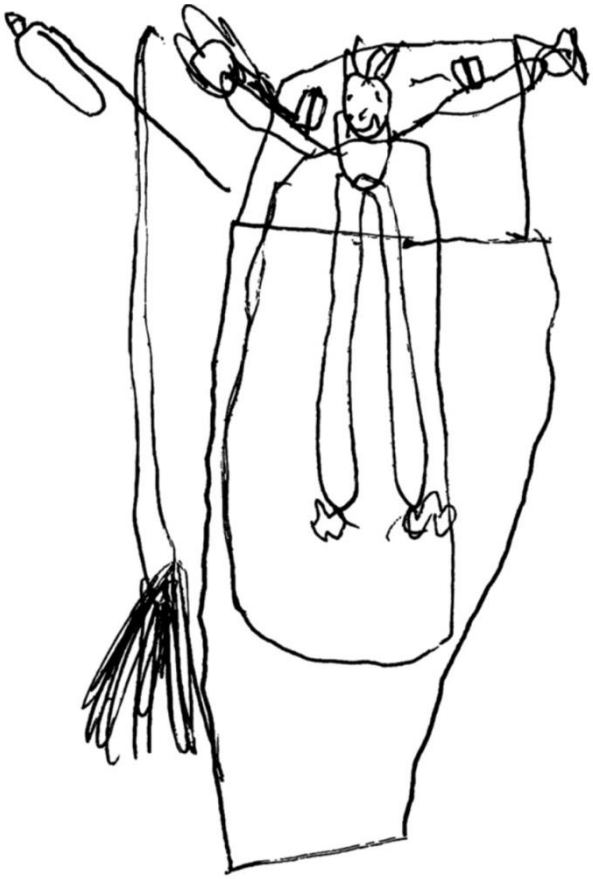
The Psychological Impact of Admission to Intensive Care



Gillian Colville

Illustrations: Front cover and Part One title page – drawings by research participants; Part Two title page – extract from a PICU story book drawn by Susie Colville

The Psychological Impact of Admission to Intensive Care

Gillian Colville

A thesis submitted for the degree of PhD by Publication

Goldsmiths, University of London

October 2021

Dedicated to my darling grand-daughters
Nina, Clara, Bea and bump

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speak with them, often about unspeakable things. In attempting to describe their experiences, I sincerely hope I have done them justice, in what has been my life's work.

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ABSTRACT

This thesis illustrates the contribution of clinical psychology to the conceptualisation, measurement and mitigation of distress in families and staff, in the acute setting of intensive care.

It examines, with reference to five separate papers, the extent and nature of the distress experienced by children and their parents in the year following discharge; the trajectory of recovery in quality of life in patient survivors and the impact of two forms of intervention - a) the provision of a follow up clinic appointment and b) Narrative Exposure Therapy - on parents' psychological symptoms.

The experience of intensive care staff is then described, drawing on the findings of two further papers which focus on the phenomenon of 'burnout' as well as examining traumatic and morally distressing aspects of this work.

Aspects of experience unique to the children included early distress related to the impact of hallucinations and later on having to cope with the continuing impact of critical illness on their quality of life. Parents were troubled by the fear of loss and having to assimilate large amounts of important medical information in an emotionally demanding situation. Staff reported significant levels of emotional exhaustion and post-traumatic stress reactions. They also identified a number of aspects of their work as giving rise to moral distress, particularly in relation to treating patients with a poor prognosis.

This synthesis demonstrates the value of examining different perspectives and the importance of measurement. It also highlights the potential role of a psychologist in intervention, both at the individual clinical level and at the organisational level, in a clinic and as part of the team. Finally

examples are provided of the contribution this work has made to international outcomes research and to the current pressing debate on the assessment of distress in staff in this challenging setting.

