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Validation of the Distress Thermometer with a Post-Intensive Care Population

by

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ABSTRACT

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VALIDATION OF THE DISTRESS THERMOMETER WITH A POST-INTENSIVE CARE POPULATION

Amy Eva Catherine Yarnold BSc MSc

Advances in medicine have resulted in more patients surviving a stay in the intensive care unit (ICU) than ever before. However, this isn't without its challenges and long term psychological distress has been reported by some clinicians working in ICU. The aim of the literature review was to identify and appraise the evidence base to date and consider the question 'what is the psychological impact of intensive care medicine in adult survivors?' A total of 15 articles were identified that aimed to answer this question. It was clear that a minimum of 10% of adult ICU survivors experience delusions, upsetting memories and nightmares, with a median of 25% of ICU survivors experiencing depression, anxiety and PTSD.

Treatment in an intensive care unit (ICU) is associated with longer term psychological and physical distress. National policy recommends that following discharge from the ICU, patients are assessed for lasting distress, ideally in a follow up clinic. Currently, lengthy and relatively demanding measures such as the Hospital Anxiety and Depression Scale (HADS) and the Impact of Events Scale-Revised (IES-R) are used. Therefore, this empirical study aimed to consider the suitability of a holistic, patient-centred assessment tool called the Distress Thermometer (DT) which could be used in place of the HADS and IES-R at a post-ICU follow up clinic. The purpose of this study was to validate the DT with a post-ICU population. Using Receiver Operating Characteristic (ROC) curve analysis, the DT was found to be good at detecting at least mild cases of anxiety (AUC = 0.81) and probable PTSD (AUC = 0.84). A score of at least two on the DT indicated likely psychological distress. The Problem List (PL) was also adapted for use with a post-ICU population. This is the first study validating the DT with a post-ICU population, and due to a small sample size of 41 patients, further research is warranted to ensure the psychometric properties are maintained. However, the findings for using the DT with this unique clinical population are very promising.

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DECLARATION OF AUTHORSHIP

I, Amy EC Yarnold declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

Validation of the Distress Thermometer with a Post-Intensive Care Population

I confirm that:

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

Signed: .....

Date: 24th August 2015 .....

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Definitions and Abbreviations

ICU	Intensive Care Unit
HADS	Hospital Anxiety and Depression Scale
HADS-A	Hospital Anxiety and Depression Scale – Anxiety subscale
HADS-D	Hospital Anxiety and Depression Scale – Depression subscale
IES-R	Impact of Events Scale – Revised
DT	Distress Thermometer
PL	Problem List
PTSD	Post-Traumatic Stress Disorder
NICE	National Institute of Health and Care Excellence

Chapter 1: Literature Review

1.1 Introduction

The development of the Intensive Care Unit (ICU) emerged from the need for specialist care following the polio epidemic in the 1950s; the manual ventilation of some 300 patients with respiratory failure led to the advent of medical technology which could mechanically ventilate patients (Reisner-Sénélar, 2011). As such advances in medicine and medical technology have continued to progress, increasing numbers of patients are now surviving a stay in intensive care. However, over the last few decades, clinicians working in the field of intensive care medicine have begun to report new challenges arising from these advances.

The use of routine ICU medications such as benzodiazepines, analgesics, and anticholinergics puts patients at risk for delirium, particularly in the ventilated patient where diagnosis, (although easy) is often not recognised (particularly in hypoactive delirium) and therefore not treated. Described as changes in a patient's mental state/fluctuating coma, plus inattention, and/or altered state of consciousness, and/or disorganised thinking; up to 80% of patients admitted to ICU will experience at least one episode of delirium (Page & Ely, 2011). Delirium is now understood to have significant medical complications, including enduring cognitive impairment, the early onset of dementia, post-traumatic stress disorder (PTSD), and death; an episode of delirium increases the risk of mortality three-fold (Ely et al, 2004; Girard et al., 2010; Page & Ely, 2011). Even in the absence of delirium, the effect of benzodiazepines on psychological wellbeing is recognised to put ICU patients at risk for PTSD; cumulative doses of sedatives coincide with increased PTSD scores (Girard et al., 2007), and anxiety and/or depression (Jones, Griffiths, Humphris, & Skirrow, 2001; Schelling et al., 2003).

Empirical research evaluating outcomes of intensive care medicine is gathering pace, such that it has led to the development of screening tools such as the Confusion Assessment Method-ICU (CAM-ICU; Ely et al., 2001) which is designed for use during the ICU stay to screen for

delirium. Further, in 2009, the National Institute of Health and Care Excellence (NICE) published guidance focusing on 'rehabilitation following critical illness' which indicated that psychological wellbeing needed close monitoring both during and after a stay in ICU as part of the patients 'non-physical dimension' (p. 1), and for ICU clinicians to be alert to psychological distress that may not be as a result of the means by which they arrived in ICU. For instance, if a patient arrives in ICU following a road traffic collision, they may experience intrusive memories that relate to the collision itself; but they may also begin to experience flashbacks and intrusive memories not related to the collision, but to their time spent in the ICU, that may likely be a direct consequence of intensive care medicine. However, it was 2010 before NICE published guidance on the diagnosis, prevention and management of delirium, which, as described above, is a key risk factor for dementia, death and longer term psychological distress. So whilst psychological distress was becoming more acknowledged as a risk for non-physical/psychological morbidity, formal guidance on how to prevent and/or manage the possible cause was slightly delayed. Indeed, a survey of ICU clinicians indicated that only 18% of intensive care consultants were aware that ICU delirium can have a long term impact on cognitive impairment, and 75% of intensive care clinicians did not screen for delirium at all (Mac Sweeney, Barber, Page, Ely, Perkins, & McAuley, 2010). This would suggest that there is disparity between clinical awareness of the impact of ICU medicine amongst medical professionals and researchers, and likely wide variability in knowledge between ICUs. Without question, this is putting many ICU patients at risk of harm.

In order to monitor and manage post-ICU distress, the NICE guideline on rehabilitation (2009) recommends that ICU patients are followed up at between 2-3 months post-ICU discharge to reassess all dimensions (biopsychosocial) of the patient's wellbeing. Some hospitals have well-established follow-up clinics but others are in their infancy. Additionally, the author has determined that not all follow-up clinics have liaison and consultation with clinical psychology services. In response to this, there has been a drive to further disseminate information about delirium amongst ICU teams, other medical professionals, and ICU survivors, with a number of

charities and projects established to support this dissemination (ICU Delirium, 2015; ICU Psychosis, 2015; ICU Steps, 2015).

1.1.1 Rationale for Literature Review

At present, only one other paper (Keikkas, Theodorakopoulou, Spyratos, & Baltopoulos, 2010) offers a literature review on psychological distress following a stay in ICU. This paper reports the findings of ten papers which aimed to evaluate the impact of critical care on psychological distress and prevalence of delusional memories, the latter of which was found to be associated with PTSD post-ICU discharge. Psychological distress was operationalised as fear, anxiety and depression, all of which were associated with a stay in ICU. Interestingly the paper noted how the development of a 'safety sense' (p. 288) was found to protect against the emotional impact of ICU, particularly in terms of stressful and delusional memories. Kiekkas et al. (2010) define this 'safety sense' as ensuring that ICU patients are orientated to time and place; that meaningful conversations take place between ICU staff and patients; that only minimal restraint is used with ICU patients; and, that adequate pain management is achieved. The paper further highlighted the need for adequate follow up care to promote psychological recovery.

However, this paper is now five years old and it is possible that more recent publications evaluating the outcome of intensive care medicine may have been published, therefore an up to date review is warranted to synthesise any new research and succinctly report its findings.

1.1.2 Research Question

The aim of this systematic review is to answer the following question: what is the psychological impact of intensive care medicine in adult survivors?

1.2 Methodology

1.2.1 Search Criteria

For the purposes of this review, the term 'psychological impact' is operationalised as the impact on the domains of memory and mental health in an adult. Impact on mental health is then discussed with respect to symptoms of depression, anxiety and post-traumatic stress disorder (PTSD). Four databases (Web of Science, PubMed, CINAHL Plus, & PsychArticles/PsychInfo) were systematically searched for titles that would answer the research question. Searches took place up to the 24th November 2014 for articles that were published from January 1990 to December 2014. Using articles already known to the author as a baseline for appropriate search terms, the following key terms were identified:

Table 1

Initial Search Criteria

Search terms/Stage	Web of Science	PubMed	CINAHL Plus	PsychArticles/ PsychInfo	*Total*
1) ICU OR intensive.care OR critical.care	458,963	277,229	11,074	1,422	748,688
2) Distress OR psychological.distress OR ptsd OR post-traumatic.stress OR anxiety OR depression OR psychological.trauma	31,065	17,131	720	212	49,128
3) Delirium OR delusional OR delusions OR memory OR memories OR sedation	1,312	1,211	120	47	2,690
4) hallucinations OR nightmares OR intrusive.memories	79	70	7	20	176

Articles were included if they observed the above search terms. Additional articles were included following expert recommendation, databases recommending the article as being similar or, through hand-searching the reference lists of other articles. Articles were excluded if they referred to under 18 year olds experiences' of ICU, were not in English, no primary data was present (i.e. in the case of commentaries, systematic reviews etc.), articles were duplicates, articles related to secondary post-traumatic stress disorder, other ICU interventions (e.g. patient diaries), nursing care, non-ICU/Critical Care Unit distress, full text was not obtainable[1], single case studies, and/or they related to during the ICU stay.

Results from the evidence base were only included where the stay in the ICU had been for 24 hours or more (with or without mechanical ventilation), and from patients who had been discharged from hospital; articles where data was collected post-ICU but whilst the patient was still in hospital were excluded (*n* = 5). This was because firstly, the patient would not be medically fit, and secondly, to prevent emotions that are considered a normal adjustment reaction to a stressful event being incorrectly pathologised.

1.2.2 Findings

As illustrated the flowchart in Appendix A, a total of 191 articles (including 15 added) were reduced to 69 possible articles. The full text of these 69 articles was screened; eight articles were identified that answered the research question but offered a qualitative methodology and were therefore excluded. A final total of 15 articles, based on a quantitative methodology and the aforementioned specific inclusion/exclusion criteria being met, conferred suitability for inclusion in the systematic review. Two articles discussed separate findings from one data set (Ringdal et al., 2006, 2009).

[1] Where attempts to obtain articles included: searching the British Library collection and, directly emailing the corresponding author of the article.

1.3 Results

Fifteen articles met the criteria for inclusion. The research question was answered in multiple ways across the papers, so where possible, results have been grouped together.

1.3.1 Constructs

The constructs of anxiety and PTSD were the most frequently reported by the papers (80%, *n* = 12), alongside the impact on memory (60%, *n* = 9), and the impact of depression (53%, *n* = 8)[2]. Discussion of any three of the above constructs was the most popular choice by authors (*n* = 6). Two articles made predictions based on their findings.

1.3.2 Measures

A number of measures were used in the papers to assess memory, symptoms of depression and anxiety, and post-traumatic stress symptoms. The most commonly used measures were the ICU Memory Tool (ICUM; Jones, Humphris, & Griffiths, 2000) or ICU Memory Tool (Jones, Griffiths, Humphris, & Skirrow, 2008); Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983); and, the Impact of Event Scale – Revised (IES-R; Weiss & Marmar, 1997) respectively.

Additional measures for depression/anxiety included: the Centre for Epidemiological Studies – Depression (CES-D; Radloff, 1977); the State-Trait Anxiety Inventory 2nd Edition (STAI-II; Spielberger, 1979); the Profile of Mood States (McNair, Lorr, & Droppelman, 1971); and, the Beck Depression Inventory 2nd Edition (BDI-II; Beck, Steer, & Brown, 1980). Additional measures for PTSD/fear included: the Post-Traumatic Stress Survey-10 (PTSS-10; APA, 1980), the UK Post-Traumatic Stress Syndrome 14-Questions Inventory (UK-PTSS-14; Twigg, Humphris, Jones, Bramwell, & Griffiths, 2008); the PTSD Checklist (PCL; Weathers, Huska, & Keane, 1991); the Posttraumatic Diagnostic Scale (PDL; Foa, Cashman, Jaycox, & Perry, 1997); the Intensive Care Stress Reactions Scale (ICUSS; Wade et al., 2012); the Fear Index (Marks & Matthews, 1979); the Intensive Care Experience Questionnaire (ICEQ; Rattray, Johnston, & Wildsmith, 2004); and, the Intensive Care Unit – Stressful Experiences Questionnaire (ICU-SEQ; Rotondi et al., 2002).

[2] Percentages are greater than 100% as more than one construct could be discussed.

Other health related measures included: the Medical Outcomes Survey (SF-36; Ware & Sherbourne, 1992) to evaluate physical and mental health outcomes, and health-related quality of life (HRQoL); the Well-Being Index (Bech, Gudex, & Johansen, 1996); and, the Psychological Adjustment to Injury Scale (PAIS; Morrow, Chiarello, & Derogatis, 1978). Also administered was the Structured Clinical Interview for DSM (SCID-CV; 1996). All data was obtained from either a questionnaire only format, or a questionnaire and interview format. Only scores that reached clinical thresholds have been reported in this literature review.

Obtaining information using standardised questionnaires ensures that the objective information meets appropriate thresholds in terms of psychometric constructs (e.g. reliability, validity) that may enable the measure to assess prevalence of symptoms relative to a particular diagnosis (e.g. the IES-R screening for symptoms of PTSD). However, gathering data in this manner fails to acknowledge the subjective, qualitative experience of the post-ICU patient and thus not fully identify all possible factors relating to a patient's distress.

1.3.3 Timescales

Data was obtained from a range of two weeks (Jones et al., 2001) post hospital discharge (duration between stay in ICU and discharge from hospital would invariably be longer than two weeks as admission to a general ward is the norm prior to discharge home), up to 12 years (Schelling et al., 1998). The modal duration post-ICU for data collection was six months (Kress et al., 2003; Schelling et al., 2003; Rattray et al., 2005; Ringdal et al., 2006; 2009; Sackey et al., 2008; Granja et al., 2008). This is a good duration after which to assess distress amongst post-ICU patients as it has allowed time for any normal adjustment reactions to take place; where data has been collected two weeks post-discharge from hospital, there is a possibility that patients' reports of distress are confounded by their medical treatment and normal recovery process.

1.3.4 Demographics

Studies were carried out across six different countries: Australia (*n* = 1: Margarey & McCutcheon, 2005), Germany (*n* = 3: Schelling et al., 1998; Stoll et al., 1999; Schelling et al., 2003), Portugal (*n* = 1: Granja et al., 2008), Sweden (*n* = 4: Samuelson et al., 2007; Sackey et al., 2008;

Ringdal et al., 2006; 2009[3]; Zetterlund et al., 2012), UK (*n* = 3: Jones et al., 2001; Rattray et al., 2005; Wade et al., 2012) and USA (*n* = 2: Kress et al., 2003; Davydow et al., 2009).

1.3.5 Designs

The majority of articles employed a prospective cohort study (*n* = 8: Schelling et al., 2003; Rattray et al., 2005; Samuelson et al., 2007; Granja et al., 2008; Sackey et al., 2008; Davydow et al., 2009; Wade et al., 2012; Zetterlund et al., 2007) which was either multi or single centre. The remainder of designs included: case series cohort (*n* = 1: Jones et al., 2001), follow-up cohort (*n* = 2: Stoll et al., 1999; Margarey & McCutcheon, 2005), retrospective cohort (*n* = 1: Schelling et al., 1998) experimental (*n* = 1: Kress et al, 2003) and explorative (*n* = 1: Ringdal et al., 2006; 2009). Despite the different designs, the same conclusions were drawn about the impact of intensive care medicine on psychological wellbeing.

1.3.6 Sample Sizes

Follow-up sample sizes ranged from eight participants (Margarey & McCutcheon, 2005) to 1,906 (Davydow et al., 2009). An acknowledged limitation in the majority of articles was the difficulty in acquiring participants, mainly due to mortality rates, impaired cognition and refusal of consent to participate. Where second (Jones et al., 2001; Margarey & McCutcheon, 2005) and third (Rattray et al., 2005) follow-ups had been conducted, all demonstrated a reduction from their original sample size. A reduction in sample size may reduce effect size and in turn the power to achieve statistical significance. Small sample sizes also increase the likelihood of Type II errors, that is, falsely accepting the null hypothesis (Pallant, 2007).

1.3.7 The Findings

Experiences in ICU and their Association with Psychological Distress

Overwhelmingly, the most frequently reported factor associated with post-ICU distress concerns the patient's experience in ICU. The citing of 'adverse', 'stressful' and/or 'traumatic' experiences of ICU was reported by several studies (Schelling et al., 1998; Stoll et al., 1999; Samuelson et al., 2007; Sackey et al., 2008). Further deconstruction of these terms notes a

[3] Data set used twice for one article

number of key factors including delusional memories, nightmares, traumatic memories, pain, respiratory distress, and anxiety that are associated with increased psychological distress, namely PTSD, anxiety and depression. Two studies (Schelling et al., 1998; Stoll et al., 1999) reported frequencies for traumatic experiences of ICU and can be found in Table 2. Where studies have clearly referred to differences between delusional and factual recall, this is discussed later.

Schelling et al. (1998) report that where either none or one adverse experience was reported by patients, their median scores on the PTSS-10 were lower than those who reported experiencing two or three adverse experiences (an increase in scores from 17 to 28; $p = .015$). Scores on the PTSS-10 were found to increase even further if four adverse experiences were reported (from 30 to 40 points). In addition, patients who reported at least two or more adverse experience were found to have a significantly ($p = .004$) poorer quality of life than post-ICU patients with only one or none adverse experience. These patients also demonstrated decreased mental health wellbeing (reduced by 20%; $p = .001$), decreased social functioning (reduced by 13%; $p = .05$), decreased energy (reduced by 17%; $p = .002$), and increased physical pain (increased by 27%; $p = .001$). Schelling et al. (2003) later reported that 20 of the 27 patients with "new" PTSD (from a sample of 148 reviewed at six months) reported a significantly higher number of categories of traumatic memory ($p < .02$) and were more likely to remember memories of anxiety/panic than patients who did not report PTSD symptoms ($p < .01$).

