

**Developing a grounded theory model of post-traumatic stress disorder
following an intensive care unit admission**

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Executive Summary

Background & Aims

There are elevated rates of Post Traumatic Stress Disorder (PTSD) in survivors of intensive care units (ICU) and those who experience PTSD after an ICU admission (PTSD-ICU) are likely to experience worse outcomes, in relation to physical health-related quality of life and increased emergency admissions, comorbid anxiety and depression, and decreased ability to return to work.

Existing research has investigated risk factors for PTSD-ICU. Systematic reviews of these studies have found that demographic factors (e.g. previous psychiatric history) and clinical factors (e.g. benzodiazepine administration, mechanical ventilation and delirium) are associated with developing later PTSD symptoms. These reviews have also found evidence for psychological risk factors for PTSD-ICU, including the presence of frightening and delusional memories of the ICU, and acute fear or stress during the ICU. However there are gaps in the psychological conceptualisation of PTSD-ICU, such as the role of cognitions, emotions and behaviour, as well as factors occurring after discharge from the ICU, such as social support and additional life stress.

As there are high rates of PTSD in the ICU population, and this may have an adverse impact on wider outcomes, guidance recommends that individuals receive a psychological follow-up after discharge from the ICU, which would comprise of

screening, assessment and treatment of PTSD. However, the research on psychological assessment and treatment of PTSD-ICU is limited to studies on peri-traumatic interventions (e.g. music therapy, mind-body therapies and ICU diaries), and the evidence for these interventions is inconclusive. Furthermore, there is no research to indicate how applicable and effective evidence-based PTSD treatments are for an ICU-specific population. Known psychological factors, such as the role of delusional memories during ICU, may pose additional challenges and the need for adaptations to general PTSD treatment models.

This thesis therefore aimed to address the gaps in the literature with regards to the psychological understanding of PTSD-ICU. The systematic review aimed to summarise the existing research on psychological variables associated with PTSD-ICU, and the empirical grounded theory study then aimed to develop a preliminary psychological model of PTSD-ICU, based on interview data from individuals suffering with PTSD symptoms after an ICU admission.

Systematic Review of Psychological Factors Associated with PTSD-ICU

Method. A systematic literature search was conducted through PubMed and PsycInfo databases, using the following keywords: intensive care, post-traumatic stress disorder and psychosocial factors. The titles and abstracts were then screened for inclusion, according to the following criteria: the study was an English language, full-length article in a peer-reviewed journal; participants were adults from a general ICU; PTSD symptoms were measured by a validated measure; the study

investigated the relationship between PTSD and psychosocial variables; and the study utilised quantitative or qualitative methodologies (excluding reviews and case studies). Where a study was deemed relevant, the full paper was included in the review, and data were extracted on study characteristics, outcomes and quality appraisal, and then synthesised using a narrative approach.

Results. Twenty-one studies were included in the review, and outcomes were organised into temporal categories, as follows.

- On pre-ICU factors, the following factors were found to be significant:
 - Previous traumatic events, and previous stressful life events;
 - Personality traits pre-ICU (e.g. optimism, resilience, trait anxiety)
- During ICU, the following factors were found to be significant:
 - Less awareness of surroundings;
 - More frightening or extremely stressful experiences on ICU
 - Total mood disturbance;
 - Perceptions of illness timeline;
 - Qualitative studies described unreal occurrences, emotions of fear and helplessness, and sensations of pain and discomfort during the ICU were linked with PTSD.
- On memories of ICU, the following was found:
 - Four of seven studies found factual memories associated with PTSD symptoms, which was confirmed in one other study using a different measure.

- Five of ten studies found that delusional memories were significantly associated with PTSD, which was again confirmed in another study using a non-standardised measure.
- Two of four studies found that memories of feelings were significantly associated with PTSD symptomatology.
- Qualitative studies supplemented these findings with information on the content of typical factual or delusional memories, and also described how participants expressed a need for help to cope with these memories.
- After ICU:
 - Sleep quality after leaving the ICU was significantly associated with ICU.
 - Qualitative studies described themes around emotional recovery (e.g. feeling fear and hopelessness), physical recovery (e.g. being limited by physical health after ICU) and the role of family support.

Conclusions. A broad range of psychological variables were implicated in PTSD ICU: previous traumatic and stressful life events; personality traits of optimism, anxiety and resilience; having less awareness, more frightening or stressful experiences, greater mood disturbance and a longer perception of the illness timeline during the ICU; less factual memories, more delusional memories and more memories of pain from the ICU; and sleep quality after the ICU. However, some of these findings were difficult to interpret due to mixed results, particularly in relation to memories. This may be due to the heterogeneity of follow-up periods and PTSD outcome measures used. Nevertheless, these findings have clinical implications for how PTSD is assessed and treated in an ICU population. Pre-ICU

factors (e.g. previous traumatic events) can be used to screen those at high-risk of developing PTSD. During ICU factors (e.g. stressful experience) have implications for reducing possible PTSD through interventions in the ICU to decrease distress while on the unit. The role of memories may have clinical implications for how psychological practitioners deliver trauma-focused interventions, and support ICU patients to reconstruct the trauma narrative when there is memory loss and memories of hallucinations. However future research is needed to further clarify the role of these psychological variables, and explore others that have not been studied, such as appraisals or methods of coping after leaving the ICU.

Developing a Grounded Theory of PTSD after an ICU admission

Method. A grounded theory design was used to analyse interview data from participants with PTSD after ICU and to develop a preliminary psychological model. Participants were recruited via advertisements placed in NHS ICU clinics and a non-NHS organisation supporting ICU survivors. Participants who responded to adverts were screened for their eligibility to take part (adults over 18, discharged from ICU between 1 months and 5 years ago, PTSD symptoms, sufficient English language to participate, no suicidal ideation). If participants met inclusion criteria, they were invited to take part in an interview, which asked questions about their psychological experiences during and after ICU. Interviews were audio recorded, transcribed and then were coded according to grounded theory methodology.

Results. Seven theoretical codes and 19 focused codes were generated from the interview data. These were organised in a temporal order from pre-ICU through to after ICU. The seven theoretical codes, and the component focused codes were as follows:

- Pre-ICU: previous life events; sudden illness.
- During ICU experiences: Being near-death; loss of autonomy; emotional reaction; ICU staff; poor sleep.
- During ICU perception: loss of awareness; distorted reality.
- After ICU memory: memory (including loss of memory, memory of hallucinations or nightmares, memory of physical sensations); difficulty making sense of memories; relying on third hand information.
- After ICU response: emotional response; appraisals.
- After ICU recovery: physical vs emotional recovery; coping.
- Family and relationships: support from others; impact on relationships; and changes in relationships.

These codes were then used to generate a diagrammatic model of PTSD-ICU.

Conclusions. The grounded theory study provided an initial theoretical framework to assist with the psychological assessment, formulation and treatment of PTSD-ICU. The findings highlight how general models of PTSD can be applied to this population, as well as emphasising psychological factors distinct to an ICU sample. These include loss of autonomy, loss of awareness and distorted reality, memory loss, and the memory fragmentation that occurs as a result of these

processes. Additionally, the recovery process is affected not only by emotional difficulties associated with PTSD symptoms, but also by physical recovery from critical illness.

The clinical implications of these findings were considered with relation to specific cognitive behavioural approaches that might be relevant to this population, and the importance of joint working and liaison between mental health and physical health ICU services.

Integration, Impact and Dissemination

Integration. The combined aim of the systematic review and grounded theory study was to increase psychological understanding of PTSD-ICU by reviewing the existing psychological literature and then developing a preliminary theoretical model of PTSD-ICU, grounded in experiential interview data. The findings of the systematic review and grounded theory were generally in accordance with each other. The following factors were consistent across existing research and this grounded theory study: previous traumatic or stressful life events; loss of autonomy, emotional reaction, distorted reality (e.g. hallucinations) and loss of awareness during ICU; types of memory (loss of memory, memory of hallucinations, pain or physical sensations) and making sense of these memories; emotional response; coping; and physical versus emotional recovery after ICU. The joint implications of the review and empirical study were considered, particularly in terms of involving the wider system (family and other professionals) in treatment. Other specific implications are

considered for individual psychological factors that were present in both studies. Finally, the systematic review and empirical study were critically appraised in terms of the methodological decisions, strengths and limitations.

Impact. It is anticipated that this thesis will make a contribution to the psychological research literature on PTSD-ICU, and provide directions for further research, including what gaps exist in the psychological literature, confirming qualitative findings with quantitative research, and intervention studies targeted at PTSD-ICU.

Additionally, it is expected that the research will impact both clinicians and service users. For ICU clinicians, this adds further information on what is specifically traumatic about the ICU experience and how this distress might be reduced. For mental health practitioners, this research gives insight into the ICU experience and provides concrete clinical recommendations for delivering psychological interventions in this group. Service users will hopefully benefit indirectly from increased understanding in clinicians of PTSD-ICU, as well as directly through reading a lay summary of the results and potentially having their experience normalised or validated.

Dissemination. A plan for dissemination to the research, clinical and service user community was discussed as follows:

- Research community: through publishing findings in a peer-reviewed journal and presenting at a conference. The decision about journal papers and conference was given consideration regarding to reaching specific audiences, either ICU researchers or psychological researchers.
- Clinical community: findings will be disseminated to the clinical community through publishing findings in a journal, and through emailing findings to local teams who have been involved in the recruitment for the study. This could be supplemented with delivering a brief presentation to teams on the findings and the clinical recommendations.
- Service user community: a lay summary of the results will be developed in consultation with service users, and then disseminated to participants in the study and through service user forums in local ICU services.

Chapter 1

A systematic review into the psychological factors associated with post traumatic stress disorder after an intensive care admission

Abstract

High rates of Post Traumatic Stress Disorder (PTSD) have been found consistently in individuals who have been discharged from an Intensive Care Unit (ICU). Existing research has highlighted the prevalence and the clinical and demographic risk factors for PTSD after ICU (PTSD-ICU). However the psychological variables associated with PTSD-ICU have received comparatively little attention. The aim of this review was to summarise the existing research on psychological risk factors associated with PTSD-ICU. A systematic literature search was conducted using PubMed and PsycInfo databases. Quantitative or qualitative studies of adult ICU participants, which investigated the relationship between PTSD and psychosocial variables were selected for inclusion. Data was extracted on study characteristics, quality appraisal and outcomes, and was synthesised using a narrative approach. In total, 21 studies were selected for inclusion in the review. The following psychological variables were associated with PTSD-ICU: previous traumatic or stressful life events and personality traits (pre-ICU); less awareness of surroundings, more frightening or stressful experiences, mood disturbance, and perceived illness timeline (during ICU); factual memories, delusional memories and memory of feelings (memories of ICU); and sleep quality (post-ICU). These findings were also supplemented with qualitative data. In conclusion, a broad range of psychological factors were associated with PTSD-ICU. However these findings were difficult to interpret due to the heterogeneity of measures and follow-up periods, and methodological limitations of the included studies and this review. The clinical and research implications of these findings were considered.

Introduction

Intensive Care Units

Intensive Care Units (ICUs) are specialist wards which are set up to provide care for individuals who are critically ill, and require intensive treatment and close monitoring, often due to organ failure (Smith & Nielsen, 1999). In England, there are over 200,000 admissions to ICUs each year (ICNARC, 2017; NHS Digital, 2017). These admissions may be planned for after surgery or unplanned (NHS Digital, 2017). Current survival rates following ICU have improved due to medical and technological advances (e.g. Hutchings et al., 2009), and so the clinical, research and policy focus has shifted from improving short-term mortality to also encompass longer term outcomes and rehabilitation after ICU. In the longer term, there are both physical and psychological consequences following intensive care (Dowdy et al., 2005; Needham et al., 2012). Numerous studies have shown that there are significant rates of depression, anxiety and Post-Traumatic Stress Disorder (PTSD) following ICU, and these problems can persist for many years after (Davydow, Gifford, Desai, Needham, & Bienvenu, 2008; Wade et al., 2012).

PTSD following an ICU Admission

PTSD is diagnosed when an individual is exposed to actual or threatened serious injury or death, and then experiences the following symptoms for more than one month after: persistent re-experiencing (e.g. nightmares, flashbacks), avoidance of trauma reminders, negative alterations in cognition and mood, and increased hyperarousal ([e.g. American Psychiatric Association, 2013](#)). Estimates of PTSD

following an ICU admission (PTSD-ICU) range from 8 to 27% (Wade, Hardy, Howell, & Mythen, 2013), and a recent meta-analysis found a pooled prevalence of 24% at 1-6 months, and 22% after 7 months (Parker et al., 2015). This is comparable to rates seen in survivors of war (e.g. Hoge et al., 2004). Furthermore, those in intensive care units experience the highest rates of PTSD compared to other groups experiencing physical illness and medical treatment (e.g. HIV, cardiac surgery, stroke), and this finding is not accounted for by the severity of physical illness (Tedstone & Tarrier, 2003). This increased risk seems to be related to the experience of the ICU rather than the reason for admission to ICU (e.g. physical trauma) (Myhren, Ekeberg, Tøien, Karlsson, & Stokland, 2010). For example, injury patients are three times more likely to have PTSD if they are admitted to the ICU, compared to those injury patients not admitted to the ICU (O'Donnell et al., 2010).

The rates of PTSD may be high in this group as patients in ICU will likely experience a number of psychological stressors during their admission, including: their own and others' life-threatening illness, pain caused by the illness or medical procedures, delirium resulting in disorientation, sleep disturbance, delusional memories, memory loss, physical restraint, loss of control, reduced ability to communicate and meet their own needs (e.g. thirst, hunger or washing), and associated loss of dignity (Biancofiore et al., 2005; Rotondi et al., 2002).

Those who experience PTSD following ICU are likely to have poorer physical health outcomes including a lower health-related quality of life (Parker et al., 2015) and

increased use of emergency health services (Davydow et al., 2014). This is in addition to comorbid psychological problems, such as anxiety or depression (Paparrigopoulos et al., 2014; Parker et al., 2015). Similar findings have been found in other health groups, where PTSD symptoms are linked with worse physical health outcomes in cardiac, stroke and chronic illness patients, compared to those without PTSD (Edmondson, 2014; Kronish, Edmondson, Goldfinger, Fei, & Horowitz, 2012; Newman et al., 2011).

Those with PTSD may be less likely to engage in follow-up care after an ICU admission (Davydow, Zatzick, Hough, & Katon, 2013). One reason this may occur is due to avoidance (Jackson et al., 2016). Studies have shown high levels of avoidance symptoms (as measured by the impact of event scale) after being in the ICU and this persists in the long-term (Rattray, Crocker, Jones, & Connaghan, 2010). Avoidance symptoms are often related to trauma cues, which in an ICU population may include the hospital and health appointments, and may therefore be a possible contributor to worse health-related outcomes.

Risk Factors for PTSD post-ICU

Given the high rates of PTSD following ICU, and the impact on long-term functional outcomes, it has been important to understand relevant risk factors in order to support prevention, assessment and intervention. Previous systematic reviews have highlighted a number of demographic, clinical and psychological factors associated with developing PTSD following ICU. The one demographic factor consistently

identified across previous reviews is psychiatric history (Davydow et al., 2008; Morrissey & Collier, 2016; Parker et al., 2015; Wade, Hardy, Howell, & Mythen, 2013). Less consistently, younger age and female gender were also identified as potential risk factors in 2 reviews (Davydow et al., 2008; Morrissey & Collier, 2016).

A number of clinical factors occurring in the ICU have been identified as possible risk factors for PTSD, including duration of ICU stay, administration of benzodiazepines, stress hormones, mechanical ventilation and delirium (Davydow et al., 2008; Morrissey & Collier, 2016; Parker et al., 2015; Wade et al., 2013). However, the findings have been mixed in relation to these, and only benzodiazepine administration was found to be significant across all four reviews. Clinical factors that have been found not to be associated with PTSD after ICU are the severity of critical illness, duration of ICU stay and ICU admission diagnosis (Davydow et al., 2008; Parker et al., 2015).

Some psychological factors have also been identified by previous reviews. These have predominantly focused on early memories of the ICU, where delusional, frightening or traumatic memories predict later PTSD symptoms (Davydow et al., 2013; Morrissey & Collier, 2016; Parker et al., 2015; Wade et al., 2013). One of the reviews also highlighted the role of fear and stress during the ICU (Wade et al., 2013) and another the possible role of trait anxiety (Davydow et al., 2008).

Predominantly, these findings originate from quantitative studies utilising standardised measures, such as checklists of types of memories or experiences

from the ICU, but this does not elucidate what specifically is so frightening or stressful about the ICU experience for those who later develop PTSD. Furthermore, frightening memories and acute stress or fear are hallmarks of PTSD, yet little is known about how individuals think, feel and act in response to the traumatic experience of ICU, both during and after the ICU admission. Whereas, the general PTSD literature highlights how traumatic events often violate an individual's beliefs and assumptions about themselves and the world (e.g. Ehlers & Clark, 2000) and that factors occurring after the trauma, such as social support and additional life stress, can be significant in predicting PTSD symptoms (Brewin, Andrews, & Valentine, 2000).

Peri-Traumatic Interventions for PTSD-ICU

The research on risk factors for PTSD-ICU has allowed for treatment protocols to be developed in the ICU, with the aim of modifying risk factors and reducing rates of PTSD after. For example, modifying benzodiazepines and sedation levels has shown to be beneficial in reducing anxiety and PTSD after leaving the ICU (Kress et al., 2003). Another example is interventions to reduce acute stress while in the ICU. A systematic review of non-pharmacological interventions designed to reduce psychological distress in the ICU found that music, sound and mind-body therapies were effective at reducing acute stress in the ICU, but longer-term outcomes in terms of PTSD were unclear (Wade et al., 2016).

ICU diaries (Egerod, Christensen, Schwartz-Nielsen, & Agård, 2011) are another common ICU intervention aimed at reducing PTSD, by producing a coherent narrative of the ICU stay that aims to fill in gaps in memory and reduce the impact of frightening memories. Wade et al. (2016) in a review found that two of two studies showed diaries to be effective in reducing longer term symptoms of PTSD (Garrouste-Orgeas et al., 2012; Jones et al., 2010). In another systematic review, focused specifically on this intervention (Ullman et al., 2015), minimal evidence of benefits or harm were found as a result of the use of patient diaries.

Furthermore, there is evidence from one study of the potential value in psychologists being part of the multidisciplinary team working in the ICU (Peris et al., 2011). It was found that the psychologist intervention led to lower rates of PTSD at 12-month follow-up (21%) compared to the non-psychologist group (57%). However this was not a controlled study and it is not clear specifically what interventions were delivered by the psychologist. So this provides limited information about the mechanisms contributing to the lower rates of PTSD in the intervention group.

Post-ICU Interventions for PTSD-ICU

When in-ICU interventions are not effective at preventing PTSD and psychological distress, it is important that there are effective psychological interventions available for PTSD-ICU after discharge. Due to the higher rates of PTSD and other mental health problems following ICU, guidelines recommend that ICU patients receive a psychological follow-up after leaving the ICU (Masterson & Baudouin, 2015; National

Institute for Health and Care Excellence, 2009). This follow-up would ideally involve screening and assessment of PTSD and either direct treatment of PTSD, if the resources are available, or referral to the appropriate services (Masterson & Baudouin, 2015).

For the treatment of PTSD, NICE recommend that either trauma-focused cognitive behaviour therapy (TFCBT) or eye movement desensitisation and reprocessing (EMDR) are offered as current evidence-based effective treatments for PTSD (NICE, 2005). At present, there is no research to indicate how effectively these interventions can be delivered with an ICU-specific group. The research on risk factors outlined above suggests that an ICU population may be more likely to have delusional or hallucinatory memories. This may pose an extra challenge or need for adaptation within the current evidence based treatment models for PTSD. However, greater detail and understanding is required about the psychological factors involved with PTSD-ICU in order to properly conceptualise and deliver effective psychological treatment to this group.

Rationale

The current research literature indicates that there is a high risk of ICU survivors experiencing PTSD symptomatology following their admission, and that these symptoms can have a significant impact on their ongoing health and functioning. For this reason, guidelines recommend the provision of psychological assessment and interventions for this group. However the current psychological understanding of

PTSD-ICU is limited by the available information on psychological risk factors, which is reflected in the evidence for psychological interventions in this group. Current research suggest that ICU survivors may have unique psychological risk factors, features and consequences that distinguish them from PTSD in the general population, and which may require consideration when offering psychological interventions. However, up to this date systematic reviews have yet to focus specifically on psychological risk factors and have only investigated psychological factors as a minor component of reviews on prevalence and general risk factors. Furthermore, these reviews have focused on acute psychological risk factors as measured by quantitative research designs, and so have failed to summarise broader psychological factors occurring at different timepoints (e.g. after discharge from ICU) and using different methodological approaches.

Aims

In order to inform effective psychological assessment and treatment of PTSD-ICU, this systematic review aimed to summarise the existing research on psychological factors associated with the development and maintenance of PTSD-ICU. In particular, this review aimed to focus on individual experience of cognitive, affective and social processes, such as support seeking and relationships. Psychological interventions were not included in the review, as they have been covered in recent systematic reviews (Parker et al., 2015; Ullman et al., 2015; Wade et al., 2016). This review will include studies using quantitative and qualitative methodologies, so that quantitative findings can be supplemented with richer data about experiences of PTSD following ICU.

Method

Search Strategy

PubMed and PsycInfo databases were searched on 24th September 2017 using the following subject headings and keywords: Intensive Care, Post-Traumatic Stress Disorder and Psychosocial Factors (table 1). The databases were chosen because PubMed searches abstracts of biomedical literature and therefore would find ICU-relevant papers, and PsycInfo because it searches abstracts of psychological literature.

The search results were limited to English papers, due to insufficient resources for translation of foreign language articles. The search terms were then combined as follows:

1. Subject heading for intensive care
2. Combine non-subject headings for intensive care with OR
3. 1 OR 2
4. Subject headings for PTSD
5. Combine non-subject headings for PTSD with OR
6. 4 OR 5
7. Subject headings for psychosocial factors
8. Combine non-subject headings for psychosocial factors with OR
9. 7 OR 8
10. 3 AND 6 AND 9

Table 1

Search Strategy

| | MeSH Terms: | Keywords |
|----------------------------------------------------------|----------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Intensive Care (combined with OR) | Critical Care Intensive Care Unit Critical Illness | ICU ITU Intensive care Intensive care unit Critical care Critical illness |
| AND | | |
| PTSD (Combined with OR) | Post traumatic stress disorder | PTSD Post-traumatic stress disorder Post traumatic stress disorder Posttraumatic stress disorder Stress disorder, post-traumatic Stress Disorder, traumatic |
| AND | | |
| Psychosocial Factors (Combined with OR) | Psychology | Psycholog* Psychosocial Social Mood Emotion Affect Cogniti* Beliefs Thoughts Behavio* Memory |
| Limits | English | |
| Total Database Yield | PubMed 323 PsycInfo 422 | |

Study Selection**Inclusion Criteria**

Participants. Studies were included if participants were adults (18 years and over) and were patients who had been admitted to a general ICU. Only general ICU

populations were included, and more specific ICU populations were excluded to ensure the findings were generalisable to general ICU populations.

Additionally, for qualitative studies, studies were only included in which all participants have PTSD symptoms (see below, 'outcome measures').

Study design. Studies were included that adopted either a quantitative or qualitative (or mixed) design. For quantitative designs, this included randomised controlled trials, cross-sectional studies and prospective studies.

Outcome measures. Studies were included where PTSD had been assessed using a validated standardised measure of PTSD or a diagnostic interview. Other variables could be assessed using standardised or non-standardised measures.

Psychosocial factors. Psychosocial factors consisted of individual psychological factors and social factors. For the purpose of this review, individual psychological factors were defined as measures of individual mental and affective processes including cognitive (e.g. memory, appraisals), affective (e.g. distress mood, stress), behavioural (e.g. coping strategies), experiential (e.g. previous trauma exposure) and personality. This definition excluded psychological interventions, as previous systematic reviews have

already covered this, and measures of other psychiatric disorders, for example, depression and anxiety.

Social factors of interest to this review were those related to interpersonal process (e.g. social support) . Socioeconomic and vocational factors were not included in the definition of social factors for the purpose of this review.

Exclusion Criteria. Studies were excluded if: The full text was not available in English.

1. They were published only as a conference paper, abstract or thesis (i.e. not available as full-text in a peer-reviewed journal).
2. The sample was neonatal or paediatric ICU samples, or consisted of nurses or family member participants only.
3. PTSD symptoms were not measured by validated questionnaires or diagnostic interviews.
4. They did not investigate psychosocial variables (as defined in the *inclusion criteria*), also excluded were psychiatric diagnoses, psychological interventions, socioeconomic and vocational factors were excluded.
5. They were review papers or case studies.

Study Selection. All abstracts identified by the searches were examined by the main author according to the inclusion and exclusion criteria. It was not possible for the study selection to be checked for reliability by a second researcher due to

resource considerations. Where a study was deemed relevant, the full paper was extracted for review. After electronic removal of duplicates using Zotero (reference management software), 690 studies were identified by the search method for review. Of these, 669 were excluded according to the following criteria: 2 were duplicates; 68 studies were not English language, full-text studies in peer-reviewed journals; 479 were not adult ICU patient participants; 18 did not measure PTSD symptoms; 48 did not investigate psychological factors associated with PTSD in ICU; and 53 studies were excluded based on the type of study (e.g. review). One study was excluded as it did not have extractable data. The flowchart shows how the studies obtained from the database searches were selected or excluded from the review (figure 1).

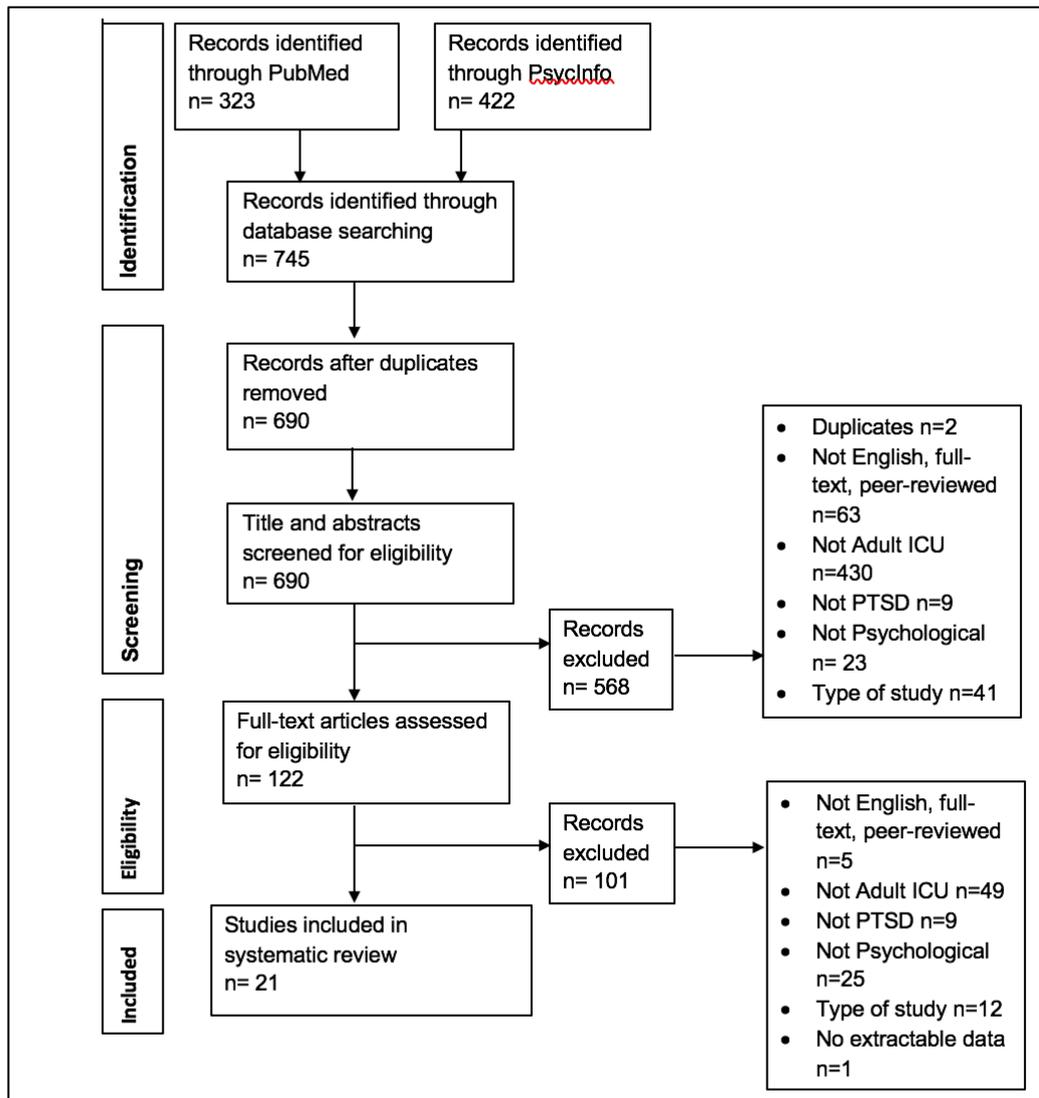


Figure 1. PRISMA flow diagram of the study selection process

Analysis

Quality analysis. Quality assessment was necessary in order to evaluate the level of bias present in the included studies. This was carried out in line with the Mixed Methods Appraisal Tool (MMAT; Pluye et al., 2011), as this allowed for the concurrent appraisal of qualitative, quantitative and mixed method studies, rather than using different tools for each type of study. The MMAT has good reliability (Pace et al., 2012) and validity (Pierre Pluye, Gagnon, Griffiths, & Johnson-Lafleur,

2009). The MMAT is composed of two screening questions for each study, and then four further criteria which are specific to the type of study (e.g. qualitative, quantitative randomised/non-randomised). Each criterion can be answered with 'yes', 'no' or 'can't tell'. A quality assessment score was created by calculating the proportion of 'yes' answers for the 4 method-specific criteria.

