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University of Southampton
Faculty of Social and Human Sciences
School of Psychology

Validation of the Distress Thermometer among Stroke Survivors

by

Rachael Gilson

October 2012

Volume I of I

Word count: 18, 768

Thesis for the degree of Doctor of Clinical Psychology

Abstract

National guidelines for stroke recommend that all patients entering rehabilitation are screened for mood disturbance using a validated measure. The first half of this thesis presents a literature review of 25 self-report screening measures for the detection of post-stroke distress. A total of 26 studies were identified as meeting the search criteria. Fifteen self-report measures met recommended levels of sensitivity (≥ 0.80) and specificity (≥ 0.60) when screening for post-stroke depression. The Hospital Anxiety and Depression Scale (HADS) was the only measure to meet recommended levels of accuracy for post-stroke anxiety. At the commencement of this thesis, the Distress Thermometer (DT) had not been validated among stroke survivors despite being recommended by NICE (2009).

The study presented in the second half of this thesis investigates the diagnostic accuracy and clinical utility of the DT and associated Problem List (PL), the Brief Assessment Schedule Cards (BASDEC), and the Yale. Relative to the HADS, the area under the curve (AUC) for the DT was significantly greater than an AUC of 0.50. Cut-off scores of at least 4 and 5 on the DT met recommended levels of sensitivity and specificity when screening for post-stroke depression and anxiety. The accuracy of the BASDEC and Yale was non-significant. Due to a small sample size, these results should be taken with caution. However, this study provides preliminary evidence to support the use of the DT and PL as a holistic and person-centred screening tool for the prevention and recognition of post-stroke distress.

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Declaration of Authorship

I Rachael Gilson declare that the thesis entitled Validation of the Distress Thermometer among Stroke Survivors and the work presented in the thesis are both my own, and have been generated by me as the result of my own original research. I confirm that:

- this work was done wholly or mainly while in candidature for a research degree at this University;
- where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
- where I have consulted the published work of others, this is always clearly attributed;
- where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
- I have acknowledged all main sources of help;
- where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
- none of this work has been published before submission

Signed:

Date:.....

Acknowledgements

I would like to thank my supervisor Dr Kate Jenkins for her time and support throughout my thesis, Dr Catherine Brignell and Dr Felicity Bishop for their help and advice on statistics, and Dr Jimmie Holland for giving me permission to use the Distress Thermometer and Problem List for the purpose of this study. I am also very grateful to Thames Valley Headway, The Stroke Association, Hannah Gooding and Zeena-Britt Sanders for their help with recruitment. Finally, I would like to thank my boyfriend and father for their patience and understanding throughout this process, which has enabled me to complete this work.

**Emotional Distress Following Stroke: A Review of Validated
Screening Measures**

by

Rachael Gilson

Doctoral Programme in Clinical Psychology

School of Psychology

University of Southampton

Abstract

The following review examines the diagnostic accuracy and clinical utility of 25 self-report screening measures for the detection of post-stroke distress. Empirical studies in AMED, CINAHL, EMBASE, MEDLINE and PsycINFO published up until 15th April 2012 were considered. The following search terms were applied: *stroke OR cerebrovascular accident AND distress OR mood OR depression OR anxiety AND screen OR assessment OR measure OR scale OR tool AND sensitivity OR specificity*. A total of 26 studies were identified as meeting the search criteria.

Three ultrashort measures (1-4 items), five short measures (5-20 items), and seven long measures (≥ 21 items) met recommended levels of sensitivity (≥ 0.80) and specificity (≥ 0.60) when screening for depression. The Hospital Anxiety and Depression Scale (HADS) was the most frequently validated measure within this review. However, it was the only measure to meet adequate levels of accuracy when screening for post-stroke anxiety. Due to methodological variation, recommended cut-off scores for each measure varied between studies. This is likely to reflect the heterogeneous nature of stroke and highlights a need to validate measures throughout the stroke care pathway. At the commencement of this study, the Distress Thermometer (DT) had not been validated among stroke survivors, despite being recommended by NICE (2009) when screening for depression among people with chronic physical health needs. In conclusion, future studies are needed to establish appropriate cut-off scores when using screening measure within stroke services, particularly for the detection of post-stroke anxiety.

Introduction

Post-Stroke Distress

It is estimated that 110,000 people experience a stroke in England every year (National Audit Office, 2005). While survival rates have improved (de Freitas, Bezerra, Maulaz, & Bogousslavsky, 2005) stroke is the most common cause of “complex disability” compared to any other chronic condition (Adamson, Beswick, & Ebrahim, 2004, p. 174).

Gainotti (1993) considers emotional disorders to be one of the most important factors in determining the outcome and success of rehabilitation following brain injury. Post-stroke emotional distress is common and can be defined as a negative mood state ranging from clinically significant mood disorders to less intense and persistent states of emotional adjustment (Carney & Freedland, 2002; De Wit et al., 2008).

Depression is one of the most frequently researched areas of post-stroke distress (Carney & Freedland, 2002). Although prevalence rates differ across studies due to methodological variation, pooled results suggest that 33% of people will experience depression within five years of having a stroke (Hackett, Yapa, Parag, & Anderson, 2005). Furthermore, patients identified as being depressed within the acute phase of recovery are at a heightened risk of remaining depressed in the long-term (Ayerbe, Ayis, Rudd, Heuschmann, & Wolfe, 2011).

Less attention has been paid to post-stroke anxiety (Campbell Burton et al., 2011), yet prevalence rates are thought to be similar to depression (De Wit, et al., 2008). Moreover, comorbid anxiety and depression has been found to occur in 46% of stroke inpatients (Castillo, Starkstein, Fedoroff, & Price, 1993) and is thought to increase the severity and duration of depressive symptoms (Shimoda & Robinson, 1998). Until recently, the majority of studies within the stroke literature have investigated the prevalence of generalised anxiety disorder. However, the acknowledgement of other anxiety disorders such as posttraumatic stress disorder (PTSD) is growing (Merriman, Norman, & Barton, 2007).

Non-clinical levels of distress may also increase the risk of developing mood disorders and therefore warrant early intervention as a preventative measure (Taylor, Todman, & Broomfield, 2011). Some people may experience less intense and persistent states of emotional distress (Barton, 2007). Other mood related difficulties, such as anger, denial, frustration and loss of confidence are also known to occur as part of the adjustment process (Ch'Ng, French, & Mclean, 2008).

Biopsychosocial Model

The development and maintenance of post-stroke distress is complex (Gainotti, 1993). The International Classification of Functioning, Disability and Health's (ICF) biopsychosocial model highlights a "dynamic interaction" between a health condition, functioning, and contextual factors (Figure 1). Change in one area of this model is thought to have the potential to modify other areas of functioning. Furthermore, a bidirectional relationship may exist where the health condition or associated disability may contribute to the development of emotional distress and vice versa (World Health Organization [WHO], 2001, p. 26).

In line with the ICF model, post-stroke distress has been associated with reduced functional outcome and quality of life (Pohjasvaara, Vataja, Leppävuori, Kaste, & Erkinjuntti, 2001), reduced cognition (Shimoda & Robinson, 1998), increased mortality (House, Knapp, Bamford, & Vail, 2001; Teasdale & Engberg, 2001), and increased stress on carers (Anderson, Linto, & Stewart-Wynne, 1995). In turn, post-stroke depression is thought to place additional demands upon health care resources through lengthened hospital stays, increased outpatient visits, and increased risk of readmission and institutionalisation (Ghose, Williams, & Swindle, 2005; Kotila, Numminen, Waltimo, & Kaste, 1999). Furthermore, the additive effect of comorbid anxiety and depression has been associated with higher impairments of activities of daily living, cognition, and social support compared to either condition alone (Shimoda & Robinson, 1998). Consequently, the early detection of post-stroke distress seems important to prevent increasing distress and to improve quality of life and functional outcome.

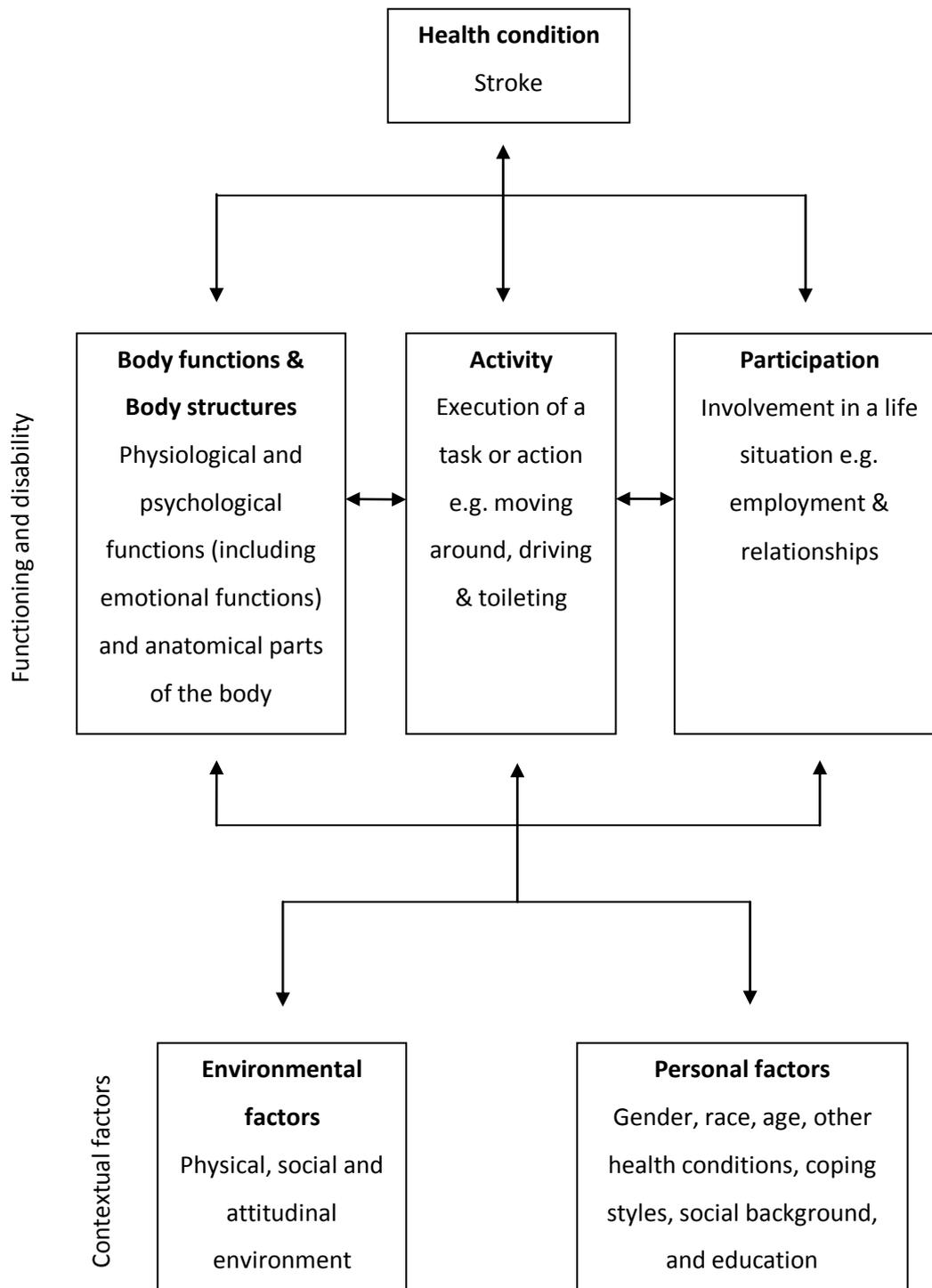


Figure 1. The ICF integrative biopsychosocial model of functioning and disability (WHO, 2001).

Mood Screening

The National Clinical Guideline for Stroke (Intercollegiate Stroke Working Party, 2008) recommends that all patients entering rehabilitation and thereafter should be screened for depression and anxiety using a validated measure. Over the years, compliance with these guidelines has been low. While this is improving (Royal College of Physicians, 2011), factors such as reluctance to ask sensitive questions, time pressure, lack of knowledge, and poor awareness of guidelines continue to prevent screening (Hammond, O'Keeffe, & Barer, 2000; Hart & Morris, 2008).

An array of measures exist which can be used to screen for mood related problems. However, the majority have been developed for psychiatric populations and contain somatic symptoms, such as loss of appetite and poor sleep, which may mimic physical, environmental, and cognitive problems following stroke (Roger & Johnson-Greene, 2009). The gold standard method for assessing mood is the structured clinical interview. However, this is often time consuming and impractical on busy medical wards (Sagen et al., 2009). Consequently, self-report measures have been developed due to their brevity, yet completion is reliant upon the individual having good insight, memory and communication into their emotional status (Taylor, et al., 2011).

To overcome communication difficulties, self-report visual analogue scales tend to be used. This is despite research suggesting that stroke patients are unable to use them (Price, Curless, & Rodgers, 1999) as they offer the only means of self-assessment (Benaim, Cailly, Perennou, & Pelissier, 2004). While observational measures and proxy reports are thought to be more practical (Lincoln, Kneebone, Macniven, & Morris, 2012), evidence has highlighted poor concordance rates between subjective reports of well-being and observer ratings (Berg, Lönnqvist, Palomäki, & Kaste, 2009; Edwards et al., 2006). Furthermore, observational measures rely upon external indicators of mood; whereas disorders of emotional expression, such as emotionality, apathy, and dysprosodia may mask or mimic internal states of distress and result in misclassification of emotional difficulties. As a result, guidelines recommend visual analogue scales in addition to proxy ratings when screening someone with cognitive and communication difficulties (Gillham & Clark, 2011).

The Ideal Measure

A stepped care approach to psychological care has been proposed which involves local service providers developing their own mood assessment pathway. The Stroke Improvement Programme (SIP) argues that at level one all patients should be screened for mood disorders using a simple and brief standardised measure (Gillham & Clark, 2011). Those identified as having a possible mood disorder are then offered further assessment and intervention. Lincoln et al. (2012) suggest that the ideal screening measure be easy to use, require minimal training and resources, and be accessible in a variety of settings, including bedside administration. To ensure generalisability, measures also need to be validated in subgroups of stroke survivors to establish reliable cut-off scores. As a result, it is up to local service providers to establish mood assessment pathways which meet the needs of the stroke population at hand.

The sensitivity and specificity of a new measure (also known as the index test) relative to a gold standard or criterion standard, offer the best indicators of accuracy when choosing a validated measure (Glasziou & Irwig, 2001; Whiting et al., 2004). Sensitivity refers to the proportion of people with a clinically significant mood disorder (as measured by the criterion standard) who are correctly identified by the index test. In contrast, specificity refers to the proportion of people without a clinically significant mood disorder who are correctly identified as not having a mood disorder by the index test.

To ensure that the majority of people with a clinically significant mood disorder are detected, several authors recommend that the sensitivity of a screening measure be greater than its specificity (Berg, et al., 2009; House, Dennis, Hawton, & Warlow, 1989; Parikh, Eden, Price, & Robinson, 1988). However, Lincoln, Nicholl, Flannaghan, Leonard and van der Gucht (2003) point out that a measure with low specificity is no better than carrying out a full assessment with all patients. Consequently, a balance is required. Within stroke, Bennett and Lincoln (2006) recommend a sensitivity of at least 0.80 and a specificity of at least 0.60.

Review Questions

The aim of the review was to critically evaluate available self-report screening measures for post-stroke distress; to find out what current self-report measures are available, and to evaluate the diagnostic accuracy and clinical utility of each measure at discriminating between people with and without clinical levels of post-stroke distress.

Method

Search Criteria

Empirical studies in AMED, CINAHL, EMBASE, MEDLINE, and PsycINFO published up until 15th April 2012 were considered. The following search terms were applied (see Appendix A for a detailed search strategy).

1. *Stroke OR cerebrovascular accident AND*
2. *Distress OR mood OR depression OR anxiety AND*
3. *Screen OR assessment OR measure OR scale OR tool OR questionnaire
OR instrument AND*
4. *Sensitivity OR specificity*

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

The following criteria were then applied.

Inclusion criteria

- The participants had a primary diagnosis of stroke
- The participants were over the age of 18 years
- The study was published in English

Exclusion criteria

- The paper contained no primary data
- The participants were carers of stroke survivors
- The focus of the study investigated the prevalence, predictor or treatment of post-stroke distress, or the assessment of change over time
- The measure was created to detect quality of life
- The study did not investigate criterion-related validity or provide cut-off scores to detect clinically significant cases of post-stroke distress
- The measures being validated were observer or clinician rated scales

Evaluation Criteria

Studies included in the review were evaluated in relation to the diagnostic accuracy and clinical utility of each measure. Diagnostic accuracy was evaluated in relation to guidelines proposed by Bennett and Lincoln (2006) which suggest that the sensitivity of a scale should be at least 0.80 and the specificity of a scale should be at least 0.60. To assess clinical utility, five factors were evaluated. These included the length of the measure, the type of training required to administer the measure, the response format of the measure, the generalisation of sample characteristics to clinical settings, and the cost of purchasing the measure. The length of each measure was categorised according to three arbitrary labels defined by a recent review within cancer where “ultrashort” measures consist of 1 to 4 items, “short” measures consist of 5 to 20 items, and “long” measures consist of 21 to 50 items (Vodermaier, Linden, & Siu, 2009).

Results

Twenty six studies met the criteria for inclusion in the review. A total of 25 self-report screening measures were described, as detailed below. A summary table containing each measure and associated study is presented in Appendix B.

Beck Anxiety Inventory (BAI)

The BAI (Beck & Steer, 1993) is a 21-item self report questionnaire designed to measure the severity of anxiety symptoms in a psychiatric population over the last week. Each item is rated on a 4-point multiple choice scale with a maximum score of 63. A cut-off score of 0-7 is considered *minimal*, scores of 8-15 are *mild*, scores of 16-25 are *moderate*, and scores between 26 -63 are *severe*.

One study was identified in the review as validating the BAI among a sample of 44 community based stroke survivors (Schramke, Stowe, Ratcliff, Goldstein, & Condray, 1998). A cut-off score of at least 16 was found to have good sensitivity but poor specificity when detecting anxiety disorders relative to the DSM-III-R criteria. However, the authors did not provide any figures to support this finding.

Beck Depression Inventory (BDI and BDI-II)

The BDI (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961) and revised BDI-II (Beck, Steer, & Brown, 1996) comprise a 21-item self report questionnaire designed to measure symptoms of depression in a psychiatric population. Each item is rated on a 4-point multiple choice scale with a maximum score of 63. Items on the BDI are rated within the last week, whereas items of the BDI-II are rated within the past two weeks. Moreover, items involving change in body image, hypochondria, and difficulty working were replaced in the BDI-II and two items were revised to assess both increases and decreases in sleep and appetite. Cut-off scores for the BDI and BDI-II are presented in Table 1.

Table 1

Standard Cut-Off Scores for the BDI and BDI-II

| Interpretation | Cut-off | |
|----------------|---------|--------|
| | BDI | BDI-II |
| Minimal | 0-9 | 0-13 |
| Mild | 10-18 | 14-19 |
| Moderate | 19-29 | 20-28 |
| Severe | 30-63 | 29-63 |

Three studies with a combined total of 424 participants were identified as validating the BDI among a sample of stroke survivors (Aben, Verhey, Lousberg, Lodder, & Honig, 2002; Berg, et al., 2009; House, et al., 1989).

House et al. (1989) questioned the accuracy of the BDI as a screening tool due to poor specificity relative to the DSM-III criteria for depression. While the sensitivity of the BDI met recommended levels of at least 0.80 at 1 month, 6 months and 12 months post-stroke, the specificity (≤ 0.59) of the BDI was poor at all three time points.

In two more recent studies, the BDI was found to meet recommended levels of accuracy. Aben et al. (2002) evaluated the accuracy of the BDI relative to the DSM-IV diagnosis of depression at 1 month post-stroke (sensitivity: 0.80; specificity: 0.61), while Berg et al. (2009) found the BDI to be acceptable at 2 weeks and at 2, 6, 12 and 18 months post-stroke. An optimal cut-off score of at least 10 was recommended in both studies when screening for depression at 2 weeks, and at 1, 2, 12 and 18 months. However, Berg, et al. (2009) suggested using a lower cut-off score of at least 7 at 6 months in order to maintain an adequate level of sensitivity and specificity (see Table 2 for a summary of cut-off scores).

Table 2

Stroke Related Cut-Off Scores for the BDI

| Study | Time since stroke | Cut-off |
|---------------------|-------------------|----------------------|
| House et al. (1989) | 1 month | ≥ 5 |
| | 6 months | ≥ 5 |
| | 12 months | ≥ 5 |
| Aben et al. (2002) | 1 month | $\geq 10_{\ddagger}$ |
| Berg et al. (2009) | 2 weeks | $\geq 10_{\ddagger}$ |
| | 2 months | $\geq 10_{\ddagger}$ |
| | 6 months | $\geq 7_{\ddagger}$ |
| | 12 months | $\geq 10_{\ddagger}$ |
| | 18 months | $\geq 10_{\ddagger}$ |

\ddagger Cut-off meeting recommended levels of sensitivity (≥ 0.80) and specificity (≥ 0.60)

Three studies with a total of 329 participants validated the BDI-II within stroke (Lincoln, et al., 2003; Turner-Stokes, Kalmus, Hirani, & Clegg, 2005; Turner et al., 2012). The BDI-II was found to meet recommended levels of accuracy in one study, as outlined in Table 3 (Turner, et al., 2012).

Lincoln et al. (2003) evaluated the accuracy of the BDI-II at detecting cases of major and minor depression relative to the Schedules for Clinical Assessment in Neuropsychiatry (SCAN; WHO, 1992). The BDI-II was found to have a good level of sensitivity (0.91, 0.83) but poor specificity (0.56, 0.44) when detecting DSM-III-R and ICD-10 cases of depression respectively. Furthermore, the optimal cut-off score varied according to the DSM-III-R (≥ 16) or ICD-10 (≥ 13) criteria.

Turner-Stokes et al. (2005) recommended using a higher cut-off score of at least 14 to detect DSM-IV cases of major and minor depression among a sample of younger inpatient stroke survivors (16-65 years). However, while specificity was good (0.80), the sensitivity of the BDI-II fell short of recommended levels (0.74).

More recently, Turner et al. (2012) evaluated the performance of the BDI-II at detecting DSM-IV cases of major depression with a heterogeneous sample of stroke survivors between 3 weeks and 45 years post-stroke. A lower cut-off score of at least 11 was recommended in order to meet adequate levels of sensitivity (0.92) and specificity (0.71).

Table 3

Stroke Related Cut-Off Scores for the BDI-II

| Study | Criterion standard | Time since stroke | Cutoff |
|-----------------------------|--------------------|-------------------|--------|
| Lincoln et al. (2003) | DSM-III-R | Up to 6 months | ≥16 |
| | ICD-10 | Up to 6 months | ≥13 |
| Turner-Stokes et al. (2005) | DSM-IV | 12 weeks | ≥14 |
| Turner et al. (2012) | DSM-IV | 3 week – 45 years | ≥11‡ |

‡ Cut-off meeting recommended levels of sensitivity (≥0.80) and specificity (≥0.60)

Beck Depression Inventory-Fast Screen (BDI-FS)

The BDI-FS (Beck, Steer, & Brown, 2000) is a 7-item self-report measure taken from the BDI-II. Somatic items are excluded to increase specificity for medical patients. Cut-off scores of 3-5 are recommended.

One study met the search criteria for validating the BDI-FS within stroke. Healey, Kneebone, Carroll and Anderson (2008) investigated the accuracy of the BDI-FS at detecting DSM-IV cases of depression in 49 inpatient stroke survivors. The BDI-FS demonstrated acceptable internal consistency (Cronbach's $\alpha = 0.75$) and test-retest reliability over a 7-10 day period ($t(43) = 0.63, p < 0.001$). Using a cut-off score of at least 4, the specificity of the BDI-FS met recommended levels of accuracy, however sensitivity fell below 0.80 (sensitivity: 0.71, specificity: 0.74). The accuracy of the BDI-FS reduced further when detecting major and minor depression (sensitivity: 0.62, specificity: 0.78).

Brief Assessment Schedule Depression Cards (BASDEC)

The BASDEC (Adshead, Cody, & Pitt, 1992) was developed to screen for depression in elderly medical inpatients. It contains 19 cards with statements relating to symptoms of depression, which the individual places next to a true or false card. A maximum score of 21 can be obtained with a score of at least 7 indicating depression which may warrant further intervention.

One study was identified as validating the BASDEC within stroke (Healey, et al., 2008). The BASDEC had acceptable reliability (Kuder-Richardson Formula 20 = 0.77, test-retest reliability: $\tau(43) = 0.66$, $p < 0.001$) and excellent criterion validity (sensitivity: 1.0, specificity: 0.95) when identifying cases of major depression using the standard cut-off score of at least 7. While the sensitivity (0.69) of the BASDEC dropped when detecting minor and major depression, the BASDEC provided better diagnostic accuracy than the BDI-FS and the depression subscale of the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983).

Centre for Epidemiologic Studies Depression Scale (CES-D)

The CES-D (Radloff, 1977) is a 20-item self-report scale designed to measure symptoms of depression in the general population. Items are rated on a 4-point scale. A maximum score of 60 is generated and a standard cut-off score of at least 16 is used to indicate depression.

Six studies with a total of 307 participants met the inclusion criteria for validating the CES-D among a population of stroke survivors (Agrell & Dehlin, 1989; Parikh, et al., 1988; Roger & Johnson-Greene, 2009; Rybarczyk, Winemiller, Lazarus, & Haut, 1996; Schramke, et al., 1998; Shinar et al., 1986). In two out of the six studies the CES-D was shown to meet recommended levels of accuracy for a screening tool in stroke, as outlined in Table 4 (Parikh, et al., 1988; Rybarczyk, et al., 1996).

Three studies were identified which recommended using the standard cut-off score of 16. Shinar et al. (1986) examined the accuracy of the CES-D at detecting DSM-III cases of depression. Twenty-seven stroke survivors were assessed at 7 to 10 days, 3 months and 6 months post-stroke. While Shinar et al. (1986) concluded that the CES-D could be used as a reliable and valid screening tool for assessing post stroke depression, it is notable that the sensitivity (0.73) of the CES-D fell short of more recent recommendations (Bennett & Lincoln, 2006). In a replica study, Parikh et al. (1988) demonstrated an adequate balance of sensitivity (0.90) and specificity (0.86) when using a larger sample of 80 stroke survivors. In contrast, Schramke et al. (1998) argued that the CES-D lacked specificity; however the authors reported no precise figures to support this conclusion.

A further two studies recommended using higher cut-off scores when using the CES-D. Agrell and Dehlin (1989) assessed the accuracy of the CES-D in a sample of 39 outpatient stroke survivors. Using a cut-off score of at least 20, the CES-D correctly identified the majority of people who did not have depression (specificity 0.91). However, a large proportion of people who did have depression were not detected (sensitivity 0.56). In contrast, Rybarczk et al. (1996) evaluated the accuracy of the CES-D in a sample of 50 inpatients. The CES-D met recommended levels sensitivity (0.82) and specificity (0.65) when using a higher cut-off score of at least 26. In a more recent study by Roger and Johnson-Greene (2009) the accuracy of the CES-D fell below recommendations despite using an optimal cut-off score of at least 15 (sensitivity: 0.66; specificity: 0.68).