These findings were mirrored by Stoll et al. (1999) who also found that scores on their developed PTSD measure were noted to significantly increase with the number of traumatic memories reported ($p < .01$), and that patients who remembered two or three categories of traumatic memories had significantly higher scores than those patients who had only reported none or one category of traumatic memory ($p < .01$). At two years post ICU discharge, patients who remembered multiple traumatic memories (2-3) still had significantly higher PTSS-10 scores than those who reported none or one ($p < .01$).

Table 2

Frequency of Traumatic Memories/Experiences

Article	Measure Used	Sample Size	Follow Up Duration	Number of Traumatic Memories/Experiences				
				None	*One*	*Two*	*Three*	*Four*
Schelling et al. (1998)	SF-36 PTSS-10	80	2-12 years	21%, (*n* = 17	21% (*n* = 17)	24% (*n* = 19)	20% (*n* = 16)	14% (*n* = 11)
Stoll et al. (1999)	SCID	52	2 years	9.6% (*n* = 5)	23.1% (*n* = 12)	28.8% (*n* = 15)	26.9% (*n* = 14)	11.5% (*n* = 6)

Similarly, Samuelson et al. (2007) reported that of their 69% (*n* = 156) of patients who had memories of ICU at two-month follow up, the median sum of scores of anxiety and PTSD were significantly higher in patients (53.3%, *n* = 121) who reported extremely stressful experiences of ICU, than those without ($p < .0001$). The items 'nightmares' and 'feeling fearful' on the ICU-SEQ (if experienced as 'extremely stressful') correlated significantly with both the HADS and IES-R scores ($p < .01$) but, interestingly, not each other ($p = .06$); it could be hypothesised that these two items are closely associated and thus they would be expected to correlate, but this was not the case in this study. In patients whose experience of nightmares and feeling fearful was reported as "extremely stressful", median sum scores for anxiety, depression and PTSD were significantly higher than those of patients who did not have such experiences ($p \leq .001$). At two months, the sum scores of the HADS significantly correlated with those of the IES-R ($p < .0001$).

Similar findings were reported by Granja et al. (2008) who evaluated the impact of ICU on memory and possible PTSD symptoms, using the ICU Memory Tool and UK-PTSS-14 at six months post ICU discharge (*n* = 313). The higher the adverse experiences (as defined by number of intrusive/delusional memories), the higher UK-PTSS-14 scores were. However, in contrast, Granja et al. (2008) also noted that there was a strong relationship between early amnesia and PTSD symptoms and hypothesised that, 'by proxy', those patients with amnesia are the most severely ill as the amnesia is reflecting brain dysfunction. It would be interesting for future research to

explore this relationship further and determine whether there is any lasting neuropsychological impairment, when compared to ICU patients with PTSD who did not report amnesia.

Although they used a small sample (n = 16), Sackey et al. (2008) found that at six months follow up, there was a significant association was found between patients' negative feelings of the ICU (defined as intrusive, distressing nightmares and memories, such as being tortured by ICU staff) and high scores on the HADS (p = .02) and IES-R (p = .01). However, when evaluating the relationship between the domains of memory and anxiety, depression, and PTSD, no significant association was found between memories of any delusions and high scores on the HADS and IES-R, which is in contrast to findings in other articles.

Ringdal et al. (2009) evaluated the impact of delusional memories on post-ICU psychological distress (discussed in detail below). They found that the number of delusional memories themselves had no bearing on the impact of anxiety and/or depression; the existence of one delusional memory alone was sufficient to impact upon the chance of developing anxiety and/or depression.

Wade et al. (2012) reviewed post-ICU patients at three months following discharge. Using the STAI, PDS, CES-D, items from the Profile of Mood States, ICUSS, and SCID-CV, the constructs of anxiety, PTSD, depression and traumatic memories were evaluated. Numerous significant findings evaluating associations between experiences in ICU and psychological distress were reported at follow up; intrusive memories (p < .01; p = .01), mood disturbances (p < .01; p < .01), stress reactions (including delirium; p < .01; p < .01), and loss of memory (p = .01; p < .05) whilst in ICU had strong associations with PTSD and depression respectively.

The above studies (Schelling et al., 1998; Stoll et al., 1999; Samuelson et al., 2007; Sackey et al., 2008; Granja et al., 2008; Ringdal et al., 2009; Wade et al., 2012) clearly demonstrate that adverse experiences within ICU, such as nightmares, pain and/or traumatic memories, is greatly associated with post-ICU distress. Further, where reported, typically the higher the frequency of adverse experiences, the higher the reported distress. However, as reported by Ringdal et al. (2009), the experience of only one delusional memory was suffice to impact on post-ICU distress.

Delusional Memories and Factual Recall

Jones et al. (2001) reported at two weeks follow up, patients' memory of ICU was found to fall into four categories based on factual and/or delusional recall: no factual, some delusional (20%, *n* = 9); factual and delusional together (56%, *n* = 25); factual, no delusional (18%, *n* = 8); and, no factual, no delusional (7%, *n* = 3). The last two categories were also combined to create a group who experienced no delusional recall (24%, *n* = 11). Significant group effects were found for both recall and anxiety ($p < .001$) and depression ($p = .041$). Patients who had only delusional memories of ICU (no factual recall) were found to have higher mean scores on the HADS subscales for both anxiety (14) and depression (13) at two weeks ($p < .001$). No association was found between this group of patients and their experience of PTSD ($p = .88$). At eight weeks, those patients who reported delusional recall only at two weeks demonstrated higher scores on the IES-R and Fear Index at eight weeks ($p < .0001$). As measured by the Avoidance subscale on the IES-R, avoidance of memories that were delusional was noted in patients who had delusional recall only ($p < .0001$). Patients who experienced delusional memories only at two weeks ($p < .0001$) and trait anxiety at eight weeks ($p = .006$) were found to be at an increased risk for post-ICU PTSD symptoms. Another finding of interest is that whilst factual memories of ICU were found to decline from two to eight weeks (failure to recall increased from 16% to 37% respectively), delusional memories did not decline and remained constant at both time points.

In 2006, Ringdal et al. evaluated the impact of ICU on memory using the ICU Memory Tool, again looking at the differences between different types of recall. It was reported that 71 patients had a clear recollection of their time in ICU. Of these patients, 97% (*n* = 69) could recall factual memories; 80% (*n* = 57) emotional memories; and, 11% (*n* = 8) delusional memories. Of those patients who could not clearly recall ICU (*n* = 167), 78% (*n* = 130) reported factual memories; 67% (*n* = 111) emotional memories; and, 32% (*n* = 53) delusional memories. There were significantly more patients in the delusional group who reported more emotional memories, such as panic, fear, confusions, and pain. Perhaps not surprisingly, patients who experienced

delusional memories reported a more unpleasant ICU stay. At six to 18 months post-ICU stay, 38% of patients with delusional memories reported feelings of panic/anxiety.

Ringdal et al. (2009) later reviewed their data to consider any associations between experiencing delirium and post-ICU distress. When patients were followed up from between 6-18 months following their ICU stay, significant correlation was found between delusional memories (as measured by the ICU Memory Tool) and anxiety (p = .0028) and, delusional memories and depression (p = .0022). There was a 51% chance of experiencing anxiety when delusional memories were present, but this risk reduced to 29% in the absence of hallucinations or delusional memories. Similarly, there was a 48% chance of depression when delusional memories were present, but again a reduction to 26% in their absence.

The above findings (Jones et al., 2001; Ringdal et al., 2006; Ringdal et al., 2009) clearly highlight the need for more routine assessment of delirium in ICU. As almost all of the post-ICU psychological distress reported relates to the experience of numerous traumatic memories, (specifically those which are intrusive and/or delusional), prompt assessment using tools such as the CAM-ICU (Ely et al., 2001) and management of delirium, could help reduce the long-term psychological impact of ICU.

The evidence also supports the need for more novel ways to help minimise post-ICU distress. The use of ICU patient diaries has been increasing since the 1980s and evidence suggests that they are effective in reducing symptoms of post-ICU anxiety and depression (Knowles & Tarrier, 2009), and can be used as a preventative intervention for PTSD (Jones et al., 2001). Furthermore, Egerod and Christensen (2010) note that the use of diaries can be particularly helpful in providing patients who often have fragmented memories of ICU with a coherent narrative, to aide recovery and reduce distress. Another important factor to consider is the ICU environment and its impact on wellbeing. For example the redesign of Salisbury District Hospital's ICU has been done with reducing distress in mind, particularly for patients who experience delirium; "plain walls, light colours and adjustable lighting can all increase the sense of day and night and help to ease confusion" (Galley, 2015). Further, reducing bedside clutter through by

using medical pendant systems helps to reduce visual stimulation. In addition, when patients are reviewed at the Salisbury ICU follow up clinic, not only are they given the opportunity to receive their patient diary (if they so wish to receive it), but they are also offered the opportunity to visit the ICU as this has been noted by some patients to further make sense of gaps in their memory.

ICU Medications and Procedures

Wade et al. (2012) reported that the strongest clinical risk factor for PTSD was duration of sedation; the longer the duration the higher the risk of developing PTSD symptoms. Associations were also noted between different psychological difficulties and ICU medications; a strong association was noted between symptoms of depression at three months and receiving benzodiazepines ($p = .001$). Symptoms of anxiety were noted to have a strong association with the use of inotropes/vasopressors in ICU ($p < .05$). Conversely, the use of corticosteroids in ICU was associated with a better quality of life post-ICU ($p < .05$).

Davydow et al. (2009) conducted the largest study into post-ICU distress with 1,906 patients. Using the SF-36 and PCL to evaluate mental, physical health and post-traumatic stress symptoms, patients were followed up at three and 12 months to examine any possible factors that could predict PTSD at 12 months. The insertion of a pulmonary artery catheter (PAC) was found to be a risk factor for PTSD ($p = .01$), and when an adjusted statistical model that considered demographic and clinical characteristics was used, PAC insertion remained a strong predictor of PTSD symptoms at 12 months ($p = .01$). This finding was reported to be the first of its kind.

Kress et al. (2003) used the IES-R, SF-36, STAI, BDI-II, and the Psychosocial Adjustment to Illness Scale (PAIS) to evaluate anxiety, depression and PTSD at six months following a stay in ICU in an intervention group ($n = 13$) who underwent daily interruption from sedation compared to a control group who did not ($n = 19$). Those patients who experienced interruption from sedation had significantly lower total PTSD scores ($p = .02$) on the IES-R (11.2 ± 14.9 in the intervention group compared to 27.3 ± 19.2 in the control group). Resultantly, six patients (32%) in the control group were diagnosed with PTSD, with no patients in the intervention group being diagnosed (p

= .06). Significant differences (p = .055) were also noted in the avoidance subscale scores (7.8 ± 9.2 in the intervention group compared to 15.7 ± 10.5 in the control), and the intrusion subscale scores (5.6 ± 7.3 in the intervention group compared to 13.8 ± 9.7 in the control). Chronic (trait) and acute (state) anxiety as measured by the STAI was reported to be higher in the control group (sedation not interrupted daily) but the differences did not reach statistical significance. Similarly, scores on the BDI-II were higher in the control group but again the differences did not reach statistical significance. Although not statistically significant (p = .08), interruption of sedation appeared to have a better impact on total psychosocial adjustment when compared to the no interruption (control) group.

Thus it seems that benzodiazepine treatment, use of inotropes/vasopressors, PAC insertion, and continuous sedation are associated with higher levels of post-ICU distress, and corticosteroid treatment with more positive psychological outcomes. These findings are critical for ICU clinicians to be aware of and raise the possibility for proactive intervention during ICU in order to reduce the likelihood of distress, which is discussed further in the Implications for Clinical Practice section of this literature review.

Respiratory Distress

Schelling et al. (1998) reported that 38% (n = 30) of their sample experienced respiratory distress. In terms of PTSD symptoms, patients who experienced acute respiratory distress syndrome (ARDS) demonstrated higher scores on the PTSS-10 than control groups although this difference was found to be not statistically significant (p = .449). Similar findings were reported by Stoll et al. (1999) with 42.3% (n = 22) of their sample reporting traumatic memories of respiratory distress. These findings are perhaps not surprising since respiratory difficulties are likely to invoke immediate fear for life, which is a criterion for PTSD diagnosis (Weiss & Marmar, 1997).

Other Predictors and Risk Factors

In addition to the insertion of a PAC, Davydow et al. (2009) found that high scores on the SF-36 for mental health difficulties and pain were a very clear predictor of PTSD at 12 months (p <

.001) as was a pre-ICU Charleston comorbidity score[4] (p = .04). Wade et al. (2012) found that at three months, other significant risk factors for PTSD were identified as mood disturbances (including delirium; p < .01) in ICU, and intrusive memories (p < .01). Similarly, one of the significant risk factors for depression was identified as mood disturbances (including delirium; p < .01).

Premorbid Psychological Difficulties

Jones et al. (2001) reported that patients (n = 8) with a premorbid history of anxiety/depression were found to be more likely to experience paranoid delusions (p = .032) and nightmares (p = .017) at two weeks post-ICU than non-premorbid counterparts, and experience higher levels of anxiety (p = .033), when assessed using the ICUM and HADS.

Wade et al. (2012) also concluded that a previous history of psychological difficulties was a risk factor for both PTSD and depression (p < .05; p < .05) at three-month follow up. In addition, socio-economic group was also identified as a risk factor for depression. However, it has not been possible to report the data as categories of socio-economic group were defined by the article's authors and no information was provided as to what each category corresponds to; reported p values were significant however.

Schelling et al. (2003) examined PTSD scores using the SF-36. No change in scores was evident in seven patients with existing PTSD when followed up at six months. Interestingly, pre-operative stress was reported to be lower in those patients with existing PTSD, than new patients with PTSD (p < .01). Davydow et al. (2009) further noted that depression prior to admission into ICU was a risk factor for developing PTSD (p = .03).

If a patient is identified as having premorbid psychological difficulties such as anxiety/depression/PTSD, it could be helpful for the ICU team to consult with the patient's mental health team if one was accessed. Not only could this identify strategies that have been helpful in the past to manage distress (e.g. if a Wellbeing Recovery Action Plan/WRAP has been completed),

[4] The Charleston Comorbidity score is used to predict ten-year morbidity for a patient with multiple comorbid conditions.

it may encourage the mental health team to consider providing earlier psychological support post-discharge; this could be particularly helpful if the patient attended an ICU away from home.

Other Findings of Interest

Schelling et al. (2003) reported that at six months, an increase in depressive symptoms was noted ($p < .01$) amongst those patients with "new" PTSD; conversely those patients identified as *not* having PTSD symptoms demonstrated significantly lower depression scores ($p < 0.1$). Another interesting finding is that 22% of patients who had not talked about their stay in ICU to anyone had significantly higher scores on the depression subscale of the HADS than those who had (52% vs 26%; $p = .001$; Ringdal et al., 2009), which perhaps raises a question as to whether families/carers of the patient feel equipped emotionally to be able to take with their loved one about their illness and recovery. It may also reflect those patients, who due to their distress, wish to avoid any reminders of ICU.

In conclusion, the evidence to date indicates that a significant number of post-ICU patients experience psychological distress, with several studies reporting associations and predictions relating to very specific aspects of ICU medicine (e.g. medications, interventions etc.). A significant number of post-ICU patients also report various traumatic and delusional memories and these appear to significantly correlate with an increased prevalence and intensity of distress, as measured by high scores on measures assessing PTSD, anxiety, depression and enduring memory difficulties.

1.3.8 Prevalence Rates of Psychological Distress

As documented above, the majority of the reviewed articles reported a stay in ICU was often associated with symptoms of anxiety, depression, or PTSD. Where articles reported prevalence rates for each mental health disorder, an attempt to summarise these can be found below. Reported prevalence rates for adverse and distressing memories are also reported. Prevalence of rates of specific disorders were determined by minimum clinical 'caseness' scores for their respective measure; as reported in the measures manual.

Prevalence rates of anxiety. Articles which stated the prevalence rates of clinical levels of anxiety are documented in Table 2. The range for the prevalence of anxiety, based on the articles included in this review, was reported to be between 4.9% and 50%, with a median prevalence rate of 40%. Anxiety symptoms were assessed using the HADS (anxiety subscale) and the STAI (State-Trait Anxiety Inventory).

Table 3

Prevalence rates and characteristics of anxiety data

Article	Measure Used	Sample Size	Follow Up Duration	Prevalence
Rattray et al. (2005)	HADS	87, 80	6 months,12 months	41%, 45%
Samuelson et al. (2007)	HADS	226	2 months	4.9%
Sackey et al. (2008)	HADS	16	6 months	50%
Ringdal et al. (2009)	HADS	239	6-18 months	39%
Wade et al. (2012)	STAI	100	3 months	44.4%
Zetterlund et al. (2012)	HADS	41	1 year, 5 years	24%, 28%

Prevalence rates of depression. Articles stated the prevalence rates of depression, are summarised documented in Table 3. The range for the prevalence of depression, based on the articles included in this review, was reported to be between 7.5% and 50%, with a median prevalence rate of 26.5%. Depression symptoms were assessed using the HADS (depression subscale) and the CES-D (Centre for Epidemiological Studies – Depression subscale).

Table 4

Prevalence rates and characteristics of depression data

Article	Measure Used	Sample Size	Follow Up Duration	Prevalence
Rattray et al. (2005)	HADS	87	6 months	26%
		80	12 months	27%
Samuelson et al. (2007)	HADS	226	2 months	7.5%
Sackey et al. (2008)	HADS	16	6 months	50%
Ringdal et al. (2009)	HADS	239	6-18 months	31%
Wade et al. (2012)	CES-D	100	3 months	46.3%
Zetterlund et al. (2012)	HADS	41	1 year, 5 years	24%, 23%

Prevalence rates of PTSD. As measured by the IES-R, ICU PTSD, PTSS-14, SCID, PCL, and PDS, where articles stated the prevalence rates for PTSD symptoms, these are documented in Table 4.