For qualitative papers, appraisal was based on the following characteristics: are the sources of the qualitative data relevant to address the question, is the analysis appropriate for the question, is consideration given to how the findings relate to the context, and is consideration given to how the findings relate to the researcher's influence. For quantitative studies, and dependent on the design, appraisal was based on the following: sampling and recruitment strategy, appropriate outcome measurement, controlling/accounting for differences between groups, randomisation and blinding (in randomised controlled trials), and response/follow-up rate.

Data extraction. The data was extracted from the included studies by the author, and it was not possible for the data extraction to be independently checked for reliability. Data was extracted systematically using a pre-determined data extraction table on study characteristics and specific outcomes related to the question of psychological factors associated with PTSD after ICU. For study characteristics, data on sample (size, gender, age, length of stay in ICU, and illness severity), methodology (including design, inclusion/exclusion criteria, outcome measures and follow-up duration) and analysis type were extracted. Only outcomes

that were relevant to the question of psychological factors linked to PTSD after ICU were extracted from each study.

Data Synthesis. The findings of the included studies were then summarised and organised into separate tables of study characteristics and outcomes. It was not appropriate to conduct a meta-analysis or meta-synthesis of the study outcomes because the design and outcomes measures varied significantly and so the extracted data was too heterogeneous. This review instead adopted a narrative synthesis approach to the included studies and their results (Popay et al., 2006).

Results

Study Characteristics

In total, 21 studies were included in this review. The studies included in this review were carried out between 2001 and 2016, in the following countries: United Kingdom (n=7), Sweden (n=5), United States of America (n=3), Australia (n=2), Italy (n=2), Denmark (n=2), Brazil (n=1), Greece (n=1), Netherlands (n=1) and Portugal (n=1). The studies included a total number of 2634 unique participants (Myhren et al., (2010) excluded as same sample as Myhren et al.,(2009)). Sample sizes ranged from five (Talisayon, Buckley, & McKinley, 2011) to 299 (Svenningsen et al., 2015) (table 2). There were 1533 males and 1103 females across all the studies, however there is a discrepancy in the totals due to one missing value (Rattray et al., 2010) and a reporting error in another study (Jones et al., 2007). The mean/median age of participants ranged from 47.9 to 67.3 years. Illness severity was measured using the Acute Physiology And Chronic Health Evaluation II (APACHE-II; Knaus, Draper, Wagner, & Zimmerman, 1985) in 13 studies. The APACHE-II is a severity of disease classification used at admission to the ICU, which ranges from 0 to 71 where higher rates indicate more severe illness and higher risk of death, and the mean/median ratings ranged from 11.8 to 22.01. The Simplified Acute Physiology Scale II (SAPS-II; Le Gall, Lemeshow, & Saulnier, 1993) measure, is also used to classify illness severity at ICU admission and ranges from 0 to 163. The SAPS-II was used in four studies and ranged from 25.9 to 37.0. The mean or median length of stay ranged from three to 19.15 days. All studies were carried out in general ICUs (medical or surgical) with patients with mixed diagnoses.

Table 2

Study Characteristics of included studies

| Study First author / date (Country) | Design | Participants N Age (years)* Gender | Inclusion | Exclusion | Length of Stay (Days)* | Illness severity (APACHE II or other, stated)* | MMAT Quality Score |
|-----------------------------------------------------|----------------------------------------------|---------------------------------------------------------------------------------------|----------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------|-------------------------------------------------------------|---------------------------|
| Buck 2007 (The Netherlands) | Quantitative: prospective cohort | 29 Age: 50.8 (14.9) Gender: 9M (31%), 20F (69%) | Unexpected admission to ICU. No previous ICU admissions. | Psychiatric disorders; insufficient language; factors affecting recollection of ICU (e.g. brain damage, head trauma, drug abuse); LOS < 24hrs | Median 10.4 | - | 75% |
| Corrigan 2007 (Sweden) | Qualitative: Phenomenological Approach | 14 Age: median 52 (range 42-74) Gender: 3M (21%), 11F (79%) | Mechanically ventilated, LOS > 24hrs; IES score > 30 | - | Median 5 (range 1-35) | - | 75% |
| Davydow 2013 (USA) | Quantitative: prospective cohort | 120 Age: 49.0 (14.6) Gender: 69M (58%), 51F (42%) | - | Admission diagnosis of traumatic injury; pre-existing cognitive impairment or dementia; communication/ language barrier; LOS < 24hrs; life expectancy < 12 months; admission due to suicide attempt | 7.5 (8.2) | SAPS-II: mean 25.9 (SD 15.3) | 100% |

| Study First author / date (Country) | Design | Participants N Age (years)* Gender | Inclusion | Exclusion | Length of Stay (Days)* | Illness severity (APACHE II or other, stated)* | MMAT Quality Score |
|-----------------------------------------------------|---------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------|----------------------------------------------------------|---------------------------|
| Elliott 2016 (Australia) | Quantitative: prospective cohort | 222 Age: 57.2 (17.2) Gender: 145M (65%), 77F (35%) | Age > 18 years; capacity for consent; LOS > 48hrs; ready for transfer to general hospital ward | Pre-existing sleep disorders; language or communication barriers | Median 3 (IQR 2-6) | 12.75 (5.8) | 75% |
| Glimelius Petersson 2015 (Sweden) | Mixed: prospective cohort & qualitative content analysis (qualitative not used) | 74 Age: Intervention 59 (20); Control 65 (13) Gender: 51M (69%), 23F (31%) | Age > 18 years; LOS > 3 days | - | Intervention : 9.4 (6.3); Control: 4.7 (2.0) | Intervention 19.0 (7.0) Control 20.0 (6.7) | 100% |
| Jones 2001 (UK) | Quantitative: case series prospective cohort | 45 Age: median 57 (range 17-82) Gender: 20M (44%), 25F (56%) | LOS > 24hrs; ventilated | Admission following suicide attempt; head injury; previous or ongoing psychotic illness | Median 8 (range 1-60) | Median 17 (range 4-18) | 50% |
| Jones 2003 (UK) | Quantitative: RCT | 126 Age: Intervention 57 (17); Control 59 (16) Gender: 70M (56%), 56F (44%) | Ventilated | LOS < 48hrs; burn injury; language or communication barriers; neurosurgery; pre-existing psychotic illness; terminal care at discharge | Intervention 14 (20) Control: 13 (18) | Intervention: 17 (5) Control 16 (5) | 50% |
| Jones 2007 (Italy, Norway, Sweden, UK) | Quantitative: Prospective cohort | 238 Age: median 61 (range 17-86) Gender: 149M, 92F ^a | Age > 18 years; ventilated; LOS > 48hrs | Admission following suicide attempt; pre-existing psychotic illness; >30km from hospital | Median 7 (range 2-76) | Median 16 (range 3-36) | 100% |

| Study First author / date (Country) | Design | Participants N Age (years)* Gender | Inclusion | Exclusion | Length of Stay (Days)* | Illness severity (APACHE II or other, stated)* | MMAT Quality Score |
|------------------------------------------------------------------|----------------------------------------|----------------------------------------------------------------------------------------------------------------------|------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------|------------------------------------------------------------|---------------------------|
| Jones 2010 (Denmark, Italy, Norway, Portugal, Sweden, UK) | Quantitative: RCT | 352 Age: intervention median 60 (range 18-81), control 59 (18-82) Gender: 227M (64%), 125F (36%) | Ventilated | LOS < 72hrs; ventilated < 24hrs; no capacity for consent; pre-existing psychotic illness | Intervention median 3 (range 3-79) Control: 13 (3-71) | Intervention: median 20 (range 5-46) Control: 18 (2-39) | 100% |
| Maley 2016 (USA) | Mixed: cross-sectional and qualitative | 43 Age: 59.0 (15.0) Gender: 18M (42%), 25F (58%) | LOS > 48hrs | Discharged to hospice | Median 5.1 (IQR 2-5-11.3) | - | 75% |
| Myhren 2009 Myhren 2010 (Norway) | Quantitative: cross-sectional | 255 Age: 47.9 (15.7) Gender: 160M (63%), 95F (37%) | Age 18-75 years; LOS > 24hrs | Language barriers; serious psychiatric problems; severe head injury or cognitive failure | 12 (CI .3-13.8) | SAPS-II 37.0 (CI 35.3-38.7) | 100% |
| Paparrigopoulos 2014 (Greece) | Quantitative: cross-sectional | 48 Age: 52.7 (2.8) Gender: 33M (69%), 15F (31%) | LOS > 24hrs | | 13.2 (2.6) | 11.8 (4.8) | 75% |
| Ratray 2010 (UK) | Quantitative: prospective cohort | 103 Age: 60.0 (range 17-84) Gender: 65M, 37F ^a | LOS > 24hrs; mechanically ventilated; age > 18 years | Head injury or elective neurosurgery patients | Median 7 (range 0-63) | 19 (range 6-34) | 50% |
| Rovatti 2012 (Brazil) | Quantitative: cross-sectional | 41 Age: 56.1 (14.8) Gender: 23M (56%), 18F (44%) | LOS > 48hrs; Age > 18 years | Vision or hearing loss; degenerative neurological disease or dementia; terminal cancer; psychiatric condition and/or psychotropic medications | 19.15 (22.31) | High 31.7% Medium 41.5% Low 26.8% | 75% |

| Study First author / date (Country) | Design | Participants N Age (years)* Gender | Inclusion | Exclusion | Length of Stay (Days)* | Illness severity (APACHE II or other, stated)* | MMAT Quality Score |
|-----------------------------------------------------|---------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------|----------------------------------------------------------|---------------------------|
| Samuelson 2007 (Sweden) | Quantitative: prospective cohort | 226 Age: 63.3 (13.4) Gender: 118M (52%), 108F (48%) | Intubated; age > 18 years; mechanically ventilated; LOS > 24hrs | Head injury; psychotic illness; intellectual disability; hearing or speaking disability; language barriers; transfers to other hospitals; mechanical ventilation at discharge | Median 3.55 (IQR 4.91) | Median 18.0 (IQR 12.0) | 75% |
| Svenningsen 2015 (Denmark) | Quantitative: prospective cohort | 299 Age: median 62 (10:90 percentile 40:78) Gender: 166M (56%), 133F (44%) | Age > 17 years; LOS > 48hrs; Language | Severe brain damage; prior PTSD diagnosis | Median 5 (10:90 percentile 2:21) | SAPS-II: median 34 (10:90 percentile 19:59) | 100% |
| Talisayon 2011 (Australia) | Mixed: cross-sectional and qualitative content analysis (<i>quantitative not used</i>) | 5 (<i>part of larger cohort of 97</i>) Age: median 56 (range 27-77) Gender: 4M (80%), 1F (20%) | Age > 18 years; mechanically ventilated > 24hrs; LOS > 48hrs; IES > 25 | Discharge destination; home > 30km from hospital;; neurological, spinal or skeletal dysfunction; language; discharged to palliative care; history of mental illness; noncompliance with treatment | Median 6 (IQR 4 – 10.5) | 19 (6.96) | 66% 25% 75% |
| Wade 2012 (UK) | Quantitative: prospective cohort | 100 Age: 57.3 (17.4) Gender: 52M (52%), 48F (48%) | ICU level 3 care; LOS > 24hrs; more than 2 organs supported | Language or communication barriers; dementia or highly confused or low GCS at discharge; severe sensory impairment; terminally ill | Median 8 (range 85) | 22.01 (7.19) | 75% |

| Study First author / date (Country) | Design | Participants N Age (years)* Gender | Inclusion | Exclusion | Length of Stay (Days)* | Illness severity (APACHE II or other, stated)* | MMAT Quality Score |
|-----------------------------------------------------|----------------------------------|-----------------------------------------------------------------------------------|--------------------------------------------------------------------------------|------------------|----------------------------------|-------------------------------------------------------------|---------------------------|
| Wade 2015 (UK) | Qualitative thematic analysis | 17 Age: 53 (range 29-89) Gender: 8M (47%), 9F (53%) | Level 3 ICU; LOS > 24hrs; High score (2 or 3) on PDS item for intrusive memory | (see Wade 2012) | 11.4 (range 2-31) | - | 50% |
| Weinert 2008 (USA) | Quantitative: prospective cohort | 277 Age: median 55 (IQR 47-65) Gender: 143M (52%), 134F (48%) | Adult patients; Mechanically ventilated > 36hrs; in medical or surgical ICU | - | - | - | 50% |

*mean and standard deviation unless stated

^a= data error

Abbreviations: APACHE II: Acute Physiology and Chronic Health Evaluation II; MMAT: Mixed Methods Appraisal Tool; LOS: length of stay; IES

– Impact of Events Scale; SAPS-II: Simplified Acute Physiology Score II; GCS – Glasgow Coma Scale; PDS – Posttraumatic Diagnostic Scale

Of the 21 studies, 16 were quantitative studies, of which 11 were prospective cohort studies, three were cross-sectional and two were randomised controlled trials. Three studies used mixed methods and two studies were qualitative studies, which utilised the following approaches: phenomenological (n=1), thematic analysis (n=1) and content analysis (n=2).

The most common inclusion criteria for the studies were length of stay (LOS) (Jones, Griffiths, Humphris, & Skirrow, 2001a; Jones et al., 2003; Myhren et al., 2010, 2009; Rattray et al., 2010) (n=17; ranged from >24 hours to > three days), age (n=11; over 17-18 years of age) and mechanical ventilation (n=9). Other inclusion criteria for studies included PTSD symptom scores (in qualitative studies) and discharge status. The most common exclusion criteria were related to previous psychiatric diagnoses or medication (n=11), language, communication or sensory barriers (n=10), cognitive impairment (including head injury or dementia; n=10), admission diagnosis (n=8; e.g. suicide attempt, neurosurgery, traumatic injury, burns and terminal cancer) and discharge to terminal or palliative care (n=6). Other exclusion criteria related to LOS, mechanical ventilation, distance from the hospital and discharge destination.

Measures of PTSD. The following outcome measures were utilised in the included studies to assess symptoms of PTSD:

- Impact of Events (IES; Horowitz, Wilner, & Alvarez, 1979) and Impact of Events Scale-Revised (IES-R; Weiss, 2007). The IES is a 15-item scale which measures intrusions and avoidance. The IES-R is the revised version with 22

items, that all measures hyperarousal. IES was used in five studies to assess PTSD symptomatology (Jones et al., 2001a, 2003; Myhren et al., 2010, 2009; Rattray et al., 2010), and IES-R used in one study (Samuelson, Lundberg, & Fridlund, 2007)

- Posttraumatic Diagnostic Scale (PDS; Foa, 1995) is a 49-item self-report measure, which assesses all diagnostic criteria for PTSD. The PDS was used in three studies to assess PTSD symptomatology (Jones et al., 2007; Wade et al., 2012; Weinert & Sprenkle, 2008).
- PTSD Check List (PCL; Weathers, Huska, & Keane, 1991) is a 17-item self-report measure used to assess PTSD symptoms in line with the diagnostic and statistic manual (DSM-IV). The PCL was used in two studies (Davydow et al., 2013; Rosalind Elliott, McKinley, Fien, & Elliott, 2016).
- Davidson Trauma Scale (DTS; Davidson, 1996) is a 17-item questionnaire of PTSD symptoms, and was used in one study (Paparrigopoulos et al., 2014).
- PTSD Scale Self-Report (PSS-SR; Foa, Riggs, Dancu, & Rothbaum, 1993) is a self-report measures consisting of 17 items that correspond to diagnostic criteria and assess severity of PTSD. This measure was used in one study (Buck, Kindt, van den Hout, Steens, & Linders, 2007).
- Post Traumatic Stress Syndrome 14-question inventory (PTSS-14; Twigg, Humphris, Jones, Bramwell, & Griffiths, 2008) is a screening tool for PTSD which measures arousal, re-experiencing and avoidance, and has been validated in an ICU sample. The PTSS-14 was used in two studies (Glimelius Petersson, Ringdal, Apelqvist, & Bergbom, 2015; Jones et al., 2010).

- Post Traumatic Stress Syndrome 10-question inventory (PTSS-10; Stoll et al., 1999) is a ten-item self-report measure used to assess PTSD symptomatology, and was used in one study (Maley et al., 2016).
- Screen for Post Traumatic Stress Symptoms (SPTSS; Carlson, 2001) is a brief 17-item screening questionnaire that measures reliving, avoidance and arousal symptoms of PTSD. The SPTSS was used in one study (Rovatti, Teodoro, & de Castro, 2012)
- Harvard Trauma Questionnaire (HTQ; Mollica et al., 1992) is made up of 16 items based on DSM-III criteria for PTSD, and was used to assess PTSD symptomatology in one study (Svenningsen et al., 2015).

Overall Quality Assessment

Using the mixed methods appraisal tool (MMAT), the overall quality assessment score was 50% for five studies (Jones, Griffiths, Humphris, & Skirrow, 2001; Jones et al., 2003; Rattray et al., 2010; Wade et al., 2015; Weinert & Sprenkle, 2008) (see table 2 for overall ratings, and appendix 1 for sub-scores). One mixed method study scored 66% overall, with 25% on the qualitative component and 75% on the quantitative component (Talisayon et al., 2011). Eight studies scored 75% on the quality assessment (Buck, Kindt, van den Hout, Steens, & Linders, 2007; Corrigan, Samuelson, Fridlund, & Thomé, 2007; Elliott, McKinley, Fien, & Elliott, 2016; Maley et al., 2016; Paparrigopoulos et al., 2014; Rovatti, Teodoro, & de Castro, 2012; Samuelson, Lundberg, & Fridlund, 2007; Wade et al., 2015). Seven studies scored 100% and met all quality assessment criteria (Davydow, Zatzick, Hough, & Katon, 2013; Glimelius Petersson, Ringdal, Apelqvist, & Bergbom, 2015; Jones et al., 2007;

Jones et al., 2010; Myhren et al., 2009, 2010; Svenningsen et al., 2015). Therefore all studies included in the review were assessed as adequate to excellent quality.

Sample sizes and power calculations were not assessed as part of the MMAT quality appraisal. Out of the 19 quantitative studies, only three reported a power calculation to justify their sample size (Jones et al., 2007, 2010; Svenningsen et al., 2015). The other studies did not report how their sample size was justified or whether there was sufficient power to find a significant result. For the three qualitative studies, only one (Wade et al., 2015) gave a justification for their anticipated sample size.

Outcomes

Data was extracted and synthesised according to the temporal sequence of factors: pre-ICU variables; during ICU; memories of ICU; and post-ICU factors associated with PTSD symptoms following an ICU admission. Each category was also split into quantitative (table 3) and qualitative findings (table 4).

Table 3

Psychological factors linked with PTSD-ICU – Quantitative studies

| Study First author / date | Follow- up period | PTSD measure & prevalence | Measures | Findings |
|----------------------------------------|----------------------------------|------------------------------------------------------|----------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Pre ICU | | | | |
| Davydow 2013 | 3 & 12 months | PCL-C: 16% at 3 months; 15% at 12 months | Interview | ↑Prior trauma exposure |
| Elliott 2016 | 2 & 6 months | PCL-S: 13.5% at 6 months | Sleep disturbance (ISI) | NS Sleep quality pre- ICU |
| Jones 2001 | 2 & 8 weeks | - | Trait anxiety (STAI) | ↑Trait anxiety |
| Maley 2016 | 6-12 months | PTSS-10: 44.2% | CD-RISC 10 | ↓Resilience |
| Myrhen 2009 | 4 weeks | IES: 26.8% | Optimism (LOT) | ↓Optimism |
| Myhren 2010 | 3 & 12 months | IES: 27% | Optimism (LOT) | ↓Optimism |
| Paparrigopoulos 2014 | 18-24 months | DTS: 25% | Interview | ↑ Adult traumatic events ↑ Stressful life events ↑Childhood trauma NS social issues |
| During ICU | | | | |
| Davydow 2013 | 3 & 12 months | PCL-C: 16% at 3 months; 15% at 12 months | Acute stress in hospital (PCL-C) | ↑Acute stress in ICU |
| Elliott 2016 | 2 & 6 months | PCL-S: 13.5% at 6 months | ICEQ RCSQ | ↓Awareness of surroundings ↑Frightening experiences NS Sleep quality during ICU |
| Myhren 2009 | 4 weeks | IES: 26.8% | ICEQ | ↓Feeling in control ↓Ability to express needs |
| Rattray 2010 | 2 & 6 months | IES: 14- 16% at 6 months | ICEQ | ↓Awareness of surroundings (at discharge; with IES- avoidance only at 2 months) ↑Frightening experiences (at discharge; with IES-avoidance only at 2 months) NS ICEQ with IES-intrusions at 2 months |

| | | | | |
|--------------------------|---------------|----------------------------------------------|-------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------|
| Samuelson 2007 | 2 months | IES-R: 8.4% | ICU-SEQ | ↑Stressful events ↑Nightmares ↑ Fear |
| Wade 2012 | 3 months | PDS: 27.1% | Mood (POMS), Stress reactions (ICUSS), Illness Perceptions (BIPQ) | ↑Mood in ICU ↑Stress Reactions ↑ Negative illness perceptions (timeline, concern, emotional representation) |
| Memories of ICU | | | | |
| Buck 2007 | 4 months | PSS-SR: 10.3% | Non-standardised measure | NS Perceptual memory representations* NS Utterance disorganisation* NS narrative incoherence |
| Glimelius Petersson 2015 | 2 & 6 months | PTSS-14: 12.2% | ICUMT | ↓Factual Memories ↑Emotional memories NS delusional memories |
| Jones 2001 | 2 & 8 weeks | IES: not reported | ICUMT | ↓ Factual memories ↑Delusional memories |
| Jones 2003 | 6 months | IES: 51% | ICUMT | ↑Delusional memories |
| Jones 2007 | 3 months | PDS: 9% | ICUMT | ↑Delusional memories |
| Jones 2010 | 3 months | PTSS-14 Controls: 13% Intervention: 5% | ICUMT | ↑Delusional memories |
| Myhren 2009 | 4 weeks | IES: 26.9% | ICUMT | ↑Pain memories Factual Recall** Delusional Memories** Memory of Feelings** |
| Myhren 2010 | 3 & 12 months | IES (>35): 27% | ICUMT | ↑Pain memories -Factual recall NS Delusional memories NS Memory of feelings |
| Rovatti 2012 | 6 months | SPTSS: 24.4% | ICUMT | ↑ Affective memories NS factual memories NS delusional memories |
| Samuelson 2007 | 2 months | IES-R: 8.4% | ICUMT | NS delusional memories NS factual memories NS amnesia |
| Svenningsen 2015 | 2 & 6 months | HTQ 2 months 7.1% 6 months 4.8% | ICUMT | NS Memories of feelings* NS factual memories NS delusional memories |

| | | | | |
|-----------------|--------------|----------------------------------------|--------------------------|-------------------------------------------------------------------------------------|
| Wade 2012 | 3 months | PDS: 27.1% | Non-standardised measure | ↓Memory of ICU ↑Early intrusive memories in ICU |
| Weinert 2008 | 2 & 6 months | PDS 2 months: 16.8% 6 months 15% | Non-standardised measure | ↑ delirious memories at 2 months NS delirious memories at 6 months NS amnesia |
| Post ICU | | | | |
| Elliott 2016 | 2 & 6 months | PCL-S: 13.5% at 6 months | Sleep disturbance (PSQI) | ↓Sleep quality post-ICU |

*Reported as significant, before controlling for another variable

**Significant in univariate, but no longer significant in multivariate

Pre-ICU: Quantitative Findings. In total, seven studies explored factors occurring prior to the ICU admission. Two studies investigated the role of life events prior to the ICU and PTSD symptoms. Both studies found that prior traumatic events (either in childhood or adulthood) were associated with greater PTSD symptoms (Davydow et al., 2013; Paparrigopoulos et al., 2014). Additionally, Paparrigopoulos et al. (2014) found that general stressful life events (e.g. marital, family, work and legal problems) were also associated with greater PTSD symptoms.

A third study explored the role of sleep quality pre-ICU, as measured by the insomnia severity index (ISI; Bastien, Vallières, & Morin, 2001) (Elliott et al., 2016) and found that sleep quality pre-ICU was not significantly associated with PTSD symptoms after ICU admission.

Four studies looked at personality traits. Two looked at the role of optimism, as measured by the life orientation test (LOT; Scheier, Carver, & Bridges, 1994). The

LOT is a scale measuring pessimistic and optimistic personality traits. Both studies looking at optimism shared the same cohort of participants at different follow-up periods, at 4 weeks and 12 months, and optimism was found to be significantly negatively related to PTSD symptoms (Myhren et al., 2010, 2009).

One study looked at trait anxiety as measured by the State-Trait Anxiety Inventory (STAI; Spielberger, 2010) (Jones et al., 2001b). The STAI is a self-report 40-item measure of state and trait anxiety. It was found that greater trait anxiety was associated with higher PTSD symptoms (Jones et al., 2001).

Finally, one study looked at the relationship between resilience and PTSD symptoms (Maley et al., 2016). Resilience was measured by the Connor Davidson Resilience Scale (CD-RISC-10; Connor & Davidson, 2003) which is a short 10-item measure that assesses resilience. This study found that resilience was inversely related to PTSD symptoms.

No qualitative studies investigated psychological variables prior to the ICU.

Summary of pre-ICU findings. Seven studies investigated pre-ICU psychological variables and the following significant results were found. Three studies investigated life events: two out of two studies found previous traumatic events, and one out of one study found stressful life events were associated with

PTSD symptoms. Four studies looked at personality traits and found the following significant findings: two of two studies found optimism was inversely related to PTSD; one out of one study found trait anxiety was positively related to PTSD; and one out of one study found resilience was inversely related to PTSD. Only sleep quality prior to ICU was found to be nonsignificant.

During ICU: Quantitative Findings. In total, six studies explored factors occurring during the ICU period. Three studies used the intensive care experience questionnaire (ICEQ; Rattray, Johnston, & Wildsmith, 2004). The ICEQ is made up of the following sub-scales: awareness of surroundings, frightening experiences, recall of experiences and satisfaction with care. Less awareness of surroundings was found to be significantly associated with greater PTSD symptoms in two studies (Elliott et al., 2016; Rattray et al., 2010). Specific items (feeling in control, ability to express needs) on this scale were also negatively associated with PTSD symptoms (Myhren et al., 2009). The frightening experiences subscale on the ICEQ was significantly associated with greater PTSD in two studies (Elliott et al., 2016; Rattray et al., 2010). Although in Rattray et al. (2010) these findings were only significant at discharge, and at two-months this finding was only significantly related with IES-avoidance and not IES-intrusions scores.

One study used the ICU stressful experiences questionnaire (ICU-SEQ; Rotondi et al., 2002) to explore the relationship between experiences in the ICU and PTSD symptoms (Samuelson et al., 2007). The ICU-SEQ is made up of 32 items, and

participants rate experiences from not at all to extremely stressful. This study found that PTSD symptoms were significantly higher in participants who had extremely stressful experiences in the ICU. Additionally, if nightmares or feeling fearful were rated as extremely stressful experiences, this was significantly associated with higher PTSD scores on IES-R (Samuelson et al., 2007).

One study looked at the role of mood and stress during the ICU, as measured by the Profile of Mood States (POMS; McNair, Lorr, & Droppelman, 1971) and the intensive care stress reactions scale (ICUSS; Wade et al., 2012) respectively. The POMS was made up of 15 items on different mood states: anger, anxiety, depression, positive mood and confusion. Total mood disturbance on the POMS was found to be significant predictor of PTSD symptoms (Wade et al., 2012). The ICUSS has four sub-scales (physical stress, delirious symptoms, control and support) and total ICUSS scores were predictive of PTSD symptoms. However, when entered into a multivariate regression, ICUSS scores were no longer significantly associated with PTSD (Wade et al., 2012), and therefore did not independently predict PTSD.

Wade et al. (2012) also looked at illness perceptions using the brief illness perception questionnaire (BIPQ; Broadbent, Petrie, Main, & Weinman, 2006). The BIPQ is a nine-item scale which measures cognitive and emotional representations of illness, where a higher score represents more negative perceptions of the illness. This study found that perceptions of timeline (how long illness will continue), concerns (how concerned they are by illness) and emotional effects of illness were

significantly positively associated with PTSD symptoms (Wade et al., 2012). However, when entered in a multivariate analysis only perceived illness timeline remained a significant factor associated with PTSD symptoms at three months, suggesting that concerns and emotional effects were not independent predictors of PTSD.