Table 4

Stroke Related Cut-Off Scores for the CES-D

| Study | Time since stroke | Cutoff |
|--------------------------------|-------------------|--------|
| Shinar et al. (1986) | 7 days-6 months | ≥16 |
| Parikh et al. (1988) | 1 week-2 years | ≥16‡ |
| Agrell and Dehlin (1989) | 4 ms -2.5 years | ≥20 |
| Rybarczyk et al. (1996) | 3-43 days | ≥26‡ |
| Schramke et al. (1998) | Mean 3.61 | ≥16 |
| Roger and Johnson-Green (2009) | Mean 8 days | ≥15 |

‡ Cut-off meeting recommended levels of sensitivity (≥0.80) and specificity (≥0.60)

Depression Intensity Scale Circles (DISCs)

The DISCs (Turner-Stokes, et al., 2005) is a six point visual analogue scale, scored from 0 (*no depression*) to 5 (*most severe depression*). Each point on the scale is represented by a circle filled in with increasing shades of grey. The patient is asked to rate how sad or depressed they feel on that day by pointing to a circle.

One study was identified as validating the DISCs with a sample of 114 inpatients with acquired brain injury including stroke (Turner-Stokes, et al., 2005). Based upon a cut-off score of at least 2, the DISCS was found to have a sensitivity of 0.60 and specificity of 0.87 when detecting DSM-IV cases of depression in a younger adult population (16-65 years). Turner-Stokes et al. (2005) concluded that the DISCs showed acceptable validity as a screening tool for depression.

While the BDI-II was found to be superior, the visual format of the DISCs was thought to be more accessible to those with severe communication difficulties.

Distress Thermometer (DT)

The DT (Roth et al., 1998) is a 1-item self-report screening tool developed to measure psychological distress among cancer patients. It consists of an 11-point visual analogue scale, measuring distress from 0 (*no distress*) to 10 (*extreme distress*). A cut-off score of 4 is recommended within oncology to indicate those who may require further assessment (National Comprehensive Cancer Network [NCCN], 2010).

One study with a sample of 72 participants was identified as validating the DT among a population of stroke survivors (Turner, et al., 2012). The accuracy of the DT was compared to DSM-IV criteria for major depression. The standard cut-off score of at least 4 did not meet recommended levels of sensitivity (0.69) and specificity (0.57). When using a lower cut-off score of at least 2, those with major depression were correctly identified by the DT (sensitivity: 1.0); however, a number of people without clinical levels of depression were incorrectly classified as having depression (specificity: 0.33). The authors concluded that due to the DT measuring global distress in a single item, poor specificity may have related to the DT capturing a range of non-depressive states of post-stroke distress.

General Health Questionnaire (GHQ-30 and GHQ-28)

The GHQ (Goldberg & Williams, 1991) is a self-report measure designed to screen for psychiatric disorders within the last few weeks. Two versions of the GHQ have been validated in stroke. The GHQ-30 consists of 30 items and the GHQ-28 contains 28 items, both of which are rated on a 4-point scale. A cut-off score of at least 5 is recommended. Unlike the GHQ-28, the GHQ-30 excludes items relating to physical illness. Although the GHQ-12 is highlighted as a suitable screening measure for post-stroke distress (Gillham & Clark, 2011), no validation studies were identified in the current review.

One study with a sample of 105 participants was identified as validating the GHQ-30 with a stroke population. An optimal cutoff score of at least 9 was recommended when screening for any form of psychiatric diagnosis, based upon the Schedule for Affective Disorders and Schizophrenia (SADS; Endicott & Spitzer, 1978). At 6 months post stroke, the GHQ-30 was found to have an acceptable level of sensitivity (0.80) and specificity (0.76), which was comparable to the HADS.

Two studies with a total of 209 participants were identified as validating the GHQ-28 with a sample of stroke survivors (Johnson et al., 1995; Lincoln, et al., 2003). In both studies, the GHQ-28 was shown to meet recommend levels of accuracy when detecting depression, as outlined in Table 5.

Johnston et al. (1995) evaluated the accuracy of the GHQ-28 in a sample of 66 stroke survivors 4 months post-stroke. Using a cut-off score of at least 5, the GHQ-28 obtained an adequate level of sensitivity (0.89) and specificity (0.75) when detecting DSM-III cases of depression. However, the performance of the GHQ-28 was less satisfactory when detecting anxiety, namely generalised anxiety disorder and agoraphobia (sensitivity: 0.71, specificity: 0.56).

In a subsequent study by Lincoln et al. (2003), an optimal cut-off score of at least 12 was recommended when detecting ICD-10 cases of depression (sensitivity: 0.81, specificity: 0.68); whereas an optimal cut-off score of at least 8 was recommended when detecting DSM-III-R cases of depression (sensitivity 0.85; specificity 0.61).

Table 5

Stroke Related Cut-Off Scores for the GHQ-28

| Study | Criterion standard | Time since stroke | Cutoff |
|-----------------------|----------------------|-------------------|-------------|
| Johnson et al. (1995) | DSM-III depression | 4 months | ≥ 5 ‡ |
| | DSM-III anxiety | 4 months | ≥ 5 |
| Lincoln et al. (2003) | DSM-III-R depression | Up to 6 months | ≥ 8 ‡ |
| | ICD-10 depression | Up to 6 months | ≥ 12 ‡ |

‡ Cut-off meeting recommended levels of sensitivity (≥ 0.80) and specificity (≥ 0.60)

Geriatric Depression Scale (GDS-30 and GDS-15)

The GDS (Yesavage et al., 1982) is a 30-item self-report questionnaire based upon a yes/no format, developed for detecting depression in older adults. A score of 0-10 is considered *normal*, with scores of 11 or more indicating possible depression. A shorter version also exists called the GDS-15, where a score of at least 5 indicates depression (Sheikh & Yesavage, 1986).

Three studies with a total of 191 participants were identified as validating the GDS-30 within stroke (Agrell & Dehlin, 1989; Johnson, et al., 1995; Sivrioglu et al., 2009). In each study, the GDS-30 met recommended levels of accuracy for a screening tool within stroke, as outlined in Table 6.

Agrell and Dehlin (1989) evaluated the accuracy of the GDS-30 at detecting major and minor depression in a sample of 40 outpatient stroke survivors. Using a cut-off score of at least 10, the GDS-30 met recommended levels of sensitivity (0.88) and specificity (0.64).

Johnson et al. (1995) provided evidence for using the standard cut-off score of at least 11 to meet recommended levels of accuracy when screening for major and minor depression (sensitivity: 0.84; specificity: 0.66). However, when using an optimal cut-off score of at least 15, the GDS-30 did not meet recommended levels of accuracy when screening for anxiety (sensitivity: 0.65; specificity: 0.79).

Sivrioglu et al. (2009) evaluated the accuracy of the GDS-30 at identifying minor depression in a population of stroke survivors who had experienced a stroke between 17 days and 2 years. In line with Agrell and Dehlin (1989), a lower cut-off score of at least 9 was recommended to meet adequate levels of sensitivity (0.80) and specificity (0.61).

Table 6

Stroke Related Cutoff Scores for the GDS-30

| Study | Time since stroke | Cutoff |
|--------------------------|-------------------|-------------|
| Agrell and Dehlin (1995) | 4ms-2.5 years | ≥ 10 ‡ |
| Johnson et al. (1995) | 4 months | ≥ 11 ‡ |
| Sivrioglu et al. (2009) | 17 days – 2 years | ≥ 9 ‡ |

‡ Cut-off meeting recommended levels of sensitivity (≥ 0.80) and specificity (≥ 0.60)

Four studies with a total of 507 participants were identified as validating the GDS-15 with a stroke population (Lee, Tang, Yu, & Cheung, 2008; Roger & Johnson-Greene, 2009; Tang et al., 2004a; Tang et al., 2004b). In two of the four studies, the GDS-15 met recommended levels of accuracy for a screening tool in stroke, as outlined in Table 7 (Lee, et al., 2008; Tang, et al., 2004a).

Tang et al. (2004a) investigated the accuracy of the GDS-15 with a group of 127 elderly Chinese stroke survivors within 3 months of having a stroke. The accuracy of the GDS-15 was compared to the DSM-IV criteria for major and minor depression and dysthymia. A cut-off score of at least 7 was recommended which produced an adequate level of sensitivity (0.89) and specificity (0.73).

In a second study, Tang et al. (2004b) recommended using an optimal cut-off score of at least 6 to detect DSM-III cases of major depression, dysthymia, or adjustment disorder in a group of 60 stroke survivors (40-90 years). However, the sensitivity (0.64) of the GDS-15 fell short of more recent guidelines (Bennett & Lincoln, 2006).

In a large sample (N=253) of Chinese stroke survivors, Lee et al. (2008) evaluated the accuracy of the GDS-15 at detecting depression 1 month post-stroke. However, in contrast to Tang et al. (2004b), their study offered promising results for the GDS-15 when using a standard cut-off score of at least 5 (sensitivity: 0.84, specificity: 0.77).

In a more recent and smaller study of stroke survivors (N=67), the GDS-15 with a cut-off score of at least 3, did not meet recommended levels of sensitivity (0.67) and specificity (0.73), despite performing better than the CES-D and Stroke Inpatient Depression Inventory (SIDI; Roger & Johnson-Greene, 2008).

Table 7

Stroke Related Cutoff Scores for the GDS-15

| Study | Time since stroke | Cutoff |
|-------------------------------|-------------------|------------|
| Tang et al. (2004a) | 3 months | ≥ 7 ‡ |
| Tang et al. (2004b) | ≤ 1 month | ≥ 6 |
| Lee et al. (2008) | 1 month | ≥ 5 ‡ |
| Roger & Johnson-Greene (2009) | Mean: 8 days | ≥ 3 |

‡ Cut-off meeting recommended levels of sensitivity (≥ 0.80) and specificity (≥ 0.60)

Hospital Anxiety and Depression Scale (HADS)

The HADS (Zigmond & Snaith, 1983) is a 14-item self-report measure. It contains two subscales which measure anxiety (HADS-A) and depression (HADS-D). The total score (HADS-T) can be used as a measure of emotional distress (Herrmann, 1997). According to the manual a sub-scale score of 0-7 is considered *normal*, scores of 8-10 are *mild*, scores of 11-14 are *moderate*, and scores between 15 -21 are *severe*.

The HADS was the most frequently validated measure identified in the review. Eight studies with a total of 755 participants validated the HADS with a stroke population (Aben, et al., 2002; Healey, et al., 2008; Johnson, et al., 1995; O'Rourke, MacHale, Signorini, & Dennis, 1998; Sagen, et al., 2009; Tang, et al., 2004b; Tang, et al., 2004c; Turner, et al., 2012).

All eight studies validated the HADS-D subscale relative to a diagnosis of depression. In five studies the HADS-D was found to meet recommended levels of accuracy proposed by Bennett and Lincoln (2006). Two out of the five studies provided support for using the standard cut-off score of 8 (Healey, et al., 2008; Turner, et al., 2012). However, three studies recommended using lower cut-off scores, as detailed in Table 8 (O'Rourke, et al., 1998; Sagen, et al., 2009; Tang, et al., 2004b). Three studies with a total of 375 participants validated the HADS-T against a diagnosis of depression, all of which met the recommend levels of accuracy for a screening tool in stroke when using a cut-off score of at least 11 (Aben, et al., 2002; Sagen, et al., 2009; Turner, et al., 2012).

Relative to a diagnosis of anxiety, three studies with a total of 272 participants validated the HADS-A subscale (Johnson, et al., 1995; O'Rourke, et al., 1998; Sagen, et al., 2009). The HADS-A met recommended levels of accuracy in two out of the three studies, both of which used a cut-off score lower than standard of at least 8, as outlined by Table 9 (O'Rourke, et al., 1998; Sagen, et al., 2009). One study validated the HADS-T relative to a diagnosis of anxiety disorder, which also met recommended levels of accuracy using a cut-off score of at least 6 (Sagen, et al., 2009).

Johnson et al. (1995) compared the ability of the HADS at detecting DSM-III cases of anxiety and depression 4 months post stroke. An optimal cut-off score of at least 5 was recommended when using the HADS-D (sensitivity: 0.83, specificity: 0.44); whereas a cut-off score of least 6 was recommended for the HADS-A (sensitivity: 0.80, specificity: 0.46). While sensitivity was good for both subscales, specificity was poor. In comparison to the GDS and GHQ-28, the HADS was rated the least satisfactory self-report scale.

In contrast, O'Rourke et al. (1998) concluded that the HADS-A and HADS-D was an acceptable screening tool for anxiety (sensitivity: 0.83, specificity: 0.68) and depression (sensitivity: 0.80, specificity: 0.79) at 6 months post-stroke. However, as detailed by Johnson et al. (1995), standard cut-off scores were suboptimal and a lower score of at least 7 was recommended when screening for post-stroke anxiety or depression.

Aben et al. (2002, p. 390) evaluated the screening abilities of the HADS to detect DSM-IV cases of major and minor depression. Optimal cut-off scores of at least 8 on the HADS-D (sensitivity: 0.73, specificity: 0.82), 5 on the HADS-A (sensitivity: 0.92, specificity: 0.56) and 11 on HADS-T (sensitivity: 0.92, specificity: 0.65) identified major depression in a sample of 202 stroke patients 1 month post-stroke. While the performance of the HADS was less accurate when screening for major and minor depression, this was not “meaningfully” different.

Healey et al. (2008) also provide support for the standard cut-off score of at least 8 when screening for depression. The ability of the HADS-D to detect DSM-IV cases of major depression met more recent recommendations within stroke (sensitivity: 0.86, specificity: 0.69). However, the accuracy of the HADS-D at detecting major and minor depression fell below these recommendations (sensitivity: 0.62, specificity: 0.69).

Tang et al. (2004c) evaluated the screening abilities of the Chinese version of the HADS-D with 100 geriatric patients with first time stroke. While an optimal cut-off score of at least 7 was recommended, specificity was poor (sensitivity: 0.88, specificity: 0.53). Due to high rates of false positives, Tang et al. (2004c) concluded that the HADS-D was not a useful screening tool for post-stroke depression. When lowering the cut-off score to at least 4 in a subsequent study of 60 Chinese stroke survivors, Tang et al. (2004b) concluded that the HADS was satisfactory when screening for post-stroke depression (sensitivity: 0.86, specificity: 0.78).

More recently, Sagen et al. (2009) compared the accuracy of the HADS at detecting DSM-IV cases of anxiety and depression in 104 Norwegian stroke patients 4 months post-stroke. When screening for anxiety or depression, lower cut-off scores of at least 4 on both subscales were also recommended to obtain acceptable levels of sensitivity (≥ 0.80) and specificity (≥ 0.60). Whereas a cut-off score of at least 11 was recommended on the HADS-T to detect depression. Similarly, Turner et al. (2012) recommended a cut-off score of at least 11 on the HADS-T, however, a standard cut-off score of at least 8 on the HADS-D met recommended levels of sensitivity and specificity when detecting DSM-IV cases of major depression.

Table 8

Stroke Related Cut-Off Scores for the HADS Relative to a Diagnosis of Depression

| Study | Subscale | Time since stroke | Cutoff |
|------------------------|----------|-------------------|-------------|
| Johnson et al. (1995) | HADS-D | 4 months | ≥ 5 |
| O'Rourke et al. (1998) | HADS-D | 6 months | ≥ 7 ‡ |
| Aben et al. (2002) | HADS-D | 1 month | ≥ 8 |
| | HADS-A | 1 month | ≥ 5 |
| | HADS-T | 1 month | ≥ 11 ‡ |
| Tang et al. (2004c) | HADS-D | 3-4 weeks | ≥ 7 |
| Tang et al. (2004b) | HADS-D | ≤ 1 month | ≥ 4 ‡ |
| Healey et al. (2008) | HADS-D | 16-113 days | ≥ 8 ‡ |
| Sagen et al. (2009) | HADS-D | 4 months | ≥ 4 ‡ |
| | HADS-T | 4 months | ≥ 11 ‡ |
| Turner et al. (2012) | HADS-D | 3 weeks-45 years | ≥ 8 ‡ |
| | HADS-T | 3 week-45 years | ≥ 11 ‡ |

‡ Cut-off meeting recommended levels of sensitivity (≥ 0.80) and specificity (≥ 0.60)

Table 9

Stroke Related Cut-Off Scores for the HADS Relative to a Diagnosis of Anxiety

| Study | Subscale | Time since stroke | Cutoff |
|------------------------|----------|-------------------|------------|
| Johnson et al. (1995) | HADS-A | 4 months | ≥ 6 |
| O'Rourke et al. (1998) | HADS-A | 6 months | ≥ 7 ‡ |
| Sagen et al. (2009) | HADS-A | 4 months | ≥ 4 ‡ |
| | HADS-T | 4 months | ≥ 6 ‡ |

‡ Cut-off meeting recommended levels of sensitivity (≥ 0.80) and specificity (≥ 0.60)

Kessler-10 (K10)

The K10 (Kessler et al., 2002) is a 10-item self-report screening scale of psychological distress, developed for the US National Health Interview Survey (NHIS). Each item is rated on a 5-point scale from 1 (*none of the time*) to 5 (*all of the time*) in relation to the past month, with a total score of 50. According to the Australian Bureau of Statistics Health Surveys (2008, p. 1), people who score between 10-19 “are likely to be well”, 20 -24 “are likely to have mild levels of mental disorder”, 25-29 “are likely to have a moderate mental disorder”, and 30-50 “are likely to have a severe mental disorder”.

One study was identified as validating the K10 among 72 stroke survivors. Turner et al. (2012) evaluated the accuracy of the K10 at discriminating between DSM-IV cases of major depression with a group of Australian stroke survivors.

While the standard cut-off score of at least 20 did not meet recommended levels of sensitivity and specificity (sensitivity: 0.77, specificity: 0.69), a cut-off score of at least 18 almost met this criteria (sensitivity: 0.85, specificity: 0.59). Turner et al. (2012) concluded that the K10 could be used as an adequate screening measure for major depression among stroke survivors.

Patient Health Questionnaire (PHQ)

The PHQ-9 (Spitzer, Kroenke, Williams, & Group, 1999) is a 9-item self-report questionnaire designed to screen for depression over the last 2 weeks. Scores range from 0 to 27 and are based upon a 4-point multiple choice scale from 0 (*not at all*) to 3 (*nearly every day*). A cut-off score of at least 10 is recommended within primary care. More recently, the PHQ-2 (Kroenke, Spitzer, & Williams, 2003) was developed and contains two items from the PHQ-9 which include depressed mood and anhedonia. As with the PHQ-9, each item is rated over the last 2 weeks on a 4-point multiple choice scale. Scores range from 0 to 6.

Three studies with a total of 559 participants were identified as validating the PHQ-9 and PHQ-2 amongst a population of stroke survivors (de Man-van Ginkel et al., 2012; Turner, et al., 2012; Williams et al., 2005). In each study, the PHQ-9 was found to meet recommended levels of accuracy when screening for depression, as outlined by Bennett and Lincoln (2006). However, the PHQ-2 was only found to meet recommended levels of accuracy in one study which consisted of 316 participants (Williams, et al., 2005). Please refer to Tables 10 and 11 for a summary of recommended cut-off scores.

Williams et al. (2005) provided the first study to validate the PHQ-9 and PHQ-2 with a sample of 316 stroke survivors at 1 and 2 months post-stroke. When using a cut-off score of at least 10, the PHQ-9 demonstrated an adequate level of accuracy for major depression and any depressive disorder (sensitivity: 0.91 and 0.78, specificity: 0.89 and 0.96, respectively). Similarly, when using a cut-off score of at least 3, the PHQ-2 had acceptable levels of accuracy for major depression and any depressive disorder (sensitivity: 0.83 and 0.78, specificity: 0.84 and 0.94, respectively). However, a major limitation of this study was that the criterion standard was only administered to those who scored within the clinical range on the PHQ-9 and PHQ-2.

Verification bias of this type can affect both sensitivity and specificity, where participants with false negative results go undetected (Whiting, et al., 2004). To overcome this limitation, a further two studies were conducted which investigated the accuracy of the PHQ-9 and PHQ-2 at discriminating between DSM-IV cases of major depression (de Man-van Ginkel, et al., 2012; Turner, et al., 2012). To prevent review bias, the clinical interview was completed blind to the results of the PHQ (Whiting, et al., 2004).

In a group of 171 stroke survivors, the PHQ-9 was found to have an acceptable level of accuracy as a screening measure for post-stroke depression (sensitivity: 0.80, specificity: 0.78) when using the standard cut-off score of at least 10 (de Man-van Ginkel, et al., 2012). However, when Turner et al. (2012) evaluated the accuracy of the PHQ-9 with a group of stroke survivors between 3 weeks and 45 years post-stroke, a lower cut-off score of at least 7 was required to meet a similar balance of accuracy (sensitivity: 0.85, specificity: 0.63). According to Turner et al. (2012), a cut-off score of at least 2 on the PHQ-2 came close to recommended levels of accuracy (sensitivity: 0.77, specificity: 0.63). Due to its brevity, the PHQ-2 was recommended as the most useful single-item screening tool.

Table 10

Stroke Related Cut-Off Scores for the PHQ-9

| Study | Time since stroke | Cutoff |
|---------------------------------|--------------------|----------------------|
| Williams et al. (2005) | 1-2 months | $\geq 10_{\ddagger}$ |
| De Man van Ginkel et al. (2011) | 5-9 weeks | $\geq 10_{\ddagger}$ |
| Turner et al. (2012) | 3 weeks – 45 years | $\geq 7_{\ddagger}$ |

\ddagger Cut-off meeting recommended levels of sensitivity (≥ 0.80) and specificity (≥ 0.60)

Table 11

Stroke Related Cut-Off Scores for the PHQ-2

| Study | Time since stroke | Cutoff |
|---------------------------------|--------------------|---------------------|
| Williams et al. (2005) | 1-2 months | $\geq 3_{\ddagger}$ |
| De Man van Ginkel et al. (2011) | 5-9 weeks | ≥ 2 |
| Turner et al. (2012) | 3 weeks – 45 years | ≥ 2 |

\ddagger Cut-off meeting recommended levels of sensitivity (≥ 0.80) and specificity (≥ 0.60)

Smiley

The smiley (Lee, et al., 2008) was developed to screen for post-stroke depression. It contains a sad/tearful face, a neutral/flat face and a happy/smiley face. Participants are asked to rate the frequency of experiencing these emotions over the past 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*).

One study was identified as validating the Smiley with 253 Chinese stroke patients 1 month post stroke relative to the DSM-IV criteria for depression (Lee, et al., 2008). Although the sad face was the most accurate face, sensitivity fell just under recommendations (sensitivity: 0.76, specificity: 0.77). The GDS was found to be superior.

Stroke Inpatient Depression Inventory (SIDI)

The SIDI (Rybarczyk, et al., 1996) is a 30-item self-report measure of depression, rated using a yes/no format. The SIDI was developed specifically for use with stroke patients in hospital and contains items unique to this population and within the time frame of having had a stroke, such as “are you worrying a great deal about how you’re going to get by after you leave the hospital?”

Two studies with a combined total of 117 participants were identified as validating the SIDI with a sample of stroke survivors (Roger & Johnson-Greene, 2009; Rybarczyk, et al., 1996). In one out of the two studies the SIDI was found to meet recommended levels of diagnostic accuracy (Rybarczyk, et al., 1996).

The SIDI was originally validated with 50 non-aphasic stroke inpatients (Rybarczyk, et al., 1996). The SIDI demonstrated good internal consistency (Cronbach's $\alpha = 0.90$). In relation to the DSM-III criteria for depression, the SIDI produced an acceptable level of validity (specificity: 0.94, sensitivity: 0.71). An optimal cut-off score of at least 17 was indicated and the SIDI showed precedence over the CES-D. However, Roger and Johnson-Greene (2009) provided contradictory evidence. While the accuracy of the SIDI continued to be superior to the CES-D, a lower cut-off score was advocated (≥ 10) and the overall accuracy of the SIDI performed below recommended levels (sensitivity: 0.66, specificity: 0.72). As a result, the GDS-15 was recommended above the SIDI and CES-D.

Symptom Checklist – 90 (SCL-90)

The SCL-90 (Derogatis, Rickels, & Rock, 1976) is a 90-item self-report measure designed to measure psychopathology in psychiatric and medical patients over the last 7 days. Each item is rated on a 5-point scale of distress from 0 (*not at all*) to 4 (*extreme*).

One study was identified as validating the SCL-90 among a population of 202 stroke survivors (Aben, et al., 2002). The SCL-90 depression subscale was found to have an acceptable level of sensitivity (0.89, 0.88) and specificity (0.61, 0.66) when detecting DSM-IV diagnoses of major depression and major and minor depression 1 month post stroke. An optimal cut-off score of 25 was recommended. While the accuracy of the SCL-90 was comparable to the HADS and BDI, the SCL-90 was less favorable due to it taking longer to complete.

Visual Analogue Mood Scale (VAMS and VAMS-SAD)

The VAMS (Stern, Arruda, Hooper, & Wolfner, 1997) consists of seven 10cm vertical lines containing a neutral cartoon face at the top of the line, and one of seven cartoon faces at the bottom of the line, depicting sad, afraid, tired, angry, confused, happy and energetic. The individual is asked to indicate their current mood on the vertical line. The VAMS was created specifically for people who have neurological disorders and communication disorders.

One study was identified as validating the VAMS amongst a sample of 100 stroke survivors relative to the HADS (Bennett, Thomas, Austen, Morris, & Lincoln, 2006) While the VAMS correlated significantly with the HADS-T ($r_s = .45$; $p < .001$), HADS-D ($r_s = .36$; $p < .001$) and HADS-A ($r_s = .43$; $p < .001$), no suitable cut-off scores were identified when screening for depression (sensitivity: 0.81, specificity: 0.05) or anxiety (sensitivity: 0.71, specificity: 0.66).

In contrast, the authors demonstrated that the one item sad face (VAMS-SAD) did meet acceptable levels of sensitivity (0.88) and specificity (0.62). However, this finding was not supported by Berg et al. (2009) who investigated the accuracy of the VAMS-SAD relative to the DSM-III-R criteria for major depression. The accuracy of the VAMS-SAD was evaluated among 100 stroke survivors at 2 months, 6 months, 12 months and 18 months post-stroke. While the specificity of the VAMS-SAD met recommended levels of accuracy, sensitivity (0.60) fell short of 0.80.

Visual Analogue Self-Esteem Scale (VASES)

The VASES (Brumfitt & Sheeran, 1999) is a self-report visual analogue scale of self-esteem. It contains 10 pairs of line drawings which represent opposite constructs of the self (cheerful/not cheerful, trapped, optimistic, confident, frustrated, confused, misunderstood, outgoing, intelligent and angry). Like the VAMS, the VASES was developed specifically for aphasic patients. The pairs of drawings are presented one at a time and are scored from 1 to 5.

One study was identified as validating the VASES among a group of stroke survivors. Bennett et al. (2006) evaluated the diagnostic accuracy of the VASES at detecting post-stroke depression and anxiety with a sample of 100 non-aphasic stroke survivors. While the VASES correlated significantly with both subscales of the HADS and total scale, the VASES failed to show acceptable cut-off scores (sensitivity: 0.81; specificity: 0.05).

Wakefield Depression Inventory (WDI)

The WDI (Snaith, Ahmed, Mehta, & Hamilton, 1971) is a 12-item self-report questionnaire designed to measure the severity of depression within a psychiatric population. Items are rated on a 4-point scale. The WDI was developed to provide a brief and simple measure of depression. A cut-off score of at least 15 was recommended in the original study when used with a general population.