CONTENTS

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Abbreviations

aMBI	abbreviated Maslach Burnout Inventory
ASD	Acute Stress Disorder
BRS	Brief Resilience Scale
COPE	Creating Opportunitiies for Parental Empowerment - PICU intervention
COPE	Coping Orientation to Problems Experienced – coping measure
COVID-19	Severe Acute Respiratory Syndrome Coronavirus 2 (SARS-CoV-2).
CRIES-8	Child Revised Impact of Event Scale (8 item version)
DSM	Diagnostic and Statistical Manual (of psychiatric disorders)
ESPNIC	European Society of Paediatric and Neonatal Intensive Care
HADS	Hospital Anxiety and Depresssion Sclae
FCC	Family Centred Care
GCS	Glasgow Coma Scale
HRQoL	Health-related Quality of Life
ICD	International Classification of Diseases
ICU	Intensive Care Unit
ICUM	Intensive Care Unit Memory Tool
IES	Impact of Event Scale
MBI	Maslach Burnout Inventory
MCID	Minimal clinically important difference
MDS	Moral Distress Scale
MDS-R	Moral Distress Scale-Revised
MMDHP	Measure of Moral Distress in Health Professsionals
NET	Narrative Exposure Therapy
NICE	National Institute of Health and Care Excellence

NNU	Neonatal Unit
PCCS	Paediatric Critical and Cardiac Intensive Care Society (formerly PICS UK)
PDS	Posttraumatic Stress Diagnostic Scale
PedsQL	Pediatric Quality of Life Inventory
PHQ-4	Patient Health Questionnaire (4 item version)
PICS UK	UK Paediatric Intensive Care Society (now known as PCCS)
PICS	Post Intensive Care Syndrome
PICS-p	Post Intensive Care Syndrome (paediatric)
PICS-F	Post Intensive Care Syndrome (family)
PICU	Paediatric Intensive Care Unit
PIM	Paediatric Index of Mortality
PMTS	Pediatric Medical Traumatic Stress
PSS:PICU	Parental Stressor Scale (Paediatric Intensive Care Unit)
PTE	Potentially Traumatising Event
PTSD	Post-traumatic Stress Dosorder
RCT	Randomised Controlled Trial
SCCM	Society of Critical Care Medicine
SPAN	Startle, Physiological Arousal, Anger and Numbness (4 screening items from the Davidson Trauma Scale)
TF-CBT	Trauma Focused-Cognitive Behavioural Therapy
TSQ	Trauma Screening Questionnaire
US	United States of America
UK	United Kingdom
WFPICCS	World Federation of Paediatric Intensive and Critical Care Societies

CHAPTER 1: Introduction

"If you do not know what is worrying a person,
ask him, he may tell you"

Kelly, 1955[1]

1.1 Aims and background

This PhD by Publication provides a critical commentary on a portfolio of seven peer reviewed journal articles published by the author in the last 10 years. In relation to the special circumstance of an admission to intensive care, it will be argued that this body of work illustrates the following three themes throughout: a) the value of examining different perspectives; b) the importance of measurement and c) the role of the psychologist.

The initial impetus for this research was the realisation that there was a serious gap in knowledge about the experiences of families of patients on the Paediatric Intensive Care Unit (PICU) and how best to support them. This impacted directly on the clinical role of the author who, faced with the intensity of parental distress on PICU, had the daunting task of providing support to families in what was often a particularly precarious emotional situation, where the one thing they feared most - the loss of their child - could actually happen. The main aim of writing these papers was to inform the medical and nursing literatures from a psychological standpoint, in the hope that this would directly impact clinical care.

There were good reasons to research this area, from a theoretical standpoint and in relation to service development – intensive care treatment is associated with psychological crises that can be planned for.[2] Most of the psychological research on trauma is based on the impact of mass trauma events[3-5], which can happen anywhere in the world, with no notice. Research on such events has led to greater understanding of full blown and sub-clinical Post-traumatic Stress Disorder (PTSD),[6] the development of screening tools and treatment packages,[7] and the adoption of novel systems for monitoring and identifying those who require intervention, such as the 'screen and treat' protocol after the London terrorist bombings in 2005.[8]

In contrast, disasters happen in medical settings every day to individuals and to families. Although they may be small scale, they can be just as devastating as an incident which makes the news, in terms of their long term psychological impact. They differ from a natural disaster or school shooting in that they are more or less predictable in terms of numbers and severity, if not in terms of who exactly will be affected from one day to the next. This makes it theoretically possible to anticipate the likely need for support and to plan services for those affected. There is consequently potential for a psychologist to work preventatively in a setting like PICU, providing acute support, monitoring risk factors for later psychological difficulties in a child, parent or staff member, and offering timely intervention later, if warranted.

