimal cut-off on the GAD-7 for identifying anxiety was a score of at least 4. At a cut-off score of 4/5 sensitivity was 0.91 and specificity was 0.83 which exceeds recommended levels (Bennett & Lincoln, 2006). As this is the first validation study of the GAD-7 with stroke, further investigation is warranted to confirm and generalise these findings to non-aphasic populations. Nonetheless, these findings suggest the observer rated GAD-7 appears to be an accurate measure of anxiety in aphasic stroke survivors.

4.1.5 Concurrent validity of the TRCs

The TRCs is an aphasia adapted anxiety test that measures subjective feelings of muscle tension. It was adapted from the DISCs (Turner-Stokes, Kalmus *et al.*, 2005) by Kneebone *et al.* (2012). It has not been subject to previous validation. The findings from this study are not supportive of the TRCs and thus do not confirm the hypothesis.

The TRCs positively correlated with all the measures, however, the correlations only accounted for 30-31% of the variance. When using the HADS-A (≥ 7) as a criterion standard, the AUC was 0.62, which is in the low range of accuracy (Streiner & Cairney, 2007). Whilst the AUC was significantly greater than 0.50, the optimal cut-off on the TRCs for identifying anxiety was a score >1. At a cut-off score of 1/2 sensitivity was 0.76 and specificity was 0.41. The low specificity would result in a large proportion of individuals requiring further assessment due to the high false-positive rate. This reduces the utility of the TRCs as a screening measure of anxiety.

This finding is in line with previous research which has highlighted low concordance rates between observer ratings and subjective reports of wellbeing in aphasic (Berg

et al., 2009) and non-aphasic stroke survivors (Edwards *et al.*, 2006). However, stroke survivors in the current study were able to complete the TRCs (albeit with questionable accuracy), which is in contrast to previous research suggesting that aphasic stroke survivors are unable to use visual analogue measures (Price *et al.*, 1999).

The variation in findings of the BOA and GAD-7 compared to the TRCs could be explained by the fact that the BOA and GAD-7 concern anxiety symptoms and behaviour over the past week and two weeks respectively, whereas the TRCs refers to tension today only. Tension is a correlate of anxiety rather than a true measure, and thus a difference exists in terms of what the self-report TRCs and observer reported HADS-A and GAD-7 assess. It would be interesting to explore whether changing the TRCs instructions to refer to a longer time period would result in greater association with carer ratings on the BOA and GAD-7.

4.2 Strengths, limitations and future directions

The quality of a validation study can be considered in terms of its internal and external validity (Whiting *et al.*, 2004). Internal validity refers to the design and conduct of the study and external validity refers to the degree to which the results of a study are applicable to clinical practice.

4.2.1 Internal validity

The BOA was developed by comparing carer ratings with survivor questionnaire responses in non-aphasic stroke survivors. The assumption is that if the items from the BOA are correlated with questionnaire measures of anxiety in non-aphasic survivors, then this will also apply to those with aphasia. This may not be the case, but in the absence of a direct means of verbally assessing anxiety in aphasic survivors, which could be used as the 'gold standard' this is the next best alternative.

In order to minimise the impact of potential fatigue, the measures were administered in a randomised order. A potential limitation refers to the uncertainty and low control

regarding how carers completed the measures when alone, given that a small proportion of questionnaires were administered postally.

Another potential cause of bias may be related to the administration of all three screening measures by the same researcher during a single session. This may have resulted in heightened agreement between the measures. However, this possibility was reduced to a minimum by adherence to the questionnaire manuals and through alternating the order of administration.

A possible limitation of this study was that survivors of very recent strokes in hospital or in the first few weeks of discharge were not included. Thus, it is not clear how the BOA (or the GAD-7) performs in the acute stages post stroke. Further research could extend the study to include survivors at a broader range of time since stroke to confirm the properties of the BOA are stable at all stages of post stroke screening and severity levels. This could investigate the performance of the BOA when completed by nursing staff, and other members of the clinical team, in light of prior studies which have highlighted that nurses' identification of depression in general is poor (Bagley *et al.*, 2000; Plummer *et al.*, 2000).

It is well established that anxiety or low mood in the acute phase may represent a response to the stroke itself or adjustment to being in hospital. Screening mood at this time may lead to an inaccurate understanding of the stroke survivor's mood state in the longer term (Gurr, 2011). Substantial bias due to recency of stroke seems unlikely in the present study since stroke survivors were screened at least two months following stroke, increasing the likelihood that their mood had stabilised.

Anxiety can persist into the chronic stage of stroke recovery (Langhorne *et al.*, 2000). Indeed, recent research by Ch'Ng *et al.* (2008) offers support to anxiety screening in the later stages post discharge. Ch'Ng *et al.* (2008) offer a model of adjustment to stroke which suggests that adjustment in the acute phase of post stroke recovery is commonly associated with the management of physical and communication problems, discontentment with the hospital environment, and confusion surrounding what has happened. They suggest the rehabilitation phase is often characterised by uncertainty surrounding prognosis, social isolation and anxiety over the rate of recovery. Discharge home is highlighted as the most challenging time, with a predominant sense of abandonment. Distress is purported to

be related to feelings of anger, frustration about loss of future plans, and negative self-perceptions (Ch'Ng *et al.*, 2008). This model therefore provides a rationale for anxiety screening at all stages post stroke, but particularly in the later post discharge phase.

The present study did not explore the prevalence of sub-types of anxiety and the measures were not able to differentiate between different anxiety types, for example health anxiety and social anxiety. Further research could explore the relevance of the BOA and GAD-7 to identifying such sub-types of anxiety which conceivably may be higher in stroke survivors, and particularly those with communication difficulties.

Another potential limitation of the study was that stroke survivors and carers were recruited via opportunistic sampling at community stroke groups. Sampling did not include carer-survivor dyads where neither partner attended a group. It is possible that the most anxious stroke survivors were not in attendance at the groups, and this may have biased the sample to include those with less severe anxiety. Moreover, twelve data sets were excluded from the initial completion of tests and 21 from the test-retest sub-group, due to failure to return the measures. This may have introduced bias. The majority of cases were due to the carers not completing the scales. Due to an opt-in approach and exclusion criteria, it is possible that participants who were highly anxious or depressed did not consent to take part in the study. Conversely, it is possible that those with anxiety or other mood difficulties were more inclined to volunteer, and indeed the very high rates of anxiety in this sample support this possibility.

The accuracy of the BOA, GAD-7 and TRCs in this study was based upon the principle that the HADS-A has sensitivity and specificity values that are perfect (i.e. 100%). As with many screening tools, this is not the case. Subsequently, anxiety 'cases' as detected by the BOA, GAD-7 and TRCs may have been misclassified by the HADS-A (Whiting *et al.*, 2004). The validation study was based on visual analogue and questionnaire measures of mood rather than psychiatric interview, due to aphasia making this very difficult, if not impossible. It is acknowledged that the clinical interview is the 'gold standard' but this was not feasible with an aphasic sample. Thus, the TRCs was considered to be the most appropriate and nearest approximation alternative, despite its limitations.

The relaxation group had a relatively high attrition rate. Only 12 out of 25 post-relaxation measures were returned, despite efforts to maximise return rate. A number of different reasons were given for withdrawal including lack of time and ability to focus on the relaxation training. It is possible that demand characteristics were involved and that those who did not perceive the relaxation training to be helpful ceased the intervention but gave alternative explanations. Due to ethical considerations and right to withdraw, there may be potential implications for the data that are available in that those who found benefit completed the intervention. This may have resulted in bias in the data.

Although not formally evaluated, anecdotal feedback from a small minority of carers suggested that the relaxation intervention may have not been fully understood by, or appropriate for, some survivors. The relaxation exercises involved progressive muscle relaxation which were reportedly difficult for some. Whilst instructions emphasised to survivors that they should only do as much as they were able to, this may have heightened anxiety or distress. Further research might utilise an alternative relaxation program that focusses on a simpler breathing or mindfulness exercise, or screen stroke survivors for suitability to commence the current relaxation intervention. For example, the progressive muscle relaxation may be better suited to those with fewer physical post stroke difficulties.

Due to survivors completing the relaxation training at home, it is not fully clear how well they adhered to the program. Survivors or carers completed a relaxation diary that recorded when the relaxation was carried out, and pre and post anxiety levels for each day. This offers a degree of assurance of adherence to the program and combined with the weekly telephone call prompts from the researcher, appeared to minimise non-compliance, although total certainty is not possible.

The present study did not measure depression as this was not the focus, however given the high rates of comorbidity (Ayerbe, Ayis, Crichton *et al.*, 2013), further research may screen for depression in order to clarify possible co-variation. No formal measures of cognitive or functional status were administered. Further validation studies might employ the Montreal Cognitive Assessment (MoCA; Nasreddine *et al.*, 2005) of mild cognitive impairment, and the Barthel Index (Mahoney & Barthel, 1965) of functional status, in order to explore possible

associations with these domains. Furthermore, studies could enquire about medication use as this may confound the results. However, the use of large numbers of measures increases participant burden and elevates refusal and dropout rates (Cape *et al.,* 2007; Patel *et al.,* 2003). Stroke survivors are prone to fatigue (Parks *et al.*, 2012) which may impair accuracy of self-reports across long test batteries.

The accuracy of screening tools is affected by the prevalence and severity of a condition (Whiting *et al.*, 2004). Positive and negative predicative values, as well as sensitivity and specificity, are directly influenced by prevalence rates (Whiting *et al.*, 2004). Sensitivity rates are typically higher in samples where clinically significant levels of distress are experienced by a larger proportion of individuals (Sackett & Haynes, 2002). The incidence of anxiety was higher in this study relative to prior studies and may be due to the presence of aphasia. Further research could investigate the accuracy of the BOA and GAD-7 with sub-groups of stroke survivors, stratified according to aphasia severity and anxiety prevalence rate. This was not undertaken in the current study due to the sample size rendering this impractical. Larger investigations could also explore variables such as time spent with the stroke survivor, education and carer levels of social support, which may enhance understanding of how the BOA performs with diverse carer-survivor dyads. Such research has the potential to guide a targeted and refined approach to its use and interpretation.