One study was identified as validating the WDI with a population of 143 stroke survivors (Lincoln, et al., 2003). Optimal cut-off scores of at least 19 and 21 were identified, relative to the ICD-10 and DSM-III criteria respectively. However, although the WDI had an acceptable level of sensitivity (0.86 and 0.92), specificity was low (0.50 and 0.46).

Yale

The Yale question (Lachs et al., 1990), 'Do you feel depressed?', is recommended by the National Clinical Guidelines for Stroke when screening for depression (Intercollegiate Stroke Working Party, 2008). The Yale was initially developed by the Yale Task Force to screen for depression in older patients.

Three studies with a combined total of 315 participants were identified as validating the Yale with a population of stroke survivors (Turner-Stokes, et al., 2005; Watkins, Daniels, Jack, Dickinson, & van den Broek, 2001; Watkins et al., 2007).

In two of the three studies (N=201) the Yale was found to meet recommended levels of accuracy (Watkins, et al., 2001; Watkins, et al., 2007).

The Montgomery-Asberg Depression Rating Scale (MADRS; Montgomery & Asberg, 1979) is a clinician-rated scale used by two studies as the criterion standard. In both studies, the Yale was seen to have good sensitivity (0.86) and specificity (0.78 and 0.84 respectively) for detecting depression at 2 weeks post stroke (Watkins, et al., 2001; Watkins, et al., 2007). At 3 months post-stroke, the accuracy of the Yale improved, with sensitivity and specificity of 0.95 and 0.89 (Watkins, et al., 2007).

More recently, Turner-Stokes et al. (2005) evaluated the ability of the Yale at predicting DSM-IV cases of depression in a younger adult population. The accuracy of the Yale question was found to be lower than the above studies (sensitivity 0.68, specificity 0.73) and outside recommended levels. In comparison to the DISCS and BDI-II, the Yale performed least well.

Zung Self-Rating Depression Scale (ZSDS)

The ZSDS (Zung, 1965) is a 20-item self-report scale developed to identify clinically significant depression within a psychiatric population. Items are rated on a 4-point likert scale over the past few days. A score of at least 55 is used to identify depression in people over the age of 60.

One study was identified as validating the ZSDS with a sample of 40 stroke survivors. Using a lower cut-off score of at least 40, Agrell and Dehlin (1989) concluded that the ZSDS was an acceptable screening tool for post-stroke depression. The sensitivity (0.76) and specificity (0.96) of the ZSDS was comparable to the GDS and superior to the CES-D.

Diagnostic Accuracy

Overall, 24 measures were evaluated as a screening tool for depression. Fifteen were found to meet recommended levels of diagnostic accuracy as a screening tool for depression, as outlined by Bennett and Lincoln (2006). These include the BDI, BDI-II, BASDEC, CES-D, GHQ-30, GHQ-28, GDS-30, GDS-15, HADS (including the HADS-D and HADS-T), PHQ-9, PHQ-2, SIDI, SCL-90, VAMS-SAD and Yale. However, the standard cut-off score for each measure was not always used to meet this balance of accuracy. For example, in one study a higher cut-off score of at least 26 was recommended when using the CES-D (Rybarczyk, et al., 1996) and in three studies a lower cut-off score of at least 4 and 7 was recommended when using the HADS-D (O'Rourke, et al., 1998; Sagen, et al., 2009; Tang, et al., 2004b).

Three measures were validated as a screening tool for anxiety, which included the BAI, GHQ-28 and HADS (HADS-A and HADS-T). However, the HADS-A was the only measure to meet recommended levels of accuracy. This finding was supported by two studies, both of which used lower cut-off scores compared to the standard of at least 8 (O'Rourke, et al., 1998; Sagen, et al., 2009).

Clinical Utility

Length of measure.

The length of each measure was categorised according to three groups including ultrashort, short and long measures. Six ultrashort measures consisting of 1 to 4 items were identified. These included the DISCS , DT, PHQ-2, Smiley, VAMS-SAD and Yale. Eleven short measures, which consisted of 5 to 20 items were identified, namely the BDI-FS, BASDEC, CES-D, GDS-15, HADS, K10, PHQ-9, VAMS, VASES, WDI and ZDRS. The remaining eight measures were classed as long measures and consisted of at least 21 items. These included the BAI, BDI, BDI-II, GHQ-28, GHQ-30, GDS-30, SIDI, and SCL-90.

Type of training required to administer each measure.

No specific training is required to use any of the measures identified in the review other than reading the manual or original paper where applicable. However, it is assumed and stipulated for the BAI, BDI-II, BDI-FS, HADS, GHQ, SCL-90, VASES and VAMS that prior training as a healthcare professional or researcher is required to administer and interpret each self-report measure.

Response format.

Thirteen measures consisted of a multiple choice format. These included the BAI, BDI, BDI-II, BDI-FS, CES-D, GHQ-28, GHQ-30, HADS, PHQ-9, PHQ-2, SCI-90, WDI and ZDRS. Apart from the SCL-90 which consisted of a 5-point scale, the remaining twelve measures were scored on a 4-point scale. Five measures consisted of a yes/no format which included the BASDEC, GDS, GDS-15, SIDI and Yale. Six measures comprised visual analogue scales and included the DISCs, DT, Smiley, VASES, VAMS, and VAMS-SAD.

Sample characteristics.*Nationality of participants.*

Eight studies were carried out in the UK (Bennett, et al., 2006; Healey, et al., 2008; House, et al., 1989; Lincoln, et al., 2003; O'Rourke, et al., 1998; Turner-Stokes, Kalmus, Hirani, & Clegg, 2005; Watkins, Daniels, Jack, Dickinson, & van den Broek, 2001; Watkins et al., 2007), six studies were carried out in the USA (Parikh, et al., 1988; Roger & Johnson-Greene, 2009; Rybarczyk, et al., 1996; Schramke, et al., 1998; Shinar, et al., 1986; Williams, et al., 2005), four studies were carried out in China (Lee, et al., 2008; Tang, et al., 2004a; Tang, et al., 2004b; Tang, et al., 2004c), two studies were carried out in Australia (Johnson, et al., 1995; Turner, et al., 2012) and the Netherlands (Aben, et al., 2002; de Man-van Ginkel, et al., 2012), and one study was carried out in Finland (Berg, et al., 2009), Norway (Sagen, et al., 2009), Sweden (Agrell & Dehlin, 1989), and Turkey (Sivrioglu, et al., 2009).

Sixteen studies recruited English speaking participants. Of the 25 measures identified in the review, only 3 measures were not validated amongst a sample of English speaking stroke survivors. These include the Smiley, SCL-90 and ZSRDS.

Study setting.

Thirteen studies were conducted within inpatient settings, such as specialist stroke units and/or rehabilitation units (Aben, et al., 2002; Bennett, et al., 2006; Healey, et al., 2008; Lee, et al., 2008; Roger & Johnson-Greene, 2009; Rybarczyk, et al., 1996; Sagen, et al., 2009; Tang, et al., 2004a; Tang, et al., 2004b; Tang, et al., 2004c; Turner-Stokes, et al., 2005; Watkins, et al., 2001; Williams, et al., 2005). In contrast, six studies recruited participants from community settings, such as support groups, hospital discharge registers, outpatient clinics, day hospitals, nursing homes, and community stroke teams (Agrell & Dehlin, 1989; de Man-van Ginkel, et al., 2012; House, et al., 1989; Johnson, et al., 1995; O'Rourke, et al., 1998; Schramke, et al., 1998). Seven studies recruited participants from both inpatient and community based settings (Berg, et al., 2009; Lincoln, et al., 2003; Parikh, et al., 1988; Shinar, et al., 1986; Sivrioglu, et al., 2009; Turner, et al., 2012; C. L. Watkins, et al., 2007).

Of the 25 measures identified 13 were validated amongst stroke survivors within inpatient and community settings. These included the BDI, BDI-II, CES-D, DT, GHQ-28, GDS-30, HADS, K-10, PHQ-9, PHQ-2, VAMS-SAD, WDI and Yale. Nine measures were validated amongst stroke survivors within inpatient settings only. These included the BDI-FS, BASDEC, DISCs, GDS-15, Smiley, SIDI, SCL-90, VAMS, and VASES. Moreover, three measures, the BAI, GHQ-30 and ZSRDS, were only validated amongst stroke survivors within community settings.

Time since stroke.

The time between onset of stroke and the completion of the mood assessment varied between studies and ranged from 3 days (Rybarczyk, et al., 1996) to 45 years (Turner, et al., 2012). Twenty two studies were carried out using a cross-sectional design, whereas three studies followed the same sample of participants over a period of time and reported follow-up data for the BDI (Berg, et al., 2009; House, et al., 1989), VAMS-SAD (Berg, et al., 2009), and Yale (Watkins, et al., 2007).

Exclusion criteria.

All of the studies identified in the review excluded participants who had cognitive and communication problems which would hinder the completion of a clinical interview and self-report measure. Various other exclusion criteria were reported, which included comorbid conditions (such as dementia, psychosis, and Parkinson's Disease), the use of antidepressant medication, and being over the age of 70 years.

Cost of purchasing measure.

Twelve measures are available in the public domain and free to use for clinical purposes with and without the express written permission from the authors, as detailed in Table 12. Eleven measure are protected by copyright and can be purchased for a fee. The availability of the Smiley is unknown as the authors did not specify whether the measure could be purchased for clinical use and the BDI is out of print due to being revised as the BDI-II.

Table 12

Cost and Availability of Each Measure

| Measure | Cost |
|---------|---|
| BAI | Manual and 25 record forms \$120.00 from www.pearsonassessments.com/pai/ca/cahome.htm |
| BDI | Out of print |
| BDI-II | Manual and 25 record forms \$120.00 from www.pearsonassessments.com/pai/ca/cahome.htm |
| BDI-FS | Manual and 50 record forms \$99.00 from www.pearsonassessments.com/pai/ca/cahome.htm |
| BASDEC | £9.99 from Amazon and Ebay |
| CES-D | Freely available from http://java2.bmedreport.netdna-cdn.com/wp-content/uploads/2009/11/CES-D-Stanford-Version.pdf |
| DISCs | Freely available from www.csi.kcl.ac.uk/files/DISCS.pdf |
| DT | Free with the express written permission of the NCCN. License obtained from www.nccn.org/clinical.asp |
| GHQ | Manual £95 and 25 record forms £65 from http://www.gl-assessment.co.uk/ |
| GDS-30 | Freely available from https://www.outcometracker.org/library/GDS.pdf |
| GDS-15 | Freely available from www.chcr.brown.edu/GDS_SHORT_FORM.PDF |
| HADS | Manual and 100 record forms £95 from http://www.gl-assessment.co.uk/ |
| K-10 | Freely available from www.gpcare.org/outcome%20measures/outcomemeasures.html |
| PHQ-9 | Freely available from http://www.phqscreeners.com/ |
| PHQ-2 | Freely available from http://www.cqaimh.org/pdf/tool_phq2.pdf |
| Smiley | Availability of measure not reported |
| SIDI | Free with the permission of the author and available from the original article |
| SCL-90 | Manual and 50 record forms \$114.70 from http://psychcorp.pearsonassessments.com/pai/ca/cahome.htm |
| VAMS | Manual, 25 response forms and metric ruler \$144 from www4.parinc.com/Products/Product.aspx?ProductID=VAMS# |
| VASES | CD ROM and booklet £55.99 + VAT from www.speechmark.net/vases-visual-analogue-self-esteem-scale |
| WDI | Freely available from the original article |
| Yale | Freely available |
| ZSRDS | Freely available from http://healthnet.umassmed.edu/mhealth/ZungSelfRatedDepressionScale.pdf |

Discussion

Summary of Main Findings

The aim of this review was to investigate the validity and clinical utility of self-report screening measures for the identification of post-stroke distress. In conclusion, 25 self-report screening measures were identified as meeting the search criteria, based upon the results of 26 studies.

Twenty four measures were evaluated as screening measures for the detection of post-stroke depression. In contrast, only three measures were evaluated for the detection of post-stroke anxiety. The HADS-A was the only measure to meet recommended levels of accuracy for post-stroke anxiety, whereas 15 measures met recommended levels of accuracy for post-stroke depression. As identified by a previous review (Bennett & Lincoln, 2006), there is a clear need to develop and validate screening measures which can accurately detect post-stroke anxiety. This is important as anxiety disorders are thought to be just as prevalent as post-stroke depression and are associated with reduced functional outcome and quality of life following stroke (De Wit, et al., 2008; Shimoda & Robinson, 1998).

Implications for Clinical Practice

While national guidelines (Intercollegiate Stroke Working Party, 2008) highlight the importance of mood screening, they do not specify which measure should be used to do this. In the current review, it was difficult to identify one measure above another due to methodological variation between studies, such as varying sample sizes, criterion standards, and clinical characteristics. Furthermore, the majority of measures were not originally designed to screen for distress among stroke survivors. Consequently, cut-off scores often varied from the standard. It is possible that this variability reflects the heterogeneous nature of stroke and supports the idea that local service providers need to choose measures and cut-off scores which have been validated most closely with the clinical population at hand.

Service providers also need to take into account the clinical utility of each measure. When screening patients on busy medical wards, validated measures are needed which are quick and easy to use (Lincoln, et al., 2012). While ultrashort measures such as the PHQ-2 and Yale may be quick to use, they do not screen for multiple domains of distress. In contrast, short and long measures, such as the HADS and GHQ-28 can be used to screen for anxiety and depression and arguably offer a greater richness of information but take longer to complete (Vodermaier, et al., 2009).

The generalisation of the current findings to people with moderate to severe cognitive and communication difficulties is limited. All of the studies identified in the review excluded people with moderate to severe cognitive and communication difficulties. Nonetheless, stroke survivors with aphasia are thought to be at a greater risk of developing clinical levels of distress (Barker-Collo, 2007). Consequently, future research is needed which evaluates self-report screening measures with stroke survivors who have cognitive and communication difficulties based upon observer-rated criterion standards.

Arguably, the visual analogue scale is thought to be more appropriate for people with communication difficulties (Benaim, et al., 2004). In the current review the VAMS-SAD was the only visual analogue scale to meet recommended levels of accuracy when detecting depression and this finding was based upon one study which excluded aphasic stroke survivors. It is also argued that a consistent and simple response format, such as yes/no, may be more beneficial for people with cognitive and communication difficulties compared to varying multiple choice formats (Bennett & Lincoln, 2006). Consequently, measures such as the BASDEC, GDS, SIDI and Yale may be more preferable when screening someone with reduced communication.

Limitations of the Review

It was outside the scope of this review to compare and contrast the positive and negative predictive values of each measure (Appendix B). The PPV indicates the probability of someone experiencing anxiety and depression when the test index is positive. However, this is affected by the prevalence of the condition in the study. Consequently, when generalising findings to clinical populations, it is important for service providers to re-calculate positive and negative predictive values according to base rates of anxiety and depression in the clinical population. As the prevalence rates of anxiety or depression increase, the PPV value will also increase (Baldessarini, Finklestein, & Arana, 1983).

Implication for future research

At the commencement of this thesis, the DT had not been validated among stroke survivors, despite being recommended by NICE (2009) for the identification of depression in adults with chronic physical health problems and significant communication difficulties. While the diagnostic accuracy of the DT as a screening tool for post-stroke depression has been evaluated more recently by Turner et al. (2012), its ability to detect post-stroke anxiety has not been investigated. As detailed above, there is a need to validate self-report screening measures for the detection of post-stroke anxiety. Furthermore, the current review highlights the importance of validating measures with stroke survivors to ascertain whether standard cut-off scores meet diagnostic accuracy. As an ultra short visual analogue scale, the DT warrants further investigation.

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Validation of the Distress Thermometer among Stroke Survivors

by

Rachael Gilson

Doctoral Programme in Clinical Psychology

School of Psychology

University of Southampton

Abstract

Post-stroke distress is common and can range from clinical levels of depression and anxiety to less intense and persistent states of emotional adjustment. National guidelines recommend that everyone should be screened for mood disturbances within six weeks of having a stroke. However, screening measures are not well validated among stroke populations. Thirty-one stroke survivors completed the Distress Thermometer (DT) and Problem List (PL), Brief Assessment Schedule Depression Cards (BASDEC), Yale, and Hospital Anxiety and Depression Scale (HADS). Receiver operating characteristic (ROC) analysis was carried out to investigate the accuracy of the DT, BASDEC and Yale at identifying clinical cases relative to the HADS. The area under the curve (AUC) for the DT (0.74, 0.86) was significantly greater than an AUC of 0.50. Cut-off scores of at least 4 and 5 on the DT met recommended levels of sensitivity (≥ 0.80) and specificity (≥ 0.60). The AUC for the BASDEC and Yale were not significantly different to an AUC of 0.50. Due to a small sample size, these results should be taken with caution. However, this study provides preliminary evidence to support the use of the DT and PL as a holistic and person-centred screening tool for the prevention and recognition of post-stroke distress.

Introduction

Emotional distress is common in many areas of physical illness or injury including stroke (Kennedy, 2007). Distress has been defined within cancer patients as:

a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis (National Comprehensive Cancer Network [NCCN], 2003, p. DIS-2).

Depression and to a lesser extent anxiety are the most frequently researched areas of post stroke distress (Carney & Freedland, 2002; Intercollegiate Stroke Working Party, 2008). Approximately one third of people will experience depression within five years of having a stroke (Hackett, Yapa, Parag, & Anderson, 2005) and around a quarter of stroke survivors are thought to experience symptoms of generalised anxiety (De Wit et al., 2008). As with other long-term physical health conditions (Naylor et al., 2012), post-stroke distress has been associated with poorer quality of life and reduced physical outcome (Jaracz, Jaracz, Kozubski, & Rybakowski, 2002; Pohjasvaara, Vataja, Leppävuori, Kaste, & Erkinjuntti, 2001).

As a result, increasing attention is being paid to the “human and economic” cost of supporting people with comorbid mental and physical health difficulties. A recent report by the King’s Fund highlighted the importance of providing a more integrative health system, which would encourage a holistic view of mental and physical health care needs. The detection of mental health difficulties is highlighted as the first step in supporting this process (Naylor, et al., 2012, p. 22).

Mood Screening

The National Clinical Guideline for Stroke (Intercollegiate Stroke Working Party, 2008) recommends that all patients entering rehabilitation and thereafter should be screened for depression and anxiety using a validated measure. However, “practitioner and system related” factors, such as reluctance to ask sensitive questions, time pressure, lack of knowledge and poor awareness of guidelines continue to prevent screening (Cully & Stanley, 2008, p. 234; Hammond, O’Keeffe, & Barer, 2000; Hart & Morris, 2008).

The detection of post-stroke distress is further complicated due to the majority of stroke survivors having an impairment in at least one cognitive domain, which may hinder the completion of self-report assessments (Leśniak, Bak, Czepiel, Seniów, & Członkowska, 2008). Furthermore, 75% of stroke survivors fall within the older adult population (National Audit Office, 2005). The older adult population are more likely to report somatic symptoms of distress, which may be misconstrued as physical or environmental consequences of stroke, and vice versa (Laidlaw & Knight, 2008; Roger & Johnson-Greene, 2009).

Consequently, measures are needed which are easy to use, require minimal training and resources, are accessible in a variety of settings, and take into account the somatic overlap of symptoms (Lincoln, Kneebone, Macniven, & Morris, 2012). Although a number of brief self-report mood screening measures exist, the majority have been developed with healthy working age adults or psychiatric populations (Antony, Orsillo, & Roemer, 2001) . As identified in the associated literature review, standard cut-off scores are often suboptimal when used with stroke survivors.

Person-Centred Assessment of Need

The International Classification of Functioning, Disability, and Health's (ICF) biopsychosocial model highlights a "dynamic interaction" between a health condition, functioning, disability, and contextual factors (WHO, 2001, p. 26). Furthermore, the experience and severity of post-stroke distress is likely to vary according to the personal meaning that someone attributes to their condition and associated disability (Wade & Halligan, 2003). Consequently, post-stroke distress is not seen as a single entity but viewed within a holistic framework of someone's subjective needs.

While there is a clear need to validate self-report measures which can accurately screen for mood disorders (Intercollegiate Stroke Working Party, 2008), many stroke survivors may experience less intense and persistent states of distress which still affect quality of life and outcome (House, Knapp, Bamford, & Vail, 2001). Measures which assess distress along a continuum of severity are required to support current needs and prevent escalating difficulties (Kessler et al., 2002).

Furthermore, it seems important to recognise factors associated with post-stroke distress in order to prevent escalating problems and tailor interventions to the person's specific needs (Hilari et al., 2010).

Factors Associated with Post-Stroke Distress

Over the years, a number of biological and psychosocial factors have been implicated in the development of post-stroke distress. Early research suggests that post-stroke depression was caused by neurological damage and lesion location (Castillo, Starkstein, Fedoroff, & Price, 1993; Robinson, Starr, Kubos, & Price, 1983). However, a more recent review of the literature disputed such claims and current interest has turned to the size of the lesion as opposed to its location (Carson et al., 2000; Santos et al., 2009).

In contrast, psychosocial explanations suggest that the development of post-stroke distress is related to a process of adjustment (Jenkins, Andrewes, Hale, & Khan, 2009). Adjustment has been defined as a "fluid process" where emotional difficulties can arise as the person learns to adapt and accommodate to change (Brennan, 2001; Taylor, Todman, & Broomfield, 2011, p. 809). Early stage models have likened post-stroke adjustment to a process of bereavement, initially characterised by shock, confusion, and anxiety, followed by a sense of high expectations, denial, and grief. As treatment progresses, the person is thought to acquire a realisation of their disability, particularly after being discharged home (Barton, 2007; Wade, Langton Hewer, Skilbeck, & David, 1985).

A more recent model of adjustment by Ch'Ng, French and Mclean (2008) suggests that within the acute phase of recovery emotional distress is likely to relate to the management of physical and communication problems, loss of control over personal care, dissatisfaction with the hospital environment, and uncertainty and confusion about what has happened. During the rehabilitation stage, uncertainty about prognosis, social isolation and anxiety over the amount of recovery become predominant, whereas discharge home is seen to be the most challenging time periods, with a sense of abandonment dominating concerns. From this stage onwards, distress is thought to be associated with feelings of anger and frustration around the loss of future plans and negative views of the self.

Stage models of adjustment suggest that the assessment and treatment of emotional distress is likely to differ depending upon the stage of recovery someone is in (Lincoln, et al., 2012). The Social Cognitive Transition Model for Stroke (SCoTS) however provides a more individualised theory where pre and post injury personal characteristics, such as attributions, coping styles, social support, and cognitive deficits are emphasised. Unlike stage models of adjustment, the SCoTS highlights a cyclical process with no set time frame or right or wrong way to adjust (Taylor, et al., 2011).

Local Protocols

Self report measures do not facilitate change by themselves (Carlson, Waller, & Mitchell, 2012). It is recommended that mood screening measures are used within the first level of a stepped care approach to psychological care, from which more detailed assessments are used to tailor interventions to the person's specific needs (Carlson, et al., 2012; Gillham & Clark, 2011). It is recommended that local service providers develop mood assessment pathways which take into account the specific needs and demographic characteristics of the patient population at hand (Intercollegiate Stroke Working Party, 2008). A primary aim of this study was to evaluate the validity of four self-report screening tools, three of which were already being used on an acute and sub-acute stroke unit.

As detailed in the associated literature review, the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) is one of the most frequently validated measures used within stroke services for people without communication difficulties (Lincoln, et al., 2012). The HADS is also one of the few measures to meet recommended guidelines as a screening tool for post-stroke anxiety in addition to depression (O'Rourke, MacHale, Signorini, & Dennis, 1998; Sagen et al., 2009).

The Brief Assessment Schedule Depression Cards (BASDEC; Adshead, Cody, & Pitt, 1992) has also demonstrated a high level of sensitivity and specificity as a screening tool within stroke. However, evidence of diagnostic accuracy is limited to one study and requires replication (Healey, Kneebone, Carroll, & Anderson, 2008).

On busy medical wards, there is a preference for ultrashort measures of distress. The one-item Yale question (Lachs et al., 1990) is currently being used as a first line approach as a screening tool for depression on the stroke unit affiliated with this study (Appendix D).

The Distress Thermometer (DT; Roth et al., 1998) is a one-item visual analogue scale measuring general distress. Although research suggests that many stroke survivors are unable to use visual analogue scales (Price, Curlless, & Rodgers, 1999), they offer the only form of self assessment for people with communication difficulties (Benaim, Cailly, Perennou, & Pelissier, 2004). The DT has been validated widely within oncology, with the HADS being used most frequently as the criterion standard (Vodermaier, Linden, & Siu, 2009). However, at the commencement of this study the DT had not been validated within stroke. This was despite the DT being recommended by NICE (2009) for the identification of depression in adults with chronic physical health problems and significant communication difficulties.

In 2003, the NCCN developed a Distress Management Screening Measure (DMSM) which consisted of the DT and an accompanying Problem List (PL). The PL is a 38-item list consisting of a yes/no format. It was designed to identify factors contributing to emotional distress rated on the DT. It contains five domains including practical, family, physical, emotional and spiritual problems. The individual is asked to state whether any of the problems have been a problem for them in the last week. The PL can be adapted for clinical use (Jacobsen et al., 2005; Vitek, Rosenzweig, & Stollings, 2007). While Turner et al. (2012) have recently evaluated the DT as a

screening tool for post-stroke depression, the accuracy of the DT as a screening tool for post-stroke anxiety has not been investigated. Moreover, the clinical utility of the PL in combination with the DT has not been investigated among stroke survivors. Unlike other self-report screening tools, the DT and PL offer a more holistic view of distress in addition to screening for clinical levels of affective disorders. The PL is designed to provide a person-centred assessment of need and assist professionals in making appropriate referrals by discussing the associated problems faced by the patient and signposting them to appropriate services. Furthermore, the visual analogue format and yes/no response of the PL are thought to be more accessible to those with cognitive and communication difficulties (Goebel & Mehdorn, 2011).

Rationale and Aims of Study

The National Stroke Strategy (Department of Health [DOH], 2007) highlights the importance of providing emotional support throughout the stroke care pathway. Although 80% of patients are now being screened for mood disturbance within 6 weeks of having a stroke, many stroke survivors continue to have unmet needs and experience a lack of emotional and psychological support (Healthcare Commission, 2006). There is a need to develop and validate screening measures to improve the detection, prevention and treatment of post-stroke distress. Stroke services also need to provide “a multidisciplinary person-centred assessment” of need and signposting to other services (DOH, 2007, p. 45). The DT and PL are being piloted on the stroke unit to offer a more unified and holistic approach, which addresses the need to screen for clinically significant mood disorders, to assess unmet needs and to promote signposting to other services.

Consequently, the aim of this study was to evaluate the ability of the DT, BASDEC and Yale to screen for post-stroke distress by comparing scores against the HADS. Notably, the study was not evaluating the ability of these three measures to diagnose psychiatric mood disorders and therefore did not attempt to compare results against a structured clinical interview.

Research Questions

1. Is the PL clinically appropriate for people who have experienced a stroke?
2. Is the DT and PL a reliable and valid measure of distress for people who have experienced a stroke?
 - a. Will scores on the DT, BASDEC and Yale significantly correlate with scores on the HADS, or in other words demonstrate good concurrent validity relative to the HADS?
 - b. Will the PL demonstrate internal consistency?
3. What cut-off scores on the DT correctly identify distressed cases?

Method

Design

A cross sectional, test-criterion design was used. The test variables were the DT, BASDEC and Yale. The criterion variables were the depression subscale of the HADS (HADS-D), the anxiety subscale of the HADS (HADS-A), and the total score on the HADS (HADS-T).

