

The Validity of the Distress Thermometer and Problem
List in the Early Stages of Stroke Care.

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Declaration

The work presented in this thesis is principally the work of the author, Jessica Holmes, and submitted exclusively as part of the Doctorate in Clinical Psychology (DClinPsy), University of Leicester.

Abstract

This thesis examined the application of psychological principles to stroke care. The literature investigating psychological adjustment post stroke was reviewed and the validity of the Distress Thermometer (DT) and Problem List was investigated in an empirical study.

A systematic review focussed on the recently published literature using psychological theory to understand what cognitive factors are protective, or not, in the process of adjustment. Twenty papers were reviewed and nine theoretical models of psychological adjustment used. The most commonly referred to model was the Transactional Theory of Stress and Coping (Lazarus & Folkman, 1984). Factors found to be associated with positive mood included internal locus of control, finding meaning and satisfaction with treatment. The complex and dynamic nature of adjustment was highlighted by the role of time and individual differences. The results of the review provided support for a recently developed model of adjustment post stroke (Social Cognitive Transition Model for Stroke, SCoTs, Taylor, Todman & Broomfield, 2011).

The DT and stroke specific Problem List offers a valuable tool for assessing and understanding distress post stroke. Forty-eight participants completed the DT, Problem List, Hospital Anxiety and Depression Scale (HADS, Zigmond & Snaith, 1983), Brief Assessment Schedule Depression Cards (BASDEC; Ashead *et al*, 1992) and the Visual Analogue Mood Scale Revised (Kontou *et al.*, 2012) at one time point. Correlation coefficients were significant and positive between all measures, supporting concurrent validity. AUC analysis suggested a cut-off of 4.5 on the DT as suitable for the detection of anxiety. Cronbach's alpha found the Problem List to be most reliable when used as one whole scale, however this was most likely because of the large number of items in the overall scale, rather than the items being clearly associated to one another. Bladder and bowel problems were the most commonly reported distressing problem, with fatigue, worry and depression being frequently identified. These findings supported the used of the DT and Problem List in the early stages post stroke.

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I would like to acknowledge the participants for their vital role in this research and thank my supervisors, Professor Nadina Lincoln and Mary O'Reilly, for their invaluable expertise and encouragement throughout this project. Special thanks goes to my friends and family for their continued enthusiasm and motivation, especially Mum, Dad, Matt and Emma.

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Literature Review

What Theoretical Models are being used, and what Cognitive Factors are Protective, in
Psychological Adjustment Post Stroke?

Abstract

Purpose: To investigate the application of psychological models in understanding how people cope and adjust post stroke and to identify cognitive factors associated with positive psychological adjustment.

Method: Cognitive factors were operationally defined as “the symbolic or conceptual processing of information” (Lang, 1984). Three search engines were used, PsychInfo, Web of Science and Scopus, to identify research into cognitive factors associated to positive adjustment. Those papers that did not report a theoretical model were excluded from the search. Data extraction and quality analysis were completed in a systematic way using predetermined guidance (CRD, 2009; Wong, Cheung & Hart, 2008; Popay et al., 2006).

Results: A total of 20 papers covering 9 theoretical models were reviewed. Dependent variables included depression, anxiety, quality of life, posttraumatic growth and perceived stress. Only 13 papers were awarded an A grading in quality analysis and methodological limitations were reported. Factors identified as protective in post stroke adjustment included higher internal locus of control, satisfaction with treatment and finding meaning. In contrast the factors associated with poorer adjustment included a negative view of the self or world and appraisals of threat. Time and gender

were identified as important factors influencing the relationship between cognitive process and adjustment outcome.

Conclusions: The quality and quantity of research was limited. The reviewed papers highlighted the complex and dynamic nature of psychological adjustment post stroke and conceptually provides support for models that view adjustment in this way, for example the Social Cognitive Transition Model for Stroke (SCoTs, Taylor, Todman & Broomfield, 2011).

Introduction

A stroke strikes fast, often without warning and may result in a multitude of acquired impairments, including those of an emotional, cognitive and physical nature. People often require support with their activities of daily living, for either a short period or indefinitely, placing significant strains on, and sometimes resulting in the breakdown of, relationships and employment. As the single largest cause of adult disability in the UK it is important to appreciate the consequences a stroke can have on people (National Audit Office, 2005; 2010: NHS Improvement, 2011). It is understandable, therefore, that the psychological impact of a stroke is a significant area of research and clinical interest.

Meta-analyses have reported rates of depression in the early, middle and later stages after a stroke to be 33% (Hackett et al., 2005) and rates of anxiety ranged between 20% and 24% from one to six months post stroke (Campbell-Burton, Murray, Holmes, Astin, Greenwood & Knapp, 2012). These point prevalence rates are from

pooled data and there is variation dependent on the assessment method used. For example, in the recent meta-analysis by Campbell-Burton et al. (2012), the overall rates of anxiety classified by clinical interview and the Hospital Anxiety and Depression Scale (HADS: Zigmond & Snaith, 1983) were 18% and 25% respectively. Post-traumatic stress symptom rates have been reported to range from 10% to 31% (Bruggiman et al., 2006; Merriman, Norman, & Barton, 2007; Sembi, Tarrier, O'Neill, Burns & Faragher, 1998) and there have been investigations into constructs such as quality of life (Donnellan, Hickey, Hevey & O'Neill, 2010), self esteem (Vickery et al. 2008), coping (Donnellan et al. 2006) and adjustment (Salter, Helings, Foley & Teasell, 2008). The understanding of the emotional sequelae following a stroke is important in rehabilitation settings as the presence of depressive symptoms can impact on functional outcome (Donnellan et al., 2010).

From the reported prevalence rates above it is clear some people experience significant emotional difficulty after stroke, and that this can have a substantial impact on their life and rehabilitation. Research has investigated why some people adapt and adjust without significant emotional problems whereas others do not. In an attempt to understand this researchers have asked for stroke survivors' experiential accounts. Salter et al. (2008) provided a meta-synthesis of qualitative research focussing on the experience of stroke patients and identified the following common themes: transition and transformation, loss, uncertainty, social isolation, adaption and reconciliation. Psychological models have been used to help understand the process of adjustment and emotional reactions post stroke. Research has focussed on models such as grief (Wade, 1985), coping (Lazarus & Folkman, 1984) and social-cognition (Taylor et al., 2011).

Brennan (2001) defined adjustment as “the processes of adaptation that occur over time as the individual manages, learns from and accommodates the multitude of changes which have been precipitated by changed circumstances in their lives” (p. 2). This definition reflects the fluid dynamic process of adjustment, changing over time, rather than it being something that has either happened or not. This definition also provides the importance of social context, which is lacking from previous process definitions. For example that “adjustment consists of the psychological processes by means of which the individual manages or copes with various demands or pressures” (Lazarus, 1969, p.18). This latter quote helps to conceptualise adjustment and coping together. Coping is a way in which people adjust and this may include behavioural and cognitive methods. Within the present review adjustment and coping will be used to describe how people manage after a stroke.

Coping has been a major area of research in the field of health psychology, with Lazarus and Folkman’s (1984) theory being widely accepted. Their Transactional Theory of Stress and Coping suggests people evaluate stressors for their level of threat as well as how well resourced they feel to cope with the stressor (primary & secondary appraisal respectively). This model has been applied to stroke care (Lyon, 2002). Models of coping and adjustment are useful for health care professionals in conceptualising and understanding the experience of stroke patients.

Taylor et al. (2011) recently adapted the Social Cognitive Transition Model for use in Stroke (SCoTS, see Figure 1). This model had been previously used to understand adjustment to cancer (Brennan, 2001). The SCoTS model integrates coping theory and traumatic stress, as applied to illness, to provide a dynamic process model.

This is in contrast to more static models, for example Wade’s four stage grief model (1985). SCoTs is based on an “assumptive world” where individuals have a cognitive map that includes a set of assumptions which are either confirmed or disconfirmed by experience. If assumptions are disconfirmed then a period of high stress is experienced until the map is re-moulded. A stroke is likely to disconfirm assumptions and subsequently distress is an expected reaction (Taylor et al., 2011). The impact of cognitive deficits, the ability to be self-aware, beliefs about illness and stroke, as well as relationships and social functioning are also integrated and considered important within this model.

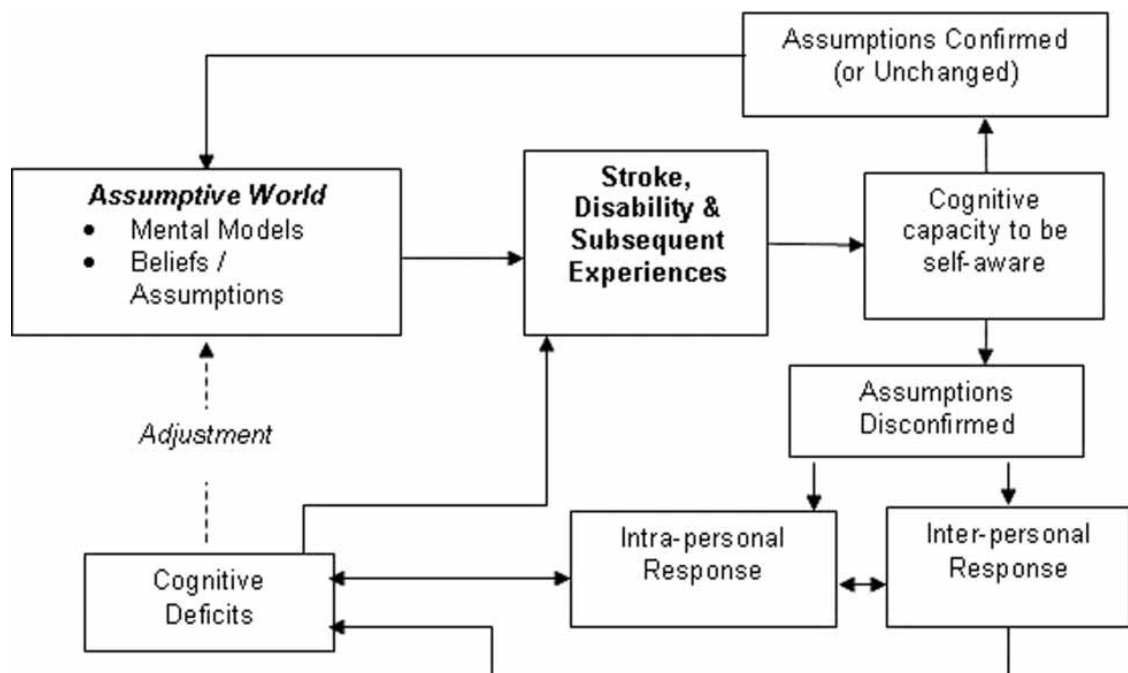


Figure 1: Directly taken from Taylor et al., 2001, pg., 812. The SCoTs model of adjustment post stroke displays the role of cognitive processes, inter and intra personal experiences and cognitive deficits experienced post stroke.

Independent and dependent variables measured within the adjustment literature differ depending on the theoretical background being applied. For example Donnellan

et al. (2006) reported a number of studies based on the Transactional Theory of Stress and Coping (Lazarus & Folkman, 1984), where the association between coping styles (independent variable) and rates of depression and anxiety (dependent variable) were reported. Brennan (2001), however, has highlighted the importance of adjustment being conceptualised as more than coping and/or the return to a normal score on measures of depression and anxiety. Donnellan's (2006) review is the most recent, known, report of a similar nature to the present study post stroke. It focussed, however, on coping alone and thus excluded studies measuring other constructs such as self-esteem, posttraumatic stress and growth. With this in mind the current review aims to build on the work of Donnellan and colleagues (2006) and take a wider inclusion of theoretical frameworks and subsequently dependent and independent variables.

The present review focussed on the cognitive and internal processes/factors, including coping, that have been found to affect the way in which people adjust. Cognitive factors are defined as thought processes, constructs and states of mind, for example; appraisal, confidence, self-esteem and causal attributions. Other previous reviews have focussed on causal attributions and appraisal in coping with a range of health conditions (Roesch & Weiner, 2001), but not stroke specifically. Stroke specific reviews focussing on the impact of lesion location on post stroke depression have reached equivocal results (Bhagal, Teasell, Foley & Speechley, 2004). A previous study has investigated the predictors of depression post stroke (Hackett & Anderson, 2005), however they only focussed on depression as an outcome measure. The current review focussed on what models are being used to understand the cognitive processes of adjustment post stroke and makes links to the SCoTs (Taylor et al., 2011) model in the discussion.

Method

The current review followed the stages recommended by the Centre for Reviews and Dissemination (CRD, 2009). These stages included: the use of specific search terms, inclusion and exclusion criteria, data extraction, assessing quality and synthesis of results.

For clarity the following operational definitions were used for the key terms in the review question:

- Psychological adjustment – “the processes of adaptation that occur over time as the individual manages, learns from and accommodates the multitude of changes which have been precipitated by changed circumstances in their lives” (Brennan, 2001, p. 2).
- Cognitive processes – “the symbolic or conceptual processing of information” (Lang 1984), for example attribution, appraisal, confidence and self-esteem.

The following search terms were entered into three search engines (PsychInfo, Web of Science, and Scopus)

- psychological adjustment OR emotional adjustment OR coping OR acceptance OR loss OR grief, Post Traumatic Stress Disorder OR posttraumatic growth OR self-esteem OR illness representation OR control.
- AND stroke OR Cerebrovascular Accident (CVA)
- AND Quality of life OR anxiety\$ OR depression\$ OR emotion\$ OR mood\$ OR locus of control OR stress OR worry OR psychosocial wellbeing OR

cognition OR appraisal OR thought OR self confidence OR self esteem OR self efficacy OR belief OR attitude.

Inclusion criteria were:

- Population – Stroke/CVA– those studies with mixed aetiology were excluded. Samples that included carers in addition to patients were included but only if the patient data were analysed separately from that of the carers'. Participants had to have sufficient language and cognitive function to be able to report on cognitive/thought processes described below.
- Intervention – investigation into thought processes, cognitions (for example self -esteem or confidence) associated with adjustment and based on adjustment or coping theory which is made explicit in the paper.
- Comparators – the influence of different cognitive factors on adjustment post stroke, for example appraisals and perceived control on depression or anxiety scores.
- Outcomes – questionnaire or other quantitative measure of quality of life, depression, anxiety, self-efficacy, any measure or description of mood, well being etc.
- Study design – quantitative observational (longitudinal, cross-sectional, retrospective and prospective). Use of statistical analysis that can infer associations and predictions, for example correlations, regression and structural equation modelling.

Exclusion criteria were:

- Non peer review journal

- Not in English language
- Publication before year 2000, to ensure the most recent literature was focussed on and reduce replication from Donnellan et al. (2006) review.
- Participants under the age of 18 years old.

In addition reference lists were hand searched for relevant citations.

Quality assessment and data extraction

Quality assessment of research is essential to a systematic literature review. However, in many reviews of observational studies quality assessments have not always been completed (Mallen, Peat & Croft, 2006). Tools have been developed for use when reviewing Randomised Controlled Trials (RCTs; CONSORT) and diagnostic tests (STARD), but those for observational studies are less well known. The CRD (2009) provide criteria to be used within a quality assessment, including design, risk of bias, choice of outcome measure, statistical issues, quality of reporting and generalisability, but this is not in a checklist format. The QATSO (Wong, Cheung & Hart, 2008) was developed as an assessment checklist for observational studies, where the study could be categorised as either bad, satisfactory or good. The QATSO structure was adapted alongside the CRD criteria in the present review (Appendix A). In addition a data extraction form was used to summarise the key areas of the research.

Synthesis

Due to the nature of the review and heterogeneity of included studies meta-analysis was not possible. Therefore, a narrative synthesis approach was used with guidance from methods described by Popay et al. (2006). The results are structured in

order to answer the two parts of the review question; what models of adjustment and coping are being used in the literature and what psychological factors have been found to be protective for adjustment? Additional conceptually related issues are also presented, for example time post stroke and outcome measures used. The results of the quality analysis are presented and studies categorised as high, moderate or low quality (A, B, and C respectively). These categories are then referred to when making inferences later on.

Results

The results of each search and exclusion of papers is displayed in Table 1. A total of 18 articles were identified from search engines and a further 2 articles were found from searching reference lists, making a total of 20 articles to review. Information regarding design, sample size and variables measured is found in Appendix B.

Study designs

Of the twenty studies, thirteen were longitudinal and seven cross sectional. Three of the cross sectional studies investigated participants between 5 and 14 days post stroke (Giaquinto, Spiridigliozzi & Caracciolo, 2007; Gillen, 2006; Vickery, Sepehri, Evans & Lee, 2008) and four investigated samples between 4 months and 15 years post stroke (Gangstad, Norman & Barton, 2009; Johnstone, Franklin, Yoon, Burris & Shigaki, 2008; Nogueira & Teixeira, 2012; Smout, Koudstaal, Ribbers, Janseen & Passchier, 2001). Longitudinal studies used either post discharge or post stroke time points for follow ups. Those using post discharge follow ups ranged between 2 weeks and 2 years (Darlington et al., 2007; Darlington et al., 2009; King et al., 2002; Otswald et al., 2009; Rochette & Desrosiers, 2002; Rochette, Bravo, Desrosiers, St-Cry/Tribble & Bourget, 2007) and those using post stroke time points ranged between 10 days and 3 years post stroke (Donnellan et al., 2012; Morrison, Johnstone, & Walter, 2000; Morrison, Pollard, Johnstone & McWalter, 2005; Townend, Tinson, Kwan & Sharpe, 2010; Twiddy, House & Jones, 2012). One study recruited participants after 3 days on a rehabilitation ward and completed follow ups twice weekly until hospital discharge (Vickery, Evans, Sepheri, Jabeen & Gayden,

2009) and another whilst participants were in hospital and then 3 months later (Field, Norman & Barton, 2008).

Country of study

Six studies were carried out in the UK and six in the United States of America. Of the remaining studies one was conducted in Ireland, two in Canada, three in the Netherlands, one in Italy and one in Brazil. Only two models were studied in more than one country. The Transactional Theory of Stress and Coping (Lazarus & Folkman, 1984) was studied in Canada, America, Netherlands and the Religious/Spiritual Coping model (Pargament, 1999) was studied in Italy and America. Studies using the Dual Process Assimilation and Adaptation Model (Brandsadter & Renner, 1990) were completed in the Netherlands only and studies using a Self Esteem model (Oosterwegel, Field, Hart & Anderson., 2001) were only completed in America. Of those studies conducted in the UK two used a Post Traumatic Stress Disorder (PTSD; Ehlers & Clark, 2000) or Posttraumatic Growth model (Calhoun, Cann, Tedeschi & McMillan, 2000), three used a Common Sense Self Regulation model (Leventhal, Nerenz & Steele, 1984), and one an Adjustment to Misfortune theory (Dembo, Levinton & Wright, 1956).

Outcome measures

Adjustment was mainly measured using depression, anxiety and quality of life outcome scales. Depression scales included the Beck's Depression Inventory (BDI, Beck, Ward, Mendelson, Mock, & Erbraugh, 1961), the Centre for Epidemiological Studies – Depression Scale (CES-D, Radloff, 1977), Structured Clinical Interview for DSM Disorders - Depression (SCID) and the Geriatric Depression Scale (GDS;

Yesavage et al., 1983) as well as the combined assessment of depression and anxiety using the Hospital Anxiety and Depression Scale (HADS, Zigmond & Snaith, 1983). Quality of life measures used included the Stroke Specific Quality of Life (SSQOL; Williams et al., 2006). One study used a measure of posttraumatic growth (Gangstad et al., 2009) and one study used a diagnostic measure for PTSD (Field et al., 2008) as an outcome.

Table 1

A Display of the Search Process and Exclusion of Studies

Database	Reason for exclusion		Number excluded	Running total
Psychinfo (with limiter of 2000-2012, and peer reviewed journal)				49
	Population	Non stroke	9	40
		Carers only	5	35
	Intervention & comparators	Non psychological factor measured	14	21
	Outcomes	Non Quantitative	5	16
	Study Design	Non Observational	11	5
		No statistical analysis	0	5
	Exclusion criteria	Not in English	0	5
Participants < 18 years old		0	5	
Total selected to review				5
Web of Science				51
	Population	Non stroke	0	51
		Carers only	14	37
	Intervention & comparators	Non psychological factor measured	12	25
	Outcomes	Non Quantitative	6	19
	Study Design	Non Observational	10	11
		No statistical analysis	0	11
	Exclusion criteria	Not in English	0	11
		Participants < 18 years old	0	11
		Duplicate from previous search	2	9
Total selected to review				9
Scopus				108
	Population	Non stroke	15	93
		Carers only	20	73
	Intervention & comparators	Non psychological factor measured	18	55
	Outcomes	Non Quantitative	15	40
	Study Design	Non Observational	31	9
		No statistical analysis	0	9
	Exclusion criteria	Not in English	0	9
		Participants < 18 years old	0	9
		Duplicate from previous search	5	4
Total selected to review				4
Papers found in reference lists				2
Total papers to review				20

Table 1: Showing the results of database searches and exclusion of non-relevant papers.

Quality Assessment

See Table 2 below for a summary of the QATSO results. Studies were given a score of 1 if the criteria had been fulfilled and 0 if not. Studies were categorised into high (A), medium (B) and low (C) quality depending on their percentage score (A = 67-100%, B= 33-66%, C=0-33%). Thirteen studies were graded A and seven grade B. The criteria fulfilled ranged from 3/8 (Johnstone et al., 2008) to 8/8 items (Gangstad et al., 2009; Vickery et al., 2009). All studies excluded people who had cognitive or language impairment which was either measured by tools such as the Frenchay Aphasia Screening Test (FAST), Mini Mental State Examination (MMSE) or through the use of clinical judgement. The sampling methods varied, the majority of studies employed a systematic method, for example inviting patients who were consecutively admitted to hospital. Convenience sampling was the most common non-systematic sampling method. Sample sizes ranged from 8 to 159 participants and some studies also recruited spouses and/or carers (Otswald et al., 2009; Twiddy et al., 2012) alongside stroke survivors. Johnstone et al. (2008) was the only one not to report the details of type of stroke. Recruitment response rate ranged between 21-97%, but 12 studies did not report it. Procedure and stroke sample were well described in all but one study (Johnstone et al., 2008). The majority of studies referred to, and if appropriate within their analysis, controlled for potential confounding variables. Only four studies (Field et al., 2008; Gangstad et al., 2009; Rochette & Desrosiers, 2002; Vickery et al., 2009) reported adequate statistical power. Other studies either did not report statistical power or did not have adequate power. Only thirteen studies reported the psychometric properties of measures used.

The grade obtained on quality assessment is referenced when discussing the studies below, for example Rochette & Desrosiers, 2002, A.

Models of coping and adjustment used

Nine articles investigated the impact of coping appraisals on emotional well being. Five studies referred to Lazarus and Folkman's (1984) Transactional Theory of Stress and Coping model (Gillen., 2006, A; Nogueira & Teixeira , 2012, B Rochette & Desrosiers, 2002, A; Rochette et al., 2007, A). Three papers (Darlington et al. 2007, A, & 2009, A; Smout et al., 2001, B;) used the Dual process model of Assimilation and Adaptation by Brandsadter & Renner (1990), and one (King et al., 2002, A) the Crisis in Physical Health model by Moos and Tsu (1977).

Of the remaining nine articles adjustment theories and conceptualisations included: models of Self Esteem by Oostergegel et al., (2001; Vickery et al., 2008, B; Vickery et al., 2009, A), cognitive models of PTSD and Posttraumatic Growth (Field et al., 2008, A; Gangstad et al., 2009, A), Illness Representation and Control (Morrison et al., 2000, A; Morrison et al., 2005, B; Twiddy et al., 2012, A), Acceptance of Illness (Townend et al., 2010, A) and Successful Aging (Donnellan et al., 2012, A). Two studies investigated a religious/spiritual coping model (Pargament, 1999) (Johnstone et al., 2008, B; Giaquinto et al., 2007, B).

Table 2: Summary of Quality Assessment Outcomes

CRD criteria	Risk of Bias	Generalisability	Quality of reporting		Statistical Considerations		Outcome measures	Ethics	
QATSO question	Was the sampling method systematic?	Did the study report a response rate?	Is the procedure described to the standard that it could be replicated?	Are the main characteristics of the sample described?	Did the investigators control for confounding factors?	Was the study powered?	Were reliability and validity of the measures used reported?	Was ethical approval noted?	Overall quality of study: %age A=High, B=Moderate, C=Poor)
Authors									
Rochette & Desrosiers, (2002)	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	7/8 =87.5% A
Rochette et al., (2007)	Yes	No	Yes	Yes	Yes	No	Yes	Yes	6/8=75% A
Gillen., (2006)	Yes	No	Yes	Yes	Yes	No	Yes	Yes	6/8=75% A
Smout et al. (2001)	No	Yes	Yes	Yes	No	No	No	Yes	4/8=50% B
Darlington et al. (2007)	Yes	Yes	Yes	Yes	Yes	No	No	Yes	6/8=75% A
Darlington (2009)	Yes	Yes	Yes	Yes	Yes	No	No	Yes	6/8=75% A

King et al. (2002)	Yes	Yes	Yes	Yes	Yes	No	Yes	No	6/8=75% A
Otswald et al. (2009)	Yes	No	Yes	Yes	Yes	No	Yes	No	5/8=62.5% B
Nogueira & Teixeira , (2012)	Yes	No	Yes	Yes	No	No	No	Yes	4/8=50% B
Johnstone et al.(2008)	No	No	Yes	No	No	No	Yes	Yes	3/8=37.5% B
Giaquinto, et al. (2007)	Yes	Yes	Yes	Yes	No	No	No	No	4/8=50% B
Vickery et al. (2008)	No	No	Yes	Yes	Yes	No	Yes	Yes	5/8=62.5% B
Vickery et al. (2009)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	8/8=100% A
Field et al. (2008)	Yes	No	Yes	Yes	No	Yes	Yes	Yes	6/8=75% A
Gangstad et al. (2009)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	8/8=100% A
Twiddy, et al. (2012)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	7/8=87.5% A
Morrison et al. (2000)	Yes	Yes	Yes	Yes	Yes	No	Yes	No	6/8=75% A
Morrison et al. (2005)	Yes	No	Yes	Yes	Yes	No	No	No	4/8=50% B

Townend et al. (2010)	Yes.	Yes	Yes	Yes	Yes	No	No	Yes	6/8=75% A
Donnellan et al. (2012)	Yes	No	Yes	Yes	Yes	No	Yes	Yes	6/8=75% A

Table 2: *Studies were scored 1 for criteria being fulfilled and 0 for not. Percentage scores then determined quality of the study, High (67-100%), Moderate (33-66%) and Low (0-33%).