As with all proxy rated measures of mood, screening is dependent on the accurate report of a carer. Following stroke, carer burden is common, with additional stressors including role changes, uncertainty regarding future plans and changed relationships due to alterations in the survivor's personality (Greenwood *et al.*, 2009). Proxy rated observational measures have been critiqued for their vulnerability to influence by carer's mood (Groom *et al.*, 2003). Given the known bidirectional association between carer and survivor wellbeing within stroke (Suh *et al.*, 2005), it is conceivable that a distressed carer may complete any mood screening measure in a manner that reflects their own emotional state (Sutcliffe & Lincoln, 1998). It is possible that carers' rating of stroke survivor's anxiety was influenced by their own distress and anxiety experience. A possible limitation of the present study was the absence of carer mood screening to confirm or reject this hypothesis. Carer mood screening was not conducted as the evidence for the validity of screening tools being

influenced by carers' own wellbeing is inconsistent. Among aphasic stroke survivors, Hilari *et al.* (2007) found no effect of carer emotional distress or strain on ratings of survivor quality of life. There is a need for further exploration of proxy-survivor agreement in mood screening, particularly for aphasic stroke survivors.

The current study could be extended to screen for carer anxiety and depression to enable firmer conclusions to be drawn. This also highlights the importance of using a range of modes of mood screening so to avoid the potential for this source of bias.

Whilst there is a growing literature on mood screening in stroke survivors, far fewer studies have directly investigated the psychometric properties of screening tools within the same sample. Screening tool psychometric properties may vary between different samples, settings and modes of administration, thus reducing the value of comparison across studies. This represents a weakness in the literature field. The current study evaluated two observer rated screening measures against the self-report visual analogue TRCs within the same sample, thus addressing this issue.

4.2.2 External validity

A strength of the study is that stroke survivors with moderate to severe communication difficulties were included, as measured by the Frenchay Aphasia Screening Test (FAST; Enderby *et al.*, 1987). The average score on the FAST (19/30) was markedly below the cut-offs for the presence of aphasia (25 or 27 out of 30), demonstrating the high level of communication impairment in the sample. This increases the external validity and enables generalisation of findings to a group of stroke survivors that are normally excluded from research studies. It is important to validate a screening tool with a sample that is representative of the clinical population (Whiting *et al.*, 2004). This study addresses the limitations of previous studies where samples were unrepresentative (e.g. Williams *et al.*, 2005).

A large sample size was employed and this provided heterogeneity in a number of ways. Participants had experienced a range of different types of strokes and a large proportion (38%) reported multiple strokes. This is important as up to 30% of stroke survivors go on to experience recurrent strokes (Stroke Association, 2015). There was a wide age range among stroke survivors and carers, which enables

generalisation of findings to younger stroke survivors through to the 'oldest old'. There was a greater proportion of male (69%) to female (31%) stroke survivors in the current sample which corresponds to national statistics highlighting that men have more strokes than women (Department of Health, National Stroke Strategy, 2007).

A strength of this study was the inclusion of stroke survivors under the age of 65 years. The proportion of younger stroke survivors (28.2%) was representative of published rates in the stroke literature (National Audit Office, 2005). However, replication of these results with a larger sample of younger stroke survivors is necessary in order to gain a more thorough understanding of the performance of the BOA in this group.

The time since stroke was wide ranging in this sample, suggesting that the BOA is suitable for use at various stages after the stroke event. This is clinically important as stroke survivors are often under the long term care and management of stroke services, sometimes for many years after the stroke (Turner *et al.*, 2012). Therefore, the findings are relevant for professionals who may screen at all stages of the stroke pathway, from the early post stroke phase through to the later stages. There is evidence that stroke survivor-proxy agreement on quality of life is higher where the survivor has had the condition long term (Pickard *et al.*, 2004), as carers benefit from the lengthier exposure to their symptoms. Conceivably this may apply to mood.

Survivors and carers were identified from community groups across a wide geographical area (south Wales). There is considerable diversity within this region in terms of socio-economic status, general health status, first language and rates of mental health problems. Although there are no comparison data for stroke survivors with aphasia, these findings are likely to generalise to the aphasic stroke population more than if the sample was recruited from a single setting. A limitation is the dearth of stroke survivors from minority ethnic backgrounds. It is known that incidence rates of stroke, adjusted for age and gender, are twice as high for black African and Caribbean people as for white people (Stewart *et al.*, 1999). Given this increased risk, further research should aim to include more black and minority ethnic stroke survivors in validation studies of screening measures, and stroke research in general.

The majority of survivor-carer dyads were married couples, which may account for the high level of agreement on anxiety ratings. Only four carers identified themselves as professional carers. Further reliability studies are required in order to extend the BOA's use to other contexts such as residential and nursing homes where stroke survivors may be cared for by professional staff. Inter-rater reliability studies would provide useful information that may inform guidance regarding who should ideally be requested to complete the BOA.

4.3 Clinical implications

The principle aim of validating a screening measure of anxiety is that those who are screened may access appropriate support, services, and ultimately achieve a better health and wellbeing outcome relative to those who are not screened (Sackett & Haynes, 2002). Screening also aims to detect those who may require further monitoring or assessment. It can provide an efficient means of capturing intensity of anxiety or distress. Screening is thus compatible with a biopsychosocial model which understands health and wellbeing in terms of a continuum as opposed to a medical disease model (WHO, 2001).

In this study the negative predictive value of HADS-A cases at a BOA cut-off score of >16 was 0.98, signifying that the majority of anxiety cases were discovered, as is desirable for an effectual screening tool. Yet, the lower positive predictive value (0.38) indicates that further assessment of survivors who scored above the cut-off by carer observation is warranted to establish need for intervention. This is in line with the findings from the preliminary BOA validation study (Linley-Adams *et al.*, 2014).

While guidelines endorse the screening of mood disturbance, specific recommendations on support and intervention for aphasic stroke survivors are not provided (NICE, 2013; Royal College of Physicians, Intercollegiate Stroke Working Party, 2012). Thus, further research is warranted into the effectiveness of psychological interventions for post stroke mood problems, including anxiety. Future research could also explore methods of supporting stroke survivors with aphasia to recognise and self-manage the emotional impact of the stroke and aphasia and the effect on daily life. This has been suggested as a potentially valuable intervention in

itself (Swinburn *et al.*, 2004). Innovative and creative approaches such as adapted family therapy and educational interventions have been recommended to alleviate depressive symptoms in people with aphasia (Barrett & Gonzalez-Rothi, 1998). Given the high level of comorbidity of depression and anxiety (57–73% of survivors, Ayerbe, Ayis, Crichton *et al.*, 2013), such approaches warrant investigation in aphasic stroke survivors with anxiety.

Due to the recent development of the BOA, feedback was sought in order to explore the acceptability of the BOA to carers. The feedback was highly positive. The majority of carers felt confident completing the BOA, and indicated that the questionnaire made sense and was easy to complete. The carers disagreed that the BOA was difficult to complete. That the BOA was well understood is also signified by the low proportion of missing and invalid responses.

Qualitative analysis revealed a main theme of acceptability of the BOA. Carers reported that completing the BOA was straightforward and that the questions made sense. Studies into mood screening in other health-care settings, such as oncology, have highlighted that acceptability of a mood screening tool often determines effective implementation, irrespective of accuracy. Few studies have examined the issue of acceptability of mood screening, and those that have explored this have typically focused on clinician's willingness to screen (Mitchel *et al.*, 2011). The length of time required to administer the screening instrument appears to be an important influence (Bermejo *et al.*, 2005; Tai-Seale *et al.*, 2005). Thus, screening must remain acceptable to front-line professionals, stroke survivors and their carers in order to be utilised in day to day clinical practice. Future work could further explore stroke carers and survivor's experience of the proxy BOA tool in the screening process.

A second main theme emerged about the difficulties with the BOA, with subthemes of difficulties interpreting the survivor's mood and the lack of relevance of some of the questions. Whilst the latter was only raised by two carers, it raises an important issue. In order to meet the requirement of brevity and simplicity, the BOA necessarily contains only ten items. It is therefore unsurprising that the items are not relevant to every stroke survivor-carer pair. Moreover, the BOA is unlikely to capture the wealth of information that a lengthier tool might without further inquiry. Research has found

that the length of time a screening tool takes to administer is a key prediction of whether it will be implemented into routine clinical practice (Mitchell *et al.*, 2008).

Feedback indicated that the items would have been relevant had the BOA been completed at an earlier date, suggesting that for at least some carers, the items correspond to anxiety and distress experienced by the survivor during an earlier post stroke phase. Whilst not a focus of the present study, this offers tentative support for the use of the BOA in the more acute stages. Indeed it is a strength of this study that carer feedback was sought as increasing emphasis in health policy is placed on the need for measurement tools to encompass the matters that are significant and relevant to service users (for example patient- reported outcome measures; Darzi, 2008).

It is acknowledged that whilst the BOA and other observational measures offer a practical solution to screening mood in individuals with aphasia (Lincoln *et al.*, 2012), they are reliant upon external displays of emotion which may be misleading or masked by disorders of emotional expression. For example, problems with initiation and dysprosodia can mask or mimic internal feelings of distress. Dysprosodia is a disorder of the production of the features of speech that communicate emotion (Levenson, 2007). Changes to the intensity, timing, rhythm, melody and intonation of words are characteristic. It is not related to inability to actually experience emotions. Dysprosodic speech frequently sounds flat, and since others must interpret the aphasic stroke survivor's internal emotional status from their behaviours, facial expression and speech content (Levenson, 2007), this may lead to misinterpretation and, therefore, misclassification. Guidelines suggest the use of visual analogue scales in addition to observer ratings to support a thorough screening of stroke survivors with communication difficulties (Gillham & Clark, 2011).