Participants

Participants consisted of an opportunity sample recruited from an inpatient rehabilitation unit for stroke survivors and four charity support groups affiliated with The Stroke Association and Headway. Recruitment took place over five months from December 2011 to May 2012. Participants were excluded if they had not experienced a stroke or transient ischemic attack (TIA), were medically unstable, under the age of 18 years, were unable to give informed consent (indicated by consultation with the stroke team and charity representatives and a score of less than 20 on the MoCA), experienced comorbid dementia, had dysphasia that would hinder completion of the questionnaires (based upon consultation with the Speech and Language Therapist and charity representatives) or were non-English speaking.

Measures

The BASDEC (Adshead, et al., 1992) is a self-report measure originally developed to screen for depression with geriatric medical inpatients. It consists of 19 cards each containing a statement derived from the depression scale of the Brief Assessment Schedule (BAS-DEP; Ramsay, Wright, Katz, Bielawska, & Katona, 1991). The client is asked to place each statement next to a true or false card based upon their current feelings. A cut off score of at least 7 is used to indicate possible depressive disorder (Adshead, et al., 1992; Healey, et al., 2008). Among stroke survivors, the BASDEC has been shown to have acceptable internal consistency (Kuder-Richardson Formula 20 = 0.77) and test-retest reliability ($\tau(43) = 0.66$, $p < 0.001$) and good concurrent validity (sensitivity: 1.0, specificity: 0.95; Healey, et al., 2008, p. 534).

The DT (Roth, et al., 1998) is a one-item self-report scale recommended for use as a distress screening tool within cancer services (NCCN, 2011). It consists of an 11-point visual analogue scale, measuring distress from 0 (*no distress*) to 10 (*extreme distress*) during the past week (Figure 1). The DT has demonstrated an adequate level of sensitivity (0.89) and specificity (0.60) when detecting symptoms of depression or anxiety among patients with intracranial tumours (Goebel & Mehdorn, 2011). A cut-off score of at least 4 is recommended by the NCCN as warranting further assessment.

The PL consists of 38-items based upon a yes/no format. The PL was designed to identify factors contributing to distress by working as a semi-structured interview where the individual is asked to indicate which items have been a problem for them in the past week. This information is used to signpost patients to other services and help tailor person-centred interventions (NCCN, 2011). The PL has been found to have a good level internal consistency (Cronbach's $\alpha = 0.81$; Hoffman, Zevon, D'Arrigo, & Cecchini, 2004). For the purpose of this study, the PL was adapted for use with people who have experienced a stroke. This was based upon the results of a focus group, literature review, and pilot phase (as detailed below). The adapted PL contains 41-items divided into six domains (Figure 2). Written permission was obtained from Dr Jimmie Holland, Head of the NCCN Distress Management panel, to use the DT and PL (Appendix E).

Distress Thermometer and Problem List

Instructions: First, please circle the number (0-10) that best describes how much distress you have been experiencing in the past week including today.

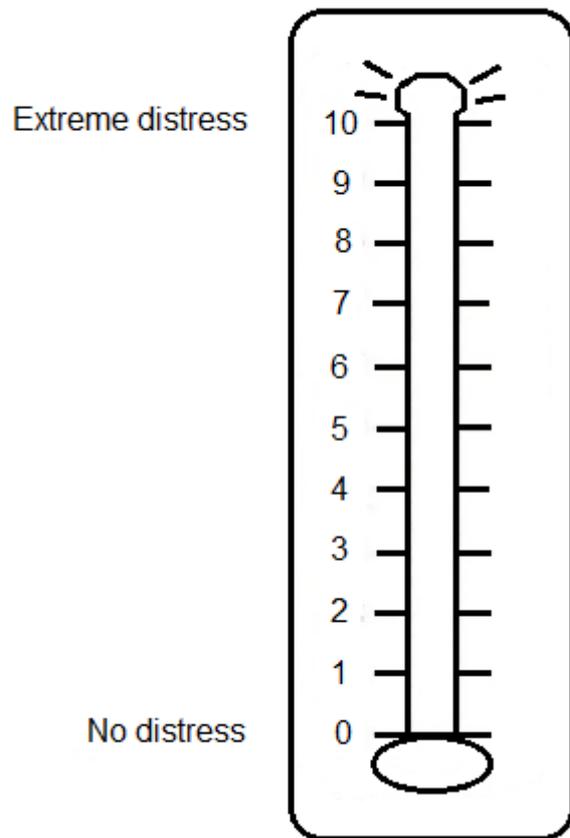


Figure 1. Distress Thermometer.

Second, please indicate if any of the following has been a problem for you in the past week including today. Be sure to check YES or NO for each.

| <u>Practical Problems</u> | YES | NO | <u>Physical Problems</u> | YES | NO |
|---|--------------------------|--------------------------|-------------------------------------|--------------------------|--------------------------|
| Care arrangements | <input type="checkbox"/> | <input type="checkbox"/> | Appearance | <input type="checkbox"/> | <input type="checkbox"/> |
| Child care | <input type="checkbox"/> | <input type="checkbox"/> | Communication | <input type="checkbox"/> | <input type="checkbox"/> |
| Driving/transportation | <input type="checkbox"/> | <input type="checkbox"/> | Continence | <input type="checkbox"/> | <input type="checkbox"/> |
| Home environment | <input type="checkbox"/> | <input type="checkbox"/> | Dizziness | <input type="checkbox"/> | <input type="checkbox"/> |
| Leaving hospital | <input type="checkbox"/> | <input type="checkbox"/> | Eating/Drinking | <input type="checkbox"/> | <input type="checkbox"/> |
| Money/insurance | <input type="checkbox"/> | <input type="checkbox"/> | Fatigue | <input type="checkbox"/> | <input type="checkbox"/> |
| Treatment decisions | <input type="checkbox"/> | <input type="checkbox"/> | Mobility | <input type="checkbox"/> | <input type="checkbox"/> |
| Work | <input type="checkbox"/> | <input type="checkbox"/> | Muscle weakness | <input type="checkbox"/> | <input type="checkbox"/> |
| Hobbies | <input type="checkbox"/> | <input type="checkbox"/> | Nausea | <input type="checkbox"/> | <input type="checkbox"/> |
| Comments: _____ | | | Pain | <input type="checkbox"/> | <input type="checkbox"/> |
| | | | Sexual | <input type="checkbox"/> | <input type="checkbox"/> |
| | | | Sleep | <input type="checkbox"/> | <input type="checkbox"/> |
| | | | Swallowing | <input type="checkbox"/> | <input type="checkbox"/> |
| | | | Tingling in hands/feet | <input type="checkbox"/> | <input type="checkbox"/> |
| | | | Vision | <input type="checkbox"/> | <input type="checkbox"/> |
| | | | Washing/dressing | <input type="checkbox"/> | <input type="checkbox"/> |
| | | | Comments: _____ | | |
| | | | | | |
| <u>Family concerns</u> | YES | NO | <u>Thinking problems</u> | YES | NO |
| Children | <input type="checkbox"/> | <input type="checkbox"/> | Confusion | <input type="checkbox"/> | <input type="checkbox"/> |
| Partner/carers | <input type="checkbox"/> | <input type="checkbox"/> | Concentration | <input type="checkbox"/> | <input type="checkbox"/> |
| Pets | <input type="checkbox"/> | <input type="checkbox"/> | Memory | <input type="checkbox"/> | <input type="checkbox"/> |
| Ability to have children <input type="checkbox"/> | <input type="checkbox"/> | | Comments: _____ | | |
| Family health issues | <input type="checkbox"/> | <input type="checkbox"/> | | | |
| Comments: _____ | | | | | |
| | | | | | |
| <u>Emotional Problems</u> | YES | NO | <u>Spiritual/religious concerns</u> | YES | NO |
| Anger | <input type="checkbox"/> | <input type="checkbox"/> | | <input type="checkbox"/> | <input type="checkbox"/> |
| Depression | <input type="checkbox"/> | <input type="checkbox"/> | Comments: _____ | | |
| Fears | <input type="checkbox"/> | <input type="checkbox"/> | | | |
| Nervousness | <input type="checkbox"/> | <input type="checkbox"/> | | | |
| Sadness | <input type="checkbox"/> | <input type="checkbox"/> | | | |
| Worry | <input type="checkbox"/> | <input type="checkbox"/> | | | |
| Loss of interest in usual activities | <input type="checkbox"/> | <input type="checkbox"/> | | | |
| Comments: _____ | | | Comments: _____ | | |

Figure 2. Adapted Problem List

The HADS (Zigmond & Snaith, 1983) is a 14-item self-report measure. It contains two subscales measuring generalised anxiety (HADS-A) and depression (HADS-D). The total score (HADS-T) can be used as a measure of emotional distress (Herrmann, 1997). It was designed for use with medical patients and has been recommended as a mood screening tool for stroke survivors without communication difficulties (Bennett & Lincoln, 2006). According to the manual, scores of 0-7 are considered *normal*, scores of 8-10 indicate *mild* levels of anxiety or depression, scores of 11-14 indicate *moderate* levels of anxiety or depression and scores of 15-21 indicate *severe* levels of anxiety or depression (Snaith & Zigmond, 1994). However, cut-off scores lower than a score of at least 8 have been recommended when screening for post-stroke distress (O'Rourke, et al., 1998; Sagen, et al., 2009; Tang, Ungvari, Chiu, & Sze, 2004b). Nonetheless, the HADS-A (Cronbach's $\alpha = .89$), HADS-D (Cronbach's $\alpha = .83$), and HADS-T (Cronbach's $\alpha = .91$) have demonstrated good levels of internal consistency and acceptable levels of sensitivity and specificity when using a lower cut-off score among stroke survivors (Sagen, et al., 2009).

The Montreal Cognitive Assessment (MoCA; Nasreddine et al., 2005) was developed as a brief cognitive screening tool to detect mild cognitive impairment (MCI) in patients who performed within the normal range on the Mini Mental State Examination (MMSE; Folstein & Luria, 1973). It consists of a 30-point test which takes about 10 minutes to administer and measures visual spatial abilities, short-term memory, executive functions, attention, working memory, language and orientation. The MoCA has demonstrated good internal consistency (Cronbach's $\alpha = .83$) and test-retest reliability ($r = .92$) with a sample of elderly patients with and without MCI or Alzheimer's disease. Based upon a cut-off score of at least 26, the MoCA was found to have good sensitivity (0.90) and specificity (0.87) for detecting MCI relative to a comprehensive neuropsychological assessment (Nasreddine, et al., 2005). When detecting post stroke cognitive impairment, a lower cut-off score of at least 20 was highlighted as providing better sensitivity (0.67) and specificity (0.90; Godefroy et al., 2011). The National Clinical Guideline for Stroke (Intercollegiate Stroke Working Party, 2008) recommends that every patient who has experienced a stroke or transient ischemic episode (TIA) should be screened for cognitive impairment using a standardised measure. As a result, the MoCA is routinely used on the stroke unit associated with the current study.

The Yale (Lachs, et al., 1990), "Do you often feel sad or depressed?", is recommended by the National Clinical Guideline for Stroke (Intercollegiate Stroke Working Party, 2008). The Yale forms part of the stroke unit mood assessment pathway and has been adapted to include two questions: "Prior to your stroke, have you often felt sad or depressed" (Yale Q1); "Since your stroke, have you often felt sad or depressed" (Yale Q2).

The Yale has been validated among stroke survivors and found to have an accurate level of sensitivity (≥ 0.80) and specificity (≥ 0.60) when screening for depression at 2 weeks and 3 months post-stroke (Watkins et al., 2007).

Procedure

Focus group.

An opt-in approach was used to recruit participants for the focus group. Information packs containing an invitation letter, information sheet, consent form, and stamped addressed envelope were handed out at a multidisciplinary team meeting on the stroke unit and to a co-ordinator from Headway (Appendix F). Once the completed consent forms had been returned, the author arranged a convenient time and place to hold the focus group.

The focus group consisted of seven members and two facilitators, including a consultant clinical psychologist, charity co-ordinator/occupational therapist from Headway, medical consultant, occupational therapist, nurse, physiotherapist, stroke survivor affiliated with Headway, trainee clinical psychologist (author and facilitator) and clinical psychologist (supervisor and facilitator). Experience of working within stroke services ranged from 3 years to 35 years. The original PL, as presented in the 2011 NCCN guidelines (Appendix G), was emailed to each member prior to the focus group. The focus group lasted for 90 minutes and used the first four stages from the nominal group technique to promote a shared discussion (Appendix H; Gallagher, Hares, Spencer, Bradshaw, & Webb, 1993).

Members were asked to state which items they would keep, omit and add to the PL to meet the needs of someone who had experienced a stroke. Lunch was provided after the group as a means of saying thank you. The focus group was audio recorded and discussions were recorded onto a flipchart (Appendix I).

Literature review.

A review of the literature identified a number of possible predictors and associated factors of post-stroke distress, which supported the focus group results. These included impaired cognition and communication (Ayerbe, Ayis, Rudd, Heuschmann, & Wolfe, 2011; Thomas & Lincoln, 2008), increased stroke severity and low activity levels (Ayerbe, et al., 2011), physical disability and reduced activities of daily living (Thomas & Lincoln, 2008), inability to work (Ayerbe, et al., 2011), loneliness and low satisfaction with social support (Hilari, et al., 2010), lack of family support and carer distress (Klinedinst et al., 2009), spirituality and religiousness (Giaquinto, Spiridigliozzi, & Caracciolo, 2007), premorbid depression, poor satisfaction with treatment and perceived confidence in recovery (Morrison, et al., 2000), fatigue (Naess, Lunde, Brogger, & Waje-Andreassen, 2012), pain (Lundström, Smits, Terént, & Borg, 2009) and sexual dysfunction (Calabrò, Gervasi, & Bramanti, 2011). The Subjective Disability Depression Questionnaire (SDDQ; Jenkins, et al., 2009), National Clinical Guideline for Stroke (Intercollegiate Stroke Working Party, 2008), and the ICF Core Set for Stroke (Geyh et al., 2004) also highlighted a range of physical, psychological and social problems which may increase post-stroke distress. For the purpose of this study, each item on the adapted PL was cross referenced with the ICF Core Set for Stroke (Appendix J).

Pilot study.

The author attended a Stroke Association support group. Five stroke survivors were shown the adapted PL and asked to comment on the clarity and content of the PL. As a result of this process, a few minor changes were made to the layout and wording of the PL. However, in general the PL was found to be acceptable and easy to complete.

Validation study.***Inpatient stroke unit.***

An opt-in approach was used to recruit participants on the stroke unit. Over the course of a 5 month period from December 2011 to May 2012 the author and colleagues from the Clinical Health Psychology Department attended weekly multidisciplinary meetings on the stroke unit to find out which patients may be suitable to complete the mood assessment measures. As part of care as usual, patients on the unit were being screened for depression and anxiety using the Yale Q2, the HADS, the Depression Intensity Scale Circles (DISCs) and the Stroke Aphasic and Depression Questionnaire (SADQ; see Appendix D). The BASDEC was also being used on the unit by a volunteer initiative. Potential participants were provided with an information sheet about the study. When requested, the author read through the information sheet with the participant and answered any questions about the study. If the participant was willing to take part, they were asked to sign a consent form (Appendix K).

The MoCA was always performed first in case there was any doubt about consent issues. The DT, HADS and BASDEC were then performed in a counterbalanced order. The Yale Q2 was completed by a member of the multidisciplinary team on admission to the unit. With the participant's consent, copies of the measures were kept in their medical file and the results and any unmet needs were fed back to the participant and the team.

Charity participants.

An opt-in approach was used to recruit participants affiliated with charities such as Headway and The Stroke Association. The author contacted the organisers of ten charities and attended two Stroke Association meetings. Suitable stroke survivors were identified by charity organisers who had a preliminary conversation with them to see if they might like to take part in the study. Information packs containing an invitation letter, information sheet, consent form, and stamped addressed envelope were handed out by the charity organisers and during the Stroke Association meetings (Appendix L). Once the completed consent forms had been returned, the author made contact with the participant to arrange a convenient time and place (either at their home or at the stroke club) to meet and complete the questionnaires. Before completing the questionnaire, the author explained the purpose of the study again, emphasised the right to withdraw, and allowed time for any questions. As with the inpatient subgroup, the MoCA was completed first, and the Yale Q2, BASDEC, HADS and DT were completed in a counterbalanced order. At the end of the assessment the results were fed back to the participant and they were asked whether the questionnaires had raised any areas of concern or unmet need which may require signposting to other services.

Statistical Analysis

The data was analysed using SPSS version 19, Microsoft Excel 2007 and MedCalc version 12. Due to a small sample size and all three mood assessment measures consisting of ordinal data, Spearman's correlation coefficients were used to determine the association between measures (Field, 2009). Receiver-operating characteristic (ROC) curves were used to evaluate the ability of the DT, BASDEC and Yale to identify distressed cases as defined by cut-off scores on the HADS-D (≥ 4 and ≥ 8), HADS-A (≥ 4 and ≥ 8) and HADS-T (≥ 11). ROC curves are graphical representations which plot the sensitivity of an index test on the X axis and plot 1-specificity on the Y axis relative to every possible cut-off score on the criterion standard. The primary statistic generated from a ROC curve is called the Area Under the Curve (AUC). The larger the AUC the more accurate the index test (Pintea & Moldovan, 2009). The AUC was calculated for all measures. An AUC of 1.0 represents a perfect test and an AUC of 0.50 suggests that the index test performed no better than chance when discriminating between someone with or without the disorder (null hypothesis). Cohen's Kappa was performed to measure the agreement between the number of people meeting the cut-off level for depression, anxiety, and general distress relative to the HADS, DT, BASDEC and Yale. Internal consistency coefficient alphas were calculated for the PL and each domain.

Sample size calculation

A priori power analysis was undertaken using MedCalc version 12 to estimate the required sample size needed to produce an AUC for the DT¹ that was significant from the null hypothesis (AUC=0.50). Based upon research within cancer, which validated the DT against the HADS (Craike, Livingston, & Warne, 2011; Goebel & Mehdorn, 2011), a total sample size between 36 and 70 cases was required, where the AUC was 0.77 and 0.87 (alpha level = .05, beta-level = .20). However, Metz (1978, p. 293) highlights that a minimum of 100 cases are needed to draw any “meaningful qualitative conclusions” from ROC curve analyses. From the outset of the study the author aimed to recruit 100 participants; however, a notably smaller sample was achieved (N=31).

Ethical considerations

The local Research and Development Service at the Hospital was consulted and confirmed that the proposed study should be classified as service evaluation and would not require review by NHS Research Ethics Committee (Appendix M). Approval was then obtained from the University Ethics Committee (Appendix N).

¹ An AUC for the BASDEC and Yale could not be found in the literature

Results

Participant Characteristics

Of the 31 participants assessed, 21 (67.7%) were inpatients on a stroke unit and 10 were (32.3%) recruited from charities and living at home. Seventeen (54.8%) participants were women and 14 (45.2%) were men. The total sample was aged between 30 and 100 years, with a mean age of 69.16 years (interquartile range: 62 to 81 years). Just over a quarter (29%) of the total sample were under the age of 65 years (National Audit Office, 2005). A Mann-Whitney U test indicated that the charity subgroup ($M = 61.30$ years) was significantly younger than the inpatient subgroup ($M = 72.90$ years), $U = 46.5$, $z = -2.48$, $p < .05$, $r = -.45$. Time since stroke ranged from 1 day to 12.8 years ($M = 13.8$ months, interquartile range: 5 days to 9.3 months). As one would expect, the time since stroke was significantly greater for the charity subgroup ($M = 3.5$ years) compared to the inpatient subgroup ($M = 8.62$ days), $U = 210.0$, $z = 4.44$, $p = .001$, $r = .80$.

Just under three quarters (71.4%) of the inpatient subgroup met the standard criteria on the MoCA (≤ 26) for MCI ($M = 21.86$, range: 11 to 28 out of 30). However, only 40% of the charity subgroup scored less than 26 out of 30 ($M = 25.40$, range: 20 to 28). The mean score on the DT was 4.26 ($SD: 2.48$), which was slightly higher than a mean of 3.80 ($SD: 2.97$) reported by Turner et al. (2012). The mean score on the BASDEC was 4.10 ($SD: 2.63$).

In relation to question seven of the BASDEC, “I’ve seriously considered suicide”, one participant from the inpatient subgroup reported that they had been suicidal prior to their stroke, but reported no current suicidal thoughts or plans.

According to the Yale Q2, 70% of the inpatient subgroup and 30% of the charity subgroup stated that they had not been sad or depressed since their stroke. None of the charity subgroup stated that they would like any further support at the end of the assessment. Please refer to Tables 2, 3 and 4 for a detailed summary of the clinical and demographic characteristics of the sample.

Table 1

Clinical and Demographic Characteristics of the Total Sample and Inpatient and Charity Subgroups

| Characteristic | N (%) | | |
|----------------------|------------------------|------------------------|----------------|
| | Total (N=31) | Inpatients (n=21) | Charity (n=10) |
| Age | | | |
| 65 years and over | 22 (71.0) | 18 (85.7) | 4 (40.0) |
| Under 65 years | 9 (29.0) | 3 (14.3) | 6 (60.0) |
| Gender | | | |
| Male | 14 (45.2) | 9 (42.9) | 5 (50.0) |
| Female | 17 (54.8) | 12 (57.1) | 5 (50.0) |
| Ethnicity | | | |
| White British | 29 (93.5) | 20 (95.2) | 9 (90.0) |
| White Scottish | 1 (3.2) | 1 (4.8) | |
| Black British | 1 (3.2) | | 1 (10.0) |
| Marital status | | | |
| Married | 17 (54.8) | 9 (42.9) | 8 (80.0) |
| Cohabiting | 2 (6.5) | 2 (9.5) | |
| Divorced | 1 (3.2) | | 1 (10.0) |
| Widowed | 7 (22.6) | 7 (33.3) | |
| Single | 4 (12.9) | 3 (14.3) | 1 (10.0) |
| Have children | 25 (80.6) | 16 (76.2) | 9 (90.0) |
| Do not have children | 6 (19.4) | 5 (23.8) | 1 (10.0) |
| Occupational status | | | |
| Employed | 6 (19.4) | 4 (19.0) | 2 (20.0) |
| Unemployed | 5 (16.1) | 1 (4.8) | 4 (40.0) |
| Retired | 20 (64.5) | 16 (76.2) | 4 (40.0) |
| First time stroke | 26 (83.9%) | 16 (76.2) | 10 (100) |
| Second stroke | 5 (16.1%) | 5 (23.8) | |
| CVA location | | | |
| Right hemisphere | 18 (58.1) | 11 (52.4) | 7 (70.0) |
| Left hemisphere | 8 (25.8) | 5 (23.8) | 3 (30.0) |
| Bilateral | 3 (9.7) | 3 (14.3) | |
| Unknown | 2 (6.5) | 2 (9.5) | |
| CVA type | | | |
| Ischemic | 18 (58.1) | 13 (61.9) | 5 (50.0) |
| Hemorrhagic | 5 (16.1) | 4 (19.0) | 1 (10.0) |
| TIA | 2 (6.5) | 2 (9.5) | |
| Unknown | 6 (19.4) | 2 (9.5) | 4 (40.0) |
| Yale Q1 | | | |
| Yes | 7 ^a (23.3) | 6 ^b (28.6) | 1 (10.0) |
| No | 23 ^a (76.7) | 14 ^b (66.7) | 9 (90.0) |

Note. N = number of cases; CVA = cerebrovascular accident; TIA = transient ischemic attack. ^a due to missing data N=30 ^b due to missing data n=20

Table 2

Means, Standard Deviations and Mann Whitney U Test Results Relative to the Demographic Characteristics of the Sample and Self-Report Measures

| Characteristic | <i>M (SD)</i> | | | <i>U</i> | <i>p</i> |
|----------------|-----------------------|----------------------------|-------------------------|----------|----------|
| | Total (<i>N</i> =31) | Inpatients (<i>n</i> =21) | Charity (<i>n</i> =10) | | |
| Age (years) | 69.16 (15.49) | 72.90 (16.8) | 61.30 (11.12) | 46.5 | .013* |
| Time since | 419.29 | 8.62 (6.57) | 1281.70 | 210. | .000* |
| MOCA | 23.00 (4.93) | 21.86 (5.34) | 25.40 (2.84) | 147. | .069 |
| DT | 4.26 (2.48) | 4.67 (2.42) | 3.4 (2.50) | 70.5 | .142 |
| BASDEC | 4.10 (2.63) | 4.05 (2.92) | 4.20 (2.03) | 117. | .102 |
| HADS-D | 5.71 (3.98) | 6.52 (4.36) | 4.00 (2.40) | 66.5 | .882 |
| HADS-A | 5.94 (3.50) | 6.10 (3.62) | 5.60 (3.41) | 101. | .270 |
| HADS-T | 11.65 (6.48) | 12.62 (7.03) | 9.60 (4.84) | 79.0 | .595 |

Note. *N*= number; *M*= mean; *SD* = standard deviation; *U* = Mann Whitney U test;

MOCA =Montreal Cognitive Assessment; DT = Distress Thermometer; BASDEC =

Brief Assessment Schedule Depression Cards; HADS-D = Hospital Anxiety and

Depression Scale – depression subscale; HADS-A = Hospital Anxiety and

Depression Scale – anxiety subscale; HADS-T = = Hospital Anxiety and Depression

Scale – total score.

**p*<.05, two tailed

***p*<.001

Prevalence of Clinically Significant Distress

When using a cut-off score of at least 8 on the HADS-D and HADS-A, a third of the total sample (32.3%) scored within the clinical range for anxiety and depression. However, the majority of these cases were classified within the mild range of severity, with only two participants experiencing severe levels of depression. When using a lower cut-off score of at least 4 on the HADS, the total number of participants being classified within the clinical range for anxiety and depression doubled (Tables 4 and 5).

Table 3

Number and Percent of Participants Classified within the Clinical Range for Mild Cognitive Impairment and Post-Stroke Distress

| Measure | N (%) | | |
|--------------|------------------------|-----------------------|----------------|
| | Total (N=31) | Inpatients (n=21) | Charity (n=10) |
| MOCA <26* | 19 (61.3) | 15 (71.4) | 4 (40.0) |
| MOCA <20† | 7 (22.6) | 7 (33.2) | 0 (0.0) |
| HADS-D ≥8* | 10 (32.3) | 9 (42.9) | 1 (10.0) |
| HADS-D ≥4† | 21 (67.7) | 16 (76.2) | 5 (50.0) |
| HADS-A ≥8* | 10 (32.3) | 6 (28.6) | 4 (40.0) |
| HADS-A ≥4† | 23 (74.2) | 16 (76.2) | 7 (70.0) |
| HADS-T ≥11† | 18 (58.1) | 13 (61.9) | 5 (50.0) |
| BASDEC ≥ 7* | 6 (19.4) | 5 (23.8) | 1 (10.0) |
| DT ≥4* | 20 (64.5) | 16 (76.2) | 4 (40.0) |
| DT ≥5* | 16 (51.6) | 14 (66.7) | 2 (20.0) |
| Yale Q2: Yes | 13 ^a (43.3) | 6 ^b (30.0) | 7 (70.0) |

Note. N = number of cases; HADS-D = Depression subscale of the Hospital Anxiety and Depression Scale; HADS-A = Anxiety subscale of the Hospital Anxiety and Depression Scale; HADS-T = Total score for the Hospital Anxiety and Depression Scale.