Psychological factors found to be associated to adjustment

The results were considered as either: internal cognitive processes, coping, appraisal, control, self esteem, acceptance and goal adjustment, or as an interaction of cognitive processes with non-cognitive and external factors, such as spousal relationships, personality style, and gender. Table 3 provides a summary of such findings.

One study, Donnellan et al., (2012), did not provide any evidence for factors which were seen as protective nor highlighted vulnerability to poorer adjustment, and so is not represented in Table 3. They reported the characteristics of Selection, Optimisation and Compensation (SOC) to be present in a sample of post stroke patients but they were not predictive of QOL, or depression at 1 year post stroke. This study suggested further research using the Successful Aging model (Baltes & Baltes, 1990) to better understand how it could be applied following stroke.

Table 3: Summary of Factors Associated with Psychological Adjustment

Study	Quality of study	Model	Protective Factor	Vulnerability Factor	Interaction with non-cognitive/external factors
Rochette & Desrosiers, (2002)	A	Transactional Theory Stress, Appraisal and Coping (Lazarus and Folkman, 1984).		Magical thinking and escape avoidance.	Positive reappraisal was negatively associated to 'handicap' level. Women used more coping strategies and more magical thinking. Actualisation potential was associated to positive coping methods.
Rochette et al., (2007)	A		Primary appraisal of challenge Secondary appraisal as controlled by others or self.	Primary appraisals of threat and centrality Secondary appraisal of uncontrollability.	
Gillen (2006)	A		Self-efficacy, active coping and positive reframing.	Venting, self blame and denial.	
Smout et al. (2001)	B	Dual Process Model (Brandsadter & Renner, 1990)	Flexible Goal Adjustment (FGA), which meant they had adapted their life and goals. Accommodative	Striving to keep life as it was before /Tenacious Goal Pursuit (TGP).	MMSE positively correlated to FGA. Physical ability predictive of QOL at 1 week pre discharge.

			coping.		
Darlington et al. (2007)	A		Flexible Goal Adjustment (FGA)		Time – coping style was not a predictor of QOL at 1 week or 2 months, but was at 5 and 9-12 months. Neuroticism was negatively associated to FGA
Darlington et al. (2009) <i>*Same sample as Darlington et al. (2007)</i>	A		At 9-12 months: Flexible Goal Adjustment (FGA) and Tenacious Goal Pursuit (TGP, not significant)		
King et al. (2002)	A	Crisis in Physical Health (Moos & Tsu, 1977)	Finding meaning coping and positive perception of physical recovery	Avoidance coping	Age, availability of support, objective burden, family function, belonging and satisfaction with support
Otswald et al. (2009)	B	Transactional of Stress and Coping (Lazarus & Folkman, 1984) & McCubbin & McCubbin, 1987 T-Double ABCX model of adjustment & adaptation	Self reported stroke recovery		Higher mutuality scores (between stroke survivor and spousal caregiver) predictor of less stress.

Nogueira & Teixeira , (2012)	B	Stress, Appraisal and Coping (Lazarus and Folkman, 1984).			Women were found to report “searching for religious practise and wishful thinking” significantly more than men. Women reported significantly more association between their emotion and their pain and were more likely to attribute their pain to internal factors, and men external.
Johnstone et al.(2008)		Religious/Spiritual Coping (Pargament, 1999).	BMMRS religious and spiritual coping. Those who had a stroke reported significantly more religious support than the healthy control group.		
Giaquinto et al.,(2007)			For each unit increase in Royal Free Interview score there was a 5% decrease in HADS score		
Vickery et al. (2008)	B	Self Esteem (Oosterwegel et al. 2001)	Self esteem		
Vickery et al. (2009)	A		Self esteem		Higher self-esteem was associated with younger age, higher education, male gender, right hemisphere stroke and no

					previous stroke history. Higher self-esteem stability was associated to older age, in contrast, but also with higher education.
Field, Norman and Barton (2008).	A	Cognitive Model of PTSD (Ehlers and Clark, 2000)		Self and world negative cognitions.	
Gangstad et al., (2009)	A	Posttraumatic Growth (Calhoun et al., 2000)	Posttraumatic Growth, denial, education, positive cognitive restructuring and downward comparison.		Time since stroke moderated the relationships between anxiety-PTGI, depression-PTGI, but these were not significant, however statistical power was low.
Twiddy et al.,(2012)	A	Common Sense - Self Regulation Model (Leventhal, Nerenz & Steele, 1984)		Low illness coherence, perception of psychological factors as cause, stronger illness identity, perceived more negative consequences	Patients were more likely to be distressed when carers reported low levels of emotional support. When carers were less distressed at time 1 this was predictive of higher patient distress at time 2.
Morrison, Johnston & Walter (2000)	A		Internal recovery Locus Of Control, higher recovery confidence, higher satisfaction with	Lower internality of control.	

			treatment and advice.		
Morrison et al. (2005 – <i>extension of study above</i>)	B			Previous anxiety predicted higher anxiety at 3 years	Female gender at 3 years predicted anxiety.
Townend et al. (2010)	A	Adjustment to misfortune theory (Dembo et al., 1956)		Non-acceptance on the Acceptance of Illness Questionnaire and attributing psychological causes of stroke	Depression at nine months was also predictive of acceptance of illness at one month

Table 3: Summarises key findings regarding factors of a protective and vulnerability nature, as well as when interaction with non-cognitive process. BMMRS =Brief Multidimensional Measure of Religion and Spirituality (Fetzer Institute and National Institute on Aging Working Group, 1999). PTGI=Post Traumatic Growth Inventory (Tedeschi & Calhoun, 1996). MMSE = Mini Mental State Examination.

Discussion:

Twenty papers provided a summary of the recent evidence investigating adjustment and/or coping post stroke, with reference to specific models. Multiple theoretical models were cited and a diverse range of constructs measured as numerous independent and dependent variables were used. The following discussion focusses on the models and subsequent factors identified as protective, or not, in the psychological adjustment process. The results of the present review are discussed in relation to the Social Cognitive Transition model of post stroke adjustment (Taylor et al., 2011) and attention is then turned to the role of time post stroke. The clinical implications and limitations of the present review are also presented.

Models of adjustment and quality of the evidence

A total of nine models were referred to, the majority of which were concerned with how the individual viewed and understood the consequences of a stroke. The most commonly referred to model was Lazarus and Folkman's (1984) Transactional Theory of Stress and Coping (1984) and this is consistent with the results of similar reviews (Donnellan, et al. 2006; Dennison, Moss-Morris & Chalder, 2009). Only the religious and spiritual coping (Pargament, 1999) model did not have any high quality evidence (A) to support its role in adjustment (Johnstone et al., 2008; Giaquinto et al., 2007). All other models had at least one study of high quality (A). The number of studies per model, however, was not equal and the models were rarely researched in more than one country. For example the Dual Process model (Brandsadter & Renner, 1990) and studies on self-esteem were only completed in the Netherlands (Smout et al., 2001; Darlington et al. 2007 & 2009) and America respectively (Vickery et al.,

2008 & 2009). The Transactional Theory of Stress and Coping (Lazarus & Folkman, 1984), however, was studied in Canada, America and the Netherlands.

It could be argued that the Transactional Theory of Stress and Coping (Lazarus & Folkman, 1984) has the most robust evidence to support its use, however there is not enough evidence available to adequately conclude that it is the most effective model to use. Rather than teasing out the “best model” the consolidation of key findings and results allows for some insight into the inevitable complexity of the adjustment process. How these models can be used alongside each other is perhaps a better way to conceptualise the literature. The Social Cognitive Transition Model for Stroke (SCoTs, Taylor et al., 2011) draws on both coping and trauma models, and appears to conceptualise adjustment in a more eclectic manner. Although none of the studies refer directly to SCoTs, which may be because it has only recently been published, many of the factors reported can be understood within this model. For example locus of control, self-esteem, posttraumatic growth, self-blame and negative cognitions can be viewed within the cognitive assumptions and intra-personal response section seen in Figure 1.

What factors help people to adjust?

Cognitive factors associated with higher scores on measures of Quality of Life, Posttraumatic growth or lower scores on measures of anxiety and depression were collated and presented in Table 3. The highest quality evidence supported the protective nature of internal locus of control, and a secondary appraisal that recovery is controlled by self or others. These results are consistent with a meta-analysis of attribution style toward illness where controllable attributions were associated with more positive adjustment (Roesch & Weiner, 2001). Satisfaction with treatment, confidence about recovery and finding meaning were also associated with better mood

post stroke. Although all these factors were supported by high quality studies (A) none were reported more than twice. In contrast, the importance of Flexible Goal Adjustment (FGA), adapting life and being flexible as a way of coping to changes following a stroke were reported in three studies, but only two were of high (A) quality. This was replicated for self-esteem, which was seen as important, but only one A grade study and one of a B standard were identified. The role of religious and spiritual beliefs as a protective factor was also not supported by grade A studies, only two grade B. The impact of religion on coping and adjustment, however, has a large evidence base and the results of studies from this review support previous research in non-stroke samples (Ross, Handal, Clark, & Vander Wal., 2009).

Denial, education, positive cognitive restructuring and downward comparison were negatively correlated with scores on a posttraumatic diagnostic scale (Gangstad et al., 2009, A), suggesting that they are protective factors. Denial and other avoidant coping strategies, such as magical thinking and escape avoidance were found to be factors of vulnerability for poorer adjustment, in high quality studies (Gillen. 2006; King et al., 2002). The concept of denial, therefore is not a straightforward negative way to cope and it may be that sometimes it is appropriate or part of the expected process. This is explained by the SCoTs model where short term denial and avoidance is said to allow the intensity of the experience to be weakened and subsequently reducing distress. Denial has been described as a way to regulate the exposure to the processing of traumatic information (Taylor et al., 2011). The concept that there is no 'right' or 'wrong' way to process information in adjustment can help us to understand why for some people denial is a vulnerability factor and for others it is a protective factor. Tenacious Goal Pursuit (TGP) was found to have both vulnerability and protective factors. For some people to see that their life will not change because of a

stroke (thought process associated to TGP) may be important, and achievable, however for others the viewpoint that they need to adapt and be flexible is associated more with positive mood. From the three studies reviewed into TGP and FGA, FGA does seem to be the most adaptive way to view post stroke goals.

Other factors associated with lower mood and poorer adjustment included: a negative view of ones' self or world, appraisals of threat, centrality and that the situation is not controllable. The evidence was of high quality but rarely investigated by more than one study. These factors can be understood within the challenged cognitive "assumptive" world described by the SCoTs model.

Interaction with non-cognitive and external factors

Although not the primary focus of the present review some studies reported results on the interaction between internal cognitive processes and external factors. The effect of gender was mentioned in a number of studies with women reporting more coping strategies, but not always helpful ones (Rochette & Desrosiers, 2002). Men were found to be significantly more likely to use a FGA approach than women (Darlington et al., 2007) and women reported associating more emotion to their post stroke pain. This supports previous gender differences found in the coping and pain literature (Unruh et al., 1999; Fillingim et al., 2009).

Many of the studies reviewed investigated the moderation of interpersonal factors on how internal factors can affect someone's adjustment. Interpersonal factors included: relationship mutuality (relationship between carer and stroke patient), family and social support, and discrepancy between patient and carer illness representation (King et al., 2002; Otswald, 2009; Twiddy et al., 2012). This evidence makes it clear, that although thought process is important it is also vital to consider the external world

and social systems for the individual. This is consistent with the SCoTs (Taylor et al., 2011) model of adjustment as it includes interactions with carers, family and social network.

Time

There are a number of ways in which time can be seen as instrumental in understanding adjustment. In the present review, samples varied from 5 days to 15 years post stroke or discharge. Longitudinal studies provided interesting results about cognitive processes and their impact on mood over time. The only study reviewed into posttraumatic growth reported time since stroke to moderate the relationships between anxiety-Post Traumatic Growth Index (PTGI) and depression-PTGI, but these were not significant. The relationship between resolution-PTGI was significant when time since stroke was moderate or high (Gangstad et al., 2009). Other constructs which were shown to interact with time included: appraisals (Rochette et al., 2007), locus of control (Morrison et al., 2000; 2005) acceptance of illness, (Townend, et al., 2010) Tenacious Goal Pursuit (TGP), FGA coping (Smout et al., 2001; Darlington et al., 2007) and carers' level of distress (Twiddy et al., 2012). Future research should utilise a longitudinal design when addressing adjustment, in order to take into account the interaction with time.

Clinical implications

Looking at the variety of models used and the quality of evidence reviewed it is not possible to suggest one definitive model for clinical use. The results of the present review, however, provide support for a multidimensional model. Assessment of adjustment should include consideration of protective and vulnerability factors. For example, how in control someone feels about their recovery, what coping strategies

they use and what meaning they have derived from their experience. In addition contextual factors such as relationships, carers' understanding of stroke and time post stroke should also be considered. The presence of denial needs to be considered in context, as it can be conceptualised as both a protective and vulnerability factor. The Social Cognitive Transition Model for Stroke (SCoTS; Taylor et al., 2011) provides a framework for a multidimensional assessment and formulation.

Methodological limitations

As discussed previously thirteen studies were awarded grade A in quality. It is important to recognise that these papers still had methodological limitations, which future research should take into consideration. Methodological issues included the range of outcome variables measured, exclusion of people with language and/or cognitive impairment, use of mixed patient and carer samples, cross sectional design and extrapolation of results across cultures.

Outcome variables

Adjustment was measured by scores on depression, anxiety, Quality of Life, PTSD and posttraumatic growth scales. Psychological adjustment has been described as more than the omission of depression (Brennan, 2001) and so by providing a summary of a wider range of constructs this review has added to the literature. Despite this the psychometric properties of measures were inadequately reported and reliability and validity of the results needs to be considered. In addition, the use of multiple independent variables (e.g. self-esteem, coping, health perception) and dependent variables (e.g. anxiety, depression, PTSD symptoms and QOL) makes it difficult to pool data and complete a high quality meta-analysis. These issues have been reported in previous reviews of the coping literature in stroke (Donellan et al., 2006). This also

highlights a key issue within the adjustment literature that there is no current widely used psychometric measure of adjustment for stroke, although attempts to develop one are currently underway in Glasgow (Taylor et al., 2011).

Cognitive and language impairment

People with cognitive and language impairment were excluded in the reviewed studies. Given the abstract nature of the internal processes investigated it is probable that different models are best suited to understand people with language and/or cognitive impairment, for example a behavioural perspective (Thomas et al., 2012). The results of the present review, therefore, may not be generalised to all stroke patients.

Mixed patient and carer/spouse sample

A number of studies recruited a combined patient and carer/spouse sample. Although this aided understanding about how these factors interact, it meant that recruitment was biased to those people with a spouse/carers. Although it was not a main focus of the present review it is important to be aware of the interaction between spouse and patient emotional well being and this could be an area of investigation in its own right.

Study design

A total of seven papers were cross-sectional in design and as the role of time appears to be a significant factor post stroke, the inferences made from these studies are limited. A longitudinal design allows for the dynamic nature of adjustment to be understood and therefore is a preferred design for future research.

Country of study

The country of study and the absence of many models being used in more than one country, is a significant issue to consider when interpreting the results of the present review. This has implications for making inferences from the literature. For example, the research into religion and coping was completed in Italy and Brazil and so cross-cultural application should be conducted with caution.

Limitations of the review

It is a clear limitation of the present review that only quantitative data have been studied. Qualitative research has used focus groups and interview to understand what helps people adjust post stroke, for example Ch'ng et al., (2008) provided a model of adjustment including uncertainty, anger, loss, acceptance and positive reinterpretation alongside social and psychological support. It is important not to neglect this area of research when reviewing only quantitative studies. The present review focussed on the cognitive, internal processes of the stroke patient and therefore was unable to provide a full summary of the evidence for external factors or cognitive and physical impairment. The impact of the patients' wider system (family, relationships, environment) should be considered further.

Conclusions

In conclusion, the quantitative literature on adjustment post stroke is limited in quality and quantity. Due to the methodology employed and models used, a variety of variables have been measured and shown to potentially have an impact on the way in which someone manages emotionally post stroke. This variation supports the inherent complexity and individual nature of psychological adjustment, yet also means it is

difficult to compare research. The possibility of using meta-analysis, even on the most frequently studied concept of appraisal, is thwarted by the variation in outcome measures. Therefore, the collated evidence reviewed has been used to support a recently suggested stroke specific model of adjustment, the SCoTs (Taylor et al., 2011). This helps to provide guidance to clinicians working with people who have experienced a stroke. The research and evidence base can most definitely be improved through more rigorous methodology and more widespread investigation into these concepts.

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The Validity of the Distress Thermometer and Problem List in the Early Stages of Stroke Care.

Abstract

Aims: The present study investigated the validity of using the Distress Thermometer (DT) and stroke specific Problem List in a sample of post stroke patients. The internal consistency and structure of the Problem List was assessed as well as the rates of distress and problems experienced.

Method: A total of 48 stroke patients, on either acute or stroke rehabilitation units, completed the DT, Problem List, Hospital Anxiety and Depression Scale (HADS, Zigmond & Snaith, 1983), Brief Assessment Schedule Depression Cards (BASDEC; Ashead *et al*, 1992) and the Visual Analogue Mood Scale Revised (Kontou *et al.*, 2012) at one time point.

Results: Spearman's rho correlations were positive and significant between DT, HADS total ($r=.52$), HADS anxiety ($r=.54$), HADS depression ($r=.41$), VAMS-R ($r=.61$), BASDEC ($r=.57$) and Problem List ($r=.61$). Receiver Operating Characteristic (ROC) curves and Area Under the Curve (AUC) analysis found the DT and Problem List, respectively, to significantly differentiate between cases of distress, anxiety and depression, as classified using HADS total (AUC =.74; AUC =.72), HADS anxiety (AUC =.81; AUC =.83) and BASDECs (AUC =.87; AUC =.85). The DT and Problem List were found to not significantly differ between cases of depression on the HADS depression scale (AUC =.66, $p=0.06$; AUC =.66, $p=0.06$). A cut-off of 4.5 on the DT provided a sensitivity of 85%, specificity of 60.71%, Positive Predictive Value (PPV) of 60.7% and Negative Predictive Value (NPV) of 85% for detection of anxiety. Appropriate cut-offs were not found for depression or distress. Internal consistency of

the Problem List as one large scale was good ($\alpha=.85$), however this was most likely because of the large number of items in the overall scale, rather than the items being clearly associated to one another. The most frequently reported problems were bladder and bowel (52.1%), fatigue and tiredness (47.9%), worry (37.5%) and depression (33.3%).

Conclusions: The DT and Problem List are valid measures of distress post stroke. Future research should focus on further development of the Problem List using patient feedback and use of the tool within an intervention program.

Introduction

Stroke and Psychology

A stroke is often a shock, an unexpected life event causing people to experience substantial changes to their lifestyle and normal level of function. With approximately 110,000 people having a stroke every year it is the largest cause of adult disability in England (National Stroke Strategy, 2007; Scarborough *et al.*, 2009). Rehabilitation is multifaceted aiming to promote restoration or adaptation to both physiological and psychological losses (NICE, Stroke Rehabilitation, 2nd draft consultation 2013). Understanding someone's emotional reaction to stroke is an essential part of the rehabilitation process.

Hackett and colleagues (2005) found the point prevalence rate of depression in the early, middle and later stages of stroke rehabilitation to be 33%. In an equivalent meta analysis anxiety point prevalence was reported to range between 20% and 24%, from one to six months post stroke (Campbell-Burton *et al.*, 2012). Both meta analyses

included studies that had used clinical interview and rating scales to classify depression and anxiety respectively and concluded, that due to variation in assessment method, these prevalence rates were likely to be a conservative representation. Anxiety, unlike depression, was found to increase over time (not statistically significant) and it was hypothesised that this may be due to both the transition from a structured hospital environment to home, coupled with the realisation that recovery potential may not be as good as anticipated (Campbell-Burton, 2012). Depression has been associated with increased time spent in hospital (Kotila, *et al.* 1999), poor engagement with rehabilitation programs (Gillen *et al.*, 2001), reduced social activities (Andersen *et al.* 1995; Paradiso & Robinson 1999) and higher number of outpatient visits (Jia *et al.*, 2006).

Understanding the emotional reaction post stroke is not restricted, however, to the concepts of depression and anxiety alone. Qualitative literature has drawn from patient experience to make us aware of the important themes of loss, transition, uncertainty, social isolation, adaption and reconciliation (Salter *et al.*, 2008; Folden *et al.*, 1994). Models of adjustment have been applied to the stroke literature in order to understand what factors are more or less associated with lower rates of depression, anxiety, quality of life and presence of trauma symptoms (Rochette *et al.*, 2007; Darlington *et al.*, 2007, 2009; Vickery *et al.*, 2008, 2009; Field *et al.*, 2008).

Assessment of mood

NICE guidance clearly states that mood should be assessed within the first 6 weeks after stroke using a validated measure (NICE quality standard, 2010). During this time, however, patients' stroke pathways can differ dependent on the severity of their stroke, their rehabilitation potential and the services available to them. For

example Early Supported Discharge (ESD) services and Community Stroke Teams are not available to everyone in the UK. The standardised application of this guidance is difficult and research has reported that it is not always adhered to (Bowen *et al.*, 2005). The Psychological Care after Stroke document (NHS Improvement, 2011) advocates a stepped care approach to psychological needs and sets out a clear pathway for the assessment of mood at 1, 3 and 6 months post stroke, as well as after discharge from any rehabilitation setting. Over recent years rates of assessment have improved and the National Sentinel Stroke Clinical Audit (2010) reported the median rate for mood screening, prior to discharge from hospital, was 84.4% (IQR= 68.8%-94.1%) although this rate dropped to 44% when the patient was not on a stroke unit. This was a substantial increase from median rates of screening in 2006 and 2008 which were 55% and 65% respectively. Lower rates of assessment have been attributed to the lack of one coherent and clinically relevant measure (Hart & Morris, 2008) and research has suggested the use of educational and support packages to improve assessment of mood (Morris *et al.*, 2012).

Mood can be assessed using self report questionnaires and observer-rated tools, for example the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) and Stroke Aphasia Depression Questionnaire (SADQ, Sutcliffe & Lincoln, 1998) respectively. Both these measures have been well validated in stroke patients (Bennett & Lincoln, 2006). More recently the Brief Assessment Schedule Depression Cards (BASDECs; Ashead *et al* 1992) was shown to have good sensitivity, specificity and concurrent validity (Healey *et al.* 2008; Hacker *et al.* 2010). This tool provides a non-verbal assessment which is well suited to a noisy ward environment, for example an acute stroke unit. A limitation of these measures, however, is that they focus on anxiety and depression alone, ignoring other mood states. One tool which does

investigate additional mood constructs is the Visual Analogue Mood Scales (VAMS; Stern, 1997) which assess feelings of being afraid, confused, sad, angry, tired, tense, happy and energetic. The VAMS has recently been revised to the VAMS-R which offers improved reliability and validity on the original measure (Kontou, *et al.*, 2012).

Conceptualisation of distress and adjustment post stroke

Mood assessments can be used to understand how someone is coping and adjusting to the consequences of a stroke. Adjustment has been defined as:

“the processes of adaptation that occur over time as the individual manages, learns from and accommodates the multitude of changes which have been precipitated by changed circumstances in their lives” (Brennan, 2001; p. 2).

Taylor *et al.* (2011) recently described the Social Cognitive Transition Model for Stroke (SCoTS) which integrates coping theory and traumatic stress, as applied to illness, to provide a dynamic process model. It is based on the cognitive framework of an “assumptive world” where individuals each have a cognitive map of how the world is and assumptions are made based upon this. Assumptions are either confirmed or disconfirmed by experience. When assumptions are disconfirmed we experience a period of stress until the map is re-moulded to make adapted assumptions. SCoTS expects a reaction of distress as a result of one’s cognitive model of the world being challenged and assumptions disconfirmed, even for people with ‘flexible assumptions’. Someone’s interpersonal response is likely to be characterised by initial denial, anger, guilt and distress. This provides an understanding for what may be an expected emotional reaction of distress following stroke.