4.4 Ethical considerations

This research supports previous work regarding the process of informed consent with individuals with communication impairments (Braunack-Mayer & Hersh, 2001) and extended this to a stroke survivor population. Adjustments to the process of informed consent were made in this study to enhance aphasic stroke survivor's

ability to participate. Survivors were provided with adequate time to process the consent information and this was offered in multiple forms when necessary in line with recommendations by Braunack-Mayer & Hersh (2001). Future studies could usefully explore and compile guidelines outlining practical, applied strategies for maximising and supporting the ability of aphasic stroke survivors to provide informed consent. This may facilitate the consent process for researchers and clinicians and enhance the inclusion of aphasic stroke survivors in future research (Kagan & Kimelman, 1995).

4.5 Further research

Whilst not a focus of this study, the findings have potential implications for the anxiety screening of individuals for whom aphasia is the result of other conditions, for example, acquired brain injury and dementia. The BOA offers a clinically useful and efficient means of screening anxiety in those who may be prone to unreliable self-reports due to aphasia, memory impairment or lack of emotional insight. Further assessment of those survivors who score above a cut-off may be offered, although precisely what cut-off should be used with other aphasic groups is subject to further validation studies.

Though the BOA has limitations, no alternative measures which can be used for this purpose with aphasic stroke survivors exist. Further research exploring the relationship between the observational BOA and the self-report TRCs in a larger sample of aphasic stroke survivors and anxiety is indicated. Whilst this study determined construct and concurrent validity and reliability (internal consistency, test-retest reliability) of the BOA and GAD-7, further investigation of other psychometric properties such as inter-rater reliability and responsiveness to clinical change, in a larger sample of stroke survivors recruited from hospital and community settings is required.

Kneebone *et al.* (2014) suggest further research might investigate the validity of the BOA by means of physiological measures of typical symptoms of anxiety such as tension. The establishment of discriminant validity with depression and the

experience of professionals using the BOA are other areas worthy of exploration (Linley-Adams *et al.*, 2014).

4.6 Conclusion

Post stroke anxiety is a pervasive and long term clinical challenge. It is associated with lower quality of life and depression, which is predictive of poorer prognosis and survival (Ayerbe, Ayis, Crichton *et al.*, 2013). The ability to identify anxiety in stroke survivors with aphasia is essential to clinical practice. The BOA aims to screen anxious mood. This denotes a continuum from a feeling of stress and worry to an atypical state of clinical anxiety. This study does not provide evidence that the BOA will identify a clinical anxiety disorder. Validation against diagnostic criteria is required for this purpose.

This study does provide evidence that the BOA can identify those aphasic stroke survivors who are judged to be anxious by a carer and whom may require further assessment. This study supports the use of the BOA as a valid and reliable screen of anxiety, with good sensitivity and specificity, in stroke survivors with aphasia residing in the community. The evidence for validity is reasonable and warrants additional evaluation. There is currently no 'perfect' screening tool for anxiety among aphasic stroke survivors and interpretation of the BOA may be most useful when combined with survivors' self-report (if this can be provided) and the observations of significant others and professionals. The current study also found preliminary evidence for the validity of the GAD-7, and further investigation is suggested.

The BOA offers professionals a more structured and reliable approach to assessing the likelihood that a stroke survivor with communication impairment is suffering with anxiety than is currently available in clinical practice. A convergence of information from several sources may offer the most accurate approach to screening. Specifically, a holistic approach could aim to combine observations and reports by various significant others or caregivers who are familiar with the individual's functioning. The BOA may therefore assist with the decision of whether to refer a stroke survivor to a specialist professional for advice on intervention or management of their anxiety problem. Thus, the BOA and the GAD-7 offer a promising method of

detecting anxiety in aphasic stroke survivors, and have the potential to fit within, and promote, a holistic and person centred approach to identifying and managing post stroke distress.

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Appendix 1.1 Systematic review search process

Total articles found:

422 papers identified following exclusion of duplicates through searching databases using search criteria (section 1.10.2)

Manual search of titles and abstracts; following irrelevant and excluded:

Studies of non-stroke populations (n= 163)

Studies focussed on stroke carers (n= 84)

Studies within the stroke field that were not mood screening related (n= 140)

Studies of translations of existing measures in different countries (n= 2)

Remaining articles reviewed in greater detail; following excluded:

Studies of tools that were designed for assessment of mood or diagnosis rather than screening tool (n= 6)

Studies of tools for the assessment of generic related constructs (e.g. quality of life; n= 3)

Conference papers or abstracts where the data could not be accessed (n= 1)

Inclusion of non-stroke survivors (e.g. TBI) or where less than 70% of the participants had suffered a stroke and where stroke data were not separately reported (n= 1)

Studies of tools where the cut-off scores did not yield sensitivity values of ≥0.80 and specificity ≥0.60 (n= 13)

Remaining articles to include in systematic review: **9**

'Grey' literature and professional bodies searched:

0 new relevant articles identified

9 studies in review

Appendix 2.1 Participant information sheet

NHS WALES GIG CYMRU

School of Psychology
Ysgol Seicoleg

South Wales Doctoral Programme in Clinical Psychology
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PARTICIPANT INFORMATION SHEET

You are invited to take part in a research study which is being carried out by Alicia Eccles, Trainee Clinical Psychologist, under the supervision of Professor Reg Morris (Consultant Clinical Psychologist, South Wales Doctoral Programme in Clinical Psychology). The results of the research will be written up as a thesis and submitted as part of the researchers' Clinical Psychology doctoral training. It may also be published as a journal article, but no participants will be identified in either published work. Before you decide whether you would like to take part, please read this information sheet which explains the purpose of the research and how you can help with it. Please feel free to discuss this with others or contact the researcher (details below) to ask any questions if there is anything you are not sure about, or if you would like more information.

What is the purpose of the study?

There is currently no validated questionnaire to assess anxiety after stroke in patients with communication difficulties. The aim of this project is to validate a 10-item anxiety questionnaire for use with stroke survivors with communication difficulties (Kneebone *et al.*, 2011). The questionnaire assesses how anxious the survivor feels by asking their carer about their appearance and behaviour. The characteristics of the test have been established in a sample of survivors without communication difficulties and this study aims to assess its performance in those with communication difficulties.

A second aim of this project is to study the effectiveness of self-administered relaxation training on anxiety levels in stroke survivors. This research project may enhance the chances of patients with communication difficulties being diagnosed and treated for anxiety. To do this we need to test the questionnaire and relaxation training on stroke survivors with communication difficulties.

If the stroke survivor has communication difficulties, can they take part?

Yes! We need to test the questionnaire on patients with varying degrees of communication difficulties in this project. Support will be provided to those who struggle to communicate to help them to complete the questionnaire.

Do I have to take part?

You are free to decide whether or not you would like to take part, as participation in this research study is entirely voluntary. If you decide to take part please fill in and return the reply slip with the demographic questionnaire (we will need both the carer and the stroke survivor to do this). If you decide to take part you are free to withdraw at any time.

Do both the stroke survivor and his/her carer/spouse need to take part?

Yes, for this project we do need both the stroke survivor and his/her carer to take part in completing the questionnaire, although only the stroke survivor will be asked to take part in the relaxation training.

What is involved if I do agree to take part?

If you decide to take part in the research there will be two forms for you to fill in: a demographics questionnaire and the Tension Rating Circles (TRCs) measure. This should take no longer than 10 minutes to fill in the two forms. You will also be asked to take part in a short assessment of communication called the Frenchay Aphasic Severity Test (FAST). This will take approximately five minutes to complete. There will also be very similar forms for your spouse/carer to complete in addition to the Behavioural Outcomes of Anxiety (BOA) questionnaire (10 tick box questions), the Generalised Anxiety Disorder-7 (GAD-7) questionnaire (7 tick box questions) and the Hospital Anxiety and Depression Scale (HADS-A) questionnaire (7 tick box questions).

A proportion of carers and survivors will then complete the questionnaires again two weeks later. Some survivors will be invited to take part in relaxation training. This will involve listening to a short relaxation CD and practicing breathing and muscle relaxation exercises every day for two weeks. You will be given the second forms when you complete the first ones and reminded to send it back. If you require assistance to complete the forms then a mutually convenient date and time will be arranged.

What are the potential advantages of taking part?

You will be making a contribution to potentially help people with communication difficulties be diagnosed and treated for anxiety in the future. You will have the opportunity to be randomly selected to take part in a relaxation training program aimed at reducing tension and the effects of anxiety.

What are the possible disadvantages of taking part?

There are no known risks involved in taking part in this study. However you can withdraw from the study at any point until the data are fully anonymised. If you feel concerned by any issues that arise from the questionnaires you would be able to contact the lead researcher, Alicia Eccles or the research supervisor, Professor Reg Morris (contact details below) to discuss.

Will my participation in the study be confidential?

Your participation in the research will be kept strictly confidential. The questionnaires will be seen only by the researcher (Alicia Eccles) and research supervisor (Prof. Reg Morris). They will be kept in a locked filing cabinet and held anonymously, using made up names, so that it is impossible to trace this information back to you individually.

Who has reviewed the study?

All research is reviewed by a Research Ethics Committee in order to protect your safety, rights, dignity and wellbeing. This study has been reviewed and approved by the Cardiff University School of Psychology Research Ethics Committee.

Further information

If you have any further questions about taking part in the study or need further information please do not hesitate to contact the researcher (contact details below).

Thank you very much for taking the time to read this information sheet, your help is greatly appreciated.