The range of prevalence for PTSD, based on the articles in this review, was reported to be between 8.4% and 50%, with a median prevalence of 25%.

Table 5

Prevalence rates and characteristics of PTSD data

Article	Measure Used	Sample Size	Follow Up Duration	Prevalence
Stoll et al. (1999)	SCID	52	2 years	25%
Kress et al. (2003)	IES-R	19 (Control)	6 months	32%
Schelling et al. (2003)	ICU PTSD	148	6 months	18.2%
Samuelson et al. (2007)	IES-R	226	2 months	8.4%
Granja et al. (2008)	PTSS-14	313	6 months	18%
Sackey et al. (2008)	IES-R	16	6 months	50%
Davydow et al. (2009)	PCL	1906	12 months	25%
Wade et al. (2012)	PDS	100	3 months	27.1%

Prevalence rates of adverse events/distressing memories. Across the articles, many evaluated the incidence of either adverse events (such as pain) or distressing memories (such as nightmares) that could contribute to psychological distress post-ICU. Memories were assessed using the ICUM (ICU Memory Tool), SF-36 (Medical Outcomes Survey), ICU PTSD, SCID (Structured Clinical Interview for DSM), and Fear Index.

1.3.9 Limitations

A number of key themes were acknowledged by the articles authors.

Sampling. As briefly mentioned earlier, several articles experienced difficulties in recruiting and retaining patients (where studies involved follow ups, e.g. Zetterlund et al., 2012; Samuelson et al., 2007 noted that older patients dropped out which could have resulted in bias), with these difficulties extended to include low response rates and/or missing data (Granja el al., 2008; Jones et al., 2001; Kress et al., 2003; Margarey & McCutcheon, 2005; Ringdal et al., 2006; Ringdal et al., 2009; Sackey et al., 2008; Schelling et al., 2003; Rattray et al., 2005). A number of articles reported possible selection bias due to being single centre (Schelling et al., 1998; Wade et al., 2012) or due to self-selection (Margarey & McCutcheon, 2005). Stoll et al. (1999) recognised that their results may have been influenced by other medical conditions (e.g. sepsis, pneumonia, trauma) when assessing for Acute Respiratory Distress Syndrome. Kress et al. (2003) further commented that

their study examining the effects of sedation interruption lacked randomisation; due to the benefits of this intervention, it was difficult for medical staff to withhold.

Premorbid functioning. Whilst a number of articles did screen patients for premorbid neurological/psychological difficulties (Kress et al., 2003; Jones et al., 2001; Schelling et al., 1998; Stoll et al., 1999; Zetterlund et al., 2012; Wade et al., 2012; Davydow et al., 2009; Margarey & McCutcheon, 2005; Sackey et al., 2008), several articles did not and recognise that this may have overestimated the prevalence and impairment relating to anxiety, depression, and PTSD (Granja et al., 2008; Rattray et al., 2005). Whilst Schelling et al. (2003) did screen for most psychological disorders, they acknowledged that they did not screen for all emotional disorders that could have contributed to a patient's distress. Ringdal et al. (2006; 2009) did exclude patients who had made previous suicide attempts but it was not clear if they screened for premorbid psychological difficulties. Samuelson et al. (2007) report excluding patients who were psychotic but did not explicitly state if patients were screened for premorbid difficulties.

Contextual factors. Where ICU patients had been in an accident involving other persons (be they known to the patient or not), and these persons had subsequently died or been seriously injured, this is likely to have impacted upon their psychological wellbeing. Ringdal et al. (2006) acknowledged that they did not routinely ask patients if this had been their experience, and thus if this had been a patient's experience, it may have influenced the manifestation of nightmares and/or delusional memories, thus influencing reporting. Similar concerns were noted by Samuelson et al. (2007), explaining that they had not considered the impact of other potentially traumatic events occurring just prior to or post ICU discharge. It should be noted that this limitation was not considered by the remaining 13 articles in this literature review.

Table 6

Prevalence rates and characteristics of memory data

Article	Measure Used	Sample Size	Follow Up Duration	Category of Memory Recalled						
				Delusional	*Hallucinations*	*Nightmares*	*Emotional*	*Anxiety*	*Pain*	*Respiratory Distress*
Schelling et al. (1998)	SF-36	80	2 – 12 years	-	-	64%	-	41%	40%	38%
Stoll et al. (1999)	SCID	52	2 years	25%	-	75%	-	46.2%	42.3%	42.3%
Jones et al. (2001)	ICUM & Fear Index	45	2 weeks	20% (DM only) 56% (DM & FM)	-	-	-	-	-	-
Schelling et al. (2003)	ICU PTSD	148	6 months	18.2%	-	37.2%	-	47.3%	37.8%	41.5%
Margarey & McCutcheon (2005)	ICU PTSD(2)	51	1 month – 2 years	27.5% (Confusion)	16%	10% (22% vivid dreams)	-	29%	-	-
Ringdal et al. (2006)	ICUM	71	6-18 months	25.5%	-	-	70.3%	-	-	-
Granja et al. (2008)	ICUM	313	6 months	39% (of which 23% intrusive)	-	-	-	-	-	-
Sackey et al. (2008)	ICUM	16	6 months	44%	-	44%	-	-	-	-
Zetterlund et al. (2012)	ICUM/ SF-36	41	1 year, 5 years	24%, 24% (of which 10% thought they were being hurt)	24%, 24%	22%, 29%	59%, 61%	10%, 29%[5]	37%, 46%	-
Range of Memories Recalled				20% - 56%	16% - 24%	10% - 75%	59% - 70.3%	10% - 47.3%	37% - 46%	38% - 42.3%
Median				25%	20%	37%	61%	29%	40%	42%

[5] $P = .021$

1.4 Conclusion

The purpose of this literature review has been to answer the question 'what is the psychological impact of intensive care medicine in adult survivors?' Through a process of systematically identifying and appraising the evidence base, a total of 15 articles were identified that aimed to answer this question. It is clear from the review that intensive care medicine can have a significant impact on psychological wellbeing, such that patients are developing anxiety, depression, PTSD and, distressing memories following a stay in ICU.

An additional rationale for completing this literature review was to consider more recent research following on from the literature review conducted by Kiekkas et al. (2010). Whilst the findings of this literature support the original review in that ICU care does impact on psychological wellbeing and that delusional memories are associated with PTSD, the inclusion of research by Wade et al. (2012) and Zetterlund et al. (2012) offered not only additional prevalence rates for psychological distress (including at five-year follow up), it also considered risk factors for psychological distress which extends the findings of the previous review. Further, slightly different search terms enabled the inclusion of 15 articles as opposed to ten; this offered broader reporting of findings, including one other paper (available at the time of Kiekkas et al. 2010 but not included) that also considered risk factors for PTSD (Davydow et al., 2009) and which warrants further dissemination.

As outlined in the results section, upsetting memories, including nightmares and delusions were common in a minimum of 10% of the post-ICU population sampled, although median scores indicate that the prevalence may be more realistic at between 20% and 61%. Similarly, the presence of depression, anxiety and PTSD was reported in a median of at least one-quarter (25%) of those post-ICU patients sampled. When one compares these figures to those of the general population for anxiety and/or depression (19%; ONS, 2013), it is apparent that post-ICU patients are at a slightly higher risk of developing depression and/or anxiety than individuals in the general population. However, when one compares the figures to those of the general population for PTSD

(3%; McManus et al., 2007), it is clear that the marked difference in prevalence indicates that post-ICU patients are at a significantly increased risk for developing PTSD.

Many of the articles examined relationships between different post-ICU factors of psychological distress and significant correlations were reported in several cases. It is evident that both the number and different categories of traumatic memories, including those of nightmares, hallucinations, delusions, anxiety, pain, and breathing difficulties, were found to significantly correlate with post-ICU symptoms of psychological distress (including PTSD and/or anxiety, and/or depression) as evidenced by raised scores on their respective psychological screening measures. Further, the use of ICU medications such as benzodiazepines and inotropes/vasopressors were strongly associated with the post-ICU development of depression and anxiety respectively. This is an interesting finding as typically benzodiazepines are prescribed to reduce anxiety (RCPSYCH, 2013) although research indicates that they can have a paradoxical effect by increasing anxiety and disinhibitions (Paton, 2002), which is perhaps the case in ICU settings. Research has also indicated that benzodiazepines can discriminatorily reduce emotional memory (Brignell, Rosenthal, & Curran, 2007) so one might have expected it to serve as a protective factor, but this appears to not be the case in these instances. Duration of sedation was strongly associated with the post-ICU development of PTSD, and indeed one article noted that ICU patients who received daily interruption from sedation were at a reduced risk for developing PTSD, whilst those who experience uninterrupted sedation were at an increased risk.

The use of ICU medications, whilst not always explicitly studied in the above articles, are implicated in development in post-ICU psychological distress as they are very often the cause for patients to experience delirium and thus report traumatic memories, which *has* been documented, and is supported by empirical research discussed in the introduction. For instance, one can conclude that the impact of sedation on development on PTSD is caused by the drugs administered to sedate, and the subsequent physiological changes that happen to the brain and body as a result of this.

Finally, a handful of the articles used statistical analyses that enabled the researchers to determine if specific factors relating to the stay in intensive care and application of intensive care medicine itself put patients at not only increased risk for psychological distress, but also could predict it. Specifically, predictors of post-ICU psychological distress (depression and/or PTSD) were identified as the insertion of a pulmonary artery catheter (PAC), mood disturbances (including delirium) whilst in the ICU, ICU patients with a previous history of psychological difficulties and, socio-economic group. Risk factors for longer term post-ICU psychological distress were identified as intrusive memories post-ICU, and high scores for mental health difficulties and pain on the SF-36.

1.4.1 Implications for Clinical Practice

The findings of this literature review add continued support to the NICE (2009, 2010) guidelines, but two articles in particular (Davydow et al., 2009; Wade et al., 2012) add further support to the need for monitoring of patient's psychological wellbeing both during and post-ICU, particularly as they identify predictors to distress.

During ICU. Whilst the need to preserve and promote life will always remain the key aim of ICU medicine, it is imperative that ICU clinicians have a solid understanding of the possible implications of those medications and procedures that are often routinely administered as part of this process, such as benzodiazepines and the insertion of a pulmonary artery catheter and/or sedation, can have on both immediate and longer term psychological wellbeing. It is appreciated that it may not be possible to deviate from clinical practice in many aspects of care, but for instance, if it is possible and medically safe for a sedated ICU patient to have their level of sedation regularly interrupted, then this may significantly reduce the risk of that patient developing PTSD. Also, the awareness of and screening for delirium needs to be more widely undertaken; as highlighted in the introduction, a very brief screen for delirium in ICU (Ely et al., 2001) can help identify a risk factor for not just psychological distress, but for dementia, and more seriously death. Yet, awareness of delirium and its implications is limited amongst some ICU clinicians (Mac Sweeney, Barber, Page, Ely, Perkins, & Mcauley, 2010). As this review has

highlighted, traumatic memories including delusions and hallucinations are clearly prevalent in a post-ICU population, and are also a feature of delirium; the presence of such memories will increase risk for longer term psychological distress. As 80% of patients will experience delirium (Ely & Page, 2011), if routine screening was undertaken then this would reduce associated risks. As discussed earlier, the completion of ICU patient diaries could be very helpful for when the patient is well enough to read them (Jones et al., 2001; Knowles & Tarrier, 2009; Egerod & Christensen, 2010).

Post-ICU. This review lends support for the NICE (2009) recommendation of post-ICU follow up to assess psychological wellbeing, amongst general recovery. Ensuring that ICU patients are appropriately screened for psychological distress at follow up is crucial to enable access to services that can help alleviate and/or minimise distress. What is evident from the findings of this review is that in studies where ICU patients have been assessed at two time points, symptoms of depression, anxiety, PTSD, and memory difficulties typically remain stable, and in certain instances, some patients demonstrated a slight deterioration (increase in reported distress) at the second time point. This suggests that symptoms of psychological distress do not spontaneously improve over time and may persist until such time when appropriate psychological help is sought, indicating a very clear clinical need for longer term psychological support for patients, following their discharge from ICU.

1.4.2 Limitations of the Literature Review

Appraising the literature with such specific search criteria can reduce the scope for broader discussion and understanding, and can lead to omitting articles that are relevant to the research question but that, due to their methodology are excluded. For instance, eight articles were excluded due to their qualitative nature but this doesn't imply that their findings were not of importance or that they do not contribute to the evidence base.

It was not possible to obtain several articles either because they were in another language and/or full text was not available. This may again have limited the discussion and minor

methodological weaknesses were found in some articles that may have reduced the validity of findings.

1.4.3 Is there a role for Clinical Psychology?

The delivery of training and consultation around delirium, in conjunction with ICU clinicians to others within the team, could help increase awareness and confidence when screening for delirium and in understanding how it impacts both in the short and longer term. Following on from the post-ICU implications, clinical psychology could be an asset to any post-ICU follow up team, not just in terms of screening for psychological distress, but in terms of providing appropriate therapeutic interventions without the need for further referral and waiting. Another aspect of ICU medicine not considered in this review, but certainly written about in the wider literature base, is the impact of ICU medicine on family members; the author noted several articles were excluded that examined the prevalence of secondary PTSD, which warrants further investigation. Additionally, the author noted articles (excluded) that raised concerns about the prevalence of delirium on general hospitals wards, so there is a need for further investigation into this to determine whether clinical psychology consultation and intervention to the wider hospital network could be of importance.

Finally, the scientist-practitioner training undertaken by clinical psychologists lends itself well to both undertaking further research into the field of intensive care medicine, but also to developing tools and techniques that could possibly help screen for psychological distress to ensure that post-ICU patients are followed up both comprehensively and in a timely manner in accordance with NICE guidelines (2009).

Chapter 2: Empirical Paper

2.1 Introduction

Over the last 20 years or so, advances in medicine and medical technology have resulted in increasing numbers of patients surviving a stay in an Intensive Care Unit[6] (ICU; Rattray, Johnston, & Wildsmith, 2005). As a result, there has been an increased interest in the need to understand the longer term implications that a stay in ICU can have on an individual's psychological and physical wellbeing.

There is a growing body of evidence indicating that a stay in an ICU is associated with subsequent psychological distress (Perrins, King, & Collings, 1998; Campbell, 1998; Scragg, Jones, & Fauvel, 2001; Jones, Griffiths, Humphris, & Skirrow, 2001; Jones et al., 2003; Jackson et al, 2003; Rattray, Johnston, & Wildsmith, 2005; Samuelson, Lundberg, & Fridlund, 2007; Kiekkas, Theodorakopoulou, Spyratos, & Baltopoulous, 2010; Myhren, Ekeberg, Tøien, Karlsson, & Stokland, 2010; de Miranda et al., 2011; Zetterlund, Plos, Bergbom, & Ringdal, 2012).

Psychological problems including anxiety, depression, and post-traumatic Stress Disorder (PTSD) are frequently reported in this population; at one year post-ICU discharge as many as 4.9% to 50% of patients will report anxiety (Rattray, Johnston, & Wildsmith, 2005; Samuelson, Lundberg, & Fridlund, 2007; Sackey, Martling, Carlswärd, Sundin, & Radell, 2008; Ringdal, Plos, Lundberg, Johansson, & Bergbom; 2009; Wade et al., 2012; Zetterlund, Plos, Bergbom, & Ringdal, 2012), with 7.5% to 50% of patients reporting depression (Rattray, Johnston, & Wildsmith, 2005; Samuelson, Lundberg, & Fridlund, 2007; Sackey, Martling, Carlswärd, Sundin, & Radell, 2008; Ringdal, Plos, Lundberg, Johansson, & Bergbom; 2009; Wade et al., 2012; Zetterlund, Plos, Bergbom, & Ringdal, 2012), and 7.5% to 50% reporting symptoms consistent with PTSD (Stoll et al., 1999; Kress et al., 2003; Schelling et al., 2003; Samuelson, Lundberg, & Fridlund, 2007; Granja et al., 2008; Sackey, Martling, Carlswärd, Sundin, & Radell, 2008; Davydow et al., 2009; Davydow,

[6] Also identified in some hospitals as the Intensive Treatment Unit (ITU) or Critical Care Unit (CCU).

Gifford, Desai, Needham, & Bienvenu, 2008; Wade et al., 2012). These figures are above the lifetime prevalence reported amongst the general population for anxiety (4.7%), depression (2.6%), anxiety/depression (9.7%), and PTSD (3%) as reported by the UK household psychiatric morbidity survey (NHS Information Centre, 2007). Although one household survey in 2013 (ONS) suggested that almost a fifth (19%) of adults were living with depression and/or anxiety at point of survey. In all of the aforementioned studies, early (either one month or three months post-discharge) distress predicted the outcomes at the one year follow up. Research has also sought the opinions of the caregivers of patients who have been in ICU; over half of caregivers reported that at one month post-discharge the patient demonstrated psychological and physical distress with a reduction in normal activities (Choi, Donahoe, Zullo, & Hoffman, 2011). There is also evidence that family members of the ICU patient are at increased risk for PTSD, anxiety and depression three months following the patient's discharge (McAdam et al., 2012).

Several factors have been identified as being associated with increased distress, notably the incidence of delirium, the use of 'heavy duty' medications such as steroids (Vincent, 1995) and benzodiazepines (used for sedation; Sharma, Malhotra, Grover, & Jindal, 2012; Barr et al., 2013), and administration of a pulmonary artery catheter (which may by proxy reflect the severity of the critically ill patient, Davydow et al., 2009). Davydow et al. (2009) also note that an increased length of stay (> five days) in the ICU and having had a tracheostomy are associated with reduced return to normal activity following discharge.