The stance of the author is that of a clinician researcher;[9] the research described in this commentary illustrates the application of the knowledge derived from one relatively new subspecialty in Clinical Psychology - Paediatric Psychology, to another, in medicine - Paediatric Intensive Care.

1.2 Paediatric Psychology

1.2.1 History: Paediatric Psychology[10] is a subspecialty of Child Clinical Psychology. It is a field of research and practice which has as its aim to 'maximise health outcomes, minimise the emotional consequences of living with chronic disease and improve the quality of life for children, young people and their relatives'.[11]

There has been a long history of collaboration between psychologists and paediatricians, which dates back more than a century,[12] but this 'marriage' was finally cemented in 1965.[13] The 'Society of Pediatric Psychology' was subsequently founded in the United States (US) in 1967 and became a separate entity, 'Section 54', within the American Psychological Association in 2001. Not long afterwards the Paediatric

Psychology Network was set up in the United Kingdom (UK) within the Faculty of Children and Young People, in the Division of Clinical Psychology of the British Psychological Society.[14]

1.2.2 Psychological problems associated with paediatric conditions: Community studies of the prevalence of emotional and behavioural problems in children in the UK have consistently shown that children with medical conditions report higher levels of mental health problems.[15] In some cases these problems are secondary to an aspect of their illness or treatment. They can also arise in otherwise well-adjusted children with good family support, as a consequence of the increased burden that dealing with illness places on a child, who still faces the usual childhood stressors. A large screening study using the Strengths and Difficulties Questionnaire,[16] has reported elevated rates of emotional and behavioural problems in children presenting to paediatrics, particularly in association with childhood epilepsy.[17]

Other measures regularly used by paediatric psychologists, which are more directly related to the experience of living with a medical condition, quantify what is known as 'health related quality of life' (HRQoL). A particularly comprehensive scoring system, developed for use with children over the past 20 years in this regard, has been the Pediatric Quality of Life Inventory (PedsQL™).[18] Separate PedsQL™ modules are now available in over 100 languages, covering children aged from one month to 18 years, and addressing many different conditions, such as diabetes, brain tumour and gastro-intestinal dysfunction.[19]

1.2.3 Pediatric Medical Traumatic Stress Model: One of the most influential models in Paediatric Psychology is the Pediatric Medical Traumatic Stress (PMTS) model.[20] It is relevant to this portfolio of research as it has implications both for the acute support of children and families in medical settings and for longer term intervention. The PMTS model emphasises the importance of normalising early reactions and facilitating coping in the acute phase of medical treatment, while a child is still in hospital,

but also recognises that hospitalisation and illness present families with numerous 'potentially traumatising events' (PTEs), for which they may need support and which may have longer term psychological repercussions on them, after discharge.

1.2.4 Post-traumatic stress in children: There have been a number of significant developments in the recognition and understanding of PTSD in children over the past couple of decades, and a number of validated measures are now available.[21] There is research evidence that PTSD in children can persist for a long time, in some cases into adulthood, if left untreated[22] and a number of risk factors have now been identified in the literature,[23] including the presence of PTSD symptoms in parents.[24] Most recently, psychiatric classification systems have been adapted in such a way that diagnostic criteria can now be applied to younger children, with new descriptions of how this condition manifests in children aged under 5 years, who make up the majority of children treated on PICU.[25] Also there is a growing evidence base demonstrating the effectiveness of a number of trauma-focused treatments with children.[26]

1.3 Paediatric Intensive Care

1.3.1 History: The term 'intensive care' refers to the special medical treatment required by a patient who is dangerously ill and requires constant observation. It frequently involves the use of life support measures such as artificial ventilation, and is usually delivered in a dedicated part of a large hospital. The first documented examples of anaesthetists cohorting critically ill patients together, in what was henceforth referred to as an 'intensive care unit' (ICU), occurred in Copenhagen in the polio epidemic in the 1950s,[27] with the first example of a PICU being opened in Sweden soon afterwards.[28] The subspecialty of intensive care grew, with the inauguration of the influential Society of Critical Care Medicine (SCCM) in the US, 50 years ago in 1971. Over time, dedicated training programmes have been developed, leading to the present day position whereby doctors and nurses are now increasingly required to study for additional qualifications in the management of critically ill patients before working

in intensive care, in recognition of the increased complexity of patients and of the new treatments available for use with them.