Alicia Eccles, Trainee Clinical Psychologist

Professor Reg Morris, Supervisor

South Wales Training Programme in Clinical Psychology
11th Floor, Tower Building
Cardiff University
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Cardiff
CF10 3AT
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Appendix 2.2 Reply slip

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REPLY SLIP FOR STROKE SURVIVOR

Please tick all that apply

For the Stroke Survivor:

☐ I am interested in taking part in the research.

☐ I would like more information before I decide whether or not to take part.

The following information is to enable initial contact; it will not be used in the study.

Name: _____

E-mail Address: _____

Telephone number: _____

Can a message be left at this telephone number (please tick)?

☐ Yes

☐ No

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REPLY SLIP FOR CARER

Please tick all that apply

For the Carer:

☐ I am happy to take part in the research.

☐ I would like more information before I decide whether or not to take part.

Name of carer: _____

E-mail Address: _____

Telephone number: _____

Can a message be left at this telephone number (please tick)?

☐ Yes

☐ No

Please post this reply slip to Alicia Eccles, Trainee Clinical Psychologist, at the address below. If you would like to take part in the research, please also both complete and return the relevant demographic questionnaires with this slip.

Thank-you

Alicia Eccles Trainee Clinical Psychologist

Professor Reg Morris, Supervisor

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Appendix 2.3 Participant consent form– stroke survivor

NHS WALES GIG CYMRU

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CONSENT FORM (stroke survivor)

Title of Project: **Validation of Behavioural Outcomes of Anxiety (BOA) questionnaire in stroke survivors with aphasia**

Name of Researcher: **Alicia Eccles**

Please initial all boxes

I understand that my participation in this study will involve completing three measures taking approximately 15 minutes.	☐
I understand that my participation in this study is entirely voluntary and that I can withdraw from the study at any time, without giving a reason.	☐
I understand that I am free to ask questions at any time. I am free to discuss my concerns with Professor Reg Morris, Consultant Clinical Psychologist and Programme Director on the South Wales Doctoral Programme in Clinical Psychology.	☐
I understand that the information provided by me will be held confidentially, such that only the Researcher can trace this information back to me individually. The information will be retained for up to 2 years then it will be destroyed. I understand I can ask for information I provide to be destroyed at any time and I can have access to the information at any time.	☐
I give permission for the information to be used in reports with the understanding that it will remain anonymous.	☐

I understand that at the end of the study I will be provided with additional information and feedback about the purpose of the study. ☐

Name of Participant	Date	Signature
Name of Person taking consent	Date	Signature

Appendix 2.4 Participant consent form– carer

NHS WALES GIG CYMRU

School of Psychology
Ysgol Seicoleg

South Wales Doctoral Programme in Clinical Psychology
De Cymru Rhaglen Doethuriaeth mewn Seicoleg Glinigol

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Prifysgol Caerdydd
Adeilad y Tŵr
70 Plas y Parc
Caerdydd CF10 3AT
Cymru Y Deyrnas Unedig

CONSENT FORM (carer)

Title of Project: **Validation of Behavioural Outcomes of Anxiety (BOA) questionnaire in stroke survivors with aphasia**

Name of Researcher: **Alicia Eccles**

Please initial all boxes

I understand that my participation in this study will involve five questionnaires taking approximately 30 minutes.	☐
I understand that my participation in this study is entirely voluntary and that I can withdraw from the study at any time, without giving a reason.	☐
I understand that I am free to ask questions at any time. I am free to discuss my concerns with Professor Reg Morris, Consultant Clinical Psychologist and Programme Director on the South Wales Doctoral Programme in Clinical Psychology.	☐
I understand that the information provided by me will be held confidentially, such that only the Researcher can trace this information back to me individually. The information will be retained for up to 2 years then it will be destroyed. I understand can ask for information I provide to be destroyed at any time and I can have access to the information at any time.	☐
I give permission for the information to be used in reports with the understanding that it will remain anonymous.	☐

I understand that the information I give will remain anonymous to the person whom to which I provide care for ☐

I understand that at the end of the study I will be provided with additional information and feedback about the purpose of the study. ☐

Name of Participant	Date	Signature
Name of Person taking consent	Date	Signature

Appendix 2.5 Demographic questionnaire for stroke survivor

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DEMOGRAPHIC QUESTIONNAIRE

The following information will be used anonymously in the study. Please answer as many questions as possible. However, you do not have to answer anything you don't want to. Thank-you.

Today's Date: _____

Gender:

☐ **Male**

☐ **Female**

Date of birth: _____

How has the stroke impacted you as you are AT PRESENT (please tick)?

	Not at all	A little	A lot
My ability to remember things			
My ability to do things			
My ability to walk			
My ability to communicate			

Date of stroke: _____

Type of Stroke (if known): _____

Current occupation: _____

Living circumstances:

- ☐ Living with a carer
- ☐ Living with someone who is not a carer
- ☐ Living alone

Have you had more than 1 stroke?

- ☐ Yes
- ☐ No

Did you suffer with anxiety or depression in the 2 years before the stroke?

- ☐ Yes
- ☐ No

Appendix 2.6 Demographic questionnaire for carer

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DEMOGRAPHIC QUESTIONNAIRE

The following information will be used anonymously in the study. Please answer as many questions as possible. However, you do not have to answer anything you don't want to. Thank-you.

Today's Date: _____

Gender:

☐ **Male**

☐ **Female**

Date of Birth: _____

Relationship to stroke survivor:

☐ **Spouse**

☐ **Offspring**

☐ **Professional carer**

☐ **Other (please specify)**

How much time have you spent with him/her in last week? _____ hours.

How has the stroke impacted on him/her as he/she is AT PRESENT (please tick)?

	Not at all	A little	A lot
Their ability to remember things			
Their ability to do things			
Their ability to walk			
Their ability to communicate			

Date of stroke: _____

Has he/she had more than 1 stroke?

☐ Yes

☐ No

Type of Stroke (if known): _____

Living circumstances:

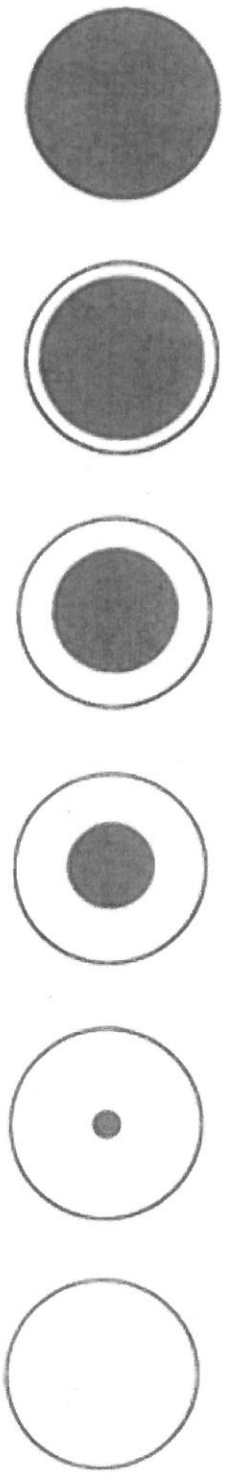
☐ I live with the survivor

☐ I do not live with the survivor

Current occupation: _____

Appendix 2.7 Tension Rating Circles (TRCs)

Tension Rating Circles (TRCs)



•This is a scale to measure tension and anxiety. Please point to each of the circles in turn to make sure that you can see them all. [Continue only if satisfactorily accomplished]

•The grey circles show how tense you feel. [Indicate the clear circle at the bottom]

•The bottom circle shows no tension. [Indicate the fully shaded circle at the top]

•The top circle shows tension as bad as it can be. [Pointing at each circle in ascending order]

•As you go from the bottom circle to the top, you can see that tension is becoming more and more severe.

•Which of these circles shows how tense and anxious you feel today?

To the administrator:

In your opinion was the person able to understand this scale?

Yes ☐

No ☐

Appendix 2.8 Frenchay Aphasia Severity Test (FAST)

Frenchay Aphasia Screening Test Administration Form

Materials required:
Picture card with attached reading cards, pencil and paper, stop watch, or watch with second hand.

Check:
Patient is wearing spectacles, if needed. Patient can hear you adequately (raise voice if necessary).

Comprehension

Show patient card with river scene. Say: 'Look at the picture. Listen carefully to what is said and point to the things I tell you to.' Score 1 for each correctly performed. If instructions require repeating, score as error. Unprompted self-correction may be scored as correct. Score range 0–10.

Instructions

(a) *River scene*
Practice item: 'Point to the river'. Do not score this item. Repeat until patient understands what is required.

1 Point to a boat
2 Point to the tallest tree
3 Point to the man and point to the dog
4 Point to the man's left leg and then to the canoe
5 Before pointing to a duck near the bridge, show me the middle hill

(b) *Shapes*
Practice item: 'Point to the circle'. Repeat until patient understands task.

1 Point to the square
2 Point to the cone
3 Point to the oblong and the square
4 Point to the square, the cone and the semicircle
5 Point to the one that looks like a pyramid and the one that looks like a segment of orange

Expression

(a) Show patient the river scene and say: 'Tell me as much about the picture as you can.' If the patient does not appear to understand, say: 'Name anything you can see in the picture.' Score range 0–5.

Score

0 Unable to name any objects intelligibly
1 Names 1–2 objects
2 Names 3–4 objects
3 Names 5–7 objects
4 Names 8 or 9 objects or uses phrases and sentences, but performance *not* normal (e.g. hesitations, inappropriate comments, etc.)
5 Normal – uses phrases and sentences, naming 10 items

(b) Remove picture card from view and inform patient that you are now going to attempt something a little different. Then ask him to name as many animals as he can think of in 1 minute. If patient appears doubtful, explain that you want the names of any kind of animal, wild or domestic, and not just those which may have been seen in the picture. Commence timing as soon as patient names first animal and allow 60 seconds. Score range 0–5.