One study investigated the role of early traumatic stress symptoms in the ICU as measured by the PTSD Checklist – Civilian version (PCL-C; Weathers, Huska, & Keane, 1991), and found that stress symptoms during the ICU stay was predictive of PTSD severity at three- and 12-month follow-up (Davydow et al., 2013).

One study investigated the role of sleep quality during ICU using the Richards-Campbell Sleep Questionnaire (RCSQ; Richards, O'sullivan, & Phillips, 2000) (Elliott et al., 2016). There was no significant relationship between RCSQ scores in the ICU (or the hospital ward) and later PTSD symptoms at two and six months follow-up.

During ICU: Qualitative studies. Two qualitative studies explored themes related to the ICU experience (Corrigan et al., 2007; Talisayon et al., 2011). Both studies found that in a PTSD sample, experiences of the ICU were characterised by unreal occurrences (e.g. nightmares, hallucinations or persecutory delusions), emotions of fear and helplessness and sensations of pain and discomfort (e.g. as a

result of medical procedures or illness). Neither of these studies reported with illustrative quotes to support these themes.

Summary of during-ICU findings. Six quantitative studies explored during-ICU factors. The following significant results were found. On the ICEQ, two out of two studies found less awareness and more frightening experiences were related to PTSD symptoms. On the ICU-SEQ, one out of one study found extremely stressful experiences on the ICU were related to PTSD symptoms. Mood disturbance as measured by POMS was significant in one out of one study. Perceived illness timeline (on BIPQ) was significant in one out of one study. The following were not significant: sleep quality during the ICU. ICU stress, perceived illness concern and perceived emotional effects of illness were not independent predictors of PTSD. Two qualitative studies found that perception of unreal occurrences, emotions of fear and helplessness and physical sensations of pain and discomfort during the ICU were described by participants with PTSD.

Memories: Quantitative Studies. Thirteen quantitative studies looked at the role of memories in relation to PTSD post-ICU. Of these studies, ten used the ICU memory tool (Jones, Humphris, & Griffiths, 2000). The ICU memory tool categorises memories into factual memories, delusional memories and memories of feelings. On factual memories, four studies found a significant relationship between factual memories and PTSD symptoms. Two studies found that less factual memories were associated with greater PTSD symptoms between two weeks and six months

(Glimelius Petersson et al., 2015; Jones et al., 2001b). Two studies found that factual memories were an independent predictor of PTSD symptoms at one year, however the direction of this effect was not stated (Myhren et al., 2010, 2009), however in one study this was no longer significant when entered into a multivariate analysis (Myhren et al., 2009). Three studies found that factual memories were not significantly associated with PTSD symptomatology between two and six months (Rovatti et al., 2012; Samuelson et al., 2007; Svenningsen et al., 2015).

Delusional memories, as measured by the ICUMT, were found to be significantly associated with increased PTSD symptoms at two weeks to six months in five studies (Jones et al., 2010, 2007, 2001a, 2003), however in one study this was no longer significant when entered into a multivariate analysis (Myhren et al., 2009). Five studies found no significant relationship between delusional memories of ICU and PTSD symptoms between two and 12 months (Glimelius Petersson et al., 2015; Myhren et al., 2010; Rovatti et al., 2012; Samuelson et al., 2007; Svenningsen et al., 2015).

Memory of feelings, as measured by the ICUMT, were significantly associated with increased symptoms of PTSD in three studies (Glimelius Petersson et al., 2015; Rovatti et al., 2012; Svenningsen et al., 2015), although in one study this finding was no longer significant after adjusting for age (Svenningsen et al., 2015). Two studies looked at a specific item from the memory of feelings subscale, memory of pain, and both found a significant association with PTSD at 4-6 weeks after discharge (Myhren

et al., 2009) and 12 months after discharge (Myhren et al., 2010). However the same study found no significant association between overall memory of feelings and PTSD symptoms (Myhren et al., 2010).

The remaining three studies used their non-standardised measures of memory. One study coded transcribed interviews according to the presence of perceptual memory representations, memory fragmentation, utterance disorganisation and narrative incoherence (Buck et al., 2007). It was found that perceptual memory representations were significant in predicting PTSD symptoms at four months, even when controlling for initial PTSD symptoms and peri-traumatic dissociation (Buck et al., 2007). Utterance disorganisation was also found to be significant in predicting PTSD symptoms, but not when initial PTSD symptoms were controlled for. Perceptual memory representations and utterance disorganisation no longer predicted PTSD symptoms when depressive symptoms were partialled out of the analysis. Narrative coherence was found to be nonsignificant in predicting PTSD symptoms.

Another study developed a questionnaire to assess memory of being admitted to the ICU, the ICU stay and early intrusive memories, and was developed with guidance from Chris Brewin, a prominent researcher on PTSD and memory (Wade et al., 2012). They found that PTSD symptoms were higher in those who had little memory of the ICU and early intrusive memories.

One study used an 11-item questionnaire focusing on common memories from the ICU (Weinert & Sprenkle, 2008). They found that the group who reported delirious memories (hallucinations, nightmares or memories of events that did not happen) had significantly increased PTSD symptoms compared to those who did not at two-months. However this finding was no longer significant when PTSD diagnoses were used instead of symptoms, and did not remain at six months follow-up.

Memories: Qualitative studies. Three qualitative studies explored themes related to memories of ICU. Two of these qualitative studies report findings related to (the extent of) factual memories. Talisayon et al. (2011) used content analysis, and found that participants reported lack of memory (n=8), having partial memory of ICU and why they were in hospital (n=5) and wanting to remember more (n=3). Wade et al. (2015) used thematic content analysis to explore the content of memories, and similarly found that patients reported factual memories of the intensive care environment (n=14), medical or clinical procedures (n=12), unpleasant or frightening physical experiences (n=10), interactions with family (n=9) and real perceived threat of own death (n=3). An example of a traumatic, factual memories include:

“Keeping the mask airtight. . .It was the feeling of panic that I wasn’t able to breathe properly with all this air being pushed in so fast. . .the anxiety, the fear of having the mask on, made my heart go like the clappers. . .I would try to get my thumb underneath it to let some air out; every time I did that the alarm would go off and I would get into trouble. . . Now I have nightmares as if it’s happening then and there.”

[Wade et al., 2015, p.14]

In relation to delusional memories, qualitative findings by Wade et al. (2015), found that participants with PTSD reported narrative or delusional hallucinations (n=12), with themes of persecution, own or others' death or self causing others' death, or interactions with staff. For example,

“They [the nurses] had to prepare so many patients for death. . . They turned you into a zombie. . . put you into a shopping trolley and wheeled you into a basement. They got paid according to how many patients they brought down... Before I knew it, a nurse came upon me. She gave me the injection...”

[Wade et al., 2015, p.13]

Participants also reported simple visual hallucinations (n=6), however no illustrative quotes were provided.

Two studies reported themes of needing help managing these memories (Corrigan et al., 2007; Wade et al., 2015). Participants talked about a real need to make sense of the memories:

“no matter how much I think about it myself, I still can't get a clear picture”

[Corrigan et al., 2007]

In another study, participants reported needing help with the memories, either from therapy or counselling (n=10) or from family or self-help (n=3). Although four participants reported no need for help (Wade et al., 2015).

Summary of memory findings. Thirteen quantitative studies explored the role of ICU memories and PTSD symptoms. Four of seven studies found that factual memories (on ICUMT) were significantly associated with PTSD symptoms, although one study found factual memories were not an independent predictor. Similarly, one study found less memory of ICU (on a non-standardised measure) was significantly associated with PTSD symptoms. Five of ten studies found that delusional memories (on ICUMT) were significantly associated with PTSD symptoms, although one study found this was not an independent predictor. Similarly, one study found delirious memories of ICU (e.g. hallucinations, on a non-standardised measure) were significantly associated with PTSD symptoms. Two of four studies found that memory of feelings (on ICUMT) were significantly associated with PTSD symptoms, and a further two of two found that memory of pain (a specific item on subscale) was significantly associated with PTSD. The following factors were nonsignificant: perceptual memory representations, utterance disorganisation and narrative incoherence. Three qualitative studies also described the role of lack of factual memories, the presence of hallucinatory or delusional memories, as well as participants reporting the need for help with managing these memories.

Post-ICU: Quantitative Findings. One study looked at the relationship between sleep quality and PTSD symptoms. Sleep quality after the ICU was measured by the Pittsburgh Sleep Quality Index (PSQI; Buysse, Reynolds, Monk, Berman, & Kupfer, 1989) two and six months after hospitalisation. This study found that sleep quality at 6 months as measured by the PSQI was significantly associated with PTSD symptoms (Elliott et al., 2016).

Post-ICU: Qualitative findings. Two studies focused on experiences post-ICU (Corrigan et al., 2007; Talisayon et al., 2011) and highlighted the following themes of emotional and physical recovery, and the effect on relationships. In terms of emotional recovery, Corrigan et al. (2007) summarised the post-ICU experience as a “transition to a life situation beyond control”, where participants feel haunted by their stay on the ICU:

“it’s the intensive care that’s the worst . . . that period haunts me”

“previously I was a harmonious, calm, positive and stable person, now things are different . . . I’m more insecure and nervous, which I wasn’t before”

[Corrigan et al., 2007]

In response to this, participants then describe a need to escape or avoid reminders of the ICU:

“I avoided catching a glimpse of the hospital, under any circumstances, and that isn’t easy... so there have been some lengthy detours”

[Corrigan et al., 2007]

This then results in emotional distress, such as feelings of hopelessness:

“why do I exist, sort of thing . . . what, what’s the point of all this?”

“I just walk around thinking, what happens if I get sick and have to have emergency surgery . . . I’d almost be on the verge of committing suicide instead”

[Corrigan et al., 2007]

This is echoed by themes reported by Talisayon et al. (2011) of emotional experiences after ICU of feeling depressed and hopeless (n=7), avoidant (n=6), and worried something bad would happen again (n=6). Although positive aspects of recovery after ICU were also described, including an improved positive outlook (n=11), making healthy lifestyle choices (n=10), and returning back to normal routine, activities or work (n=7) (Talisayon et al., 2011).

In terms of physical recovery, themes were reported regarding physical condition restricting activities (n=22), sleeping problems (n=5), medications affecting functioning (n=3) and regular tasks being difficult (n=2) (Talisayon et al., 2011).

Corrigan et al. (2007) similarly raised how interviewees had lasting physical difficulties following the ICU, combined with the bodily reactions to trauma and poor sleep:

“can’t say what keeps me awake . . . it’s just that. . . I really feel . . . I can’t relax at all . . . there are a thousand and one thoughts in my head”

[Corrigan et al., 2007, p.211]

In both studies, participants also described the quality of relationships post-ICU. In Talisayon paper, participants reported friends and family as being supportive when needed (n=11), that relationships were strengthened (n=10), and in one case the breakdown of relationships (n=1). In contrast, Corrigan et al. (2007) reports that post-ICU, while participants found family and friends supportive, that they may struggle to be understood and felt like a burden to family:

“I’ve let them down...yes, I feel I’ve let them down...yes I have, I think, a... big, heavy burden to shoulder...but when I tell them this, they really can’t understand how I can feel that way’

[Corrigan et al., 2007, p.211]

Summary of post-ICU findings. One quantitative study explored the role of post-ICU sleep quality, and this result was not significant. Two qualitative studies explored post-ICU themes, and highlighted that participants feel haunted by memories of ICU, experiences emotions of anxiety or hopelessness, and use avoidance to cope. Additionally, participants described the emotional impact of physical limitations after the ICU, and the role of family and friends in recovery.

Table 4

Psychological factors linked with PTSD-ICU – Qualitative studies

| Study First author / date | Follow-up period | Analysis | Themes |
|-------------------------------------|-------------------------|-----------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Corrigan 2007 | 2 months | Phenomenological approach | <p>During ICU: Traumatic experience characterised by fear and helplessness; breathing difficulties; extreme pain; staff care; unreal experiences, hallucinations & nightmares</p> <p>Memories of ICU: A need to make sense of the traumatic memories</p> <p>Post ICU: lasting physical difficulties after ICU resulting in changed life situation</p> <p>Transition to a life situation beyond control: A need to make sense of the traumatic memories Being haunted by the trauma A need to escape Distress and strain in life-situation Interaction with others</p> <p>Traits & Post-ICU: Transformation of self</p> |
| Talisayon 2011 | 23 weeks | Content analysis | <p>During ICU: Distorted perception during ICU (e.g. unreal occurrences, persecutory delusions); Experiences in ICU (e.g. embarrassed of dependent state, discomfort, fear)</p> <p>Memory of ICU: Memory of critical illness (e.g. loss of memory, wanting to know more)</p> <p>Post-ICU: Emotional experiences after ICU (e.g. depression and avoidant) Relationships after ICU (e.g. strengthening or breakdown of relationships); Experiences after ICU (e.g. return to usual activities, support); Fear</p> |
| Wade 2012 | 4-8 months | Thematic & Content analysis | <p>Memory of ICU: Interactions with ICU staff (persecutory, pleasant) Environment of ICU (e.g. breathing masks, gastric tubes) Narrative or delusional hallucinations Medical or clinical procedures Unpleasant or frightening sensations (e.g. pain, blood, breathlessness) Death or afterlife Perceived threat to own life Interactions with family Simple hallucinations Perceived need for help with hallucinations</p> |

Discussion

This review aimed to summarise the psychological factors associated with developing PTSD after an ICU admission by considering both quantitative and qualitative data. Whereas previous systematic reviews only covered psychological factors as part of a larger question about prevalence and risk factors, this review focused in depth on psychological factors linked to PTSD after ICU.

Principal Findings

There were a number of psychological factors associated with developing PTSD-ICU, which were split into pre-ICU, during ICU, post-ICU, and memories of ICU. Psychological factors pre-ICU that were found to be significant in developing PTSD-ICU were a prior history of trauma in adulthood or childhood, and experiencing more stressful life events. In terms of traits, it was found that PTSD symptoms were associated with less optimism and resilience, and greater trait anxiety.

Psychological factors occurring during the ICU that were linked with PTSD-ICU were having less awareness of surroundings, more frightening experiences, experiencing the ICU as extremely stressful, greater mood disturbance, more negative perceptions of illness while in ICU and early PTSD symptoms on the ward. These quantitative findings were supplemented by qualitative findings that in a sample of

individuals with PTSD-ICU, the ICU experience was characterised by unreal experiences, emotions of fear and hopelessness and pain and discomfort.

Memories of ICU were the most commonly studied psychological factor associated with PTSD-ICU, and had the most homogeneity as the majority of studies had used the ICUMT to assess this factor. Memory of feelings was also found to be significantly associated with later PTSD, and in particular, memory of pain. For both factual memories and delusional memories, there was evidence to suggest that less factual memories and greater delusional memories was associated with PTSD symptoms, however this finding was inconclusive as there were a number of studies that reported nonsignificant results with regards to factual and delusional memories. The differences in findings across studies on factual and delusional memories may be accounted for by the variety of different PTSD outcome measures used, ranging from shorter screening type measures (e.g. PTSS-14) to more comprehensive diagnostic assessments (e.g. PDS). Additionally, studies that found a significant result tended to have shorter follow-up periods than non-significant studies, however this was not consistently the case. Overall, the inconclusive findings may reflect that simply measuring the type of memory does not represent the complexity of the relationship between factual and delusional memories and PTSD symptoms. Other factors that may play a role, along with types of memory, are the specific content of memories, the emotions associated with memories, the salience given to different memories, and the balance between factual and delusional memories. Furthermore, qualitative studies which explored the content of ICU memories in people with symptoms of PTSD found that they reported delusional memories, with themes of

persecution and threat of death, some factual memories of the ICU including medical procedures and interactions with staff and family, and feeling the need for support with these memories.

Only one quantitative study looked at post-ICU psychological factors, and found that sleep quality after ICU was associated with greater PTSD symptoms. However, as poor sleep is a symptom of PTSD, this finding is confounded by PTSD symptomatology. There were a number of qualitative studies that explored psychological factors post-ICU within a PTSD-ICU sample, and these focused on themes of emotional and physical recovery, and changes in relationships. Themes around emotional recovery focused on coping with a complete change in life situation, trying to either escape or make sense of the ICU experience and feeling depressed and hopeless. Physical recovery was also a theme post-ICU, and it may be that poor physical recovery hindered recovery from PTSD symptoms, however this was not clear from the quotes provided. Finally, relationships after ICU were often described, either as supportive or as breaking down following the ICU, as well as a sense that it was difficult for family and friends to understand what participants were going through.

Limitations

There were a number of limitations to the findings of this systematic review. First of all, the reliability of the review may be limited as the study selection and data extraction were not duplicated by a second researcher. Best practice guidelines on

conducting systematic reviews recommends that at least two researchers conduct the study selection and data extraction to minimise errors and increase the reliability of the findings (Higgins & Green, 2005; Shea et al., 2017). Furthermore, the review may be limited by the sensitivity of the search strategy. The database searches yielded a large number of studies, however in comparison with a related review, there were six studies included in another review (Wade et al., 2013) that were not yielded by the database search in this review. However, only two of the six studies would have been included in this review, as the other four would have been excluded as they did not investigate psychological factors. Nevertheless, the database search could have been supplemented with other methods. First, further databases could have been searched, such as another medical database (e.g. Medline or EMBASE) to capture medical ICU literature, as well as a more general scientific database, such as Web of Science. Second, the search strategy could have utilised reference lists and citations of other key papers, to ensure a comprehensive data set. Finally, the search strategy could also be broadened to encompass non-English language papers, which were excluded mainly due to resource considerations. As a result the findings of this study may not be applicable in a global context, and may be subject to language bias (Egger, Dickersin, & Smith, 2008).

Secondly, the review was limited by the quality of the included studies. In particular, by the heterogeneity of the studies and the outcome measures used. It was difficult to synthesise outcomes meaningfully as the included studies used such a wide variety of measures, with the exception of the ICUMT for measuring memories.

Although, on the other hand, this heterogeneity was a strength of the review as the included studies covered a broad range of psychological variables.

Furthermore, the quality of the outcome measures used also limits the findings of these studies. Few of the studies used actual diagnostic measures of PTSD, and many of the studies used measures that do not map onto diagnostic tools, thus limiting their validity. For example, five studies used the IES (Horowitz et al., 1979) to assess PTSD symptoms, where the previous unrevised version of the IES only measures intrusion and avoidance symptoms, and so does not assess PTSD diagnostic criteria of hyperarousal, and negative changes in cognition and mood. This criticism has been raised by previous reviews (Parker et al., 2015; Wade et al., 2013) and recommendations were made to use more diagnostic measures. Additionally, three studies used non-standardised measures for psychological variables (Buck et al., 2007; Wade et al., 2012; Weinert & Sprenkle, 2008) and therefore it is not known how reliable or valid these measures are. Furthermore, most studies measured psychological variables using self-report measures completed after the ICU admission, and so these results may be influenced by participants' current experience of trauma in the ICU. This may be particularly true of measures of personality traits, as traumatic experiences in the ICU and state anxiety may affect how participants rate their own resilience, optimism or trait anxiety, and not truly reflect their stable and enduring personality traits.

Comparison with existing literature

This review found that pre-ICU psychological variables of previous trauma and stressful life events were associated with PTSD symptoms. This has been found in the general PTSD literature (Brewin et al., 2000) and in similar populations of traumatically-injured patients (Zatzick et al., 2008). It has been suggested that this occurs as a result of a 'sensitisation effect' where previous trauma intensifies reactions to subsequent stressors (Hammen, Henry, & Daley, 2000). The mechanism of this relationship could be mediated by appraisal style and social support (Littleton, Grills-Taquechel, Axsom, Bye, & Buck, 2012) or changes in dorsal anterior cingulate activation in the brain (Herringa, Phillips, Fournier, Kronhaus, & Germain, 2013). However, multiple lifetime traumas have also been found to have a cumulative effect on physical health (Sledjeski, Speisman, & Dierker, 2008), and so previous traumas may in itself be a risk factor for chronic health problems, hospitalisation and admission to ICU. Finally, findings that traits of resilience and optimism are related to PTSD-ICU have also been found in the general PTSD literature (Bensimon, 2012; Gil & Weinberg, 2015).

Psychological factors occurring during the ICU, such as fear, stress and frightening memories were also found to be significant in previous systematic reviews of wider risk factors (Parker et al., 2015; Wade et al., 2013). It has been suggested that these experiences in the ICU may all be the result of delirium (Elliott et al., 2016; Griffiths & Jones, 2007; Wade et al., 2013) and so it has been recommended that ICUs attempt to reduce delirium in the ICU so that in turn this psychological risk factors are reduced. Additionally, the role of acute stress is supported by findings from general

PTSD literature, where greater levels of acute stress are predictive of a later PTSD diagnosis (Brewin, Andrews, Rose, & Kirk, 1999). This has implications for how PTSD may be screened and assessed within an ICU environment, in terms of identifying those most at risk of PTSD-ICU.

The finding that more delusional memories may be related to PTSD symptoms was supported by a previous systematic review that focused specifically on the role of delusional memories (Kiekkas, Theodorakopoulou, Spyrtatos, & Baltopoulos, 2010), as well as systematic reviews on prevalence and risk factors for PTSD in general (Davydow et al., 2008; Parker et al., 2015; Wade et al., 2013). These findings are also supported by qualitative studies of delusional memories, where participants express common themes such as being imprisoned, being trapped or being in a foreign place (Guttormson, 2014). However, the role of factual memories has been unclear. Kiekkas et al. (2010) did not find evidence for the protective role of factual memories, however there were only two studies in common between their review and this one, and so these findings are based on different studies. In qualitative studies, participants often report a lack of factual memories from the ICU (Adamson et al., 2004), however these studies were not specific to PTSD sufferers.

Sleep quality after ICU has also been associated with PTSD symptoms in one other ICU study (McKinley et al., 2012), and poor sleep quality is a core feature of PTSD symptomatology (Spoormaker & Montgomery, 2008). This may not be surprising as nightmares are a common reliving symptom and are bound to impact on overall

sleep quality. A more specific hypothesis presented for this result, is that similar neural mechanisms in the amygdala and prefrontal cortex underlie both PTSD and quality of sleep (Germain, Buysse, & Nofzinger, 2008).

In summary, a number of the findings from this systematic review converge with the general PTSD literature and suggest that mainstream models of PTSD may be applicable to this population. This includes the role of previous traumatic events and life stress, the role of acute emotional reactions during the traumatic events, and poor sleep quality after the event. However, the role of factual and delusional memories in PTSD-ICU, and how this compares to memory fragmentation seen in PTSD in the general population still remains unclear, and the implications for this need to be considered.

Implications for clinical practice and future research

The identification of psychological factors, such as previous trauma and early trauma symptoms, have implications for supporting early screening and identifying those most at risk of developing PTSD after leaving the ICU. ICUs and follow-up clinics can use this information to develop screening programmes, which may involve assessment of previous childhood or adult trauma, and measuring early symptoms of PTSD in the ICU. This has been advocated for in research and guidelines regarding ICU follow-up provision (Long, Kross, Davydow, & Curtis, 2014; Masterson & Baudouin, 2015; National Institute for Health and Care Excellence, 2009), however in a recent survey only 52% of follow-up clinics were fully compliant with guidance,

and this decreased as patients progress through the care pathway (Berry, Cutler, & Himsworth, 2013).

Factors that were shown to occur during the ICU admission, such as acute stress, fear and frightening experiences, have implications for care in the ICU and possible prevention of post-traumatic symptomatology. A number of studies have investigated the role of music and body therapies to reduce stress levels in the ICU, and showed promising results in reducing short-term anxiety and physiological stress levels, however longer term effects were unclear (Wade et al., 2016).

Given the potential role of increased delusional memories and fewer factual memories, there may be a particular emphasis on supporting ICU patients to make sense of ICU memories (Corrigan et al., 2007) within trauma-focused interventions. Currently the use of ICU diaries is one intervention suggested to help ICU patients make sense of these memories, although there is inconclusive evidence for any significant benefit (Ullman et al., 2015; Wade et al., 2016). However, there is little research to indicate how trauma-focused interventions are impacted by loss of memory or hallucinations at the point of trauma. Those with PTSD-ICU may therefore need extra support to construct a narrative of the trauma. Furthermore, literature from psychosis-related PTSD and other groups who have experienced memory loss of trauma, for example, drug-facilitated sexual assault or traumatic brain injury groups, may guide practitioners towards helpful adaptations for working with these types of memories. For example, one author suggests that when there is

limited memory of the trauma itself, there may be a greater emphasis on peri-traumatic processing and restructuring appraisals (Gauntlett-Gilbert, Keegan, & Petrak, 2004).

There are also implications for future research to further explore psychological risk factors for PTSD-ICU. A large number of the studies focused on the relationship between ICU memories and PTSD symptoms, however the findings were fairly inconclusive, with many studies finding nonsignificant results. This may partly be due to differing follow-up periods and outcome measures used. It may also be that types of memories need to be investigated in more depth, and with simultaneous focus on other contributing factors, such as specific content, salience of memories, associated emotions and appraisals, and the balance between factual and delusional memories. Additionally, specific to delusional memories, these could be explored in more depth by looking at factors such as belief flexibility or explanations in relation to the delusion, by using a measure such as the explanation of experiences measure (Freeman et al., 2004). Furthermore, further research could take a greater focus on specific thoughts, emotional reactions, and behavioural responses, as guided by mainstream models of PTSD (e.g. Ehlers & Clark, 2000). Similarly, a previous meta-analysis of risk factors for PTSD suggested that factors occurring during and after the trauma were more predictive of PTSD symptoms than risk factors occurring before the trauma (Brewin et al., 2000), yet there were limited studies focusing on factors occurring after the ICU, such as social support, physical recovery and ongoing life stress.

Conclusions

There are a number of studies investigating psychological factors associated with PTSD-ICU, however it is not possible to draw clear conclusions from this research. The included studies used a wide, heterogeneous range of psychological measures and PTSD assessment tools, which made the results difficult to meaningfully compare and combine. Additionally, this review has limited reliability as the study selection and data extraction were not duplicated by a second author. Nevertheless, the following psychological factors may have some relationship to the development and maintenance of PTSD-ICU: previous trauma history and stressful life events; traits of optimism, resilience and anxiety; acute stress, mood disturbance, less awareness of surroundings and more frightening experiences in the ICU; more delusional and feeling memories, and less factual memories of the ICU; and sleep quality after the ICU. These findings have clinical implications for how PTSD-ICU is screened, assessed and treated after the ICU, however further research is needed to clarify the role of these psychological variables.

Chapter 2

Developing a grounded theory model of post-traumatic stress disorder following an intensive care unit admission

Abstract

Previous research has highlighted elevated prevalence rates of PTSD after an ICU admission, and that those with PTSD after ICU are more likely to have worse outcomes and poor quality of life. Therefore guidance recommends that individuals receive a psychological follow-up after leaving the ICU, including screening, assessment and treatment of PTSD. However, the ability to offer effective psychological interventions for PTSD-ICU is limited by the paucity of psychological understanding and models of PTSD in this population. This study aimed to build a preliminary psychological model of PTSD-ICU based on individuals' experiences . Six semi-structured interviews were conducted with participants who had been discharged from an ICU and were experiencing symptoms of PTSD. The audio-recorded interviews were then transcribed and analysed using a grounded theory methodology. Through this process, seven theoretical codes and 19 focused codes were generated from the interview data, and organised into a diagrammatic model of PTSD-ICU. Specific ICU factors that may require extra consideration when delivering psychological interventions were: loss of autonomy; loss of awareness; distorted reality; memory loss; difficulty making sense of memories; relying on third-hand information; and the balance between physical and emotional recovery. Clinical recommendations for psychological treatment were made based on these findings, including the importance of joint working between mental and physical health services, and specific cognitive-behavioural approaches to target distinct characteristics. Further research is needed to confirm this preliminary psychological model of PTSD-ICU, and to develop and test interventions specifically aimed at treating PTSD-ICU.

Introduction

PTSD post-ICU

Over 200,000 individuals are admitted to intensive care units (ICUs) in England every year as a result of critical, life-threatening illness (Intensive Care National Audit and Research Centre (ICNARC), 2017; NHS Digital, 2017). Once patients are discharged from the ICU, there is significant mortality, and survivors may often suffer with ongoing physical and psychological health difficulties, including depression, anxiety and post-traumatic stress disorder (PTSD).

PTSD is characterised by exposure to a life-threatening traumatic event, and a reaction to the event with symptoms of re-experiencing (e.g. flashbacks, nightmares), avoidance, alterations in cognition and mood, and hyperarousal (e.g. American Psychiatric Association, 2013). Estimates of PTSD following an ICU admission range from 5 to 64%, dependent on how PTSD symptoms are measured and at what time point (Long et al., 2014), with pooled estimates of rates at 24% up to 6 months and 22% from 6-12 months (Parker et al., 2015). This is elevated compared to one year incidence rates of lower than 3.6% in the general population (e.g. Kessler et al., 2005) and to rates of PTSD in other physical illness groups (Tedstone & Tarrier, 2003).