As has been recommended in all of the above-referenced articles, early assessment of psychological distress is fundamental; it is hoped that the earlier distress is detected, the earlier treatment can be commenced. Thus there is a clear and significant clinical need to assess and manage the psychological wellbeing of these patients to ensure that long-term psychological problems, such as depression, anxiety and post-traumatic stress disorder (PTSD) are identified at the earliest opportunity and are afforded the appropriate treatment.

2.1.1 National and Local Protocols

Such is the importance of early psychological assessment, the NICE Guideline (2009) on rehabilitation after critical care states that clinical assessment prior to and post discharge should include "underlying factors such as pre-existing psychological or psychiatric distress; and any symptoms that developed during the critical care stay (for example delusions or intrusive memories, anxiety or panic episodes, nightmares or flashbacks, depression" (p. 2). In order to adhere to this guideline, ICU clinicians routinely administer screening measures such as the Hospital Anxiety and Depression Scale (HADS: Zigmond & Snaith, 1983) and Impact of Events Scale-Revised (Weiss & Marmar, 1997) at follow up; should a patient's scores be above a clinical cut off on either or both measures, further assessment is warranted and clinicians are instructed to refer to the relevant NICE Guideline on anxiety, depression or post-traumatic stress disorder (PTSD). In addition, the Department of Health (2000) Comprehensive Critical Care strategy recommends that NHS trusts ensure there is appropriate provision for follow up care; it notes that despite the well-documented long term psychological and physical effects of intensive care treatment, very few NHS trusts offer follow up reviews and/or support.

Despite these strategies, neither stipulates which measures should be utilised to assess psychological distress; the HADS (for anxiety/depression) and IES-R (PTSD) are readily used in practice as both have good reliability and validity, plus they are relatively brief to complete. In reality though, neither offers a holistic assessment of the patient's difficulties – physical health and social difficulties are ignored, which may be contributing to, or perpetuating a patient's distress. The WHO (2001) reports that there is a "dynamic interaction" (p. 26) between physical health, level of functioning, disability and context, positing a biopsychosocial model is best placed to understand and assess an individual's needs. With this in mind, current protocols for assessing distress in post-ICU follow up clinics fail to consider the biopsychosocial model.

2.1.2 The Distress Thermometer (DT)

The Distress Thermometer (DT; Roth et al., 1998) and Problem List (PL, NCCN, 2001) are measures that were initially developed to assess distress following cancer treatment (Appendix

B). The primary feature of these measures is that they offer a holistic, patient-centred, assessment of distress, evaluating biological, psychological and social factors that may be mediating distress, therefore conforming to the WHO's (2001) recommended biopsychosocial model. Such has been the success of validation within the cancer services (Bultz & Holland, 2006; Baken & Woolley, 2011; Goebel & Mehdorn, 2011; Craike, Livingston, & Warne, 2011); validation of the DT has been undertaken in bone marrow transplant services (Ransom, Jacobsen, & Booth-Jones, 2006) and in stroke services (Gilson, 2012). When considering the complex needs of the post-ICU population, it appears that the DT could be a valuable tool for assessing distress, with a focus on improving patient care and health outcomes (Sackett & Haynes, 2002).

2.1.3 Rationale

The rationale of the proposed study is to validate the DT with a post-ICU population. As is documented in both the Critical Care Strategy (Department of Health [DOH], 2000) and NICE Guideline for Critical Care (2009), psychological and physical health problems are common following treatment in intensive care. Both documents highlight the importance of screening for distress and recommend that this is done post-discharge to ensure that patients receive the appropriate psychological and physical health care and support at the earliest opportunity.

2.1.4 Research questions.

1. Is the PL clinically appropriate for patients who have received treatment in an ICU?
2. Is the DT and PL a valid and reliable measure of distress for patients who have received treatment in an ICU?
    - **a.** Will scores on the DT significantly correlate with those of IES-R and HADS and do they demonstrate good concurrent validity relative to each measure?
    - **b.** Will the PL demonstrate good internal consistency?
3. What cut-off scores on the DT correctly identified distressed cases with the post-ICU population?

2.2 Methodology

2.2.1 Design

The PL was adapted for post-ICU use based on a focus group described in Appendices C, D and E. The ICU DT (with adapted PL) can be found in Appendix F. The study utilised a cross-sectional design. The test variable was the DT. The criterion variables were the IES-R and the HADS; this included the HADS-T (total score), HADS-A (anxiety subscale) and HADS-D (depression subscale).

2.2.2 Participants.

A total of 41 participants were recruited using opportunity sampling from the ICU follow-up clinic over a period of 25 months from February 2013 to March 2015. As this study was conducted as part of treatment as usual (TAU), invitation to the clinic from the ICU follow-up team, by its very nature, determined the clinical suitability for inclusion in the study. However, suitability to complete questionnaires for the validation aspect of the study was based on the following criteria. Patients (1) must have been admitted for treatment in the ICU, have been discharged and remain medically stable; (2) must have a good command of English; should a patient have a physical/visual impairment then the clinical psychologist assisted the patient to complete the questionnaires verbally; (3) must be able to give informed consent; this was indicated by the clinicians involved in the patients care and those who run the follow up clinic. The Montreal Cognitive Assessment (Nasreddine et al., 2005) would have been administered if clinicians suspected a patient had cognitive difficulties but it was not required; a score of less than 20 would exclude the patient's completed questionnaires from being included in the research; (4) were between the ages of 18-100 without a co-morbid diagnosis of Learning Disability; (5) did not have had a case open to mental health services prior to their admission into hospital; patients who were discharged from mental health services prior to their admission were included. Additional exclusion criteria included (6) patients under the care of the Mental Capacity Act (2005) and thus lack capacity to give informed consent.

2.2.3 Measures

The measures below are used routinely as part of the ICU follow up clinic, with the exception of the DT. The Problem List (PL) which forms part of the DT was amended prior to administration to ensure that the PL is clinically relevant to a post-ICU population and that any inappropriate items were not included. All measures were deemed to be reliable, valid and sensitive, and (following adjustment of the PL) suitable for use with a post-ICU population.

The Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) is a brief, 14-item screening questionnaire with two subscales, one measuring symptoms of anxiety (HADS-A) and the other symptoms of depression (HADS-D) over the last week. Responses are scored on a four-point Likert scale, with scores ranging from zero to 21; subscales scores are classed as normal (0-7), mild (8-10), moderate (11-14) and severe (15-21). HADS subscale cut-off scores are suggested as those ≥8 when used with post-ICU or post Critical Care patients (Schandl, Bottai, Hellgren, Sundin, & Sackey, 2013; Hatchett, Langley, Schmollgruber, 2010; Ringdal, Plos, Lundberg, Johansson, & Bergbom, 2009; Scragg, Jones, & Fauvel, 2001). A HADS-Total score of ≥ 12 can also be used with ICU/Critical Care patients (Hatchett, Langley, Schmollgruber, 2010; Scragg, Jones, & Fauvel, 2001). Cronbach's alpha was reported as 0.83 for the HADS-A, and 0.82 for the HADS-D, with sensitivity and specificity at an acceptable level (0.80). Cronbach's alpha for the HADS-Total was reported at 0.88 in a non-ICU sample (Michopoulos et al., 2008).

The Impact of Events Scale-Revised (IES-R; Weiss & Marmar, 1997) is a brief, 22-item screening questionnaire to assess symptoms of PTSD over the last week. It has three subscales; avoidance, intrusion and hyperarousal. A total IES-R score can be obtained from the sum of the three subscale scores. Responses are on a 5-point Likert scale, with scores ranging from zero to 88; scores are classed as normal (0-23), clinical concern (24-32), probable diagnosis of PTSD (33-88). An IES-R cut off scores is suggested as ≥33 with a Cronbach's alpha of 0.96, with sensitivity and specificity at an acceptable level (0.84; Creamer, Bell, & Failla, 2003).

The Distress Thermometer (DT; Roth et al., 1998) is a one-item visual analogue screening measure of distress during the last week. Responses range from 0 (no distress) to 10 (extreme

distress). Following validation within cancer services, the NCCN (2007) recommended a cut-off of 3v4 would indicate further investigation of distress. Data following a 38-study review of the DT within cancer services suggested pooled sensitivity and specificity of 0.77 and 0.57 respectively for anxiety; 0.81 and 0.60 for depression; and 0.77 and 0.66 for general distress (Mitchell, 2007). At the time of writing and to the best of the author's knowledge, there is no data determining the sensitivity and specificity of the DT to detect psychological distress with a post-ICU population.

The Problem List was adapted from the National Comprehensive Cancer Network (NCCN; 2001) and comprised of 47-items, concerning distress experienced over the past week. Respondents were required to tick items that were causing distress. Where factors were identified as contributing to the patients distress, the PL was used to signpost them to appropriate services. Items cover a range of biopsychosocial factors that were identified as contributing to distress in post-ICU patients.

2.2.4 Procedure

Following adjustment of the PL, it was administered with the DT with patients at the monthly ICU follow-up clinic, along with the HADS and IES-R. Patients were given an information sheet and consent form (Appendix G) if they wished to take part in the study. The procedure followed treatment as usual. Any items on the PL that were identified by the patient as a problem or concern were talked through with ICU follow-up team. Where patients reported distress and/or scores on the HADS/IES-R were clinically significant, patients were offered an opportunity to discuss this further, with some patients being offered a separate appointment with a clinical psychologist or referred elsewhere.

2.2.5 Statistical Analysis

Quantitative data obtained was analysed using SPSS for Windows (Version 19) and MedCalc for Windows (Version 15.4; MedCalc Software, Mariakerke, Belgium). Pearson's product moment correlation coefficients were used to determine whether the HADS, IES-R and DT correlate with one another (Clark-Carter, 2004). In addition, Receiver-Operating Characteristic (ROC) curves were used to determine the accuracy with which scores on the DT are able to

identify distress on the HADS and IES-R. The Area Under the Curve (AUC) is crucial in interpreting accuracy (specificity and sensitivity) to determining distress. The AUC statistic ranges from 0.50 – 1.00; scores around 0.5 would suggest that the DT is no better at accurately determining a patient with or without distress. Higher scores would however indicate that the DT is an accurate measure at differentiating between a patient with or without distress.

2.2.6 Sample Size Calculation

An a priori power calculation was carried out using MedCalc for Windows (Version 12; MedCalc Software, Mariakerke, Belgium); data from a validation of the DT against the HADS in cancer services (Goebel & Mehdorn, 2011; Craike, Livingston, & Warne, 2011) reports that total sample sizes of between 36 and 70 cases would be required. This is based on Area Under the Curve (AUC) figures of 0.77 and 0.87 (alpha level = .05, beta level = .20, null hypothesis value = .5). Metz (1978), however, suggests that 100 cases are required for results of ROC analysis to be significant. A study which successfully validated the DT with a stroke population had only 31 cases (Gilson, 2012). Following discussion with the ICU follow up team, it was noted that due to the nature of intensive care medicine, attendance at the ICU follow up clinic is often poor (sometimes one patient out of a possible five per month), therefore aiming to achieve a sample of 36 participants might be realistic whilst still satisfying sample size requirements.

2.2.7 Ethical Considerations

The host hospital's Clinical Governance Office confirmed that this study did not require ethical approval from the NHS Research and Ethics Committee (Appendix H) as it is a service evaluation. Ethical approval was also obtained from the University of Southampton Ethics Committee (Appendix I). Permission was not required from the National Comprehensive Cancer Network (NCCN) to adapt the DT and PL for this study:

> "Permission is not required for the use, translation, or adaptation of the content within the NCCN Distress Thermometer and Problem List for personal use (including use with patients, in grants, or for research). If adaptations are being made to the NCCN Distress

Thermometer or Problem List, all NCCN logos, trademarks, and names must be removed prior to production."

Quoted from http://www.nccn.org/about/permissions/thermometer.aspx

Written informed consent was obtained from patients in order for their data to be analysed for the purposes of service evaluation. All data from outcome measures was inputted to SPSS without any identifying characteristics, with participants being assigned a participant number. Completed TAU measures were then filed in the patient's ICU follow up file, unless otherwise indicated. Patients scoring significantly on any of the measures were offered a referral to the Clinical Psychology service at the host hospital, self-help materials or a referral to their local IAPT service, if preferred. Data was analysed collectively to protect anonymity and stored securely, using passwords and encryption, in accordance with information governance and the Data Protection Act (1998). There was no risk of deception or harm to patients; there were no modifications to the format or content of the follow up clinic than what would have been offered as treatment as usual.

2.3 Results

2.3.1 Descriptive Statistics

A total of 41 participants took part in the study. Over half of participants were male (male 56.1%, *n* = 23; female 43.9%, *n* = 18). Data relating to participant age was not always documented, but a range of 34 years to 91 years was generated from that which had been recorded, with the majority of participants being within the 60-69 years of age range.

Independent samples *t* tests were conducted to explore whether gender accounted for differences in reported levels of psychological distress. Significant differences were reported in the anxiety (HADS-A) levels of males (*M* = 3.52, *SD* = 2.74) and females (*M* = 7.28, *SD* = 4.65), *t*(26.04) = -3.04, *p* = .005, the magnitude of the difference in the means was large (*d* = 0.99) with a mean difference of -3.76, 95% CI [-6.30, -1.21].

Significant differences were reported in the depression (HADS-D) levels of males (*M* = 3.04, *SD* = 2.25) and females (*M* = 5.17, *SD* = 3.05), *t*(39) = -2.57, *p* = .014, the magnitude of the difference in the means was borderline large (*d* = 0.79) with a mean difference of -2.12, 95% CI [-3.80, -.45].

Significant differences were reported in the overall anxiety/depression (HADS-Total) levels of males (*M* = 6.57, *SD* = 4.11) and females (*M* = 12.44, *SD* = 6.74), *t*(39) = -3.45, *p* = .001, the magnitude of the difference in the means was large (*d* = 1.05) with a mean difference of -5.88, 95% CI [-9.33, -2.43].

No significant differences were reported in the post-traumatic stress (IES-R) levels of males (*M* = 14.63, *SD* = 12.39) and females (*M* = 26.79, *SD* = 21.09), *t*(19.54) = -1.93, *p* = .069, the magnitude of the difference in the means was moderate (*d* = 0.70) with a mean difference of -12.15, 95% CI [-25.34, -1.04].

No significant differences were reported in the overall distress (DT) levels of males (*M* = 1.91, *SD* = 2.35) and females (*M* = 3.12, *SD* = 2.52), *t*(38) = -1.55, *p* = .129, the magnitude of the

difference in the means was moderate (*d* = 0.50) with a mean difference of -1.20, 95% CI [-2.78, .37].

2.3.2 Prevalence of Psychological Distress post-ICU

Clinical score ranges for the HADS and IES-R are found in Table 7. These are based on the classifications used by the measures' authors.

Anxiety and depression. When applying suggested cut off scores of ≥8 for the HADS-A and HADS-D, over a quarter (29.3%, *n* = 12) of patients reported at least mild anxiety with 14.6% (*n* = 6) reporting at least mild depression. When applying the suggested total cut off score of ≥12 for the HADS-Total, overall anxiety/depression was reported by over a third (39.0%, *n* = 16) of patients. No cases of moderate or severe depression were reported. A paired-samples *t* test indicated a significant difference between patient's anxiety (*M* = 5.17, *SD* = 4.11) and depression scores (*M* = 3.98, *SD* = 2.81), *t*(40) = 2.19, *p* < .001[7]. The mean difference in anxiety and depression scores was 1.20 (*SD* = 3.49), 95% CI [.09, 2.30] with a small effect size (eta squared = .11).

Post-traumatic stress. When applying the suggested cut-off score of ≥33 for the IES-R, almost a quarter of patients reported likely post-traumatic stress symptoms (24.2%, *n* =8).

Table 7

Interpretation of Psychological Scores

Psychological Measure	Interpretation	*n* (%)
HADS-A	Normal	29 (70.7)
	Mild	9 (22.0)
	Moderate	2 (4.9)
	Severe	1 (2.4)
HADS-D	Normal	35 (85.4)
	Mild	6 (14.6)
	Moderate	-
	Severe	-
IES-R	Normal	22 (66.7)
	Clinical Concern	3 (9.1)
	Probable Diagnosis	8 (24.2)

Note. HADS *N* = 41. HADS-A = Hospital Anxiety & Depression Scale – Anxiety subscale; HADS-D = Hospital Anxiety & Depression Scale – Depression subscale; IES-R = Impact of Events Scale – Revised. Score ranges for both subscales: normal = 0 – 7, mild = 8 – 10, moderate = 11 – 14, severe = 15 – 21. IES-R *N* = 33. Post-traumatic stress score ranges: normal = 0 – 23, clinical

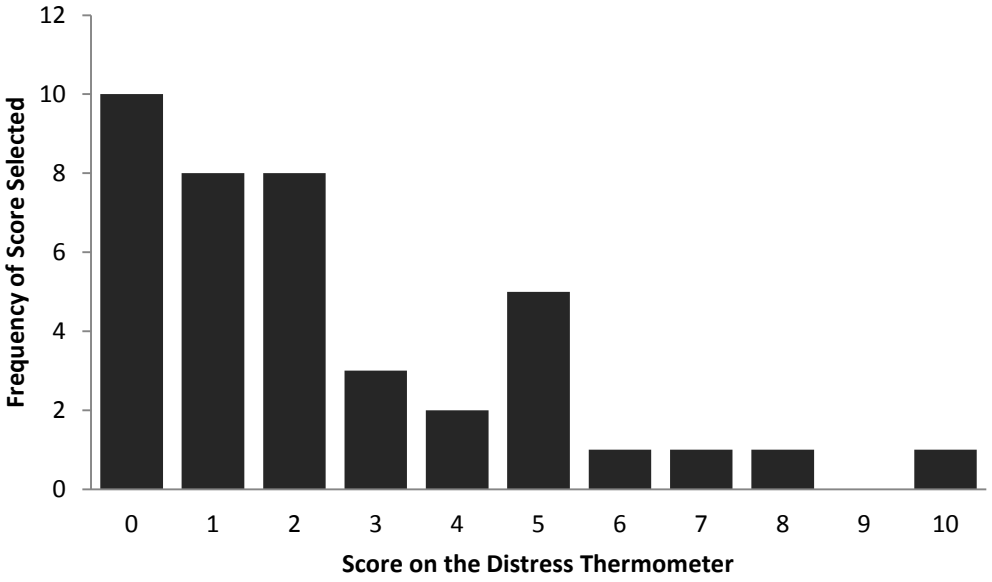
[7] Two-tailed

concern = 24 – 32, probable diagnosis = 33 – 88. Interpretation classification language reflects that used by measure's author and existing literature.