The language used here has significance; the word distress provides a more general overview of an uncomfortable emotional reaction, as well as being something that should be expected post stroke. Distress has been defined within the cancer literature as:

“A multifactorial unpleasant emotional experience of a psychological (cognitive, behavioural, 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, 2010, pg. DIS-2).

The word distress has additional advantages including, being less stigmatising than psychiatric terminology, such as depression and anxiety (NCCN Distress Management Guidelines, 2010). Factors such as social problems, cognitive impairment and communication barriers are likely to increase someone’s vulnerability to distress and the potential development of mood difficulties (NCCN, Distress Management Guidelines, 2011). Drawing on the cancer literature, Williams *et al.* (2010) have suggested that measurement of distress, rather than depression and/or anxiety, would be a beneficial approach for stroke care, especially in the early stages when there is an expectation that someone will experience a degree of distress.

There is currently no validated single measure of distress within stroke care. Some researchers have used the total score from the HADS (Molloy *et al.*, 2005) and the General Health Questionnaire-12 (GHQ; Goldberg & Williams, 1988) to measure distress (Hilari *et al.*, 2010). Both of these are likely to represent distress to some

extent; however each have their own drawbacks. The total HADS score, for example, is a sum of anxiety and depression constructs and does not measure other emotions, such as anger, shock and disbelief, which may be equally related to distress. There is a problem with using the GHQ early post stroke as the questions ask people to state their mood on a Likert scale in relation to how they usually feel, for example “better than usual” “worse than usual” etc. If administered early after a stroke the expected response would be for things to be very different from usual and so this comparison is not likely to be the most appropriate way of assessing distress at this time. The GHQ can be useful later on after stroke when such a comparison takes into account the effects of the stroke.

The Distress Management System (DMS) has been promoted as a useful tool post stroke (Williams, 2010). It includes a Distress Thermometer (DT), asking people to give themselves a score out of 10 for the degree of distress experienced and a Problem List. The Problem List includes items of emotional, cognitive, relationship and mobility function that are appropriate for people who have had a stroke and was adapted from the NCCN version (Williams, 2010). This list helps individuals communicate what they feel is causing them the most distress and provides care staff with direction for offering support, whether this is through additional education/information or continued monitoring (Tuinman *et al.*, 2008; Williams *et al.*, 2010). The recommended intervention for people with high levels of distress includes working to fully understand someone’s difficulty and the use of a psychological treatment/rehabilitation pathway (NCCN, Distress Management System, 2010). This approach is consistent with the stepped care model suggested for psychological care after stroke (NHS Improvement, 2011).

The DT has been validated within the field of oncology (Mitchell, 2007) and was found to have 66.8% specificity and 78.4% sensitivity for a diagnosis of depression (Mitchell, 2007). These figures suggest the measure may be appropriate following stroke as recommended specificity is $\geq 60\%$ and sensitivity $\geq 80\%$ for a stroke screening measure of mood (Bennett & Lincoln, 2006). The DT alone was found to significantly correlate to the HADS anxiety, depression and total scores in a sample of cancer patients (Akizuki *et al.*, 2005), supporting concurrent validity.

There is one known published research article using the DT in a sample of stroke patients and the need for further investigation within this population was acknowledged (Turner *et al.*, 2012). A sample of 72 stroke patients in Australia completed a number of screening measures for depression. This included the DT and the Structured Clinical Interview for DSM disorders (SCID) was used to classify people as suffering depression or not. The DT was found to be significantly positively correlated to the HADS total score ($r=0.59$, $P<0.001$), HADS-Depression ($r=0.50$, $p<0.001$), Kessler-10 (Kessler, *et al.*, 2003; $r=0.55$, $p<0.001$) PHQ-2 and PHQ-9 (Kroenke, Spitzer, Williams, 2001; $r=0.59$, $P<0.001$). The DT was found to have 69% sensitivity, 57% specificity using a cut-off of >3 and subsequently did not meet criteria for good sensitivity-specificity of a depression screening measure (Bennett & Lincoln, 2006). The role of the DT in detecting additional emotional states was suggested as a reason for it being less sensitive in the detection of depression than specific depression screens (e.g. BDI). A limitation of this study was the large variation in time post stroke with a range from between 3 weeks and 6 months (38.9%) to ≥ 24 months (38.9%). Time is important in the dynamic process of adjustment and so to have such a varied range in time in the sample questions the generalisability of these results to the stroke population (Taylor *et al.*, 2011). Considering the clinical guidance on mood

assessment (NICE; Psychological guidance SIP, 2009), as well as models of psychological adjustment that predict a level of distress in the early stages following stroke, the DT and Problem List seem best suited for use in the early stages. Investigation at this time point is therefore warranted alongside further study into the Problem List, as this was not addressed by Turner *et al.* (2012).

In the UK the DT and Problem List have been trialled for use within a stroke rehabilitation service and disseminated at conference level (Williams *et al.*, 2010). Williams and colleagues (2010) provided staff with a training package for using the DT and Problem List to identify and manage the individual's distress. The use of key clinical skills, provision of information, monitoring and referral to specialist were the main ways distress was managed (Lincoln *et al.*, 2012). This model is supported by other training provided by psychologists within stroke, for example where education has improved screening for depression and anxiety in hospital based stroke services (Morris *et al.*, 2012). Further work needs to be done to investigate the validity and reliability of the DT and Problem List in stroke patients, to support its use as a clinical tool.

The present study focuses on the early stages of stroke care investigating the concurrent validity of the DT and the internal consistency and structure of the Problem List. An association between the scores on the DT and other measures of mood is expected due to the notion of a continuum of mood intensity. It is expected that the scores on the DT will be associated with the number of problems identified on the Problem List. The present study also addresses the factors people report to cause them most distress post stroke.

Research questions and hypotheses

Question 1: Is the Distress Thermometer (DT) and Problem List a valid measure of distress post stroke?

Hypothesis 1: The scores on the DT and Problem List will correlate significantly and positively with other measures of mood (HADS, BASDECS, VAMS-R) and each other.

Hypothesis 2: The higher someone scores on the DT, and the more problems identified on the Problem List, the more likely they would be to be classified as distressed, depressed or anxious.

Question 2: Is the Problem List a reliable way to assess problems causing distress post stroke?

Hypothesis 3: The structure of the Problem List will provide reliable subscales.

This research question is of an exploratory nature as it is acknowledged that many of the items on the subscales of the Problem List would be unlikely to be related to one another. The limitation of using Cronbach's alpha on a larger scale and the likelihood of an over reporting of internal consistency in this instance is also acknowledged.

Question 3: What are the sources of distress for people who are in hospital following a stroke?

Hypothesis 4: The frequency of items rated as causing distress on the Problem List including; mobility, physical, relationships, practical, emotional, cognitive and spiritual items will vary, highlighting the multifactorial nature of distress.

Method

Design

The study was a cross-sectional cohort design. Participants completed the Distress Thermometer (DT) and Problem List, Hospital Anxiety and Depression Scale (HADS, Zigmond & Snaith, 1983), Brief Assessment Schedule Depression Cards (BASDEC; Ashead *et al*, 1992) and the Visual Analogue Mood Scale Revised (Kontou *et al.*, 2012) to measure their mood post stroke. The most recent Barthel Index score was taken from participants' medical notes, and reading and comprehension ability was assessed using subtests from the Frenchay Aphasia Screening Test (FAST; Enderby, Wood & Wade, 2006).

Concurrent validity of the DT and Problem List was investigated using correlations with other measures of mood. The internal consistency and the structure of the Problem List were investigated using Cronbach's Alpha and Hierarchical Cluster Analysis respectively. Receiver Operating Characteristic (ROC) and Area Under the Curve (AUC) analysis was used to assess the sensitivity and specificity of using a cut-off on the DT, and Problem List, for detecting the cut-off for likely depression or anxiety by the HADS and BASDECs.

Participants

Stroke patients in acute and rehabilitation wards were invited to take part. Stroke was defined as "a clinical syndrome characterised by an acute loss of focal cerebral function with symptoms lasting more than 24 hours or leading to death, and which is thought to be due to either spontaneous haemorrhage into the brain substance

(haemorrhagic stroke) or inadequate cerebral blood supply to part of the brain (ischemic stroke)” (pg. 35, Warlow *et al*, 2008).

Inclusion criteria were that the participant was at least 18 years old, had a stroke diagnosed in medical records and was able to give informed consent. Participants were excluded if they were blind (unable to read size 14 print), deaf, had a diagnosis of dementia in their medical notes or were unable to understand the English language sufficiently to complete the questionnaires.

Sample size

The main research question was analysed using correlation analysis between the DT and the HADS: the sample size required to complete this analysis with 80% power was calculated (Cohen, 1988, 1992). Previous correlation coefficients from the oncology literature were used; at the time of completing this analysis Turner *et al*.(2012) had not been published and so coefficients from a stroke sample could not be used. Coefficients between the DT and HADS anxiety score included $r=0.447$, $r=0.5$ and $r=0.65$ (Ozlap *et al*, 2007; Gil *et al*, 2005; Akizuki *et al*, 2005), DT and HADS depression score $r=0.39$, $r=0.40$ and $r=0.65$ (Ozlap *et al*, 2007; Gil *et al*, 2005; Akizuki *et al*, 2005) and HADS total scores $r=0.446$ and $r=0.70$ (Ozlap *et al*, 2007; Akizuki *et al*, 2005).

Using the smallest, most conservative, coefficients (Ozlap *et al*, 2007) a power calculation was completed using the software MedCalc, with alpha value of 0.05 and beta value of 0.2. Assuming that the correlations between the DT and the HADS were identical to those found by Ozlap (2007), the sample sizes required for 80% power were: HADS–anxiety $n=37$, HADS–depression $n=48$ and HADS–total $n= 37$. Therefore the required sample size was 48 participants.

Measures

Demographic information was collected from participants' medical records and consisted of date of birth, gender, marital and employment status. Time since stroke, type of stroke and lesion location were also recorded. In addition the Oxford Classification (Bamford *et al*, 1991) of stroke was used to record type of infarction. Cerebral infarctions were categorised into one of four categories: Total Anterior Circulation Infarction (TACI), Partial Anterior Circulation Infarction (PACI), Lacunar Infarction (LACI) and Posterior Circulation Infarction (POCI). Participants completed four measures of mood and one assessment of reading and comprehension. Disability was recorded from the participants' most recent Barthel Index Score (Collin *et al*. 1988). Details of the assessments are presented below.

Distress Thermometer and Problem List (Williams, 2010).

This is a measure of general distress taken from the Distress Management System, originally designed to be used with cancer patients. Permission was gained from the National Comprehensive Cancer Network (NCCN), for use of the DT, and Dr Luke Williams, for use of the adapted problem list for stroke (2010). Participants rated their distress for the past week using the DT and identified what problem areas caused their distress using the Problem List. The DT ranged from 0-10, 10 represented extreme distress and 0 no distress at all. The categories of problems on the Problem List included physical problems (appearance, bathing/dressing, breathing problems, bladder/bowel, eating/drinking, fatigue/tiredness), mobility (pain, paralysis, sexual, skin problems, sleeping problems, visual problems), practical (child care responsibilities, finances, housing, transport/driving, work/activities), cognitive (attention and concentration, communication, confusion, memory, problem solving),

relationships (dealing with family members, friends, staff/carers, roles and responsibilities), emotional (anxiety/worry, fears, depression, crying, laughing, loss of interest in usual activities, anger, guilt, denial), and spiritual (spiritual and religious) concerns. Some of the items within the categories appear clustered illogically, for example sexual function within mobility. There was also an open text box for individuals to add other factors that may have been causing them distress (See Appendix C, for a copy of the measure).

A review of its specificity for a diagnosis of depression was found to be 66.8% and sensitivity was 78.4% (Mitchell, 2007). Construct validity was supported as the DT was found to significantly correlate to the HADS anxiety, depression and total scores within a sample of cancer patients (Akizuki *et al*, 2005). This research was all conducted with samples of cancer patients.

Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983).

The HADS (Zigmond & Snaith, 1983; Appendix D) was used because it provided a measure of anxiety, depression and distress and was designed to be used in hospital settings. Participants answered the 14 items and scores were calculated for the two 7 item subscales (anxiety and depression) as well as a HADS total score (distress). The HADS is a well validated measure of mood (Bejelland *et al.*, 2002) and has also been validated within a sample of stroke patients (Lincoln & Bennett, 2006). The factor structure has been supported by confirmatory factor analysis with stroke patients (Johnston *et al.*, 2000). In a sample of 104 stroke patients, in Norway, Sagen *et al* (2009) found the HADS anxiety, depression and total subscales to have high internal consistency with Cronbach's alpha values being $\alpha=0.83$, $\alpha=0.89$, $\alpha=0.91$ respectively. The sensitivity and specificity of the depression and anxiety subscales, using the cut-

off of ≥ 8 , was between 70% and 90% in a range of studies (Bjelland *et al.*, 2002). Stroke specific research has found sensitivity and specificity to be 86% and 69% respectively using the recommended cut-off of ≥ 8 for depression against the SCID interview for major depression (Healey *et al.*, 2008). Other studies have suggested varying cut-offs for stroke samples (Aben *et al.*, 2002; Sagen *et al.*, 2009), however there is no overwhelming evidence to suggest an alternative cut-off is clearly superior. The present study used the cut-off ≥ 8 for the identification of possible depression and anxiety and ≥ 15 for the Total HADS and identification of overall distress (Bjelland *et al.*, 2002; Ibbotson *et al.*, 1994).

Brief Assessment Schedule Depression Cards (BASDEC; Ashead et al, 1992).

The BASDEC (Ashead *et al.*, 1992; Appendix E) is a non-verbal screening measure for depression designed to be used with older people in a noisy ward environment. It provided an additional well validated measure of depression and the card format helped to maintain confidentiality for participants when sharing a hospital ward/room with other patients. A total of 19 cards (8.2 cm by 10.4 cm), each with a written statement relating to a symptom of depression were presented. The participant was required to match the statement with a true, false or don't know card, depending on how accurately they felt the statement described how they felt. The overall score was calculated and the maximum score was 21. The BASDEC has been shown to have good specificity (95%) and sensitivity (100%) in detecting major depression, diagnosed using the Structured Clinical Interview, in hospitalised stroke patients (Healey *et al.*, 2008). Internal consistency (KR-20=0.77) and test-retest reliability ($t(43) = 0.66$, $p < 0.001$) were also found to be good (Healey *et al.*, 2008). Good concurrent validity has been reported (Hacker *et al.*, 2010) from significant correlations

with the HADS depression scale, Beck's Depression Inventory-Fast Screen (Beck *et al.* 2000) and Stroke Aphasia Depression Questionnaire Hospital version (SADQ –H10; Lincoln, Sutcliffe & Unsworth, 2000).

Visual Analogue Mood Scale Revised (VAMS-R; Stern et al. 1997; Kontou, 2012).

The VAMS-R is a modified version of the VAMS. The VAMS (Stern *et al.* 1997) is a vertical visual scale used to assess mood for people who have language difficulties. It was included because it measures multiple mood states including afraid, confused, sad, angry, tired, tense, happy and energetic. The participant was required, using a pen, to make a mark on a 100mm line which represented the continuum between a mood state and neutral. The scales were presented in a vertical orientation to overcome invalid responses due to hemianopia and inattention (Price *et al.*, 1999; Nyenhuis, 1997). Internal consistency has been reported as $\alpha=0.71$ in stroke patients and when happy and energetic items were taken out this increased to $\alpha=0.81$ (Bennett *et al.* 2006). Recently adaptations were made to the VAMS, creating the VAMS-R (Kontou *et al.*, 2012; Appendix F) which was used in the present study. In the VAMS-R positive mood states have been placed above the neutral state and negative mood states placed below, making the scale more logical. The VAMS-R has higher internal consistency ($\alpha=.74$) and was shown to have good concurrent validity with significant correlations with HADS depression ($r = 0.49$, $P = 0.001$) and anxiety ($r= 0.59$, $P < 0.001$) subscales as well as the Visual Analogue Self Esteem Scale (VASES; $r = -0.69$, $P < 0.001$) and Stroke Aphasic Depression Questionnaire 21 (SADQ-21; $r= 0.43$, $P = 0.001$) (Kontou *et al.*, 2012).

Reading and comprehension: Frenchay Aphasia Screening Test (FAST; Enderby, Wood & Wade, 2006).

The spoken word comprehension and reading subtests were used in the present study to confirm participants' ability and ensure they were able to complete the questionnaires reliably (Appendix G). Participants were asked to complete 10 spoken word instructions which included pointing to shapes or parts of a picture for example 'point to the square' and 'before pointing to a duck near the bridge, show me the middle hill'. The FAST reading subtest required participants to read five sentences, ranging in complexity, and point to items on a picture, for example 'show me the bridge'. They received one mark for successfully following each written or verbal instruction. The total combined maximum score for the subtest was 15 (5 for reading and 10 for spoken word comprehension). In a review of aphasia assessments the FAST was found to be a widely used and thoroughly evaluated screening measure within the stroke literature (Salter *et al.* 2006). The FAST has good test-retest and inter-observer reliability as well as high convergent, construct and concurrent validity (Salter *et al.* 2006). The sensitivity (87%) and specificity (80%) of the measure to detect aphasia is good (Salter *et al.* 2006).

Physical Disability: Barthel Index (Collin et al. 1988).

The Barthel Index Score (Collin *et al.* 1988) was used as a measure of independence in personal activities of daily living. These data were collected to be able to accurately describe characteristics of the sample. The scale covered 10 areas of activity (bowels, bladder, grooming, toilet use, feeding, transfer, mobility, dressing, stairs and bathing). The participant's most recent score on this measure was obtained

from their nursing notes. Each subscale was scored from 0-2 or 0-3, with higher scores representing greater independence. The maximum total score was 20 (Collin *et al.* 1988) and the measure has been used to categorise people into very severe (0-4) severe (5-9), moderate (10-14), mild (15-19) difficulties and independent (20). Internal consistency has been reported as good ($\alpha=0.80-0.89$) and excellent ($\alpha=0.93$) and the measure was reported to have good concurrent validity (Quinn *et al.* 2011).

Procedure

Participants were recruited from one acute and five rehabilitation stroke wards in the East Midlands. Three researchers were involved in recruitment overall due to geographical locations of stroke wards. Two researchers recruited from one district and one researcher from another. Each participant had contact with only one researcher. Participants who met the inclusion criteria were identified by clinical staff and provided with an information sheet (Appendix P). They had at least 24 hours to decide whether they wished to take part or not and if they agreed they were asked to complete the consent form (Appendix P). The researcher then completed the questionnaires with the participant, in either one or two sessions. Questionnaires were completed at the bedside or in a private room on the hospital ward, depending on the preference of the participant and availability of space. When at the bedside, efforts were made to reduce distractions, for example TV and radios were turned down. After completing the questionnaires with the participant the researcher obtained demographic and medical information from their medical records, as well as the most recent Barthel Index score. If the participant's performance on the comprehension subtest of the Frenchay Aphasia Screening Test (FAST; Enderby, Wood, & Wade, 1997) was poor, then they were excluded from the study at this point. As there are no specific cut-offs for the spoken

comprehension and reading subtests alone, clinical judgement was used in conjunction with performance, to decide whether the participant would be able to reliably complete the questionnaires. This included whether other clinical staff had already highlighted that communication was an issue and the extent to which the patient engaged and asked questions following receipt of the information sheet. If deemed appropriate the accuracy of yes/no responses were assessed for example, is X your name? (when X is the person's name), is your name Harry? Are you in hospital? Are you a woman?

Ethical Considerations

Ethical approval was obtained from the NRES Committee East Midlands, Derby (Appendix Q).

Informed consent

Participants were given at least 24 hours to consider their participation in the research and the purpose, requirements and potential risks or benefits were detailed in the participant information sheet. The researcher discussed the information sheet with participants, and answered any questions raised. Due to the potential cognitive impairments post stroke it sometimes became clear at this stage that the participant would be unable to provide informed consent and so the recruitment process stopped.

Confidentiality and data protection

The data obtained were stored anonymously and each participant given an ID number which was placed on the corresponding questionnaires. The consent forms had both the ID numbers and names of participants and were stored separately from the questionnaires.

A copy of the participant's consent form was placed in their medical records. The researchers had an obligation to report, to the ward staff, and record any risk to self or others which became apparent during the participant's involvement in the study. This was highlighted to the participant in the information sheet.

Potential distress and rights to withdraw

If a participant found their distress difficult to manage when completing the questionnaires the researchers, who are trained to deal with difficult emotions, provided immediate emotional support. If the participant was highly distressed and agreed to information being shared with the clinical staff then researchers communicated an overall impression with clinical staff, including scores on mood screens and the participants primary complaints. If appropriate and with the permission of the participant, the researcher suggested a referral to the Clinical Psychology services available within the usual care mood pathway.

Results

Introduction

A description of the data and sample characteristics is provided and followed by analysis to address respective research questions and hypotheses. Correlation analysis was used to test the hypothesis that the mood measures (HADS, BASDECs, VAMS-R) would be positively associated with the Distress Thermometer (DT) and Problem List, and the DT and Problem List to each other. Receiver Operating Characteristic (ROC) and Area Under the Curve (AUC) analysis was carried out to test the hypothesis that if someone scored higher on the DT and Problem List they were more likely to be classified as distressed, depressed and anxious. The appropriate use of cut-offs was also investigated with values for sensitivity and specificity. Cronbach's alpha was used to test the hypothesis that the Problem List would have reliable subscales and the structure of the problem list was investigated using cluster analysis. Finally the hypothesis that the sources of distress would vary was tested by the presentation of the Problem List frequencies.

SPSS version 20 was used to analyse the results (SPSS Inc., Chicago, IL, USA) except for the AUC and ROC analysis which was completed using MedCalc (MedCalc Software, Acacialaan 22, B-8400 Ostend, Belgium).

Normality of data

The data were tested for normality of distribution using the Shapiro-Wilk test, which is recommended for samples ≤ 50 (Field, 2005). Normality plots were also investigated (Appendix H). This was completed with the following continuous variables; age, time post stroke, Barthel total score, FAST comprehension, FAST

reading, total problems, DT score, BASDEC, HADS depression, HADS anxiety and Total VAMS-R.

The variables found to be normally distributed were: age ($D(48) = .983$, $p = .717$), DT score ($D(48) = .955$, $p = .065$), HADS anxiety ($D(48) = .965$, $p = .166$), HADS total ($D(48) = .966$, $p = .181$), VAMS-R ($D(48) = .969$, $p = .223$). The remainder of the variables were found to be significantly different from the normal distribution and therefore not normally distributed. This included: Total Problems ($D(48) = .943$, $p = .021$), Time post stroke ($D(48) = .791$, $p = .000$), FAST reading ($D(48) = .395$, $p = .000$), FAST comprehension ($D(48) = .700$, $p = .000$), Barthel total ($D(48) = .279$, $p = .000$), BASDEC ($D(48) = .909$, $p = .001$) and HADS depression ($D(48) = .943$, $p = .022$).

Description of participant sample

A total of 129 stroke patients were approached to take part in the study across both sites, 93 at research site 1 and 36 at research site 2. A total of 81 patients did not give consent to take part in the study, 47 patients were discharged before they could consent to take part and 34 declined to take part. Specific reasons for people declining to take part were not recorded, although anecdotally, people often said the study was “not for them” or that they were too busy at the moment. Of the 48 patients who consented, 40 were recruited from a stroke rehabilitation ward and 8 from an acute ward.

A total of 22 men (45.8%) and 26 (54.2%) women took part. Twenty-nine (60.4%) participants were recruited from research site 1 and nineteen (39.6%) from research site 2. Participants were recruited between April 2012 and February 2013 and dates of stroke ranged from 08.02.2012 to 31.01.2013. Stroke characteristics (Oxford Classification; Bamford *et al.*, 1991) and categorical demographic variables are

presented in Table 4 and age, time post stroke and scores on measures of mood, disability, reading and comprehension are presented in Table 5.

Using recommended cut-off scores (Bejelland *et al.*, 2002; Ashead *et al.*, 1992) 25% (n=12) of the sample met the criteria for depression as measured by the BASDECs and the rate of anxiety and depression determined by the HADS was 41.7% (n=20) and 29.2 % (n=14) respectively. Overall distress, as classified by the HADS total score, was 37.5% (n=18).

Table 4: Stroke and Demographic Data

Stroke characteristic	Number of Participants (n=48)	Percentage (%) of sample
Type of stroke:		
LACS	12	25%
TACS	10	20.8%
PACS	7	14.6%
POCS	1	2.1%
Haemorrhage	7	14.6%
Missing data	11	22.9%
Lesion location:		
Left hemisphere	17	35.4%
Right hemisphere	26	54.2%
Bilateral	1	2.1%
Missing data	4	8.3%
Demographic characteristic	Sample size (n=48)	Percentage (%) of sample
Marital Status:		
Married	24	50%
Cohabiting	2	4.2%
Single	6	12.5%
Divorced/separated	3	6.3%
Widowed	11	22.9%
Missing data	2	4.2%
Employment status		
Retired	40	83.3%
Employed full time	5	10.4%
Employed part time	1	2.1%
Unemployed	2	4.2%

Table 4: Displaying the proportions of demographic and stroke characteristics within the sample.