Score

0 None named
1 Names 1–2
2 Names 3–5
3 Names 6–9
4 Names 10–14
5 Names 15 or more

Reading

Check that the patient is wearing correct spectacles for reading purposes. Show patient river scene and first reading card. Ask him to read the sentence to himself, not aloud, and do whatever it instructs him to do. Proceed in the same manner with the remaining four reading cards. Score range 0–5.

Score 1 for each correct.

Writing

Show patient river scene and say: 'Please write as much as you can about what is happening in the picture.' If he does not appear to understand say: 'Write anything that you can see in the picture.' If dominant hand is affected ask patient to attempt with non-dominant hand. Encourage if he stops prematurely. Allow a MAXIMUM of 5 minutes. Score range 0–5.

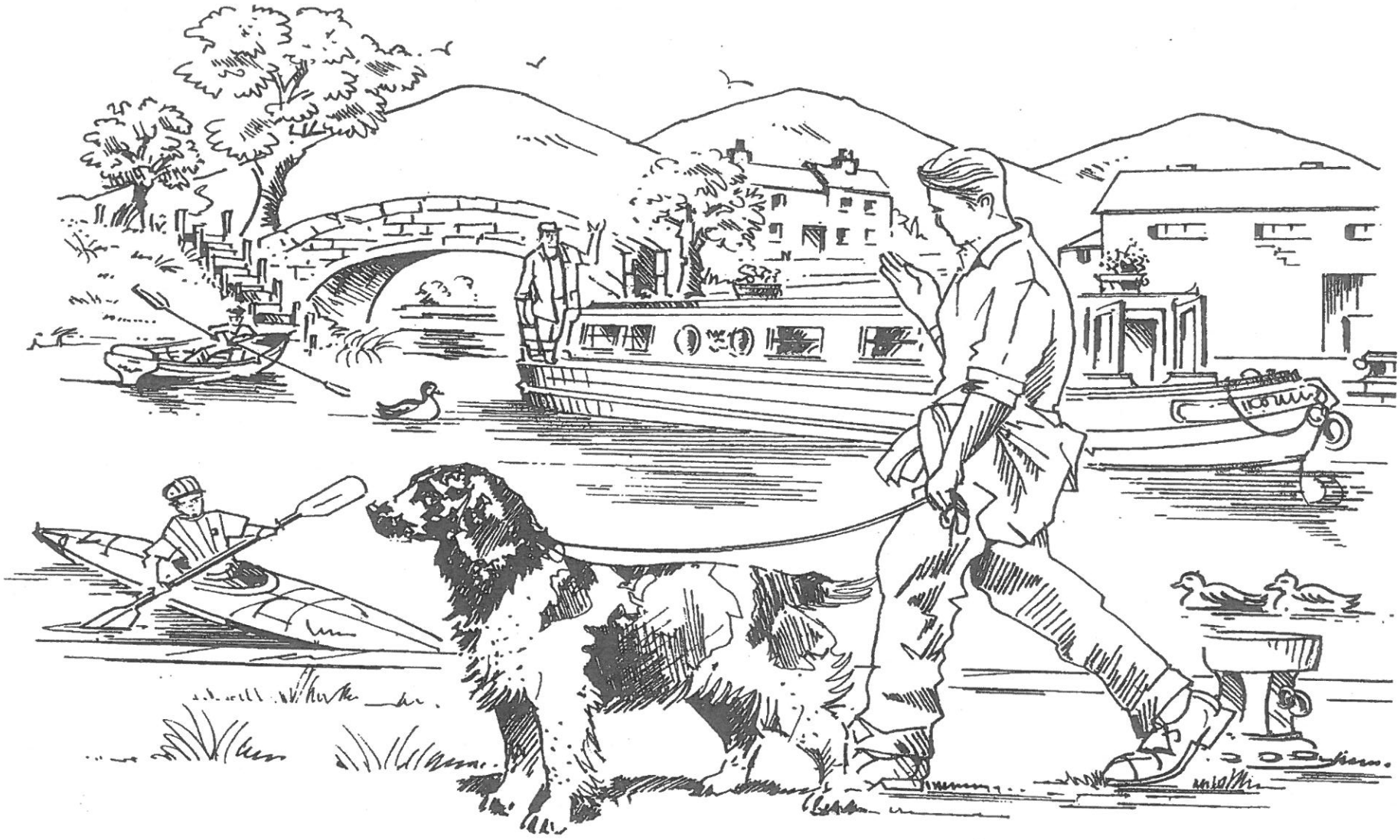
Score

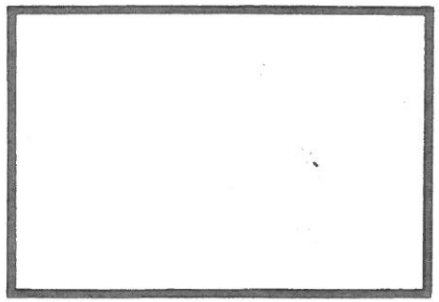
0 Able to attempt task but does not write any intelligible or appropriate words
1 Writes 1 or 2 appropriate words
2 Writes down names of 3 objects or a phrase including 2 or 3 objects
3 Writes down names of 4 objects (correctly spelled), or 2 or 3 phrases including names of 4 items
4 Uses phrases and sentences, including names of 5 items, but *not* considered 'normal' performance, e.g. sentence is not integrating people and actions
5 Definitely normal performance, e.g. sentence integrating people and actions

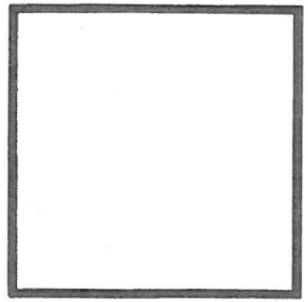
Interpretation

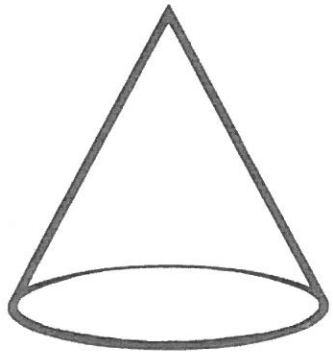
The presence of aphasia is indicated if the patient scores below the following cut-off points. (Referral to speech therapy for full assessment is suggested.)

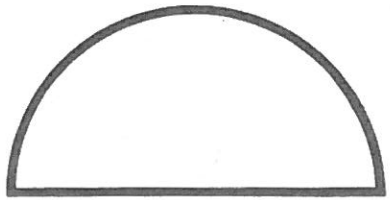
Age	*Raw Score*
Up to 60	27
61+	25

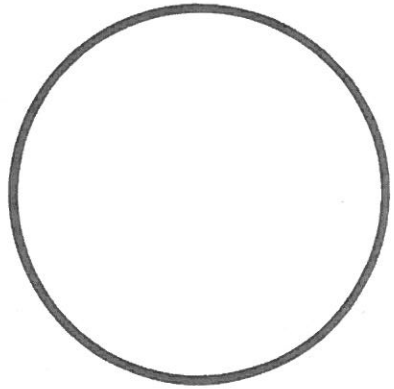












Appendix 2.9 Behavioural Outcomes of Anxiety (BOA) Questionnaire

BEHAVIOURAL OUTCOMES OF ANXIETY (BOA)

You should give your own views on each question and NOT ask the stroke survivor about how they feel when answering. Please read each item and place a tick in the box which comes closest to how you think he/she has been feeling in the PAST WEEK. Try not to take too much time over it, as your immediate reaction should be accurate.

Participant ID_____ **Date**_____

	Often	Sometimes	Rarely	Never
He/she has appeared particularly tense or on edge.	☐	☐	☐	☐
He /she has had a strained face.	☐	☐	☐	☐
He /she has had trouble falling asleep.	☐	☐	☐	☐
He /she has been getting tired easily.	☐	☐	☐	☐
He /she has been restless or constantly on the move (e.g. pacing).	☐	☐	☐	☐
He /she has appeared anxious.	☐	☐	☐	☐
He /she has appeared to suddenly panic.	☐	☐	☐	☐
He /she has appeared fearful of falling.	☐	☐	☐	☐
He /she has avoided activities or social engagements.	☐	☐	☐	☐
He /she has been jumpy or easily startled.	☐	☐	☐	☐

Appendix 2.10 Hospital Anxiety and Depression Scale- Anxiety Subscale

Hospital Anxiety and Depression Scale- Anxiety Subscale (HADS-A)

You should give your own views on each question and NOT ask the stroke survivor about how they feel when answering. Please read each item and place a tick in the box opposite the reply which comes closest to how you think they have been feeling in the past week. Don't take too long over your replies; your immediate reaction to each item will probably be more accurate than a long thought out response.

Participant ID_____ **Date**_____

He/she has felt tense or 'wound up':

- ☐ Most of the time
- ☐ A lot of the time
- ☐ Sometimes
- ☐ Not at all

He/she has had a sort of frightened feeling like 'butterflies' in the stomach:

- ☐ Not at all
- ☐ Occasionally
- ☐ Quite often
- ☐ Very often

He/she has had a sort of frightened feeling as if something awful is about to happen:

- ☐ Very definitely and quite badly
- ☐ Yes, but not too badly
- ☐ A little
- ☐ Not at all

He/she has felt restless as if he/she has to be on the move:

- ☐ Very much indeed
- ☐ Quite a lot
- ☐ Not very much
- ☐ Not at all

Worrying thoughts have gone through his/her mind:

- ☐ A great deal of the time
- ☐ A lot of the time
- ☐ From time to time but not too often
- ☐ Only occasionally

He/she has had sudden feelings of panic:

- ☐ Very often indeed
- ☐ Quite often
- ☐ Not very often
- ☐ Not at all

He/she has been able to sit at ease and feel relaxed:

- ☐ Definitely
- ☐ Usually
- ☐ Not often
- ☐ Not at all

Appendix 2.11 Generalised Anxiety Disorder 7-item (GAD-7) Scale

Generalised Anxiety Disorder 7-item (GAD-7)

You should give your own views on each question and NOT ask the stroke survivor about how they feel when answering. Please read each item and place tick in the box opposite the reply which comes closest to how you think they have been feeling in the past 2 weeks. Don't take too long over your replies; your immediate reaction to each item will probably be more accurate than a long thought out response.