Those who experience PTSD following ICU (PTSD-ICU) are more likely to have increased physical health burden, more adverse health outcomes and increased

healthcare costs (Edmondson et al., 2012; Katon, Lin, & Kroenke, 2007; Walker et al., 2003) and may be less likely to engage in follow-up care (Davydow et al., 2013). Additionally PTSD and other mental health problems are an independent factor in inability to return to work after an ICU admission (Ringdal, Plos, Örténwall, & Bergbom, 2010; Zatzick et al., 2008).

Psychological Interventions for PTSD post-ICU

Given the high rates of PTSD in this group and the impact on physical and social longer-term outcomes, it is recommended that ICU patients receive a psychological follow-up after leaving the ICU, which would involve screening, assessment and treatment of PTSD (or referral to appropriate services) (Masterson & Baudouin, 2015; National Institute for Health and Care Excellence (NICE), 2009).

Current NICE guidance for the treatment of PTSD recommends that PTSD sufferers are offered a course of trauma-focused psychological treatment, such as trauma-focused cognitive behaviour therapy (TF-CBT) or eye movement desensitization and reprocessing (EMDR) (NICE, 2005). However there is a gap in the literature, as no studies have specifically investigated how feasible or effective these evidence-based treatments for PTSD are in an ICU population. So far, intervention studies in this group have focused predominantly on preventative and peri-traumatic interventions, for which there is some minimal evidence of benefit (Ullman et al., 2015; Wade et al., 2016).

Psychological Understanding of PTSD-ICU

One of the potential challenges that may arise in delivering evidence-based treatment for PTSD in an ICU population is the lack of a detailed psychological account of PTSD-ICU. Current psychological understanding of PTSD-ICU is limited. Systematic reviews on risk factors for PTSD-ICU have been published, but psychological risk factors have not been considered in depth, apart from the role of early intrusive, frightening or delusional memories (Davydow et al., 2008; Parker et al., 2015; Wade et al., 2013). Additionally, delusional memories have been the focus of one systematic review, which has confirmed their role (Kiekkas et al., 2010). Otherwise there is lack of research in an ICU population on other psychological processes implicated in PTSD, such as appraisals and emotional responses.

Therefore it is not clear how evidence based treatment models, such as Ehlers and Clark's (2000) model, can be best applied to formulation and treatment of PTSD symptoms in this population. Ehlers and Clark's (2000) cognitive model of PTSD proposes that persistent PTSD symptoms are the result of how the trauma memory is processed and how the event is appraised. It is suggested that trauma memories are distinct from other autobiographical memories as they are not successfully integrated with other memories and contextual information about time and place, which would account for the current sense of threat elicited by trauma memories. These memories are also likely to be highly perceptual and sensory in nature, and triggered by associative cues. Additionally, this theory posits that negative cognitive

appraisals of the event and its consequences are key to the development of PTSD. Cognitive Therapy for PTSD (CT-PTSD), based on this theoretical model, focuses on elaborating and re-contextualising the traumatic memory and restructuring appraisals of the trauma.

Greater understanding is needed about how psychological experiences, such as hallucinations and delusional memories of the ICU, would impact on psychological formulation and treatment of PTSD. For example, it is unclear whether hallucinations of traumatic experiences are processed in the same way as 'factual' trauma memories, and whether resulting PTSD symptoms have the same qualities, and respond to treatment in the same way. Research from psychosis-related PTSD on hallucinations may provide some clues. Hallucinations have not been recognised by diagnostic systems as a traumatic event that may lead to PTSD. However research has found high rates of psychosis-related PTSD, where the traumatic experience is caused by a psychotic symptom or hospitalisation experience (Berry, Ford, Jellicoe-Jones, & Haddock, 2013; Brewin, 2015). There is some initial evidence to suggest that trauma-focused interventions may be safe and effective for psychosis-related PTSD (Swan, Keen, Reynolds, & Onwumere, 2017), which may extrapolate to ICU patients who have PTSD as a result of hallucinations and delusional memories of the ICU, but further research is required.

Another potential challenge in how PTSD treatments are delivered to an ICU population relates to concomitant physical health difficulties. First, there is evidence that chronic health conditions can exacerbate symptoms of mental health, such as depression or PTSD, and vice versa (Naylor et al., 2012). Second, it has been suggested there are conceptual differences in PTSD in medical populations versus general populations (Edmondson, 2014; Green et al., 1998), for example with greater future-oriented threats regarding the return of illness and more somatic than cognitive symptoms (Jackson et al., 2014). Third, physical health problems may create barriers to effective engagement in traditional face-to-face modalities of psychological treatment. Particularly as after discharge from ICU, patients may be commonly referred on to primary care mental health services for any psychological difficulties, rather than treated in ICU follow-up clinics, and these mental health service providers may not be fully aware of the physical and psychological health needs resulting from an ICU admission. Specific models or treatment protocols have been developed in other health populations, to address some of the complex interplay between physical and mental health, to supplement existing mental health formulation and treatment (Iles & Pote, 2015; Magidson & Weisberg, 2014; Moorey & Greer, 2011, p.11).

In summary, existing psychological research on PTSD-ICU has predominantly focused on the role of memories and acute stress or fear during the ICU, and there has been very limited examination of other psychological factors, such as cognitive and affective processes. As a result, little is known about the detailed psychological experience of those experiencing PTSD after ICU. This is reflected in the theoretical models of PTSD-ICU, and means there is a dearth of information available to provide

insight to practitioners offering psychological assessment and treatment to individuals with PTSD-ICU. Therefore there is need for the development of a detailed psychological account of the experience of PTSD-ICU to guide practitioners in delivering interventions to this population.

Rationale

There is an elevated risk of PTSD in individuals who have been treated in the ICU, which is higher than expected compared to the general population, other health groups and is similar to rates seen in individuals affected by war. Furthermore, individuals with PTSD post-ICU are likely to have worse health-related outcomes compared to their peers without PTSD. Guidance therefore recommends that ICU patients receive a psychological follow-up post-ICU to screen, assess and treat PTSD. However this task is made difficult by the lack of a comprehensive psychological account of PTSD-ICU. The majority of studies of PTSD-ICU have been conducted from a medical or nursing perspective, and have focused on prevalence or clinical factors in the ICU. In order to effectively implement guidance on psychological follow-up and treatment, further research is first needed to better understand the psychological experience of ICU patients who suffer from PTSD symptoms after discharge, and how best to support them.

Aims of the Study

The study aimed to conduct semi-structured interviews with individuals who have been in ICU and were experiencing PTSD symptoms, with the purpose of:

1. Creating an in-depth, contextualised description of the psychological experience of PTSD-ICU to give practitioners an insight and support psychological assessment, formulation and treatment for this population;
2. If possible, to create a preliminary theoretical model of PTSD-ICU to explain the development and maintenance of PTSD in an ICU population.

Method

Participants

Sample. Participants were recruited through adverts placed in ICUs, ICU follow-up clinics, and a charitable organisation for ICU survivors. Recruitment was completed in line with inclusion and exclusion criteria (see next section). It was estimated that a sample size of 10 would be required, but to continue recruitment until theoretical saturation had been reached. Grounded theory also recommends the use of theoretical sampling, in order to achieve theoretical sufficiency, however this was not possible due to the recruitment method of participants self-referring in response to adverts.

Inclusion/Exclusion Criteria. The inclusion criteria for the study were: adults (over the age of 18 years), admitted to an ICU unit in the past 1 month to 5 years and experiencing symptoms of PTSD. The minimum time since ICU was chosen on the basis that PTSD cannot be diagnosed until at least 1 month after the event (American Psychiatric Association, 2013), and the maximum time was chosen as 5 years. This timeframe was chosen as research has shown that memories of ICU persist up until 5 years, so it was thought that participants would still be able to recall memories of ICU at 5 years post-ICU (Zetterlund, Plos, Bergbom, & Ringdal, 2012). Furthermore, as it was anticipated that there might be difficulties recruiting a sample, a narrow time frame may have limited recruitment.

The exclusion criterion at screening was insufficient spoken English language to complete the interview and questionnaires. Insufficient spoken English language was an exclusion criterion because as a doctorate research project, there were not sufficient resources to cover the cost of interpreters for the interview and for translation of questionnaires.

At interview, individuals who demonstrated high suicidal risk were excluded. The reason for excluding high risk of suicidal ideation was that participants may not necessarily be engaged with physical or mental health services, and the interview could raise distressing memories and there may not be adequate systems to manage any extra distress or risk caused by the research. High suicidal risk was assessed by the Columbia Suicide Severity Rating Scale (see 'materials and measures'), and participants were excluded if they disclosed intentions or plans to act on suicidal thoughts. If any participants disclosed suicide risk, this information was shared with their GP and individuals were referred to relevant crisis services.

Ethical Considerations. Ethical approval for the study was obtained from the South Central-Oxford C Research Ethics Committee on 2nd November 2017 (appendix 2). The study also subsequently received ethical approval from Royal Holloway University of London on 11th November 2017 (see appendix 3).

During the interviews, participants were required to talk about potentially distressing and frightening memories, which may have caused discomfort or stress. Therefore, prior to the interview, participants were provided with sufficient information of what the study would involve, including the aim of the project, methods, risks and confidentiality procedures, in order to give informed consent for participating in the study. Additionally, participants were aware of their rights as participants, including being able to withdraw from the study at any point, or for their data to be destroyed at a later time point (see participant information sheet – appendix 4).

All participants were signposted to relevant advice or support services (e.g. the Samaritans, PTSD services, GP) through the participant information sheet, as it was expected that some participants may not be engaged with mental health services for their symptoms of PTSD. Furthermore, any participants who requested or required more specific information regarding further support, were signposted to relevant services, either directly or through a written letter to the GP.

Participants' data and confidentiality were protected throughout the study, by the following means: audio recordings and transcripts of interviews were stored on an encrypted USB; all personal identifiers were removed from research data; and consent forms with participants' identifiable information were stored in a secure location and separate from anonymised research data.

Materials and Measures

A battery of measures were used in order to screen eligibility for the study and to locate the sample in terms of demographic information and symptomatology.

1. *Screening Measures*

- Descriptive and demographic information – information was collected on the age, gender, ethnicity, previous mental health diagnosis and basic information about the ICU admission (date, duration and reason for admission).
- The Trauma Screening Questionnaire (TSQ; Brewin et al., 2002) is a brief 10-item screening questionnaire for PTSD symptoms, where scores range from 0 to 10 and an optimal cut-off of 6 is recommended for detecting PTSD (appendix 6). The TSQ has good sensitivity and specificity, 0.86 and 0.93 respectively, for identifying PTSD symptoms in a rail crash sample (Brewin et al., 2002). Data on the reliability of the TSQ was not available. The TSQ was administered by phone to check eligibility for the study prior to interview. Participants were invited to take part in the interview part of the study if they had a total score greater than 6.

2. *Symptom measures*

- The PTSD Checklist for DSM-5 (PCL-5; Blevins, Weathers, Davis, Witte, & Domino, 2015) is a 20-item self-report measure which maps onto diagnostic criteria for PTSD (appendix 7). The PCL-5 is a reliable measure, with strong internal consistency ($\alpha = 0.94$) and test-retest reliability ($r = 0.82$), as well as strong convergent ($r_s = 0.74$ to 0.85) and discriminant validity ($r_s = 0.31$ to 0.60) (Blevins et al., 2015). The criterion

A questions on the PCL-5 were not utilised, as the criterion A event was assessed using the life events checklist. A cut-off score of 33 has been suggested as an indication of a probable PTSD diagnosis (Bovin et al., 2016).

- The Life Events Checklist (LEC-5; Weathers et al., 2013) is a self-report measure used to screen for potentially traumatic events over a person's lifetime (appendix 8). The LEC-5 was used to formally measure a criterion A event in relation to DSM-5 criteria and to give further information about past traumas and to identify which event was perceived as the main trauma by the person. The LEC-5 has inter-rater reliability of kappa = 0.61 and test-retest reliability of $r = 0.82$, and correlates with the Trauma Life Events Questionnaire ($r = -0.55$) (Gray, Litz, Hsu, & Lombardo, 2004).
 - Suicidality - the Columbia Suicide Severity Rating Scale (C-SSRS; Posner et al., 2011) was used to assess risk of suicidality prior to conducting the interview (appendix 9). The C-SSRS is designed for interviews rather than self-report. The C-SSRS has good specificity (99.4%) and sensitivity (100%). The internal consistency of the C-SSRS is high (Cronbach's alpha = 0.73 to 0.946).
3. Semi-structured interview schedule - The interview schedule was developed in consultation with supervisors, who have research and clinical experience in PTSD and health psychology, and aimed to cover areas related to the psychological experience of PTSD-ICU including: memories, cognitions, emotions and behaviour (appendix 10). Additionally the interview schedule was piloted with a service user prior to use in the study.

Service user consultation. Service users were consulted on the materials used in the studies. A service user group was consulted for feedback on the study materials, such as the participant information sheet, to ensure that the information was clear and understandable. Additionally the interview schedule was piloted with a service user with PTSD-ICU. This provided information on the clarity and acceptability of the questions, and whether any additional questions might be relevant.

Procedure

Screening. Having seen an advert for the study, participants registered interest in the study by emailing or phoning the researcher. Participants were then provided with information about the study (appendix 4) and were contacted by the researcher (in person, Skype or by phone) to complete the screening questionnaires, which assessed eligibility against the inclusion criteria of PTSD symptomatology, age and time since leaving ICU.

Interview. Those who were eligible, were then invited to participate in the interview-part of the study and were contacted by email or phone to arrange the interview. Informed consent was re-visited prior to starting the interview. Prior to starting the interview, the PCL-5, LEC-5 and CSSRS were administered to assess PTSD symptoms and suicidality. The interview was then conducted (either in person or by Skype if the participant was unable to travel), and was semi-structured in

format to allow for other themes to be explored (see appendix 10). The interview was audio recorded and then transcribed.

Post interview. Participants were debriefed and signposted to any relevant services or support. Participants gave consent for the researcher to contact their General Practitioner (GP) to inform them of their participation and to provide information about referring to appropriate services (see appendix 11). Participants were paid out of pocket travel expenses for attending the interview, and were paid £10 for their participation in the interview. The payment was to reimburse participants for the extra time given above what might be expected in routine clinical practice, and as an incentive to encourage participation.

Design

A qualitative grounded theory design (Charmaz, 2006; Glaser & Strauss, 1967) was used in the study. A qualitative approach was justified as it is more suitable than quantitative methods for an exploratory research question and for gaining a detailed understanding of individual experiences. A grounded theory approach was chosen as it meets the main aims of the study:

1. One aim of this interview study is to create a preliminary psychological model of PTSD-ICU that is grounded in the experiences of individuals who have symptoms of PTSD after leaving the ICU. Grounded theory method was specifically developed for the purpose of building theories of social

processes, and that emerges from the data, rather than based on existing theory and research.

2. The other aim of the study was to describe in detail the psychological experience of PTSD-ICU using data from one-on-one semi-structured interviews. The line-by-line coding process involved in grounded theory methodology is well-suited for close analysis of the interview data to create a detailed narrative of the PTSD-ICU experience
3. Alternative qualitative methods that could have been utilised to provide a detailed account of the psychological experience of PTSD-ICU were thematic analysis or interpretative phenomenological analysis, which would both allow themes to be analysed related to internal experience. However these methods were less suitable towards the second aim of developing a preliminary model or organising framework for understanding the themes that emerged. Furthermore, these methodological approaches could be deemed more at risk of analysing the data in light of existing theory and knowledge, whereas grounded theory has methodological features built in to safeguard against this.

Grounded theory holds a realist approach to research, as it assumes there is an objective reality which can be observed. Therefore, grounded theory has been criticized for not considering reflexivity and how the observer's standpoint affect the analysis of the data. As such, a constructivist version of grounded theory was developed to address these concerns (e.g. Charmaz, 2006) and was used in this study. A social constructionist view of grounded theory was beneficial for

acknowledging the role of the researcher's assumptions and expectations on shaping the questions, data and analysis. As a researcher, I brought pre-existing knowledge which may have influenced the design of the study and analysis of the data. In particular, I brought knowledge and experience of working with PTSD in general, and specifically in ICU, from previous clinical and academic experiences. As a trainee clinical psychologist, knowledge of and adherence to existing models is an important part of the scientist practitioner way of working, and therefore existing models such as the cognitive model of PTSD were well known to me before embarking on the study. Additionally, background literature review of psychological factors related to PTSD-ICU was conducted prior to the data analysis, and so awareness of the existing literature was likely to influence the analysis process.

Analysis

Process. The analysis was conducted according to the following process:

1. *Transcribing:* Audio recordings of the interviews were transcribed by the researcher, as this was another opportunity to become immersed in the data and gain initial ideas and understanding about the data (Charmaz, 2014).
2. *Initial coding:* Transcribed interviews were then coded line-by-line, as recommended by Charmaz (2006), to allow for a detailed examination of the data. (Glaser, 1978) suggests using gerunds in initial coding in order to stay closely to the data and describe actions rather than topics, and to prevent making theoretical leaps, and so this approach was adopted in initial coding (appendix 12).

3. *Iterative process of data collection and analysis*: In full grounded theory, it is recommended that the researcher moves between data collection and analysis, so that initial codes emerging from the data then inform ongoing data collection. This is to support the theory building process, through focusing and triangulating initial data and analysis with later data collection (Willig, 2013, p.72). In this study, the iterative process was achieved as follows: interviews were transcribed shortly after the interview took place, and initial reflections were noted down to inform future interviews (e.g. additional questions); initial line-by-line coding of interviews was then conducted in batches of 2-3 interviews; and this initial coding then informed the later interviews that took place.
4. *Focused coding*: This process involved making decisions about the initial codes, and selecting focused codes that are the most significant or frequent, and can be used to categorise the data concisely and completely (Charmaz, 2006).
5. *Theoretical coding and developing the diagram*: theoretical coding follows on from focused codes, and involves considering possible relationships between focused codes, and how they can be integrated into a theory (Charmaz, 2006). The model was developed throughout the coding process through the use of memo-writing and integrative diagrams (Urquhart, 2012). A visual diagram of the theoretical and focused codes was then generated to display the relationships between codes.

Constant comparative method. Data collection and analysis took place simultaneously, as recommended by grounded theory, so that new data is constantly compared with existing data (Glaser & Strauss, 1967) and emerging theory informs

and focuses the ongoing data collection. Through this process, theoretical sampling procedures would ideally be used to recruit further participants who may elaborate or challenge emerging themes from the data. However, theoretical sampling was not possible due to challenges recruiting a sufficient sample size.

Quality Standards. Quality standards for grounded theory were referred to and used to guide the analysis (Elliott, Fischer, & Rennie, 1999). The study aimed to meet these standards in the following ways:

- *Owning one's perspective:* the theoretical orientation and perspective of the researcher are acknowledged (see 'design' section) and reflected on in more detail (see '*Integration, Impact and Dissemination*') in terms of how this may have influenced the design and analysis of the study.
- *Situating the sample:* Data was collected on each participant, including age, gender, ethnicity, details about their ICU stay and their PTSD symptom profile in order to adequately describe the characteristics of the sample, and so allow readers to reflect on the applicability of the sample to other samples.
- *Grounding in examples:* For each focused code, illustrative quotes were provided in order to provide evidence of the fit between the data and the codes, and allow the reader to make alternative appraisals of the raw data.
- *Providing credibility checks:* it is best practice to verify the credibility of the coding and analysis by using a second auditor. However it was not possible to do so within the time constraints of the study (also see '*Discussion: Limitations*'). The principal findings were validated through consultation with participants.

- *Coherence*: this was achieved through categorising focused codes into smaller groups, which were organized temporally, and then mapping these codes into diagrammatic format to provide the reader with a complete overview.

Results

Sample Characteristics

The sample interviewed for the study was made up of five females and one male, who ranged in age from 40 to 69 years (mean 51.5, SD=11.9), and were mostly of white British ethnic origin (n=5) and one participant was black British (table 5).

Participants had been admitted to the ICU mostly due to severe infections, and the length of stay ranged from 9 to 92 days (mean 48.5, SD=35.1). In total, ten participants self-referred to the study, of the four who did not participate in the interview: three did not meet eligibility criteria (time since ICU n=2; PTSD symptoms n=1); and one participant was lost to follow-up between screening and interview.

Of the six participants, three had a history of previous mental health difficulties. On the TSQ, which was used to screen for inclusion, the mean score was 6.7 (SD=1.2), where scores range from 0 to 10, and a cut-off of 6 indicates a diagnosis of PTSD.

On the CSSRS, which was used to screen for high suicidal ideation, participants scored either 0 or 1 (mean 0.7, SD=0.5) and only endorsed the item on wishing to be dead, but did not endorse further items on thoughts, intentions or plans to kill themselves.. Suicidal ideation scores can range from 0 to 5, and participants were excluded if they endorsed items on suicidal ideation with intent or plans.

Table 5

Demographic, ICU and screening information

| ID | Gender | Age | Ethnicity | ICU length of stay (days) | Reason for ICU admission | Previous mental health | TSQ score | C-SSRS score |
|---------------------|--------|--------------|---------------|---------------------------|--------------------------|------------------------|------------|--------------|
| 1 | F | 40 | White British | 14 | Sepsis | Y | 7 | 1 |
| 2 | M | 44 | White British | 86 | Acute pancreatitis | N | 6 | 1 |
| 3 | F | 40 | White British | 49 | Strep A infection | N | 6 | 1 |
| 6 | F | 59 | White British | 42 | Sepsis | Y | 6 | 0 |
| 7 | F | 57 | Black British | 92 | Lung infection | Y | 9 | 1 |
| 8 | F | 69 | White British | 9 | Atrial fibrillation | N | 6 | 0 |
| Total sample | 5F, 1M | 51.5 (11.9)* | - | 48.5 (35.1)* | - | 3Y, 3N | 6.7 (1.2)* | 0.7 (0.5)* |

*Mean and standard deviation for sample

In terms of PTSD symptomatology, a criterion A event was measured by the LEC-5 measure. All participants endorsed having experienced 'life-threatening illness or injury' in relation to their ICU experience, and between one and four further traumatic life events that they had experienced directly. Additionally, all participants rated their ICU experience as the worst traumatic event. On the PCL-5, total scores were all above a suggested clinical cut-off of 33, indicating a probable diagnosis of PTSD (Bovin et al., 2016), and the mean total score was 43.0 (SD=11.3) (table 6).

Table 6

PTSD symptomatology as measured by PCL-5 and LEC-5

| ID | LEC-5 | PCL-5 | | | | |
|--------------|------------------|------------|-----------|-------------|-------------|--------------|
| | Number of events | Cluster B | Cluster C | Cluster D | Cluster E | Total Score |
| 1 | 5 | 10 | 3 | 11 | 19 | 43 |
| 2 | 3 | 7 | 3 | 14 | 11 | 35 |
| 3 | 2 | 3 | 2 | 14 | 16 | 35 |
| 6 | 2 | 4 | 1 | 14 | 19 | 38 |
| 7 | 3 | 15 | 8 | 24 | 18 | 65 |
| 8 | 2 | 13 | 0 | 21 | 8 | 42 |
| Total sample | Range 2-5 | 8.7 (4.8)* | 2.8 (2.8) | 16.3 (5.0)* | 15.2 (4.6)* | 43.0 (11.3)* |

**Mean and standard deviation for sample*

Abbreviations: DC – met diagnostic criteria

Overview of results

Seven theoretical codes emerged from the data, from 19 focused codes which consisted of initial codes generated through line-by-line coding (see table 7).

Illustrative quotes have been provided for each of the focused codes and to show how the codes are grounded in the data. These have been categorised in temporal order, although there was inevitable overlap between categories and codes.

Table 7 Results: theoretical codes, focused codes and initial codes

| Theoretical codes | Focused codes | Initial codes |
|--------------------------|-----------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Pre-ICU | Previous life events | Being reminded of earlier life events |
| | Sudden illness | Feeling suddenly ill |
| | | |
| During ICU: Experiences | Near death experience | Being near death, life & death hanging in balance Being threatened with death or being dead in hallucinations |
| | Loss of autonomy | Being unable to speak Being unable to move Having procedures done to you Being unable to meet basic needs Feeling trapped or not in control Linking recovery to return of autonomy Theme present in nightmares |
| | Intense emotional distress | Agitated in ICU Anxiety Frustration Hopelessness |
| | Conflicted reactions to ICU staff | Having positive experiences of care Having negative experiences of care Being present in hallucinations |
| | Sleep problems | Being unable to sleep Not wanting to sleep Feeling scared to sleep |
| During ICU: Perception | Loss of awareness | Not knowing or understanding what happened Feeling disorientated, confused Being in darkness Feeling disbelief Waking up, becoming aware |
| | Distorted reality | Having hallucinations, nightmares Merging of reality and unreal Losing sense of time Bizarre nature of own reality Attributing to coma period |
| | | |
| After ICU: Memory | Memory disturbances | Loss of memory Memory of hallucinations or nightmares Remembering pain, unpleasant physical memories Remembering factual memories Vagueness of memories |

| | | |
|-----------------------------|---------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| | Difficulty making sense of experience | Making sense of nightmares Piecing things together Trying to find explanations Questioning experience |
| | Relying on third hand information | Returning to ICU Using diaries Talking to others Reading literature Providing timeline, information, asking questions |
| After ICU: response | Heightened emotional response | Feeling fear, horror, anxiety Feeling sadness Feeling irritable, angry, frustrated Feeling gratitude |
| | Appraisals | Questioning why it happened to them Judging their own reaction Seeing the silver lining |
| After ICU: recovery process | Physical vs emotional recovery | Needing to physically recover before emotional recovery Impact of physical recovery on emotional recovery Returning to usual/valued activities Being hypervigilant due to physical health Impact of emotional difficulties on physical recovery |
| | Coping | Struggling to cope Avoiding or distancing from memories Accessing support – family / friends / support groups / professionals |
| | | |
| Family & Relationships | Support from others | Family being present Recognising the importance of others in recovery Others struggling to understand |
| | Impact on others | Family witnessing, being aware of what happening Family suffering |
| | Change in relationships | Feeling less tolerant, trusting towards others Making or breaking relationships |

Summary of Focused Codes

For each focused code, a short description of the initial codes that emerged from the interviews, and at least one illustrative quote have been provided for each code. For further examples of illustrative quotes for each code, see appendix 13.

Pre ICU

Previous life events. Participants (n=3) talked about being reminded of previous life events within different aspects of their ICU experiences, such as how they were treated by staff, themes in nightmares or hallucinations or the overall experience.

“Someone said to me when you go into a trauma as an adult, the old traumas of the past come up and sort of meet it sort of thing. And actually yeah, I froze then and didn’t have a voice, couldn’t speak. And there, I was restricted and didn’t have a voice, the same thing...” P06

Sudden illness. A number of participants (n=4) reported the suddenness or unexpected nature of the illness that brought them into the ICU. For some this was unexpected, although they might have been in hospital for another procedure and something unexpectedly changed. For other they might have been feeling normal the day before and going about their usual activities.

“...12 hrs before I was in hospital, I was you know, we were out enjoying ourselves, you know, not realising” P08

During ICU: experiences

Near death experience. Participants (n=6) talked about being near death or how their life hung in the balance during their time in the ICU, which was often reported to them after the fact. Participants were also near death in terms of proximity to those who were dying. Additionally, being near death or threatened with death was a common theme described by participants in hallucinations or nightmares during the ICU.

“I think the first few days were quite Touch and Go but then I was starting to turn a corner” p01

“There was a dying patient next to me that was hard because I was alert enough at that point and so I kind of figured what was going on and family were coming in...the guy in the bed opposite me was a guy who you had had some kind of cancer and they'd done an incredible operation...but he couldn't speak either... just writing 'why won't you let me die' on pieces of paper he only lasted a few days after that.” P02

“...then I just had this vision of all these demons above me, coming at me, trying to stab me.” P08

Loss of Autonomy. Participants (n=5) talked about their experience of losing their autonomy, in terms of losing their ability to speak, move and meet their basic needs in terms of tasks such as toileting, eating, managing thirst or heat levels. Additionally, participants talked about feeling trapped, and one participant likened this experience to torture and being imprisoned.

“well it was like torture really. Because you wake up, because I was in a coma for about a week or two, and then you woke up strapped down and can't talk... from there it just went on and it was a nightmare. My life wasn't my own and it was horrible, and prodding and poking. You just had no control over your life, I felt as if I was kidnapped and being tortured.” P07

When participants had medical support removed that was limiting speech and ability to move, for example, tracheotomies and mechanical ventilation, and being able to meet their own needs again, this was described as a turning point when they started to feel more hopeful:

“And I remember, I was absolutely broke down and cried down after because I had my voice, and I just said, it makes me cry when I think about, ‘I'm nearly home’, I'm

on my way to going home so that was a really big thing...a hurdle, a really big hurdle.” P06

Loss of autonomy was also a theme that was present in some participant’s hallucinatory memories of their time on ICU, in this case not having a voice and trying to communicate with others:

“I was in this rotating spaceship going down the Thames and I was trying to communicate with the lights on the embankment with my pelvic floor muscles to call out SOS, because that was how I would contact people...” P01

Intense emotional distress. Participants (n=5) reported experiencing a range of emotions while on the ICU, including agitation, anxiety, frustration and hopelessness.