Paediatric Intensive Care has only been recognised as a distinct discipline for just over 30 years,[27] with the first dedicated text book on the subject published in 1987[29] and the first specialist journal, Pediatric Critical Care Medicine, only published in 2000. The fact that critical illness in children is, thankfully, rare, means that there are 10 times fewer paediatric than adult ICUs in the UK. The requisite professional experience on PICU has therefore been harder to come by in nursing or medical school training. Furthermore, 'on the job' training in general posts on first qualifying has not been deemed sufficient to ensure safe practice in this fast developing subspecialty. Extra training has consequently been particularly important for those wishing to specialise in this field.

1.3.2 Paediatric Intensive Care: The story of Paediatric Intensive Care over the last three decades has been one of enormous success medically, in that mortality rates over this period have halved to 5%.[30] However there has been growing recognition of the fact that a significant number of children who now survive PICU treatment do so with significant levels of morbidity.[31] This reflects, in part, the increasing survival of very premature babies, a proportion of whom then go on to be repeatedly re-admitted to PICU in infancy, with respiratory and neurological problems related to their immature lung development. Other reasons for admission to PICU include accidental injury, such as that caused by a road traffic collision or near drowning; sudden acute illness, such as meningitis; a deterioration in a neurological condition, such as status epilepticus and planned post-operative care after major surgery (termed 'elective' admission).

Advances in medical technology have also led to the situation whereby children with severely compromised function can now expect to receive life sustaining treatments for extended periods, when

they would previously have died. Whilst some of these patients will recover, others are transferred home with many of these treatments still in place (eg direct tube feeding into the stomach and home ventilatory support). The care of these 'technology dependent' children, and their frequent need for re-admission related to their 'acute on chronic' problems, place a heavy caregiving burden on parents[32] and pose new ethical dilemmas for health professionals,[33] who report increasing levels of work-related stress.[34]

1.3.3 Post Intensive Care Syndrome (PICS): A concept which is relevant to this portfolio and which has been very influential in the field of intensive care in the last 10 years, in relation to psychological follow up with patients and survivors, is that of Post Intensive Care Syndrome (PICS).[35] This refers to the constellation of difficulties adult and paediatric[36] patients report after discharge from intensive care and encompasses functioning across a number of domains – physical, cognitive, emotional and social. It also encompasses the issues impacting on family members[37] who regularly report persisting psychological difficulties themselves, in relation to the experience of being a caregiver of someone who has required critical care.[38,39]

1.4 Methodological challenges

There are a number of challenges involved in carrying out research on the psychological impact of PICU admission on children and families. Principal amongst these is the age distribution of children admitted to intensive care (42% aged under 1y[25]) which makes it difficult to collect data on large samples of children who are old enough to comment directly on their experiences. There are also other constraints inherent in this work: a proportion of PICU survivors have a significant degree of cognitive impairment; this is also a particularly heterogeneous group in terms of age and medical condition; families from lower socio-economic groups are over-represented[25] and it is usually not possible to speak at any length to a child acutely as they are often heavily sedated or unconscious whilst on the unit.

Also in relation to recruiting parents to research projects, the high degree of life threat to their child begs important ethical questions about the appropriateness of approaching families acutely when they may not be truly able to give informed consent, by virtue of the extent of their distress.

Another issue is that there has not traditionally been a culture of follow up in intensive care settings, where at discharge the clinical responsibility reverts back to the referring specialist or primary care doctor, and many families live some distance from the hospital as PICUs tend to be centralised in major conurbations.