Table 5: Distribution of Scores for Continuous Variables

Variable	Sample size (n)	Mean	Standard Deviation (SD)	Median	Inter Quartile Range (IQR)
Age	48	72.2	11.7	74.1	64.2-80
Time post stroke* (days)	48	24.3	24.1	18.5	2.5-30.75
Barthel Index*	45	9.4	5.5	9.5	5-14.8
FAST reading*	48	4.8	0.5	5	5-5
FAST comprehension*	48	8.9	1.6	10	9-10
DT	48	4.6	2.7	5	2.5-6.5
VAMS-R	48	299	146.8	284.5	194.3-381.3
Total HADS	48	13	7.8	12	7-19.8
HADS anxiety	48	7	4.5	7	4-9.75
HADS depression*	48	6	4.1	5	2.3-8.8
BASDEC*	48	5.5	4.2	4.3	2-8.4
Total problems*	48	7.6	5.7	7.5	3-11.75

Table 5: Mean, SD, Median and IQR for age, time post stroke, disability, reading, comprehension and measures of mood. Mean and SD should be interpreted with caution for those variables not normally distributed ().*

Concurrent Validity of DT and Problem List - Correlations

Concurrent validity of the DT and Problem List was investigated using correlations with other measures of mood. Spearman rho correlations were carried out between the DT, Problem List and other measures of mood. This non-parametric measure was chosen because not all measures met the assumption of normality. All correlations were positive and significant: see Table 6 below for coefficients.

Table 6: Correlations between DT, Problem List and other Measures of Mood (n=48)

	DT (<i>r</i>)	P value	Total problems (<i>r</i>)	P value
DT	-	-	.61	P<0.001
Total problems	.61	P<0.001	-	-
HADS total	.52	P<0.001	.54	P<0.001
HADS anxiety	.54	P<0.001	.56	P<0.001
HADS depression	.41	P<0.001	.42	P<0.001
VAMS-R	.61	P<0.001	.5	P<0.001
BASDEC	.57	P<0.001	.6	P<0.001

Table 6: Relation between DT, Problem List and measures of mood and corresponding p values.

Receiver Operating Characteristics (ROC) and Area Under the Curve (AUC) analysis.

Whether a score on the DT or problem list could be used to detect a clinically significant level of anxiety or depression, with adequate sensitivity and specificity, was investigated. ROC curves and AUC statistics were calculated for the DT and Problem List predicting the accurate identification of cases classified as significantly anxious or depressed, as determined by the HADS anxiety, HADS depression and BASDECS. Total HADS score was used as the gold standard for overall distress (Tuinman *et al.*, 2008). MedCalc was used to calculate the ROC curves, AUC, sensitivity, specificity, Positive and Negative Predictive Values (PPV, NPV). MedCalc is the recommended computer program for this analysis (Pintea & Moldovan, 2009).

AUC values between 0.50 - 0.70, 0.70 - 0.90 and above 0.90 are low, moderate and high respectively; an AUC score of <0.5 means the test is performing worse than chance (Fischer *et al.*, 2003). Sensitivity of .80 and specificity of .60 has been recommended as the appropriate level for a mood screen post stroke and means the test has a 80% likelihood of detecting a true positive and 60% likelihood of detecting a true

negative (Bennett & Lincoln, 2006). These criteria were used for deciding on an optimum cut-off. The NPV and PPV provide the probability of the test result accurately detecting the presence (PPV) or absence of the condition of interest, taking into account the prior odds of the individual being depressed or anxious (Strauss, Sherman & Spreen, 2006). The base rates for depression and anxiety were used in calculating PPV and NPV. These were taken from respective meta-analysis of prevalence rates and the rate used for depression was 33% (Hackett *et al.*, 2005) and 20% for anxiety (Campbell-Burton *et al.*, 2012). The base rate of distress/HADS-total from the present sample was used in the Total HADS analysis.

ROC Curve graphs, AUC calculations and optimum cut-offs with optimum sensitivity, specificity, NPV and PPV are presented below (see Appendix I for tables showing the different sensitivity, specificity, NPV and PPV).

Distress, DT and Problem List

The results of AUC analysis found that the DT and Problem List significantly differentiated between distressed and non-distressed participants as determined by the HADS-total score (AUC =.74, $z=3.3$, $p<0.001$) and (AUC =.72, $z=2.9$, $p=0.003$) respectively. This indicated a 74% probability that a participant from the distressed group will have a larger DT score and a 72% probability they would have a larger Problem List score than a participant from the non-distressed group. A cut-off of ≥ 4 on the DT provided a sensitivity of 77.78%, specificity of 50%, PPV of 48.3% and NPV of 78.9%. A cut-off of ≥ 5 on the Problem List provided sensitivity of 77.78%, specificity of 53.33%, PPV of 50% and NPV of 80%. ROC curves are presented in Figures 2 and 3.

Figure 2:

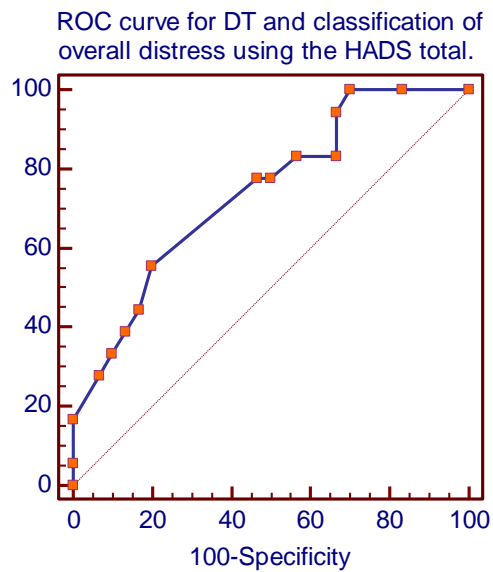


Figure 2: Displays the ROC curve for DT and HADS total. Markers correspond to criterion values and subsequent specificity and sensitivity points.

Figure 3:

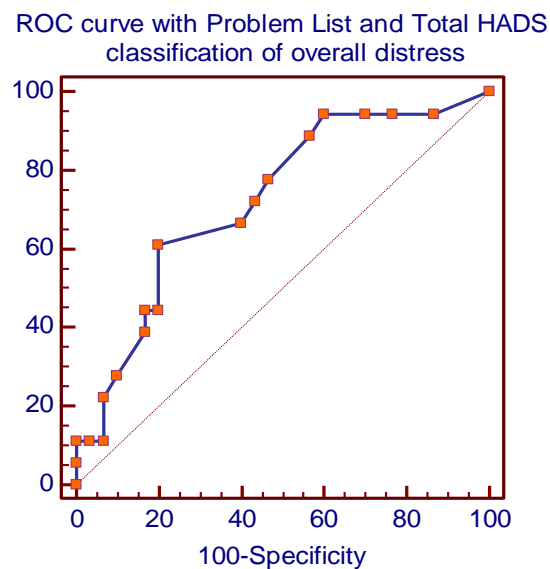


Figure 3: Displays the ROC curve for Problem List and HADS total. Markers correspond to criterion values and subsequent specificity and sensitivity points.

The results of AUC analysis found that the DT and Problem List significantly differentiated between anxious and non-anxious participants as determined by the HADS anxiety scale (AUC =.81, $z=4.5$, $p<0.001$, and, AUC =.83, $z=5.7$, $p<0.001$) respectively. This indicated an 81% probability that a participant from the anxious group will have a larger DT score and an 83% probability they would have a larger Problem List score than a participant from the non-anxious group. ROC curves are presented in Figures 4 and 5. The cut-off of ≥ 4.5 on the DT provided a sensitivity of 85%, specificity of 60.71%, PPV of 60.7% and NPV of 85%. A cut-off of ≥ 6 on the Problem List provided a sensitivity of 80%, specificity of 64.29%, PPV of 61.5% and NPV of 81.8%.

Figure 4:

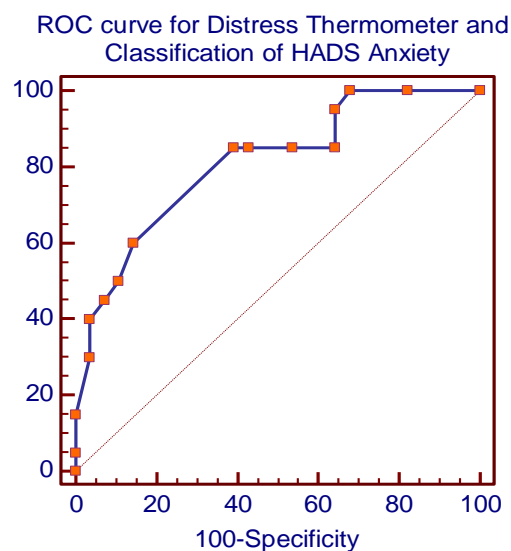


Figure 4: Displays the ROC curve for DT and HADS anxiety. Markers correspond to criterion values and subsequent specificity and sensitivity points.

Figure 5:

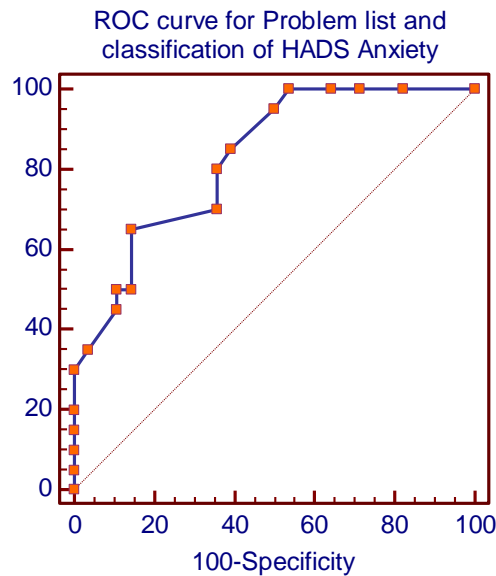


Figure 5: Displays the ROC curve for Problem List and HADS anxiety. Markers correspond to criterion values and subsequent specificity and sensitivity points.

Depression and DT

The results of AUC analysis found that the DT significantly differentiated between depressed and non-depressed participants as determined by the BASDECs (AUC =.87, $z=7.4$, $p<0.001$), indicating a 87% probability that someone from the depressed group would have a higher DT score than someone from the non-depressed group. The results of AUC analysis found the DT to not significantly differentiate between those classified as depressed or not, as determined by the HADS-depression scale (AUC =.66, $z=1.9$, $p=0.06$) ROC curves are presented in Figures 6 and 7. A cut-off of ≥ 4 on the DT provided 71.43% sensitivity, 44.12% specificity, 34.5% PPV and 78.9% NPV for the HADS depression classification. A cut-off of ≥ 5 on the DT provided sensitivity of 75%, specificity 80.56%, PPV of 56.2% and NPV of 90.6% for the BASDEC depression classification.

Figure 6:

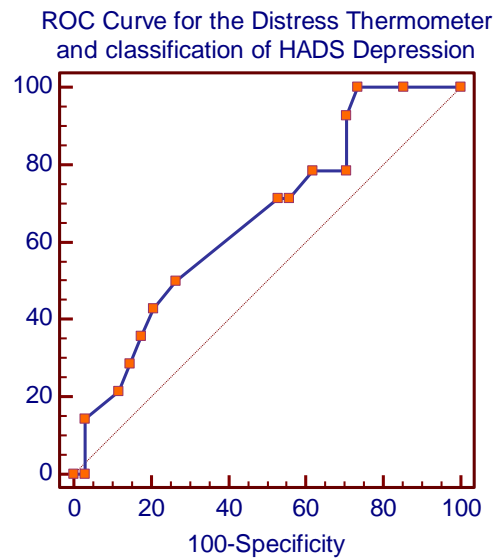


Figure 6: Displays the ROC curve for DT and HADS Depression. Markers correspond to criterion values and subsequent specificity and sensitivity points.

Figure 7:

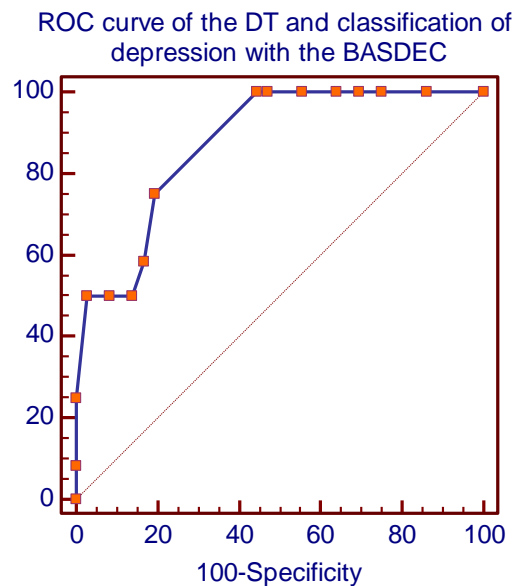


Figure 7: Displays the ROC curve for DT and BASDEC depression classification. Markers correspond to criterion values and subsequent specificity and sensitivity points.

Depression and Problem List

The Problem List significantly differentiated between depressed and non-depressed participants as determined by the BASDEC scale (AUC =.85, $z=5.4$, $p<0.001$). This indicates an 85% probability that a participant from the depressed group will have a larger problem list score than a participant from the non-depressed group. In contrast, however, AUC analysis found that the Problem List could not significantly differentiate between depressed and non-depressed participants as determined by the HADS depression scale (AUC =.66, $z=1.9$, $p=0.06$). ROC curves are presented in figure 8 and 9. An appropriate cut-off meeting 60% specificity and 80% sensitivity was not found. The cut-off of ≥ 5 on the Problem List provided 78.57% sensitivity, 50% specificity, PPV 39.3% and PPV 85%, for depression as classified by the HADS. A cut-off of ≥ 7 on the Problem List provided 83.33% sensitivity, 55.56% specificity, 38.5% PPV and 90.9% NPV for detection of depression using the BASDECs.

Figure 8:

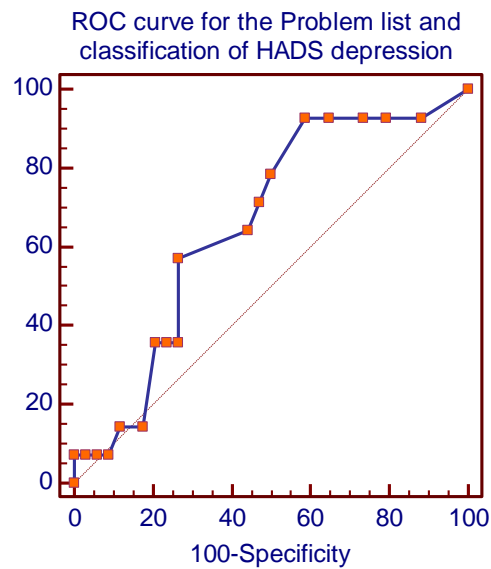


Figure 8: Displays the ROC curve for Problem List and HADS depression classification. Markers correspond to criterion values and subsequent specificity and sensitivity points.

Figure 9:

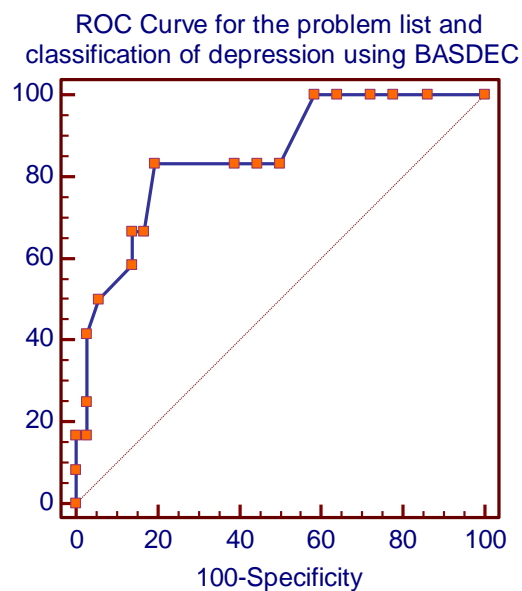


Figure 9: Displays the ROC curve for Problem List and BASDEC depression classification. Markers correspond to criterion values and subsequent specificity and sensitivity points.

Internal consistency and structure of the problem list

The internal consistency and the structure of the problem list were investigated using Cronbach's alpha (α) and cluster analysis respectively. Cronbach's alpha scores were calculated for the different subscales of the problem list and then for the scale as a whole. A Cronbach's alpha score of .7 is said to indicate a reliable scale (Field, 2005). Both Cognitive and Emotional subscales had an $\alpha \geq 0.7$ with $\alpha = .71$ and $.78$ respectively. The remaining subscales Physical ($\alpha = .60$), Mobility ($\alpha = .45$), Practical ($\alpha = .36$) and Relationships ($\alpha = .66$) did not obtain a value of $\alpha = .7$ or above. When the bladder bowel item was removed from the Physical subscale the α value increased to $\alpha = .7$, when the roles and responsibilities item was removed from the Relationships subscale this improved the α to $.66$ and when attention and concentration was removed from the cognitive subscale it increased the α value to $.73$. Item correlations ranged from $.06$ to $.68$, and these can be seen in Appendix J.

The item of child care responsibilities was removed from the practical problems subscale as there was zero variance for this item in the sample. The alpha score for the spiritual subscale was not reported because the covariance matrix was zero, or close to zero.

Cronbach's alpha for the total problem list (ignoring the subscales) was $\alpha = .85$. Although caution should be taken with interpretation as a large number of items can inflate α value and so inter-item correlations were also examined (Field, 2005). Item correlations and the alpha value if items are deleted and are presented in Table 7. Item-total correlations $< .3$ are said not to correlate with the overall subscale well (Field, 2005).

Table 7: Total Problem List Inter-Item Correlations and Overall Cronbach's Alpha Value if Item Deleted.

Problem List Item	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
Appearance	.39	.85
Bathing and Dressing	.26	.85
Breathing problems	.19	.85
Bladder and bowel	.5	.84
Eating and drinking	.39	.85
Fatigue and tiredness	.18	.85
Pain	.30	.85
Paralysis	.12	.85
Sexual	.29	.85
Skin problems	.31	.85
Sleeping problems	.34	.85
Visual problems	.12	.85
Finances	.47	.85
Housing	.26	.85
Transport/driving	.43	.85
Work/activities	.35	.85
Attention and concentration	.62	.85
Communication	.42	.85
Confusion	.5	.85
Memory	.49	.85
Problem solving	.24	.85
Family	.22	.85
Friends	.24	.85
Staff/carers	.61	.84
Roles and responsibilities	.47	.85
Anxiety/worry	.53	.84
Fears	.27	.85
Depression	.36	.85
Crying	.45	.85
Laughing	.34	.85
Loss of interest in usual activities	.3	.85
Anger	.53	.84
Guilt	.3	.85
Denial	.3	.85

Table 7: Showing the Cronbach's alpha (α) for the total scale. Inter item correlations $< .3$ and items that would improve overall α if removed are presented in bold.

Cluster analysis

Hierarchical Cluster Analysis was used and clusters were analysed by variables, not cases. The measure was binary, as the participant identified the problem to be present or not. Between-group linkage was used meaning variables were clustered dependent on them having the least distance between them. As the data were binary/categorical, factor analysis was not an option: unlike cluster analysis, factor analysis uses the variance in producing factors and it is not possible to calculate variance on a categorical data set.

The clusters created from this analysis did not provide clear subscales or show similarities between items. When the items were placed in a model of between 2 and 6 clusters only 10 items showed any distance from a larger pool of items. Sleeping, fatigue, bathing and dressing, bladder-bowel and paralysis formed, in different combinations, the 2nd-5th clusters in the models with between 2 and 5 clusters. When 6 clusters were introduced the items attention concentration, anxiety, worry, depression and loss of interest in usual activities were grouped together as the 6th cluster. All other items remained together in the 1st cluster in all models: see Appendix K for full description. The Dendrogram in Figure 10 also displays the lack of clear clusters within the problem list.

Figure 10:

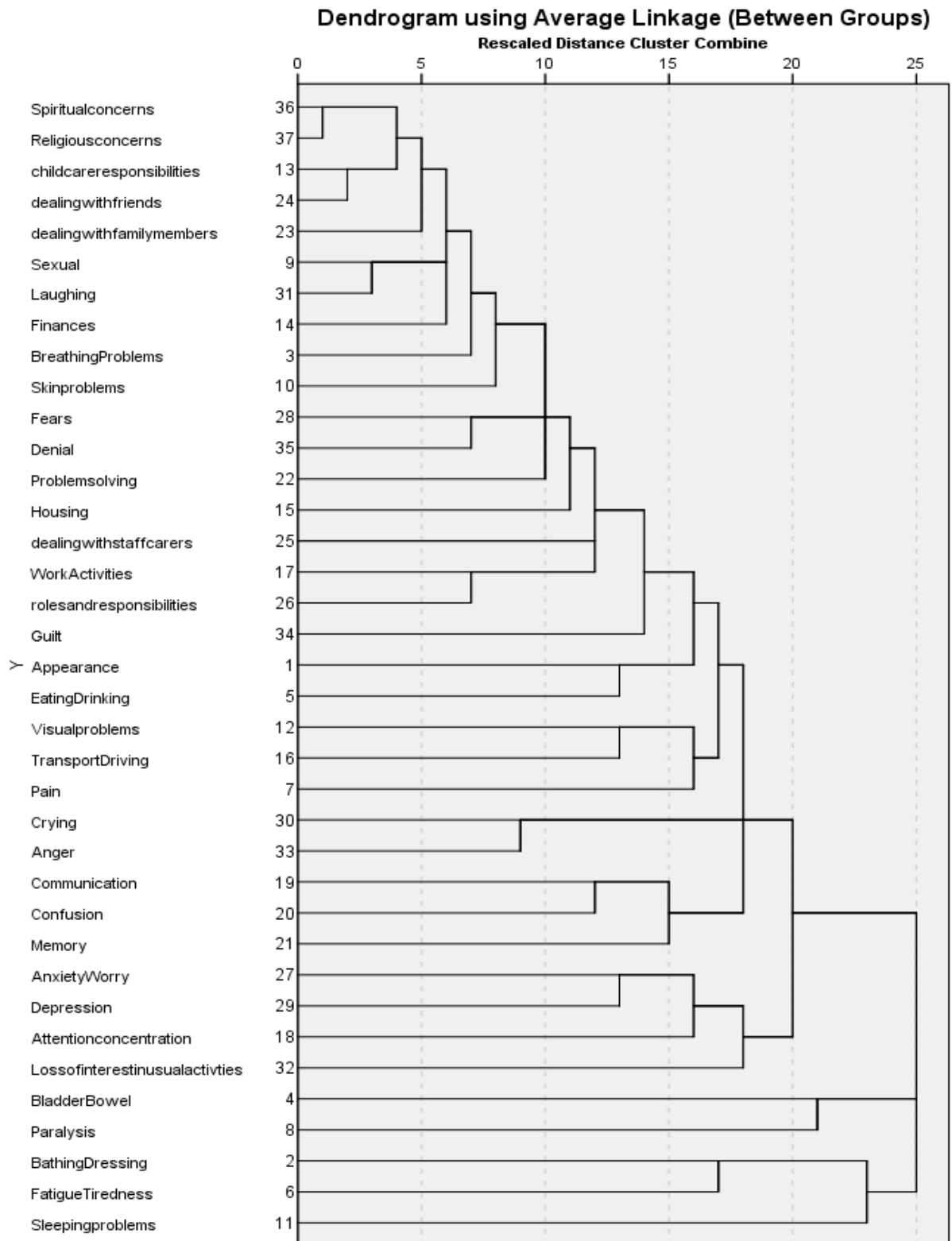


Figure 10: Dendrogram of the between group links for the problem list items Displaying the distance between variables at different steps of the analysis.

Problem List descriptive statistics

The percentage of participants finding each problem distressing is presented below.

Table 8: The Frequency of Participants who Identified each Problem as Distressing.

Problem category	Number of participants (n=48)	Percentage (%) yes
Physical		
Appearance	10	20.8%
Bathing and Dressing	22	45.8%
Breathing problems	4	8.3%
Bladder and bowel	25	52.1%
Eating and drinking	10	20.8%
Fatigue and tiredness	23	47.9%
Mobility		
Pain	12	25%
Paralysis	13	27.1%
Sexual	3	6.3%
Skin problems	4	8.3%
Sleeping problems	19	39.6%
Visual problems	12	25%
Practical Problems		
Child care responsibilities	0	0%
Finances	3	6.3%
Housing	6	12.5%
Transport/driving	12	25%
Work/activities	9	18.8%
Cognitive problems		
Attention and concentration	13	27.1%
Communication	10	20.8%
Confusion	13	27.1%
Memory	15	31.3%
Problem solving	7	14.6%
Relationships		
Family	4	8.3%
Friends	1	2.1%
Staff/carers	7	14.6%
Roles and responsibilities	6	12.5%
Emotional Problems		
Anxiety/worry	18	37.5%
Fears	7	14.6%
Depression	16	33.3%
Crying	13	27.1%
Laughing	3	6.3%
Loss of interest in usual activities	16	33.3%
Anger	8	16.7%
Guilt	9	18.8%
Denial	6	12.5%
Spiritual		
Spiritual concerns	2	4.2%
Religious concerns	2	4.2%

Table 8: The percentage of people who said that the problems caused them distress.

Discussion

The primary objective of the present study was to investigate the validity of the Distress Thermometer (DT) alongside the validity and internal consistency of the Problem List, in a sample of stroke patients. A further objective was to report the distribution of problems as recorded using the Problem List. How the results of the present study met these objectives is addressed sequentially, making references to the literature and suggestions for future research. Clinical implications and limitations of the study are then discussed.