Distress as reported on the DT. As illustrated in Graph 1, the majority of responses were skewed towards the lower end of the distress range (where 0 = no distress and 10 = severe distress). Mean scores on the DT were 2.45 (*SD* = 2.47).

Graph 1.

Distribution of DT Scores



2.3.3 Internal Consistency of Measures

All measures were checked for their reliability in this study and results compared against those previously reported. All scales were found to have acceptable Cronbach's alphas with the exception of the HADS-A which was below the recommended acceptable level of 0.7 (Pallant, 2007). In addition, inter-item correlation for the HADS-A was below that expected (.2 to .4; Briggs & Cheek, 1986) for a scale with less than ten items (.17), but this increased to .22 when item 7 was deleted ('I can sit at ease and feel relaxed'). It's possible that this item, for this group of participants, does not correlate as well with the other anxiety items on the scale. Further, due to the manner of data collection, only a limited number of cases had a complete list of item scores for the HADS which may contribute to the poor internal consistency of the HADS-A subscale, and all of the HADS alphas being below that reported in the literature.

Table 8

Internal Consistency of Measures

	Cronbach's Alpha (Mean inter-item correlation[a])	Cronbach's Alpha: Scale if Item Deleted (Item) (Mean inter-item correlation)
HADS-A	0.50 (.17)	0.55 (Item 7) (.22)
HADS-D	0.79 (.35)	0.80 (Item 10) (.4)
HADS-Total	0.74	0.77 (Item 5)
IES-R	0.95	0.95 (Item 8)

Note. DT = Distress Thermometer; HADS-A = Hospital Anxiety & Depression Scale – Anxiety subscale; HADS-D = Hospital Anxiety & Depression Scale – Depression subscale; HADS-Total = Hospital Anxiety & Depression Scale – Total anxiety/depression; IES-R = Impact of Events Scale – Revised.
[a]Where the scale consists of ten items or less, an optimal mean inter-item correlation would be between 0.2 and 0.4.
[b]Cronbach's Alpha as reported in the literature: HADS-A = 0.83; HADS-D = 0.82; HADS-Total = 0.88; IES-R = 0.96

2.3.4 Concurrent Validity of Measures

Preliminary analyses across all variables were performed to ensure no violation of the assumptions of normality, linearity and homoscedasticity, and relationships were investigated using Pearson product-moment correlation. The DT significantly correlated between all four measures, with strong positive correlation unless specified: HADS-A (r = .54, n = 40, p < .001**, r^2 = .29), HADS-D[8] (r = .34, n = 40, p = .035*, r^2 = .12), HADS-Total (r = .52, n = 40, p < .001**, r^2 = .27), IES-R (r = .65, n = 32, p < .001**, r^2 = .42), sharing between 12% and 42% of the variance between measures. In addition, the IES-R significantly correlated with the other measures, including the HADS-Total (r = .78, n = 33, p < .001**, r^2 = .61), HADS-A (r = .81, n = 33, p < .001**, r^2 = .66), and HADS-D (r = .60, n = 33, p < .001**, r^2 = .36), sharing between 36% and 61% of the variance between measures.

[8] Medium positive correlation

Table 9

Pearson product-moment Correlation Coefficients between Measures of Psychological Distress

	1	2	3	4	5
DT	-	.54**	.34*	.52**	.65**
HADS-A		-	.54**	.92**	.81**
HADS-D			-	.83**	.60**
HADS-Total				-	.78**
IES-R					-

Note. DT = Distress Thermometer; HADS-A = Hospital Anxiety & Depression Scale – Anxiety subscale; HADS-D = Hospital Anxiety & Depression Scale – Depression subscale; HADS-Total = Hospital Anxiety & Depression Scale – Total anxiety/depression; IES-R = Impact of Events Scale – Revised.
**Significant at .01 level. *Significant at .05 level.

2.3.5 Diagnostic Accuracy using ROC Curve Analysis

The assessment of diagnostic accuracy of the DT, in comparison to HADS-A, HADS-D, HADS-Total and IES-R was undertaken using ROC curves with the aim of detecting clinically significant levels of psychological distress. Where the area under the curve (AUC) is less than 0.50, this implies that a measure is no greater than chance at detecting clinically significant levels of distress. Above 0.5 the following interpretations are suggested: 0.51 - 0.69 poor; 0.7 – 0.79 fair; 0.8 - 0.89 good; 0.9 – 0.99 excellent; 1.0 perfect (Ebell, 2015). Visual inspection of a ROC curve demonstrating good signal detection should show a sizeable gap between that and the reference line, with is positioning towards the top left corner of the *y* axis. In order to determine cut-off scores, suggested sensitivity (≥.80) and specificity integers were applied (≥.08) with Youden Index scores also determined in order to best summarise the performance of the ROC curve (Table 10). The Youden index is a way of summarising the combined sensitivity and specificity of a diagnostic test. Values range from 0 to 1, with a value of 0 indicating a useless test and a value of 1 indicating a perfect test.

Anxiety. The DT generated an AUC of 0.81 which is significantly greater that an AUC of 0.5 ($p < .0001$). This indicates that the DT is good at distinguishing between clinical and non-clinical cases of anxiety. A suggested cut-off score was identified as 2 on the DT to meet the acceptable

levels of sensitivity and specificity (Table 10). A fair level of agreement between the HADS-A and DT was observed (k = .38, p = .005) using a DT cut-off of 2.

Depression. The DT generated an AUC of 0.69 which is not significantly greater than an AUC of 0.5 (p = .08). This indicates that the DT is poor at distinguishing between clinical and non-clinical cases of depression. A suggested cut-off score was identified as 3 on the DT to meet an appropriate level of specificity but not sensitivity (Table 10). As a poor level of agreement between the HADS-D and DT was observed (k = .12, p = .005) using a DT cut-off of 3 as an indicator of possible depression should be interpreted with caution.

Total anxiety/depression. The DT generated an AUC of 0.80 which is significantly greater that an AUC of 0.5 (p < .0001). This indicates that that the DT is able to distinguish between clinical and non-clinical cases of mixed anxiety/depression better than chance. A suggested cut-off score was identified as 2 on the DT to meet the recommended level of specificity but not sensitivity (Table 10). A fair level of agreement between the HADS-Total and DT was observed (k = .37, p = .014) using a DT cut-off of 2.

Post-traumatic stress. The DT generated an AUC of 0.84 which is significantly greater that an AUC of 0.5 (p < .0001). This indicates that that the DT is good at distinguishing between clinical and non-clinical cases of post-traumatic stress. A suggested cut-off score was identified as 2 on the DT to meet the recommended level of sensitivity but not specificity (Table 10). A fair level of agreement between the IES-R and DT was observed (k = .25, p = .039) using a DT cut-off of 2.

Table 10

Diagnostic Accuracy of the Distress Thermometer (DT)

Measure	AUC	Cut-off	Index test positive	Index test negative	Sensitivity (95% CI)	Specificity (95% CI)	Youden index *J*	PPV (95% CI)	NPV (95% CI)	SE
HADS-A ≥ 8	0.81**	≥ 2	11	29	72.73 (39.0 – 94.0)	79.31 (60.3 – 92.0)	0.52	57.1 (28.9 – 82.3)	88.5 (69.8 – 97.6)	.07
HADS-D ≥ 8	0.69	≥ 3	5	35	60.00 (14.7 – 94.7)	77.14 59.9 – 89.6)	0.37	27.3 (6.0 – 61.0)	93.1 (77.2 – 99.2)	.11
HADS-Total ≥ 12	0.80**	≥ 2	15	25	66.67 (38.4 – 88.2)	84.00 (63.9 – 95.5)	0.51	71.4 (41.9 – 91.6)	80.8 (60.6 – 93.4)	.07
IES-R ≥ 33	0.84**	≥ 2	8	32	87.5 (47.3 – 99.7)	78.12 (60.0 – 90.7)	0.66	50.0 (23.0 – 77.0)	96.2 (80.4 – 99.9)	.08

Note. HADS-A = Hospital Anxiety & Depression Scale – Anxiety subscale; HADS-D = Hospital Anxiety & Depression Scale – Depression subscale; HADS-Total = Hospital Anxiety & Depression Scale – Total anxiety/depression subscale; IES-R = Impact of Events Scale-Revised; AUC = Area Under the Curve; PPV = Positive Predictive Value; NPV = Negative Predictive Value; *CI* = Confidence Interval; *SE* = Standard Error.
** $p<.001$

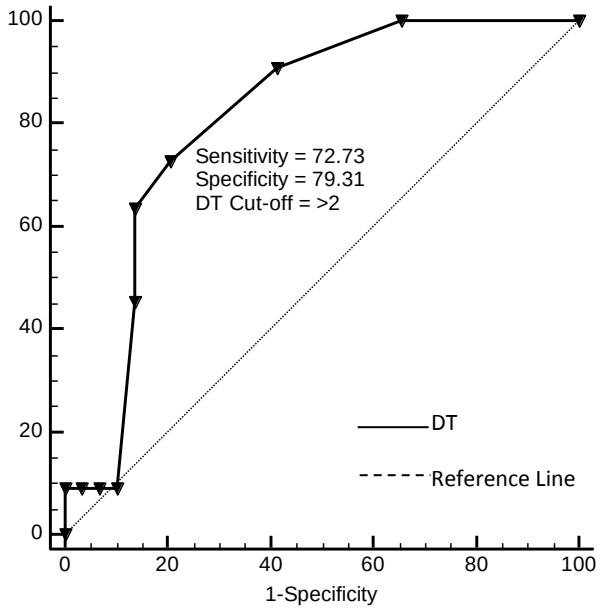


Figure 1. Receiver Operating Characteristic (ROC) curve evaluating the ability of the DT to detect probable cases of post-ICU anxiety using the HADS-Anxiety score (HADS-A ≥ 8) as the criterion standard. AUC = 0.81, $p < .001$. Sensitivity and specificity = %.

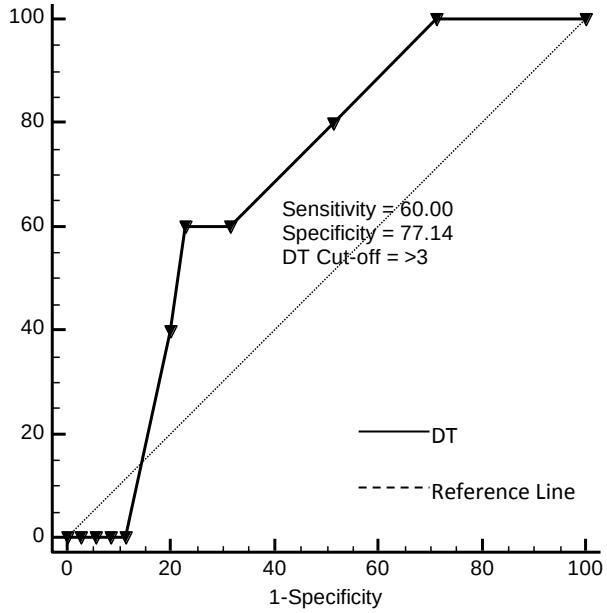


Figure 2. Receiver Operating Characteristic (ROC) curve evaluating the ability of the DT to detect probably cases of post-ICU depression using the HADS-Depression score (HADS-D ≥ 8) as the criterion standard. AUC = 0.69, $p = .76$. Sensitivity and specificity = %.

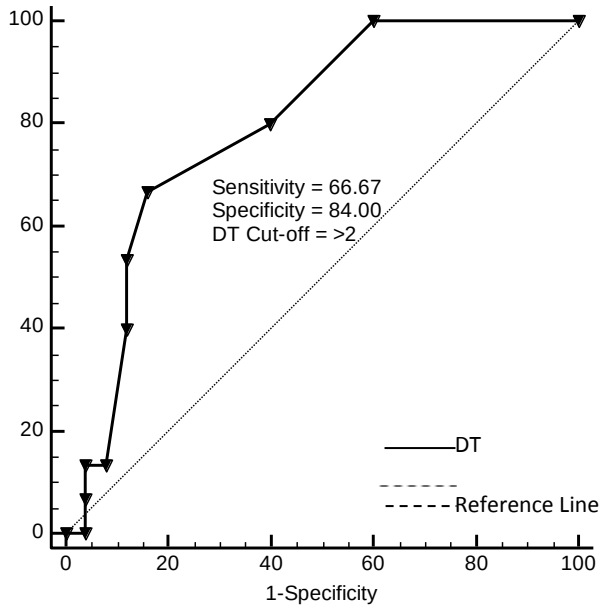


Figure 3. Receiver Operating Characteristic (ROC) curve evaluating the ability of the DT to detect probable cases of post-ICU anxiety/depression using the HADS-Total (HADS-Total ≥ 12) as the criterion standard. AUC = 0.80, $p < .001$. Sensitivity and specificity = %.

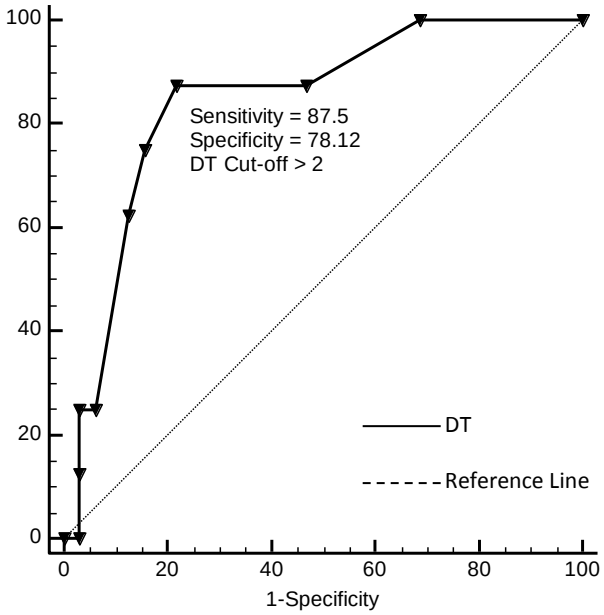


Figure 4. Receiver Operating Characteristic (ROC) curve evaluating the ability of the DT to detect probably cases of post-ICU post-traumatic stress using the IES-R (IES-R ≥ 33) as the criterion standard. AUC = 0.84, $p < .001$. Sensitivity and specificity = %.

2.3.6 Prevalence Rates on the Problem List (PL)

Items on the PL were reported on a nominal scale with a binary "yes" or "no" response. Frequencies of reported problems are outlined below.

Practical concerns. Transport and care provisions (e.g. personal/domestic) were equally the most frequently reported concern in this domain (*n* = 6, 15%), followed equally by concerns about work and insurance/financial (*n* = 3, 7.5%), followed again equally by housing and child care (*n* = 1, 2.5%).

Social concerns. Concerns about family (including children/grandchildren) was the most frequently reported concern in this domain (*n* = 9, 22.5%), followed by concerns about hobbies (*n* = 6, 15%), socialising (*n* = 4, 10%), friends (*n* = 3, 7.5%), and pets (*n* = 1, 2.5%).

Emotional concerns. Concerns about frustration was the most frequently reported concern, noted by over half of patients (*n* = 22, 55%), followed by concerns about worry/anxiety (*n* = 11, 27.5%), intrusive memories and self-esteem respectively (*n* = 9, 22.5), sadness and worry respectively (*n* = 6, 15%), depression and fears/specific phobias (e.g. driving) respectively (*n* = 4, 10%), nightmares and loss of interest in usual activities respectively (*n* = 2, 5%), and hallucinations (*n* = 1, 2.5%).

Religious/spiritual concerns. No patients reported any concerns of this nature.

Physical concerns. The most commonly reported physical concerns related to fatigue with almost half of patients noting this option (*n* = 19, 47.5%), followed just over a third equally reporting mobility and pain (*n* = 14, 35%), and just under a third equally reporting sleep and memory problems (*n* = 13, 32.5%). The prevalence of other reported concerns is outlined in Table 11. In terms of other concerns reported by patients these included "*follow up treatment by GPs*" (*n* = 1, 2.5%), "*problems with catheter*" (*n* = 1, 2.5%), "*loss of strength in legs/lower body*" (*n* = 2; 5%), "*ability to travel by airplane*" (*n* = 1, 2.5%), and "*sense of smell*" (*n* = 1, 2.5%).

Table 11

Prevalence of reported Physical Concerns

Physical Concern	*n* (%)
Appearance	11(27.5)
Appetite	4(10)
Breathing	7(17.5)
Changes in urination	9(22.5)
Changes in bowel habits	8(20)
Discomfort with scars (e.g. tracheostomy issues)	6(15)
Eyesight/hearing changes	8(20)
Fatigue	19(47.5)
Feeling swollen	3(7.5)
Hair loss	7(17.5)
Mobility	14(35)
Muscle wastage	10(25)
Nausea	2(5)
New joint changes	3(7.5)
Pain	14(35)
Problems with concentration	12(30)
Problems with memory (incl. lapses/gaps)	13(32.5)
Rate of recovery	9(22.5)
Sexual	1(2.5)
Skin issues (e.g. itchy/dry/bruising)	10(25)
Sleep	13(32.5)
Tingling in hands/feet	9(22.5)
Voice changes	4(10)
Weight changes	10(25)
Other	6(15)

2.3.7 Internal Consistency of the Problem List

The internal consistency of the practical and social concerns domains was poor (0.44, 0.31 respectively), even following consideration of the mean inter-item correlation statistic (see Table 12). Both the Emotional and Physical Concerns domains demonstrated acceptable levels of internal consistency (0.74 and 0.74 respectively), with the Total Problem List Concerns demonstrating very good internal consistency (0.86).