*standard cut-off scores

†Cut-off scores recommended in the stroke literature

^a due to missing data N=30

^b due to missing data n=20

Table 4

Interpretation of the HADS Scores

| Criterion standard | Interpretation | N (%) | | |
|--------------------|----------------|--------------|-------------------|----------------|
| | | Total (N=31) | Inpatients (n=21) | Charity (n=10) |
| HADS-D | Normal | 21 (67.7) | 12 (57.1) | 9 (90.0) |
| | Mild | 8 (25.8) | 7 (33.3) | 1 (10.0) |
| | Moderate | | | |
| | Severe | 2 (6.5) | 2 (9.5) | |
| HADS-A | Normal | 21 (67.7) | 15 (71.4) | 6 (60.0) |
| | Mild | 7 (22.6) | 4 (19.0) | 3 (30.0) |
| | Moderate | 3 (9.7) | 2 (9.5) | 1 (10.0) |
| | Severe | | | |

Note. N = number of cases; HADS-D = Hospital Anxiety and Depression Scale – depression subscale; HADS-A = Hospital Anxiety and Depression Scale – anxiety subscale; ‘normal’ represents scores of 0-7; ‘mild’ represents scores of 8-10; ‘moderate’ represents scores of 11-14; and ‘severe’ represents scores of 15-21.

Concurrent Validity of the DT, BASDEC and Yale Q2

The DT was significantly correlated with all four measures, including the BASDEC ($r_s = .55, p < .01; r_s^2 = .30$), HADS-D ($r_s = .44, p < .05; r_s^2 = .19$), HADS-A ($r_s = .55, p < .01; r_s^2 = .30$) and HADS-T ($r_s = .58, p < .01; r_s^2 = .34$), sharing between 19 and 34% of the variance in the ranks with each of the four measures. The BASDEC was not significantly related to the HADS-D, but was significantly related to the HADS-A ($r_s = .36, p < .05, r_s^2 = .13$), and HADS-T ($r_s = .37, p < .05, r_s^2 = .14$), sharing between 13 and 14% of the variance in the ranks with each measure. In terms of the criterion standards, the HADS-D and HADS-A were significantly related to one another ($r_s = .47, p < .01, r_s^2 = .22$), sharing 22% of the variance in ranks (Table 6). In contrast, the Yale Q2 was not significantly associated with any of the measures, relative to the standard and stroke cut-off scores specified in Table 4 (Fisher's exact test, $p > 0.05$).

Table 5

Correlations between the DT, BASDEC, HADS-D, HADS-A and HADS-T

| Measure | 1 | 2 | 3 | 4 | 5 |
|-----------|---|-------|------|-------|-------|
| 1. DT | - | .55** | .44* | .55** | .58** |
| 2. BASDEC | | - | .22 | .36* | .37* |
| 3. HADS-D | | | - | .47** | - |
| 4. HADS-A | | | | - | - |
| 5. HADS-T | | | | | - |

Note. DT =Distress Thermometer; BASDEC = Brief Assessment Schedule

Depression Cards; HADS-D = Depression subscale of the Hospital Anxiety and

Depression Scale; HADS-A = Anxiety subscale of the Hospital Anxiety and

Depression Scale; HADS-T = Total score for the Hospital Anxiety and Depression Scale.

** $p < .01$, two tailed.

* $p < .05$, two tailed.

Diagnostic Accuracy of the DT, BASDEC and Yale Q2

ROC curve analyses were performed to evaluate the accuracy of the DT, BASDEC and Yale Q2 at detecting clinically significant levels of post-stroke distress relative to the HADS. As a general rule of thumb, an AUC between 0.50 and 0.70 represents “low” accuracy; between 0.70 and 0.90 “moderate” accuracy; and over 0.90 “high” accuracy (Fischer, Bachmann, & Jaeschke, 2003, p. 1047). When inspecting the ROC curves, the further the curve lies above the reference line (in other words, the further the curve is to the left-hand corner of the graph), the more accurate the test is at identifying stroke survivors with or without clinically significant levels of distress (Figures 3-5). Ideal cut-off scores were determined when recommended levels of sensitivity (≥ 0.80) and specificity (≥ 0.60) were obtained (Bennett & Lincoln, 2006). Cut-off scores corresponding with the highest Youden Index (highest average of sensitivity and specificity) were also calculated (Table 7).

Accuracy of the Distress Thermometer.

Depression.

The DT obtained an AUC of 0.74 relative to the HADS-D (≥ 8), which was significantly greater than an AUC of 0.50 ($p < 0.01$). This suggested that the DT was able to distinguish between clinical and non clinical levels of depression better than chance. An ideal cut-off score of at least 5 on the DT met recommended levels of sensitivity and specificity and also yielded the highest Youden Index (Table 7 and Figure 3).

A fair level of agreement between the DT (≥ 5) and HADS-D (≥ 8) at identifying clinical cases was found ($k = 0.36$, $p < 0.05$; Table 8). Just under a third (32%) of the total sample scored at least 8 or more for depression. When the DT obtained a positive result (a score of at least 5), there was a 50% probability (PPV = 0.50) that this result was true and the person was experiencing clinical levels of depression. When a negative result was obtained on the DT, there was an 87% chance (NPV = 0.87) that the DT was correct and the person was not meeting clinical levels of depression.

Anxiety.

In relation to the HADS-A (≥ 8), the AUC for the DT of 0.68 was not significantly greater than an AUC of 0.50 (Appendix O). However, when using a lower cut-off score, the DT obtained an AUC of 0.86 relative to the HADS-A (≥ 4) and an AUC of 0.74 relative to the HADS-T (≥ 11), both of which were significantly greater than an AUC of 0.50 ($p < 0.05$). An ideal cut-off score of at least 4 on the DT met recommended levels of accuracy when screening for anxiety and emotional distress (Table 7 and Figures 4 and 5).

A good level of agreement between the DT (≥ 4) and the HADS-A (≥ 4) and HADS-T (≥ 11) at identifying clinical cases was found ($k = 0.63$ and 0.46 respectively, $p < 0.05$; Table 8). However, an AUC of 0.67 was not significantly greater than the null hypothesis for the HADS-D (≥ 4). Furthermore, due to lower cut-off scores on the HADS, the prevalence of participants meeting clinical levels of anxiety (74%) and emotional distress (58%) increased beyond published base rates (Sagen, et al., 2009; Turner, et al., 2012).

Consequently, the PPVs (0.95 and 0.75, respectively) and NPVs (0.64 and 0.73, respectively) should be viewed with caution (Baldessarini, Finklestein, & Arana, 1983).

Accuracy of the BASDEC and Yale Q2.

In relation to the HADS-D and HADS-T, the AUCs for the BASDEC (0.68 and 0.67) and Yale Q2 (0.53 and 0.67) were not significantly different to an AUC of 0.50 (Appendix O). As illustrated in Table 8, the BASDEC and Yale Q2 did not show any significant agreement with the HADS-D and HADS-T but the BASDEC did show good agreement with the HADS-A ($k = 0.63, p < 0.01$).

Table 6

Validity of the DT where the AUC was Significantly Greater than the Null Hypothesis (AUC=0.50) and Sensitivity was at Least 0.80 and Specificity was at Least 0.60

| Reference standard | Cut off | Index test positive/ HADS positive | Index test negative/ HADS negative | Sensitivity (95% CI) | Specificity (95% CI) | PPV (95% CI) | NPV (95% CI) | AUC (95% CI) | SE |
|----------------------|------------|------------------------------------|------------------------------------|----------------------|----------------------|------------------|------------------|--------------------|------|
| HADS-D (≥ 8) | ≥ 5 † | 16/10 | 15/21 | 0.80 (0.44-0.98) | 0.62 (0.38-0.82) | 0.50 (0.25-0.75) | 0.87 (0.58-0.99) | 0.74* (0.56-0.88) | 0.09 |
| HADS-A (≥ 4) | ≥ 4 † | 20/23 | 11/8 | 0.83 (0.61-0.95) | 0.88 (0.47-1.0) | 0.95 (0.75-1.0) | 0.64 (0.31-0.89) | 0.86** (0.69-0.96) | 0.09 |
| HADS-T (≥ 11) | ≥ 4 | 20/18 | 11/13 | 0.83 (0.59-0.96) | 0.62 (0.32-0.86) | 0.75 (0.51-0.91) | 0.73 (0.37-0.95) | 0.74* (0.55-0.88) | 0.10 |

Note. HADS-D = Hospital Anxiety and Depression Scale – depression subscale; HADS-A = Hospital Anxiety and Depression Scale – anxiety subscale; HADS-T = Hospital Anxiety and Depression Scale – total score; PPV=Positive Predictive Value; NPV = Negative Predictive Value; CI = confidence interval; AUC = area under the curve; SE = Standard error.

* $p < 0.01$

** $p < 0.001$

† Optimal cut-off score determined using the Youden Index

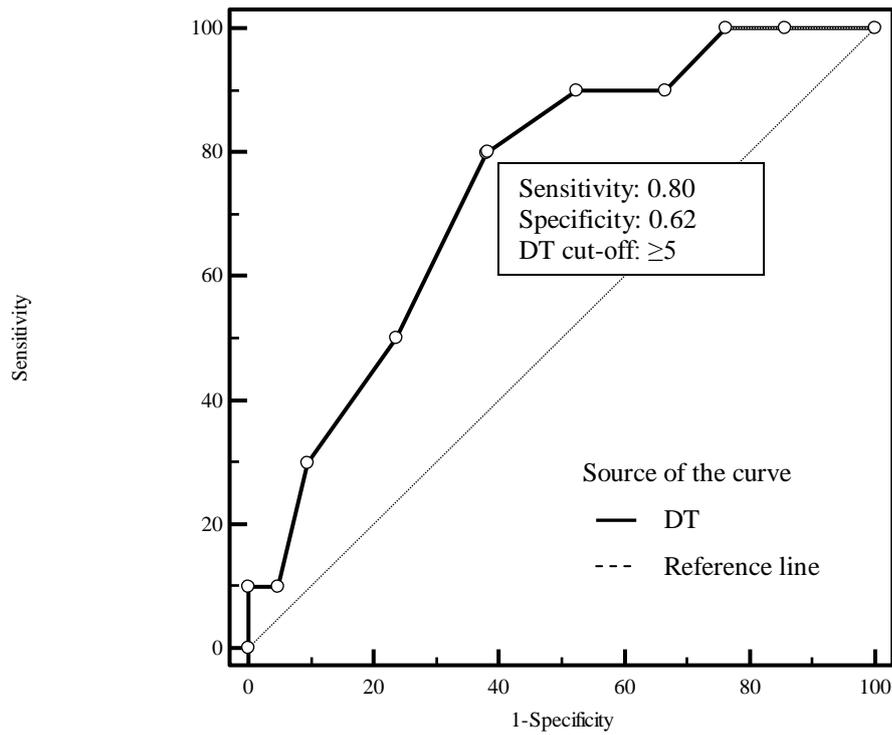


Figure 3. Receiver operating characteristic (ROC) curve evaluating the ability of the Distress Thermometer (DT) to detect possible cases of post-stroke depression using the depression subscale of the Hospital Anxiety and Depression Scale (HADS-D ≥ 8) as the criterion standard. AUC = 0.74.

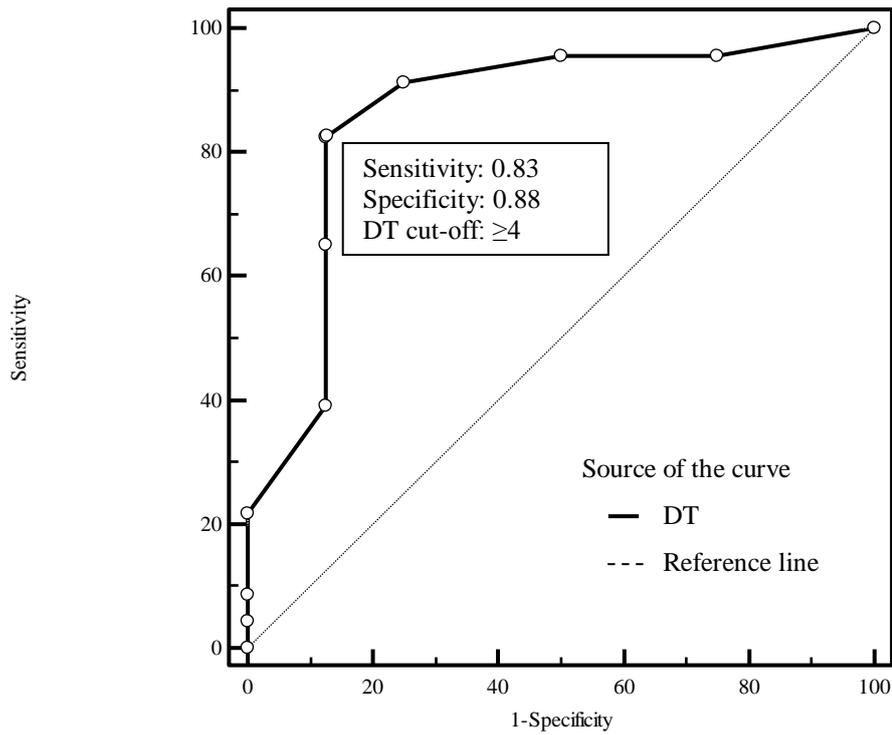


Figure 4. Receiver operating characteristic (ROC) curve evaluating the ability of the Distress Thermometer (DT) to detect possible cases of post-stroke anxiety using the anxiety subscale of the Hospital Anxiety and Depression Scale (HADS-A ≥ 4) as the criterion standard. AUC = 0.86.

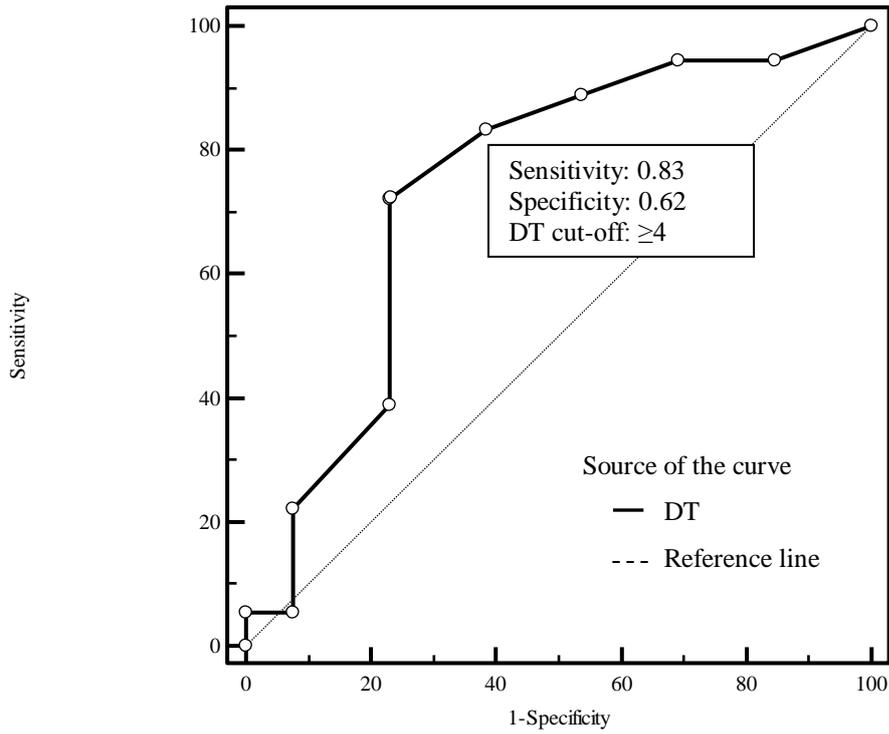


Figure 5. Receiver operating characteristic (ROC) curve evaluating the ability of the Distress Thermometer (DT) to detect possible cases of post-stroke distress using the Hospital Anxiety and Depression Scale - total score (HADS-T ≥ 11) as the criterion standard. AUC = 0.74.

Table 7

Cohen's Kappa Measure of Inter-Rater Reliability

| Measure | DT \geq 5 | DT \geq 4 | BASDEC \geq 7 | Yale Q2 |
|------------------|-------------|-------------|-----------------|---------|
| HADS-D \geq 8 | 0.36* | 0.30* | 0.18 | 0.08 |
| HADS-D \geq 4 | 0.41* | 0.21 | 0.10 | 0.02 |
| HADS-A \geq 8 | 0.24 | 0.19 | 0.34* | 0.00 |
| HADS-A \geq 4 | 0.41* | 0.63** | 0.15 | -0.08 |
| HADS-T \geq 11 | 0.48** | 0.46* | 0.18 | 0.03 |

Note. DT =Distress Thermometer; BASDEC = Brief Assessment Schedule

Depression Cards; HADS-D = Depression subscale of the Hospital Anxiety and Depression Scale; HADS-A = Anxiety subscale of the Hospital Anxiety and Depression Scale; HADS-T = Total score for the Hospital Anxiety and Depression Scale

* $p < 0.05$

** $p < 0.01$

Problem List

The total score on the PL and physical domain demonstrated an acceptable level of internal consistency (Cronbach's $\alpha = .84$ and $.71$ respectively). In contrast, the internal consistencies of the practical ($\alpha = .38$), family ($\alpha = .59$), emotional ($\alpha = .69$) and cognitive domains ($\alpha = .57$) were poor. While the total number of problems reported did not significantly relate to the DT ($r_s = .27, p = .146$), a significant correlation was found between the total number of problems reported within the emotional domain and DT ($r_s = .41, p < .05$; Table 10).

Fisher's exact tests were used to determine whether cut-off scores of at least 4 or at least 5 on the DT were associated with the selection of items on the PL. Of the 41 items, a score of at least 5 on the DT was significantly associated with the selection of *fears* (Fisher's Exact test, $p < 0.05$). In relation to the HADS-A (≥ 8), *family health issues, fears, nervousness* and *confusion* were significantly associated with scoring in the clinical range for anxiety. In relation to the HADS-D (≥ 8), a further six items were significantly related to scoring in the clinical range for depression, these included concerns with *hobbies* and *partner, loss of interest in usual activities, problems with sleep, swallowing* and *tingling in hands and feet*.

The frequency and percentage of all items identified as a problem or a concern are presented in Appendix P. Overall, the mean number of items selected was 8.84 (range: 3 to 28 items). Two items were not selected by anyone: *child care* and *ability to have children*. The least frequently reported item was *spiritual or religious concerns*, with one person identifying this as a problem.

In contrast, the most consistent and frequently ranked items across all population groups were *movement*, *muscle weakness* and *fatigue*. Over half the study population indicated that these items had been a problem for them in the past week. This suggested that problems or concerns with movement and fatigue were not only present within the acute and sub-acute phases of recovery but persisted many years after having had a stroke. Just under half (43%) of the inpatient subgroup reported difficulties around *sleep* and *fears* (Table 9).

Table 8

Mean Number of Items Selected, Cronbach's Alphas and the Most Frequently Reported Item within Each Domain of the PL Relative to the Total Sample

| Problem List | <i>M</i> (<i>SD</i>) | α | Highest item (%) |
|------------------------|------------------------|----------|--|
| Practical | 1.26 (1.26) | 0.38 | Driving (29) |
| Family | 0.52 (0.93) | 0.59 | Children (22.6) Family health issues (22.6) |
| Emotional | 2.06 (1.90) | 0.69 | Worry (41.9) |
| Physical | 4.19 (3.29) | 0.80 | Movement (61.3) Muscle weakness or paralysis (61.3) |
| Cognitive | 0.65 (0.88) | 0.57 | Memory (38.7) |
| Spiritual ^a | 0.03 (0.18) | | |
| Total Problem List | 8.84 (6.0) | 0.84 | Movement (61.3) Muscle weakness or paralysis (61.3) |

Note. *M* = mean; *SD* = standard deviation; α = Cronbach's alpha.

^a spiritual domain consists of one item

Table 9

Correlations between the DT, PL Total Score and Individual Domains

| Measure | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
|--------------|---|-----|------|-------|-------|-------|-------|------|
| 1. DT | - | .27 | .14 | .09 | .41* | .20 | .32 | .31 |
| 2. Total PL | | - | .43* | .53** | .59** | .77** | .54** | .27 |
| 3. Practical | | | - | .32 | .15 | .13 | .19 | .32 |
| 4. Family | | | | - | .19 | .34 | .45* | -.15 |
| 5. Emotional | | | | | - | .21 | .36* | .29 |
| 6. Physical | | | | | | - | .29 | .02 |
| 7. Cognitive | | | | | | | - | .15 |
| 8. Spiritual | | | | | | | | - |

Note. DT = Distress Thermometer; PL = Problem List

* $p < 0.05$

** $p < 0.01$

Discussion

The study investigated the accuracy of three self-report mood screening measures with a heterogeneous sample of stroke survivors. The performance of three index tests, the DT, BASDEC and Yale Q2, was compared against three criterion standards, the HADS-D, HADS-A and HADS-T. A primary aim of the study was to evaluate whether each index test met recommended levels of sensitivity (≥ 0.80) and specificity (≥ 0.60) for a screening tool within stroke (Bennett & Lincoln, 2006).

Prevalence of Post-Stroke Distress

When using a cut-off score of at least 8 on the HADS-D and HADS-A (Snaith & Zigmond, 1994) the overall prevalence rates for depression and anxiety (32.3%) were comparable to base rates reported within the stroke literature of around 33% (De Wit, et al., 2008; Hackett, et al., 2005). However, the majority of clinical cases fell within the mild range of severity. Only two participants from the inpatient subgroup scored within the severe range for depression. The Stroke Quality Standards (NICE, 2010) specify that all patients should be screened for mood disturbance within 6 weeks of diagnosis. However, Gillham and Clark (2011, p. 11) argue that “screening in the first few days is likely to be an unreliable measure of mood”. Due to the provision of early supported discharge (Langhorne et al., 2005) nine participants had been screened within the first week of having a stroke, which may have resulted in lower levels of depression being reported. Furthermore, participants from the stroke unit may not have had time to develop awareness into the consequences of their stroke (Fure, Wyller, Engedal, & Thommessen, 2006).

Only one stroke survivor from the charity subgroup scored within the clinical range for depression (mild range). Stage models of adjustment suggest that the immediate period following discharge from hospital is one of the most challenging phases (Ch'Ng, et al., 2008; Wade, Langton Hewer, Skilbeck, & David, 1985). A limitation of this study was that it did not include people within the first few weeks of discharge. However, it was notable (albeit non-significant, Fisher's exact test, $p=0.056$) that 70% of charity participants said that they had often felt sad or depressed following their stroke on the Yale Q2. Unlike the HADS or DT, the Yale Q2 is not limited to a specific time period. It can be hypothesised that a higher number of positive responses on the Yale Q2 (70%) in contrast to the HADS-D (10%) may have related to a process of adjustment. It is also possible that charity group members were less likely to consent to take part in the study if they were feeling depressed. Consequently, the ability to generalise these findings to other clinical settings where the rates of depression are higher is limited.

A higher proportion of charity participants reported clinical levels of anxiety (40%) compared to the inpatient population (28.6%). This supports the need to screen for anxiety disorders in addition to depression during all stages of the stroke care pathway (Intercollegiate Stroke Working Party, 2008). A focus of this study was to evaluate a mood assessment pathway being used on an acute stroke unit (Appendix D). At present, all patients are screened with the Yale Q2 to determine whether they need to complete the HADS or DISCs. However, the Yale question was not designed to screen for anxiety. Theoretically, this could result in a number of false negatives, where patients with symptoms of anxiety are not being detected.

Consequently, an accurate yet brief and accessible screening measure for anxiety is needed to replace the Yale Q2 when used as the first point of contact within a mood assessment pathway.

Concurrent Validity of the DT

At the commencement of this study, the DT had not been validated among stroke survivors, despite being recommended by NICE (2009). However, due to a small sample size the ability to investigate an ideal cut-off score on the DT was purely exploratory and these results need to be replicated with a larger sample before being generalised to clinical practice.

The DT significantly correlated with all measures. However, the correlations only accounted for 19 to 34% of the variance in ranks. When using the HADS-D (≥ 8) and HADS-T (≥ 11) as a criterion standard, the AUC (0.74 and 0.86 respectively) fell within the moderate range of accuracy (Fischer, et al., 2003) and was significantly greater than an AUC of 0.50. These results provide preliminary evidence for the concurrent validity of the DT as a screening tool for symptoms of post-stroke depression and overall distress.

A cut-off score on the DT of at least 5 for depression and at least 4 for emotional distress met recommended levels of sensitivity and specificity (Bennett & Lincoln, 2006). While this is comparable to cut-off scores recommended within oncology (Baken & Woolley, 2011; Craike, et al., 2011; NCCN, 2011), this finding is not supported by a recent study among stroke survivors where the sensitivity (0.69) and specificity (0.57) of the DT fell below recommended levels when using a cut-off score of at least 4 (Turner, et al., 2012).

The AUC for the DT, relative to the HADS-A (≥ 8), was not significantly different to an AUC of 0.50. When lowering the cut-off score on the HADS-A to at least 4 (O'Rourke, et al., 1998) the AUC of 0.86 was significantly greater than an AUC of 0.50. Furthermore, a cut-off score of at least 4 met recommended levels of accuracy (Bennett & Lincoln, 2006). However, by lowering the cut-off score on the criterion standard, 64% of participants were classified as suffering from clinical levels of anxiety. This was higher than published base rates (Hackett & Anderson, 2005) and would result in a higher proportion of patients requiring further assessment. Consequently, further research is needed to develop a brief screening tool for post-stroke anxiety, which meets recommended levels of accuracy. A single measure which can be used to screen for multiple domains of distress would appear to be preferable over two measures.

Concurrent Validity of the BASDEC and Yale Q2

It seemed surprising that the BASDEC did not correlate significantly with the HADS-D, which was contrary to prior findings (Healey, et al., 2008). However, it is possible that a non-significant result was caused by a small sample size as opposed to the correlation not existing. A post hoc power analysis indicated that there was insufficient power (0.23) to detect the observed effect size ($r_s=.22$; Appendix Q). However, the construct of the BASDEC differs to the HADS-D in two ways. First, the BASDEC includes questions about giving up hope and suicide whereas the HADS-D is based upon the construct of anhedonia (Zigmond & Snaith, 1983). Second, the BASDEC screens for depression prior to the person having a stroke whereas the HADS-D screens for depression within the last week. Both points may have contributed to a poor correlation and a non-significant AUC (Appendix O).

A similar results was found for the Yale Q2, which was in contrast to prior findings (Turner-Stokes, Kalmus, Hirani, & Clegg, 2005; Watkins, et al., 2007). As with the BASDEC, this may have related to a number of methodological problems. All of the patients entering the stroke unit were being screened by the Yale Q2 on admission. Consequently, the time period between completing the Yale Q2 and the HADS, DT and BASDEC ranged from 0 to 22 days ($M = 6$ days). As a state condition, distress is likely to change over time (Chaplin, John, & Goldberg, 1988). It is possible that the Yale Q2 was not significantly associated with the other measures due to a time difference between administration. This finding highlights the importance of screening participants on a regular basis to detect change in mood.

Gillham and Clark (2011) suggest that mood assessment should take place on at least three occasions (just before discharge, 3 months and 6 months post stroke). To the author's knowledge, the ability of the DT to detect change over time has not been investigated among stroke survivors.