Validity of the DT and Problem List

The DT and Problem List were both positively and significantly correlated to other well-validated measures of mood, including the BASDECs ($r=.57$, $r=.60$), VAMS-R ($r=.61$, $r=.50$), HADS total ($r=.52$, $r=.54$), anxiety ($r=.54$, $r=.56$) and depression ($r=.41$, $r=.42$) scores. This supports good concurrent validity of the DT and Problem List and is the first, known, report of an association between the DT and Problems List with the VAMS-R, BASDECs and HADS anxiety in a sample of stroke patients. Correlations between the DT, HADS total and depression scores have been previously reported with stroke patients (Turner *et al.*, 2012) and the present study provided similar correlations, adding to the evidence. The HADS and DT correlation coefficients were similar to those reported in the cancer literature (Ozlap *et al.*, 2007; Gil *et al.*, 2005; Akizuki *et al.*, 2005). In addition the DT and the Problem List were significantly positively correlated ($r=.61$) to each other, supporting the expected association between a higher score on the DT and a higher number of problems identified. This replicated findings from the cancer literature ($r=.68$; Tuinman *et al.*, 2008).

It is interesting to note the largest correlation coefficient was between the DT and the VAMS-R. This supports the definition by the National Comprehensive Cancer Network (NCCN, 2010) that states distress is a multifactorial unpleasant emotional experience, therefore not solely about feelings of depression or anxiety. The VAMS-R was the only measure used that included emotions such as being angry, afraid and tense. This is an important conceptual issue regarding the understanding of emotional reactions to an essentially traumatic event. As suggested by the SCoTs model of adjustment (Taylor *et al.*, 2011), it is expected that people experience significant distress whilst their assumptive model about themselves and their world changes. It is also important to understand this emotional reaction as different to the experience of depression, which seems to be the most widely reported emotional reaction following a stroke in the literature. These results provide explanation for why the DT has performed poorly in predicating the presence or absence of depression alone using the Structured Clinical Interview for DSM disorders (SCID) in comparison to measures such as the Beck Depression Inventory (BDI) (Turner *et al.*, 2012). It is important to understand the differences between the constructs of depression and distress. The findings of the present study support the hypothesis that the DT has an association to depression as well as having strong associations to other emotional reactions such as anxiety, anger and tension.

Using a cut-off of ≥ 8 for anxiety and depression subscales, and ≥ 15 for total score on the HADS, as well as a cut-off of ≥ 7 on BASDECS for depression, medium and significant AUC values were found for the DT and Problem List in conjunction with classification by the HADS total (AUC=.74, AUC=.72), anxiety (AUC=.81, AUC=.83) and BASDEC (AUC=.87, AUC=.85) scales respectively. The results of the AUC analysis with HADS-depression scale was in the same direction but not

significant (AUC=.66, AUC=.66). These results suggest that, with a moderate probability, someone scoring higher on the DT or Problem List is more likely to be classified as distressed, anxious or depressed than someone with a lower score. This further supports the convergent validity of the DT and Problem List through its associations with measures of distress, depression and anxiety. When sensitivity, specificity, Negative and Positive Predictive Values (NPV, PPV) were calculated the DT and Problem List only provided an appropriate cut-off for the classification of anxiety. A cut-off of >4.5 on the DT provided 85% sensitivity and 60.71% specificity, which meets required criteria for a mood screen (Bennett & Lincoln, 2006). When a base rate of anxiety of 20% (Campbell-Burton, 2012) was taken into consideration the DT accurately detected the presence of anxiety with 60.7% (PPV) and the absence of anxiety with 85% (NPV) accuracy. A cut-off of >6 problems on the Problem List provided sensitivity of 80%, specificity of 64.29% and a PPV of 61.5% and NPV of 81.8% for anxiety. This is concurrent with the optimum cut-off for the DT suggested within the cancer literature, where studies have often reported a cut-off of 4 or 5 (Mitchell *et al.*, 2007). A suitable cut-off for the DT or Problem List was not found for the detection of depression or distress, as appropriate rates of sensitivity and specificity could not be met. The closest score for distress/ HADS total was a cut-off of >4 which provided 77.78% sensitivity and 50% specificity, with PPV 48.3% and NPV of 78.9%. Previous research, in a sample of 277 cancer patients, using the HADS total to classify distress found the DT cut-off score of 5 to provide 85% sensitivity and 67% specificity, with PPV of 39% and NPV of 95% (Tuinman *et al.*, 2008). Previous research using the HADS depression scale and DT with samples of cancer patients found a cut-off between 5 and 2 to provide sensitivity of 63%, 77% and specificity of 68%, 55% respectively (Butt *et al.*, 2008; Vignaroli *et al.*, 2006). It is not possible to

make such recommendations for a use of a cut-off from the present study for overall distress and depression.

The ROC and AUC analysis, however, should be interpreted with caution as it may not have sufficient power to confidently detect an effect between the DT and the HADS depression. Retrospective power analysis (Appendix L) showed larger sample sizes were required for 80% power with the AUC values provided in the current study. Further research with a larger sample size is warranted.

Reliability of the Problem List

Investigation into the internal reliability of the Problem List found only the Cognitive and Emotional subscales to obtain adequate values of Cronbach's alpha ($\alpha=.71$ and $\alpha=.78$) (Field, 2005). This disconfirmed the hypothesis that the Problem List had reliable subscales. When the Problem List was treated as one large, 35 item, scale it showed good internal reliability ($\alpha=.85$). Through investigating the similarity of items, cluster analysis, did not provide any alternative, or better fitting, clusters of items on the Problem List. This, alongside the subscale Cronbach's alpha scores being low, suggests that the Problem List is more internally consistent when seen as one long list of potential problems. The present study, therefore, suggests that the subscales (Physical, Mobility, Practical, Cognitive, Relationships, Emotional and Spiritual) should not be used individually but the items merged into one large scale.

Cronbach's alpha analysis found a total of 11 items (bathing and dressing, breathing, pain, paralysis, visual, housing, problem solving, family, friends and fears) to have inter-item correlations of $<.3$, suggesting their suitability for the Problem List should be reconsidered (Field, 2005). This does, however, raise questions about the heterogeneity of problems experienced and the individual nature of distress. To

eliminate these items from the scale is likely to be an overzealous reaction to the analysis. For example, to eliminate the item 'paralysis' from the list would be to exclude one of the primary physical effects after a stroke. The item of child care was removed prior to analysis, because no one had identified it as a problem within the sample studied. This may be due to the age of the sample (M 72.2, $SD=11.7$ years). Had a number of younger adults, who would have been more likely to have dependent children, taken part then child care may have been identified as an issue. In addition the religion/spirituality items were not included in analysis as there was not enough reported variance, with only 2 participants (4.2%) identifying it as a problem. The Problem List does offer an open text box to allow for idiosyncratic problems to be noted however no one in the present sample identified any additional problems.

This highlights a distinction between psychometric properties of measures and clinical utility. The stroke specific Problem List was created by Williams and colleagues (2010) and stemmed from discussion and agreement amongst a number of professionals, using the NCCN Problem List as a guide (2010). This is similar to the further development of the list within cancer services in the UK. The use of the DT and Problem List within oncology clinical settings has been discussed by Brennan *et al.* (2012) and others (Tuinman *et al.*, 2008; Garssen & de Kok, 2008). The importance of seeing the measure as a clinical tool, alongside a psychometric measure, was highlighted. The important point here is that it is not the psychometric properties that makes the difference to patients, but it's the start of a conversation about what is distressing and helping patients to understand and manage their distress. This highlights the need to consider the qualitative and clinical application of the Problem List, in addition to acknowledging reliability and validity.

It may be that the Problem List is best used as a qualitative tool to explore distress with patients, with the DT providing a quantitative measure. Future investigation, therefore, should investigate the DT and Problem List at a clinical level. Implementation projects in the Netherlands (Garssen & de Kok, 2008) have highlighted the need for tools such as the DT and Problem List to promote communication about distress amongst all patients and provide a systematic approach to psychosocial care. The oncology literature has more frequently reported research into the psychometric properties of the DT and Problem List, in comparison to research investigating the clinical utility. A recent study by Brennan and colleagues (2012) investigated the validity of the Problem List developed by the NCCN with a sample of UK cancer patients. They obtained copies of different Problem Lists from across the country that had been developed and amended in an *ad hoc* way. A focus group of patients, health professionals and researchers reviewed the many items that had been added to the amended Problem Lists. A total of 753 ex-patients were then contacted by post and 395 participants provided the researchers with feedback on the items that they found relevant. They refined the Problem List and suggested a 42- item list. This methodology could be replicated in future research into the Problem List with stroke patients.

Distribution of problems on Problem List

The distribution of items identified on the Problem List supported the hypothesis that what people identified as being distressing would vary between participants. The highest recorded item was bladder and bowel problems with 25 participants (52.1%) stating this was causing them distress at the time of assessment. Other commonly reported problems included fatigue and tiredness (47.9%), bathing

and dressing (45.8%), sleeping problems (39.6%), worry (37.5%) and depression (33.3%). The least recorded item was child care responsibilities, which no one identified as a problem. Only 2 (4.2%) people identified having any religious or spiritual concerns. In addition 31.3% and 27.1% of people highlighted memory and confusion as a distressing problem respectively. These findings support previous research which has acknowledged high rates of fatigue, tiredness and difficulty sleeping (De Groot *et al.*, 2003), bladder and bowel problems (Barrett., 2002) and the rate of depression (33%, Hackett *et al.*, 2005). This provides an insight into the key areas that people find distressing, whilst in hospital and in the early stages, post stroke. It also highlights the importance of understanding distress post stroke as a multifactorial construct, as it is defined by the NCCN. The Problem List can be used in conjunction with the DT to provide a holistic understanding of what is underlying an individual's distress (Brennan *et al.*, 2012).

Rates of anxiety and depression as classified by the HADS and BASDEC

The rate of anxiety was higher in the sample (41.7%) recruited in the present study than what might have been expected from a recent meta-analysis which reported pooled anxiety rates to be 20% within the first month post stroke (Campbell-Burton *et al.*, 2012). It was, however, in line with previous studies using the HADS anxiety and using the same cut-off (>8) within hospital samples 1 month following a stroke. Such studies have reported anxiety prevalence rates to be 33% (Donnellan *et al.*, 2010), 47% (Knapp & Hewison, 1998) and 20% (Stone *et al.*, 2004). The rate of depression in the present study was 25% (n=12) and 29.2% (n=14), using the BASDECs and HADS depression scales respectively. This is in line with the expected prevalence of

depression (33%; 32%), in the early stages after stroke (Hackett *et al.*, 2005; Hacker *et al.*, 2010).

Clinical implications

The present study provides evidence for the concurrent validity of the DT, and overall internal consistency of the Problem List within a sample of stroke patients. The use of the DT and Problem List with people who have suffered a stroke, whilst they are still in hospital, and in the early stages post stroke is, therefore, supported. It is important to consider how the tool will be used in practice. “What seems to be clear is that in order to reduce distress, one must be asking patients the right questions and engaging them in the process of resolving their distress” (Brennan *et al.*, 2012., pg. 1347). Williams and colleagues (2010), when piloting the use of the DT and Problem List in Scotland, also developed a number of folders which corresponded to the problems areas. This allowed patients to be provided with some self-help material, additional advice or support on certain areas. This intervention is an example of how the stepped care model of psychological support, promoted by the Stroke Improvement Strategy Psychological Guidelines (NHS Improvement, 2011), can be put into practice.

The effectiveness of such an intervention could be an area for future research. Brennan *et al.* (2012) are currently trialling a similar project within cancer services where patients go through the DT and Problem List at a review meeting. They offer three options to provide support and management of distress: 1) discuss how to resolve the problem in the present, 2) provide self-help, relaxation or a support group or 3) a referral to another service, one of which maybe a Clinical Psychologist. This model and methodology would be supported within stroke care and research.

Another important clinical implication to consider is the language used within services surrounding mood and post stroke care. There is a clear bias within the literature toward the investigation of rates of depression and the effect on overall rehabilitation. For example, the first meta-analysis on rates of anxiety was published only last year (Campbell-Burton, 2012) and the clinical guidelines specify the screening of depression and anxiety rather than general mood (National Stroke Guidelines, 2008). It is recognised that detecting likely depression and anxiety is important and represents a positive shift to specific, clear instructions that mood should be assessed. It does, however, signify the two most researched mood states and subsequently neglects constructs such as general distress. It could be argued that the DT and Problem List in measuring distress, also provides an assessment of depression, anxiety as well as other mood states. The present study, as well as the promoted use of the Distress Thermometer and Problem List, provides support for the communication of emotions in a dimensional, rather than categorical, manner. This can allow for the exploration of other mood states between professionals and patients, the normalising of fear and sense of loss which the patient is likely to be experiencing. This is most applicable to the early and acute stages post stroke, as expected from models of adjustment such as the Social Cognitive Transition model for stroke (SCoTs: Taylor *et al.*, 2011). The present study, in assessing the validity and reliability of the tool, offers support for the use of the term assessment of distress in early stages post stroke, although further research into clinical utility of the DT and Problem List is warranted.

Critique and limitations of the present study

Representative nature of the sample

The sample had a representative gender dispersion (45.8% men) when compared to the most recent Sentinel Stroke Clinical Audit (SSCA, 2010) (49%; n=5563 men). The median time post stroke (18.5 days, IQR=6.5-30.75) was higher than the median (10 days) stay in hospital for 2010 (SSCA, 2010). This is likely to reflect the difficulty in recruiting stroke patients in the early stages post stroke especially when a total of 47 were discharged before they could be recruited to the study (*see methodology discussion below*). The proportion of haemorrhagic to ischemic strokes was representative of the larger stroke population (Mant, 2011) with 14.6% of the present study having had a haemorrhage. There was, however, a total of 22.9% missing data on type of stroke. A slightly higher proportion of participants had right hemisphere strokes (54.2%), but this is understandable due to the higher likelihood of people with a left hemisphere stroke experiencing aphasia, meaning they would have been less likely to meet inclusion criteria. Of those included in the study the scores on the FAST Reading and Comprehension subsections were high, with median scores being 5/5 and 10/10 respectively. This confirmed that the participants were able to reliably complete the questionnaires.

Methodology and analysis

Methodology

The present study had high rates of non-consenting, potentially leading to bias in the sample. The main reason for this was due to patients being discharged before they could be given a full 24 hours to read the information sheet (required by NHS

ethics) or be able to consent to take part. Due to the nature of the research project researchers recruiting patients were not able to be present on the wards for long periods of time nor revisit every 24 hours. Therefore people had often been discharged before they could consent. The methodology could have been improved if consecutive patients, who met inclusion criteria, had been approached and researchers had a higher profile on wards. The reasons for non-consenting were not formally recorded. Although comments such as “its not for me” and “I’ve got a lot on at the moment” were noted. This may reflect patients not wanting to take part in a study into emotional and psychological states, perhaps due to stigma, or not wishing to take on additional commitments. There was a higher proportion of non-consenting at research site 1, than site 2. Site 1 was part of a large NHS University Trust and it was likely that people were asked to take part in a number of research studies whilst on the ward. The researcher at site 2 had more of a clinical presence within the stroke services as well as a research role which may have aided recruitment.

It is also important to note the present study excluded patients who had language or cognitive difficulties and were unable to complete questionnaires. Within the stroke population this constitutes around a third of patients (Sinanović, 2010) and therefore the generalisability of the results is limited. Williams *et al.* (2010) designed an aphasia-friendly version of the tools and the accessibility of this measure is clearly another area for future research.

Analysis

There is debate over the use of ROC analysis with measurement tools such as the HADS and BASDECS. Guidelines for ROC analysis state that the ‘gold standard’ should be used to classify the presence or absence of the ‘disease’ (Pintea &

Moldovan, 2009; Streiner & Norman, 2008). The HADS total score has been labelled a gold standard measure for distress in previous studies (Jacobsen *et al.*, 2004; Tuinman *et al.*, 2008) and other studies have used the HADS depression and anxiety (Butt *et al.*, 2008) cut-offs and BASDECs (Hacker *et al.*, 2010) as ways of classifying anxiety and depression. Other literature, however, has stated that a diagnostic interview (e.g. SCID) of depression, anxiety or adjustment disorder should be used for such analysis. In 2009 a total of 15 studies were reviewed that had investigated the reliability and validity of the DT in cancer patients (Vodermaier *et al.*, 2009), in which two used the clinical interview as criterion and eight used the HADS. In the present study it was not deemed appropriate to carry out a diagnostic interview for depression, anxiety or adjustment disorder with people at such an early stage post stroke. Clinical interview for adjustment disorder would not have been suitable for a number of reasons, primarily because the diagnosis requires a longitudinal context. In addition interview criteria such as the SCID require all other diagnoses to be excluded before adjustment disorder can be assessed (Casey & Bailey, 2011). The HADS and BASDECs are also highlighted in clinical guidance as appropriate measures for the early stages following stroke (NHS Improvement, 2011).

Conclusion

The present study provides evidence for the concurrent validity of the DT and Problem List. The Problem List was found to be more reliable when viewed as a whole, rather than with combined subscales, and its clinical utility highlighted. Reasons for distress are consistent with previously reported areas of difficulty for people post stroke including fatigue, bladder and bowel problems mood and cognitive difficulties. The importance of heterogeneity in problems post stroke is also

highlighted as well as that of balancing a psychometrically reliable and valid tool with a clinically useful one. Clinical implications include the importance of communication about distress between patient and health care professionals as well as normalising language of the emotional experience post stroke. As one of few studies using this measure post stroke suggestions for future research include the further development of the Problem List and the implementation of the tool as part of an intervention process.

Critical Appraisal

Development of ideas and research questions

When, at the start of training, I was asked to consider research ideas I was drawn to considering my previous experience. I had previously worked as an Assistant Psychologist on a stroke unit, as well as a research assistant on a Randomised Controlled Trial, investigating the use of Behavioural Therapy with people who had aphasia post stroke. I was aware of areas of research and clinical interest for stroke care, in particular the introduction of new Early Supported Discharge Teams (ESD). I was also aware of the role of psychology in promoting the use of psychological models and thinking within the medical setting of stroke. Starting the course at the time of the New Ways of Working document and an emphasis on Clinical Psychologists providing “more than 1:1 therapy” I was also interested in ways of promoting psychological mindedness and working with other health professionals on issues of a psychological nature. I was able to see how this fit with the stroke rehabilitation ward I had just come from working on. As I have progressed through my training, I have developed this interest and way of working further and I feel that my research project has helped me to do that.

Having approached my supervisors I became aware of a number of possible options for future research. Something which they were both enthusiastic to research was the Distress Management System within stroke care. It was both an exciting and daunting prospect that it was a relatively new area of research. Dr Luke Williams had presented about using the DMS at a National Stroke Conference and there was a presentation and poster abstract disseminated. Through literature searching the DMS, it was clear to see there had been a wealth of research within the cancer literature investigating the validity and reliability of the Distress Thermometer and Problem List. Noticing the lack of this within stroke I felt this was a place to start with a research proposal. I am tempted to say that the presence of the wealth of literature in cancer on the psychometric properties of the DT and Problem List meant that was why my focus lay there. Looking back, however, throughout the whole project, I was aware of the other questions about the implementation of the DMS as an intervention and part of a stepped care model. I was also interested in what ward staff may think about the measure, whether their concerns about using it would be the same as those reported by previous research that has studied the low rates of mood screening post stroke. Through discussions with my supervisors I curbed my enthusiasm. I became aware of the enormous nature of those questions and how they actually reflected a bigger research project than I had the scope to investigate. Having completed the project now, I am still intrigued by the clinical application of the DMS. If circumstances allow it I hope to continue with research in this area in the future.

Research design and recruitment – strengths, weaknesses and reflections

Despite the notorious reputation of the IRAS process and NHS ethics my experience was relatively systematic and non-eventful. This is not to say that the

process was not anxiety-provoking and lengthy, but I was granted ethical approval, after a few small changes to the consent form, and it felt a fair process. I was also well supported through this process by both supervisors, which definitely helped.

Recruitment started at the end of April 2012 and finished in February 2013. It took longer than had been planned, as the aim was to have all participants by December 2012, yet at this time I was 3 short of making 48. Recruitment was done across two sites and I was very lucky to have assistance from an MSc student and a research assistant, at different times. This, to me, reflected the way research works “in the real world”. It is rarely left to one sole researcher to be involved with all the data collection or other parts of the research process. Keeping in close contact with the researchers (CW and EB) was vital in ensuring they followed the procedure required. This involved meeting with them regularly, phone calls and emails.

Rate of recruitment – getting the numbers

The pace of recruitment was not steady and at times I remember visiting the wards or telephoning to find there was no one suitable to approach. During the summer months there was a bed crisis at the acute hospital in site 2 and this meant that the stroke unit and stroke rehab ward were actually occupied with many non-stroke patients for a while. It also seemed that the rate of strokes had reduced at this time also, in contrast to the winter months. This was difficult as my ability to recruit was being reduced by circumstances out of my control. I recognised some frustration here but this was also an uncomfortable feeling because I knew that it was a good thing that there were less people experiencing a stroke at this time. I was also able to start thinking about the writing up of the project and the Literature Review, and focus the time I had on these tasks instead.

Recruiting from an acute ward and a rehabilitation ward

I approached patients on both acute and rehabilitation wards. There was a clear difference in pace on the wards, although in both settings there was a sense of the busy and 'hustle bustle' nature from staff. On a number of occasions on the acute ward patients were suggested as appropriate by clinical staff, however when they were approached it was clear they were not or that the environment was too noisy and disruptive. I remember one occasion well, I approached a patient in a bay, they agreed for me to talk with them but at the same time a patient in the bed next to them was being moved and getting ready to go home. Staff were talking to each other and talking loudly when talking to the patient, who appeared confused and/or hard of hearing. I knew I was unable to fully concentrate, and I can't imagine the patient I was talking to was able to block the noise out either. I offered for us to use a different, quiet, room however the patient wanted to stay where she was. She seemed worried and with the backdrop of high levels of noise and being in a bay where people appeared very unwell I could clearly see why. The noise subsided, but there was still a sense of distraction from the ward environment as people worked around us. This was one of those situations where the patient declined to take part in the study and, although at the time part of me was disappointed, I knew that it was not the best time or place for her to be completing the questionnaires and whether she would have had the concentration to complete them was questionable. This highlights some of the challenges when recruiting on an acute medical ward. Often the environment is not best suited for research. It does raise questions about how the DT and Problem List could be used in such an environment and that clinical staff are also likely to come across similar barriers. This, highlights, again the role of psychology in motivating and encouraging other professions to use the DT and Problem List and have conversations about mood

and adjustment. This experience does help me to appreciate the reasons for lower rates of mood screening on stroke units and the difficulties and time pressures staff do face.

Participants' stories

When people did agree to take part, there would often be conversation alongside completing the questionnaires. For some people this was quite limited and there was the sense they wanted to complete the questionnaires and then for me to leave them to the rest of their day. For others, however, there was a sense of them taking the opportunity to share their story. On a number of occasions participants became emotional when describing their experience of having had a stroke. The sense of loss, trauma and dramatic change was often talked about, as well as the uncertainty of the future and rehabilitation. Hearing people talk about their own mortality and the impact of illness was striking and I felt it was vital to listen to their story and important to show respect to their journey. These experiences reminded me of the clinical importance of the work. It is also an example of where I became aware of the roles I was fulfilling, and how the role of researcher differed to that of a clinician. There were times when I may have asked certain questions or offered more had this not been within the context of a research project.

Bias in the sample

In writing this critical appraisal I am drawn to the obvious discontinuity between my previous experience working on a stroke research project where the sole focus was to recruit people who had aphasia and the present study that excluded such patients. This bias in the sample was a weakness of the present study, especially when

such a larger number of people post stroke experience aphasia. I was aware of the development of an aphasia-friendly tool for the DT and Problem List, however it was decided not to include this in the present study due to the additional complications. These complications included the use of additional measures that were also aphasia friendly and so would have required a separate analysis and generally increased the size of the study beyond what was realistically possible. For example the overall sample required would have been much greater and the study on the aphasia-friendly version would have warranted a project in itself. Also it would have required obtaining assent on behalf of patients who would be unable to read patient information sheets, required by NHS ethics, and this would have made the overall project bigger than what was manageable in the time frame and context of a DClinPsy. I do however, recognise that in clinical practice it is very important to be considering the emotional reaction of everyone post stroke and to exclude people who have cognitive and or language impairments is problematic.

Methodology

The methodology of the study could have been improved. If consecutive stroke patients had been approached and the presence of the researchers been greater this would have reduced potential bias in the sample and limited the chance of patients being discharged prior to consent. Due to the nature of the research, and all those recruiting participants having additional commitments, this was just not feasible. Had this project been part of a funded research study, however, such a method could have been planned for. It was important to remember that this project was essentially completed on a small scale and with far less resources than many other research studies.