“I started freaking out and kicking my legs and everything.” P07

“When I was fully awake and fully aware, that was when all the anxiety kicked in... I got myself in such a state, I was hysterical, because I thought, I don’t know what I thought, I thought it was going to hurt, it’s gonna be terrible or whatever” P06

“the frustration at not being able to talk for the first couple of weeks was very difficult”

P02

“And I just didn’t want to live then, I did have thoughts then, I didn’t want to live.” P08

Conflicted reactions to ICU staff. When participants (n=6) spoke about their interactions with ICU staff, these were mainly spoken about in positive terms of the care they received, although this did not necessarily mitigate the trauma. Whereas negative experiences of care from staff were generally the exception (n=2), some experiences were described as intrusive or uncaring. Additionally, ICU staff were also present in memories of hallucinations.

“I just sort of marvel at how hard they work and all that sort of stuff, I mean from that point of view. But it’s not sort of stopped me from thinking I don’t want to (return).”

P08

“some of the nurses wasn’t very nice, and some of them all they did was chat and chat and chat over you about their personal life instead of properly attending to you. and two of these nurses went to lift me, started prodding and poking at me...” P07

“all the...doctors and nurses, male and female, were all dressed as terrorists, carrying AK47s and for some reason I thought the double doors there were a lift and they were going up and down and killing patients on different floors and then they kept coming towards me” P02

Sleep problems. Participants (n=5) often indicated how they had difficulties sleeping on the ICU, either because of disruptions in environment (e.g. noises, lighting, regularity of procedures), or due to fear, stress or anxiety. Added to this, some participants stated feeling a desperate need for sleep.

“amongst the things I found really difficult were the constant lights...you could never, um I mean you could go to sleep, you didn’t sleep well anyway” P03

“and then I just didn't sleep for days. I stayed awake it wasn't that I refused to sleep I was terrified to sleep, not that I wouldn't wake up but that the nightmares would happen again.” P01

During ICU: Perception

Loss of awareness. Participants (n=6) consistently spoke about having little awareness of what happened during their ICU stay, and as a result often feeling disorientated, confused and disbelief about what had happened to them, and finding

it hard to believe or understand how unwell they were. Some participants reported a sense of being in complete darkness during their ICU stay. Participants also described the disorientating process of waking up or gaining more consciousness.

“my husband said when they got me into {place}, the paramedics took me to {hospital}, he said you was conscious, because he said, You were asking me for, but I don't remember it... don't remember nothing.” P06

“I had no idea, whether it was day, whether it was night. See in my mind, it was pitch black, but having gone back and looked round it, it's the brightest place the ICU” P08

“I remember coming around in the renal ward and I was in a little room on my own, and I thought...I'm fine now, I'll go home tomorrow. I thought I'd only been in for a day... I then didn't fully register I think for a several weeks what or how badly I'd been. how poorly I'd been” P01

Distorted reality. As well of losing awareness of what was happening in reality, all participants (n=6) described having a distorted perception of reality, including hallucinations, nightmares, merging of real and unreal experiences. There were some repeated themes in the descriptions of hallucinations or nightmares across participants: themes of moving in a vehicle (e.g. aeroplane, boat), being in space, and being persecuted or threatened in some way. Additionally, bizarre

elements of nightmares or hallucinations were often combined with aspects of what could have been reality (e.g. presence of nurses and doctors). Participants also reported a distorted sense of time on the ICU, as either stretched or fluid.

“the next thing I remember was waking up, having these hallucinations in in dark places, for a long time everything was dark and space rockets...I used to think I was on a spaceship, it was horrible, these things. as far as I was concerned all these people around me had kidnapped me, now I think that could have been whilst I was in a coma. “ P07

“I thought I was lying in that hospital bed, and I had a little bundle, wrapped up in some cloth and it was my legs and in my dreams or whatever, I was asking...I think it was my husband or brother, I’m not sure...saying, well we can’t put in back on anyway so can we get rid of it now, I don’t want to have this lying next to me..., that makes me think I had been told that I had lost my legs, so I knew I had lost my legs. Because other than that it’s more an awareness that came after, when I was out of the coma” P03

“Whilst I was only out for 2 weeks they lasted decades in my head.” P01

After ICU: memory

Memory disturbances. Most commonly participants described loss of memory from their time in ICU (n=5) and memories of hallucinations or nightmares (n=6). Participants also spoke about memories of painful or uncomfortable physical sensations, medical procedures and interactions with ICU staff (n=6).

“well what happened was I went to the GP, last thing I remember was going into [the nurses] room, and taking off my hat and didn't remember nothing else... the next thing I remember was waking up, having these hallucinations in in dark places, for a long time everything was dark and space rockets...that's the next thing I remembered. and then the third thing I remembered was when the doctor was over me.” P07

“I remember sitting down on that, I remember calling out ‘I feel faint’ and what happened is something had burst inside and I lost four litres of blood very quickly.” P02

In terms of the quality of memories, participants either described memories as often being very vague, or intrusive memories of hallucinations were often described as very vivid and clear.

“vague, I think. I think probably vague is the word because some of it is quite vague...um, yeah a lot of it feels quite vague, and I don't know how much of that is my mind trying to protect me,” P06

“It's very clear and vivid... very vivid, very easy to picture, which I think most dreams you might remember them when you wake up for a while but then they're gone after that. But these are very clear.” P02

Difficulty making sense of memories. In response to the experiences of loss of awareness and memory in the ICU, as well as hallucinatory memories, participants often talked about trying to make sense of their ICU experience (n=6). This might be trying to piece together a narrative of what really happened versus what was hallucinated, or trying to find explanations for what happened.

“When they come on, I think like - when I was having those nightmares about being in the spaceship and all that, and I think to myself, when it flashes through me, I think to myself, well you must have been in the coma to have felt like that... sometimes it feels like it don't quite fit and then other times it feels really real.” P07

“it's strange, sometimes it almost feels like, it's difficult to say because it doesn't make sense but sometimes I almost wonder if this really happened. Even though I know of course it did, because I've got a visual reminder in front of my eyes.” P03

Relying on third-hand information. Due to memory loss and difficulty making sense of experiences on the ICU, all participants (n=6) described relying on information from other sources to understand what happened to them. Sources of information were typically family and friends, professionals, diaries (written by staff or family), returning to the ICU and literature on the ICU (e.g. leaflets or information online). These sources were apparently helpful for providing a sense of timeline, filling in gaps in memory and providing information.

“I still have to do this with my wife as to why did they do this, why did they do that, well she would say you were doing this, you were doing that. and the diary was quite useful for just filling in the blanks, he was on this drug because it helped with this - it just explained a few of the things that you come out the other side not knowing about.” P02

“On that visit...just seeing where I was and to see it was a safe environment finding out more about... the fact that I'd been in 3 different rooms and it wasn't a dark hole where there were people [trying to kill me]” P08

After ICU: response

Heightened *emotional response*. Participants described a range of emotional reactions to their ICU experience: the most frequently talked about were

fear or anxiety (n=6), anger (n=4), and sadness (n=5). Increased fear and anxiety were sometimes in relation to the ICU or hospitals, as well as situations not directly linked to the ICU. In addition, participants often reported feeling grateful (n=5), towards others (e.g. ICU staff, family and friends) but also that their life was saved.

“Horror is the main, and anxiety perhaps. I don’t think I feel fear that it would happen again because it’s so unlikely... I don’t know if that’s a feeling that can be put in that category but just the fact that it feels very real...” P03

“because it was my fault... well anger in myself...because I wasn’t in tune enough with myself, but now I am 100% in tune and I know what’s going on” P07

“Just everything about it was, just, feels a bit horrific really when I (remember)... very sad, very very sad... that I had to go through that” P06

“I’m so eternally grateful for being here and I am forever in the debt of the people at [hospital] who saved my life.” P01

Appraisals. Some of the types of negative thoughts that were described regularly by participants were centered around themes of questioning why this had happened to them and judging how they had reacted to the experience. Participants

also described thoughts in relation to the experience, expressing how it had changed their perspective or priorities.

“for the first 12 months after really, you get a lot of ‘why me’ and all the rest of it. I’ve got diabetes as a result of it, again you get the ‘why me’, ‘why do I have to take 20 tablets a day for the rest of my life’ and all the rest of it” P02

“thinking ‘why on earth did I survive?’...when a very good friend, a number of years, a few years before that died...I wish it could have been the other way round , because it just doesn’t feel right... Other thoughts could be, on days where I do feel bad, or I do feel very negative about myself, having a bad time....thoughts I’ve had where, should I be angry with the doctor... Should I be angry with that person, who before I landed in intensive care, could not even be bothered taking my blood pressure?...Or should I be angry with the doctors and surgeons who saved my life, so that occasionally I have these thoughts of feeling ‘well, should I be angry that this happened to me or should I be angry that I survived”” P03

“So you do realise, it’s almost like when people fantasize about about going to their own funeral, it’s almost like that, you know you are loved and you know you’re cared about. yeah it’s a weird but privileged position to be in” P01

After ICU: recovery process

Coping. Participants described how at first (and intermittently afterwards), they struggled to cope and would just stay at home (n=4). Later, as time progressed, participants found other ways of trying to cope with their experience. In some cases, participants tried to avoid or suppress the memories in order to cope (n=3). Others coped with the experience by gaining support from others, either through their support network, by attending groups or accessing professional support (n=5). Getting support from others was often linked to codes around making sense of the memory and using third-hand information, and attending groups was helpful for normalising their experience.

“when I did eventually get home I just wanted to sit in a chair all the time, I didn’t want to go out. But that was partly, that was the same when I was still in hospital, I didn’t want to, I didn’t really want to see people and if I was out, I would be dreading meeting someone.”P08

*“with others who have been in intensive care has been good, because there’s quite a lot of common threads I think in terms of the feeling that you’re being attacked or you’re a victim of some sort. That seems to come through from those I’ve spoken to”
P03*

“...because you're still poorly and because not necessarily getting back to a hospital that is a 40 minutes drive away, that's why I trying to get to the mental health side of it was so difficult.” P02

“I saw 2 psychologists through that service...but there was nothing... that I gathered was specialised in that kind of trauma... I didn't think it was anything particularly relevant to the new situation unfortunately. Um, then I discovered, it was about a year ago, through a trial they were conducting here, a special type of counselling but geared towards.... intensive care...using a very different approach and technique that I'd never experienced before. It was really extraordinary because it was specifically aimed at working with the actual traumatic memories, revisiting them while feeling safe... it feels really relevant and targeted” P03

Physical vs emotional recovery. All participants (n=6) referred to a tension between their physical and emotional recovery, and how the two impacted on each other. Some felt that the physical recovery took precedence initially and only when they felt more physically well, did they experience the emotional impact. Additionally, physical recovery impacted on emotional difficulties, particularly in terms of being able to return to their usual or valued activities, such as work and hobbies. Also some participants were increasingly hypervigilant as a result of the physical consequences of their ICU stay. Finally, participants' emotional experience on the ICU impacted on physical recovery, in terms of feeling ambivalent about having further medical interventions.

“...went back to work in May, which I think was absolutely essential mentally. Now, I realise later on that I went back way too early physically, it probably extended various physical health complaints.” P02

“I’ve had to learn my limitations I guess, which I was never very good at because I would push myself... But can’t do that today, I have to know my limitations, because I can’t do what I used to do...I don’t feel I’m the same, I don’t know if I’ll ever be the same. The same in the sense that I’m limited to what I can do.” P06

“the fact that the disability is quite visual, so I’m always on high alert, thinking that I’m being stared at, a lot of the time yes some people do stare, but not very long.” P03

“I mean I am anxious because they have talked about maybe excising the wound and restitching it, and on one hand I think well if that heals then, you know, great but on the other hand, what if the whole cycle starts again...so when did I see the consultant, end of February, so that’s been on my mind as well, brings things back, thinking you know ‘this could all happen again’... I think ‘oh if went in, would I catch c. difficile again and all that sort of stuff, can I put my family through it.’” P08

Family and Relationships

Support from others. Participants often talked about the support they had received from partners, family and friends during their time in ICU and afterwards. Generally this was talked about positively (n=5), how grateful they were for this and how important it was in their recovery. Occasionally, participants did describe how it was difficult for others to understand what they had been through and support them accordingly (n=2).

“she had put her life on hold and she was giving with it all, so that I mean brought all that into perspective to me as well. How much she’d given up and how much she’d been there...yeah... it just makes me feel, you know, they care.” P08

“Because even if I did have friends on the outside, they just don’t get it.” P07

Impact on others. The other way in which participants also talked about family and relationships was thinking about the impact the ICU experience had on those around them (n=4). Participants reported how they felt it was harder for their family as they were aware of what was happening, unlike some of the participants, and therefore may have felt significant anxiety or trauma from witnessing it.

“She had actually written in her book, you know that at times that I had written ‘let me die, let me die’, you know it makes me feel how she must have felt about it.” P08

"I think it's affected my husband more because he's got the memories, so he had to have therapy afterwards and he had EMDR...because he kept having flashbacks of me in the hospital. Whereas mine are memories of me on the renal ward" P01

Change in relationships. Participants also reported how their ICU experience had brought about changes in how they related to others since (n=5). For some, this was feeling less tolerant or trusting towards others. Whereas others reported that the experience could be seen as 'making or breaking' relationships and had helped them realise who was important to them.

"I just don't trust them (nurses), you get too familiar with them, they take liberties... I don't trust them at all." P07

"Yeah I don't suffer fools gladly now, whereas before I would, I was such a mug and so gullible. I guess it's hardened me, a bit." P01

"I think it either makes you stronger or it breaks you up. and I can't decide where we are at the moment...realised some people are just fair weather friends. and some people are brilliant friends, really really and people who you wouldn't have expected to do stuff" P01

A Thematic Map of Psychological Experiences of PTSD-ICU

The theoretical codes, and the component focused codes were then used to create a thematic map of the psychological experience of PTSD-ICU (figure 2). This map was developed throughout the coding process, through the use of memos and integrative diagrams (Urquhart, 2012), and moving between initial codes (and the relationships between them) and iterative drafts of the diagram. The focused codes were organised into a temporal sequences to show what factors occur prior, during and after ICU. Circles and rectangles represent theoretical and focused codes, and arrows represent the direction of influence.

At the pre-ICU stage, two codes were identified as potentially related to the traumatic experience of ICU, which were the sudden, unexpected nature of the illness or ICU admission and feeling reminded of 'previous life events' that were stressful or traumatic. The reminders of previous life events often arose together with another code, 'distorted reality', where dreams or hallucinations reflected previous life events.

During ICU, codes were separated into experiences while in the ICU and how these experiences were then perceived. The following codes described common traumatic or stressful experiences in the ICU: 'loss of autonomy'; the 'near death experience' in ICU; 'intense emotional distress'; 'sleep problems'; and 'conflicted reactions to ICU staff'. These experiences were then perceived through a lens of 'distorted reality' and 'loss of awareness'. For example, loss of autonomy and threat of death were often themes in dreams or hallucinations.

Linked to loss of awareness and distorted reality during the ICU, after-ICU codes identified the task of having to make sense of their disturbed memories from the ICU, and the need to 'rely on third hand information' to do so. Additional after-ICU codes described the response participants had once leaving the ICU, including a 'heightened emotional response' and 'appraisals' to attempt to understand what happened to them. These codes were linked to other after-ICU codes on 'coping' and the tension between 'physical vs emotional recovery'. Throughout the whole ICU process, codes related to 'family and relationships' arose including the support that was received, the impact ICU had on relationships and changes in relationships that occurred as a result.

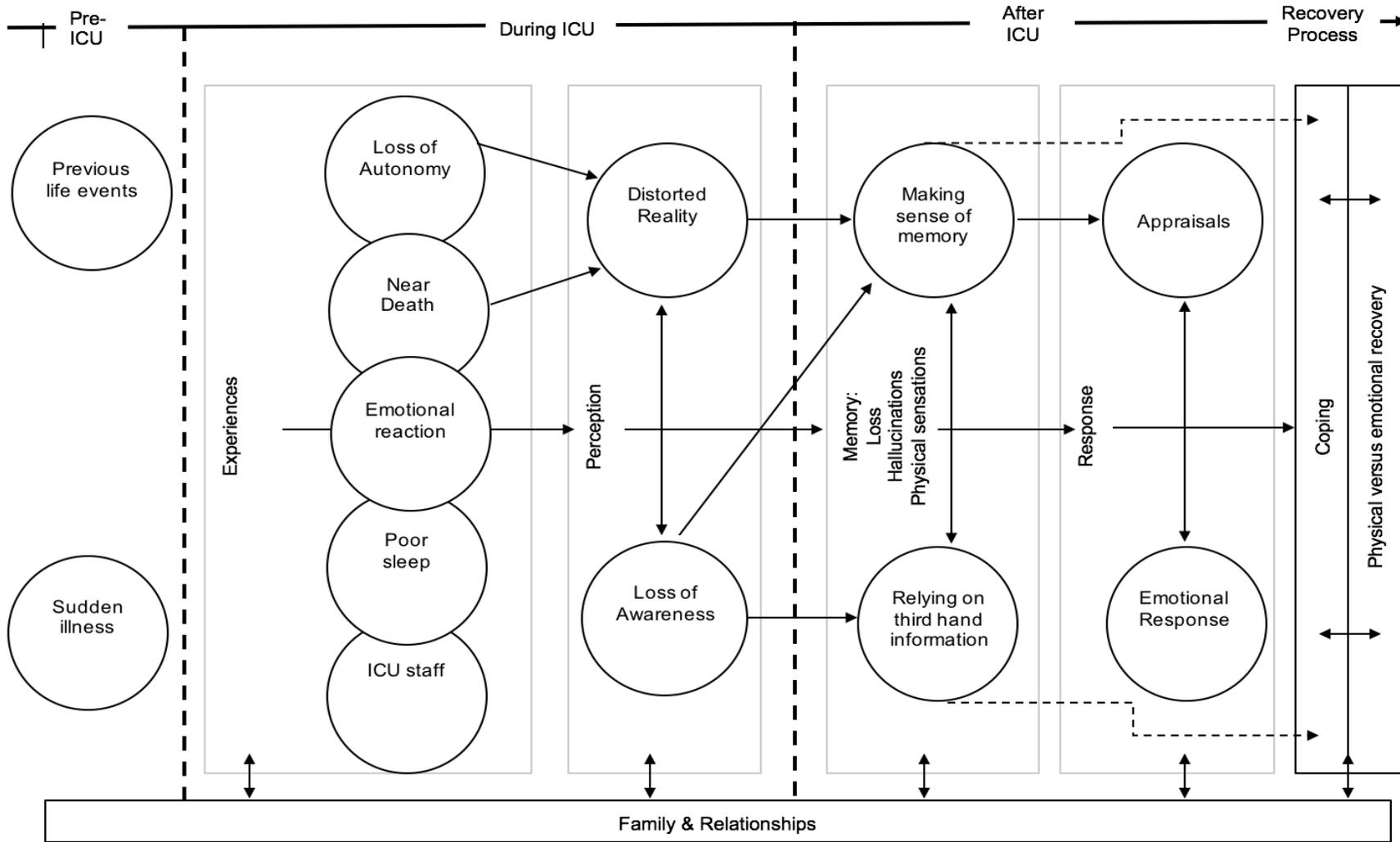


Figure 2. Diagrammatic representation of grounded theory of PTSD-ICU

Discussion

While existing research has demonstrated that there are high prevalence rates of PTSD-ICU and studied the risk factors, there is limited research on the psychological factors associated with PTSD-ICU. This has implications for how effectively guidance on delivering psychological follow-up for this group can be implemented. Therefore this study aimed to use grounded theory methodology to develop a model of the psychological experience of PTSD following an ICU admission, based on interview data from previous ICU patients with symptoms of PTSD.

Summary of Findings

Seven theoretical codes were generated from the interviews with participants suffering from PTSD-ICU, which were made up of 19 focused codes. These theoretical codes were organised into temporal order of factors occurring prior, during, after and in recovery from the ICU, and were used to create a preliminary theoretical model to assist the psychological conceptualisation of PTSD-ICU.

Prior to the ICU, there were two possible themes that may contribute to the development of PTSD. One was that some participants described how their traumatic experience of the ICU reminded them of previous traumatic or stressful life events. More proximal to the ICU, was the sudden or unexpected nature of the illness and ICU admission, either because they described feeling normal the day

prior, or because they had been admitted for a surgery and been discharged. This was normally described alongside loss of memory, where participants remember starting to feel unwell and then the next memory is waking up in ICU.

During ICU, the following experiential and perceptual factors were identified as potential contributors to later PTSD symptoms: being near death; losing autonomy over one's own body and needs; an intense emotional distress in the ICU; sleep problems; loss of awareness; and distorted reality. Additionally, participants often talked about the role of ICU staff in shaping their experience of ICU, but this was not necessarily traumatic for most. After leaving the ICU, participants often described a loss of memory, memory of hallucinations, or some memories of painful, unpleasant medical procedures. The combination of loss of awareness, distorted reality in the form of hallucinations and loss of factual memories, meant that participants were often left with difficulties trying to make sense of their experience and what had happened to them, and one way they tried to make sense of this was by using third-hand information from sources such as their family or diaries. How participants made sense of their ICU experience influenced their emotional and cognitive response to the trauma, and in turn how they tried to cope. They described experiencing emotions such as horror, anger and fear after the event and thoughts questioning why this had happened and how they had reacted to the experience, as well as expressions of gratitude towards staff and family who had helped them. Often participants referred to struggling to cope initially, often staying at home or in bed, which was also likely linked to the physical recovery process. Other coping strategies involved avoidance or distancing themselves from the memories, or accessing help

either from family and friends, or from support groups or professionals. However, the recovery process was affected by the interaction between physical and emotional health. For some, there was a sense that the physical recovery took precedence and only when they were physically well, did they notice emotional difficulties.

Furthermore, their physical health and the physical consequences of ICU often impacted on their emotional wellbeing, for example, by limiting their ability to return to valued activities, or being hypervigilant about their physical health. The opposite was also true, where the emotional impact of ICU affected their ongoing physical health, in terms of ambivalence towards further medical interventions.

Running concurrently along their experience of ICU as a patient, were descriptions of partner, family and friend's experiences. Three themes emerged within this theoretical code, of the importance of and gratitude for the support from others, the impact on significant others, and changes in their relationships as a result of the ICU experience.

Comparison of Findings with the Literature

With PTSD-ICU literature. The following codes are also supported by existing research into PTSD-ICU: the role of previous traumatic events (Davydow et al., 2013; Paparrigopoulos et al., 2014); intense emotional distress during the ICU generally in terms of total mood disturbance, and specifically fear and stress (Wade et al., 2013, 2012); loss of awareness (Rosalind Elliott et al., 2016; Rattray et al., 2010); loss of autonomy (Myhren et al., 2010); distorted reality (e.g. hallucinations)

(Kiekkas et al., 2010; Parker et al., 2015; Wade et al., 2015, 2013); difficulties making sense of memories (Corrigan et al., 2007) and using diaries as third-hand information (Egerod et al., 2011); heightened emotional response after the ICU, coping by avoidance and the interaction between physical and emotional recovery and the impact on family and relationships (Corrigan et al., 2007; Talisayon et al., 2011). However this study supplements this existing research with further information. For example, quantitative studies have demonstrated the role of overall mood disturbance in the ICU in developing PTSD symptoms (Wade et al., 2012) but it was unclear which specific mood states were implicated. This study described specific emotions of agitation, anxiety, frustration and hopelessness, which were in reaction to events in the ICU, such as being unable to express self, loss of autonomy, or worries about never leaving the ICU.

This study also adds context and experiential detail to research areas where there were inconclusive findings. For example, previous studies had found inconsistent findings regarding the role of factual memories (Kiekkas et al., 2010). This study found that participants generally experienced significant loss of factual memories, often from the early period of their admission, in the context of other delusional memories and hallucinations, and memories of physical sensations. Furthermore, the factual memories of the ICU were often traumatic, for example related to loss of autonomy, and varied in level of clarity and salience for different participants.

With PTSD models. A number of the codes generated from the interviews describe hallmark symptoms of PTSD: experiencing a life-threatening or near death event; avoidance of trauma-related stimuli; a negative change in emotions and thoughts since the traumatic event; and hyperarousal symptoms, such as hypervigilance and irritability. This is perhaps not surprising given included participants met some or all diagnostic criteria for PTSD. Nevertheless, this shows that existing models of PTSD, such as Ehlers and Clark's (2000) cognitive model, are compatible with this specific population. Central to Ehlers and Clark's model is the role of appraisals of the traumatic event and its consequences, and interview data in this study showed similar types of appraisals present in an ICU sample, including appraisals about why the event happened to them and appraisals regarding their reaction to the event. Additionally, their model highlights the nature of traumatic memories, as fragmented, disorganised, and poorly contextualised when intentionally recalled, and as highly sensory, emotional and marked by a current sense of threat when involuntarily recalled. The description of memories given by this ICU sample are indeed fragmented, disorganised and poorly contextualised, however it is likely this is exacerbated in this population due being in and out of consciousness and the role of sedative medications. It is difficult to disentangle to what extent fragmented memory is due to common trauma processes affecting memory or to ICU processes affecting memories, and this may be a target for further research. Furthermore, participants in this sample are unique in that they describe memories of events that did not happen (i.e. hallucinations or nightmares).

Limitations

There were some methodological limitations to the current study, in particular with the use of grounded theory methodology to develop a theoretical model of PTSD-ICU. Grounded theory methodology was designed in order to build explanatory models of sociological processes that are grounded in the data being studied, rather than from existing theory or knowledge. It has been suggested that when grounded theory methodology is applied to questions about individual experience, rather than social processes, there is a risk that the grounded theory becomes a method for categorising data instead of generating theory ([Willig, 2013, p.78](#)). This was a limitation for this study where the results, and the diagram produced, were more of a descriptive, thematic map than an explanatory framework of the PTSD-ICU experience, as a result of applying the grounded theory method to a research question about the nature of individual experience. Alternatively, it may have been more appropriate to use another qualitative method, such as interpretative phenomenological analysis, to explore the individual experiences of PTSD-ICU.

Furthermore, there were limitations with regards to the sample recruited. In grounded theory methodology, theoretical sampling is a key strategy to support theory building, whereby further participants are sought based on certain characteristics that support the elaboration or refinement of emerging data (Glaser & Strauss, 1967). It was not possible to use theoretical sampling due to the recruitment method employed. The study was advertised across a number of NHS sites and one charitable organisation, and so relied on participants self-referring to the study. This had implications in terms of reaching the desired sample size, for theoretical sampling and for the representativeness of the sample. Although the intended sample size of 10 was not

reached, the data from the interviews was approaching theoretical saturation as there was convergence in themes across the interviews, and few new themes emerged by the final interview. In terms of representativeness, the sample was predominantly made up of White British, female participants and had a mean age of 51.5 years. ICU statistics show that over half (56.8%) of admissions are male, and over half of ICU admissions are adults aged over 65 years (NHS Digital, 2017), so this sample was not representative of the wider ICU population in terms of age and gender. However reviews have suggested that younger age and female gender are risk factors for PTSD, albeit not consistently (Davydow et al., 2008; Morrissey & Collier, 2016), so the sample may be more applicable to the sub-group of ICU patients who experience PTSD. Finally, the sampling is biased in that it was likely to select participants who were already accessing some type of further support, whether in an ICU follow-up clinic or support group or through an online charity aimed at ICU survivors. Therefore the findings may not apply to those who have not accessed further support as there may be difference in the severity of the symptoms and how far along they are in the process of understanding these symptoms.

Additionally, quality standards for qualitative and grounded theory research recommend that researchers use several methods for checking the credibility of their findings (Elliott et al., 1999), for example through a second auditor checking and verifying a sample of the coding process. Due to difficulties recruiting the sample, the last participant was interviewed late in thesis process, which created time constraints between interviews and writing up, and it was not possible for a second researcher to audit the coding process, which may limit the reliability of the findings. However

the credibility of the findings was checked through sending the principal findings to a selection of participants for validation (Elliott et al., 1999).

Finally, quality standards recommend reflexivity and 'owning your own perspective' (Elliott et al., 1999). Classic grounded theory methodology recommends that literature reviews are not conducted prior to the coding process to avoid imposing existing theoretical ideas (Glaser & Strauss, 1967). However as part of this thesis, a systematic review of the literature was conducted concurrently to the current study and may have influenced how the interview data was coded and interpreted. This is not completely incompatible with the constructivist approach to grounded theory (Charmaz, 2006) used in this study, which recognises that data and theory is constructed through our interactions with it, rather than the researcher being separate to the data (Glaser & Strauss, 1967) and so the researcher's previous knowledge and perspective was already acknowledged earlier on (see '*methods*'). As identified in the method section, it is clear that the findings of the systematic review influenced the findings of this empirical study, at least in how the findings are presented and categorised according to a temporal sequence. Furthermore the knowledge of existing models, particularly cognitive-behavioural models, was apparent in the analysis process as codes were identified in relation to emotions and appraisals, which was a natural by-product of the design of the interview schedule with questions asking about these facets of their ICU experience.