Table 12

Internal Consistency of the Problem List

Domain	Cronbach's Alpha (mean inter-item correlation)
Practical concerns	0.44 (.09[a])
Social concerns	0.31 (.13[a])
Emotional concerns	0.74
Physical concerns	0.74
Total PL concerns	0.86

Note. [a]Where the scale consists of ten items or less, an optimal mean inter-item correlation would be between 0.2 and 0.4.

2.3.8 Concurrent Validity of the Problem List

As reported in Table 13, significant correlations were observed between almost all problem-specific domains and the DT, with two exceptions outlined below. Moderate, positive correlations were observed between the Practical Concerns domain and the following: Social Concerns (r = .47, n = 40, p = .002**[9], r^2 = .22), Emotional Concerns (r = .46, n = 40, p = .003**, r^2 = .21), Physical Concerns (r = .48, n = 40, p = .002**, r^2 = .23), accounting for between 21% and 23% of the variance. Moderate, positive correlation was observed between the Social Concerns domain and Emotional Concerns (r = .36, n = 40, p = .023*[10], r^2 = .13), Physical Concerns (r = .45, n = 40, p = .004**, r^2 = .20), but not between the Social Concerns and DT (r = .22, n = 40, p < .172, r^2 = .05), accounting for between 5% and 20% of the variance. Strong, positive correlation was observed between the Emotional Concerns domain and Physical Concerns (r = .71, n = 40, p < .001**, r^2 = .50). Moderate, positive correlation was observed between the Emotional Concerns domain and DT (r = .47, n = 40, p = .003**, r^2 = .22), accounting for between 22% and 50% of the variance. Moderate positive correlation was observed between the Physical Concerns domain and DT (r = .42, n = 40, p = .006**, r^2 = .18). Finally, moderate, positive correlation was observed between the PL Total and the DT (r = .45, n = 40, p = .003**, r^2 = .20). The religious/spiritual concerns domain could not be computed as it is a single (constant) item.

[9] ** Significant at the .01 level
[10] * Significant at the .05 level

2.4 Discussion

The aim of this study was to determine whether the Distress Thermometer (DT) and Problem List (PL) is appropriate for use with a post-ICU population following exploration of reliability and validity, when compared to the existing clinical measures of the HADS and IES-R. In addition, it was hoped that the DT could correctly identify distressed cases with the post-ICU population, following determination of a suitable cut-off.

2.4.1 Prevalence of Post-ICU Psychological Distress

A review of prevalence rates for anxiety, depression and PTSD are outlined forthwith. The prevalence of anxiety amongst the post-ICU population, where HADS-A subscale scores were at least ≥8 was found to be well within the range reported by the existing post-ICU literature (Rattray, Johnston, & Wildsmith, 2005; Samuelson, Lundberg, & Fridlund, 2007; Sackey, Martling, Carlswärd, Sundin, & Radell, 2008; Ringdal, Plos, Lundberg, Johansson, & Bergbom; 2009; Wade et al., 2012; Zetterlund, Plos, Bergbom, & Ringdal, 2012). The majority of the detected cases of anxiety were classified as being within the mild range of anxiety, but three were detected as being within the moderate or severe range.

The prevalence of depression amongst the post-ICU population, where HADS-D subscale scores were at least ≥8 was found to be within the range reported by the existing post-ICU literature (Rattray, Johnston, & Wildsmith, 2005; Samuelson, Lundberg, & Fridlund, 2007; Sackey, Martling, Carlswärd, Sundin, & Radell, 2008; Ringdal, Plos, Lundberg, Johansson, & Bergbom; 2009; Wade et al., 2012; Zetterlund, Plos, Bergbom, & Ringdal, 2012). All detected cases of depression were within the mild range of severity.

The prevalence of post-traumatic stress symptoms amongst the post-ICU population, where IES-R total scores were at least ≥33 was also found to be well within the range reported by the existing post-ICU literature (Stoll et al., 1999; Kress et al., 2003; Schelling et al., 2003; Samuelson, Lundberg, & Fridlund, 2007; Granja et al., 2008; Sackey, Martling, Carlswärd, Sundin, & Radell, 2008; Davydow et al., 2009; Wade et al., 2012).

The rates of anxiety and PTSD amongst the post-ICU population in this study are higher than those reported amongst the general population and thus this reiterates the finding that psychological distress amongst post-ICU patients is highly prevalent. This serves further evidence for the need for adequate follow up support as recommended by NICE guidelines (2009). NICE (2009) recommends functional assessment of the patient to determine any difficulties across physical and non-physical domains, which includes screening for possible psychological morbidity, just prior to discharge home from hospital and a functional re-assessment at 2-3 months post-discharge. The purpose of this re-assessment is to gauge a sense of the patient's recovery in a physical capacity but also to screen for any possible mood disorders (including anxiety/depression) and possible PTSD that may have developed following the patient's discharge home. If screening of psychological functioning indicates any disorder-specific difficulties (qualitative examples of such difficulties are included in the 2009 NICE guideline), then clinicians are directed towards the relevant NICE guidelines for those specific conditions (e.g. anxiety, depression, PTSD).

Limitations. As discussed in the results section, the internal consistency of the HADS-A, HADS-D, and HADS-Total scales were below that reported by the existing literature. Therefore reducing the reliability of the scales and suggesting that particular items did not correlate with the remaining items. Further, missing data (due to the manner of data collection, as explained earlier) meant that only subtotal (anxiety/depression) scores and the HADS-Total score was available to the author for much of the data. Consequently, the internal consistency of the items on those particular questionnaires could not be ascertained. It would be important that, as this study is the first of its kind, it is replicated to ensure reliability.

2.4.1 The Distress Thermometer (DT)

Validity. The DT demonstrated acceptable concurrent validity, with higher scores on the DT correlating with higher scores on the anxiety (HADS-A), depression (HADS-D), anxiety/depression (HADS-Total) and, PTSD (IES-R) measures included in this study.

Diagnostic accuracy. The DT demonstrated an acceptable level of diagnostic accuracy when used to detect anxiety amongst a post-ICU population, achieving an acceptable level of specificity (i.e. correctly identifying patients that do not have anxiety), with a slightly less but still acceptable level of sensitivity (i.e. correctly identifying patients that *do* have anxiety). Given these findings, there is a slightly higher chance of a type II error than would be expected given the existing literature.

The DT did not demonstrate diagnostic accuracy when used to detect depression amongst a post-ICU population, with similarly poor sensitivity but better specificity. This suggests that there is an increased chance of a type II error being made such that the DT is not much better than chance at accurately detecting depression and should be used and interpreted with caution. This finding is possibly due to the lack of variation in depression scores; i.e. fewer were suffering from clinical levels of depression.

By contrast, the DT did demonstrate diagnostic accuracy when used to detect total anxiety/depression (HADS-Total) of which the HADS-D scores form half of the total score. This suggests that those patients with a mixed presentation of anxiety and features of depression can be detected by the DT. Whilst good levels of specificity were reported (i.e. correctly identifying patients who do not have anxiety/depression), thus reducing the chance of a type I error, poor levels of sensitivity (i.e. correctly identifying patients who *do* have anxiety/depression) were reported increasing the chance of a type II error. Therefore, the DT should be used with caution when screening patients for anxiety/depression as it may falsely indicate that patients do not have such symptoms.

The DT demonstrated an acceptable level of diagnostic accuracy when used to detect PTSD amongst a post-ICU population, achieving a good level of sensitivity (i.e. correctly identifying patients who *do* have PTSD), better than that reported in the literature, with a slightly less but still acceptable level of specificity (i.e. correctly identifying patients who do not have PTSD). The chances of a type I error being made are slightly higher than that of a type II error.

The DT presents good diagnostic accuracy for detecting anxiety and PTSD in a post-ICU population. Whilst the reported levels of sensitivity and specificity were not always consistent with those reported by the respective measures (HADS-A, HADS-D, IES-R), they were within the ranges reported by the NCCN (2007) where the DT has been validated within cancer services. Ultimately, mental health difficulties should be assessed using questionnaires *alongside* standardised clinical interviews; not only does this counter any flaws in the diagnostic accuracy of questionnaires, it allows for the consideration of other factors that may be contributing to or maintaining a patient's distress (which may not be assessed via questionnaire), and would be imperative to know to aide treatment planning.

In terms of cut-off scores, the use of the Youden Index assisted in determining a score which achieved a balance of acceptable sensitivity and specificity and thus balanced the chances of a type I and type II error. To this end, a score of two or more on the DT indicates at least mild cases of anxiety and/or mild anxiety with features of depression, and/or likely cases of PTSD. This means that out of 41 patients, 51% met the threshold for psychological distress (n = 21) which as discussed earlier, is consistent with the existing literature. The cut-off of two is lower than has been reported by other studies (cancer) where cut-off scores of 3v4, 7, 6, and 4 have been reported (NCCN, 2001; Ransom, Jacobsen, & Booth-Jones, 2006; Hegel et al., 2008; Goebel & Mehdorn, 2011).

As this study comprised of a small sample, it will be important that it is replicated on a larger scale to determine whether its psychometric properties can be maintained or better still, improved (particularly in relation to the HADS-A, HADS-D, and HADS-Total), and whether the evidence suggests a DT cut-off of two remains appropriate. If the DT cut-off does remain the same, then it may be more helpful to consider replacing the thermometer with a binary measure of distress (e.g. yes/no) or tripart system whereby distress (if present) is ranked as mild, moderate or severe in relation to impact on functioning over the last week. Whilst this would detract from the measure using a thermometer (and its namesake per se), it may make it easier for clinicians to screen for distress. Further testing would be important to determine the diagnostic accuracy of

such a change, and it would be helpful to run a focus group with both patients and clinicians to ascertain their view (particularly as Subject Units of Distress scales typically run from 0-10 and are used widely in the hospital system, e.g. to check pain etc.). It should be recognised that the HADS and IES-R in themselves "rough and ready" measures designed to indicate the presence of a possible problem, rather than gold standard diagnostic tools. To this end, it would be wise to replicate this study comparing the DT with clinical diagnostic interviews. This would enable better assessment of the sensitivity and specificity of the DT to detect anxiety, depression, mixed anxiety/depression and PTSD within a post-ICU population.

In summary, the DT has demonstrated acceptable statistical evidence that it is suitable for use with a post-ICU population. However, as this study is possibly the first of its kind to evaluate the DT with this population, it has not been possible to compare the findings to any other post-ICU study. Subsequently, there is much scope for further investigation to support the author's findings and for further comparisons.

2.4.3 The Problem List (PL)

Adaptation. Following the administration of a focus group of ICU clinicians who have experience of post-ICU care, it was deemed that a number of items on the original PL needed amending to better suit the clinical needs of this population. Subsequently, a number of items were changed, and the group came to a consensus that the final PL would be suitable for use with a post-ICU population. The adjusted PL was found to meet the clinical needs of this unique population. Furthermore only six additional concerns were added by the total 40 patients who completed the measure. One could argue that if the PL did not meet the needs of this population, it might be expected that an even greater number of additional concerns would have been reported by patients. On average, post-ICU patients selected eight items from the PL, with a range of zero to 23 items.

The most frequently reported concerns were frustration and fatigue with (55% and 47.5% respectively). This was followed by mobility and pain (35% each), sleep and memory (32.5% each). These concerns are typical of a population for whom intensive care medicine has been

administered (Davydow et al., 2009). It was interesting to note that no patients selected the Religious/spiritual concerns and yet items were selected in all other concern domains; the author observed a common dialogue being discussed in some of the post-ICU follow up clinics about 'being grateful' for being alive, thus one wonders whether the likelihood of experiencing concerns of a religious/spiritual nature is reduced under these circumstances?

Where items of the PL explicitly state concerns about anxiety/worry and depression, and indicate key diagnostic features of PTSD (e.g. intrusive memories), it was helpful to note that the reported prevalence of the specific concern and respective scale of measurement (HADS-A, HADS-D, IES-R) reported very similar prevalence rates. A total of 27.7% of patients selected 'anxiety' on the PL, which was consistent with that reported by the HADS-A (29.3%). Similarly a total of 10% of patients selected 'depression' on the PL, with 14.6% prevalence reported by the HADS-D. Where the concern of 'intrusive memories' was selected by patients (22.5%), this was also consistent with the prevalence found by the IES-R (24.2%). This finding perhaps suggests that patients completed all measures with a similar degree of motivation and accuracy.

Internal consistency. The PL demonstrated acceptable levels of internal consistency with regards to the Emotional Concerns and Physical Concerns domains but not those of the Practical Concerns and Social Concerns domains, even after statistical adjustment due to fewer scale items. One would expect all domains to show internal consistency, so the absence of this finding is unexpected. A possible explanation for this is that fewer patients responded to the Practical and Social Concerns overall, compared to a higher response rate across the other domains with the exception of the Religious/spiritual Concerns which had no responses. The Total Problem Concerns, however, demonstrated very good internal consistency, indicating that as a whole, the PL is a reliable measure at evaluating post-ICU distress in terms of its biopsychosocial components, which is consistent with the aims of the WHO (2001).

Concurrent validity. When compared against the DT, the PL domains of Emotional Concerns and Physical Concerns demonstrated acceptable levels of concurrent validity. Further, the Total Problem List Concerns also demonstrated an acceptable level of concurrent validity with

the DT, which is consistent with previous findings when evaluated in cancer services (Ransom, Jacobsen, & Booth-Jones, 2006; Goebel & Mehdorn, 2011; Dilworth, Thomas, Sawkins, & Oyebode, 2011). Low levels of concurrent validity were reported between the DT and PL domains of Practical Concerns and Social Concerns. Similar to the poor internal consistency, the concurrent validity of these domains may have been influenced by the low response rate.

In summary, the PL was successfully adapted for use with a post-ICU population demonstrating acceptable levels of internal consistency and concurrent validity in the Emotional Concerns, Physical Concerns and Total Problem concerns domains, but poor in the Practical Concerns and Social Concerns domains, which may have been affected by a poor response rate.

2.4.4 Clinical Utility of the Distress Thermometer (DT) and Problem List (PL)

Patients who completed the DT and PL verbally reported finding it a useful measure, not least because it served as a reminder to highlight any concerns which they may have minimised, but that were of importance to the clinical team. For instance, the reporting of obscure intrusive "flashback" memories was often downplayed by the post-ICU patients but when selected on the PL, opened up an insightful discussion about how commonly these are reported. Where physical concerns were selected, it was often the case that the Consultant Anaesthetist and ICU ward Sister then wanted to explore these concerns in more detail in order to determine whether further medical input was required. Similarly, medical staff reported finding it helpful for the same reasons, and as a prompt to consider all of the aspects of possible post-ICU concerns, enabling the delivery of holistic person-centred care, in accordance with the NICE guidelines (2009) for post-ICU follow up. It would be particularly important that the DT and PL are used when patients have experienced delirium, have received steroids and benzodiazepines and/or were treated using a pulmonary artery catheter, as the existing literature associates these factors with increased psychological distress, post-ICU.

Where patients scored highly on any measures of psychological distress (HADS, IES-R, high score on DT with corresponding items selected on PL) and/or talked about their mental health in the ICU follow up clinic, the clinical psychology team used this as an opportunity for further

discussion and intervention. In such instances, a number of outcomes occurred including the patient declining the opportunity to talk about their difficulties; the patient agreeing to watchful waiting with their GP being informed; the patient being signposted to self-refer to talking therapy services (i.e. IAPT; Improving Access to Psychological Therapies) for mild to moderate depression and/or anxiety. For those patients for whom their psychological recovery from ICU was more significantly impaired (as evidenced by high scores on the HADS and/or IES-R, alongside clinical judgement) they were invited to meet with the Clinical Psychologist in a separate appointment. Where the difficulties related to sleep, information on sleep hygiene was given to the patient. Patients were also given the opportunity to take receipt of their ICU patient diary and visit the ICU ward as evidence suggests that this can help reduce symptoms of anxiety, depression, PTSD, and help the patient make sense of gaps in their memory (Jones et al., 2001; Knowles & Tarrier, 2009; Egerod & Christensen, 2010).

Whilst the HADS and IES-R were effective at screening for psychological distress post-ICU, the screening for other concerns that may be contributing to distress were neglected, thus the DT and PL offer an opportunity for these concerns to be acknowledged and addressed. Given the ICU follow-up clinic appointments were only 45 minutes in length, the utility of the DT and PL as a brief, one-page measure meant it was quick to complete.

In terms of practical utility, due to different functional impairments (e.g. visual impairments, fine motor/hand impairments), on a number of occasions the DT and PL had to be discussed verbally with the patients, with staff noting responses down.

Critique of the Study

Whilst the a priori power calculation suggested at least 36 patients (Goebel & Mehdorn, 2011; Craike, Livingston, & Warne, 2011) would be needed for the statistical analyses and 41 were included, it would be helpful for this study to be replicated with a larger sample size from multiple ICUs to reduce selection bias, the chance of a type II error, to re-assess the internal consistency of the PL concern domains and, determine that a score of two or more on the DT remains an appropriate cut-off when used with a post-ICU population. A larger sample size would also

hopefully enable a broader age-range of patients; that majority of patients in this study were within the 60-69 years of age range, thus one might hypothesise that they may have lesser concerns and perhaps lesser distress due to being towards the end of their working age and/or that the nature of their concerns is different. It is also important to remember that the HADS and IES-R are not perfect measures in themselves and questionnaires should always be used alongside clinical judgement in order to best assess psychological distress.