Theoretical and epistemological underpinnings

In addressing the limitations of the present study I was faced with considering the epistemological position of the present study and statistical analysis. The positivist framework provided a clear and objective way to proceed with the research questions and to test the hypothesis. It did however, at times, leave me wondering about the limitations of this framework for a concept such as distress. As soon as considering this, I was also faced with the thought of how the stroke and medical world is very much a positivist world. The field of psychology, however, is not so clearly placed in its assumptions about knowledge and different theoretical models can enforce different views about what really constitutes knowledge and what does not. In particular the assumption of positivism, that knowledge is separate from the person who constructs it, is something that I personally and clinically do not always agree with. Having said that I recognise the importance of this assumption in being able to study something across a large group of people and make relevant assumptions and generalisations. In the field of neuropsychology, for example, this assumption has great value for the use of neuropsychological assessment. I make reference, in my introduction and discussion, to the importance of the language used, and I think it is at this point where I feel the view of post positivist/social constructionist viewpoint is perhaps useful. Some recommendations I made for future research, for example the use of focus groups including patients to further validate the problem list, sit more within the post-positivist framework. This makes me aware of the bias within the literature to the positivist and quantitative method and stance, for example with the high number of papers reporting the reliability of the DT and less about the clinical application of this. It could be argued that the DT and Problem List, alongside the potential conversation and intervention that can follow provides both a quantifiable (reductionist) measure of

distress, the DT and number of problems experienced, and then moves to the more post-positivist view where the conversation that proceeds is more about what the meaning of this distress is to the individual. What does it mean to them? How do they understand the world, their experience of stroke and how can they see moving forward? To be able to record the narrative used within such discussions and provide an analysis of this would provide an interesting research project. This highlighted that distinction between researcher and clinician for me.

Learning outcomes

Completing this research study has enabled me to see a project through from development of an idea to the writing up and making recommendations for future research. Although the project has been challenging at times, it has given me the experience and confidence to consider carrying out other research projects in the future. I feel it has consolidated the role of scientist practitioner for me within the role of Clinical Psychologist. Key amongst my learning outcomes is the importance of obtaining expertise from supervisors as well as support with recruitment. For me this highlights the importance of a research team and this would be something I'd look for when considering research in the future.

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Appendix A:

Data extraction form and quality checklist:

Study number	
Title	
Author (1st)	
Journal	
Study aim	
Adjustment theory – study is based on measures used to gauge psychological factors and adjustment outcomes	
Participant sample Time since stroke Age range Gender Location Size	
Inclusion/exclusion criteria Cognitive function Communication difficulties	
Study design Qualitative or quantitative Longitudinal, cross sectional prospective or retrospective	
Recruitment process	
Analysis used	
Study findings – conclusions, key findings - outcomes	
Methodological limitations	
Conclusions	

Quality Assessment

CRD area of quality	Question adapted from QATSO	
Risk of bias	Was the sampling method representative of the population intended to the study? 1) Non-probability sampling (e.g. convenience, snowball, purposive) 2) Probability sampling (e.g. simple random, systematic, stratified, cluster)	
Generalisability	Did the study report a response rate? Is the procedure described to the standard that it could be replicated?	
Quality of reporting	Are the main characteristics of the sample described? (stroke type, time since stroke, age, gender)	
Statistical considerations	Did the investigators control for confounding factors (e.g. stratification/matching/restriction or adjustment for variables) when analysing the associations?	
Outcome measures	Were reliability and validity of the measures used stated clearly for stroke specific samples?	
Ethical issues	Was privacy and sensitivity considered when conducting the study, was ethical approval noted?	

Appendix B – Description of studies reviewed.

Category	Authors	Model	Measures used to measure adjustment (dependent variable)	Other Variables measured and how (independent variable)	Design	Sample size (n=)	Time post stroke	Country of study
Coping	Rochette & Desrosiers, 2002	Transactional Theory Stress, Appraisal and Coping (Lazarus and Folkman, 1984).	Becks' Depression Inventory (BDI, Beck et al., 1961)	Revised Ways of Coping Questionnaire (RWCQ, 1988), Measure of Actualisation Potential (Leclerc et al., 1998; Lefrancois et al., 1997).	Longitudinal	76	2 weeks and 6 months post discharge	Canada
	Rochette et al, 2007		Becks' Depression Inventory (BDI, Beck et al., 1961) Assessment of Life Habits (LIFE-H; Fougereyrollas & Noreau, 1998)	Revised Ways of Coping Questionnaire (RWCQ) Folkman & Lazarus (1988), Stress Appraisal Measure (Peacock & Wong, 1990),	Longitudinal	122	2 weeks, 3 and 6 months post discharge	Canada
	Gillen et al, 2006		Orpington Prognostic Scale.	The COPE (Carver et al, 1989).	Cross section	16	5-7 days into a 6	America (New York)

			Centre for Epidemiological Studies Depression Scale (Kalra, Dale, & Crome, 1994).		nal.		day rehabilitation program	
	Smout et al (2001) and	Dual Process Model (Brandsdatter & Renner, 1990)	Schedule for the Evaluation of Individual Quality of Life Barthel Index Impact of Events Scale (Krabbe, 1998; William et al., 1999).	Interview including Visual Analogue Scale (To measure assimilation and accommodation type coping)	Cross sectional - Pilot study	8	1.1-3.1 years	Netherlands
	Darlington et al (2007)		EQ-5D (Dolan, et al 1997), Eysenck Personality Scale (Sanderman et al., 1995), Mini Mental State Examination (MMSE, Folstein, Folstein & McHugh, 1975).	Assimilative-Accommodative Coping Scale (Dutch translation, Brandsdatter & Renner, 1990)	Longitudinal	80	1 week pre discharge, 2, 5 and 9-12 months post discharge.	Netherlands
	Darlington et al (2009) <i>*Same sample as Darlington</i>		<i>As above</i>	<i>As above</i>	Longitudinal	80	Further analysis on data at discharge and 9-12	Netherlands

	<i>et al (2007)</i>						months post discharge.	
	King et al (2002)	Crisis in Physical Health (Moos & Tsu, 1977)	Stroke Survey, Interpersonal Support Evaluation List (ISEL; Cohen et al., 1985), Centre for Epidemiological Studies – Depression Scale (CES-D, Radloff, 1977).	Ways of Coping Questionnaire (WOC; Folkman & Lazarus, 1989).	Longitudinal	53	6-10 weeks post discharge, 1 and 2 years post discharge.	America
	Otswald et al (2009)	Transactional of Stress and Coping (Lazarus & Folkman, 1984) & McCubbin & McCubbin, 1987 T-Double ABCX model of	The Perceived Stress Scale (PSS -10, Cohen et al., 1983)	Family Crisis Oriented Personal Evaluation Scale (F-COPES) McCubbin et al., 1991.	Longitudinal	159	3,6, 9 and 12 months post discharge form hospital	America

		adjustment & adaptation						
Gender and coping	Nogueira & Teixeira , 2012	Stress, Appraisal and Coping (Lazarus and Folkman, 1984).	Revised Illness Perception Questionnaire (IPQ-R) translated into Portuguese. Beck Depression Inventory (BDI)	Ways of Coping with Problems Scale (WCPS) adapted for the Brazilian population. Gender Visual analogue pain scale.	Cross sectional	50	Participant s experienci ng post stroke pain for at least 3 months, mean length was 94.7 months for men and 82.7 months for women.	Brazil
Religion & Coping	Johnstone et al 2008,	Religious/ Spirtual Coping (Pargamen t, 1999).	SF-36 (Ware et al, 1993)	Religion - Brief Multidimensional Measure of Religious and Spirituality (BMMRS; Fetzer Institute and National Institute on Aging Working Group 1999).	Cross sectional	32	4-180 months post stroke	America (Columbia)
	Giaquinto et		HADS (Zigmond	Religion - Royal	Cross	132	Rehabilitat	Italy

	al., 2007		& Snaith, 1983),	Free Interview (King, Speck & Thomas, 1995).	sectional		ion centre sample, mean 9 days post stroke.	
Self Esteem	Vickery et al (2008)	Self Esteem (Oosterwegel et al 2001)	Geriatric Depression Scale (GDS, Yesavage et al, 1983).	Visual Analogue Self Esteem Scale (VASES, Brumfitt & Sheeran, 1999) and Rosenberg self esteem scale (RSES, Rosenverg, 1979),	Cross sectional	80	Inpatient rehabilitation program. Approximately 14 days post stroke.	America
	Vickery et al (2009)		Geriatric Depression Scale(GDS; Yesavage et al 1983), Impairment Distress Scale (IDS: Vickerey et al., 2009), Perceived Recovery Scale (PRS), Hospital Hassels Scale (HHS: Koenig, George, Stangl, & Tweed, 1995).	State Self Esteem Scale (SESS, Heatherton & Polivy, 1991),	Longitudinal	120	3 days after admission onto rehabilitation setting, then twice weekly assessment.	America

PTSD & Posttraumatic growth	Field, Norman and Barton (2008)	Cognitive Model of PTSD (Ehlers and Clark, 2000)	Hospital Anxiety and Depression Scale (HADS, Zigmond & Snaith, 1983),	Posttraumatic Cognitions Inventory (PTCI, Foa et al, 1999), Posttraumatic Diagnostic Scale (PDS, Foa, 1995)	Longitudinal	81	Hospital and 3 months later	UK
	Gangstad et al., (2009)	Posttraumatic Growth (Calhoun et al, 2000)	HADS (Zigmond & Sanith, 1983),	Cognitive Processing of Trauma Scale (CPOTS, Williams et al, 2002), Post Traumatic Growth Inventory (PTGI, Tedeschi & Calhoun, 1996)	Cross sectional	60	5-99 months post stroke, mean 32 months	UK
Illness representations and control	Twiddy et al., 2012;	Common Sense - Self Regulation Model (Leventhal , Nerenz & Steele, 1984)	General Health Questionnaire 28 (Goldberg & Williams, 1972).	The Illness Representations Questionnaire (IPQ; Moss-Morris et al, 2002).	Longitudinal	64	3 & 6 months post stroke	UK
	Morrison, Johnston & Walter (2000)		HADS (Zigmond & Snaith, 1983).	Recovery Locus of Control (RLOC; Partridge & Johnstone, 1989), confidence in recovery and satisfaction with care	Longitudinal	101	10-20 days, one and 6 months post stroke.	UK
	Morrison et		HADS (Zigmond	Recovery Locus of	Longi	101	10-20	UK

	al (2005 – <i>extension of study above</i>)		& Snaith, 1983).	Control (RLOC; Partridge & Johnstone, 1989), confidence in recovery and satisfaction with care	tudina l		days, one and six months and 1 and 3 years post stroke.	
Acceptanc e of illness	Townend et al (2010)	Adjustmen t to misfortune theory (Dembo et al, 1956)	Structured Clinical Interview for Depression (SCID).	Acceptance of Illness Questionnaire (Felton & Revenson, 1984).	Longi tudina l.	89	1 & 9 months	UK
Successfu l aging	Donnellan et al (2012)	Baltes's SOC model of successful aging (Baltes & Baltes, 1990)	HADS (Zigmond & Snaith, 1983) and Stroke Specific Quality of Life (SSQOL; Williams et al., 2006).	A modified version of Baltes SOC -48 questionnaire (Baltes et al, 1999), called the SOC-15, Recovery Locus of Control Scale (Partridge & Johnston, 1989).	Longi tudina l.	153	1 month and 1 year	Ireland

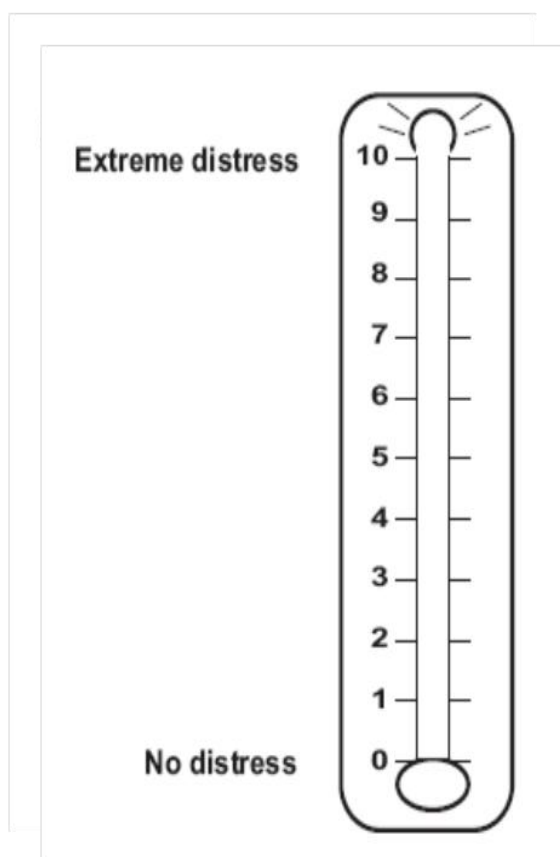
Appendix C:

Please note: for the purpose of the Appendix the Distress Thermometer and Problem List are shown on two separate sheets of paper, however in the research they were presented on one piece of A4.

Distress Thermometer

Participant ID

Date



The image shows a vertical thermometer-like scale used for measuring distress. The scale is a vertical line with horizontal tick marks and numbers from 0 to 10. At the top of the scale, near the number 10, there are several short diagonal lines radiating outwards, resembling a sunburst. To the left of the scale, the text "Extreme distress" is positioned next to the top of the scale, and "No distress" is positioned next to the bottom of the scale, near the number 0. The entire scale is enclosed in a rounded rectangular border.

Permissions gained from NCCN for use of Distress Thermometer and Dr Williams for use of Problem List.

Problem List

Secondly, please tick any of the following that has been a cause of distress to you in the past week, including today.

Physical problems

- Appearance ☐
- Bathing/dressing ☐
- Breathing problems ☐
- Bladder/bowel ☐
- Eating/drinking ☐
- Fatigue/tiredness ☐

Relationships

- Dealing with family members ☐
- Dealing with friends ☐
- Dealing with staff/carers ☐
- Roles and responsibilities ☐

Mobility

- Pain ☐
- Paralysis ☐
- Sexual ☐
- Skin problems ☐
- Sleeping problems ☐
- Visual problems ☐

Emotional Problems

- Anxiety/worry ☐
- Fears ☐
- Depression ☐
- Crying ☐
- Laughing ☐
- Loss of interest in usual activities ☐
- Anger ☐
- Guilt ☐
- Denial ☐

Practical problems

- Child care responsibilities ☐
- Finances ☐
- Housing ☐
- Transport/Driving ☐
- Work/activities ☐

Spiritual

- Spiritual concerns ☐
- Religious concerns ☐

Cognitive problems

- Attention and concentration ☐
- Communication ☐
- Confusion ☐
- Memory ☐
- Problem-solving ☐

Other problems:

Appendix D

Hospital Anxiety and Depression Scale



Name Date

Clinicians are aware that emotions play an important part in most illnesses. If your clinician knows about these feelings she or he will be able to help you more.

This questionnaire is designed to help your clinician to know how you feel. Ignore the numbers printed on the left of the questionnaire. Read each item and underline the reply which comes closest to how you have been feeling in the past week.

Don't take too long over your replies; your immediate reaction to each item will probably be more accurate than a long thought-out response.

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I feel tense or 'wound up':

- Most of the time
- A lot of the time
- From time to time, occasionally
- Not at all

I still enjoy the things I used to enjoy:

- Definitely as much
- Not quite so much
- Only a little
- Hardly at all

I get a sort of frightened feeling as if something awful is about to happen:

- Very definitely and quite badly
- Yes, but not too badly
- A little, but it doesn't worry me
- Not at all

(continued overleaf)



HOSPITAL ANXIETY AND DEPRESSION SCALE

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fold along dashed line

I can laugh and see the funny side of things:

- As much as I always could
- Not quite so much now
- Definitely not so much now
- Not at all

Worrying thoughts go through my mind:

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

I feel cheerful:

- Not at all
- Not often
- Sometimes
- Most of the time

I can sit at ease and feel relaxed:

- Definitely
- Usually
- Not often
- Not at all

I feel as if I am slowed down:

- Nearly all the time
- Very often
- Sometimes
- Not at all

I get a sort of frightened feeling like 'butterflies' in the stomach:

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

(continued overleaf)



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Appendix E

Research Title: Validity of the Distress Management System in stroke

BASDECS score sheet

Participant ID Date

Instructions: I am going to show you a number of cards with questions on them. I would like you to show me your answer using the True and False cards here – or, if you are unsure - don't know.

Question	True	False	Don't know
I feel anxious most of the time			
I've felt very low lately			
I feel worst at the beginning of the day			
I feel life is hardly worth living			
I've cried in the past month			
I've given up hope			
I've seriously considered suicide			
I cant recall feeling happy in the past month			
I'm so lonely			
I've lost interest in things			
I'm too miserable to enjoy anything			
I have regrets about my past life			
I am a nuisance to others being ill			
I've been depressed for weeks at a time in the past			
I suffer headaches			
I seem to have lost my appetite			
I'm not sleeping well			
I'm kept awake by worry and unhappy thoughts			
I'm not happy at all			

Appendix F

Please note: This is an example of two moods from the VAMS-R, other moods measured include confused, tense, angry, tired, sad and energetic.

Research Project: Validity of the Distress Management System in stroke.

The VAMS-R

Participant ID Date

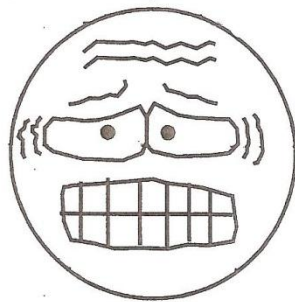
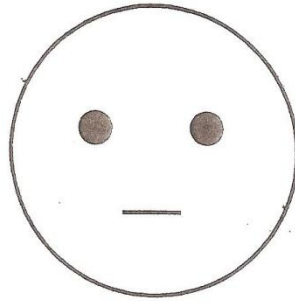
On the following pages you will see eight set of scales. On each of these you will see drawings of two faces connected to a long line. The name of the emotion the face represents will be printed above or beneath the face.

For each scale please place a mark across the line at the point which best describes HOW YOU ARE FEELING RIGHT NOW.

If you wish to change an answer please clearly erase you incorrect answer and mark a new one.

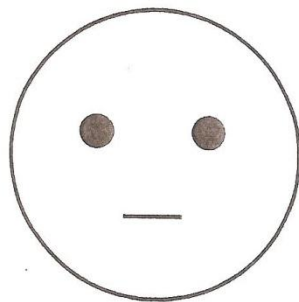
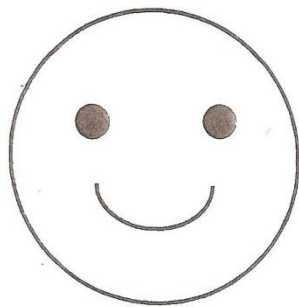
Acknowledgment to Stern for the original VAMS items and Kontou for revised items

Neutral



Afraid

Happy



Neutral

Appendix G

Research Title: Validity of the Distress Management System in stroke

Participant ID Date

FAST Score Sheet

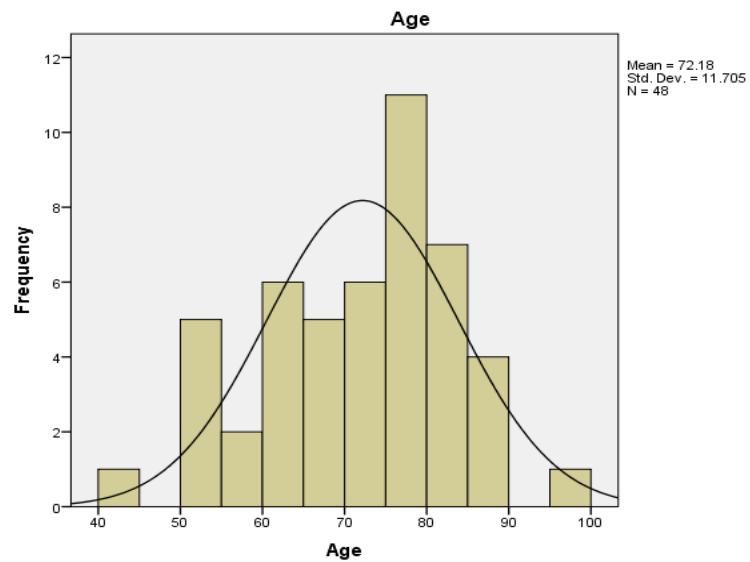
Reading <i>Instructions:</i> Check that the patient is wearing correct spectacles for reading purposes. Show patient river scene and first reading card. Ask him/her to read the sentence to him/herself, not aloud, and do whatever it instructs him/her to do. Proceed in the same manner with the remaining four reading cards.				Score: 1 for each correct	
1.		Point to the dog	=		
2.		Show me the bridge	=		
3.		Point to the man standing in the barge	=		
4.		Touch the left-hand corner of the card	=		
5.		Touch the bottom of the card and then the top of it	=		
				(Score range 0-5)	
				TOTAL	=
Scoring: 1 for each correctly performed. If instructions require repeating, score as error. Unprompted self-correction may be scored as correct. Score range 0-10.					
Comprehension – River Scene <i>Instructions:</i> Show patient river scene and say: <i>Listen carefully to what is said and point to the things I tell you to.</i> Practice item: "Point to the river". Do not score this item Repeat until patient understands what is required.					
				1= correct 0= incorrect	
		Point to a boat	=		
		Point to the tallest tree	=		
		Point to the man and point to the dog	=		
		Point to the man's left leg and then to the canoe	=		
		Before pointing to a duck near the bridge, show me the middle hill	=		
Score:				TOTAL	=
Comprehension - Shapes <i>Instructions:</i> show the participant the shapes <i>Listen carefully to what is said and point to the things I tell you to.</i> Practice item: "Point to the circle". Repeat until patient understands					
				1= correct 0= incorrect	
		Point to the square			
		Point to the cone	=		
		Point to the oblong and the square	=		
		Point to the square, the cone and the semicircle	=		
		Point to the one that looks like a pyramid and the one that looks like a segment of orange	=		
				Total River scene	/5
				Total shapes	/5
				Total comprehension	/10

Appendix H

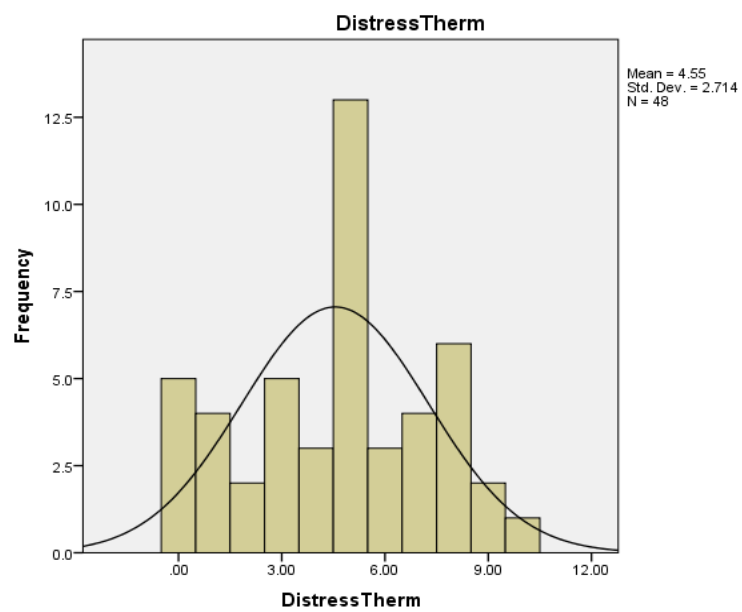
Normality plots and distribution of continuous variable

Variables found to be normally distributed by Shapiro-Wilk test:

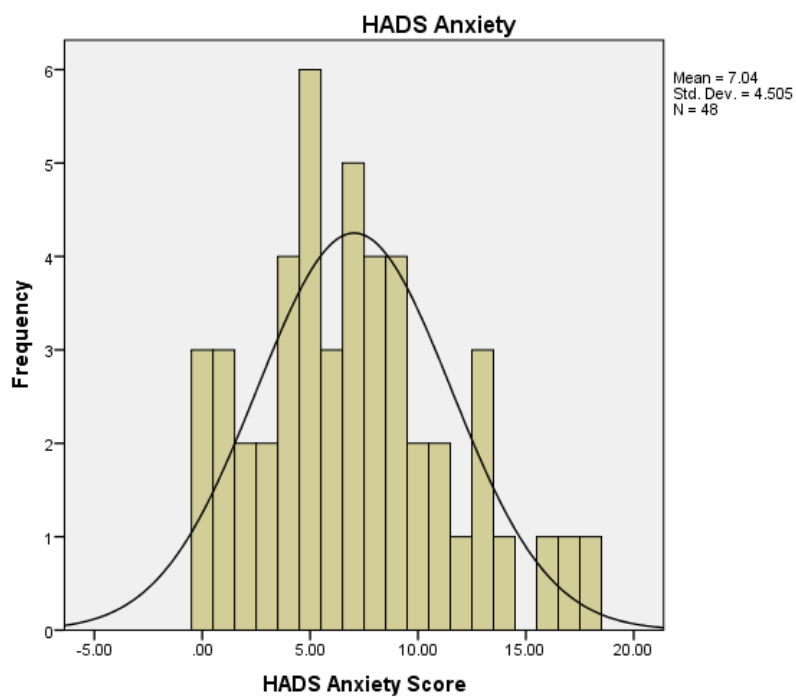
Age



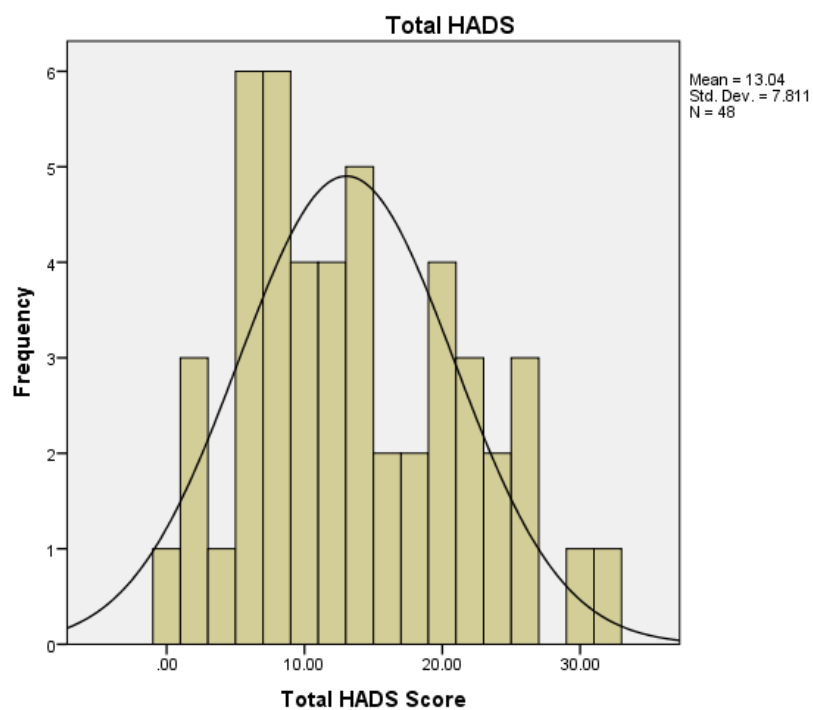
Distress Thermometer Scores:



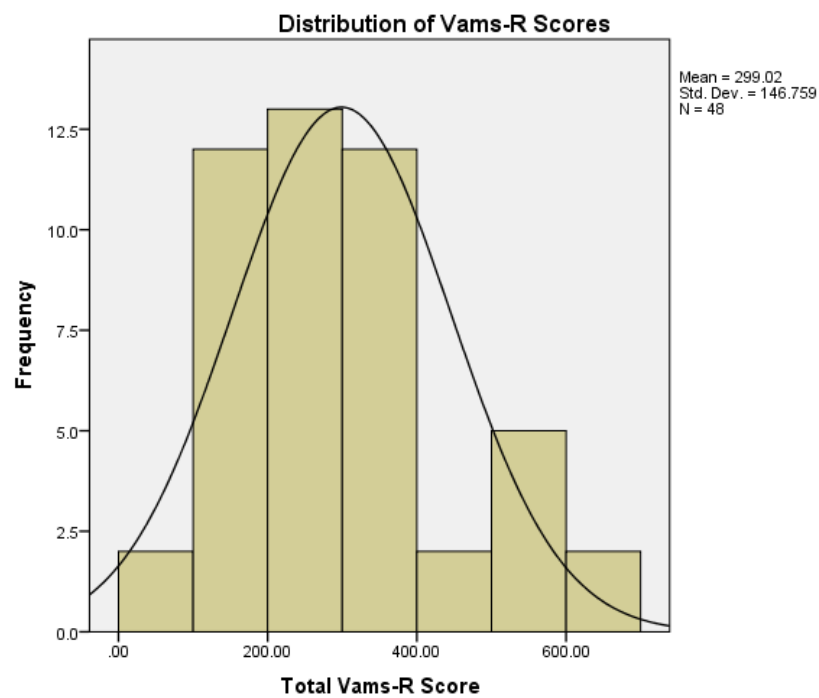
HADS Anxiety:



Total HADS:



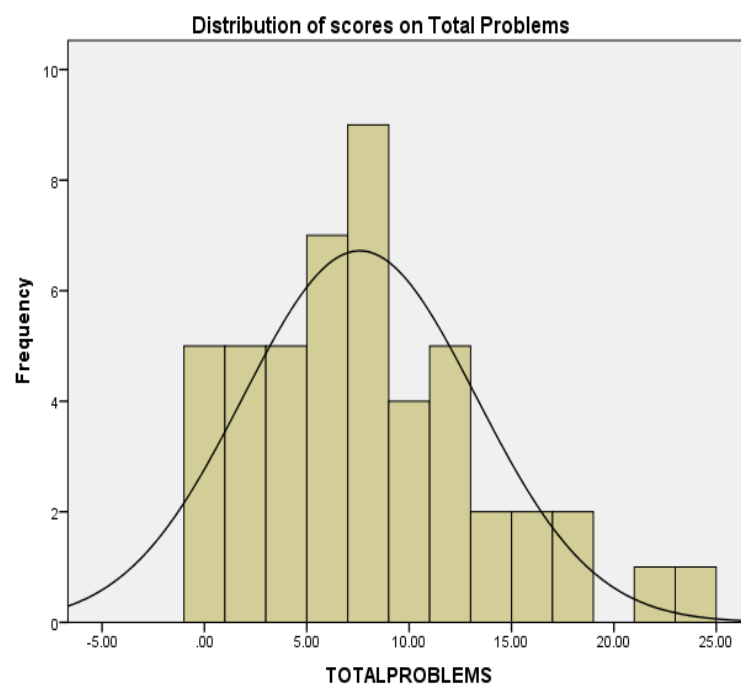
VAMS-R



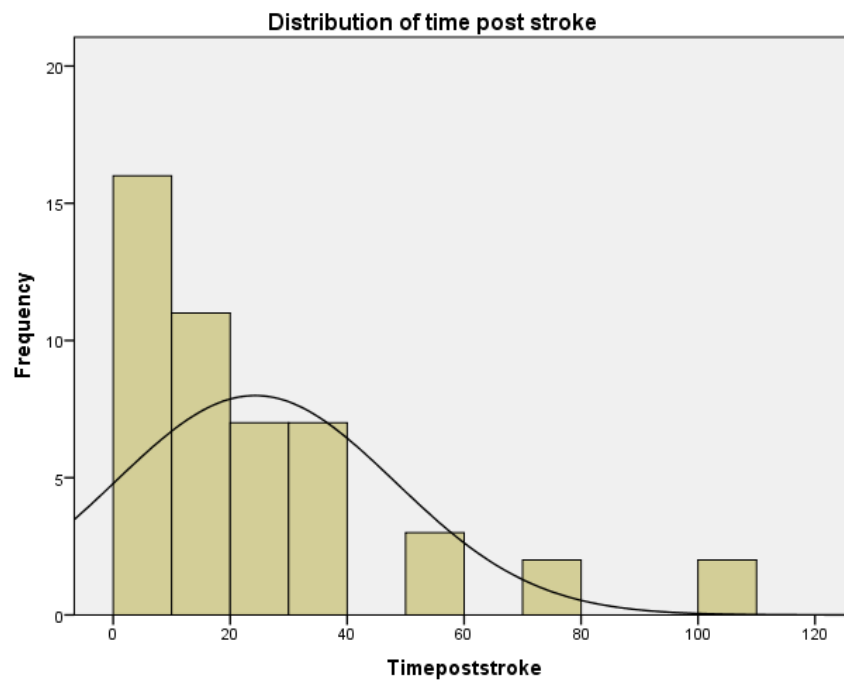
Variables found to be significantly different from the normal distribution with

Shapiro Wilk

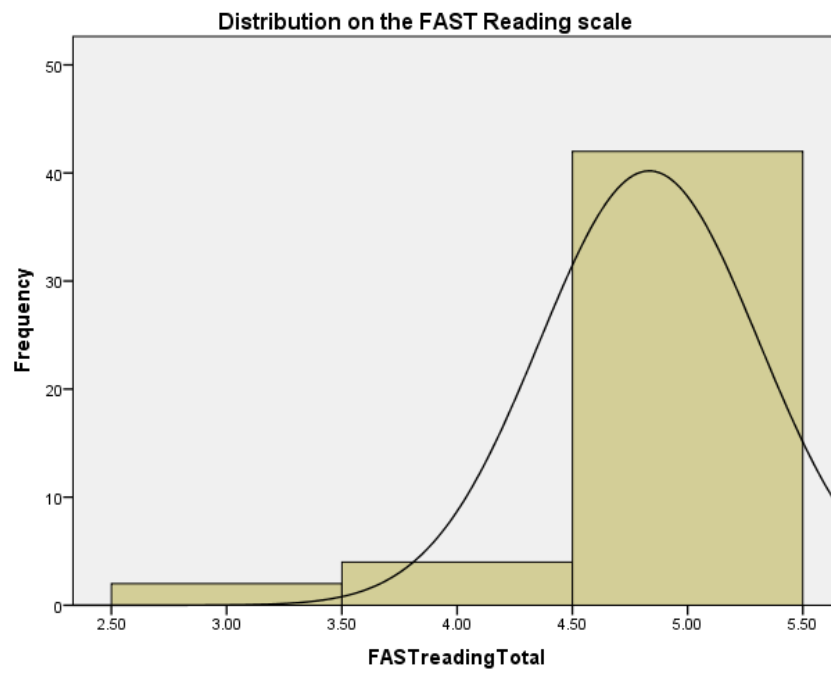
Total Problems:



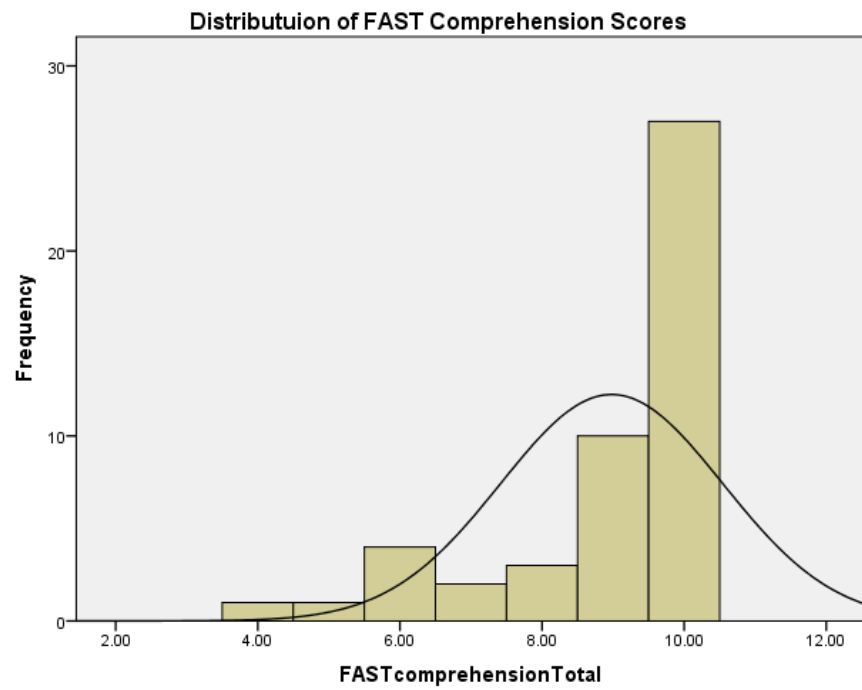
Time post stroke



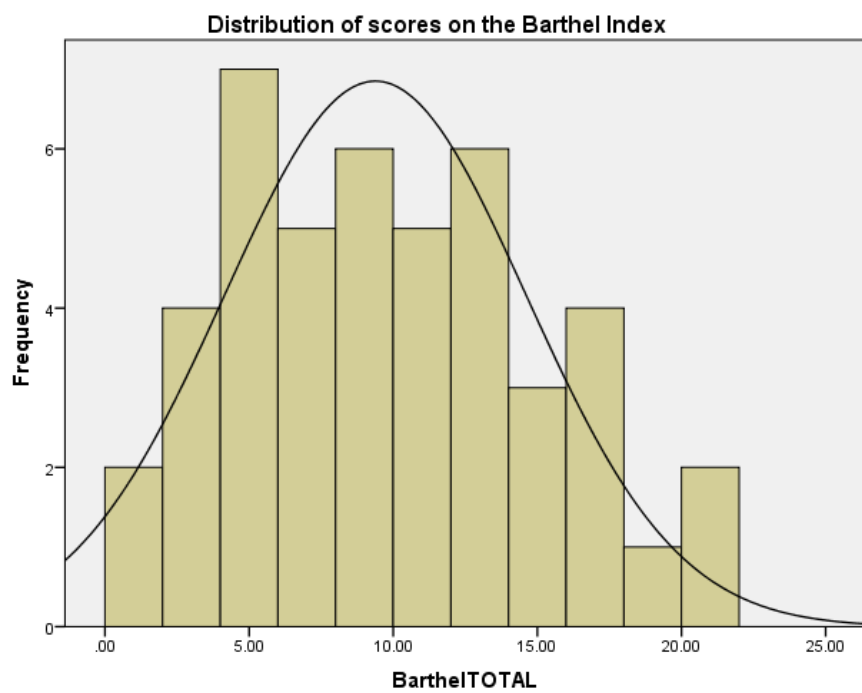
FAST Reading



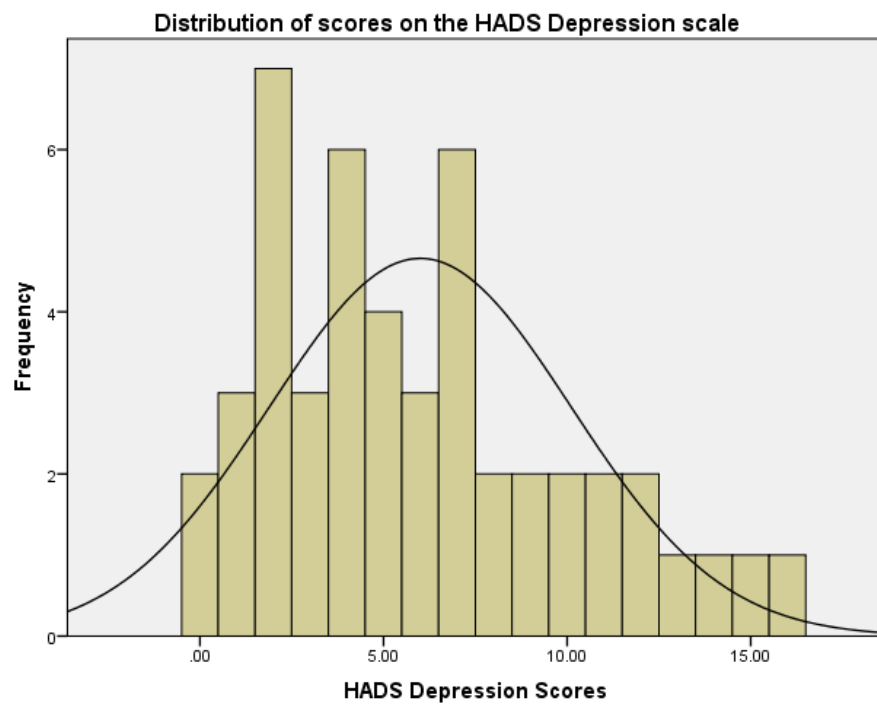
Fast Comprehension



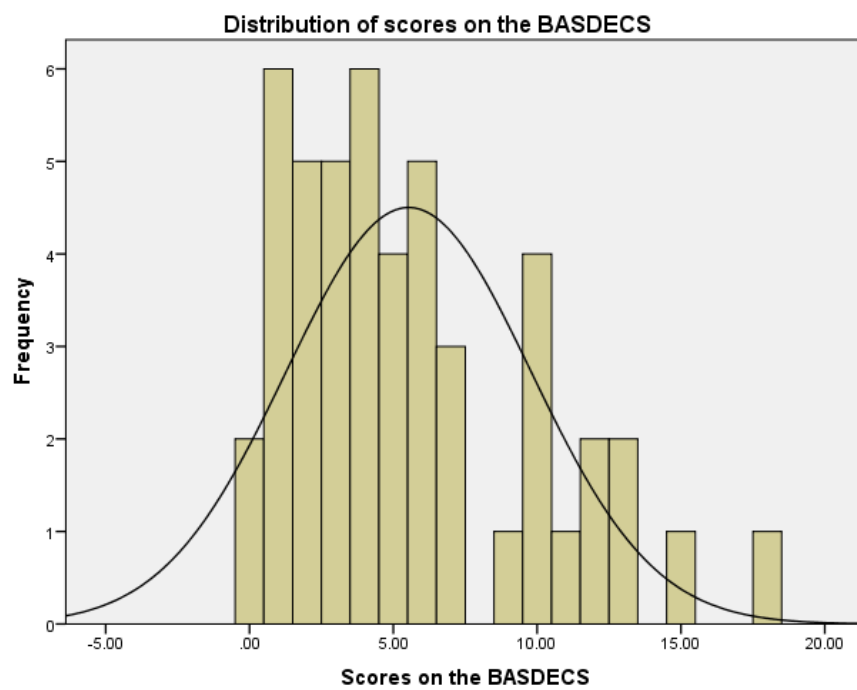
Barthel Index



HADS –Depression



BASDECS



Appendix I

Table 9: DT and Total HADS score

Criterion	Sensitivity	95% CI	Specificity	95% CI	PPV	NPV
≥0	100.00	81.5 - 100.0	0.00	0.0 - 11.6	37.5	
>0	100.00	81.5 - 100.0	16.67	5.6 - 34.7	41.9	100.0
>1	100.00	81.5 - 100.0	30.00	14.7 - 49.4	46.2	100.0
>2	94.44	72.7 - 99.9	33.33	17.3 - 52.8	45.9	90.9
>2.5	83.33	58.6 - 96.4	33.33	17.3 - 52.8	42.9	76.9
>3	83.33	58.6 - 96.4	43.33	25.5 - 62.6	46.9	81.3
>4	77.78	52.4 - 93.6	50.00	31.3 - 68.7	48.3	78.9
>4.5	77.78	52.4 - 93.6	53.33	34.3 - 71.7	50.0	80.0
>5	55.56	30.8 - 78.5	80.00	61.4 - 92.3	62.5	75.0
>6	44.44	21.5 - 69.2	83.33	65.3 - 94.4	61.5	71.4
>6.5	38.89	17.3 - 64.3	86.67	69.3 - 96.2	63.6	70.3
>7	33.33	13.3 - 59.0	90.00	73.5 - 97.9	66.7	69.2
>7.5	27.78	9.7 - 53.5	93.33	77.9 - 99.2	71.4	68.3
>8	16.67	3.6 - 41.4	100.00	88.4 - 100.0	100.0	66.7
>9	5.56	0.1 - 27.3	100.00	88.4 - 100.0	100.0	63.8
>10	0.00	0.0 - 18.5	100.00	88.4 - 100.0		62.5

Table 9: Displays the criterion values of the Distress Thermometer, corresponding sensitivity and specificity values with 95% confidence intervals, and positive and negative predictive values (PPV, NPV) for classification of distress using the HADS. Base rate was taken from the sample (37.5%).

Table 10: Problem List and Total HADS score

Criterion	Sensitivity	95% CI	Specificity	95% CI	PPV	NPV
≥0	100.00	81.5 - 100.0	0.00	0.0 - 11.6	37.5	
>0	94.44	72.7 - 99.9	13.33	3.8 - 30.7	39.5	80.0
>1	94.44	72.7 - 99.9	23.33	9.9 - 42.3	42.5	87.5
>2	94.44	72.7 - 99.9	30.00	14.7 - 49.4	44.7	90.0
>3	94.44	72.7 - 99.9	40.00	22.7 - 59.4	48.6	92.3
>4	88.89	65.3 - 98.6	43.33	25.5 - 62.6	48.5	86.7
>5	77.78	52.4 - 93.6	53.33	34.3 - 71.7	50.0	80.0
>6	72.22	46.5 - 90.3	56.67	37.4 - 74.5	50.0	77.3
>7	66.67	41.0 - 86.7	60.00	40.6 - 77.3	50.0	75.0
>8	61.11	35.7 - 82.7	80.00	61.4 - 92.3	64.7	77.4
>9	44.44	21.5 - 69.2	80.00	61.4 - 92.3	57.1	70.6
>10	44.44	21.5 - 69.2	83.33	65.3 - 94.4	61.5	71.4
>11	38.89	17.3 - 64.3	83.33	65.3 - 94.4	58.3	69.4
>12	27.78	9.7 - 53.5	90.00	73.5 - 97.9	62.5	67.5
>13	22.22	6.4 - 47.6	93.33	77.9 - 99.2	66.7	66.7
>16	11.11	1.4 - 34.7	93.33	77.9 - 99.2	50.0	63.6
>17	11.11	1.4 - 34.7	96.67	82.8 - 99.9	66.7	64.4
>18	11.11	1.4 - 34.7	100.00	88.4 - 100.0	100.0	65.2

Table 10: Displays the criterion values of the Problem List, corresponding sensitivity and specificity values with 95% confidence intervals, and positive and negative predictive values (PPV, NPV) for classification of distress using the HADS. Base rate was taken from the sample and was 37.5%.

Table 11: DT and HADS Anxiety

Criterion	Sensitivity	95% CI	Specificity	95% CI	PPV 20% base rate	NPV 20% base rate
≥0	100.00	83.2 - 100.0	0.00	0.0 - 12.3	41.7	
>0	100.00	83.2 - 100.0	17.86	6.1 - 36.9	46.5	100.0
>1	100.00	83.2 - 100.0	32.14	15.9 - 52.4	51.3	100.0
>2	95.00	75.1 - 99.9	35.71	18.6 - 55.9	51.4	90.9
>2.5	85.00	62.1 - 96.8	35.71	18.6 - 55.9	48.6	76.9
>3	85.00	62.1 - 96.8	46.43	27.5 - 66.1	53.1	81.2
>4	85.00	62.1 - 96.8	57.14	37.2 - 75.5	58.6	84.2
>4.5	85.00	62.1 - 96.8	60.71	40.6 - 78.5	60.7	85.0
>5	60.00	36.1 - 80.9	85.71	67.3 - 96.0	75.0	75.0
>6	50.00	27.2 - 72.8	89.29	71.8 - 97.7	76.9	71.4
>6.5	45.00	23.1 - 68.5	92.86	76.5 - 99.1	81.8	70.3
>7	40.00	19.1 - 63.9	96.43	81.7 - 99.9	88.9	69.2
>7.5	30.00	11.9 - 54.3	96.43	81.7 - 99.9	85.7	65.9
>8	15.00	3.2 - 37.9	100.00	87.7 - 100.0	100.0	62.2
>9	5.00	0.1 - 24.9	100.00	87.7 - 100.0	100.0	59.6
>10	0.00	0.0 - 16.8	100.00	87.7 - 100.0		58.3

Table 11: Displays the criterion values of the Distress Thermometer, corresponding sensitivity and specificity values with 95% confidence intervals, and positive and negative predictive values (PPV, NPV) for classification of anxiety using the HADS. The optimal criterion is in bold.

Table 12: Problem List and HADS Anxiety

Criterion	Sensitivity	95% CI	Specificity	95% CI	PPV 20% base rate	NPV 20% base rate
≥0	100.00	83.2 - 100.0	0.00	0.0 - 12.3	41.7	
>0	100.00	83.2 - 100.0	17.86	6.1 - 36.9	46.5	100.0
>1	100.00	83.2 - 100.0	28.57	13.2 - 48.7	50.0	100.0
>2	100.00	83.2 - 100.0	35.71	18.6 - 55.9	52.6	100.0
>3	100.00	83.2 - 100.0	46.43	27.5 - 66.1	57.1	100.0
>4	95.00	75.1 - 99.9	50.00	30.6 - 69.4	57.6	93.3
>5	85.00	62.1 - 96.8	60.71	40.6 - 78.5	60.7	85.0
>6	80.00	56.3 - 94.3	64.29	44.1 - 81.4	61.5	81.8
>7	70.00	45.7 - 88.1	64.29	44.1 - 81.4	58.3	75.0
>8	65.00	40.8 - 84.6	85.71	67.3 - 96.0	76.5	77.4
>9	50.00	27.2 - 72.8	85.71	67.3 - 96.0	71.4	70.6
>10	50.00	27.2 - 72.8	89.29	71.8 - 97.7	76.9	71.4
>11	45.00	23.1 - 68.5	89.29	71.8 - 97.7	75.0	69.4
>12	35.00	15.4 - 59.2	96.43	81.7 - 99.9	87.5	67.5
>13	30.00	11.9 - 54.3	100.00	87.7 - 100.0	100.0	66.7
>16	20.00	5.7 - 43.7	100.00	87.7 - 100.0	100.0	63.6
>17	15.00	3.2 - 37.9	100.00	87.7 - 100.0	100.0	62.2
>18	10.00	1.2 - 31.7	100.00	87.7 - 100.0	100.0	60.9

Table 12: Displays the criterion values of the problem list, corresponding sensitivity and specificity values with 95% confidence intervals, and positive and negative predictive values (PPV, NPV), for classification of anxiety determined by the HADS. The optimal criterion is in bold.