Implications

Clinical. This grounded theory model of PTSD-ICU facilitates understanding of the experiences of those suffering with PTSD-ICU, which can assist psychological formulation and treatment of this group. Guidance recommends that ICU patients receive a psychological follow-up after leaving the ICU, including screening, assessment and treatment of PTSD (National Institute for Health and Care Excellence, 2009), however there has been limited research to suggest how this treatment may be delivered, and what theories or models might guide it. The grounded theory model generated by this study is compatible with existing PTSD theories and evidence-based interventions, but also highlights specific targets and methods for treatment using existing cognitive-behavioural approaches. Traditional trauma-focused approaches generally use exposure techniques which involve reliving the traumatic memory in a way that elaborates on and contextualises the memory within a wider timeline in order to reduce the current sense of threat. As ICU patients often experience a loss of awareness, memory and a sense of timeline during their admission, as well as traumatic memories of events that did not happen (i.e. hallucinations), there may be challenges to fully reliving the traumatic event of ICU. However, for some, this might be overcome by involving the wider system or sources of information (e.g. family, ICU staff or diaries) in part of treatment to help construct a narrative around the fragmented memories they do have. Similarly, the same system may also play a key role in facilitating sense-making of memories and cognitive approaches targeting appraisals of the trauma, as a common theme in the interview was difficulty making sense of what happened. For example, ICU staff or literature may be able to assist in normalising the experience of memory loss and

hallucinations during the ICU and challenge appraisals about their reaction (e.g. 'I'm mad/insane'). Therefore, psychological practitioners may need to be proactive in seeking involvement from local ICUs, follow-up clinics or family and friends.

Additional liaison with the ICU may be helpful for organising in-session exposure by returning to the ICU, if working within a prolonged exposure model. Participants stated the helpfulness of returning to the ICU for dispelling myths that existed due to hallucinations, but also it has value for overcoming avoidance related to trauma-stimuli that may prevent engaging in follow-up physical health care.

Another common theme in the traumatic experience of ICU regarded the loss of autonomy and not being able to express themselves or meet their own needs. This is linked to the idea of mental defeat, which is common in prolonged and inescapable traumatic events and is defined as a perceived loss of psychological autonomy and often leads to negative appraisals of the self. It is particularly important to target a sense of mental defeat as it is a predictor of poor treatment outcome (e.g. Ehlers et al., 1998). Mental defeat may be targeted through cognitive restructuring (Ehlers & Clark, 2000) or through imagery rescripting techniques (e.g. Hackmann, 2011), where images from ICU are revisited and then rescripted, for example, so that they are able to use their voice and express what they are feeling or needing.

Additionally, loss of autonomy seemed associated with shame, and therefore compassion-focused interventions (Lee & James, 2012) may be a valuable approach in this group. Frequent expressions of gratitude were also observed, and one hypothesis is that this was linked to a sense of guilt about not being sufficiently

grateful to have survived, which could again be targeted by compassion-focused approaches.

Given the interaction between physical health and mental health described in the interviews, there is an additional reason for potential liaison and joint working between psychological services and physical health services. ICU follow-up clinics are likely to have limited capacity for directly delivering psychological interventions, such as TF-CBT. Therefore it is important that established pathways exist for follow-up clinics to refer to appropriate mental health services that can offer treatment for PTSD, such as primary care Improving Access to Psychological Therapies (IAPT) services or specialist secondary care trauma services. As part of this pathway, it would be beneficial for ICU services to provide consultation to mental health services regarding the specific physical needs of this population, as well as sharing the realities of what it is like being on the ICU. Additionally, physical limitations as a result of severe illness or injury may impact on engagement or specific interventions, such as behavioural activation for comorbid depression. For those whose mobility is severely restricted, interventions that are facilitated via internet or phone may be worthwhile (e.g. Wild et al., 2016). For those who are physically able to attend, but also suffer from long-term health conditions (LTCs), models such as Moorey's (1996) adjustment model or Acceptance or Commitment Therapy (ACT) (e.g. Wetherell et al., 2011) that are aimed at those with LTCs may be beneficial models for adapting treatment accordingly to the physical health limitations. This is particularly relevant given the NHS' five year forward plan (NHS, 2014) to expand IAPT services to deliver psychological interventions to those with LTCs.

For future research. The current study has implications for future research into PTSD-ICU. The current study aimed to develop a psychological model to assist in formulation and treatment of PTSD-ICU. The model developed by this study has suggested the role of factors such as loss of autonomy, loss of awareness, making sense of memories, appraisals of the event and the balance between physical and emotional recovery. These factors can be further investigated using quantitative methods and standardised measures, for example appraisals could be investigated using standardised measures, such as the Post-Traumatic Cognitions Inventory (PTCI; Foa, Ehlers, Clark, Tolin, & Orsillo, 1999) or the World Assumptions Scale (WAS; Janoff-Bulman, 1989).

Additionally, some of the psychological factors indicated in this study can be explored further using a similar qualitative design employed with different sub-sets of this population. For example, a study could focus on only individuals with delusional memories but with varying levels of PTSD symptoms (e.g. full, partial, none) to further investigate the role of delusional memories in PTSD and to potentially understand other factors that may mediate this relationship, such as ways of making sense of delusional memories.

Finally, this study aimed to develop a model to assist in psychological formulation and treatment of PTSD-ICU. Further research is generally needed regarding evidence-based interventions for PTSD-ICU. Service-related research is needed to

examine how many ICU patients are being assessed for PTSD symptoms, and in turn, being referred and treated for PTSD in order to map treatment pathways for this group. For those who are receiving evidence-based trauma-focused interventions, research on how feasible, effective and acceptable these treatments are for PTSD-ICU is greatly needed. This could be achieved through more pragmatic research in services, using existing outcome measures and qualitative data from satisfaction questionnaires or focus groups of PTSD-ICU sufferers. A challenge of doing this type of research is finding the sample as treatment pathways for PTSD after ICU are hugely variable. Furthermore, a randomised controlled trial could be conducted to investigate the effectiveness of any new developments in treatments for PTSD-ICU, or an adapted version of an existing evidence treatment for PTSD.

Conclusions

The current study provides an initial theoretical framework to assist with the psychological formulation and treatment of PTSD-ICU. The findings of the study highlight the compatibility of existing models of PTSD for an ICU population, as well as emphasising specific ICU factors and the implications this may have for treatment. Specific ICU factors that may require consideration when delivering psychological interventions are: the loss of autonomy, loss of awareness and distorted perception of reality during ICU; the fragmentation of memory that occurs as a result, and the difficulty in making sense of these experiences, even with the additional help of third-hand information; and lastly how the physical health consequences impact on emotional recovery and wellbeing, and vice versa. Clinical implications were considered in terms of cognitive-behavioural approaches relevant

to an ICU population, as well as the importance of joint working and liaison between physical and mental health services. However, further research is required to confirm the role of the suggested psychological factors from this study, and generally into psychological interventions for this group.

Chapter 3

Integration, Impact and Dissemination

Integration

The systematic review chapter of this thesis aimed to summarise the existing research on psychological factors involved in developing PTSD after ICU. The empirical study then aimed to develop a preliminary theoretical model of the psychological factors involved in PTSD-ICU that was grounded in the experiences and interview data from previous ICU patients with symptoms of PTSD. Together, it was hoped that the systematic review and empirical study would combine to provide a more detailed psychological understanding of PTSD-ICU to assist practitioners in formulating and treating PTSD in this population.

Integration of findings. Taken together, the systematic review and empirical paper have made progress towards the aim of building up psychological understanding of PTSD-ICU, and mostly the two complement each other well, with a number of the findings being confirmed between the review and the empirical study. This is demonstrated in an integrated diagram representing the findings of both parts of the study (figure 3). The findings are organised in temporal order, in accordance with the two parts of the study, from before ICU through to after ICU. Generally, this shows that the findings of the review and empirical study synthesise well and are generally in accordance with one another. In particular, the following factors were consistent across existing research and this grounded theory study: previous traumatic or stressful life events; loss of autonomy, intense emotional distress, distorted reality (e.g. hallucinations) and loss of awareness during ICU; types of memory (loss of memory, memory of hallucinations, pain or physical sensations),

making sense of these memories, emotional response, coping and physical versus emotional recovery after ICU.

Other factors that were not consistent across the two are not necessarily less significant, but may not have been studied sufficiently. For example, there is lack of research on appraisals in PTSD-ICU prior to this study. Furthermore, exclusion criteria used in the systematic review may have excluded studies that may have confirmed other findings, in at least two examples. One, family and relationships was constructed as a theoretical code, however as only studies investigating ICU patients were included in the review, this did not allow for outcomes regarding family members. There is however a wide literature base focusing on family members of ICU patients (e.g. Al-Mutair, Plummer, O'Brien, & Clerehan, 2013; Petrinec & Daly, 2016). Second, the review excluded psychological intervention studies, which would have included ICU diary studies. Diaries were one of the sources of third-hand information, and studies on diaries have found that they are a source of third-hand information that helps make sense of ICU experiences (Egerod et al., 2011), as suggested in the qualitative study.

This integrated diagram does also highlight which factors and timepoints previous research has focused on, compared to this study. The studies included in the systematic review focused more on pre-ICU and during ICU factors. After ICU, the main factor that quantitative studies investigated was memory. The support from

previous research for other after-ICU factors, such as making sense, coping, physical vs emotional recovery, comes only from previous qualitative studies.

One of the main difficulties in integrating the findings was in relation to categorisation. In the systematic review, findings were categorised in order to allow the reader to digest the findings more readily, and in grounded theory, initial codes are then grouped into focused codes. Within these categories, there is substantial overlap both within each study and between. In some cases, this has appeared as if findings have not been replicated but this may instead be an artefact of the categorisation system. For example, frightening experiences as measured by the ICEQ was found to be significant in predicting PTSD in the systematic review, and ostensibly there wasn't a matching category in the grounded theory. However, participants undoubtedly described frightening experiences, and this would certainly overlap with codes of emotional reaction (particularly feeling fearful) and near death experiences during ICU.

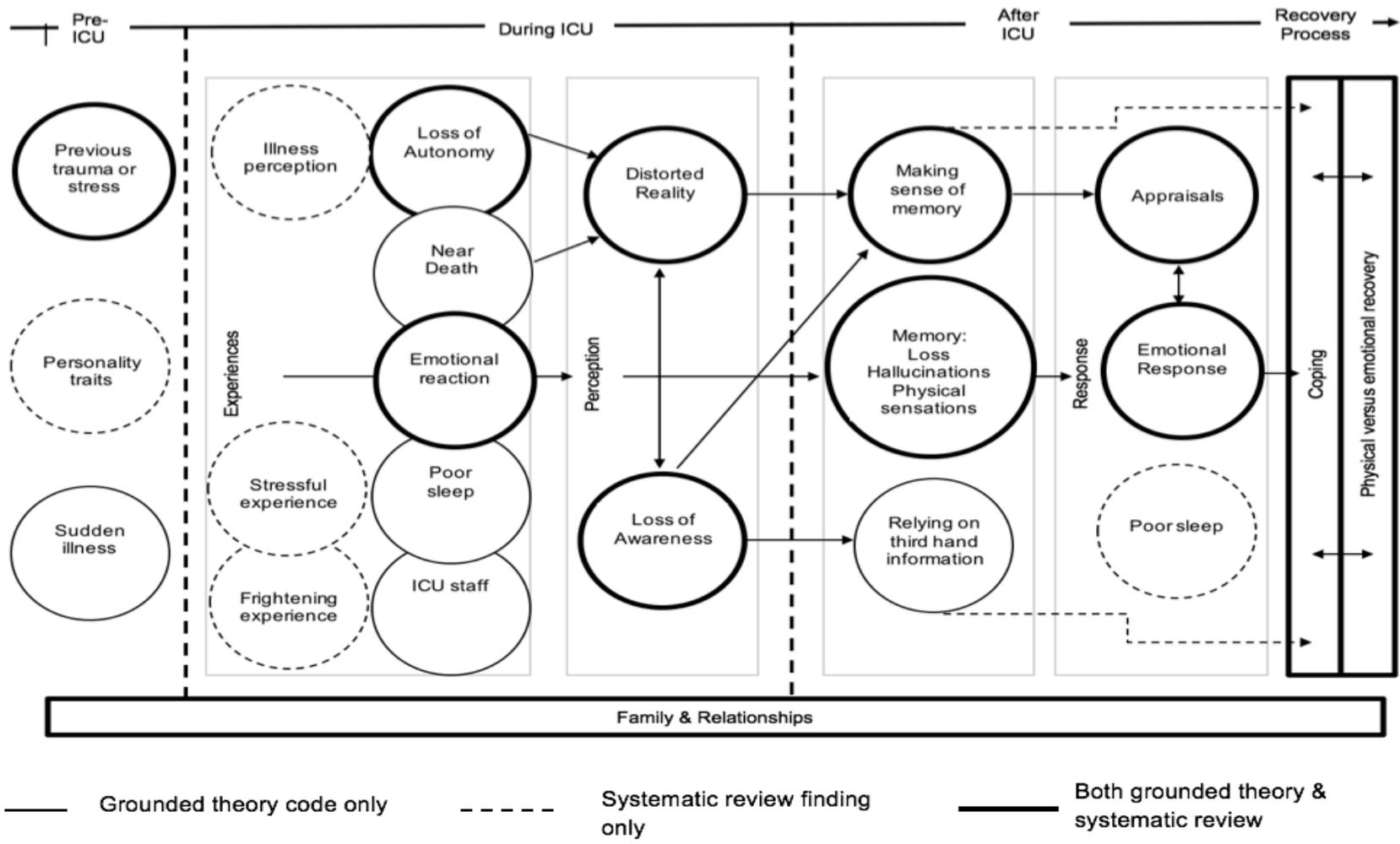


Figure 3. Integrated diagram of grounded theory and existing research findings from systematic review

While the grounded theory study did not necessarily identify any novel psychological factors that haven't been identified through previous studies, it was novel in identifying patterns of psychological experiences and placing these within the wider context of ICU. This allows consideration for how multiple psychological factors may interact and lead to the development of PTSD symptoms.

Implications of integrated findings. Following integration of the findings of the systematic review and grounded theory, the clinical implications are considered (table 8). One of the implications that stands out overall is the suggestion to involve wider systems when delivering psychological, trauma-focused interventions. In general, trauma-focused interventions are likely to be offered on a one-to-one basis, and while this may still be the case for the majority of sessions for individuals with PTSD-ICU, there are key roles that the wider system (e.g. ICU staff, family, friends) can play. First of all, the system may be key in helping individuals to make sense of their experience and to provide information that can help them piece together their memories and what happened to them. Second, given the interactions between physical and mental health, it may be important for there to be good liaison between physical and mental health services to support engagement and manage barriers to treatment. Finally, given the potential impact on family and friends, and the role they play in supporting individuals throughout the process, it is essential that support for family and carers is also kept in mind.

Table 8

Clinical implications of integrated findings

| Timepoint | Integrated codes / psychological factors | Implications |
|-------------------|-------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <i>During ICU</i> | Loss of autonomy | <ul style="list-style-type: none"> • <i>In ICU</i>– when patient is conscious, enhancing sense of autonomy as much as possible within practical or physical health limitations • <i>Psychological interventions after</i>– consider imagery rescripting (e.g. of expressing self/needs in memory) (Hackmann, 2011) |
| | Intense emotional distress | <ul style="list-style-type: none"> • <i>In ICU</i> – reducing distress in ICU; assessing hopelessness and suicidality throughout ICU and follow-up |
| | Distorted reality | <ul style="list-style-type: none"> • <i>Psychological interventions after</i> – using third-hand information to help patients understand hallucinations; or working within delusional system (e.g. as in CBT for psychosis) |
| | Loss of awareness | <ul style="list-style-type: none"> • Possible use of diaries, timelines to fill in gaps – albeit with consideration that evidence of harm/benefit is inconclusive (Ullman et al., 2015) • Liaison with ICU services to arrange visits to ICU or to get collaborating information from medical record |
| <i>After ICU</i> | Memory | <ul style="list-style-type: none"> • <i>Psychological interventions</i> - use of third hand information to support contextualisation and elaboration of memory. • <i>Psychological interventions</i> - focusing more on cognitive strategies where insufficient memory for reliving |
| | Making sense of memory | <ul style="list-style-type: none"> • <i>Psychological interventions</i>: use of third hand information; liaison with ICU staff to support professional to understand/ make sense; psychoeducation regarding hallucinatory or delusional memories in ICU |
| | Appraisals | <ul style="list-style-type: none"> • <i>Psychological interventions</i> – use of standard cognitive restructuring techniques |

| | | |
|------------------------|--------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| | | <ul style="list-style-type: none"> Referring patients to ICU support groups and literature, where available, to provide specific psychoeducation and normalise experience and reactions |
| | Heightened emotional response | <ul style="list-style-type: none"> <i>Psychological interventions</i>: standard CBT techniques; potential role of compassion focused techniques |
| | Coping | <ul style="list-style-type: none"> <i>Psychological interventions</i>: use of standard CBT techniques |
| | Physical vs emotional recovery | <ul style="list-style-type: none"> Joint working between physical and mental health services Use of psychological models aimed at long-term health conditions Consider accessibility and use of internet or telephone based interventions |
| Family & Relationships | Support from others Impact on others Change in relationships | <ul style="list-style-type: none"> Involvement of wider system in support offered at all stages of the ICU and mental health treatment pathway |

Methodological Reflections

Systematic review: decision making, strengths and limitations. The topic of the review was chosen primarily to complement the main aim of the empirical study so that the review summarised existing research into psychological factors associated with ICU, and the grounded theory study would explore and develop a theoretical model of psychological factors associated with PTSD-ICU. Additionally, a number of systematic reviews had already been conducted that summarised prevalence and general risk factors (Davydow et al., 2008; Parker et al., 2015; Wade et al., 2013), and so an additional review on this topic was not needed. A possible disadvantage of the topic choice was the breadth of the question and operationalising the question. There can be significant variability in how psychological factors are defined by researchers, and this review chose to focus on

factors such as cognitions, mood, behaviour, memory and social factors, but to exclude psychological interventions and prior psychiatric history. Instead, it may have been beneficial to have chosen more specific psychological variables to allow for a more focused question and homogeneous data set. However, the only psychological variable that has been studied consistently enough to review is the role of memory, and a similar review had been conducted recently (Kiekkas et al., 2010).

For data synthesis, it was decided to use a narrative synthesis approach (Popay et al., 2006). This was appropriate as there was significant heterogeneity across the papers, both in terms of the inclusion of quantitative and qualitative papers, but also in terms of the outcomes measured across the papers. It is debatable whether meta-analytic approaches would have been suitable for the included quantitative data. When used in these circumstances, meta-analysis findings can be misleading (Matthias Egger, Smith, & Sterne, 2001) and can suggest objectivity and certainty, when in reality the process can have many subjective and uncertain components (Moncrieff, 2003). The advantage of a narrative approach is that it can allow the reader to draw their own interpretations and conclusions. In contrast, results of statistical tests can be less intuitive to interpret and so more difficult to challenge (Boden, 1992).

A strength of the review is that it included a quality appraisal of all the included studies. This quality appraisal was conducted using the MMAT tool (National

Collaborating Centre for Methods and Tools, 2015). This was chosen primarily because one tool can be used across a number of different methodologies, and as this paper included different quantitative and qualitative study design, it felt appropriate. Furthermore, there is evidence that the MMAT has good reliability for judging quality of included papers (Pace et al., 2012). However, the MMAT is by nature a brief assessment tool, with only four criteria per methodology. Instead, a more comprehensive tool could have been used to assess each type of methodology (e.g. Critical Appraisal Skills Programme (CASP)), which may have resulted in a more detailed assessment of different facets of study quality.

Empirical paper: decision making, strengths and limitations. One of the principal dilemmas when planning the empirical study was the recruitment strategy for the sample. At the proposal stage of the planning process, it was decided to adopt a wide recruitment strategy by advertising the study across a number of sites, including NHS and non-NHS organisations, instead of focusing recruitment on one or two specific sites. The benefit of a more focused recruitment strategy would have been the ability to build a close relationship with the team based at the site and potentially take a more proactive approach to screening and approaching potential participants. However, the obvious choice of service to do this would have been an ICU follow-up clinic, and initial conversations with a number of follow-up clinics revealed that the numbers presenting in clinic with PTSD were not reflective of the numbers suggested by research, and that this would not be a viable approach. Therefore it was decided to advertise the study widely and to adopt relatively inclusive criteria for participation. The implication of this was that theoretical

sampling, a key strategy used in grounded theory, could not be used as we were reliant on participants self-referring. Additionally, this created challenges in reaching the target sample, however the sample size of 6 did almost allow for theoretical saturation to be obtained. Theoretical saturation is defined as when no new codes occur in the data, and by the last interview, very few new codes were emerging in the coding process.

Initially it was hoped to screen participants online and for participants to complete a battery of cognitive measures. A secondary aim at this point of the planning process was to gather data on cognitive characteristics of the interview sample and those excluded. However at the first ethical approval committee, concerns were raised about the possibly distressing nature of some of the questionnaires and participants completing these online without the presence of another to help manage distress. Therefore the decision was made to focus on the qualitative aspect of the empirical study, and to cut the number of standardised measures used so that only those necessary to screen and assess PTSD symptomatology were kept. However, it was important to keep a remote screening process in place, as the recruitment strategy meant that participants may be from a wide range of geographical locations and it would not be feasible to screen them in person without a time burden for the participant or researcher. As a result, it was decided to screen by phone or skype, which would be more personal than an online approach, and would allow for distress to be monitored, and to use a brief screening measure (TSQ) instead of the longer PCL-5 measure, which was completed at the interview instead. This was felt to be more ethically acceptable, however the downside of this change was that

participants were only screened for a PTSD diagnosis prior to entering study. This could impact the validity of the study as participants may not meet criteria for a PTSD diagnosis, however the data is likely to have good ecological validity in that individuals seen in services are likely to have varied symptom profiles and still be experiencing significant distress in relation to their ICU experience.

During the interviews themselves, I noticed tension between the dual roles of a trainee clinical psychologist, as clinicians and as researchers. The content of the interviews was similar in nature to the type of conversations held in clinical settings, and I found myself wanting to use my clinical skills to help participants reflect on their experience and to help alleviate their distress. However, as a researcher, I felt I needed to be aware of this so as not overly influence what participants described and act as an observer. I was aware of this through listening and transcribing audio recordings of interviews and writing memos. I tried to manage this dual role by keeping reflective statements to simple repetition to demonstrate I was listening or to clarify what I had heard, and to minimise more complex reflections.

Finally, quality standards for qualitative methods emphasise the importance of reflecting on how, as a researcher, your experiences, perspective and theoretical orientation may have influenced the design of the study and interpretation of the findings (Elliott et al., 1999). In the design of the empirical study, it is likely that my professional background as a trainee clinical psychologist influenced how I designed the study. Before starting to plan the study, I came with clinical experience of

working with mental health difficulties, and in particular PTSD, and my training background had given me predominantly a cognitive-behavioural model for understanding these problems. Therefore, I came into the study with pre-existing knowledge and ideas about the role of cognitions and behaviour in the development and maintenance of PTSD, and specific knowledge of general theoretical models of PTSD. One example where this is apparent is in the draft interview schedule, in which questions focus on the thoughts, emotions and behaviour in relation to the traumatic ICU experience. This is very much a reflection of a cognitive-behavioural conceptualisation, in which a cross-sectional formulation often labels the thoughts, feelings, behaviour and physical sensations associated with a given situation or problem. I attempted to balance this out by asking open questions about these elements, as well as starting with open questions asking generally about their ICU experience. I was also aware of my knowledge and training as a trainee clinical psychologist during the coding process. While reading through and completing initial coding, I noticed technical terms of psychological processes coming into my awareness. I tried to manage this by sticking to guidelines for initial coding by using descriptive, open codes that focused on actions and to bracket my own assumptions about the data (Charmaz, 2006; Urquhart, 2012).

Furthermore, the systematic review of the literature conducted as part of this thesis was also likely to impact on the grounded theory approach. The role of the literature review in grounded theory has been controversial and a topic for debate. Classic grounded theory recommends that a literature review is not done until after completing the analysis in order to avoid seeing your data through the lens of

previous research (e.g. Glaser & Strauss, 1967) and contaminating your theory with existing research. However, it has also been acknowledged that it is impossible for a researcher to be a completely blank slate and that all researchers bring previous professional knowledge and experience to their research. As a result, later grounded theorists often reject this initial position regarding the literature review (Charmaz, 2006). Regardless, due to the practical requirements of writing a proposal and the systematic review, it was not possible to delay the literature review until after analysis. The systematic review was conducted prior to and alongside the interviews and data analysis, and so could have influenced the coding process most of all. It is possible that the codes are organised as they are, in a temporal fashion, due to how I had previously categorised the findings of the systematic review. I cannot rule out that without the systematic review, I may have been more attentive to other theoretical groupings that were more grounded in the data. On the other hand, interviewees were prone to talk through their ICU experience in this way, from pre-admission to during the ICU and then afterwards, and so it could be argued that this was a natural coding that emerged from the data.

Impact

Academic impact. The combined systematic review and grounded theory study make a valuable addition to the research on PTSD-ICU. First of all, there was a dearth of information regarding psychological factors associated with PTSD-ICU, and the systematic review is a useful summary of the existing research on these psychological factors and where gaps continue to exist, and further research is needed. The grounded theory study then further explores psychological factors that

may be involved with PTSD-ICU and suggests a preliminary theoretical framework. The findings of the grounded theory study may be beneficial for researchers in guiding future research, in terms of designing further quantitative studies that test out the qualitative codes that emerged from this study.

It's also possible that the benefit of this research may extend beyond researchers interested in PTSD and ICU. Previously, parallels have been drawn between PTSD-ICU and psychosis-related PTSD (Jackson et al., 2016; Wade et al., 2015), due to the common feature of having a traumatic reaction to a hallucination or delusion, or even a hospitalisation experience. Additionally, this research may be valuable in considering other physical health populations who experience traumatic reactions, and also to groups who have traumatic reactions and a loss of memory of the traumatic event, such as drug-facilitated sexual assault or traumatic brain injury patients.

Clinical impact

Impact on clinicians. This combined findings presented in this thesis are mostly likely to impact on clinicians, working either in intensive care services (on the ward or follow-up clinics) or clinicians working in mental health services. For clinicians working in intensive care services this adds to the understanding of PTSD-ICU. Particularly in relation to providing detailed, first-hand information about how those who go on to develop PTSD actually experience the ICU environment and what specifically is traumatic. Although previous research has made progress in this

regard, which have led to interventions to reduce distress (Wade et al., 2016), the more experiential data from qualitative research may help to think about nuanced approaches to reducing distress and gives a voice to service users.

For clinicians working in mental health services, the combined findings are beneficial as they will provide insight into the ICU experience, and what is traumatic about it, as this may be somewhat opaque for clinicians outside of the ICU. This insight and the clinical recommendations that have been generated can then be used to guide their psychological formulation and treatment approach. As above, clinicians working with psychosis-related PTSD, other health populations with PTSD or individuals who have memory loss associated a traumatic memory may also benefit from some of the ideas generated by this thesis.

The impact to clinicians could be maximised by disseminating the findings to local clinical teams through a brief presentation and explanation of the model. To evidence any potential impact, in terms of increased understanding, a brief questionnaire could be given to clinicians afterwards to assess any changes in their understanding of PTSD-ICU.

Impact on service users. Service users may be indirectly by the above, in terms of the support they receive from clinicians working in ICU and mental health services. Additionally, this research could have a more direct impact on service

users with PTSD after ICU through disseminating plain English summaries of the research to service user groups. It is envisaged that this would help service users with normalising, and in turn making sense of, their experience during and after ICU.

Dissemination

Research community. In order to disseminate the findings of this study to the research community, I plan to submit the grounded theory study to a peer-reviewed journal and present it at a relevant conference. The conference choice would depend on the audience that trying to reach, for example: for ICU clinicians the British Association for Critical Care Nurses (BACCN) conference; for psychologists, presenting at a British Psychological Society conference. In terms of choice of journal to submit to, one route under consideration is ICU-specific journals (e.g. intensive care medicine or critical care), which would be most likely to reach ICU researchers and professionals. However it is also important for this study to reach psychological practitioners and researchers. Therefore peer-reviewed journals, such as the British Journal of Health Psychology (with an impact factor of 2.5510) will be considered for submission, as it publishes papers on the psychology of health, including emotional and behavioural responses to ill health and medical procedures.

Clinical community. It is anticipated that some of the clinical community will be reached via publishing findings in peer-reviewed journals. However, in addition the findings will be disseminated to clinical practitioners working with individuals with

PTSD-ICU, through emailing a summary of findings to local stakeholders working in ICU services. Furthermore, if it is of interest to local stakeholders and teams, the study and its findings could be presented in person by the researcher.

Service users. A lay summary of the study and key findings will be developed in consultation with service users. This will then be sent out to all those who took part in the study. Additionally, some local ICU services have service user forums who may be interested in receiving a summary of the findings and hearing a brief presentation on the study.