1.5 Chapter outlines

Over the course of the following six chapters, a total of seven papers will be presented. These papers comprise a series of studies examining the ICU-related experiences of children, parents and healthcare staff (see Figure 1.1). For each study the main findings are discussed and critically evaluated in the context of the literature at the time and the evidence of the contribution and impact of the research is summarised.

The 'PTSD Study',[40] a prospective study of post-traumatic stress symptoms in 66 child-parent dyads over the year following discharge from PICU, will first be described in Chapter 2. In this study children aged 7 to 17 years were interviewed, along with one parent, at 3 months and 12 months post-discharge, about their experiences and any associated symptoms of post-traumatic stress.

In Chapter 3 two studies, the 'Quality of Life Study'[41] and the 'Fatigue Study'[42] are presented. These examine self-reported quality of life and fatigue during the recovery of a cohort of 97 children after

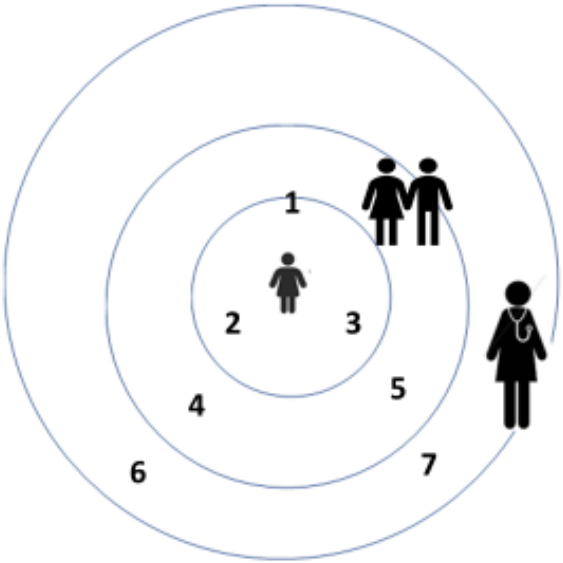
treatment on PICU. Data are presented at 3 months and 12 months post-discharge, and scores compared with healthy norms.

Chapters 4 and 5 focus on two different forms of intervention with parents after a child's admission to PICU. In Chapter 4 the 'Follow up Clinic Study'[43] a randomised controlled trial (RCT) of the offer of a specialised PICU follow up clinic appointment is presented and in Chapter 5 the clinical treatment of a case series of parents using Narrative Exposure Therapy (NET) is described in the 'NET Study'.[44]

In Chapters 6 and 7 the findings of two studies exploring the psychological impact on staff of working on ICU/PICU are outlined. In Chapter 6 the 'Staff Stress Study'[45] explores the prevalence of symptoms of post-traumatic stress and burnout and their associations with coping strategies and resilience, in a sample of n=377. The prevalence of moral distress symptoms in a group of n=171 staff is then examined in the 'Moral Distress Study'.[46]

Finally, in Chapter 8, the findings common and unique to the three groups studied (children, parents and staff) are identified, in relation to the three core themes, listed above, of a) the value of different perspectives, b) the importance of measurement and c) the role of the psychologist. Implications for future research and clinical practice are then made, alongside a concluding summary on the contribution and impact of this body of work to the wider literature.

Figure 1.1: Papers in this portfolio relating to the PICU experiences of children, parents and staff, by chapter heading



Paper 1: PTSD Study (Chapter 2)

Paper 2: Quality of Life Study (Chapter 3)

Paper 3: Fatigue Study (Chapter 3)