Table 13: DT and HADS Depression

Criterion	Sensitivity	95% CI	Specificity	95% CI	PPV 33% base rate	NPV 33% base rate
≥0	100.00	76.8 - 100.0	0.00	0.0 - 10.3	29.2	
>0	100.00	76.8 - 100.0	14.71	5.0 - 31.1	32.6	100.0
>1	100.00	76.8 - 100.0	26.47	12.9 - 44.4	35.9	100.0
>2	92.86	66.1 - 99.8	29.41	15.1 - 47.5	35.1	90.9
>2.5	78.57	49.2 - 95.3	29.41	15.1 - 47.5	31.4	76.9
>3	78.57	49.2 - 95.3	38.24	22.2 - 56.4	34.4	81.2
>4	71.43	41.9 - 91.6	44.12	27.2 - 62.1	34.5	78.9
>4.5	71.43	41.9 - 91.6	47.06	29.8 - 64.9	35.7	80.0
>5	50.00	23.0 - 77.0	73.53	55.6 - 87.1	43.8	78.1
>6	42.86	17.7 - 71.1	79.41	62.1 - 91.3	46.2	77.1
>6.5	35.71	12.8 - 64.9	82.35	65.5 - 93.2	45.5	75.7
>7	28.57	8.4 - 58.1	85.29	68.9 - 95.0	44.4	74.4
>7.5	21.43	4.7 - 50.8	88.24	72.5 - 96.7	42.9	73.2
>8	14.29	1.8 - 42.8	97.06	84.7 - 99.9	66.7	73.3
>9	0.00	0.0 - 23.2	97.06	84.7 - 99.9	0.0	70.2
>10	0.00	0.0 - 23.2	100.00	89.7 - 100.0		70.8

Table 13: Displays the criterion values of the DT, corresponding sensitivity and specificity values with 95% confidence intervals, and positive and negative predictive values (PPV, NPV), for classification of depression using the HADS depression scale.

Table 14: DT and BASDECs

Criterion	Sensitivity	95% CI	Specificity	95% CI	PPV 33% base rate	NPV 33% base rate
≥0	100.00	73.5 - 100.0	0.00	0.0 - 9.7	25.0	
>0	100.00	73.5 - 100.0	13.89	4.7 - 29.5	27.9	100.0
>1	100.00	73.5 - 100.0	25.00	12.1 - 42.2	30.8	100.0
>2	100.00	73.5 - 100.0	30.56	16.3 - 48.1	32.4	100.0
>2.5	100.00	73.5 - 100.0	36.11	20.8 - 53.8	34.3	100.0
>3	100.00	73.5 - 100.0	44.44	27.9 - 61.9	37.5	100.0
>4	100.00	73.5 - 100.0	52.78	35.5 - 69.6	41.4	100.0
>4.5	100.00	73.5 - 100.0	55.56	38.1 - 72.1	42.9	100.0
>5	75.00	42.8 - 94.5	80.56	64.0 - 91.8	56.2	90.6
>6	58.33	27.7 - 84.8	83.33	67.2 - 93.6	53.8	85.7
>6.5	50.00	21.1 - 78.9	86.11	70.5 - 95.3	54.5	83.8
>7	50.00	21.1 - 78.9	91.67	77.5 - 98.2	66.7	84.6
>7.5	50.00	21.1 - 78.9	97.22	85.5 - 99.9	85.7	85.4
>8	25.00	5.5 - 57.2	100.00	90.3 - 100.0	100.0	80.0
>9	8.33	0.2 - 38.5	100.00	90.3 - 100.0	100.0	76.6
>10	0.00	0.0 - 26.5	100.00	90.3 - 100.0		75.0

Table 14: Displays the criterion values of the DT, corresponding sensitivity and specificity values with 95% confidence intervals, and positive and negative predictive values (PPV, NPV), for classification of depression using the BASDEC.

Table 15: Problem List and HADS Depression

Criterion	Sensitivity	95% CI	Specificity	95% CI	PPV 33% base rate	NPV 33% base rate
≥0	100.00	76.8 - 100.0	0.00	0.0 - 10.3	29.2	
>0	92.86	66.1 - 99.8	11.76	3.3 - 27.5	30.2	80.0
>1	92.86	66.1 - 99.8	20.59	8.7 - 37.9	32.5	87.5
>2	92.86	66.1 - 99.8	26.47	12.9 - 44.4	34.2	90.0
>3	92.86	66.1 - 99.8	35.29	19.7 - 53.5	37.1	92.3
>4	92.86	66.1 - 99.8	41.18	24.6 - 59.3	39.4	93.3
>5	78.57	49.2 - 95.3	50.00	32.4 - 67.6	39.3	85.0
>6	71.43	41.9 - 91.6	52.94	35.1 - 70.2	38.5	81.8
>7	64.29	35.1 - 87.2	55.88	37.9 - 72.8	37.5	79.2
>8	57.14	28.9 - 82.3	73.53	55.6 - 87.1	47.1	80.6
>9	35.71	12.8 - 64.9	73.53	55.6 - 87.1	35.7	73.5
>10	35.71	12.8 - 64.9	76.47	58.8 - 89.3	38.5	74.3
>11	35.71	12.8 - 64.9	79.41	62.1 - 91.3	41.7	75.0
>12	14.29	1.8 - 42.8	82.35	65.5 - 93.2	25.0	70.0
>13	14.29	1.8 - 42.8	88.24	72.5 - 96.7	33.3	71.4
>16	7.14	0.2 - 33.9	91.18	76.3 - 98.1	25.0	70.5
>17	7.14	0.2 - 33.9	94.12	80.3 - 99.3	33.3	71.1
>18	7.14	0.2 - 33.9	97.06	84.7 - 99.9	50.0	71.7

Table 15: Displays the criterion values of the problem list, corresponding sensitivity and specificity values with 95% confidence intervals, and positive and negative predictive values (PPV, NPV) and HADS Depression classification.

Table 16: Problem List and BASDECs

Criterion	Sensitivity	95% CI	Specificity	95% CI	PPV 33% base rate	NPV 33% base rate
≥ 0	100.00	73.5 - 100.0	0.00	0.0 - 9.7	25.0	
> 0	100.00	73.5 - 100.0	13.89	4.7 - 29.5	27.9	100.0
> 1	100.00	73.5 - 100.0	22.22	10.1 - 39.2	30.0	100.0
> 2	100.00	73.5 - 100.0	27.78	14.2 - 45.2	31.6	100.0
> 3	100.00	73.5 - 100.0	36.11	20.8 - 53.8	34.3	100.0
> 4	100.00	73.5 - 100.0	41.67	25.5 - 59.2	36.4	100.0
> 5	83.33	51.6 - 97.9	50.00	32.9 - 67.1	35.7	90.0
> 6	83.33	51.6 - 97.9	55.56	38.1 - 72.1	38.5	90.9
> 7	83.33	51.6 - 97.9	61.11	43.5 - 76.9	41.7	91.7
> 8	83.33	51.6 - 97.9	80.56	64.0 - 91.8	58.8	93.5
> 9	66.67	34.9 - 90.1	83.33	67.2 - 93.6	57.1	88.2
> 10	66.67	34.9 - 90.1	86.11	70.5 - 95.3	61.5	88.6
> 11	58.33	27.7 - 84.8	86.11	70.5 - 95.3	58.3	86.1
> 12	50.00	21.1 - 78.9	94.44	81.3 - 99.3	75.0	85.0
> 13	41.67	15.2 - 72.3	97.22	85.5 - 99.9	83.3	83.3
> 16	25.00	5.5 - 57.2	97.22	85.5 - 99.9	75.0	79.5
> 17	16.67	2.1 - 48.4	97.22	85.5 - 99.9	66.7	77.8
> 18	16.67	2.1 - 48.4	100.00	90.3 - 100.0	100.0	78.3

Table 16: Displays the criterion values of the problem list, corresponding sensitivity and specificity values with 95% confidence intervals, and positive and negative predictive values (PPV, NPV) and BASDEC Depression classification.

Appendix J: Cronbach's alpha and inter item correlations for subscales.

Problem category	Cronbach's Alpha	Item Total Correlation	Cronbach Alpha if Item Deleted
Physical	.599	.389	.530
Appearance		.473	.473
Bathing and Dressing		.242	.607
Breathing problems		.389	.530
Bladder and bowel		.308	.571
Eating and drinking		.389	.530
Fatigue and tiredness			
Mobility	.446		
Pain		.461	.234
Paralysis		.150	.446
Sexual		.091	.455
Skin problems		.069	.465
Sleeping problems		.331	.320
Visual problems		.191	.419
Practical Problems	.356	<i>Item deleted/no variance</i>	
Child care responsibilities			
Finances		.271	.247
Housing		.178	.305
Transport/driving		.190	.302
Work/activities		.163	.327
Cognitive problems	.710		
Attention and concentration		.293	.733
Communication		.517	.642
Confusion		.617	.595
Memory		.442	.674
Problem solving		.506	.652
Relationships	.656		.581
Family		.449	
Friends		.535	.606
Staff/carers		.580	.475
Roles and responsibilities		.350	.661
Emotional Problems	.782		
Anxiety/worry		.567	.746
Fears		.378	.773
Depression		.680	.725
Crying		.341	.781
Laughing		.379	.775
Loss of interest in usual activities		.440	.767
Anger		.489	.759
Guilt		.419	.768
Denial		.563	.751

Appendix K

Results of 2-6 cluster analysis

Number of clusters	Cluster	Problem items with the least distance between them.
2	1	Appearance, breathing, bladder bowel, eating drinking, pain, paralysis, sexual, skin, sleeping, visual, childcare*, finances, housing, transport driving, work activities, attention concentration, communication, confusion, memory, problem solving, dealing with family members, dealing with friends, dealing with staff/carers, roles and responsibilities, anxiety worry, fears, depression, crying, laughing, loss of interests, anger, guilt, denial, spiritual and religious.
	2	Sleeping, fatigue and bathing dressing.
3	1	Appearance, breathing, eating drinking, pain, , sexual, skin, sleeping, visual, childcare*, finances, housing, transport driving, work activities, attention concentration, communication, confusion, memory, problem solving, dealing with family members, dealing with friends, dealing with staff/carers, roles and responsibilities, anxiety worry, fears, depression, crying, laughing, loss of interests, anger, guilt, denial, spiritual and religious.
	2	Sleeping, fatigue and bathing dressing.
	3	Bladder-bowel, Paralysis
4	1	Appearance, breathing, eating drinking, pain, , sexual, skin, sleeping, visual, childcare*, finances, housing, transport driving, work activities, attention concentration, communication, confusion, memory, problem solving, dealing with family members, dealing with friends, dealing with staff/carers, roles and responsibilities, anxiety worry, fears, depression, crying, laughing, loss of interests, anger,

		guilt, denial, spiritual and religious.
	2	Fatigue and bathing dressing.
	3	Paralysis, bladder bowel,
	4	Sleeping
5	1	Appearance, breathing, eating drinking, pain, , sexual, skin, sleeping, visual, childcare*, finances, housing, transport driving, work activities, attention concentration, communication, confusion, memory, problem solving, dealing with family members, dealing with friends, dealing with staff/carers, roles and responsibilities, anxiety worry, fears, depression, crying, laughing, loss of interest, anger, guilt, denial, spiritual and religious.
	2	Sleeping, fatigue and bathing dressing.
	3	Bladder bowel,
	4	Paralysis
	5	Sleeping
6	1	Appearance, breathing, eating drinking, pain, , sexual, skin, sleeping, visual, childcare*, finances, housing, transport driving, work activities, communication, confusion, memory, problem solving, dealing with family members, dealing with friends, dealing with staff/carers, roles and responsibilities, fears, depression, crying, laughing, anger, guilt, denial, spiritual and religious.
	2	fatigue and bathing dressing.
	3	Bladder bowel,
	4	Paralysis
	5	Sleeping
	6	Attention concentration, anxiety worry, depression, loss of interest.

Appendix L

Retrospective Power Analysis for AUC:

Power analysis was calculated in MedCalc using the AUC values to obtain the sample size required for an adequately powered test using the AUC values obtained in the present study. The traditional hypothesis testing method was used where the null hypothesis is represented by an AUC value of 0.50. The sample size for an alpha value of $\alpha=0.05$ and beta value of $\beta=0.20$ was calculated (Streiner & Norman, 2008).

Table 17:

Analysis	AUC value	Sample (n) required for 80% power per group (present/not present).
DT and Total HADS	.74	n=44
Problem List and HADS Total	.72	n=53
DT and HADS anxiety	.81	n=26
Problem List and HADS anxiety	.83	n=23
DT and HADS Depression	.66	n=101
DT and BASDECs	.87	n=18
Problem List and HADS Depression	.66	n=101
Problem List and BASDECs	.85	n=20

Table 17: displays the sample required for 80% power. $\beta=0.2$ and $\alpha=0.05$.

Appendix M:

Epistemological position

The present study was conducted within a positivist framework. Therefore hypotheses were set and statistical analyses was used to decide whether to accept or reject the hypotheses. The experience of distress was quantified, the sample was seen as representative and statistical power was reached for the primary analysis. This position was deemed the most appropriate to answer the research questions. It provided a clear method of investigation of validity and reliability and enabled a quantifiable outcome, for example reliability is expressed between 0 and 1 where 0 indicates no reliability and 1 indicates perfect reliability (Streiner & Norman, 2008). In addition the validity of the measure is clearly tested in this position by comparison with other well validated measures.

Appendix N:**Chronology of research**

Stage of research	Date
Development of idea and research proposal.	March-October 2011
Application to NHS ethics	January 2012
Attended REC committee	February 2012
Ethical approval granted	March 2012
Recruitment	April 2012-Januray 2013
Data analysis	February – March 2013
Writing of Thesis	September 2012 – April 2013

Appendix O:

[http://onlinelibrary.wiley.com/journal/10.1111/\(ISSN\)2044-8287/homepage/ForAuthors.html](http://onlinelibrary.wiley.com/journal/10.1111/(ISSN)2044-8287/homepage/ForAuthors.html)

Author Guidelines – (used for literature review, excluding word limit)

The aim of the British Journal of Health Psychology is to provide a forum for high quality research relating to health and illness. The scope of the journal includes all areas of health psychology across the life span, ranging from experimental and clinical research on aetiology and the management of acute and chronic illness, responses to ill-health, screening and medical procedures, to research on health behaviour and psychological aspects of prevention. Research carried out at the individual, group and community levels is welcome, and submissions concerning clinical applications and interventions are particularly encouraged.

The types of paper invited are:

- papers reporting original empirical investigations;
- theoretical papers which may be analyses or commentaries on established theories in health psychology, or presentations of theoretical innovations;
- review papers, which should aim to provide systematic overviews, evaluations and interpretations of research in a given field of health psychology; and
- methodological papers dealing with methodological issues of particular relevance to health psychology.

1. Circulation

The circulation of the Journal is worldwide. Papers are invited and encouraged from authors throughout the world.

2. Length

Papers should normally be no more than 5000 words (excluding the abstract, reference list, tables and figures), although the Editor retains discretion to publish papers beyond this length in cases where the clear and concise expression of the scientific content requires greater length.

3. Editorial policy

The Journal receives a large volume of papers to review each year, and in order to make the process as efficient as possible for authors and editors alike, all papers are initially examined by the Editors to ascertain whether the article is suitable for full peer review. In order to qualify for full review, papers must meet the following criteria:

- the content of the paper falls within the scope of the Journal
- the methods and/or sample size are appropriate for the questions being addressed
- research with student populations is appropriately justified
- the word count is within the stated limit for the Journal (i.e. 5000 words)

4. Submission and reviewing

All manuscripts must be submitted via Editorial Manager. You may like to use the Submission Checklist to help you prepare your manuscript. The Journal operates a policy of anonymous peer review. Authors must suggest three reviewers when submitting their manuscript, who may or may not be approached by the Associate

Editor dealing with the paper. Before submitting, please read the terms and conditions of submission and the declaration of competing interests.

5. Manuscript requirements

- Contributions must be typed in double spacing with wide margins. All sheets must be numbered.
- Manuscripts should be preceded by a title page which includes a full list of authors and their affiliations, as well as the corresponding author's contact details. A template can be downloaded from [here](#).
- **Statement of Contribution:** All authors are required to provide a clear summary of 'what is already known on this subject?' and 'what does this study add?'. The 2-3 (maximum) sentences for each point should identify existing research knowledge relating to the specific research question/topic and a summary of the new knowledge added by your study. Under each of these headings, please provide 2-3 clear outcome statements (not process statements of what the paper does); the statements for 'what does this study add?' should be presented as bullet points of no more than 100 characters each. The Statement of Contribution should be a separate file.
- Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript with their approximate locations indicated in the text.
- Figures can be included at the end of the document or attached as separate files, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be

avoided. Captions should be listed on a separate sheet. The resolution of digital images must be at least 300 dpi.

- For articles containing original scientific research, a structured abstract of up to 250 words should be included with the headings: Objectives, Design, Methods, Results, Conclusions. Review articles should use these headings: Purpose, Methods, Results, Conclusions.
- For reference citations, please use APA style. Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full and provide doi numbers where possible for journal articles.
- SI units must be used for all measurements, rounded off to practical values if appropriate, with the imperial equivalent in parentheses.
- In normal circumstances, effect size should be incorporated.
- Authors are requested to avoid the use of sexist language.
- Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations, etc. for which they do not own copyright. For guidelines on editorial style, please consult the APA Publication Manual published by the American Psychological Association.
- Manuscripts describing clinical trials are encouraged to submit in accordance with the CONSORT statement on reporting randomised controlled trials (<http://www.consort-statement.org>).

6. Supporting Information

Supporting Information can be a useful way for an author to include important but ancillary information with the online version of an article. Examples of Supporting Information include appendices, additional tables, data sets, figures, movie files, audio clips, and other related nonessential multimedia files. Supporting Information should be cited within the article text, and a descriptive legend should be included. Please indicate clearly on submission which material is for online only publication. It is published as supplied by the author, and a proof is not made available prior to publication; for these reasons, authors should provide any Supporting Information in the desired final format.

For further information on recommended file types and requirements for submission, please visit: <http://authorservices.wiley.com/bauthor/supinfo.asp>

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Colour illustrations can be accepted for publication online. These would be reproduced in greyscale in the print version. If authors would like these figures to be reproduced in colour in print at their expense they should request this by completing a Colour Work Agreement form upon acceptance of the paper. A copy of the Colour Work Agreement form can be downloaded **here**.

10. Pre-submission English-language editing

Authors for whom English is a second language may choose to have their manuscript professionally edited before submission to improve the English. A list of independent suppliers of editing services can be found

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The corresponding author will receive an email alert containing a link to a web site. A working e-mail address must therefore be provided for the corresponding author. The proof can be downloaded as a PDF (portable document format) file from this site.

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Eg Jones, A.B. (2010). Human rights Issues. *Journal of Human Rights*. Advance online publication. doi:10.1111/j.1467-9299.2010.00300.x

Further information about the process of peer review and production can be found in this document. What happens to my paper?

Appendix P:

Information for Participants

Title: The validity of the Distress Management System within Stroke Care

Investigators: Jessica Holmes, Prof Nadina Lincoln, Ms Mary O'Reilly, Dr Posy Knights and Christopher Watson.

You are being invited to take part in a research study which is being completed as part of a qualification in clinical psychology. Before you decide it is important that you understand what it would involve and why the study is being done.

Please take your time to read through the following information and discuss it with others if you wish. One of the researchers will go through the information sheet with you and answer any questions you have.

Please ask if there is anything you are unsure about.

What is the purpose of the study?

We would like to know whether a new questionnaire, from the Distress Management System, will be useful for understanding sources of distress after a stroke. The questionnaire asks about how distressed people feel and what the causes of distress are after a stroke. This questionnaire will be compared with established measures of mood to understand if it measures what it says it measures (validity).

Who can take part?

We are asking people who are in hospital following a stroke to take part. The study is being conducted between February 2012 and April 2013.

Do I have to take part?

It is up to you to decide if you take part or not, either way it will not affect your standard of care. If you do decide to take part you will be given this information sheet to keep and asked to sign a consent form. If you decide to take part you can withdraw at any time without giving a reason.

What will it involve?

If you decide to take part you will be asked to complete a number of questionnaires asking you about your mood. These will be completed with a trained researcher and will take a maximum of fifty/50 minutes. This can be done all at once or spread out over two sessions.

You will receive all other treatment and care as usual.

Are there any disadvantages, risks or benefits of taking part?

There are no particular risks or disadvantages to taking part.

There may also be no benefit to you by taking part. We expect people's participation will help us to understand more about how people feel after they have had a stroke and whether we can improve services in any way.

What if something goes wrong?

If you wish to complain about the research study or any aspect related to the study then you may do this through the normal NHS complaints procedure, PALS Tel: 0800 028 3693 or the University of Leicester, Clinical Psychology Office Tel: 0116 2231639.

Will my taking part be kept confidential?

If you consent to take part in the study we will consult your medical records in order to gather information about your stroke.

The questionnaires you complete will be kept anonymously, therefore will **not** have your name on and will be stored securely in a locked cabinet. You will be allocated a study number. Your consent form will have both your name and study number on and will be stored separately from your questionnaires, also in a locked cabinet. They will **not** be stored in your medical records. The questionnaires and consent forms will be stored securely in the University of Leicester Clinical Psychology building for a period of 5 years.

All information you share with us will be kept in confidence, although with your permission we may share clinically relevant information with other health professionals involved in your overall care.

If at any time the researcher becomes seriously concerned about your mood they will inform the health professionals caring for you at the time. You will be told about this if it happens.

What will happen with the results of the study?

The results will be written up as part of a Doctorate of Clinical Psychology thesis. The results of the study will also be written up for publication in a scientific journal. You will not be identified in any of the publications.

Who has reviewed the study?

The Derby Ethics Committee has reviewed this study.

Further information

If you would like any further information about the study please contact

Consent Form

Title: The validity of the Distress Management System within Stroke Care

Investigators: Jessica Holmes, Prof Nadina Lincoln, Ms Mary O'Reilly, Dr Posy Knights and Christopher Watson.

The patient should complete the whole of this sheet themselves.

Please initial in the boxes if you agree with the statements

I have read and understand the information sheet (version 3, 14.03.12)

☐

I understand I have the right to withdraw:

at any time

☐
☐

without giving a reason

without it affecting my future medical care

☐

I have had opportunity to ask questions and if so they have been answered
satisfactorily

☐

I agree to the researchers checking my medical records

☐

I have spoke to Ms/Mr about the study.

I would like to receive a short summary of the study when the study is complete - *if yes*

I consent to my address being taken.

☐

Do you agree to take part in the study

☐

Signature (Patient) Date

Name (In block capitals)

I have explained the study to the above patient and he/she has indicated his/her willingness to take part.

Signature (Researcher)Date


Name (In block capitals)

Participant ID number assigned:

☐

Appendix Q:

REC Letter.

		
		Health Research Authority
		NRES Committee East Midlands - Derby
		Research Ethics Office The Old Chapel Royal Standard Place Nottingham NG1 6FS
		Telephone: 0115 8839436 Facsimile: 0115 8839294
 09 March 2012		
 Ms Jessica Holmes Trainee Clinical Psychologist Leicestershire Partnership Trust 104 Regent Road Leicester LE1 7LT		
 Dear Ms Holmes		
Study title:	Validity of the Distress Management System in acute stroke care	
REC reference:	12/EM/0082	
 The Research Ethics Committee reviewed the above application at the meeting held on 01 March 2012. Thank you for attending to discuss the study.		
Ethical opinion		
The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.		
Ethical review of research sites		
NHS Sites		
The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).		
Conditions of the favourable opinion		
<ol style="list-style-type: none">1. Please include initial boxes on the consent form2. Please include contact details of who to complain to in section 'What if something goes wrong' in the participant information sheet		
The favourable opinion is subject to the following conditions being met prior to the start of the study.		
<u>Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.</u>		
<i>Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.</i>		
 A Research Ethics Committee established by the Health Research Authority		

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

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

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

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

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

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Confirmation should also be provided to host organisations together with relevant documentation

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Investigator CV		27 January 2012
Letter from Statistician		29 January 2012
Other: CV for Mary O'Reilly		09 January 2012
Other: CV for Christopher Watson		07 November 2011
Participant Consent Form	1	16 January 2012
Participant Information Sheet	2	29 January 2012
Protocol	4	23 January 2012
Questionnaire: Hospital Anxiety and Depression Scale		
Questionnaire: FAST Score Sheet		
Questionnaire: BASDECS Score Sheet		
Questionnaire: The VAMS-R		
Questionnaire: BARTHEL ADL Index		
Questionnaire: Patient Demographics Information Sheet	1	29 January 2012
Questionnaire: Distress Thermometer and Problem List	1	29 January 2012
REC application		03 February 2012

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

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

After ethical review

Reporting requirements

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

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

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

Feedback

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

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

12/EM/0082

Please quote this number on all correspondence

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

Yours sincerely



Mr Peter Korczak
Chair

Email: carol.marten@nottspct.nhs.uk

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments
"After ethical review – guidance for researchers"

Copy to: Mr David Clarke, Leicestershire Partnership NHS Trust

NRES Committee East Midlands - Derby

Attendance at Committee meeting on 01 March 2012

Committee Members:

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Dr Peter Allmark	Principal Lecturer	Yes	
Dr Helen Busby	Researcher	Yes	
Mr Peter Fox	Principal Pharmacist	Yes	
Ms Karon Glynn	Head of Mental Health	No	
Mr David Grenz	Lay Member	No	
Dr Brian Hands	General Practitioner	Yes	
Dr David Henson	Principal Clinical Biochemist	Yes	
Mr Peter Korczak (Chair)	Consultant Maxillo-facial Surgeon	No	
Mrs Janet Mallett	Lay Member	Yes	
Dr Helen Sammons	Associate Professor in Child Health	Yes	
Dr Nick Taub	Statistician	Yes	
Mr Michael Wakeman	Consultant Pharmacist	Yes	
Mrs Anne Walker	Lay Member	Yes	
Ms Kay Wheat	Academic Lecturer	No	

Also in attendance:

<i>Name</i>	<i>Position (or reason for attending)</i>
Mrs Carol Marten	Coorindator