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Appendices

Appendix 1. Quality Appraisal of studies – using the Mixed Methods Appraisal Tool

| Study | Screening 1 | Screening 2 | 1 Quantitative: selection bias RCTs: randomisation Qualitative: relevant sources | 2 Quantitative: appropriate measures RCTs: blinding Qualitative: relevant analysis | 3 Quantitative: comparable groups RCTs: complete outcome data Qualitative: Context | 4 Quantitative: Complete outcome data RCTs: withdrawal / drop-out Qualitative: researcher influence | Total score |
|--------------------------|-------------|-------------|----------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------|-------------|
| Buck 2007 | Y | Y | Y | Y | N | Y | 75% |
| Corrigan 2007 | Y | Y | Y | Y | N | Y | 75% |
| Davydow 2013 | Y | Y | Y | Y | Y | Y | 100% |
| Elliot 2016 | Y | Y | Y | Y | N | Y | 75% |
| Glimelius Petersson 2015 | Y | Y | Y | Y | Y | Y | 100% |
| Jones 2001 | Y | Y | Y | Y | N | N | 50% |
| Jones 2003 | Y | Y | Y | Y | C | N | 50% |
| Jones 2007 | Y | Y | Y | Y | Y | Y | 100% |
| Jones 2010 | Y | Y | Y | Y | Y | Y | 100% |
| Maley 2016 | Y | Y | Y | Y | C | Y | 75% |
| Myhren 2009 | Y | Y | Y | Y | Y | Y | 100% |
| Myhren 2010 | Y | Y | Y | Y | Y | Y | 100% |
| Paparrigopoulos 2014 | Y | Y | Y | Y | Y | C | 75% |
| Ratray 2010 | Y | Y | Y | Y | C | N | 50% |
| Rovatti 2012 | Y | Y | Y | Y | Y | C | 75% |
| Samuelson 2007 | Y | Y | Y | C | Y | Y | 75% |
| Svenningsen 2015 | Y | Y | Y | Y | Y | Y | 100% |

| | | | | | | | |
|----------------|---|---|--------------------------------------------|--------------------------------------------|--------------------------------------------|---------------------------------|-------------------|
| Talisayon 2011 | Y | Y | Y mixed Y qualitative Y quantitative | Y mixed C qualitative Y quantitative | N mixed N qualitative Y quantitative | N qualitative C quantitative | 66% 25% 75% |
| Wade 2012 | Y | Y | Y | Y | Y | N | 75% |
| Wade 2015 | Y | Y | Y | Y | N | N | 50% |
| Weinert 2008 | Y | Y | Y | Y | N | N | 50% |

Screening 1 – are there clear research questions or objectives?

Screening 2 – do the collected data allow the research question to be addressed?

Appendix 2. NHS ethical approval



South Central - Oxford C Research Ethics Committee

Level 3, Block B
Whitefriars Building
Lewins Mead
Bristol
BS1 2NT

Telephone: 0207 104 8049

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

02 November 2017

Ms Isabel Sweetman
Clinical Psychology
Royal Holloway
Egham
TW20 0EX

Dear Ms Sweetman

Study title: Developing a grounded theory model of post-traumatic stress disorder following an intensive care unit admission
REC reference: 17/SC/0512
IRAS project ID: 234709

Thank you for your letter of 27 October 2017, responding to the Committee's request for further information on the above research and submitting revised documentation.

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

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Confirmation of ethical opinion

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

Conditions of the favourable opinion

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

You should notify the REC once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Revised documents should be submitted to the REC electronically from IRAS. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which you can make available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

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

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

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

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

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

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

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

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

Ethical review of research sites

NHS sites

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

Non-NHS sites

Approved documents

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

| <i>Document</i> | <i>Version</i> | <i>Date</i> |
|------------------------------------------------------------------------------------------------------------------------------|----------------|-------------------|
| Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [RHUL research subcommittee correspondence] | 1 | 07 March 2017 |
| Copies of advertisement materials for research participants [Poster] | 6.0 | 10 October 2017 |
| Covering letter on headed paper [Covering letter] | 2 | 01 September 2017 |
| Covering letter on headed paper [Covering letter] | | |
| Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Proof of indemnity] | 1 | 01 August 2016 |
| GP/consultant information sheets or letters [GP template letter] | 3 | 31 August 2017 |
| Interview schedules or topic guides for participants [Draft interview schedule] | 2 | 07 June 2017 |
| IRAS Application Form [IRAS_Form_04092017] | | 04 September 2017 |
| IRAS Checklist XML [Checklist_05092017] | | 05 September 2017 |
| IRAS Checklist XML [Checklist_27102017] | | 27 October 2017 |
| Non-validated questionnaire [Demographics and ICU information] | 2 | 07 June 2017 |

| | | |
|---------------------------------------------------------------------|-----|-------------------|
| Other [17 LO 1292 Unfavourable opinion at first review] | 1 | 29 August 2017 |
| Other [Telephone screening protocol] | 1 | 01 September 2017 |
| Participant consent form [Consent Form] | 3 | 04 July 2017 |
| Participant information sheet (PIS) [Participant information sheet] | 6.0 | 10 October 2017 |
| Research protocol or project proposal [Research protocol] | 5.0 | 25 October 2017 |
| Summary CV for Chief Investigator (CI) [CV Isabel Sweetman] | 1 | 31 May 2017 |
| Summary CV for student [CV Isabel Sweetman] | 1 | 31 May 2017 |
| Summary CV for supervisor (student research) [CV Gary Brown] | 1 | 02 March 2017 |
| Summary CV for supervisor (student research) [CV Hannah Murray] | 1 | 09 June 2017 |
| Validated questionnaire [TSQ] | 1 | 01 September 2017 |
| Validated questionnaire [CSSRS] | 1 | 07 June 2017 |
| Validated questionnaire [PCL-5 adapted] | 1 | 09 June 2017 |
| Validated questionnaire [LEC-5 adapted] | 1 | 07 June 2017 |

Statement of compliance

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

After ethical review

Reporting requirements

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

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

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

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

17/SC/0512

Please quote this number on all correspondence

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

Yours sincerely

A handwritten signature in black ink, appearing to read 'H Sivey', with a horizontal line extending to the right.

pp. Ms Helen Sivey
REC Manager

Professor Nigel Wellman
Chair

Email: nrescommittee.southcentral-oxfordc@nhs.net

Appendix 3. Royal Holloway ethical self-certification



Ethics Review Details

| | |
|-----------------------------------------------|----------------------------------------------------|
| You have chosen to self certify your project. | |
| Name: | Sweetman, Isabel (2015) |
| Email: | PCVA068@live.rhul.ac.uk |
| Title of research project or grant: | A grounded theory study of PTSD after ICU |
| Project type: | Royal Holloway postgraduate research project/grant |
| Department: | Psychology |
| Academic supervisor: | Dr Gary Brown |
| Email address of Academic Supervisor: | gary.brown@rhul.ac.uk |
| Funding Body Category: | No external funder |
| Funding Body: | |
| Start date: | 20/11/2017 |
| End date: | 01/06/2018 |

Research question summary:

Post-traumatic stress disorder (PTSD) is an anxiety disorder caused by exposure to a traumatic event, and which results in reliving symptoms (e.g. flashbacks, nightmares), avoidance, feeling nervous or on edge, and a change in thoughts and feelings. PTSD is higher in survivors of intensive care units (ICU), and is linked with decreased health-related quality of life. Existing research in this area has focused primarily on prevalence rates, and the medical risk factors for developing PTSD post-ICU. Less is known about the psychological factors and experiences of this group once they have left the ICU. This project aims to add to the existing psychological knowledge about PTSD following ICU in order to help guide effective psychological interventions.

This project will recruit individuals who have been in ICU and are experiencing PTSD symptoms as a result of this experience. Participants will complete a questionnaire to screen for eligibility in terms of PTSD symptoms. Eligible participants will then be invited to take part in a semi-structured interview. These interviews would focus on psychological aspects of participant's experience after ICU, including memory, thoughts, emotions and behaviour. This would lead to the development of a theoretical model of how PTSD is experienced by individuals following intensive care. Such a model would aim to increase our theoretical understanding of PTSD in ICU patients, as well as inform clinicians on formulation and delivering interventions for this particular group.

Research method summary:

Design: A qualitative grounded theory design (Charmaz, 2006) will be used to explore experiences of PTSD post-ICU, and published quality criteria (e.g. Elliott, Fischer, & Rennie, 1999) will be used to guide the methodology and analysis. A qualitative approach is justified as it is suitable for an exploratory research question and for gaining a detailed understanding of individual experiences. A grounded theory approach was chosen because it allows for model development of intra- and inter-personal processes.

Sample: • Inclusion criteria: adults aged over 18 years old; who have been admitted and discharged from ICU, between 1 month and 5 years ago; experiencing symptoms of PTSD (as measured by the TSQ and PCL-5). • Exclusion criteria: current suicidal ideation or risk; speaking insufficient English to engage in the interview. • Sample size: it is estimated that 10 participants will be required. If possible, recruitment will continue until theoretical sufficiency has been achieved. This will be defined as when new themes no longer emerge from further interviews.

Recruitment Strategy: The study will be advertised using posters and leaflets, which detail information about the study and what is involved. These poster and leaflets will be placed in ICUs, ICU follow-up clinics, ICUsteps (a service user led support group) and PTSD treatment clinics.

Measures:

1. Descriptive and demographic information – age, gender, ethnicity, previous mental health diagnosis and basic information about the ICU admission.
2. PTSD symptomatology
The Trauma Screening Questionnaire (TSQ; Brewin et al., 2002) and the PTSD Checklist for DSM-5 (PCL-5; (Blevins, Weathers, Davis, Witte, & Domino, 2015).
3. Suicidality

The Columbia Suicide Severity Rating Scale (C-SSRS, Posner et al., 2011)

Risks to participants

Does your research involve any of the below?

Children (under the age of 16),

No

Participants with cognitive or physical impairment that may render them unable to give informed consent,

No

Participants who may be vulnerable for personal, emotional, psychological or other reasons,

Yes

Participants who may become vulnerable as a result of the conduct of the study (e.g. because it raises sensitive issues) or as a result of what is revealed in the study (e.g. criminal behaviour, or behaviour which is culturally or socially questionable),

Yes

Participants in unequal power relations (e.g. groups that you teach or work with, in which participants may feel coerced or unable to withdraw),

No

Participants who are likely to suffer negative consequences if identified (e.g. professional censure, exposure to stigma or abuse, damage to professional or social standing),

No

Details,

Participants will be previous intensive care unit patients who have symptoms of post-traumatic stress disorder (PTSD), and therefore are psychologically vulnerable.

During the interviews, participants will be required to talk about distressing and frightening memories, which may cause discomfort or stress to participants. Therefore, participants need to be fully informed of what the study will involve, including the aim of the project, methods, risks and confidentiality procedures, in order to give informed consent for participating in the study. Additionally, participants should be aware of their rights as a participant, including being able to withdraw from the study at any point, or for their data to be destroyed at a later time point.

During the interview, the researcher will be sensitive to levels of distress and if needed, the interview will be stopped. The researcher is a clinician working with individuals with psychological disorders in the NHS, and is supervised by qualified Clinical Psychologists, and so is equipped to manage psychological distress and apply risk management processes.

All potential and actual participants will be signposted to relevant advice or support services (e.g. the Samaritans, PTSD services, GP).

This study is being conducted in the NHS and therefore has already been subjected to a full NHS ethics review (documentation attached).

Design and Data

Does your study include any of the following?

Will it be necessary for participants to take part in the study without their knowledge and/or informed consent at the time?,

No

Is there a risk that participants may be or become identifiable?,

No

Is pain or discomfort likely to result from the study?,

No

Could the study induce psychological stress or anxiety, or cause harm or negative consequences beyond the risks encountered in normal life?,

Yes

Does this research require approval from the NHS?,

Yes

If so what is the NHS Approval number,

17/SC/0512, IRAS: 234709

Are drugs, placebos or other substances to be administered to the study participants, or will the study involve invasive, intrusive or potentially harmful procedures of any kind?,

No

Will human tissue including blood, saliva, urine, faeces, sperm or eggs be collected or used in the project?,

No

Will the research involve the use of administrative or secure data that requires permission from the appropriate authorities before use?,

No

Will financial inducements (other than reasonable expenses and compensation for time) be offered to participants?,

Yes

Is there a risk that any of the material, data, or outcomes to be used in this study has been derived from ethically-unsound procedures?,

No

Details,

As above, participants may experience distress while discussing their traumatic ICU experiences in the interview. Participants will be informed of the possible distress they might experience so they can provide informed consent and can withdraw at any time. The interviewer will also be sensitive to distress and will stop or pause the interview at any time if needed. Further the interviewer is a clinician in the NHS who has experience of working with this patient group and applying distress and risk management procedures. Finally, all participants will be signposted to relevant support agencies for ongoing help if required.

This study has been approved by a NHS ethics committee and the relevant documentation has been attached to this application.

Participants will be given £10 in compensation for their time in completing the interview as this is longer in duration than standard clinical procedures. Furthermore, participants will be reimbursed travel expenses (up to the cost of a zone 1-6 London travelcard).

Risks to the Environment / Society

Will the conduct of the research pose risks to the environment, site, society, or artifacts?,

No

Will the research be undertaken on private or government property without permission?,

No

Will geological or sedimentological samples be removed without permission?,

No

Will cultural or archaeological artifacts be removed without permission?,

No

Details,

Risks to Researchers/Institution

Does your research present any of the following risks to researchers or to the institution?

Is there a possibility that the researcher could be placed in a vulnerable situation either emotionally or physically (e.g. by being alone with vulnerable, or potentially aggressive participants, by entering an unsafe environment, or by working in countries in which there is unrest)?,

No

Is the topic of the research sensitive or controversial such that the researcher could be ethically or legally compromised (e.g. as a result of disclosures made during the research)?,

No

Will the research involve the investigation or observation of illegal practices, or the participation in illegal practices?,

No

Could any aspects of the research mean that the University has failed in its duty to care for researchers, participants, or the environment / society?,

No

Is there any reputational risk concerning the source of your funding?,

No

Is there any other ethical issue that may arise during the conduct of this study that could bring the institution into disrepute?,

No

Details,

Declaration

By submitting this form, I declare that the questions above have been answered truthfully and to the best of my knowledge and belief, and that I take full responsibility for these responses. I undertake to observe ethical principles throughout the research project and to report any changes that affect the ethics of the project to the University Research Ethics Committee for review.

Certificate produced for user ID, PCVA068

| | |
|--------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------|
| Date: | 14/11/2017 08:11 |
| Signed by: | Sweetman, Isabel (2015) |
| Digital Signature: | Isabel Sweetman |
| Certificate dated: | 11/14/2017 8:52:05 AM |
| Files uploaded: | 234709 17 SC 0512 Favourable_opinion_on_further_information 02.11.17.pdf IRASForm v3 04.09.17.pdf Full-Review-673-2017-11-10-13-19-PCVA068.pdf |

Appendix 4. Participant Information Sheet

An Interview Study of Post-Traumatic Stress Disorder following an Intensive Care Unit Admission

We'd like to invite you to take part in our research study, which is being conducted as part of a Doctorate programme in Clinical Psychology. Participating in the study is completely voluntary. Before you decide if you want to participate, we would like to give you information to help you understand why the research is being done and what it would involve for you. Please take time to read the following information, and discuss it with others if you wish.

1. What is the purpose of the study?

Post-traumatic stress disorder (PTSD) is a common problem which occurs after witnessing or being involved in a very frightening or life-threatening event. Symptoms include reliving of the event through flashbacks or nightmares, feeling on edge, avoiding feelings or memories and experiencing difficult thoughts or emotions. PTSD rates are higher in survivors of intensive care units (ICU), and this is linked with decreased health-related quality of life. As a result, guidelines recommend that ICU patients receive a psychological follow-up after leaving the ICU. In order to effectively support patients with PTSD following ICU, we need a greater understanding of the psychological factors and experiences of this group once they have left the ICU. This study aims to explore the experiences of individuals with PTSD symptoms following ICU and to use this information to develop a psychological theory of PTSD post-ICU to help inform assessment and treatment.

2. What will the study involve?

This project involves completing a short screening questionnaire in person (or Skype or phone if not possible), and will ask questions about your ICU admission and symptoms of PTSD. It is estimated that the questionnaires will take approximately 10 minutes to complete.

After the questionnaire, you may be invited to take part in the next stage of the study, which involves filling out some questionnaires and participating in an interview with a researcher. The interview will take place in person or by Skype, and ask questions about your experiences during and after ICU. This interview will take approximately between 1 and 1.5 hours to complete.

3. Will I be reimbursed for taking part?

If you are eligible for the interview part of the study, you will be reimbursed £10 for your time in completing the interview. Furthermore, travel expenses on public

transport within London will be reimbursed. If you need to travel further than this, other options will be considered for participating in the interview (e.g. skype).

This payment is funded by the Doctorate in Clinical Psychology at Royal Holloway, University of London.

4. Who can take part?

We are looking for participants who have been admitted to an intensive care unit between 1 month and 5 years ago, and who have been experiencing increased stress or anxiety since leaving the ICU. You will complete a questionnaire by phone to assess for symptoms of PTSD. Participants have to be over the age of 18 to take part.

5. Do I have to take part?

Participation in this research is entirely voluntary. You are under no obligations to take part and have a right to withdraw from the study at any point.

6. What will happen to my data?

Your responses will remain confidential, and all questionnaire data will be anonymised and combined with data from other participants, so your data cannot be personally identifiable.

If you disclose information that indicates risk of harm to yourself or others through the misconduct or malpractice of health professionals or services, then this information will be shared with the relevant authorities. Where possible, this will be done anonymously in order to protect your privacy.

Interviews will be audio-recorded and then transcribed. This data will be stored on a password-protected, encrypted USB. All interview transcripts will be anonymised and personally identifiable information removed.

The data will be handled only by the research team. In line with Royal Holloway, University of London's policy, all data will be securely stored for a minimum of 5 years. The study will be completed, written up and submitted to the University. It is usual practice for researchers to publish their findings in professional journals so that research can be shared within the profession. Again, your anonymity will be upheld throughout this process. If you would like to receive a summary of the findings, please contact the researcher to request a copy (details below).

7. What are the possible benefits and disadvantages of taking part?

One possible benefit is the opportunity to discuss your experiences with a health

professional, which for some, can be a helpful experience. Additionally, you will be directed to appropriate support and treatment for PTSD symptoms, if required. Furthermore, your experiences are invaluable in helping researchers develop a better understanding of post-ICU PTSD and improving treatment for those who are affected.

During the interview part of the study, you will be asked questions about memories or experiences that may be distressing to you, and may cause you discomfort or stress to talk about. The researcher will be sensitive to any distress experienced, and will stop or pause the interview if needed.

Participating in this study will not affect the standard care offered to you by the NHS.

8. Will my General Practitioner (GP) be informed of my participation?

After completing the screening questionnaires by phone, and if you are eligible for the interview part of the study, we will request your personal contact details to arrange interview participation. We will also request your GP details in order to inform them of your participation in the study. Your answers will not be shared with your GP, however they will be informed that your results indicate possible PTSD symptoms and we will inform them how to refer to appropriate treatment if required. Also, if you become very distressed during the interview or disclose suicidal intentions or plans, your GP will be contacted by telephone so that immediate support can be arranged.

9. Who has reviewed this study?

This study has been reviewed and received a favourable ethical opinion from Royal Holloway ethics committee (Ref no: 673) and by the Oxford C Research Ethics Committee (17/SC/0512).

10. What if something goes wrong?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions (see contact details below). If you remain unhappy and wish to complain formally, you can do this by contacting the sponsor (see contact details below).

Indemnity to meet the potential legal liability of investigators for harm to participants arising from the conduct of the research is provided by the NHS indemnity scheme.

Royal Holloway is the Sponsor for the study and holds professional indemnity insurance (Royal & Sun Alliance Insurance plc) to meet the potential legal liability

of the Sponsor and employees for harm to participants arising from the design and management of the research.

11. Where can I get additional help or support?

If you are experiencing any distress related to the issues raised in this information sheet or think you may be experiencing symptoms of PTSD, you can also seek further help in the following ways:

- Visit your GP to discuss any distress you are experiencing and they can refer you to local mental health services who can offer support
- Call the Samaritan's for free on 116 123
- Visit the ICU steps website (<http://www.icusteps.org/>) - this is charity set up to support intensive care patients

12. Who can I contact about this research?

Chief Investigator:
Isabel Sweetman (Trainee Clinical Psychologist)
Doctorate in Clinical Psychology
Royal Holloway, Egham, Surrey, TW20 0EX
Email: Isabel.sweetman.2015@live.rhul.ac.uk

Sponsor:
Craig Bryce
Royal Holloway
craig.bryce@rhul.ac.uk

Thank you for taking the time to read this information sheet.

Appendix 5. Consent Form



Consent Form

An Interview Study of Post-Traumatic Stress Disorder following an Intensive Care Unit Admission

| | Tick |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------|
| I confirm that I have read the information sheet (version 6) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily | |
| I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. | |
| I agree to my General Practitioner (GP) being informed of my participation in the study. | |
| I agree to the interview being audio recorded | |
| I agree to take part in the above study | |

Name of participant: _____

Signature of participant: _____ Date: _____

Name of researcher: _____

Signature of researcher: _____ Date: _____

Appendix 6. Standardised Measure - Trauma Screening Questionnaire

Trauma Screening Questionnaire (Brewin et al., 2002)

Please consider the following reactions which sometimes occur after a traumatic event. This questionnaire is concerned with your personal reactions to the traumatic event (i.e. ICU). Please indicate whether or not you have experienced any of the following AT LEAST TWICE IN THE PAST WEEK:

| | YES, AT LEAST TWICE IN THE PAST WEEK | NO |
|------------------------------------------------------------------------------------------------------------------|--------------------------------------|----|
| 1. Upsetting thoughts or memories about the event that have come into your mind against your will | | |
| 2. Upsetting dreams about the event | | |
| 3. Acting or feeling as though the event were happening again | | |
| 4. Feeling upset by the reminders of the event | | |
| 5. Bodily reactions (such as fast heartbeat, stomach churning, sweatiness, dizziness) when reminded of the event | | |
| 6. Difficulty falling or staying asleep | | |
| 7. Irritability or outbursts of anger | | |
| 8. Difficulty concentrating | | |
| 9. Heightened awareness of potential dangers to yourself and others | | |
| 10. Being jumpy or startled at something unexpected | | |

Appendix 7. Standardised Measures – PCL-5 adapted

PCL-5

Instructions: Below is a list of problems that people sometimes have in response to a very stressful experience. Please read each problem carefully and then select the answer to indicate how much you have been bothered by that problem in the past month.

Please answer these questions in relation to your ICU experience.

| In the past month, how much were you bothered by: | Not at all | A little bit | Moderately | Quite a bit | Extremely |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------|--------------|------------|-------------|-----------|
| 1. Repeated, disturbing, and unwanted memories of the stressful experience? | 0 | 1 | 2 | 3 | 4 |
| 2. Repeated, disturbing dreams of the stressful experience? | 0 | 1 | 2 | 3 | 4 |
| 3. Suddenly feeling or acting as if the stressful experience were actually happening again (as if you were actually back there reliving it)? | 0 | 1 | 2 | 3 | 4 |
| 4. Feeling very upset when something reminded you of the stressful experience? | 0 | 1 | 2 | 3 | 4 |
| 5. Having strong physical reactions when something reminded you of the stressful experience (for example, heart pounding, trouble breathing, sweating)? | 0 | 1 | 2 | 3 | 4 |
| 6. Avoiding memories, thoughts, or feelings related to the stressful experience? | 0 | 1 | 2 | 3 | 4 |
| 7. Avoiding external reminders of the stressful experience (for example, people, places, conversations, activities, objects, or situations)? | 0 | 1 | 2 | 3 | 4 |
| 8. Trouble remembering important parts of the stressful experience? | 0 | 1 | 2 | 3 | 4 |
| 9. Having strong negative beliefs about yourself, other people, or the world (for example, having thoughts such as: I am bad, there is something seriously wrong with me, no one can be trusted, the world is completely dangerous)? | 0 | 1 | 2 | 3 | 4 |
| 10. Blaming yourself or someone else for the stressful experience or what happened after it? | 0 | 1 | 2 | 3 | 4 |
| 11. Having strong negative feelings such as fear, horror, anger, guilt, or shame? | 0 | 1 | 2 | 3 | 4 |
| 12. Loss of interest in activities that you used to enjoy? | 0 | 1 | 2 | 3 | 4 |
| 13. Feeling distant or cut off from other people? | 0 | 1 | 2 | 3 | 4 |
| 14. Trouble experiencing positive feelings (for example, being unable to feel happiness or have loving feelings for people close to you)? | 0 | 1 | 2 | 3 | 4 |
| 15. Irritable behavior, angry outbursts, or acting aggressively? | 0 | 1 | 2 | 3 | 4 |
| 16. Taking too many risks or doing things that could cause you harm? | 0 | 1 | 2 | 3 | 4 |
| 17. Being "superalert" or watchful or on guard? | 0 | 1 | 2 | 3 | 4 |
| 18. Feeling jumpy or easily startled? | 0 | 1 | 2 | 3 | 4 |
| 19. Having difficulty concentrating? | 0 | 1 | 2 | 3 | 4 |
| 20. Trouble falling or staying asleep? | 0 | 1 | 2 | 3 | 4 |

Appendix 8. Standardised Measures – LEC-5 adapted

LEC-5

Part 1

Instructions: Listed below are a number of difficult or stressful things that sometimes happen to people. For each event, check one or more of the boxes to the right to indicate that: (a) it happened to you personally; (b) you witnessed it happen to someone else; (c) you learned about it happening to a close family member or close friend; (d) you were exposed to it as as part of your job (for example, paramedic, police, military or other first responder); (e) you're not sure if it fits; or (f) it doesn't apply to you.

Be sure to consider your entire life (growing up as well as adulthood) as you go through the list of events.

| Event | Happened to me | Witnessed it | Learned about it | Part of my job | Not sure | Doesn't apply |
|------------------------------------------------------------------------------------------------------------------|----------------|--------------|------------------|----------------|----------|---------------|
| 1. Natural disaster (for example, flood, hurricane, tornado, earthquake) | | | | | | |
| 2. Fire or explosion | | | | | | |
| 3. Transportation accident (for example, car accident, boat accident, train wreck, plane crash) | | | | | | |
| 4. Serious accident at work, home, or during recreational activity | | | | | | |
| 5. Exposure to toxic substance (for example, dangerous chemicals, radiation) | | | | | | |
| 6. Physical assault (for example, being attacked, hit, slapped, kicked, beaten up) | | | | | | |
| 7. Assault with a weapon (for example, being shot, stabbed, threatened with a knife, gun, bomb) | | | | | | |
| 8. Sexual assault (rape, attempted rape, made to perform any type of sexual act through force or threat of harm) | | | | | | |
| 9. Other unwanted or uncomfortable sexual experience | | | | | | |
| 10. Combat or exposure to a war-zone (in the military or as a civilian) | | | | | | |
| 11. Captivity (for example, being kidnapped, abducted, held hostage, prisoner of war) | | | | | | |
| 12. Life-threatening illness or injury | | | | | | |
| 13. Severe human suffering | | | | | | |
| 14. Sudden violent death (for example, homicide, suicide) | | | | | | |
| 15. Sudden accidental death | | | | | | |
| 16. Serious injury, harm, or death you caused to someone else | | | | | | |
| 17. Any other very stressful event or experience | | | | | | |

Part 2

A. If you checked anything for #17 in PART 1, briefly identify the event you were thinking of:

B. If you have experienced more than one of the events in PART 1, think about the event you consider the worst event, which for this questionnaire means the event that currently bothers you the most. If you have experienced only one of the events in PART 1, use that one as the worst event. Please answer the following questions about the worst event (check all options that apply):

1. Briefly describe the worst event (for example, what happened, who was involved, etc.).

2. How long ago did it happen? _____ (please estimate if you are not sure)

3. How did you experience it?

It happened to me directly

I witnessed it

I learned about it happening to a close family member or close friend

I was repeatedly exposed to details about it as part of my job (for example, paramedic, police, military, or other first responder)

Other, please describe: _____

4. Was someone's life in danger?

Yes, my life

Yes, someone else's life

No

5. Was someone seriously injured or killed?

Yes, I was seriously injured

Yes, someone else was seriously injured or killed

No

6. Did it involve sexual violence? Yes No

7. If the event involved the death of a close family member or close friend, was it due to some kind of accident or violence, or was it due to natural causes?

Accident or violence

Natural causes

Not applicable (The event did not involve the death of a close family member or close friend)

8. How many times altogether have you experienced a similar event as stressful or nearly as stressful as the worst event?