In summary, non-significant results may suggest that the BASDEC and Yale Q2 performed no better than chance. However, a major limitation of this study was its small sample size ($N=31$). Future research would need to replicate this study using a larger sample. MedCalc version 12 was used to carry out a priori power analysis. In order to correctly reject the null hypothesis ($AUC = 0.50$) when the AUC was 0.67 and 0.68, a sample size of at least 178 and 158 cases would be needed. Consequently, caution should be taken when generalising these findings.

The Problem List

The total number of problems selected on the PL did not significantly correlate with the DT ($r_s = .27, p = .146$). This is in contrast to studies within oncology and among older adults (Bevans et al., 2011; Dilworth, Thomas, Sawkins, & Oyeboode, 2011; Goebel & Mehdorn, 2011).

All participants reported at least three problems. However, nobody reported concerns about *ability to have children or child care*, which seems understandable when considering that the majority of participants were over the age of 65 years (71%). The two participants who reported concerns about *work* were both under the age of 65 years. Similarly, the majority of participants who reported concerns about *money* were younger stroke survivors (80%). While the older adult population are more likely to experience a stroke (National Audit Office, 2005), working age stroke survivors are more likely to live for longer and may have different needs (Lincoln, et al., 2012). Employment issues are often neglected following stroke, yet represent a significant concern for younger stroke survivors and have been linked to low self-esteem (Corr & Wilmer, 2003).

The most frequently selected items on the PL were *movement* and *muscle weakness* (61%). While the effects of a stroke are multifaceted, hemiparesis has been described as the “hallmark” of stroke (Intercollegiate Stroke Working Party, 2008, p. 80). However, by running a Fisher’s exact test, the selection of *movement* and *muscle weakness* was not significantly associated with scoring within the clinical or non-clinical range for anxiety or depression. It is possible that the instructions for the PL, “please indicate if any of the following have been a problem for you in the past week including today”, resulted in people selecting items that were not necessarily related to the experience of distress. For example, three participants scored 0 on the DT and selected 4, 5, and 8 items on the PL.

In contrast, the selection of *fears* was significantly associated with a score of at least 5 on the DT and a score of at least 8 on the HADS-A and HADS-D.

Participants reported fears about the amount of recovery they would make, fears about having another stroke and fears about falling, which have all been documented within the stroke literature (Townend, Tinson, Kwan, & Sharpe, 2006; Watanabe, 2005). The selection of *nervousness* was also significantly related to scoring within the clinical range for anxiety, which provides some evidence for the construct validity of the PL as a measure of generalised anxiety. However, it is notable that despite 29% of participants selecting *depression* on the PL, this item did not significantly relate to the HADS-D or DT. This may in part reflect the finding that the majority of participants who scored 8 or more on the HADS-D scored within the mild range.

It must be noted that a significant association between clinical levels of distress and the selection of a specific item on the PL does not imply a causal relationship. In line with the ICF biopsychosocial model of functioning, health and disability (WHO, 2001) a bidirectional relationship may exist. While the selection of *family health concerns*, *sleep* and *confusion* were significantly associated with clinical levels of depression (HADS-D), research suggests that the mental health of carers (Klinedinst, et al., 2009), sleep related difficulties (W.-K. Tang et al., 2011) and cognitive impairment (Taylor, et al., 2011) not only contribute to the development of post-stroke depression but also result from it. Nonetheless, the results of this study provide preliminary evidence to support the use of a PL to assist staff and patients in identifying potential areas of distress and unmet needs.

Strengths, Limitations and Future Directions

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

External validity.

It is important to validate an index test with a sample that represents the clinical population (Whiting, et al., 2004). A strength of this study was the inclusion of stroke survivors under the age of 65 years. The proportion of younger stroke survivors (29%) represented published rates in the stroke literature (National Audit Office, 2005). However, these results would need to be replicated in settings where a higher proportion of patients are under the age of 65 years, in order to gain a better understanding and representation of the needs of younger stroke survivors.

A limitation of this study, as with all of the validation studies identified in the literature review, is the exclusion of participants with moderate to severe cognitive and communication difficulties. This not only hinders the ability to generalise the current findings to all stroke survivors, but denies those with cognitive and communication difficulties the right to benefit from healthcare advances.

In hindsight, a less stringent exclusion criterion could have been used to enhance the current sample size. However, informed consent is a fundamental principle of clinical research and issues around capacity are raised when recruiting stroke survivors with moderate to severe cognitive and/or communication difficulties (BPS, 2010). While it is important to carry out research with people who lack capacity, ethical approval and provisions surrounding proxy consent are needed (The Stationery Office, 2007). As a result, future studies which investigate the validity of self-report mood screening measures with stroke survivors who have cognitive and communication difficulties are clearly needed. In doing so, consideration needs to be given to the assessment of capacity to consent to identify participants who lack capacity and the provision of proxy consent if the study is deemed to be in the person's best interest.

There is no reason not to screen for mood disorders in aphasic patients, particularly when the evidence points to an elevated risk of depression among people with communication difficulties (Astrom, Adolfsson, & Asplund, 1993; Laska, Mårtensson, Kahan, von Arbin, & Murray, 2007). It is possible that the DT and PL would be more accessible to people with communication difficulties compared to other measures, as it consists of a visual analogue scale and simple yes/no format. During the completion of this study, an aphasia-friendly version of the DT and PL was published (Lincoln, et al., 2012; Williams, Lowdon, & Thomas, 2010).

Internal validity.

Due to a small sample size, there was an increased risk of making a Type II error, where non-significant results are falsely accepted. Although priori power analysis was undertaken, a number of methodological and clinical factors contributed to a limited sample size. These included the exclusion of participants unable to give informed consent due to comorbid dementia or moderate to severe cognitive and communication difficulties, patients being admitted to the stroke unit who did not have a stroke, and patients not being medically well. Such factors need to be considered when evaluating the clinical utility of a screening measure and highlight the importance of developing ultra-short yet accurate screening measures.

Another limitation of the study was that participants were recruited via opportunity sampling. The accuracy of all four measures may be biased as the full spectrum of post-stroke distress was not measured. Due to an opt-in approach and exclusion criteria, it is possible that participants who were depressed and suffering from anxiety did not consent to take part in the study. The prevalence and severity of a condition is known to affect measurements of accuracy (Whiting, et al., 2004). While positive and negative predicative values are directly affected by prevalence rates, sensitivity and specificity rates are also affected by the spectrum of a condition (Whiting, et al., 2004). In settings where there is a greater proportion of people with clinically significant levels of distress, sensitivity rates are likely to be higher (Sackett & Haynes, 2002). It would have been interesting to investigate the accuracy of the DT, BASDEC and YQ2 with each subgroup of stroke survivors. However, this was not possible due to a small sample size.

Lastly, the accuracy of the DT, BASDEC and Yale Q2 in this study was based upon the premise that the HADS was 100% sensitive and specific. As with most criterion standards, this is not the case. Consequently, positive and negative results on the DT, BASDEC and Yale Q2 may have been misclassified by the HADS (Whiting, et al., 2004).

Clinical Implications

The main purpose of validating a new measure is the hope that people being screened have a better health outcome compared to those who are not screened (Sackett & Haynes, 2002). While guidelines promote the screening of mood disturbance, they do not specify how someone should be supported thereafter (Intercollegiate Stroke Working Party, 2008; NICE, 2010). This study aimed to evaluate the accuracy of the DT in view of using it within a mood assessment pathway, which would direct referrals and associated input. While the detection of clinically significant mood disorders is important, health care services are moving away from a medical-model which views health as the absence of disease, to a biopsychosocial model which views health along a continuum (WHO, 2001).

The modernisation of the NHS has promoted partnership working with patients and carers, as “experts in their own conditions” (DOH, 2004; Hilari, Wiggins, Roy, Byng, & Smith, 2003, p. 366). The DT and accompanying PL aim to promote a holistic and subjective assessment of someone’s needs. While, the majority of stroke survivors may not meet clinical levels of anxiety or depression, many do experience less intense and persistent states of distress which warrant further support.

As a one item self-report measure, the DT is a quick and easy self-report screening tool to use within inpatient and community settings. However, compared to longer self-report measures which assess multiple aspects of anxiety and depression, such as the HADS, the DT is unlikely to capture the same richness of information without further inquiry into the nature of someone’s distress. Consequently, the strength of the DT would appear to be the accompanying PL. In contrast to other self-report measures, the DT and PL have been developed as a semi-structured interview which aims to encourage a dialogue between staff and patients to highlight any unmet needs and associated distress, whether these are within a clinically significant range or not. Furthermore, within oncology the DT and PL are also being used with members of the patient’s family (Bevans, et al., 2011). Due to the known bidirectional relationship between carer and patient wellbeing within stroke (Suh et al., 2005), future research is needed which evaluates the validity and clinical utility of the DT and PL among carers of stroke survivors.

Conclusions

This study provides preliminary evidence in favour of using the DT and accompanying PL within stroke services. A cut-off score of at least 5 and at least 4 met recommended levels of sensitivity and specificity when screening for depression and general distress (Bennett & Lincoln, 2006). However, the accuracy of the DT when detecting anxiety was less supportive, albeit significantly better than chance relative to a cut-off score of at least 4 on the HADS-A. Furthermore, the BASEDEC and Yale Q2 were not significantly accurate in screening for post-stroke depression. However, due to a number of methodological limitations, caution should be taken when generalising these findings. While national guidelines highlight the importance of screening for mood disturbances following stroke, they do not specify which measure to use (Intercollegiate Stroke Working Party, 2008). Local service providers are required to establish protocols which support patient well being (Gillham & Clark, 2011). The DT and PL have the potential to promote a holistic and person-centred approach when detecting and managing of post-stroke distress.

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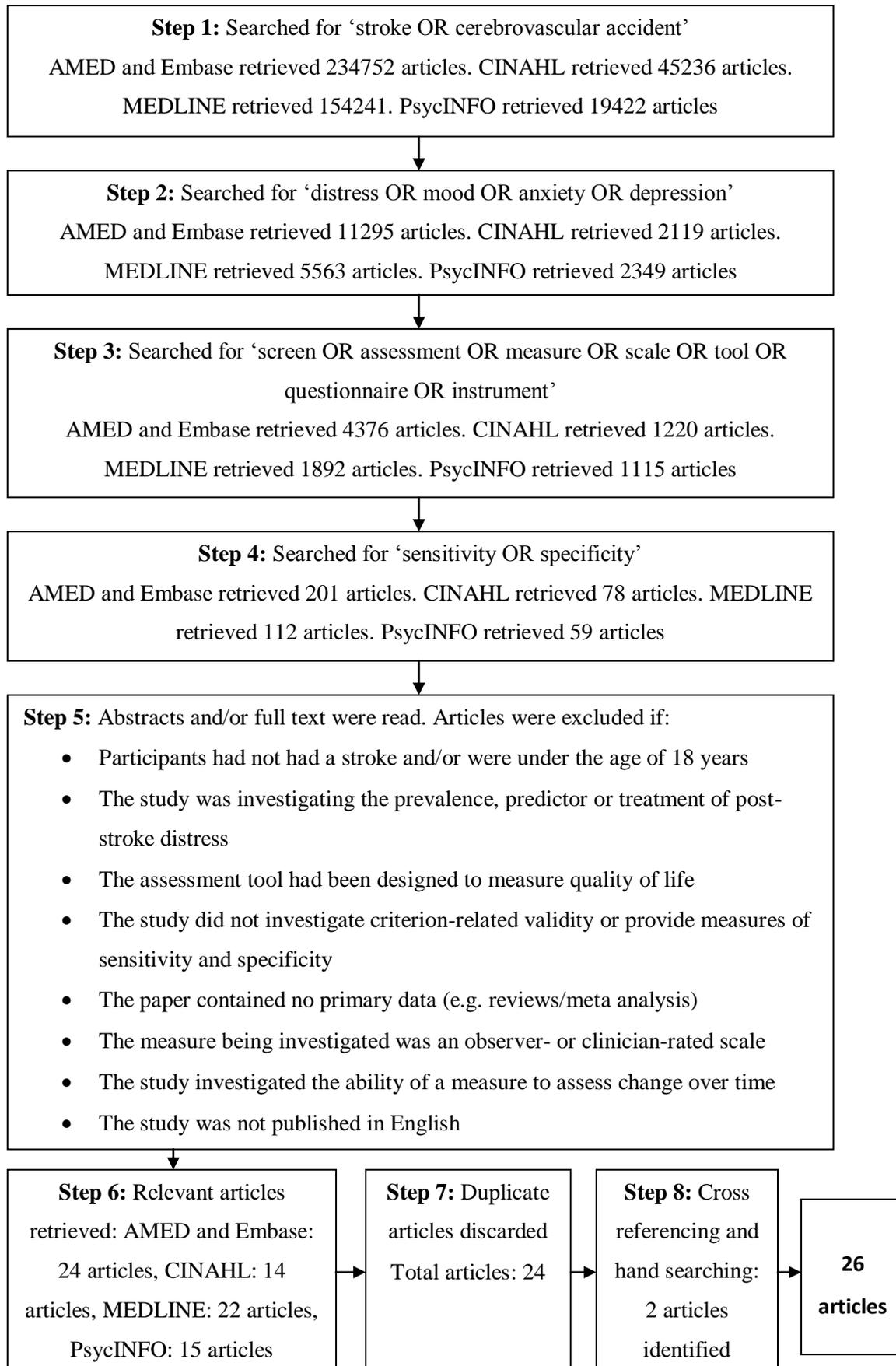
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Appendix A

Search strategy used to identify studies meeting criteria for the literature review



Appendix B

Psychometric Properties of Each Validation Study

| Measure | Study | Sample | Age (yrs) | Criterion standard | Time | Cutoff | Sens. | Spec. | PPV | NPV | AUC | |
|---------|------------------------|-------------|-----------------|-------------------------------|------------------|--------|-------|-------|------|------|------|------|
| BAI | Schramke et al. (1998) | N=44 | M: 64.6 63.4 | GAD & other anxiety SCID-R | 2.4m- 7.02yrs | ≥16* | good | poor | - | - | - | |
| BDI | House et al. (1989) | n=95 (1m) | 18-96 | MD, MIND & AD | 1m | ≥5†‡ | 1.0 | 0.59 | - | - | - | |
| | | n=122 (6m) | M:71.2 | PSE: DSM-III | | ≥10* | 0.85 | 0.21 | - | - | - | |
| | | n=115 (12m) | | | | 6ms | ≥5† | 1.0 | 0.54 | - | - | - |
| | | | | | | | ≥10* | 0.83 | 0.22 | - | - | - |
| BDI | Aben et al. (2002) | N=202 | M: 68.5 | SCID: MD | 1m | ≥10*‡ | 0.80 | 0.61 | 0.22 | 0.96 | 0.78 | |
| | | | | SCID: MD & MIND | | ≥10* | | | | | | 0.77 |

Table B1 continues

Table B1 continued

| Measure | Study | Sample | Age (yrs) | Criterion standard | Time | Cutoff | Sens. | Spec. | PPV | NPV | AUC | |
|---------|-----------------------------|----------------------|-------------------|--------------------|-------|--------------|-------|-------|------|------|------|---|
| BDI | Berg et al. (2009) | N=100 | ≤70 (M:55.2) | DSM-III-R: MD | 2 wks | ≥10*‡ | 0.80 | 0.76 | - | - | 0.88 | |
| | | | | | 2 ms | ≥10*‡ | 1.00 | 0.76 | - | - | 0.86 | |
| | | | | | 6 ms | ≥7‡ | 1.00 | 0.66 | - | - | 0.88 | |
| | | | | | 12 ms | ≥10*‡ | 1.0 | 0.86 | - | - | 0.93 | |
| | | | | | 18 ms | ≥10*‡ | 0.83 | 0.84 | - | - | 0.89 | |
| BDI-II | Lincoln et al. (2003) | N=143 | (M:66) | SCAN: DSM-III-R | 1-6ms | ≥10* | 0.95 | 0.18 | - | - | - | |
| | | | | | | ≥16 | 0.91 | 0.56 | - | - | - | |
| | | | | | | SCAN: ICD-10 | ≥10* | 0.93 | 0.24 | - | - | - |
| | | | | | | MD & MIND | ≥13 | 0.83 | 0.44 | - | - | - |
| BDI-II | Turner-Stokes et al. (2005) | N=114 n=76 stroke | (M:42.8) | DSM-IV: MD & MIND | 12wks | ≥14* | 0.74 | 0.80 | 0.69 | 0.84 | - | |
| BDI-II | Turner et al. (2012) | N=72 | 25-91 (M:66.7) | SCID: MD | 3wks- | ≥14*‡ | 0.85 | 0.75 | - | - | 0.89 | |
| | | | | | 45yrs | ≥12†‡ | 0.92 | 0.71 | - | - | | |

Table B1 continues

Table B1 continued

| Measure | Study | Sample | Age (yrs) | Criterion standard | Time | Cutoff | Sens. | Spec. | PPV | NPV | AUC |
|---------|--------------------------|------------|--------------------|------------------------------------|----------------|--------|-------|-------|------|------|-----|
| BDI-FS | Healey et al. (2008) | N=49 | 65yrs+ | SCID: MD | 16- | ≥4* | 0.71 | 0.74 | 0.31 | 0.94 | - |
| | | Inpatients | (M:78.8) | SCID: MD & MIND | 113days | ≥4* | 0.62 | 0.78 | 0.50 | 0.85 | |
| BASDEC | Healey et al. (2008) | N=49 | 65yrs+ (M:78.8) | SCID: MD | 16- | ≥7*‡ | 1.00 | 0.95 | 0.78 | 1.00 | - |
| | | | | SCID: MD & MIND | 113days | ≥7* | 0.69 | 0.97 | 0.90 | 0.90 | |
| CES-D | Shinar et al. (1986) | N=27 | 28-73 (M:56) | PSE: DSM-III MD & MIND | 7days - 6ms | ≥16* | 0.73 | 1.0 | 1.0 | 0.84 | - |
| CES-D | Parikh et al. (1988) | N=80 | 58.4 (13.5) | MD & MIND | 1wk-2yrs | ≥16*‡ | 0.86 | 0.90 | 0.80 | - | - |
| | | | | PSE: DSM-III | | ≥21 | 0.72 | 0.94 | 0.85 | - | |
| CES-D | Agrell and Dehlin (1989) | N=39 | 61-93 (M:80) | MD & MIND Psychiatric interview | 4m- 2.5yrs | ≥20 | 0.56 | 0.91 | 0.82 | 0.75 | - |
| CES-D | Rybarczyk et al. (1996) | N=50 | (M:71) | MD & MIND | 23days | ≥21 | 0.56 | 0.65 | 0.44 | 0.60 | - |
| | | | | SADS-C: DSM-III | ±20 | ≥26‡ | 0.82 | 0.65 | 0.65 | 0.76 | |

Table B1 continues

Table B1 continued

| Measure | Study | Sample | Age (yrs) | Criterion standard | Time | Cutoff | Sens. | Spec. | PPV | NPV | AUC |
|---------|---------------------------------|----------------------|-------------------|---|----------------|-------------|--------------|--------------|--------------|--------------|------|
| CES-D | Schramke et al. (1998) | N=44 | 55.5-71.3 | SCID-R: MD, MIND & DD | 0.2-7.02yrs | ≥16* | good | poor | - | - | - |
| CES-D | Roger and Johnson-Greene (2009) | N=67 | 45-89 (M:71) | SCID: MD & MIND | 8days ±4.5 | ≥15 ≥16* | 0.66 0.60 | 0.68 0.76 | 0.34 0.28 | 0.35 0.38 | 0.71 |
| DISCs | Turner-Stokes et al. (2005) | N=114 n=76 stroke | (M:42.8) | MD & MIND Psychiatric interview: DSM-IV | 12wks | ≥2* | 0.60 | 0.87 | 0.75 | 0.77 | - |
| DT | Turner et al. (2012) | N=72 | 25-91 (M:66.7) | SCID: MD | 3wks- 45yrs | ≥2† ≥4* | 1.0 0.69 | 0.33 0.57 | - - | - - | 0.73 |
| GHQ-30 | O'Rourke et al. (1998) | N=105 | 18-90 (M:68) | Any psychiatric disorder SADS:DSM-IV | 6m | ≥5* ≥9‡ | 0.90 0.80 | 0.47 0.76 | - - | - - | - |

Table B1 continues

Table B1 continued

| Measure | Study | Sample | Age (yrs) | Criterion standard | Time | Cutoff | Sens. | Spec. | PPV | NPV | AUC |
|---------|--------------------------|--------|-----------------|------------------------------------|--------|--------|-------|-------|------|------|-----|
| GHQ-28 | Johnson et al. (1995) | N=66 | 23-95 (M:71) | MD & MIND | 4m | ≥5*‡ | 0.89 | 0.75 | 0.47 | 0.96 | - |
| | | | | | | ≥6† | 0.78 | 0.81 | 0.50 | 0.94 | |
| | | | | | | ≥5* | 0.71 | 0.56 | 0.30 | 0.88 | |
| GHQ-28 | Lincoln et al. (2003) | N=143 | (M:66) | SCAN: DSM-III-R | 1-6ms | ≥5* | 1.00 | 0.24 | - | - | - |
| | | | | | | ≥8‡ | 0.85 | 0.61 | - | - | |
| | | | | | | ≥5* | 0.98 | 0.35 | - | - | |
| | | | | | | ≥12‡ | 0.81 | 0.68 | - | - | |
| GDS-30 | Agrell and Dehlin (1989) | N=40 | 61-93 (M:80) | MD & MIND | 4m- | ≥10‡ | 0.88 | 0.64 | 0.58 | 0.88 | - |
| | | | | Psychiatric interview | 2.5yrs | | | | | | |
| GDS-30 | Johnson et al. (1995) | N=66 | 23-95 (M:71) | MD & MIND | 4m | ≥11*‡ | 0.84 | 0.66 | 0.53 | 0.90 | - |
| | | | | GAD & Agoraphobia PAS – DSM-III | | ≥15 | 0.65 | 0.79 | 0.51 | 0.86 | |

Table B1 continues

Table B1 continued

| Measure | Study | Sample | Age (yrs) | Criterion standard | Time | Cutoff | Sens. | Spec. | PPV | NPV | AUC |
|---------|-------------------------------|--------|--------------------|-----------------------------------|---------------|-----------|--------------|--------------|--------------|--------------|------|
| GDS-30 | Sivrioglu et al. (2009) | N=85 | 25-87 (M:60.1) | DSM-IV: MIND | 17 days – | ≥11* | 0.69 | 0.75 | 0.67 | 0.77 | 0.82 |
| | | | | Psychiatric interview | 2 yrs | ≥12† | 0.66 | 0.79 | 0.70 | 0.76 | |
| | | | | | | ≥9‡ | 0.80 | 0.61 | 0.60 | 0.81 | |
| | | | | | | ≥8‡ | 0.80 | 0.61 | 0.60 | 0.60 | |
| GDS-15 | Tang et al. (2004a) | N=127 | ≥65yrs (M:75.7) | SCID: MD, MIND, DD | 3ms | ≥7‡ | 0.89 | 0.73 | 0.37 | 0.98 | 0.90 |
| GDS-15 | Tang et al. (2004b) | N=60 | 40-90 (M:71.3) | SCID-R:MD, DD & AD | ≤1m | ≥6 | 0.64 | 0.83 | 0.53 | 0.88 | 0.76 |
| GDS-15 | Roger & Johnson-Greene (2009) | N=67 | 45-89yrs (M:71) | SCID: MD & MIND | 8days ±4.5 | ≥3 ≥5* | 0.67 0.46 | 0.73 0.90 | 0.31 0.23 | 0.32 0.49 | 0.73 |
| GDS-15 | Lee et al. (2008) | N=253 | 50yrs+ | DSM-IV: MD & MIND | 1m | ≥5*‡ | 0.84 | 0.77 | 0.75 | 0.85 | - |
| HADS-D | Johnson et al. (1995) | N=66 | 23-95 (m:71) | MD & MIND | 4m | ≥5 | 0.83 | 0.44 | 0.26 | 0.92 | - |
| HADS-A | | | | GAD & Agoraphobia: PAS:DSM-III | | ≥6 | 0.80 | 0.46 | 0.31 | 0.89 | |

Table B1 continues

Table B1 continued

| Measure | Study | Sample | Age (yrs) | Criterion standard | Time | Cutoff | Sens. | Spec. | PPV | NPV | AUC |
|---------|------------------------|--------|-------------------|-------------------------------|--------|--------|-------|-------|------|------|------|
| HADS-D | O'Rourke et al. (1998) | N=105 | 18-90 (M:68) | MD, AD, DD | 6m | ≥7‡ | 0.80 | 0.79 | - | - | - |
| HADS-A | | | | Anxiety disorder ^a | | ≥7‡ | 0.83 | 0.68 | - | - | |
| | | | | SADS: DSM-IV | | | | | | | |
| HADS-D | Aben et al. (2002) | N=202 | 56.9-80.1 | SCID: MD | 1m+ | ≥8* | 0.73 | 0.82 | 0.41 | 0.95 | 0.82 |
| | | | | SCID: MD&MIND | | ≥7 | 0.73 | 0.79 | 0.51 | 0.91 | 0.83 |
| HADS-A | | | | SCID: MD | | ≥5 | 0.92 | 0.56 | 0.26 | 0.98 | 0.78 |
| | | | | SCID: MD&MIND | | ≥5‡ | 0.89 | 0.72 | 0.64 | 0.92 | 0.77 |
| HADS-T | | | | SCID: MD | | ≥11‡ | 0.92 | 0.65 | 0.30 | 0.98 | 0.83 |
| | | | | SCID: MD&MIND | | ≥11‡ | 0.87 | 0.70 | 0.45 | 0.95 | 0.84 |
| HADS-D | Tang et al. (2004c) | N=100 | 60-94 (M:74.2) | SCID-R: MD, DD, AD | 3-4wks | ≥7† | 0.88 | 0.55 | 0.28 | 0.96 | - |
| | | | | | | ≥8* | 0.82 | 0.58 | 0.29 | 0.95 | |
| HADS-D | Tang et al. (2004a) | N=60 | 40-90 (M:71.3) | MD, DD, AD SCID: DSM-III-R | ≤1m | ≥4‡ | 0.86 | 0.78 | 0.55 | 0.93 | 0.84 |

Table B1 continues

Table B1 continued

| Measure | Study | Sample | Age (yrs) | Criterion standard | Time | Cutoff | Sens. | Spec. | PPV | NPV | AUC |
|---------|----------------------|--------|--------------------|-------------------------------------|--------|-------------------------------------|-------|-------|------|------|------|
| HADS-D | Healey et al. (2008) | N=49 | 65yrs+ (M:78.8) | SCID:MD | 16-113 | ≥8*‡ | 0.86 | 0.69 | 0.32 | 0.97 | - |
| | | | | SCID: MD & MIND | days | ≥8* | 0.62 | 0.69 | 0.42 | 0.83 | |
| HADS-D | Sagen et al. (2009) | N=101 | (M:54.5) | SCID: MD, MIND, DD | 4ms | ≥4‡ | 0.84 | 0.73 | 0.42 | 0.95 | 0.87 |
| | | | | | | ≥8* | 0.58 | 0.94 | 0.69 | 0.91 | |
| HADS-A | | | | SCID: anxiety disorder ^b | | ≥4‡ | 0.83 | 0.65 | 0.41 | 0.93 | 0.85 |
| | | | | | | ≥8* | 0.52 | 0.90 | 0.60 | 0.86 | |
| HADS-T | | | | SCID: MD, MIND, DD | | ≥11‡ | 0.90 | 0.83 | 0.55 | 0.97 | 0.91 |
| | | | | | | SCID: anxiety disorder ^b | ≥6‡ | 0.83 | 0.60 | 0.38 | 0.92 |
| HADS-D | Turner et al. (2012) | N=72 | 25-91 (M:66.7) | SCID: MD | 3wks- | ≥6†‡ | 0.92 | 0.68 | - | - | 0.87 |
| | | | | | 45yrs | ≥8*‡ | 0.92 | 0.63 | - | - | |
| HADS-T | | | | | | ≥11‡ | 0.92 | 0.63 | - | - | 0.85 |
| | | | | | | ≥15†‡ | 0.85 | 0.75 | - | - | |