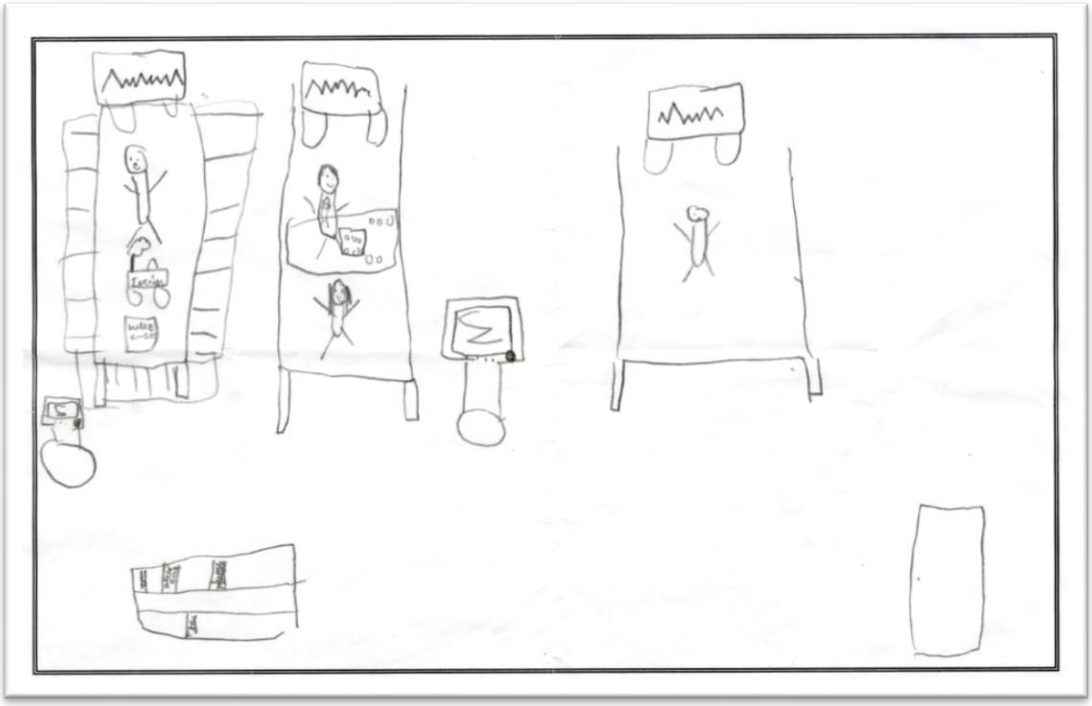
Paper 4: Follow up Clinic Study (Chapter 4)

Paper 5: NET Study (Chapter 5)

Paper 6: Staff Stress Study (Chapter 6)

Paper 7: Moral Distress Study (Chapter 7)

PART ONE: The Impact on the Child and Family



CHAPTER 2: Post-traumatic Stress Symptoms in the Child and Parent

"After the fairytale ending the ugly truth is that since waking up, Sleeping Beauty needs physical therapy, tutoring at school, and her mother has posttraumatic stress disorder"

Typpo and Mendelson 2016[47]

PAPER 1 The 'PTSD Study': Colville G, Pierce C. Patterns of post-traumatic stress symptoms in families after paediatric intensive care.
Intensive Care Medicine 2012;38:1523-1531

2.1 Distress associated with a child's admission to intensive care

The nature of parents' fears when a child is sick is well documented,[48] but there can be few things as frightening as watching a child's health deteriorate to the point where they are critically ill. Children are only admitted to an intensive care unit if they need life sustaining treatment, whether they have developed sepsis and need multi organ support to have any chance of surviving or because they have gone into 'status epileptics' for which they require a thiopentone coma just to bring their seizures under control.

Apart from the obvious fear of death – which looms particularly large in the minds of parents[49] – there are many traumatic events associated with an intensive care admission. These may include the accident which preceded the admission and also the painful life-saving procedures directly associated with it, such as ventilation and resuscitation,[50] which are experienced by the child and witnessed by the parents. There may also be a number of potential losses that have to be faced – of limbs; of previous appearance in the case of disfigurement; of personality and cognitive capacity in the example of a head injury, but also, in the situation of a terrible diagnosis, of the hoped for future of the child. All of these challenges place the child on PICU, and their parents, at elevated risk of developing what has come to be termed 'Pediatric Medical Traumatic Stress' (PMTS).[20]

2.1.1 Literature on distress in child PICU survivors: At the time of the publication of the 'PTSD Study' there was a small literature developing on the nature of the experiences of children on PICU and their subsequent psychological sequelae. Table 1 in Appendix 10.1 summarises quantitative studies of distress in children following PICU admission at that time. This list of studies was derived from three reviews examining the literature on the psychological impact of PICU between and 1966 and 2010,[51-53] after excluding intervention studies; those addressing quality of life only; qualitative studies such as Carnevale (1997);[54] those which just examined the nature of the child's recall, such as Playfor et al

(2000);[55] and studies addressing a specific disease group only (eg meningococcal disease[56] and paediatric burns[57]).