Participant ID_____ **Date**_____

Over the last 2 weeks, how often has he/she been bothered by the following problems?

	Not at all	Several days	Over half the days	Nearly everyday
1. Feeling nervous, anxious, or on edge				
2. Not being able to stop or control worrying				
3. Worrying too much about different things				
4. Trouble relaxing				
5. Being so restless that it's hard to sit still				
6. Becoming easily annoyed or irritable				
7. Feeling afraid as if something awful might happen				

Appendix 2.12 Experience of using the BOA questionnaire

Experience of using the BOA questionnaire

We are interested to hear your views on completing the Behavioural Outcomes of Anxiety (BOA) questionnaire.

Please read each statement and write the number that corresponds to how much you agree or disagree. There is space below to write any additional comments about your experience of using the BOA.

1	2	3	4	5
Strongly Disagree	**Disagree**	**Neither Agree Nor Disagree**	**Agree**	**Strongly Agree**

Write a number 1 to 5 in the box below

1. **I felt confident completing the BOA questionnaire** ☐

2. **The questions made sense to me** ☐

3. **The questionnaire was easy to complete** ☐

4a. It was difficult to complete the questionnaire ☐

4b. If you agree or strongly agree please write down some of the reasons it was difficult

.....

.....

.....

.....

.....

.....

.....

Please use the space below to write any comments about <u>your</u> experience of completing the BOA questionnaire:

.....

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Appendix 2.13 Progressive muscle relaxation training CD

Relaxation training instruction pack

This handout will tell you how to get the best from the relaxation CD. This kind of relaxation is called:

Progressive Muscular Relaxation (PMR)

Anxiety affects two main parts of the body:

Muscles e.g.:

- tight chest
- pain at the back of the neck
- aches and pains

Autonomic Nervous System (ANS) e.g.:

- heart racing
- feeling breathless
- sweating

Anxiety tenses your muscles. Anxiety speeds up your body. PMR teaches you:

- to relax the muscles
- to control your breathing. This, in turn, controls the ANS and slows down your body

Together these two skills will teach you how to control your body.

Deep Relaxation

One word of warning. If you have any problems such as a back problem and think that PMR might make it worse, ask your GP before you play it.

Let us look at some of the common questions about PMR:

What is it?
PMR teaches you how to relax your body and mind. You first become aware of the way stress affects your body (*'I didn't realise that my shoulders were up at my ears all day'*). Once you are aware of this, you then use it to get rid of it. Once you get good at it, you will spot stress creep into your body at a much earlier stage. So you will be able to nip it in the bud.

Like all skills, PMR takes time to pick up. You should expect that it will take a while to start to feel relaxed when you play it. Bear in mind you are learning something you have lost the knack of or even haven't had in the first place. So be patient.

How can I find the time?
When you feel anxious, it can be hard to find time to get anything done. So the first major test is to find time each day to play it. If you can, try to play it at the same time each day to build up a routine.

Where should I play it?
Play it in a room where you can get some peace and quiet. Play it where you can be warm and comfy. You could try different rooms to see which is best for you.

Should I sit or lie down?
Suit yourself. The best places may be the bed or the settee. You may prefer the floor. If you have a comfy chair (recliners are very good), you could use this.

When should I play it?
Every day. You have to give it top priority if you want to learn to relax. Decide what time of day suits you best and, if you can, stick to this time.

What will happen when I play it?
The presenter will get you to tense and relax your muscles. The idea is that you become aware of the difference between tension and relaxation in your muscles. You will work your way through all the major muscles in your body, relaxing them as you go.

As you do this, it will help you to slow your breathing to a steady pace. This will help slow down your body and help it relax more.

Toward the end of it, you will move onto ways to relax your mind. After the talking stops, you can just stay where you are to enjoy the relaxed feeling. You count back from 4 to 1 to end.

10 tips to help you relax

1. Get as comfy as you can before you start. Take off your shoes and wear loose clothes. Make sure the room is warm. If you can, take the phone off the hook. Make sure no one comes in the room while you play it. If they want to join in from the start then that is fine.

2. At first, you should play it when you are feeling fairly calm. You will be able to concentrate better. This will let you pick up the skill more quickly.

3. When you go to play it, you may think of all the other things you should be doing instead. This is a common problem. Do not get distracted. You must set aside time to relax.

4. As with learning any skill, practice makes perfect. So play it each day. Try to use it at the same time.

5. Don't worry about how well or badly you are doing. Most people find that their mind wanders during the first few sessions. This is normal. As you get used to it, this will improve. Let relaxation come in its own time. Don't try to rush it and, when the feeling comes, enjoy it.

6. Practise slowing down your breathing to about 10-12 breaths per minute at various times of the day. Use the seconds hand on your watch. This will help you keep your body calm right across the day.

7. PMR can leave you feeling nicely drowsy. Some people fall asleep. If you are one of them, don't worry but bear in mind that you are learning a skill. So you will get more out of it if you can stay awake.

8. You may find that when you tense your muscles, you hold your breath. Don't worry; most people do this at the start. Try to keep the muscle tensing and breathing control separate.

9. Keep a diary. There are diaries at the end of this handout. Fill them in after you play it each time. These will let you check your progress as the days go by.

10. Keep playing your Deep PMR until you can relax well.

Summary

Start with Deep Relaxation / keep a diary.

Play it every day until you learn to relax.

Relaxation diary

Before you begin, rate how anxious you feel using the 1-10 scale below. A score of 10 would mean your anxiety could not be worse. A score of 1 would mean you were not feeling any anxiety. When it ends, rate your anxiety again using the same scale. You can also make some notes about how you got on. Look at the example below.

|------|------|------|------|------|------|------|----**X**|------|
1 2 3 4 5 6 7 8 9 10

This rating would mean you were under a lot of anxiety.

Fill out the diary each time you play it.

	Time and Place	Anxiety level before playing	Anxiety level after playing
Day 1			
Day 2			
Day 3			
Day 4			
Day 5			
Day 6			
Day 7			
Day 8			
Day 9			
Day 10			
Day 11			
Day 12			
Day 13			
Day 14			

Appendix 2.15 Participant debriefing information sheet for carer and stroke survivor

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DEBRIEFING INFORMATION SHEET

Thank-you very much for taking part in the project, your time and effort is very much appreciated. The information that you have provided in the questionnaires will be put together and analysed with the information collected from other stroke survivors and carers for this research. We hope that the results from this study will help us to validate the Behavioural Outcomes of Anxiety (BOA) questionnaire to assess anxiety after stroke in stroke survivors with communication difficulties. We compared the answers on the BOA completed by carers with the Tension Rating Circles completed by the stroke survivor to see whether giving the questionnaire to the carer of a stroke survivor with communication difficulties is likely to be effective in assessing the patient's anxiety. This may provide a way for stroke patients with language difficulties to be diagnosed with anxiety disorders and to receive treatment in the future.

Some stroke survivors also did relaxation training exercises. We will compare the answers on the questionnaires completed after the relaxation training against a group of stroke survivors who did not do any relaxation training to see whether self-administered relaxation exercises are effective in reducing anxiety and tension. This may increase the availability of anxiety management treatment in the future.

The information you provided will be coded and analysed with that from the other participants in this research project. Your data will be held confidentially and you have the right to withdraw your data without explanation and retrospectively if you so choose, up until the point that the data are fully anonymised.

If taking part in this study has caused you distress, please contact us so that we may explore avenues for you to gain extra support. If you did not take part in the relaxation training but would like to receive the information and a relaxation CD please inform us and we will be happy to provide you with copies.

If you wish to have information about the results of the study please contact Alicia Eccles and she will send you a summary of the results as soon as they are available.

If you have any further questions or comments please contact us:

Researcher

Alicia Eccles

Trainee Clinical Psychologist

alicia.eccles@wales.nhs.uk

Research Supervisor

Professor Reg Morris

Consultant Clinical Psychologist

reg.morris@wales.nhs.uk

South Wales Training Programme in Clinical Psychology
11th Floor, Tower Building
Cardiff University
70 Park Place
Cardiff
CF10 3AT
02920 876970

If you have any concerns or complaints about the research you can contact the School of Psychology Research Ethics Committee in writing at:

Secretary to the Research Ethics Committee

Tower Building
Cardiff University
70 Park Place
Cardiff
CF10 3AT
02920 876970
psychethics@cardiff.ac.uk

Appendix 2.16 Copy of ethical approval from Cardiff University School of Psychology research ethics committee

From: psychethics@cardiff.ac.uk
Sent: 19 February 2014 10:56:48
To: ecclesaf1@cardiff.ac.uk
Cc: reg.morris@wales.nhs.uk
Subject: Ethics Feedback - EC.13.11.12.3594R

Dear Alicia,

The Ethics Committee has considered the amendment to your postgraduate project: Validation of Behavioural Outcomes of Anxiety (BOA) questionnaire and Generalised Anxiety Disorder 7-item scale (GAD-7) to assess anxiety and effectiveness of self-help relaxation (EC.13.11.12.3594RA).

The amendment has been approved.

Please note that if any further changes are made to the above project then you must notify the Ethics Committee.