Table B1 continues

Table B1 continued

| Measure | Study | Sample | Age (yrs) | Criterion standard | Time | Cutoff | Sens. | Spec. | PPV | NPV | AUC |
|---------|---------------------------------|--------|-------------------|----------------------------------|----------------|--------|-------|-------|------|------|------|
| K-10 | Turner et al. (2012) | N=72 | 25-91 (M:66.7) | SCID: MD | 3wks- 45yrs | ≥18 | 0.85 | 0.59 | - | - | 0.80 |
| | | | | | | ≥20* | 0.77 | 0.69 | - | - | |
| | | | | | | ≥26† | 0.54 | 0.95 | - | - | |
| PHQ-9 | Williams et al. (2005) | N=316 | - | SCID: MD | 1-2ms | ≥10*‡ | 0.91 | 0.89 | - | - | 0.96 |
| | | | | SCID: Any depression | | ≥10* | 0.78 | 0.96 | - | - | |
| PHQ-9 | de Man-van Ginkel et al. (2011) | N=171 | 20-97 (M:70.6) | CIDI: DSM-IV & ICD-10 depression | 5-9wks | ≥10*‡ | 0.80 | 0.78 | 0.34 | 0.97 | 0.87 |
| PHQ-9 | Turner et al. (2012) | N=72 | 25-91 (M:66.7) | SCID: MD | 3wks- 45yrs | ≥7‡ | 0.85 | 0.63 | - | - | 0.82 |
| | | | | | | ≥9† | 0.77 | 0.75 | - | - | |
| | | | | | | ≥10* | 0.69 | 0.78 | - | - | |
| PHQ-2 | Williams, et al. (2005) | N=316 | - | SCID: MD | 1-2ms | ≥3‡ | 0.83 | 0.84 | - | - | - |
| | | | | SCID: Any depression | | ≥3 | 0.78 | 0.95 | - | - | |

Table B1 continues

Table B1 continued

| Measure | Study | Sample | Age (yrs) | Criterion standard | Time | Cutoff | Sens. | Spec. | PPV | NPV | AUC |
|---------|---------------------------------|--------|--------------------|--|----------------|-----------------|----------------------|----------------------|----------------------|----------------------|------|
| PHQ-2 | de man-van Ginkel et al. (2011) | N=171 | 20-97 (M:70.6) | CIDI: DSM-IV & ICD-10 depression | 5-9wks | ≥2 | 0.75 | 0.76 | 0.30 | 0.96 | 0.82 |
| PHQ-2 | Turner et al. (2012) | N=72 | 25-91 (M:66.7) | SCID: MD | 3wks- 45yrs | ≥2 ≥3 ≥4† | 0.77 0.69 0.62 | 0.63 0.83 0.92 | - - - | - - - | 0.83 |
| Smiley | Lee et al. (2008) | N=253 | 50yrs+ | Sad face Flat face Happy face DSM-IV: MD & MIND | 1m | Yes / No | 0.76 0.98 0.48 | 0.77 0.18 0.73 | 0.74 0.50 0.60 | 0.79 0.93 0.66 | - |
| SIDI | Rybarczyk et al. (1996) | N=50 | (71±6.1) | MD & MIND SADS-C: DSM-III | 23 days ±20 | ≥17‡* | 0.94 | 0.71 | 0.86 | - | - |
| SIDI | Roger & Johnson-Greene (2009) | N=67 | 45-89yrs (M:71) | SCID: MD & MIND | 8days ±4.5 | ≥10 ≥17* | 0.66 0.19 | 0.72 0.95 | 0.32 0.10 | 0.37 0.46 | 0.79 |

Table B1 continues

Table B1 continued

| Measure | Study | Sample | Age (yrs) | Criterion standard | Time | Cutoff | Sens. | Spec. | PPV | NPV | AUC |
|--------------|-----------------------|--------------------------------------|-----------------------|-------------------------------------|--------|-------------------|-------|-------|------|------|------|
| SCL-90 | Aben et al. (2002) | N=202 | 56.9-80.1 | SCID: MD | 1m+ | $\geq 25\ddagger$ | 0.89 | 0.61 | 0.28 | 0.97 | 0.81 |
| | | | | SCID: MD & MIND | | $\geq 25\ddagger$ | 0.88 | 0.66 | 0.44 | 0.95 | 0.85 |
| VAMS | Bennett et al. (2006) | N=100 | 65-76 (M:71.5) | HADS-D | 2-4wks | ≥ 124 | 0.81 | 0.51 | - | - | - |
| | | | | HADS-A | | ≥ 256 | 0.71 | 0.66 | - | - | - |
| VAMS- SAD | Bennett et al.(2006) | N=100 | 65-76 (M:71.5) | HADS-D | 2-4wks | $\geq 23\ddagger$ | 0.88 | 0.62 | - | - | - |
| VAMS- SAD | Berg et al. (2009) | N=100 Inpatients & outpatients | ≤ 70 (M:55.2) | MD | 2 ms | ≥ 50 | 0.20 | 0.84 | - | - | ns |
| | | | | Psychiatric Interview: DSM-III-R | 6 ms | ≥ 50 | 0.40 | 0.89 | - | - | ns |
| | | | | | 12 ms | ≥ 50 | 0.00 | 0.93 | - | - | ns |
| | | | | | 18 ms | ≥ 50 | 0.60 | 0.87 | - | - | 0.85 |
| VASES | Bennett et al. (2006) | N=100 | 65-76 (M:71.5) | HADS-D | 2-4wks | ≥ 32 | 0.81 | 0.05 | - | - | - |
| | | | | HADS-A | | ≥ 34 | 0.73 | 0.15 | - | - | - |
| WDI | Lincoln et al. (2003) | N=143 | (M:66) | SCAN: ICD-10 | 1-6ms | ≥ 19 | 0.92 | 0.46 | - | - | - |
| | | | | SCAN: DSM-III-R | | ≥ 21 | 0.86 | 0.50 | - | - | - |

Table B1 continues

Table B1 continued

| Measure | Study | Sample | Age (yrs) | Criterion standard | Time | Cutoff | Sens. | Spec. | PPV | NPV | AUC |
|---------|-----------------------------|----------------------|------------------|---|---------------|-------------|--------------|--------------|--------------|--------------|-----|
| Yale | Watkins et al. (2001) | N=79 | 70-79 (M:75) | MADRS | 7-14days | Yes/ No‡ | 0.86 | 0.78 | 0.82 | 0.82 | - |
| Yale | Turner-Stokes et al. (2005) | N=114 n=76 stroke | (M:42.8) | MD & MIND Psychiatric interview: DSM-IV | (12wks) | Yes/ No | 0.68 | 0.73 | 0.62 | 0.78 | - |
| Yale | Watkins et al. (2007) | N=122 | 68-79 (M:74) | MADRS | 2 wks 3 ms | Yes/ No‡ | 0.86 0.95 | 0.84 0.89 | 0.86 0.93 | 0.84 0.91 | - |
| ZSDS | Agrell and Dehlin (1989) | N=40 | 61-93 (M: 80) | MD & MIND Psychiatric interview | 4m- 2.5yrs | ≥45 | 0.76 | 0.96 | 0.93 | 0.84 | - |

Note. Time = time since stroke; Sens. = sensitivity; spec. = specificity; PPV = positive predictive value; NPV = negative predictive value; M= Mean; GAD = generalized anxiety disorder; MD = major depression; MIND = minor depression; AD = adjustment disorder; DD: Dysthmic Disorder; CIDI = Composite International Diagnostic Interview; DSM-IV= Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition; DSM-III-R = Diagnostic and Statistical Manual of Mental Disorders, Third Edition, Revised; ICD-10 = International Statistical Classification of Diseases and Related Health Problems 10th Revision; SCID-R = Structured Clinical Interview for DSM-III-R; SCID = Structured Clinical Interview for DSM-IV; SCAN = Schedules for Clinical Assessment in Neuropsychiatry; PSE = Present State Examination; SADS-C = Schedule for Affective Disorders and Schizophrenia – Change version; MADRS = Montgomery–Åsberg Depression Rating Scale

^a generalized anxiety disorder, agoraphobia with or without panic disorder, adjustment disorder with anxious mood, adjustment disorder with mixed anxiety and depressed mood and specific phobia

^b generalized anxiety disorder, posttraumatic stress disorder, social phobia, agoraphobia, panic disorder with or without agoraphobia, anxiety not otherwise specified and obsessive compulsive disorder

* standard cut-off score

† highest sum of specificity and sensitivity

‡ cutoff meeting recommended levels of sensitivity ($\geq .80$) and specificity ($\geq .60$) for stroke survivors (Bennett & Lincoln, 2006)

- indicates data not reported

ns indicates non-significant

Appendix C

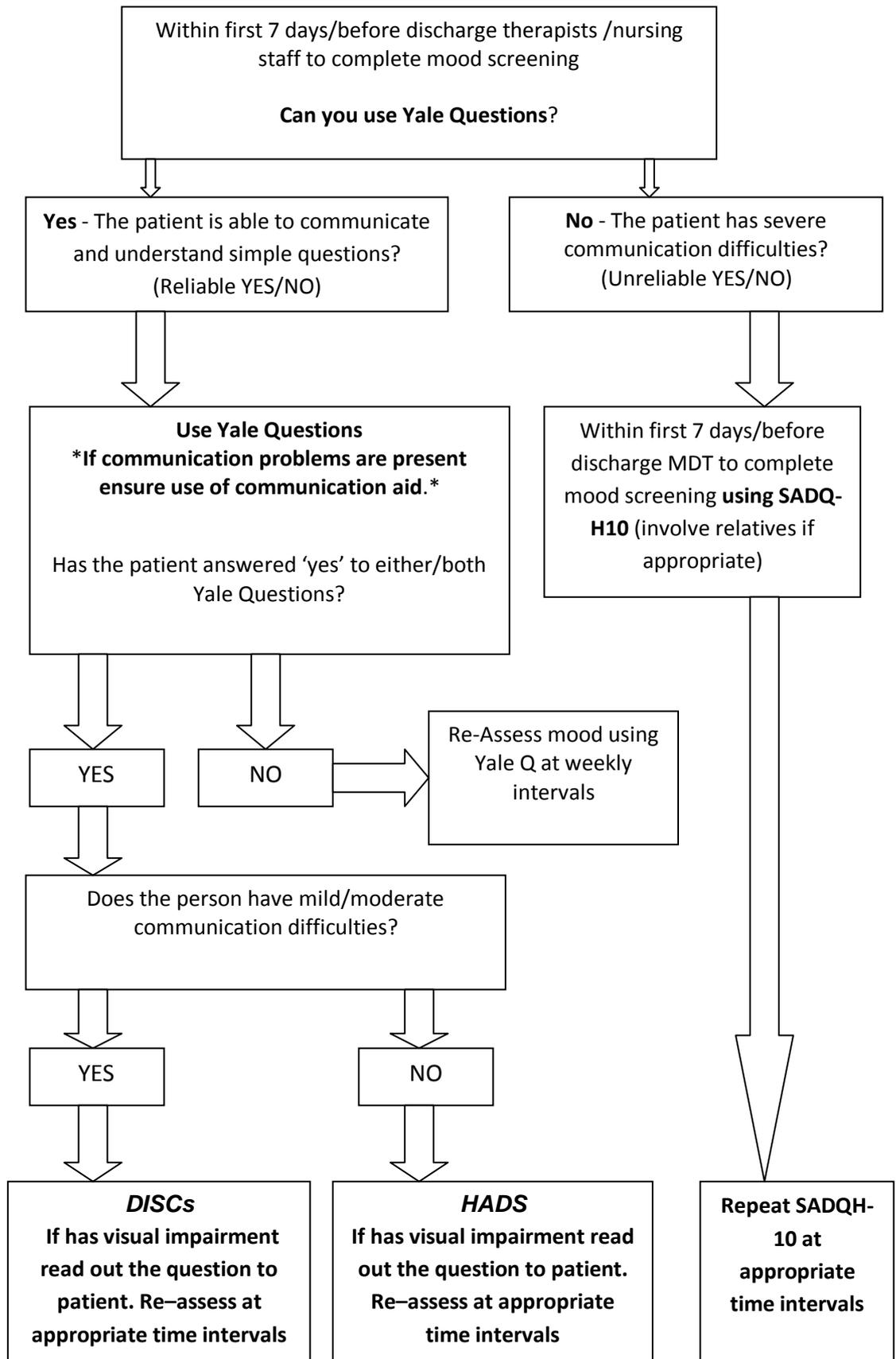
General Description of Self-Report Mood Screening Measures

| Measure | Type of distress | No. of Items | Response format | Period being measured | Original population |
|---------|------------------|--------------|-----------------|-----------------------|----------------------------|
| BAI | A | 21 | Multiple choice | Last week | General & psychiatric |
| BDI | D | 21 | Multiple choice | Last week | General & psychiatric |
| BDI-II | D | 21 | Multiple choice | Last 2 weeks | General & psychiatric |
| BDI-FS | D | 7 | Multiple choice | Last 2 weeks | Medical patients |
| BASDEC | D | 19 | Yes/No | Past | Elderly medical inpatients |
| CES-D | D | 20 | Multiple choice | Last week | General |
| DISCs | D | 1 | VAS | That day | Acquired Brain injury |
| DT | A & D | 1 | VAS | Last week | Cancer |
| GHQ-28 | A & D | 28 | Multiple choice | Last few weeks | General and psychiatric |
| GHQ-30 | A & D | 30 | Multiple choice | Last few weeks | |
| GDS | D | 30 | Yes/No | Past week | Elderly |
| GDS-15 | D | 15 | Yes/No | Past week | Elderly |
| HADS | A & D | 14 | Multiple choice | Last week | Medical patients |
| PHQ-9 | D | 9 | Multiple choice | Last 2 weeks | Primary care |
| PHQ-2 | D | 2 | Multiple choice | Last 2 weeks | Primary care |
| Smiley | D | 3 | VAS | Last week | Stroke |
| SIDI | D | 30 | Yes/No | Current | Stroke inpatients |
| SCL-90 | D | 90 | Multiple choice | Last week | Psychiatric and medical |
| VASES | A & D | 10 | VAS | Current | Aphasic population |
| VAMS | A & D | 7 | VAS | Current | Neurological population |
| VAMS-S | A & D | 1 | VAS | Current | Neurological population |
| WDI | D | 12 | Multiple choice | Current | Psychiatric population |
| YALE | D | 1 | Yes/No | Current | Elderly patients |
| ZDRS | D | 20 | Multiple choice | Past few days | Psychiatric population |

Note. A = anxiety; D = depression

Appendix D

Local Stroke Unit Mood Assessment Pathway



Appendix E

Written Permission to Use the DT and PL

FW: Distress thermometer

<https://www.outlook.soton.ac.uk/owa/?ac=Item&t=IPM.Note&id=R..>

FW: Distress thermometer

Gilson R.C.

Sent: 19 May 2012 09:45

To: Gilson R.C.

Dear Kate

All good news. I think a validation in stroke would be great. I am going to include you in our screening network, just evolving, so you will hear from me again about it. Jimmie

Jimmie C. Holland, MD
Wayne E. Chapman Chair in Psychiatric Oncology
Attending Psychiatrist
Department of Psychiatry & Behavioral Sciences

[Redacted contact information]

From: Kate Jenkins [Redacted]
Sent: Thursday, July 08, 2010 7:25 AM
To: Holland, Jimmie C./Counseling Center
Subject: Distress Thermometer

Dear Jimmie

As you are no doubt aware, the DT is now being used extensively in cancer services across the UK, with great success! So much so that clinicians in other areas are starting to become aware of it and asking if they can use it in their services.

In particular, our Stroke unit are interested in using it and I wondered what your thoughts would be on this. We also have some trainee Clinical Psychologists who are looking for doctoral dissertations in Clinical Health Psychology and I wondered how you would feel about us potentially running a validation study for the use of the DT with Stroke patients? This is very much an idea at the moment and would be some time in the future, but I would be grateful to hear what you thought before mentioning it as a possibility to any of the trainees. I wouldn't want to get their hopes up if you thought it would not be suitable!

Best wishes - [Redacted]

Kate

Dr Kate Jenkins
Chartered Clinical Psychologist
[Redacted contact information]

Appendix F

Focus Group Information Sheet and Consent Form



Focus Group Information Sheet

Project title: Validation of the Distress Thermometer in Stroke

Researcher: Rachael Gilson, Trainee Clinical Psychologist

Ethics number: 561

I would like to invite you to take part in a focus group to discuss how a mood assessment tool called the Distress Thermometer can be adapted for use with people who have experienced a stroke. The following will give you a short overview of what will be involved.

Please read the following information carefully before deciding to take part. If you are happy to participate you will be asked to sign a consent form at the end of this pack, which you can return in the stamped addressed envelope provided.

Who is running the focus group?

My name is Rachael Gilson. I am a Trainee Clinical Psychologist studying at the University of Southampton. As part of my doctorate in Clinical Psychology, I am working with the Clinical Psychology team at [REDACTED]. My supervisor is Kate Jenkins, Clinical Psychologist.

What is the focus group about?

The aim of this focus group is to produce an adapted version of the Distress Thermometer for people who have experienced a stroke. It is hoped that this will be implemented on the unit and form part of the mood assessment pathway.

What is the Distress Thermometer?

The Distress Thermometer is a mood assessment tool which has been created and validated for use with oncology patients. It consists of a 10-point visual scale in the form of a thermometer, and a 'problem list'. The person completing the measure is asked to indicate their current level of distress by using the scale. They are then asked to indicate which items, listed on a 'problem list', have been distressing for them over the past week.

Why does the Distress Thermometer need to be adapted?

All patients should be screened within 6 weeks of diagnosis to identify any mood disturbances (NICE, 2010). However, guidelines do not specify which measures to use. Therefore, local service providers are required to develop their own guidelines and

protocols. The Distress Thermometer offers a holistic measure of global distress. It differs from other mood assessment tools which tend to pathologise mood disturbances. It also guides referral decisions when taking into account why the person is feeling distressed.

What will be involved?

A focus group is simply a group 'focused' on a particular topic. You will be asked to comment on how the Distress Thermometer could be adapted for use with people who have experienced a stroke. There are no right or wrong answers. The group simply aims to capture your views. Discussions during the focus group will be audio-taped, transcribed (written down) and analysed to aid the development of an adapted version.

Following the focus group, you will be given a copy of the transcript and adapted Distress Thermometer to comment on.

How long will the group last for?

The group is expected to last for a maximum of 2 hours. Refreshments will be provided.

How many people will be involved?

The focus group will involve a maximum of 8 people and 2 facilitators. Participants will be professionals working on [REDACTED] stroke unit and a service user representative.

When and where will it happen?

The focus group will take place at [REDACTED]. If you are interested in taking part, you will be contacted to arrange a convenient date and time. This is likely to occur sometime in October 2011.

Why am I being invited to take part?

You are being asked to take part in this focus group as you either form part of the multi-disciplinary team on [REDACTED] or you have experienced a stroke and represent other service users. As a result, you are likely to know about the types of issues which result in someone feeling distressed after a stroke.

Are there any benefits in taking part?

An adapted version of the Distress Thermometer will be created and implemented on the unit. The effectiveness and validity of the Distress Thermometer will then be evaluated.

Do I have to take part?

No. It is up to you to decide whether or not to take part in this study.

When do I need to decide by?

If you decide to take part, please complete the attached consent form by the **30th September** and return it in the stamped addressed envelope provided.

What if I change my mind about taking part?

You have the right to withdraw from the focus group at any time without giving a reason and without your decision impacting on future interactions with Southampton University or [REDACTED].

Will my participation be confidential?

Yes. Compliance with the 1998 Data Protection Act and the University of Southampton ethics policy will be maintained at all times.

You will be given a pseudonym so that you are not identifiable in the typed transcription. The tapes will not be heard by anyone other than the researchers. All tapes will be stored securely in locked premises and electronic material will be password protected. Audiotapes will be destroyed confidentially after five years.

The transcripts may be used in future publications, reports and research. However, in all cases, you will not be identifiable as all quotations will be anonymised.

Are there any risks involved?

There are no foreseeable risks identified. However, if you have any questions about your rights as a participant in the study or if you feel that you have been placed at risk or have a complaint, please contact:

The Chair of the Ethics Committee
Department of Psychology
University of Southampton
Southampton
SO17 1BJ.
Tel: 023 8059 5578

Where can I get more information from?

If you would like any further information or wish to discuss participating in the focus group, please contact me or Kate Jenkins on:

Rachael Gilson, Trainee Clinical Psychologist, University of Southampton



Kate Jenkins, Clinical Psychologist,





Focus group consent form

Project title: Validation of the Distress Thermometer in Stroke

Facilitator: Rachael Gilson, Trainee Clinical Psychologist

Ethics number: 561

Please initial the boxes if you agree with the following statements:

I have read and understood the information sheet (18/09/11 Version 1), and I have had the opportunity to ask questions about the focus group

I agree to take part in the focus group and I agree for my data to be used for the purpose of future reports, service evaluation and research

I understand my participation is voluntary and I may withdraw at any time without my legal rights being affected

Name (print name).....

Signature

Date.....

Contact telephone number.....

Email address.....

Appendix G

Original 38-Item Problem List (National Comprehensive Cancer Network, 2011)

| Practical problems | Family problems | Emotional problems | Physical problems | Spiritual/religious concerns |
|---------------------|--------------------------|--------------------------------------|----------------------|------------------------------|
| Child care | Dealing with children | Depression | Appearance | Getting around |
| Housing | Dealing with partner | Fears | Bathing/dressing | Indigestion |
| Insurance/financial | Ability to have children | Nervousness | Breathing | Memory/concentration |
| Transportation | Family health issues | Sadness | Changes in urination | Mouth sores |
| Work/school | | Worry | Constipation | Nausea |
| Treatment decisions | | Loss of interest in usual activities | Diarrhea | Nose dry/congested |
| | | | Eating | Pain |
| | | | Fatigue | Sexual |
| | | | Feeling swollen | Skin dry/itchy |
| | | | Fevers | Sleep |
| | | | | Tingling in feet |

Appendix H

Focus Group Structure

| Group stages | Content | Questions |
|--|--|---|
| Introductions 20 minutes | Welcome participants Explain aim and structure of group (timing) Ground rules: confidentiality, no right or wrong answers Group introductions | “name and role within stroke care” “What do you think of the DT?” |
| Silent generation of ideas 15 minutes | Each participant is asked to write down/think about their answers to the following three questions: | “How would you adapt the DT to meet the experiences of someone who has suffered a stroke? On the paper in front of you jot down your answers to the following three questions:” 1) Which items should be excluded from the list? 2) Which items should be kept? 3) What should be added to the list? |
| Listing ideas on flipchart/round-robin phase 15 minutes | Ask each person in turn to share one item which they have written down (under the 3 headings) | |
| Discussion of ideas on flip chart 30 minutes | Discussion around ideas to clarify, elaborate, defend or dispute items | |

Appendix I

Focus Group Results

| Items added | Items removed | Items altered | Items kept |
|-------------------|-----------------|------------------------|---------------------|
| Speech – | Breathing | Money/insurance | Child care |
| Care arrangements | Feeling swollen | Driving/transportation | Treatment |
| Home environment | Fevers | Work | Ability to have |
| Leaving hospital | Indigestion | Children | Family health |
| Hobbies | Mouth sores | Partner/carers | Depression |
| Anger | Nose | Pets | Fears |
| Communication | Skin dry/itchy | Continence | Nervousness |
| Dizziness | | Eating/drinking | Sadness |
| Muscle weakness | | Mobility | Worry |
| Swallowing | | Washing/dressing | Loss of interest in |
| Vision | | Concentration | Appearance |
| Confusion | | memory | Fatigue |
| | | | Nausea |
| | | | Pain |
| | | | Sexual |
| | | | Sleep |
| | | | Tingling in |

Appendix J

Adapted Problem List and Corresponding ICF Codes Based Within the ICF Core Set for
Stroke (Geyh, et al., 2004)

| PL items | ICF Code | ICF category title |
|------------------------|----------|--|
| Care arrangements | e340 | Personal care providers and personal assistants |
| | e355 | Health professionals |
| | e360 | Health-related professionals |
| | e450 | Individual attitudes of health professionals |
| | e455 | Individual attitudes of health-related professionals |
| | e580 | Health services, systems and policies |
| Child care | (d660) | Assisting others |
| Driving/transportation | d475 | Driving |
| | d470 | Using transport |
| | e540 | Transportation services, systems and policies |
| Home environment | e525 | Housing services, systems and policies |
| Leaving hospital | - | - |
| Money/insurance | d870 | Economic self-sufficiency |
| Treatment decisions | - | - |
| Work | d845 | Acquiring, keeping and terminating a job |
| | d850 | Remunerative employment |
| | d855 | Non-remunerative employment |
| Hobbies | d920 | Recreation and leisure |
| Children | e310 | Immediate family |
| Partner/carers | e310 | Immediate family |
| | e340 | Personal care providers and personal assistants |
| Pets | (e350) | (Domesticated animals) |

Table J1 continues

Table J1 continued

| PL items | ICF Code | ICF category title |
|--------------------------------------|-------------|--|
| Ability to have children | (b660) | (Procreation functions) |
| Family health issues | e310 | Immediate family |
| Anger | b152 | Emotional functions |
| Depression | b152 | Emotional functions |
| Fears | b152 | Emotional functions |
| Nervousness | b152 | Emotional functions |
| Sadness | b152 | Emotional functions |
| Worry | b152 | Emotional functions |
| Loss of interest in usual activities | b152 | Emotional functions |
| Appearance | - | - |
| Communication | b167 | Mental functions of language |
| | d310 | Communicating with–receiving–spoken messages |
| | d315 | Communicating with–receiving–nonverbal |
| | d325 | messages |
| | d330 | Communicating with–receiving–written messages |
| | d335 | Speaking |
| | d345 | Producing nonverbal messages |
| | d360 | Conversation |
| | | Using communication devices and techniques |
| | d360 | Conversation |
| | | Using communication devices and techniques |
| Toileting | d530 | Toileting |
| | b525 | Defecation functions |
| | b620 | Urination functions |
| Dizziness | (b240) | Sensations associated with hearing and vestibular function |

Table J1 continues

Table J1 continued

| PL items | ICF Code | ICF category title |
|------------------------------|-------------|---|
| Eating/drinking | d550 | Eating |
| | (d560) | Drinking |
| Fatigue | b134 | Sleep functions |
| Movement | d450 | Walking |
| | d455 | Moving around |
| | d460 | Moving around in different locations |
| | d465 | Moving around using equipment |
| Muscle weakness | b730 | Muscle power functions |
| Nausea | (b535) | (Sensations associated with the digestive system) |
| Pain | b280 | Sensations of pain |
| Sexual | b640 | Sexual functions |
| | d770 | Intimate relationships |
| Sleep | b134 | Sleep functions |
| Swallowing | b510 | Ingestion functions |
| Tingling in hands and feet | b265 | Touch functions |
| Vision | b210 | Seeing functions |
| | b215 | Functions of structures adjoining the eye |
| Washing and dressing | d510 | Washing oneself |
| | d540 | Dressing |
| Confusion | b114 | Orientation functions |
| Concentration | b140 | Attention functions |
| Memory | b144 | Memory functions |
| Spiritual/religious concerns | (d930) | (Religion and spirituality) |

Note. ICF = International Classification of Functioning, Disability and Health

The brief ICF Core Set for Stroke are shown in boldface. Items not detailed within the ICF

Core Set for Stroke are presented in parenthesis.