Just once

More than once (please specify or estimate the total # of times you have had this experience _____)

C. If you experienced a traumatic event while you were in intensive care/hospital; did it relate to:

(a) dreams or hallucinations

(b) medical procedures

(c) the illness or event that lead to your hospitalisation

(d) other

Appendix 9. Standardised Measures – C-SSRS

COLUMBIA-SUICIDE SEVERITY RATING SCALE Screen Version

| SUICIDE IDEATION DEFINITIONS AND PROMPTS | Past month | |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------|----|
| | YES | NO |
| Ask questions that are bolded and <u>underlined</u>. | | |
| Ask Questions 1 and 2 | | |
| 1) Wish to be Dead: Person endorses thoughts about a wish to be dead or not alive anymore, or wish to fall asleep and not wake up. <u>Have you wished you were dead or wished you could go to sleep and not wake up?</u> | | |
| 2) Suicidal Thoughts: General non-specific thoughts of wanting to end one's life/commit suicide, "I've thought about killing myself" without general thoughts of ways to kill oneself/associated methods, intent, or plan. <u>Have you actually had any thoughts of killing yourself?</u> | | |
| If YES to 2, ask questions 3, 4, 5, and 6. If NO to 2, go directly to question 6. | | |
| 3) Suicidal Thoughts with Method (without Specific Plan or Intent to Act): Person endorses thoughts of suicide and has thought of a least one method during the assessment period. This is different than a specific plan with time, place or method details worked out. "I thought about taking an overdose but I never made a specific plan as to when where or how I would actually do it....and I would never go through with it." <u>Have you been thinking about how you might kill yourself?</u> | | |
| 4) Suicidal Intent (without Specific Plan): Active suicidal thoughts of killing oneself and patient reports having some intent to act on such thoughts, as opposed to "I have the thoughts but I definitely will not do anything about them." <u>Have you had these thoughts and had some intention of acting on them?</u> | | |
| 5) Suicide Intent with Specific Plan: Thoughts of killing oneself with details of plan fully or partially worked out and person has some intent to carry it out. <u>Have you started to work out or worked out the details of how to kill yourself? Do you intend to carry out this plan?</u> | | |
| 6) Suicide Behavior Question: <u>Have you ever done anything, started to do anything, or prepared to do anything to end your life?</u> Examples: Collected pills, obtained a gun, gave away valuables, wrote a will or suicide note, took out pills but didn't swallow any, held a gun but changed your mind or it was grabbed from your hand, went to the roof but didn't jump; or actually took pills, tried to shoot yourself, cut yourself, tried to hang yourself, etc. <u>If YES, ask: How long ago did you do any of these?</u> • Over a year ago? • Between three months and a year ago? • Within the last three months? | | |

For inquiries and training information contact: Kelly Posner, Ph.D.
 New York State Psychiatric Institute, 1051 Riverside Drive, New York, New York, 10032; posnerk@nyspi.columbia.edu
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Appendix 10. Semi-structured interview schedule

1. Tell me about your experience of ICU
2. What do you remember about being in ICU?
3. What's it like when you are reminded about ICU? (prompts around sensory qualities, flow, narrative and coherence of memory)
4. In what kind of situations are you reminded of these memories?
5. When you are reminded of ICU, how do you feel?
6. Did any of your ICU experiences remind you of anything earlier in your life? Or did anything you dreamed/imagined remind you of earlier events in your life?
7. What thoughts do you notice having in response to your memories of ICU?
8. Has your experience of ICU changed how you view your self, if so, how? How you view others? How you view your future?
9. Has your experience of ICU changed the way you act? (prompts: are there activities you have started or stopped doing? Is there anything you avoid as a result?)
10. How have you tried to cope with your experience of ICU? Have these strategies been helpful?

Appendix 11. Template letter to GP



Clinical Psychology Department
Royal Holloway,
Egham
TW20 0EX

PRIVATE AND CONFIDENTIAL
[INSERT GP ADDRESS]

[Date]

Dear Dr [Insert Name]

Re: [Name & DOB of Research Participant]

I am writing to inform you that the above named patient has enrolled on a research study which is investigating post-traumatic stress disorder (PTSD) symptoms following admission to ICU. The study itself involves completing an online questionnaire about themselves, symptoms of PTSD, and then completing a semi-structured interview about their experience of ICU and their memories. I have enclosed a copy of the participant information sheet for your reference.

[Insert patient name] reported symptoms of PTSD that meet diagnostic criteria. They have been provided with information about how to receive support and treatment for their PTSD symptoms, and they may require a referral from you to the relevant local PTSD treatment service or IAPT service [insert individualised local or specialist treatment providers].

Yours Sincerely,

Isabel Sweetman
Trainee Clinical Psychologist

Appendix 12. Extract of a transcript and initial codes

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| <p>apparently, I didn't really know that but apparently it really helped so... I had lots of friends come and visit me but I don't remember any of it, all my family came, people would talk to me constantly, I don't remember much at all, I just remember my mum, 1 Things She Said, which apparently she said it over and over again and it is the only thing I recall was that she would swap places with me. and that drifted into one of my nightmares. my first, so when I was coming round, it was very very strange, I thought I was in a corridor, and I was screaming at my family why am I in a corridor, I've got effin Bupa. I was swearing my head off, my friends had been stopped from visiting me because I was getting really agitated, I bitten two tubes, they were having to lay across me and keep the tube down my throat and that came in part of my nightmares as well.</p> <p>I remember having quite a bad response to the senior staff nurse, saying he's evil he's trying to kill me, it was just everything in my head, these nightmares whilst I was only out for 2 weeks they lasted decades in my head. and I felt like I was in hell, and that's the only thing I can attribute it to.</p> <p>When I woke up I remember being really beastly to my husband but not really because it was all in my mind,</p> <p>but apparently I was screaming, I was trying to scream at them but I couldn't because I had the tube down my throat. and then I was trying to scream at them but I couldn't as I couldn't make any noise. and I remember waking up in well I didn't wake up in actually, I remember coming around in the renal Ward and I was in a little room on my own, and I thought oh brilliant they rang Bupa and I'm in my own little room and I'm fine now, I'll go home tomorrow. I thought I'd only been in for a day, I had Rice Krispies for breakfast and my husband came down the corridor and I said oh there comes my beautiful husband. and I think after the way I've spoken to him the day before he was a bit shocked but I then didn't fully register I think for a several weeks what or how badly I'd been. how poorly I'd been . I was, before I had the Rice Krispies, I've been feeling out where I was in the bed... and I thought I need the toilet so I tried to show me down the end of the bed, it was taking me forever because I couldn't get the railing down and then I tried to step out of the bed and I couldn't put any weight on my</p> | <p>Loss of memory – friends visiting</p> <p>Memory of mum speaking</p> <p>Merging of reality and nightmare</p> <p>Waking up as strange, bizarre</p> <p>Screaming at others, being agitated and aggressive</p> <p>Friends not allowed to visit</p> <p>Being restrained to keep well</p> <p>Merging of reality and nightmare</p> <p>Believing staff trying to kill them</p> <p>Knowing not real, that just in head</p> <p>Time feeling stretched in nightmares</p> <p>Memory of being horrible to partner</p> <p>Confusion between reality and dream</p> <p>Not knowing, 3rd hand info</p> <p>Not being able to express self, unable to speak</p> <p>Memory of waking up</p> <p>Not understanding what had happened, how unwell was</p> <p>Loss of time, timeline confused</p> <p>Factual memories returning in normal ward</p> <p>Big change/shift in mood</p> <p>Not understanding how severe illness was</p> |
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| <p>legs. I had I didn't realise at the time but all my muscles has started to waste Away, and then I was scratching at my neck going what the hell's this? I couldn't figure out there was something on my neck that I was trying to get off, and it was my central line. I didn't realise I was catheterised so I didn't even need to go to the toilet. and I wanted a cigarette because I used to smoke and I was just there thinking I'll just go for a fag. I don't know what I was thinking. and then I just didn't sleep for days. I stayed awake it wasn't that I refused to sleep I was terrified to sleep, not that I wouldn't wake up but that the nightmares would happen again. and that was 4 nights on the bounce. my friends came up to see me and they burst into tears when they saw me when I was on the renal Ward. and I was like well what's wrong, it's so hard to comprehend because I didn't know how poorly I been. and I was like I'm going on a hen do in March, and my husband went, that's next week, and I went yeah yeah, I'll be fine, what do you mean it's next week. he was like we're at the end of February, and I was like no we're not. and just having that conversation with him , You didn't sleep 2 weeks, and it was just so surreal, and then trying to get my head around it and trying to find a way to actually get some semblance of sleep which is hard in itself in hospital anyway. and then not wanting to sleep. and I thought I was dead for about 3 months after. I was still in hospital. everything just seem to go so slowly but not as slow as it has done in the nightmares because I swear I lived two lives in those dreams.</p> <p>and they sound so insanely bizarre and when I tell people what, there's that really stick quite vividly in my mind, I tend, I have written about them but I tend not to talk to people too much about them, because it then comes straight back to the fore.</p> <p>just having that thought that nothing matters because I'm dead anyway so I can say what I want do what I want, it's really strange. and it took a long time for me to realise I wasn't dead, which is yeah, when I talk about it now I think oh god you're a bit insane.</p> <p><i>so it sounds like there a lot of thoughts, that this is a bit insane that I was acting or feeling like this</i></p> | <p>Not understanding how ill was, trying to meet basic needs, unable to walk, go to toilet</p> <p>Not knowing that had lines and catheters</p> <p>Confusion – trying to do normal things, realizing that couldn't</p> <p>Unable to sleep</p> <p>Scared to sleep, fear of nightmares</p> <p>Not understanding emotional reaction of friends, unaware of how ill had been</p> <p>Expecting to do usual plans</p> <p>Loss of time</p> <p>Experience surreal, confusion, trying to understand it</p> <p>Difficulty sleeping, not wanting to sleep</p> <p>Belief that was dead</p> <p>Time moving slowly on ward, slower in nightmares</p> <p>Bizarre nature of nightmares</p> <p>Vivid quality of nightmares</p> <p>Writing about nightmares - ?way of coping.</p> <p>Avoid talking to others about nightmares</p> <p>Belief that had died</p> <p>Doing what I want</p> <p>Taking time for confusion, unreal perception to pass</p> <p>Thinking about self as insane</p> |
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Appendix 13. Supplementary quotes to illustrate focused codes

| Theoretical codes | Focused codes | Initial codes | Illustrative Quotes |
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| Pre-ICU | Previous life events | Being reminded of earlier life events | <p><i>“everything was so abstract in my nightmares I think other than feeling I wasn’t worthy in my marriage...things like maybe there was some guilt that I had treated him badly and that was coming through and it’s all coming to pass.” P01</i></p> <p><i>“...but I just won’t be man-handled by them. I had all that in my childhood. I had to grow up with all that, you know mishandling and all that sort of hard life.” P07</i></p> |
| | Sudden illness | Feeling suddenly ill | <p><i>“I last remember phoning my wife and saying ‘you can come and pick me up in an hour, they just want me to have something to eat’, that’s the last that I remember at... hospital.” P02</i></p> <p><i>“what um, brought me into intensive care at the end of February 2013 was, started with flu-like symptoms that ..um...nothing worrying at all really. But it um sort of, um, I felt weaker and weaker over the following days” P03</i></p> <p><i>“when I left home I didn’t feel ill, breathless or anything. and I got outside, and I got as far as the laundry on the corner, and I thought this is a bit weird... and then when I was going that day to the doctor’s, I got to the laundry and I</i></p> |

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| | | | <i>felt absolutely breathless. I had to stop and start and stop and start. I'm thinking what on earth is going on." P08</i> |
| During ICU: Experiences | Near death experience | Being near death, life & death hanging in balance Being threatened with death or being dead in hallucinations | <i>"there was one night where they called everyone in and said we'll don't think he'll necessarily make tonight, you need to be aware of that." P02</i> <i>"...I know now, which I didn't know at the time, that they called my brother and sister in because they weren't certain" p08</i> <i>"I remember having quite a bad response to the senior staff nurse, saying he's evil he's trying to kill me, it was just everything in my head, these nightmares whilst I was only out for 2 weeks they lasted decades in my head. " P01</i> |
| | Loss of autonomy | Being unable to speak Being unable to move Having procedures done to you Being unable to meet basic needs Feeling trapped or not in control Linking recovery to return of autonomy Theme present in nightmares | <i>"I remember being extremely thirsty and just wanted to reach the tap in the corner of the room" P03</i> <i>"I'm pinned really to the bed, I've got a breathing machine and all of that so I'm sort of stuck like that, I can't move." P06</i> <i>"I couldn't express it, because I couldn't talk. And that was a really big thing for me because all my life I've never had a voice and I've done a lot of work on myself.... I've had my voice the last 5-6 years and it was taken away from me like that... And there, I was restricted and</i> |

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| | | | <p><i>didn't have a voice, the same thing, so maybe that makes me feel a little bit better about, maybe that attaching to all of that other past trauma. So maybe, was that what the anxiety was, I don't know. Or partly." P06</i></p> <p><i>"it was terribly scary but then after, bits started to come off. like every other day or week, bits would start to come off...and I thought oh my goodness I'm going to get out...and so the first time going to the toilet was like oh my goodness, when I actually left that bed and out of the unit..." P07</i></p> <p><i>"I was in a sort of, massive ship somewhere in the ocean...They were changing the lines, but in my head, I was being fed some drugs that were making me unable to get off the ship." P03</i></p> |
| | <p>Intense emotional distress</p> | <p>Agitated in ICU Anxiety Frustration (link to loss of autonomy & making sense) Hopelessness – about getting better</p> | <p><i>"they kind of mentioned in when we went back, because I wasn't settled and I was shouting at and that" P08</i></p> <p><i>"sometimes I would get in such a state I had panic attacks. I don't know why but I just had panic attacks... I think it was just the whole surrounding, and I thought I'd never ever get out of there." P07</i></p> <p><i>"I'm thinking oh my goodness I'm never going to get out of here, and then as the month went</i></p> |

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| | | | <p><i>on and the weeks went on..., I'm never going to get out of here, I'm never going to get out. I just couldn't see an end to the tunnel... it was terribly scary but then after, bits started to come off. like every other day or week bits would start to come off, I thought oh my goodness I'm going to get out, and then...I felt less anxious" P07</i></p> <p><i>"Only I used to fantasise about jumping out the window... because then I don't have to do it then, do I. It's too much, I can't do it." P06</i></p> <p><i>"yeah, I'm never going to do it, I'm never gonna get out of here... I thought "I can't do this', you know but of course you do, before you know it, you're off and you're breathing without it and you don't realise. Um, but...I used to think 'oh god, just can't do this, it's too hard' P06</i></p> |
| | <p>Conflicted reactions to ICU staff</p> | <p>Having positive experiences of care Having negative experiences of care Being present in hallucinations</p> | <p><i>"...hated all of them, wanted them to keep me on that breathing machine...the nurse, she was lovely...she was beautiful. She used to take me off that breathing machine, to learn to breath again, I thought "I can't do this... they were fantastic, they saved my life and they nursed me back to health." P06</i></p> |
| | <p>Sleep problems</p> | <p>Being unable to sleep Not wanting to sleep Feeling scared to sleep</p> | <p><i>"you've just got nurses keeping you awake all night, you are opposite the doors, the doors let light in. Even when you are trying to sleep you are just generally awake. I remember for the</i></p> |

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| | | | <i>first couple of weeks of being awake... just saying 'you've got to get me some sleep'" P02</i> |
| During ICU: Perception | Loss of awareness | Not knowing, understanding what happened Feeling disorientated, confused Being in darkness Feeling disbelief Waking up, becoming aware | <i>"well it was kind of like...obviously I was there, but it's like I didn't know where I was if that makes sense, and I don't know if it was a vision, I thought I could see people round my bed when I was slowly waking up... and my husband said to me 'we need to talk about how ill you've been' and I remember thinking 'what's he talking about'. So confusion I guess." P06</i> <i>"perhaps a little bit of disbelief, feeling really that it's bizarre because I obviously know it happened, but how on earth did it happen?" P03</i> <i>"...and I was like well what's wrong, it's so hard to comprehend because I didn't know how poorly I been." P01</i> |
| | Distorted reality | Having hallucinations, nightmares Merging of reality and unreal Losing sense of time Bizarre nature of own reality Attributing to coma period | <i>"so that was lots of times being folded up into a box shape and then placed into the overhead locker on a plane and then going somewhere, never, I never knew where we were going" P02</i> <i>"...was the impression that it was all a total con and that my parents had been led to believe that I was in danger. Physically, in terms of my health. When I wasn't and I had been taken to a, some sort of, fake hospital, with fake doctors who were trying to get money out of my family."</i> |

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| | | | <p>P03</p> <p><i>“there didn’t seem to be any difference, whether it was day or night. Because obviously I wasn’t being fed, um, everything was being done by tubes, so it was...and there were coming and doing things sort of all the time, so it wasn’t as if, when you’re in the ward there was very definitely.. The lights went out, it could be night time if you wanted it” P08</i></p> <p><i>“whether you're in a general Ward or ICU, time it just starts to, it's very fluid and you're not sure.” P02</i></p> |
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| After ICU: Memory | Memory | <p>Loss of memory</p> <p>Remembering pain, unpleasant physical memories</p> <p>Remembering factual memories</p> <p>Vagueness of memories</p> | <p><i>“I don’t remember saying that, I don’t remember getting put in the ambulance, I don’t remember the journey” p01</i></p> <p><i>“I do think about, but I don’t want it to come back, if I’m honest. I’m quite happy that I don’t remember.” P06</i></p> <p><i>“I don’t remember any of it, all my family came, people would talk to me constantly, I don’t remember much at all...” P01</i></p> <p><i>“I remember the impression of suffocation” P03</i></p> <p><i>“I remember some of the nurses in there, and they give you a bed bath in there, they’d use cold water, I used to go (shivers), I’d freeze.</i></p> |

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| | | | <p><i>Like oh my god why are you using cold water. And when I thought about it, I think that's fucking wicked. I mean I suppose as if you don't feel ill enough and then someone slaps a cold bloody flannel on you. I can still feel it now, it used to make me go like that (shivers)" P06</i></p> <p><i>"But my memory of in there was very very vague, it was just this dark, dark place that I was in, with lots of machines" P08</i></p> |
| | <p>Difficulty making sense of experience</p> | <p>Making sense of nightmares Piecing things together Trying to find explanations Questioning experience</p> | <p><i>"everything rotated 90 degrees which is really bizarre and I think it was to do with when they were turning me." P01</i></p> <p><i>"even now, I have a problem trying to put things, two pieces together. Sometimes if I'm having a quiet moment, I'm just sitting there, and things are going through my head and replay things." P07</i></p> <p><i>"make sense of it really, I mean that might, he might have been saying that to me, the doctor...might have been saying that to me, I don't know..." P06</i></p> <p><i>"I don't know what that light is, I don't know whether it will show itself, I don't know. Um, but that does take me back to being in hospital. It's funny isn't it, because when you said, like the dark, and I listened to you say it, and then the light, it's as if, I was in the dark and then you're</i></p> |

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| | | | <p><i>coming out to the light.” P06</i></p> <p><i>“I think it was as well when I was coming out of, you know sort of like when they’re waking you up and you’re semi-conscious...I remember thinking they’d put my head in this machine, my head was like that... but they never, it’s mad...” P06</i></p> <p><i>“well it feels surreal, because they’ll tell me things like, she said to me “mum, you had places on your face that were going black” which is bad circulation and all, that’s where the source of infection was. And it feels surreal, she’s telling me all these things, and all these things that the doctors were doing to me, and I don’t remember...it’s not, I wasn’t aware of it” P06</i></p> <p><i>“my biggest request and my biggest regret is that I don’t have a photo because that would help me process it in my head because I literally can’t recall anything about you know.” P01</i></p> |
| | Relying on third hand information | Returning to ICU Using diaries Talking to others Reading Literature Providing timeline, information, asking questions | <p><i>“I’ve read bits of ICU material that’s a guide usually for relatives who are in, to say ‘this is what will happen, this is why they are doing this thing’ which then helps you piece things together or that’s probably why I was dreaming that I was being bundled on a aircraft and being put into one of the overhead luggage</i></p> |

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| | | <p><i>compartments was probably them turning you every however often they did it.” P02</i></p> <p><i>“I think talking, you know, talking to, as I mentioned before, for example asking my parents and my husband about things, at least makes sense, even though my brain might have distorted the real experience. It’s actual facts so it made me think, like ‘ok well, it was not just, it was not a total invented story of some sort, it has roots in real facts. I was sedated and I was on a lot of drugs so, that’s why.” P03</i></p> <p><i>“...and just from talking with my parents and my husband about, you know, what happened then, why do you think I remember this thing, and then telling me what procedures were being done to me...to make more sense of it, I would quite like, perhaps to just ask a consultant one day. Um, yes or a doctor who would know.” P03</i></p> <p><i>“...and that made me start asking her more, because I don’t think initially I had appreciated just how ill I was, because I never knew at the time that they had called them in or anything like that. I didn’t know anything” P08</i></p> <p><i>“the other thing is what you think you know is wildly different to what you actually know. So</i></p> |
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| | | | <p><i>even when you're out of the Coma time is, as I'm sure it's the same for anyone whether you're in a general Ward or ICU, time it just starts to, it's very fluid and you're not sure. I had things in the wrong order that mum's diary sorted out" P02</i></p> |
| After ICU: response | Heightened emotional response | <p>Feeling fear, horror, anxiety Feeling sadness Feeling irritable, angry, frustrated Feeling gratitude</p> | <p><i>"I don't think I felt angry, I feel angry at god...I feel angry at god, it's like you know, cos I've had a couple of near death experiences, I've had cancer before, and then I had a problem with my heart, and I feel like he pushes me right to the edge and says 'no, you ain't going yet' and pulls me back." P06</i></p> <p><i>"but that's part of being more fearful generally. Generally I didn't really ever have a care in the world about anything, um, and it does, each year I go to get the bike out of the garage and there's just for some reason I've got a fear of coming off it, being knocked off it, being killed, that I just never used to have before... Yeah, it's odd that it's that particular one though." P02</i></p> <p><i>"I think I'm quicker to anger than I used to be but I was always reasonably quick to anger anyway... I can drag out a mood for longer." P02</i></p> <p><i>"I think that's where confusion comes in, and a bit of frustration, 'cos perhaps I'm not meant to</i></p> |

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| | | | <p><i>make sense of it, I don't know" P06</i></p> <p><i>"...a deep sense of gratitude to what the ward staff did for me, as well as towards my family and friends and the support." P03</i></p> |
| | Appraisals | <p>Questioning why it happened to them</p> <p>Judging their own reaction</p> <p>Seeing the silver lining</p> | <p><i>"...when I talk about it now I think oh god you're a bit insane." P01</i></p> <p><i>"and tell myself not to be so stupid, you know there are a lot more people who are far worse off than me, and far iller than me, so just get on with it" P08</i></p> <p><i>"well I often think ' why me?'... what have I done for it to be me" P08</i></p> <p><i>"I can identify that they were were irrational and illogical, and that they were nightmares but they were very real and it sounds like you're trying to pitch you're the stupidest film plot going and it makes no sense to anyone except you and your mind and you realise I sound like a lunatic." P01</i></p> <p><i>"that I'm not making the most of my second chance at life... I find I'm just sort of getting on with my life. Sometimes I think I should do more, because I was so lucky to escape." P03</i></p> <p><i>"I have thought, which is a bit of a scary thought actually, supposing I get ill again,</i></p> |

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| | | | <p><i>would I be able to cope with it... I don't think about loads but it does come up, and that scares me a little bit I guess. I get a bit scared about that, because I don't want to go through that and feel that bad again" P06</i></p> <p><i>"I kind of don't worry about stuff that I used to...um, how do I view myself. I don't know that I view myself any different to how I did before." P06</i></p> <p><i>"Well, my illness, you don't know whether I'm going to be well tomorrow or...not. Who's going to really want somebody in this condition, these illnesses? There ain't one (a future) really, it's like I'm in god's waiting room." P07</i></p> <p><i>"Other thoughts in relation to the whole experience, is 'ok I've been given a second chance, I'm very lucky I made it through' and yes sometimes I'm definitely in that frame of mind" P03</i></p> <p><i>"Even after that I was moved to a rehabilitation ward in a different hospital, and I had plenty of time to think and what not, I mean overall I was in hospital for about 13 months. Initially, you know, I was thinking 'well you know what, I'm really lucky I've survived, so after the rehabilitation I'll be able to go home, be with my husband again, and I had this sort of grand</i></p> |
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| | | | <p><i>plan that after all there were more important things in life... I was, I think, able to rethink my priorities, and if I'm lucky to be alive then I better enjoy the time we have together instead of focusing on petty issues." P03</i></p> <p><i>"I think it comes back to what I was saying earlier, you know, even though it was a traumatic experience, it has opened up perhaps new avenues and made us, of course we've met lots of new, wonderful people." P03</i></p> |
| After ICU: recovery process | Physical vs emotional recovery | <p>Needing to physically recover before emotional recovery</p> <p>Impact of physical recovery on emotional recovery</p> <p>Returning to usual/valued activities</p> <p>Being hypervigilant due to physical health</p> <p>Impact of emotional difficulties on physical recovery</p> | <p><i>"I think I was too ill to feel it if that makes sense. It was when I started to get back on my feet that I started doing the 'why me'." P02</i></p> <p><i>"Um, I mean, in my case, having a disability now, well it makes me feel a lot more useless because of the height of things, and there's certain things I can probably not do and I have to ask my husband for help. He doesn't mind at all. But I have a very independent nature, and hate the feeling that I'm less able than I was before." P06</i></p> <p><i>"IT changed my life completely, I can't go out as freely as I used to go out, you know. Because of infections... I used to, I can't do stairs anymore, I just can't do the stairs." P07</i></p> |

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| | | | <p><i>“...and I used to cycle. I couldn’t get on a bike, it would kill me, I couldn’t do it. I can’t walk far, when we used to go on holidays we used to go on walking holidays. I couldn’t do that. And I feel sad about that, ‘cos there’s a loss, there’s a loss for my husband and there’s a loss for me.” P06</i></p> <p><i>“it’s been hard...yeah, i did think before christmas, would I go back. I only do 1 day per week, I’m a hairdresser, it’s a very physical job. Um, it’s been hard because standing on my feet all day, my legs are not very good. Um, but then on the other hand it feels really good to be back at work, because it feels a little bit of that’s what I’d done before and I can still do it, know what I mean?”P06</i></p> <p><i>“there are things I’ve stopped doing because of like – jogging, you know things like that, or, I used to love baking and this time of year, I would bake traditional Christmas cookies so I’ve not done that because it would be very fiddly, might not be impossible but...I can still bake some cakes but it’s more time consuming and so much more messier. It kind of takes the joy out of it.” P03</i></p> <p><i>“now it’s all about me me me, so I keep my eye on everything that’s going on with my body, I’m in tune with my body now. since I’ve been in tune with my body and with myself,</i></p> |
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| | | | <p><i>I've been safe from having to go to the hospital, I know when I need to take my emergency pack" P07</i></p> <p><i>"I don't even go to the doctor's to do my repeat prescription, I do it online and then the medicine Board brings them round... Yeah, if I've had a chest infection and I've taken all my medication and that, a week later I go (to the GP) so he can check me over and listen" P07</i></p> <p><i>"I've still got a hole in my side now that leaks occasionally and we've actually just said that we're going to leave it because I don't want another medical intervention when it's not causing any harm" P02</i></p> |
| | Coping | <p>Struggling to cope</p> <p>Avoiding or distancing from memories</p> <p>Accessing support – family / friends / support groups / professionals</p> | <p><i>"well, i've had a great family around me, my family were great. And amazing friends. How did I cope? I just took each day as it comes, and that's all I could do. Sometimes I didn't cope, some days I felt hopeless, used to sit there crying all day, thinking I'm never going to feel better." P06</i></p> <p><i>"I don't know, trying to be disconnected from it and remember it as a part of what happened, um, but other times it comes with stronger feelings. But I do try and maybe keep some , um, distance from it, even when it crops up. I don't know if it's something I do consciously,</i></p> |

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| | | | <p><i>but it's not very pleasant" P03</i></p> <p><i>"I've definitely not actively sought out a way of dealing with them. So you could say the omission of doing anything is something in itself. Various other people... said, you know, once she had the right counselor everything was much better and did I ever consider that. After the experiences, it was something I've never wanted to go back to." P02</i></p> |
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| Family & Relationships | Support from others | <p>Family being present</p> <p>Recognising the importance of others in recovery</p> <p>Others struggling to understand</p> | |
| | Impact on others | <p>Family witnessing, being aware of what happening</p> <p>Family suffering</p> | <p><i>"I don't know. It made me think more, because that's when I got tearful, that they maybe need to have support things, and this is why it was good, for family. Family and coping with it, you know because although my sister did say that they were very, you know they explained everything to her, there wasn't anything there, emotional support for the families" P08</i></p> <p><i>"it was all a terrible ordeal for, particularly my parents and now husband, and my brother. It was terrible experience, I think...in my point of view, it would be worse for them the ICU experience, because they are there and they</i></p> |

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| | | | <i>see you like that and they can't do anything for you." P03</i> |
| | Change in relationships | Feeling less tolerant, trusting towards others Making or breaking relationships | <p><i>"I'm often quite abrupt, I think. In particular with my husband, because he's the one I see very day and so he gets it all. So I am, I can be quite unpleasant, for example, you know he's always very kind and helpful and offers his help. But it irritates me because I wouldn't want help, to resort to external help." P03</i></p> <p><i>I used to be really helpful to everyone, to the grandchildren, to my son, and he turned out to be very ungrateful, he showed his true colours. When I ended up in IT, I couldn't believe it, I was so shocked of his behaviour... It's just that I'm not bothered, if they're not going to go out their way to look out for me, the way I looked out for them, um, I just can't be bothered, I just need to look out for myself" P07</i></p> |