Best wishes,

Natalie

Appendix 3.1 Kolmogorov-Smirnov normality test results for each variable

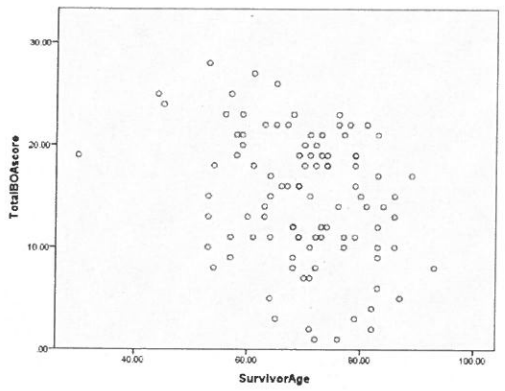
Tests of Normality

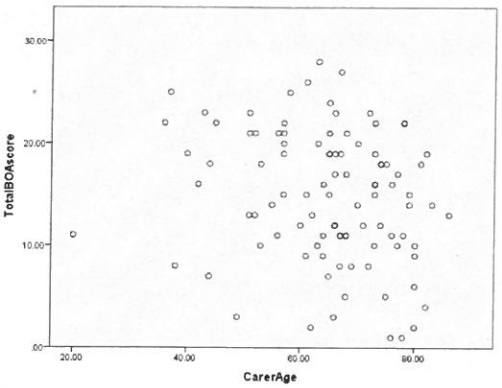
	Kolmogorov-Smirnov[a]			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
SurvivorAge	.073	110	.200*	.977	110	.056
Yearssincestroke	.162	107	.000	.868	107	.000
CarerAge	.121	108	.000	.953	108	.001
CarerYearssincestroke	.173	107	.000	.857	107	.000
TotalBOAscore	.094	111	.018	.981	111	.115
TotalHADSAscore	.104	111	.005	.956	111	.001
TotalGAD7score	.172	111	.000	.878	111	.000
FASTscore	.129	111	.000	.928	111	.000
TotalPostBOAscore	.146	29	.116	.957	29	.270
TotalPostHADSAscore	.237	29	.000	.822	29	.000
TotalPostGAD7score	.204	29	.003	.828	29	.000

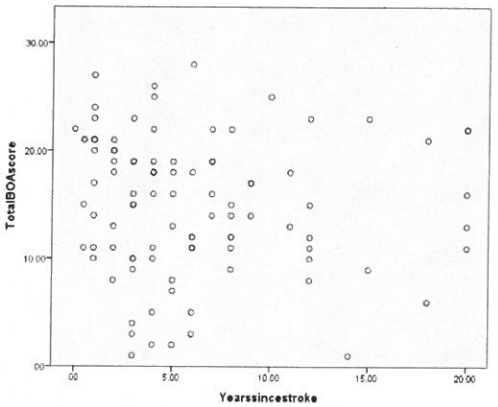
*. This is a lower bound of the true significance.

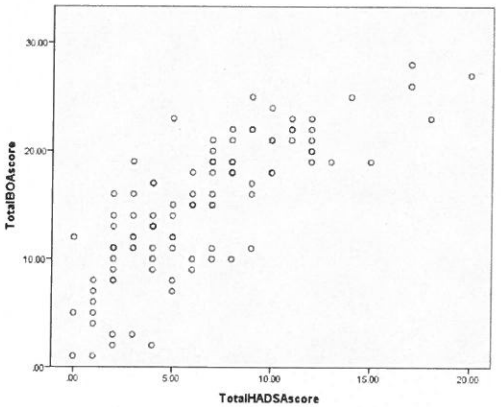
a. Lilliefors Significance Correction

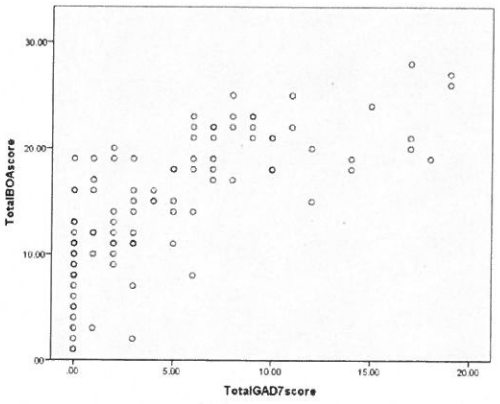
Appendix 3.2 Scatter plots of BOA scores against each independent variable

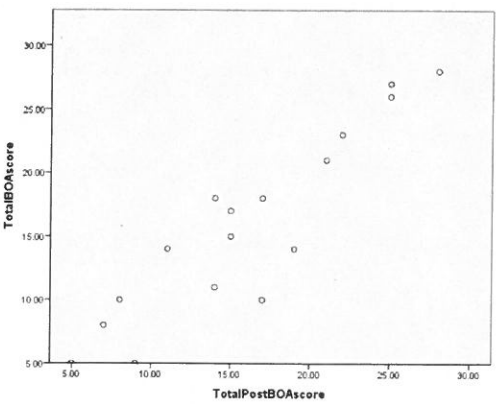


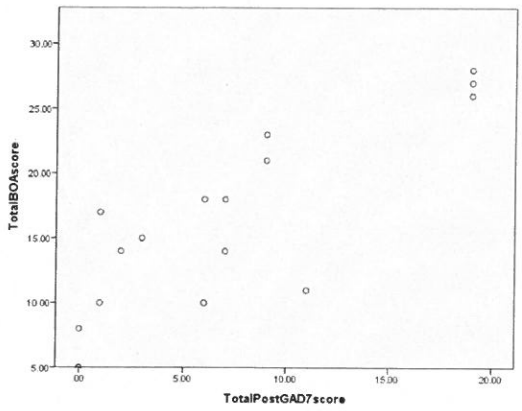











TotalBOAscore
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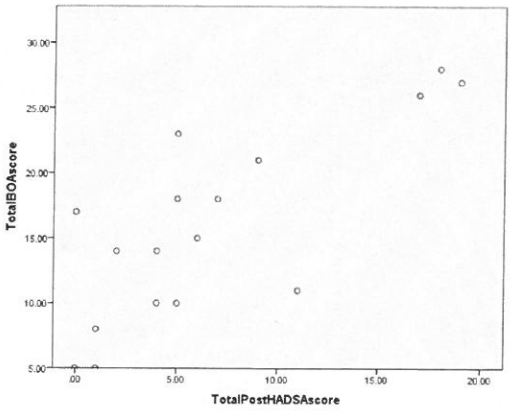
25.00
20.00
15.00
10.00
5.00
.00
5.00
10.00
15.00
20.00
TotalPostGAD7score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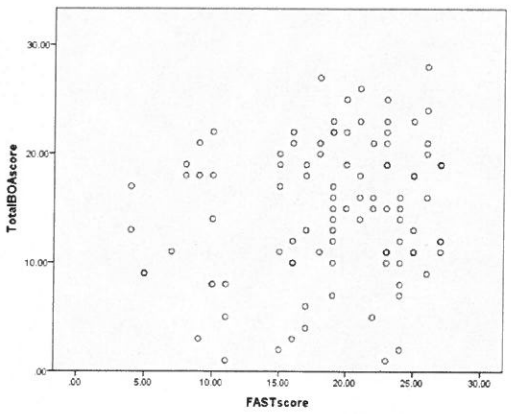
20.00
15.00
10.00
5.00
.00
5.00
10.00
15.00
20.00
TotalPostHADSAscore


TotalBOAscore
30.00
20.00
10.00
.00
.00
5.00
10.00
15.00
20.00
25.00
30.00
FASTscore

Appendix 3.3 Kendall's Tau correlation matrix of continuous variables

		1	2	3	4	5	6	7	8	9	10	11	12
1. Survivor Age		-											
2. Years since Stroke	τ	.069											
	p	.158	-										
	N[a]	106											
3. Carer Age	τ	.492**	.055										
	p	.000	.213	-									
	N	108	105										
4. Carer years since Stroke	τ	.063	.936**	.036									
	p	.181	.000	.304	-								
	N	106	106	104									
5. Total Pre BOA Score	τ	-.163**	-.119*	-.161**	-.122*								
	p	.007	.042	.008	.038	-							
	N	110	107	108	107								
6. Total Pre HADS-A Score	τ	-.168**	-.112	-.141*	-.106	.618**							
	p	.006	.054	.019	.064	.000	-						
	N	110	107	108	107	111							
7. Total Pre GAD-7 Score	τ	-.134*	-.133*	-.120*	-.111	.582**	.660**						
	p	.025	.030	.040	.058	.000	.000	-					
	N	110	107	108	107	111	111						
8. FAST Score	τ	-.140*	-.084	-.053	-.093	.130*	.132*	.096					
	p	.018	.114	.215	.089	.026	.026	.081	-				
	N	110	107	108	107	111	111	111					
9. Total Post BOA Score	τ	.019	-.087	-.112	-.047	.372**	.128	.187	-.085				
	p	.445	.271	.213	.367	.003	.173	.087	.266	-			
	N	28	27	27	28	29	29	29	29				
10. Total Post HADS-A Score	τ	-.031	-.089	-.179	-.106	.427**	.393**	.339**	.013	.585**			
	p	.413	.269	.103	.229	.001	.002	.007	.462	.000	-		
	N	28	27	27	28	29	29	29	29	29			
11. Total Post GAD-7 Score	τ	-.042	-.081	-.172	-.054	.513**	.408**	.452**	.034	.633**	.756**		
	p	.382	.291	.114	.352	.000	.002	.001	.402	.000	.000	-	
	N	28	27	27	28	29	29	29	29	29	29		
12. TRC Score	τ	-.078	-.057	-.054	-.072	.241**	.240**	.246**	.074	-.063	.157	.090	-
	p	.137	.220	.225	.166	.000	.000	.000	.151	.329	.139	.268	
	N	110	107	108	107	111	111	111	111	29	29	29	

a*N*= number of survivors/carers; *p<0.05; **p<0.01 (one-tailed), differences in significance compared to Pearson's correlation coefficient (*r*) highlighted