Appendix K

Stroke Unit Information Sheet and Consent Form



Participant Information Sheet

Study title: Validation of the Distress Thermometer in Stroke

Researcher: Rachael Gilson, Trainee Clinical Psychologist

Ethics number: 561

I would like to invite you to take part in a study which is looking at the usefulness of a mood assessment tool called the Distress Thermometer.

The following information will give you a short overview of what will be involved.

Please read the following information carefully before deciding to take part in this study. If you are happy to participate you will be asked to sign a consent form.

Who is running the study?

My name is Rachael Gilson. I am a Trainee Clinical Psychologist studying at the University of Southampton. As part of my doctorate in Clinical Psychology, I am working with the Clinical Psychology team at [REDACTED]. My supervisor is Kate Jenkins, Clinical Psychologist.

What is the study about?

As part of my third year dissertation I am looking into the effectiveness of a questionnaire called the Distress Thermometer. The Distress Thermometer measures the level and cause of someone's distress. It was created for use with people who have experienced cancer, however, this study aims to investigate whether it is useful for people who have experienced a stroke.

Why am I being invited to take part?

The National Clinical Guideline for Stroke (2008) highlights the importance of identifying someone's emotional needs while in hospital and at regular intervals once they have left hospital. While this is currently happening on [REDACTED], it is hoped that the addition of the Distress Thermometer will enhance this process.

What will be involved?

You will be asked to complete three questionnaires, including the Distress Thermometer, which assess how you have been feeling over the last few days. You will also be asked to

complete a number of tasks which measure your thinking skills, such as memory and concentration.

How long will this take?

It is expected that this will take between 30-60 minutes.

What will happen once I have completed the questionnaires?

After completing the questionnaires, your results will be fed back to you. If you would like to receive any further support with regard to how you are feeling, you will be given the opportunity to discuss this after completing the questionnaires and additional support will be arranged where appropriate.

Will my participation be confidential?

Compliance with the 1998 Data Protection Act and the University of Southampton ethics policy will be maintained at all times.

As part of your routine care on [REDACTED], the completed questionnaires will be kept in your medical file along with details of any further recommendations and referrals. This information will only be accessible to professionals who are involved in your care. If you do not want this to happen please indicate this on the consent form. However, if during the completion of the questionnaires you raise concerns about your safety or the safety of others, this will need to be discussed with other professionals.

To evaluate the effectiveness of the Distress Thermometer, your results will be anonymised, so that nobody can identify you, data coded and transferred to a password protected computer for analysis. This data will then be used to write and publish academic articles.

If after the study you would like to receive a summary of the findings or a copy of any written articles, please contact Rachael Gilson, at the below details.

Are there any benefits in taking part?

Your participation has the potential to shape future practice within stroke services with regard to the assessment and treatment of someone's emotional needs after stroke.

Do I have to take part?

No. It is up to you to decide whether or not to take part in this study.

What if I change my mind about taking part?

You have the right to withdraw from the study at any time without giving a reason and without your decision impacting on future interactions with Southampton University or [REDACTED]

Are there any risks involved?

The questionnaires involve talking about how you have been feeling following your stroke. Understandably, this may be upsetting for you at times.

What happens if something goes wrong?

If you have any questions about your rights as a participant in the study or if you feel that you have been placed at risk or have a complaint, please contact:

The Chair of the Ethics Committee
Department of Psychology
University of Southampton
Southampton
SO17 1BJ.
Tel: 023 8059 5578

Where can I get more information from?

If you would like any further information or wish to discuss participating in this study, please contact me or Kate Jenkins on:

Rachael Gilson, Trainee Clinical Psychologist, University of Southampton



Kate Jenkins, Clinical Psychologist,





Consent form

Focus group topic: Validation of the Distress Thermometer in stroke

Facilitator: Rachael Gilson, Trainee Clinical Psychologist

Ethics number: 561

Please initial the boxes if you agree with the following statements:

I have read and understood the information sheet (date/version 2),
and I have had the opportunity to ask questions about the study

I agree to take part in this study and I agree for my data to be used
for the purpose of future reports and research

I agree for the completed questionnaires to be kept within my medical
file

I understand my participation is voluntary and I may withdraw
at any time without my legal rights being affected

Name (print name).....

Signature

Date.....

Appendix L

Charity Information Sheet and Consent Form



Participant Information Sheet

Study title: Validation of the Distress Thermometer in Stroke

Researcher: Rachael Gilson, Trainee Clinical Psychologist

Ethics number: 561

I would like to invite you to take part in a study which is looking at the effectiveness of a mood assessment tool called the Distress Thermometer. The following information will give you a short overview of what will be involved.

Please read the following information carefully before deciding to take part in this study. If you are happy to participate you will be asked to sign a consent form which you can return in the stamped addressed envelope provided.

Who is running the study?

My name is Rachael Gilson. I am a Trainee Clinical Psychologist studying at the University of Southampton. As part of my doctorate in Clinical Psychology, I am working with the Clinical Psychology team at [REDACTED]. My supervisor is Kate Jenkins, Clinical Psychologist.

What is the study about?

As part of my third year dissertation I am investigating the effectiveness of a mood assessment measure called the Distress Thermometer, which measures the level and cause of someone's distress. It is used with people who have experienced cancer, however, this study aims to investigate whether it is useful for people who have experienced a stroke.

Why am I being invited to take part?

You are being asked to take part in this study as you have experienced a stroke. The National clinical guideline for Stroke (2008) highlight the importance of identifying someone's "emotional" needs while in hospital and at regular intervals once they have left hospital. However, these guidelines do not specify how to do this.

What will be involved?

You will be asked to complete three questionnaires, including the Distress Thermometer, which assess how you have been feeling over the last few days. You will also be asked to complete a number of tasks which measure your thinking skills, such as memory and concentration.

How long will this take?

It is expected that this will take between 30-60 minutes.

Will my participation be confidential?

Yes. Compliance with the 1998 Data Protection Act and the University of Southampton ethics policy will be maintained at all times.

The questionnaires will remain anonymous so nobody can identify you. Your scores will be data coded and transferred to a password protected computer for analysis.

Are there any benefits in taking part?

Your participation has the potential to shape future practice within stroke services with regard to the assessment and treatment of someone's emotional needs after stroke.

Do I have to take part?

No. It is up to you to decide whether or not to take part in this study.

What do I need to do if I decide to take part?

If you decide to take part, please complete the attached consent form and return it in the stamped addressed envelope provided.

I will then contact you to arrange a convenient time and place to complete the questionnaires. Any travel expenses will be paid for and you will be given a £5 M&S voucher for your time.

What if I change my mind about taking part?

You have the right to withdraw from the study at any time without giving a reason and without your decision impacting on future interactions with Southampton University or [REDACTED].

Are there any risks involved?

Several of the questionnaires involve talking about how you have been feeling following your stroke. Understandably, this may be upsetting for you at times. The results of the questionnaires will be fed back to you once completed. If at the end of the session you would like to receive additional support, this can be discussed and local services/resources will be made available to you where appropriate.

What happens if something goes wrong?

If you have any questions about your rights as a participant in the study or if you feel that you have been placed at risk or have a complaint, please contact:

The Chair of the Ethics Committee
Department of Psychology
University of Southampton
Southampton
SO17 1BJ.
Tel: 023 8059 5578

Where can I get more information from?

If you would like any further information or wish to discuss participating in this study,

please contact me or Kate Jenkins on:

Rachael Gilson, Trainee Clinical Psychologist, University of Southampton

[REDACTED]

Kate Jenkins, Clinical Psychologist,

[REDACTED]

[REDACTED]

[REDACTED]

If at the end of the study you would like to receive a summary of the findings please contact Rachael Gilson at the above details.



Consent form

Study title: Validation of the Distress Thermometer in Stroke

Researcher: Rachael Gilson, Trainee Clinical Psychologist

Ethics number: 561

Please initial the boxes if you agree with the following statements:

I have read and understood the information sheet (09/01/12/version 3),
and I have had the opportunity to ask questions about the study

I agree to take part in this study and I agree for my data to be used
for the purpose of future reports and research

I understand my participation is voluntary and I may withdraw
at any time without my legal rights being affected

Name (print name).....

Signature

Date.....

Contact telephone number.....

or

Email address.....

Please return the completed consent form in the enclosed stamped addressed envelope

Appendix M

Local Research and Development Email of Approval

FW: trainee

<https://www.outlook.soton.ac.uk/owa/?ac=Item&t=IPM.Note&id=R...>

FW: trainee

Gilson R.C.
Sent: 19 May 2012 22:19
To: Gilson R.C.

From: Louise Bell
Sent: 15 April 2011 14:29
To: Kate Jenkins
Subject: RE: trainee

Hi Kate

The way I understand your project is that you are implementing a new questionnaire and then evaluating this change to service, which will then inform future practice at [redacted]. If this is the case, then I am happy to confirm that we would consider it service evaluation and therefore you would not need REC review or NHS permission to proceed.

Good luck with your project.

All the best,

Louise Bell

Louise Bell
Consortium Research Governance Facilitator

[redacted]
[redacted]
[redacted]
[redacted]
[redacted]

From: Kate Jenkins
Sent: 11 April 2011 10:12
To: Louise Bell
Subject: RE: trainee

Hi - thanks for this -

All but one of the questionnaires are currently used as the mood screening/cognitive screening. We are adding in one that has been validated with cancer patients, but hasn't been used with the stroke population before. Rachael is going to do all sorts of fancy stats to validate it against the current questionnaires, as if it is valid with stroke patients it will do away with the need for half the ones we use now, as it's a much more holistic tool - so people will only have to do one, rather than lots.

Does that make sense? Sorry, it reads a bit "rambling" to me! If you need clarification give me a buzz on [redacted]

Kate

FW: trainee

<https://www.outlook.soton.ac.uk/owa/?ac=Item&t=IPM.Note&id=R...>

Dr Kate Jenkins
Clinical Psychologist


From: Louise Bell
Sent: 08 April 2011 15:27
To: Kate Jenkins
Subject: FW: trainee

Hi Kate

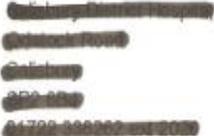
From the sounds of it we could quite easily classify this as a service evaluation. However to be sure I need a little more information.

Are the all measures that you mention routinely given to patients at the moment?

How will you determine the utility of the questionnaires? Is this part of routine practice?

All the best,

Louise Bell

Louise Bell
Consortium Research Governance Facilitator


From: Stef Scott
Sent: 08 April 2011 14:53
To: Louise Bell
Subject: FW: trainee

Louise

can you take this one forward for me?

Thanks

S

FW: trainee

<https://www.outlook.soton.ac.uk/owa/?ac=Item&t=IPM.Note&id=R...>

From: Kate Jenkins
Sent: 30 March 2011 16:52
To: Stef Scott
Subject: trainee

Dear Stef

It's that time of year again! We have got another final year Clinical Psychology trainee who would like to do their dissertation with us. She wants to evaluate a project that has already started on [REDACTED] in terms of finding the best tool to assess mood in patients after a stroke, as 100% of patients should now be assessed according to national guidance.

She has written a paragraph as you asked us to do last year with [REDACTED] project, and I have attached it here.

Let me know what you think - it seems to me that it definitely falls into a service evaluation and audit bracket as opposed to research. Happy to tweak the proposal if you think it needs to be worded differently.

Best wishes
Kate

Dr Kate Jenkins
Clinical Psychologist

[REDACTED]
[REDACTED]
[REDACTED]

Appendix N

University Ethics Email of Approval

Research Governance Feedback on your Ethics Submission (Ethics ... <https://www.outlook.soton.ac.uk/owa/?ac=Item&t=IPM.Note&id=...>

Research Governance Feedback on your Ethics Submission (Ethics ID:561)

ERGO [DoNotReply@ERGO.soton.ac.uk]

Sent: 19 September 2011 13:55

To: Gilson R.C.

Submission Number 561:

Submission Title Validation of the Distress Thermometer in Stroke:

The Research Governance Office has reviewed and approved your submission

You can begin your research unless you are still awaiting specific Health and Safety approval (e.g. for a Genetic or Biological Materials Risk Assessment) or external ethics review (e.g. NRES). The following comments have been made:

"No issues - thanks for supplying the emails from R&D; Best of luck with the project."

ERGO : Ethics and Research Governance Online

<http://www.ergo.soton.ac.uk>

DO NOT REPLY TO THIS EMAIL

Appendix O

Table O1

Screening Properties of the Distress Thermometer (DT) Relative to the HADS

| DT Cut off | HADS-D ≥ 8 | | | | HADS-D ≥ 4 | | | | HADS-A ≥ 8 | | | | HADS-A ≥ 4 | | | | HADS-T ≥ 11 | | | |
|------------------|-----------------|------|------|------|-----------------|------|------|------|-----------------|------|------|------|-----------------|------|------|------|------------------|------|------|------|
| | Se | Sp | PPV | NPV | Se | Sp | PPV | NPV |
| ≥ 1 | 1.00 | 0.00 | 0.32 | 1.00 | 0.90 | 0.10 | 0.68 | 0.33 | 0.90 | 0.10 | 0.32 | 0.67 | 0.96 | 0.25 | 0.79 | 0.67 | 0.94 | 0.15 | 0.61 | 0.67 |
| ≥ 2 | 1.00 | 0.24 | 0.39 | 1.00 | 0.86 | 0.20 | 0.69 | 0.40 | 0.90 | 0.19 | 0.35 | 0.80 | 0.96 | 0.50 | 0.85 | 0.80 | 0.94 | 0.31 | 0.65 | 0.80 |
| ≥ 3 | 0.90 | 0.33 | 0.39 | 0.88 | 0.81 | 0.40 | 0.74 | 0.50 | 0.80 | 0.29 | 0.35 | 0.75 | 0.91 | 0.75 | 0.91 | 0.75 | 0.89 | 0.46 | 0.70 | 0.75 |
| ≥ 4 | 0.90 | 0.48 | 0.45 | 0.91 | 0.71 | 0.50 | 0.75 | 0.46 | 0.80 | 0.43 | 0.40 | 0.82 | 0.83 | 0.88 | 0.95 | 0.64 | 0.83 | 0.62 | 0.75 | 0.73 |
| ≥ 5 | 0.80 | 0.62 | 0.50 | 0.87 | 0.67 | 0.80 | 0.88 | 0.53 | 0.70 | 0.57 | 0.44 | 0.80 | 0.65 | 0.88 | 0.94 | 0.47 | 0.72 | 0.77 | 0.81 | 0.67 |
| ≥ 6 | 0.50 | 0.76 | 0.50 | 0.76 | 0.38 | 0.80 | 0.80 | 0.38 | 0.50 | 0.76 | 0.50 | 0.76 | 0.39 | 0.88 | 0.90 | 0.33 | 0.39 | 0.77 | 0.70 | 0.48 |
| ≥ 7 | 0.30 | 0.90 | 0.60 | 0.73 | 0.19 | 0.90 | 0.80 | 0.35 | 0.40 | 0.95 | 0.80 | 0.77 | 0.22 | 1.00 | 1.00 | 0.31 | 0.22 | 0.92 | 0.80 | 0.47 |
| ≥ 8 | 0.10 | 0.95 | 0.50 | 0.69 | 0.05 | 0.90 | 0.50 | 0.31 | 0.10 | 0.95 | 0.50 | 0.69 | 0.09 | 1.00 | 1.00 | 0.28 | 0.06 | 0.92 | 0.50 | 0.41 |
| ≥ 9 | 0.10 | 1.00 | 1.00 | 0.70 | 0.05 | 1.00 | 1.00 | 0.33 | 0.10 | 1.00 | 1.00 | 0.70 | 0.04 | 1.00 | 1.00 | 0.27 | 0.06 | 1.00 | 1.00 | 0.43 |
| $=10$ | 0.00 | 1.00 | 1.00 | 0.68 | 0.00 | 1.00 | 1.00 | 0.32 | 0.00 | 1.00 | 1.00 | 0.68 | 0.04 | 1.00 | 1.00 | 0.27 | 0.06 | 1.00 | 1.00 | 0.43 |
| Prevalence (%) | 32.3 | | | | 67.7 | | | | 32.3 | | | | 74.2 | | | | 58.1 | | | |
| Area under curve | 0.74** | | | | 0.67 | | | | 0.68 | | | | 0.86** | | | | 0.74* | | | |

Note. Se = sensitivity; Sp = specificity; PPV = positive predictive value; NPV = negative predictive value

* $p < 0.05$ ** $p < 0.001$

Table O2

Screening Properties of the Brief Assessment Schedule Depression Cards (BASDEC) Relative to the HADS

| BASDEC Cut off | HADS-D ≥ 8 | | | | HADS-D ≥ 4 | | | | HADS-A ≥ 8 | | | | HADS-A ≥ 4 | | | | HADS-T ≥ 11 | | | |
|-------------------|-----------------|------|------|------|-----------------|------|------|------|-----------------|------|------|------|-----------------|------|------|------|------------------|------|------|------|
| | Se | Sp | PPV | NPV | Se | Sp | PPV | NPV |
| ≥ 2 | 1.00 | 0.24 | 0.39 | 1.00 | 0.81 | 0.10 | 0.65 | 0.20 | 1.00 | 0.24 | 0.39 | 1.00 | 0.87 | 0.25 | 0.77 | 0.40 | 0.89 | 0.23 | 0.62 | 0.60 |
| ≥ 2.5 | 0.80 | 0.33 | 0.36 | 0.78 | 0.67 | 0.20 | 0.64 | 0.22 | 0.80 | 0.33 | 0.36 | 0.78 | 0.74 | 0.38 | 0.77 | 0.33 | 0.78 | 0.38 | 0.64 | 0.56 |
| ≥ 3 | 0.80 | 0.38 | 0.38 | 0.80 | 0.67 | 0.30 | 0.67 | 0.30 | 0.80 | 0.38 | 0.38 | 0.80 | 0.74 | 0.50 | 0.81 | 0.40 | 0.78 | 0.46 | 0.67 | 0.60 |
| ≥ 3.5 | 0.70 | 0.62 | 0.47 | 0.81 | 0.48 | 0.50 | 0.67 | 0.31 | 0.70 | 0.62 | 0.47 | 0.81 | 0.52 | 0.63 | 0.80 | 0.31 | 0.61 | 0.69 | 0.73 | 0.56 |
| ≥ 4 | 0.70 | 0.67 | 0.50 | 0.82 | 0.48 | 0.60 | 0.71 | 0.35 | 0.70 | 0.67 | 0.50 | 0.82 | 0.52 | 0.75 | 0.86 | 0.35 | 0.61 | 0.77 | 0.79 | 0.59 |
| ≥ 4.5 | 0.60 | 0.71 | 0.50 | 0.79 | 0.43 | 0.70 | 0.75 | 0.37 | 0.60 | 0.71 | 0.50 | 0.79 | 0.43 | 0.75 | 0.83 | 0.32 | 0.50 | 0.77 | 0.75 | 0.53 |
| ≥ 5 | 0.60 | 0.71 | 0.50 | 0.79 | 0.43 | 0.70 | 0.75 | 0.37 | 0.60 | 0.71 | 0.50 | 0.79 | 0.43 | 0.75 | 0.83 | 0.32 | 0.50 | 0.77 | 0.75 | 0.53 |
| ≥ 5.5 | 0.40 | 0.76 | 0.44 | 0.73 | 0.33 | 0.80 | 0.78 | 0.36 | 0.60 | 0.86 | 0.67 | 0.82 | 0.39 | 1.00 | 1.00 | 0.36 | 0.39 | 0.85 | 0.78 | 0.50 |
| ≥ 6 | 0.40 | 0.76 | 0.44 | 0.73 | 0.33 | 0.80 | 0.78 | 0.36 | 0.60 | 0.86 | 0.67 | 0.82 | 0.39 | 1.00 | 1.00 | 0.36 | 0.39 | 0.85 | 0.78 | 0.50 |
| ≥ 6.5 | 0.40 | 0.86 | 0.57 | 0.75 | 0.29 | 0.90 | 0.86 | 0.38 | 0.50 | 0.90 | 0.71 | 0.79 | 0.30 | 1.00 | 1.00 | 0.33 | 0.33 | 0.92 | 0.86 | 0.50 |
| ≥ 7 | 0.30 | 0.86 | 0.50 | 0.72 | 0.23 | 0.90 | 0.83 | 0.36 | 0.40 | 0.90 | 0.67 | 0.76 | 0.26 | 1.00 | 1.00 | 0.32 | 0.28 | 0.92 | 0.83 | 0.48 |
| Prevalence (%) | 32.3 | | | | 0.68 | | | | 0.32 | | | | 0.74 | | | | 0.58 | | | |
| Area under curve | 0.68 | | | | 0.51 | | | | 0.73 | | | | 0.68 | | | | 0.67 | | | |

Note. Se = sensitivity; Sp = specificity; PPV = positive predictive value; NPV = negative predictive value

Table O3

Screening Properties of the Yale Question (YQ2) Relative to the HADS

| YQ2 | HADS-D \geq 8 | | | | HADS-D \geq 4 | | | | HADS-A \geq 8 | | | | HADS-A \geq 4 | | | | HADS-T \geq 11 | | | |
|------------------|-----------------|------|------|------|-----------------|------|------|------|-----------------|------|------|------|-----------------|------|------|------|------------------|------|------|------|
| | Se | Sp | PPV | NPV | Se | Sp | PPV | NPV |
| =1 | 0.67 | 0.67 | 0.46 | 0.82 | 0.45 | 0.60 | 0.69 | 0.35 | 0.44 | 0.57 | 0.31 | 0.71 | 0.64 | 0.63 | 0.82 | 0.39 | 0.47 | 0.62 | 0.62 | 0.47 |
| Prevalence (%) | 30.0 | | | | 66.7 | | | | 30.0 | | | | 73.3 | | | | 56.7 | | | |
| Area under curve | 0.67 | | | | 0.53 | | | | 0.51 | | | | 0.63 | | | | 0.54 | | | |

Note. Se = sensitivity; Sp = specificity; PPV = positive predictive value; NPV = negative predictive value; YQ2 = Yale question; HADS-D = Hospital Anxiety and Depression Scale – depression subscale; HADS-A = Hospital Anxiety and Depression Scale – anxiety subscale; HADS-T = Hospital Anxiety and Depression Scale – total score

Appendix P

Number and Percent of Items Selected on the Problem List

| Domain | Item | N (%) | | |
|--------------------|--------------------------|---------------------------|-------------------------------|-----------------------------|
| | | Total (<i>N</i> = 31) | Inpatient (<i>n</i> = 21) | Charity (<i>n</i> = 10) |
| Practical problems | Care arrangements | 6 (19.4) | 4 (19.0) | 2 (20.0) |
| | Child care | - | - | - |
| | Driving | 9 (29.0) | 7 (33.3) | 2 (20.0) |
| | Home environment | 5 (16.1) | 5 (23.8) | - |
| | Leaving hospital | 4 (12.9) | 4 (19.0) | - |
| | Money | 5 (16.1) | 3 (14.3) | 2 (20.0) |
| | Treatment decisions | 5 (16.1) | 4 (19.0) | 1 (10.0) |
| | Work | 2 (6.5) | 1 (4.8) | 1 (10.0) |
| | Hobbies | 3 (9.7) | 3 (14.3) | - |
| Family concerns | Children | 7 (22.6) | 4 (19.0) | 3 (30.0) |
| | Partner | 3 (9.7) | 3 (14.3) | - |
| | Pets | 3 (9.7) | 3 (14.3) | - |
| | Ability to have children | - | - | - |
| | Family health issues | 7 (22.6) | 4 (19.0) | 3 (30.0) |
| Emotional problems | Anger | 7 (22.6) | 5 (23.8) | 2 (20.0) |
| | Depression | 9 (29.0) | 7 (33.3) | 2 (20.0) |
| | Fears | 9 (29.9) | 9 (42.9) | - |
| | Nervousness | 7 (22.6) | 6 (28.6) | 1 (10.0) |
| | Sadness | 12 (38.7) | 6 (28.6) | 6 (60.0) |
| | Worry | 13 (41.9) | 6 (28.6) | 7 (70.0) |
| | Loss of interest | 7 (22.6) | 6 (28.6) | 1 (10.0) |
| Physical problems | Appearance | 8 (25.8) | 6 (28.6) | 2 (20.0) |
| | Communication | 6 (19.4) | 4 (19.0) | 2 (20.0) |
| | Toileting | 5 (16.1) | 4 (19.0) | 1 (10.0) |
| | Dizziness | 6 (19.4) | 6 (28.6) | - |
| | Eating | 3 (9.7) | 3 (14.3) | - |

Table P1 continues

Table P1 continued

| Domain | Item | N (%) | | |
|------------------------------|--------------------|-------------------|-----------------------|---------------------|
| | | Total (N = 31) | Inpatient (n = 21) | Charity (n = 10) |
| | Fatigue | 16 (51.6) | 11 (52.4) | 5 (50.0) |
| | Movement | 19 (61.3) | 13 (61.9) | 6 (60.0) |
| | Muscle weakness | 19 (61.3) | 13 (61.9) | 6 (60.0) |
| | Nausea | 2 (6.5) | 2 (9.5) | - |
| | Pain | 5 (16.1) | 4 (19.0) | 1 (10.0) |
| | Sexual | 2 (6.5) | 1 (4.8) | 1 (10.0) |
| | Sleep | 11 (35.5) | 9 (42.9) | 2 (20.0) |
| | Swallowing | 6 (19.4) | 5 (23.8) | 1 (10.0) |
| | Tingling | 9 (29.0) | 7 (33.3) | 2 (20.0) |
| | Vision | 9 (29.0) | 6 (28.6) | 3 (30.0) |
| | Washing/dressing | 4 (12.9) | 4 (19.0) | - |
| Thinking problems | Confusion | 3 (9.7) | 3 (14.3) | - |
| | Concentration | 5 (16.1) | 4 (19.0) | 1 (10.0) |
| | Memory | 12 (38.7) | 6 (28.6) | 6 (60.0) |
| Spiritual/religious concerns | Spiritual concerns | 1 (3.2) | 1 (4.8) | - |

Note. N = number

Appendix Q

Post-Hoc Power Analysis

Field (2009, p. 58) states that “the power of a test is the probability that a given test will find an effect assuming that one exists in the population”. GPower 3.1.2 was used to calculate the post-hoc power for an effect size of $r_s = .22$. When the standard α -level was .05 and the total sample size was $N=31$, power was 0.23, which was well below a level of .80 (Cohen, 1992). Consequently, future research is needed to replicate this study using a larger sample to clarify whether an association between the BASDEC and HADS-D exists. According to Cohen (1992), a sample size greater than 85 cases would be needed when the correlation r is less than or equal to .30, as detailed below

| Effect size | Correlation r | % shared variance | Minimum number of people |
|-------------|-----------------|-------------------|--------------------------|
| Large | .50 | 25% | 28 |
| Medium | .30 | 9% | 85 |
| Small | .10 | 1% | 783 |