It is important to note that because this study achieved ethical approval as a service evaluation for delivering treatment as usual, it was not possible to include any other measures that may have been interesting or perhaps better placed to assess distress following ICU. For instance, it perhaps would have been helpful to have included the ICU Memory Tool (Jones, Griffiths, Humphris, & Skirrow, 2008) to evaluate the prevalence and categories of memory. There is also a Primary Care PTSD Screen (PC-PTSD; Prins et al., 2003) which contains the inclusion of items concerning the startle response and emotional numbing; these latter two items could be a useful addition to the Problem List, which would enable incorporation of the PC-PTSD. These two items are also already included in IES-R (items 10 and 13 respectively). As the IES-R is also one of the IAPT (Improving Access to Psychological Therapies) recommended screening tools for PTSD (IAPT, 2011), it may be worth future research including the GAD-7 (Generalised Anxiety Disorder 7: Spitzer, Kroenke, Williams, & Löwe, 2006) to assess anxiety, and the PHQ-9 (Spitzer, Kroenke, & Williams, 1999) for depression, and then re-evaluating the diagnostic accuracy of the DT with these measures. This could be particularly useful if signposting patients to IAPT services as referrals may likely be accepted more readily if patient's meet clinical thresholds on the same measures that the service already use. It would also have been informative to used and included data from medical assessment tools such as the APACHE-II (Acute Physiology and Chronic Health Evaluation-II; Knaus et al., 1985) which would have enabled further exploration of illness severity.

Patients frequently did not attend the follow-up clinic; whilst this may have been because patients did not have any concerns and thus did not see a need for the service, alternatively it is possible that non-attendance was due to ongoing distress. For instance, some patients may not

have wished to attend the clinic in order to avoid to avoid talking about their experiences (avoidance is in itself a key feature of PTSD and anxiety; Wells, 1997; Ehlers & Clark, 2000; Borkovec, Alcaine, & Behar, 2004) or because their depression is such that they lack the motivation to attend, alongside negative views about their future (Beck, Rush, Shaw, & Emery, 1979). Therefore, perhaps this highlights a rationale for attempting to contact patients by telephone in order to ensure that those who may benefit from ongoing medical and psychological care are not missed. Here the DT and PL could be used as part of a telephone interview to screen for post-ICU distress. Another reason for non-attendance was due to geographical location; for some patients, the ICU was not the patient's nearest one (e.g. if they required admission when away on holiday for instance), therefore it will have proved difficult for patients to attend, particularly if transport to appointments generally is an issue; indeed, several local patients relied on the use of the Patient Transport Service.

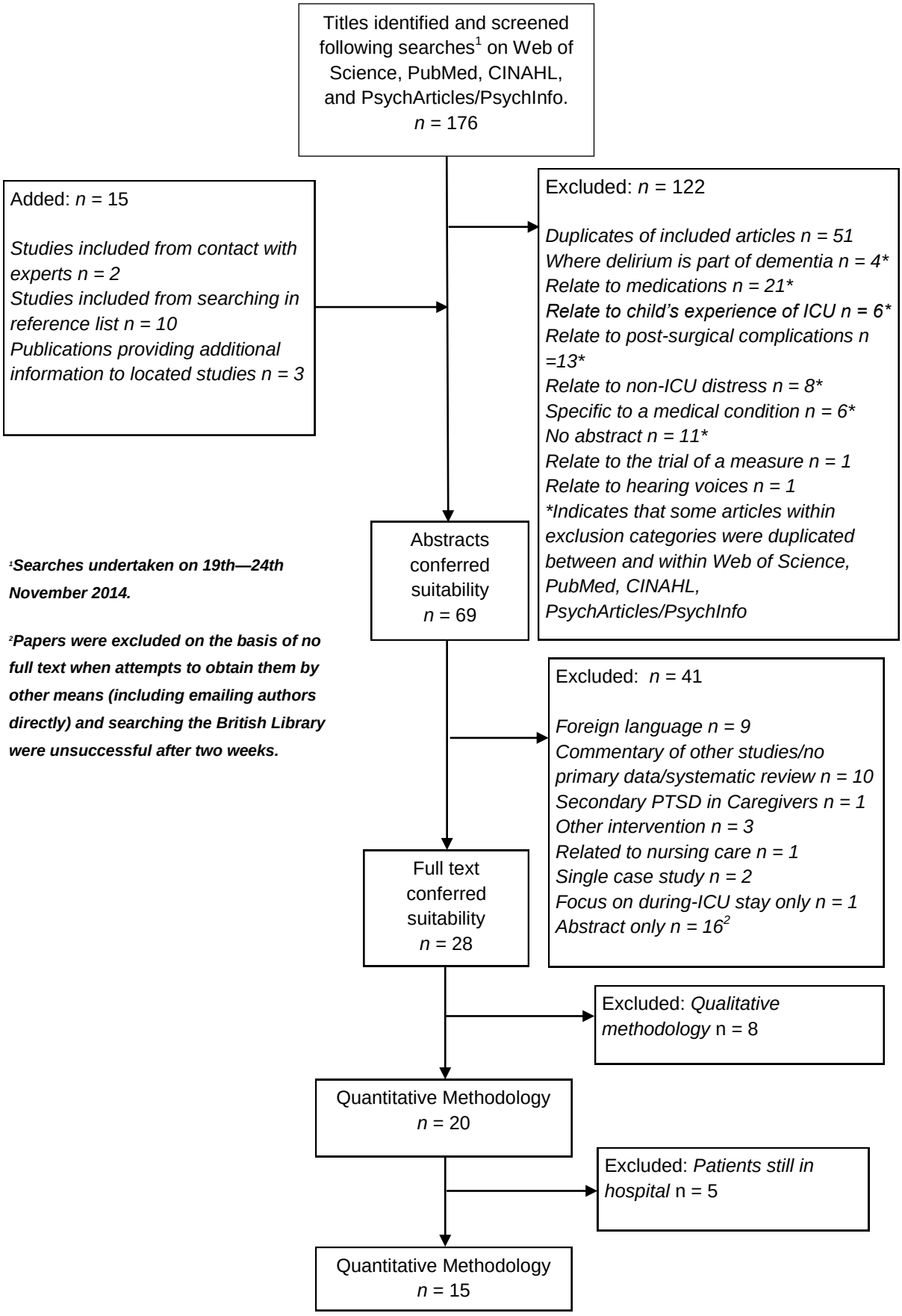
Another limitation of this study (highlighted in previous studies including Ringdal et al., 2006; Samuelson et al., 2007) is that consideration of other contextual factors (e.g. the death or serious injury of someone in the same accident as the patient or other significant life event coinciding at the same time) at the time of the patient's admission into ICU was not explicitly assessed for. This may therefore have influenced their experience of nightmares and delusions and the subsequent reporting of these.

2.5 Conclusion

To the best of the author's knowledge, this study appears to be the first of its kind validating the Distress Thermometer (DT) and Problem List (PL) with a post-ICU population. The findings suggest that the DT and PL are reliable and valid for use with this population, and are able to accurately detect post-ICU anxiety and PTSD. As there is a high prevalence of psychological distress amongst ICU survivors, ultimately, the rationale for using the DT and PL with this population is that it will enable the assessment of both physical and non-physical factors that may be perpetuating distress, and enable these to be addressed through person-centred care in accordance with the NICE guidelines (2009).

Appendices

Appendix A: Systematic Literature Review Search Criteria



[1]Searches undertaken on 19th—24th November 2014.

[2]Papers were excluded on the basis of no full text when attempts to obtain them by other means (including emailing authors directly) and searching the British Library were unsuccessful after two weeks.

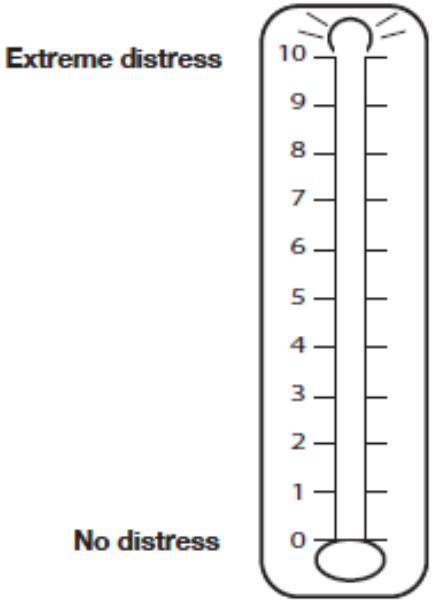
Appendix B: Original NCCN Distress Thermometer & Problem List

National Comprehensive Cancer Network®

NCCN Distress Thermometer for Patients

SCREENING TOOLS FOR MEASURING DISTRESS

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



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

YES	NO	Practical Problems
❑	❑	Child care
❑	❑	Housing
❑	❑	Insurance/financial
❑	❑	Transportation
❑	❑	Work/school
❑	❑	Treatment decisions
		Family Problems
❑	❑	Dealing with children
❑	❑	Dealing with partner
❑	❑	Ability to have children
❑	❑	Family health issues
		Emotional Problems
❑	❑	Depression
❑	❑	Fears
❑	❑	Nervousness
❑	❑	Sadness
❑	❑	Worry
❑	❑	Loss of interest in usual activities
❑	❑	**Spiritual/religious concerns**

YES	NO	Physical Problems
❑	❑	Appearance
❑	❑	Bathing/dressing
❑	❑	Breathing
❑	❑	Changes in urination
❑	❑	Constipation
❑	❑	Diarrhea
❑	❑	Eating
❑	❑	Fatigue
❑	❑	Feeling Swollen
❑	❑	Fevers
❑	❑	Getting around
❑	❑	Indigestion
❑	❑	Memory/concentration
❑	❑	Mouth sores
❑	❑	Nausea
❑	❑	Nose dry/congested
❑	❑	Pain
❑	❑	Sexual
❑	❑	Skin dry/itchy
❑	❑	Sleep
❑	❑	Substance abuse
❑	❑	Tingling in hands/feet

Other Problems: _____

_____

Appendix C: Adaptation of the PL for a Post-ICU Population

A total of 6 clinicians who form the multidisciplinary ICU follow-up Team participated in a focus group, to ensure that all items on the PL were suitable for use with a post-ICU population. Information packs containing an information sheet and consent form were distributed amongst the team (Appendix E). The focus group was facilitated by the author. Data was collected and analysed using the four-step nominal group technique (CDC, 2006) which is described in detail in Appendix X). In summary, the four-step technique consists of (1) the silent review of the original DT and generation of ideas; (2) the collective review of ideas recorded onto a flip chart; (3) the discussion of ideas: clinicians decided which items on the PL were appropriate to a post-ICU population. Any items deemed inappropriate were omitted from the list and conversely, some items were added to ensure that any factors which may contribute to the patient's distress were identified; and (4) voting and prioritising: clinicians then ranked items from three categories (keep, omit or add) to amend the PL accordingly. The group was also audio recorded in case of review at a later date. Table 14 overleaf outlines which items from the original PL were kept, omitted and added. All group members voted and agreed on the final version of the PL being suitable for use with a post-ICU population.

Table 14

Item adaptation from the Original PL

	Items Kept	Items Omitted	Items Added
Practical Concerns (concerns replaces problems)	Child care, housing, insurance/financial, work/school, transport (amended from transportation)		Care provisions (e.g. personal/domestic)
Social Concerns (reworded from Family Problems)	Family (incl. children/grandchildren - grandchildren added), friends	Dealing with partner	Pets, hobbies
Spiritual/religious concerns	Spiritual/religious concerns		
Emotional Concerns (concerns replaces problems)	Depression, fears/specific phobias (e.g. driving) – elaborated, sadness, worry/anxiety, loss of interest in usual activities	Nervousness	Anger, frustration, nightmares, intrusive memories, hallucinations (e.g. hearing or seeing things), self-esteem (e.g. body image/change of roles)
Physical Concerns (concerns replaces problems)	Appearance, changes in urination, fatigue, feeling swollen, mobility (reworded from 'getting around'), nausea, pain, problems with concentration, problems with memory (incl, lapses/gaps – elaborated), sexual, skin issues (e.g. itchy/dry/bruising – elaborated), sleep, tingling in hands/feet	Bathing/dressing, eating, fevers, indigestion, mouth sores, nose dry/congested	Appetite, changes in bowel habits, discomfort with scars (e.g. tracheostomy issues), eyesight/hearing changes, hair loss, muscle wastage, new joint changes, rate of recovery, voice changes, weight changes

Appendix D: Focus Group Format

FOCUS GROUP FORMAT (18.01.2013, v.1)

Stage of the Focus Group	Content	Questions
Introductions (10 minutes)	Clinicians are welcomed and thanked for agreeing to participate in the focus group. The aim and structure of the focus group will be explained, along with timings. Clinicians will be reminded that the focus group is being audio-recorded so that it can be transcribed. Ground rules regarding confidentiality, no correct or incorrect answer will be highlighted. I will then initiate the group introduction. Initial question to the group; all clinicians will be provided with a copy of the existing Distress Thermometer (DT) and original 38-item Problem List (PL)	"Whilst I know you're all colleagues, it would be helpful to go round and give your name, discipline and role within the ICU service" "What do you think of the DT?"
Silent Review of Existing DT/Generation of new ideas (10 minutes)	Clinicians are advised that the next section will require them to think about the usefulness of the DT and PL for a post-ICU population. Paper and pens will be provided; the questions will be written up on the flip chart for clinicians to refer to.	"The DT in front of you was originally developed for use in oncology service. However, it could be an important and helpful resource to use at the ICU follow up clinic. How would you adapt the existing DT to meet the experiences of a patient who has survived treatment in the ICU? On the paper in front of you, please write down your answers to the following three questions: 1) Are there any items that you think should be excluded from the list, if so, which ones? 2) Which items should be kept? 3) Are there any items that should be added to the list, if so, what?"
Collective review of ideas on flipchart (7 minutes)	Each clinician in turn will be asked to share the items which they have written down under the three headings. This will take place without a discussion.	"What items would you exclude?" "What items would you keep?" "What items would you add?"

Discussion of ideas on flip chart (15 minutes)	For each item under each of the three heading, the following question will be asked:	"Are there any questions or comments group members would like to make about the item?"
Voting and Prioritising (15 minutes)	Each clinician will be given an index card and asked to rate from 5 to 1 (where 5 = most favoured and 1 = least favoured) the items within each of the three categories; exclude, keep, add. The co-facilitator will help rank the items on the flipchart, whilst the next category is worked through. Once all the items have been ranked, the ideas that have been most favoured for their respective category will be excluded, kept or added to the Distress Thermometer. Summary of voting.	"In front of you are five index cards. For the first category – exclude, I would like you to rate the items in from 5 to 1, where 5 is the most favoured and 1 is the least." "I will then collect those cards in and rank the items to exclude." "Next, I would like you to rate items in the second category – keep. Again from 5 to 1." "Finally, I would like you to rate items in the third category – add. Again from 5 to 1." "Based on your votes, I will exclude …, keep …, and add … to the revised Distress Thermometer." "Does anyone have any final questions?"
Group Closure **(3 minutes)**	Clinicians are again thanked for their time.	"Thank you again for participating in the focus group. I will now go away and amend the DT following today's group discussion. I will leave a copy of the revised DT for you to look at; please feel free to get back to me with any comments. The revised DT will be introduced for use at the next follow up clinic" "Due to my clinical training commitments, it will take me several weeks to complete the focus group transcription. I will endeavour to keep Dr Jenkins updated of my progress with this and email it out to those of you who requested a copy as soon as I can." "Please don't hesitate to get in touch with either Dr Jenkins or myself if you have any further comments or questions."

Materials required for 'Nominal Group Technique' focus group:

- Meeting room to accommodate approximately 8 persons
- Dictaphone for audiotaping
- Flipchart and pen
- 8x copies of the original Distress Thermometer and 38-item Problem List
- Papers and pens to complete review task
- 8x index cards (15 for each clinician, five for each category)
- Watch to ensure timekeeping
- Refreshments by way of a thank you
- Spare Focus Group Information Sheets and Consent Forms (in case any clinicians have forgotten to submit/complete theirs

Appendix E: Focus Group Information Sheet & Consent Form

UNIVERSITY OF Southampton

FOCUS GROUP INFORMATION SHEET (18.01.2013, v.1)

Study Title: Validation of the Distress Thermometer with a Post-Intensive Care Population

Researcher: Amy Yarnold

Ethics Number: 5214

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

As you are aware, patients who survive a stay in an ICU are at increased risk of both long-term physical and psychological distress. At present, patients who have been discharged from the hospital's ICU are invited back to a dedicated follow up clinic, which is run by yourself and colleagues. At this clinic, patients complete a number of questionnaire measures in order to assess any resulting distress and problems with functioning so that appropriate help and support can be sought to ameliorate these.

The follow up clinic already administers the Hospital and Anxiety Depression Scale (HADS) and the Impact of Events Scale-Revised (IES-R). However, the focus of this study is to introduce a new measure of distress which will assess difficulties across biopsychosocial domains; your help and expertise is required to help ensure that this new measure is appropriate for use with a post-ICU population. It is hoped that this can be achieved by way of a focus group with clinicians who understand the extent of the challenges facing those who have survived treatment in an ICU.

Who is running the focus group?
My name is Amy Yarnold. I am a Trainee Clinical Psychologist studying for a Doctorate in Clinical Psychology at the University of Southampton. As part of my doctorate, I am working with the Clinical Psychology Team at Salisbury District Hospital, under the supervision of Dr Kate Jenkins, Clinical Psychologist. I am also supervised by Dr Catherine Brignell at the University of Southampton.

What is the focus group about?
The aim of this focus group is to produce a revised version of the Distress Thermometer for patients who have survived a stay in the ICU. Once adapted, it is hoped that the Distress Thermometer will be used as a routine screening questionnaire at the follow up clinic.

What is the Distress Thermometer?

The Distress Thermometer is a two-part tool that was initially developed to assess mood with oncology patients. The first part is the 11-point visual analogue scale in the design of a thermometer. Patients are asked to rate their level of distress (where 10 = extreme distress and 0 = no distress) over the past week. The second part is the 38-item Problem List which contains a list of biopsychosocial factors that are likely to contribute to that patient's distress; patients tick the items relevant to them. The Distress Thermometer is unique in that it affords a holistic assessment of the patient's needs where other measures tend to pathologise towards specific disorders such as anxiety, depression or Post Traumatic Stress Disorder (PTSD). Should a patient select items from the Problem List, these can be discussed there and then in the follow up clinic. By assessing the patient in this manner, it means that should they require further support, advice or a referral to another service (such as Clinical Psychology, Occupational Therapy etc.), this can achieved without delay.