Appendix 3.4 ROC analysis results for BOA against HADS-A

Variable	Total_BOA_scores Total BOA scores
Classification variable	Case?_1__y__0__no Case? 1= y, 0= no

Sample size	111
Positive group [a]	46 (41.44%)
Negative group [b]	65 (58.56%)

[a] Case?_1__y__0__no = 1
[b] Case?_1__y__0__no = 0

Disease prevalence (%)	10

Area under the ROC curve (AUC)

Area under the ROC curve (AUC)	0.900
Standard Error [a]	0.0298
95% Confidence interval [b]	0.828 to 0.949
z statistic	13.428
Significance level P (Area=0.5)	<0.0001

[a] DeLong *et al.*, 1988
[b] Binomial exact

Youden index

Youden index J	0.7030
Associated criterion	>17
Sensitivity	82.61
Specificity	87.69

Criterion values and coordinates of the ROC curve [Hide]

Criterion	Sensitivity	95% CI	Specificity	95% CI	+LR	-LR	+PV	-PV
≥1	100.00	92.3 - 100.0	0.00	0.0 - 5.5	1.00		10.0	
>9	100.00	92.3 - 100.0	29.23	18.6 - 41.8	1.41	0.00	13.6	100.0
>10	97.83	88.5 - 99.9	35.38	23.9 - 48.2	1.51	0.061	14.4	99.3
>11	95.65	85.2 - 99.5	47.69	35.1 - 60.5	1.83	0.091	16.9	99.0
>12	93.48	82.1 - 98.6	55.38	42.5 - 67.7	2.10	0.12	18.9	98.7
>13	91.30	79.2 - 97.6	63.08	50.2 - 74.7	2.47	0.14	21.6	98.5
>14	86.96	73.7 - 95.1	69.23	56.6 - 80.1	2.83	0.19	23.9	97.9
>15	86.96	73.7 - 95.1	78.46	66.5 - 87.7	4.04	0.17	31.0	98.2
>16	84.78	71.1 - 93.7	84.62	73.5 - 92.4	5.51	0.18	38.0	98.0
>17	82.61	68.6 - 92.2	87.69	77.2 - 94.5	6.71	0.20	42.7	97.8
>18	69.57	54.2 - 82.3	90.77	81.0 - 96.5	7.54	0.34	45.6	96.4
>19	54.35	39.0 - 69.1	95.38	87.1 - 99.0	11.78	0.48	56.7	95.0
>20	50.00	34.9 - 65.1	96.92	89.3 - 99.6	16.25	0.52	64.4	94.6
>21	39.13	25.1 - 54.6	98.46	91.7 - 100.0	25.43	0.62	73.9	93.6
>22	23.91	12.6 - 38.8	98.46	91.7 - 100.0	15.54	0.77	63.3	92.1
>23	15.22	6.3 - 28.9	100.00	94.5 - 100.0		0.85	100.0	91.4
>28	0.00	0.0 - 7.7	100.00	94.5 - 100.0		1.00		90.0

Appendix 3.5 ROC analysis results for GAD-7 against HADS-A

Variable	GAD_7 GAD-7
Classification variable	HADS_A HADS-A

Sample size	111
Positive group [a]	46 (41.44%)
Negative group [b]	65 (58.56%)

[a] HADS_A = 1
[b] HADS_A = 0

Disease prevalence (%)	10

Area under the ROC curve (AUC)

Area under the ROC curve (AUC)	0.936
Standard Error [a]	0.0245
95% Confidence interval [b]	0.873 to 0.974
z statistic	17.778
Significance level P (Area=0.5)	<0.0001

[a] DeLong *et al.*, 1988
[b] Binomial exact

Youden index

Youden index J	0.7465
Associated criterion	>5
Sensitivity	86.96
Specificity	87.69

Criterion values and coordinates of the ROC curve [Hide]

Criterion	Sensitivity	95% CI	Specificity	95% CI	+LR	-LR	+PV	-PV
≥0	100.00	92.3 - 100.0	0.00	0.0 - 5.5	1.00		10.0	
>0	97.83	88.5 - 99.9	40.00	28.0 - 52.9	1.63	0.054	15.3	99.4
>2	97.83	88.5 - 99.9	66.15	53.4 - 77.4	2.89	0.033	24.3	99.6
>3	93.48	82.1 - 98.6	80.00	68.2 - 88.9	4.67	0.082	34.2	99.1
>4	91.30	79.2 - 97.6	83.08	71.7 - 91.2	5.40	0.10	37.5	98.9
>5	86.96	73.7 - 95.1	87.69	77.2 - 94.5	7.07	0.15	44.0	98.4
>6	80.43	66.1 - 90.6	93.85	85.0 - 98.3	13.07	0.21	59.2	97.7
>7	69.57	54.2 - 82.3	95.38	87.1 - 99.0	15.07	0.32	62.6	96.6
>8	58.70	43.2 - 73.0	95.38	87.1 - 99.0	12.72	0.43	58.6	95.4
>9	47.83	32.9 - 63.1	96.92	89.3 - 99.6	15.54	0.54	63.3	94.4
>10	36.96	23.2 - 52.5	98.46	91.7 - 100.0	24.02	0.64	72.7	93.4
>11	32.61	19.5 - 48.0	98.46	91.7 - 100.0	21.20	0.68	70.2	92.9
>12	26.09	14.3 - 41.1	100.00	94.5 - 100.0		0.74	100.0	92.4
>19	0.00	0.0 - 7.7	100.00	94.5 - 100.0		1.00		90.0

Appendix 3.6 ROC analysis results for TRCs against HADS-A

Variable	TRCs
Classification variable	Case?_1__y__0__no Case? 1= y, 0= no

Sample size	111
Positive group [a]	46 (41.44%)
Negative group [b]	65 (58.56%)

[a] Case?_1__y__0__no = 1
[b] Case?_1__y__0__no = 0

Disease prevalence (%)	10

Area under the ROC curve (AUC)

Area under the ROC curve (AUC)	0.622
Standard Error [a]	0.0528
95% Confidence interval [b]	0.525 to 0.713
z statistic	2.316
Significance level P (Area=0.5)	0.0206

[a] DeLong *et al.*, 1988
[b] Binomial exact

Youden index

Youden index J	0.1950
Associated criterion	>2
Sensitivity	45.65
Specificity	73.85

Criterion values and coordinates of the ROC curve [Hide]

Criterion	Sensitivity	95% CI	Specificity	95% CI	+LR	-LR	+PV	-PV
≥0	100.00	92.3 - 100.0	0.00	0.0 - 5.5	1.00		10.0	
>0	86.96	73.7 - 95.1	23.08	13.5 - 35.2	1.13	0.57	11.2	94.1
>1	76.09	61.2 - 87.4	41.54	29.4 - 54.4	1.30	0.58	12.6	94.0
>2	45.65	30.9 - 61.0	73.85	61.5 - 84.0	1.75	0.74	16.2	92.4
>3	17.39	7.8 - 31.4	90.77	81.0 - 96.5	1.88	0.91	17.3	90.8
>4	4.35	0.5 - 14.8	95.38	87.1 - 99.0	0.94	1.00	9.5	90.0
>5	0.00	0.0 - 7.7	100.00	94.5 - 100.0		1.00		90.0

Appendix 3.7 Qualitative feedback on experience of using the BOA- carer quotes

Main theme	Subtheme	Responses
1. Acceptability of the BOA	1. Easy to understand and complete	*1. The form was reasonably easy to fill in* *2. Easy to complete & understand* *3. Easy to understand & complete* *4. The questionnaire was clearly explained and easy to complete* *5. I found the questionnaire quite simple to fill in* *6. I fully understood the questionnaire* *7. I found it not difficult to complete the forms, the questionnaire was easy to understand* *8. No problem at all* *9. Fairly straight forward* *10. Not difficult* *11. It was easy to fill in the questionnaire as each question was clear and concise* *12. The questionnaire was easy to complete as all questions were given in a clear and concise manner* *13. Not difficult the questions were quite clear & straight forward* *14. I didn't find the questions difficult to complete, I thought the questionnaire was straight forward and had no difficulty completing* *15. (cont.) I found the BOA straightforward & was able to complete it confidently* *16. It was simply written & didn't require me to 'overthink'* *17. It was fine and I think it's a positive thing that information is being collected and provided to enable help for people who have suffered a stroke* *18. I think it was appropriate to our situation. The questions made sense & I had no problem answering*
2. Difficulties of the BOA	1. Difficulty interpreting survivor's mood	*19. Professional carer only spend a few hours a week with survivor* *20. (cont.) I also found some questions I didn't know if (husband) doesn't tell me* *21. It's hard to figure out what (husband) is thinking sometimes* *22. I found it hard because (husband) is not able to tell me how he feels as maybe he doesn't want to worry me, I am not sure. Often he finds it hard to tell me things, and gets frustrated and gives up.* *23. I found it difficult because I can only assume & sometimes I have been proved wrong* *24. Not always able to state how things were [in relation to anxiety], due to other illnesses (i.e. chronic heart failure)*
	2. Lack of relevance	*25. Some questions did not really apply to my husband* *26. If questions related to last six months, some answers may have been slightly different (e.g. fear of another stroke, or being unable to answer the phone- lack of confidence)*

		27. Although I understand the questions need to be put in a certain way to go into the computer, there could be more leeway with the questions
3. Additional benefits of using the BOA	1. Prompted reflection	*28. One or two questions made me really think about my mother's behaviour/anxiety because I am not with her all the time at her home environment e.g. she has been restless or constantly on the move/ being so restless that it's hard to sit still. I do not think that her restlessness causes a physical response in her, but that her response is more mental/ thinking anxiety. But when she is alone, I am, of course unsure of her behaviour.* *29. It made me think of how my husband has been affected by his stroke*