Why does the Distress Thermometer need to be adapted?
NICE guidelines (2009) state that all critical care survivors should be screened to identify any psychological (and physical) distress. At present, no guideline stipulates which measures should be used and local service providers are required to develop their own protocols. In order to ensure that the Distress Thermometer meets the clinical needs of the local service, it would benefit from being reviewed and adapted by those who work with this population.

What will be involved?
At the focus group, you will be invited to comment on how the Distress Thermometer could be adapted for use with patients who have survived treatment in the ICU. There are no correct or incorrect answers; the group format is there to promote a focused discussion amongst key clinicians who work in critical care, who are therefore best placed to recognise the biopsychosocial factors that influence distress in this population.

The focus group will be audio-recorded, transcribed (typed up) and analysed to facilitate development of the Distress Thermometer for use in the post ICU follow up clinic. Anyone who attends the focus group will be given a copy of the adapted Distress Thermometer, which they will be able to comment on. A copy of the transcription will be available on request, please ensure that you have indicated this on the consent form and included an email address to receive the final, anonymised version.

How long with the focus group last for?
The focus group will last for approximately one hour. Refreshments will be provided by way of a thank you.

How many people will attend the focus group?
It is anticipated that six clinicians and two facilitators will attend the group.

Where and when will the focus group be held?
The focus group will take place on Friday 1st February at 12noon in the meeting room (TBC).

Why am I being invited to take part?
You are being invited to take part in this focus group as you are part of the multidisciplinary team on the ICU. Therefore, you are best placed to understand the needs of the post-ICU population.

Are there any benefits in taking part?
Once the Distress Thermometer has been adapted for use with a post-ICU population, it will be utilised at the monthly follow up clinic; once sufficient numbers of patients have been assessed using the Distress Thermometer alongside standardised measures already administered, its effectiveness and validity as a measure will be evaluated.

Do I have to take part in the focus group?
No. It is up to you whether or not you decide to take part in this study.

When do I need to decide by?
If you decide to take part in the focus group, please complete the attached consent form by 31st January 2013 and return it to Dr Kate Jenkins. I will then collect the consent forms from Dr Jenkins on Friday 1st February 2013.

What if I change my mind about taking part?
You have the right to withdraw from the focus group at any time and without reason. Your decision to withdraw would not have any bearing on future interactions with Salisbury District Hospital or the University of Southampton, and would not affect your legal rights.

Will my participation be confidential?
Your participation will be confidential to a point; the nature of a focus group means that you will be sharing your ideas and views on the Distress Thermometer amongst other colleagues. However, prior to starting the focus group, attendees will be advised that for the benefit of everyone's confidentiality, any information discussed in the focus group should not be discussed outside of the group.
In addition, this study will comply with the Data Protection Act (1998), the University of Southampton ethics policy, and the British Psychological Society's Code of Ethics and Conduct (2009) at all times. This study has also been identified as service evaluation and been approved by Salisbury District Hospital's Research and Development Team.

When the audiotape is being transcribed, all attendees will be given a pseudonym in order to protect their anonymity. The tapes will not be listened to by anyone other than the researchers. All tapes will be stored securely in a locked cabinet and electronic material will be encrypted and password protected. Audiotapes will be securely destroyed after five years. Any written material (from flipcharts) will also be stored securely in a locked cabinet.

The transcripts may be used for future service evaluation, research or publication. However, quotations will always be anonymised and no identifiable information contained.

Are there any risks involved in taking part in the focus group?
There are no probable risks identified. However, should you have any questions about your rights as a participant in this study; feel that you have been placed at risk; or, have a complaint, please contact:

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

Where can I get more information from?
If you would like any further information or wish to discuss participating in the group, please do not hesitate to contact me of Dr Kate Jenkins:

Amy Yarnold, Trainee Clinical Psychologist, University of Southampton
Email: amy.yarnold@nhs.net or aecw1g11@soton.ac.uk
Tel: 02380 595320
(C/o Doctorate in Clinical Psychology Admin)

Dr Kate Jenkins, Clinical Psychologist, Salisbury District Hospital
Tel: 01722 425105

UNIVERSITY OF Southampton

FOCUS GROUP CONSENT FORM (18.01.2013, v.1)

Study title: Validation of the Distress Thermometer with a Post-Intensive Care Population

Researcher name: Amy Yarnold

Ethics reference: 5214

Please initial the box(es) if you agree with the statement(s):

I have read and understood the focus group information sheet (18.01.2013, v.1) and have had the opportunity to ask questions about the study.	☐
I agree to take part in the focus group and agree for my data to be used for the purpose of this service evaluation and any future research or reports.	☐
I understand my participation is voluntary and I may withdraw at any time without my legal rights being affected.	☐
I would like to receive an anonymised copy of the focus group transcription (please include your email address).	☐

Name of participant (print name)……..

Signature of participant……

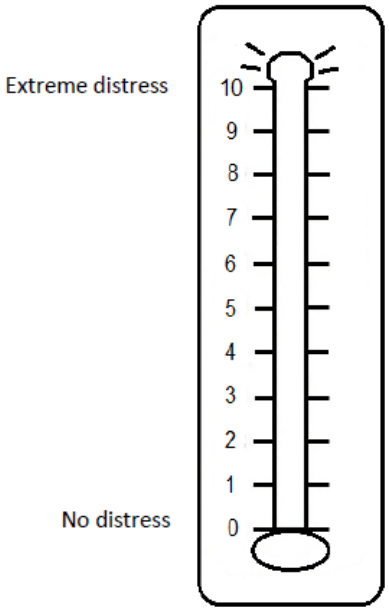
Date……

Email……

Appendix F: The Distress Thermometer for Post-ICU Follow Up (incl. adapted Problem List)

The Distress Thermometer for Post-ICU Follow Up

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



Second, please indicate if any of the following have been a concern or problem for you in the past week, including today.

Practical Concerns
- ☐ Housing
- ☐ Child care
- ☐ Insurance/financial
- ☐ Transport
- ☐ Work/school
- ☐ Care provisions (e.g. personal/domestic)

Social Concerns
- ☐ Concerns about family (incl. children/grandchildren)
- ☐ Concerns about friends
- ☐ Concerns about socialising
- ☐ Concerns about pets
- ☐ Concerns about hobbies

Emotional Concerns
- ☐ Depression
- ☐ Fears/specific phobias (e.g. driving)
- ☐ Sadness
- ☐ Anger
- ☐ Worry/anxiety
- ☐ Frustration
- ☐ Nightmares
- ☐ Intrusive memories
- ☐ Hallucinations (e.g. hearing or seeing things)
- ☐ Self-esteem (e.g. body image/change of roles)
- ☐ Loss of interest in usual activities

☐ **Religious/Spiritual Concerns**

Physical Concerns
- ☐ Appearance
- ☐ Appetite
- ☐ Breathing
- ☐ Changes in urination
- ☐ Changes in bowel habits
- ☐ Discomfort with scars (e.g. tracheostomy issues)
- ☐ Eyesight/hearing changes
- ☐ Fatigue
- ☐ Feeling swollen
- ☐ Hair loss
- ☐ Mobility
- ☐ Muscle wastage
- ☐ Nausea
- ☐ New joint changes
- ☐ Pain
- ☐ Problems with concentration
- ☐ Problems with memory (incl. lapses/gaps)
- ☐ Rate of recovery
- ☐ Sexual
- ☐ Skin issues (e.g. itchy/dry/bruising)
- ☐ Sleep
- ☐ Tingling in hands/feet
- ☐ Voice changes
- ☐ Weight changes

Other Concerns

_____

_____

_____

Appendix G: Patient Information Sheet & Consent Form

UNIVERSITY OF Southampton

PATIENT INFORMATION SHEET (18.01.2013, v.1)

Study Title: Validation of the Distress Thermometer with a Post-Intensive Care Population

Researcher: Amy Yarnold

Ethics Number: 5214

I would like to invite you to take part in a study which is evaluating the usefulness of a questionnaire call the Distress Thermometer.

Outlined below is some information which will give you an overview of what will be involved.

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

Who is running the study?
My name is Amy Yarnold. I am a Trainee Clinical Psychologist studying for a Doctorate in Clinical Psychology at the University of Southampton. As part of my doctorate, I am working with the Clinical Psychology Team at Salisbury District Hospital, under the supervision of Dr Kate Jenkins, Clinical Psychologist. I am also supervised by Dr Catherine Brignell at the University of Southampton.

What is the study about?
I am looking into the effectiveness of a questionnaire called the Distress Thermometer, which measures how distressed a patient is, as well as what factors might be contributing to their distress. The Distress Thermometer has already been evaluated for use within the cancer services, and is now routinely administered to patients. Work is currently underway to evaluate it for use within stroke services also. I am hoping to evaluate it for use with a post-Intensive Care Unit (ICU) population.

Why am I being invited to take part?
The National Institute of health and Clinical Excellence (NICE, 2009) recommend that patients who have been treated in an Intensive Care Unit

(ICU) should have their psychological and physical wellbeing assessed whilst in hospital and following their discharge home.

Every patient, like you, who has been treated in the Intensive Care Unit (ICU) is reviewed at this follow up clinic. In order for the hospital to adhere to the recommendations set out by NICE, it is now standard clinical practice that you will be asked to complete different questionnaires in order for the team (the doctors, nurses, psychologist, occupational therapist etc.) to find out how things are going for you following your discharge home and to assess any problems you may be having.

Therefore, you are being invited to take part in this study as you have been treated in the Intensive Care Unit and have recently been discharged home.

What will be involved?
As from February 2013, the team who run the follow up clinic will be handing out an extra questionnaire, the Distress Thermometer. This is the questionnaire that I am interested in evaluating. You will complete this and the other questionnaires as normal. However, in order for me to evaluate the Distress Thermometer, I need your consent to use the data from all of the questionnaires you complete.

How long will this take?
Your whole appointment at the follow up clinic will last approximately one hour; completion of the extra questionnaire will only take a couple of minutes.

What will happen once I have completed the questionnaires?
After completing the questionnaires, the team will discuss your results with you. Depending on your results you may be offered further advice and/or support, or may be referred to another team or service that might be better placed to help you with any difficulties you may have.

If you consent to taking part in this study, the data from your questionnaires will be inputted into a computer; any identifiable information such as your name, date of birth or NHS number will not be included and your data will instead be assigned a participant number. Data stored on the computer will be password protected and encrypted. Once I have data from enough patients, it will be analysed to see if, when compared against the other questionnaires, the Distress Thermometer is a useful tool for a post-ICU follow up clinic. This study will then be written up as part of my thesis and may be published in an academic journal.

Will my participation be confidential?
Yes. This study will comply with the Data Protection Act (1998), the University of Southampton ethics policy, and the British Psychological Society's Code of Ethics and Conduct (2009) at all times. This study has

also been identified as service evaluation and been approved by Salisbury District Hospital's Research and Development Team.

As completing the questionnaires forms part of your normal care, they will be kept in your medical file along with details of any further recommendations, including any referrals. Your medical file is only accessible to those professionals involved in your care. Should you wish for any information arising from the follow up clinic appointment to kept separately, please state this on the consent form.
The only time where it would be necessary to break confidentiality is if you disclose information that raises concerns about your safety, or the safety of someone else.

Are there any benefits in taking part?
Participating in this study has the potential to affect future clinical practice within ICU services; specifically the assessment and treatment of difficulties arising from a stay in intensive care.

Do I have to take part in the focus group?
No. It is up to you whether or not you decide to take part in this study.

What if I change my mind about taking part?
You have the right to withdraw your data from the study at any time and without reason. Your decision to withdraw would not affect your NHS care nor have any bearing on future interactions with Salisbury District Hospital or the University of Southampton. It would not affect your legal rights either.

Are there any risks involved in taking part?
The questionnaires you complete will ask about how you have been feeling (both psychologically and physically) following your discharge from the ICU. Understandably, this may be upsetting for you at times.

What if something goes wrong?
If you have any questions about your rights as a participant in this study; feel that you have been placed at risk; or, have a complaint, please contact:

The Chair of the Ethics Committee
Department of Psychology
University of Southampton
Southampton
SO17 1BJ
Tel: 023 8059 5578
Email: slb1n10@soton.ac.uk

Where can I get more information from?

If you would like any further information or wish to discuss participating in the study, please do not hesitate to contact me of Dr Kate Jenkins:

Amy Yarnold, Trainee Clinical Psychologist, University of Southampton
Email: aecw1g11@soton.ac.uk
Tel: 02380 595320
(C/o Doctorate in Clinical Psychology Admin)

Dr Kate Jenkins, Clinical Psychologist, Salisbury District Hospital
Tel: 01722 425105

UNIVERSITY OF Southampton

PATIENT CONSENT FORM (18.01.2013, v.1)

Study title: Validation of the Distress Thermometer with a Post-Intensive Care Population

Researcher name: Amy Yarnold

Ethics Number: 5214

Please initial the box(es) if you agree with the statement(s):

I have read and understood the Patient Information sheet (18.01.2013, v.1) and have had the opportunity to ask questions about the study.	☐
I agree to take part in this study and agree for my data to be used for the purpose of this study.	☐
I understand my participation is voluntary and I may withdraw at any time without it affecting my NHS care or legal rights.	☐
I agree for the completed questionnaires to be kept in my medical file.	☐

Name of patient (print name)……

Signature of patient……

Date……

Appendix H: Email from Salisbury District Hospital R & D Team confirming study does not require approval from NRES.

From: Kate Jenkins [Kate.Jenkins@salisbury.nhs.uk]
Sent: 14 February 2013 16:56
To: Yarnold Amy (TAUNTON AND SOMERSET NHS FOUNDATION TRUST)
Subject: FW: Student project

See below - great news!

Dr Kate Jenkins

Clinical Psychologist

Salisbury District Hospital

Direct Line: 01722 425105

X 2105

From: Louise Bell
Sent: 14 February 2013 11:49
To: Kate Jenkins
Subject: RE: Student project

Dear Kate

Sorry about the delay in responding..

I can confirm that we do not consider your project to be research as defined by NRES guidelines. This means that you must abide by all relevant Trust policies, for example information governance and data protection, but you do not require NHS Ethics or NHS Permission to proceed (research governance).

Good luck with your project.

All the best,

Louise Bell

Louise Bell

Consortium Research Governance Facilitator

Salisbury NHS Foundation Trust

Block 24

Salisbury District Hospital

Odstock Road

Salisbury

SP2 8BJ

01722 425026

From: Kate Jenkins
Sent: 04 February 2013 16:32
To: Louise Bell
Subject: FW: Student project

Hi Louise - Claire has said she is happy for it to go ahead. Is it possible to get an email or very brief letter from you just to say that the R&D department are aware of the project and happy for it to go ahead without going through ethics?

The title would be "Validation of the Distress Thermometer with patients at ITU follow-up clinic" and the student is Amy Yarnold.

Many thanks for all your help - give me a buzz if you need anything from me.

Kate

Dr Kate Jenkins

Clinical Psychologist

Salisbury District Hospital

Direct Line: 01722 425105

X 2105

From: Claire Gorzanski
Sent: 04 February 2013 15:27
To: Kate Jenkins
Subject: RE: Student project

Dear Kate,

I am assuming from what you said that this is not a 'research project' and does not need to conform with the research process. If you could confirm please?.

I think as long as you have the patient's consent and you are not identifying any patient then it is fine for you to go ahead with writing up the proposal and getting it published. I think the author should acknowledge SFT's input in the study and the support you have given her to do it.

Otherwise, happy for you to proceed.

Many thanks. Claire

From: Kate Jenkins
Sent: 04 February 2013 13:12
To: Claire Gorzanski
Subject: Student project

Hi Claire - as mentioned on the phone, we have got a trainee Clinical Psychologist from Southampton University who would like to write up a report based on some of the outcome date we collect.

In essence, at ITU follow-up clinic we use psychological screening tools to assess for distress, which the patients fill in whilst they are in the waiting room. We can then use the results of the tools to steer the clinic appointment to the specific individual issues that are affecting them. The NICE guidance for critical care rehabilitation says we should be screening for distress, but doesn't recommend specific measures.

I've started using the distress thermometer (DT - which we use in cancer services as the gold standard screening) as well as the HAD (anxiety and depression) and the Impact of Events Scale (ptsd) as it's a better holistic tool for people who may be distressed about more general adjustment issues rather than specifically anxiety or depression.

Amy is a final year trainee and she would like to write up the results in terms of specifically validating the DT against the HAD and IoES (anonymised obviously and with patients consent to use their data in the analysis). It therefore wouldn't mean giving patients any measures other than those we would be giving them anyway, but if we find out the DT is just as good or better at picking up issues, then we could ditch the HAD and IoES in the future making it less things for the patient to fill in.

It hasn't got any cost implications to the Trust and would actually save my time as I won't have to do the data entry myself!

What the University ask for is a letter/statement from the Trust saying the project has been passed by the R&D department.

What do you think? It's "care as usual" so there doesn't seem to be any need to go through ethics from my perspective, but I'd appreciate your thoughts. Louise Bell was happy to be led by your conclusions.

Best wishes

Kate

Dr Kate Jenkins

Clinical Psychologist

Salisbury District Hospital

Direct Line: 01722 425105

X 2105

Appendix I: University of Southampton Email Confirming Ethical Approval

Your Ethics Submission (Ethics ID:5214) has been reviewed and approved
ERGO [ergo@soton.ac.uk]

Sent: 06 March 2013 15:55
To: Yarnold A.E.C.

Submission Number: 5214
Submission Name: Validation of the Distress Thermometer with a Post-Intensive Care Population
This is email is to let you know your submission was approved by the Ethics Committee.

Comments
None
Click here to view your submission

ERGO : Ethics and Research Governance Online
http://www.ergo.soton.ac.uk

DO NOT REPLY TO THIS EMAIL

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