For the most part earlier studies focused on behavioural measures completed by parents, whereas later studies employed standardised measures of PTSD. Comparisons with control data (were provided in 4 of the other 10 studies and supported the hypothesis that the PICU group were more distressed than those less severely ill and as traumatised as child survivors of a fire.[58]

2.1.2 Literature on parental distress related to a child's admission to PICU: The literature on parental distress in this situation was, in comparison, more established but as Shudy et al (2005)[67] summarise, it was 'largely anecdotal and based on small samples', leading the reviewers to call for greater rigour in terms of outcome measurement in this field.

Table 2 in Appendix 10.1 summarises quantitative studies of distress in *parents* following PICU admission, which were published prior to this one. This list of studies was derived from two systematic reviews of the literature on the impact of PICU between 1960 and 2010.[53,67] As was the case for Table 1, qualitative studies, intervention studies and those based on particular disease subgroups only were excluded from these comparisons. So too were those which exclusively examined family, as opposed to individual, outcomes.

Before 2004 measures of PTSD symptoms were not used in these outcome studies, but a number made use of the Parental Stressor Scale: Pediatric Intensive Care Unit (PSS:PICU),[68] a scale specially developed for use with parents on PICU, which has good psychometric properties and was designed to assess acute stressors such as the sound of alarms or witnessing medical procedures. These early papers focused mainly on parents' experiences during admission or shortly after discharge and highlighted some

interesting differences between the experiences of mothers and fathers and the parents of intubated versus non-intubated children. They also demonstrated that staff did not always correctly identify what parents found most stressful.

The few studies that employed a control group demonstrated greater distress in PICU parents than parents on the general ward and only two other studies provided contemporaneous child data.[58,63] Bronner et al[69-71] recruited larger samples, but reported significant attrition between timepoints studied and did not report associated child psychological data. Another notable study[49] assessed the association between symptoms of Acute Stress Disorder (ASD) and later PTSD in a larger group of parents, but again no information was reported on child symptoms and the length of follow up varied widely between 2 and 11 months, making prevalence over time difficult to determine.

2.2 Design of the study

2.2.1 The Health Foundation Project: The 'PTSD Study' the was one of a series of four papers on data collected for a project funded by the Health Foundation (ref 2224/2386) (see Figure 2.1). The primary focus of this project was the nature and extent of children's memories of their experiences of PICU and the relationship between these memories and their post-traumatic stress symptoms, 3 months post-discharge. The initial paper published in 2008,[61] demonstrated that a significant number of children reported having hallucinations during admission (see Figure 2.2), which were associated with higher sedation during admission and with higher post-traumatic stress scores at 3 month follow up. This work built on work by Jones et al (2001)[86] which had demonstrated hallucinations were associated with post-traumatic stress in adult ICU survivors.

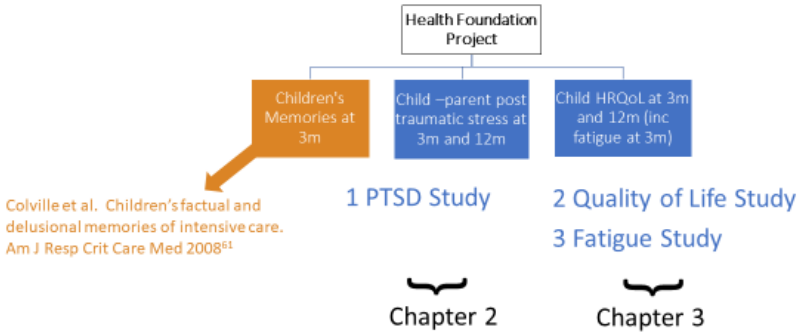


Figure 2.1: Papers written on data collected as part of the 'Children's Memories of PICU' project, funded by the Health Foundation (Colville PI)

As recruitment to the study was better than expected, an approach was made to the Ethics Committee to request permission to contact the cohort again at 12 months, in order to gather more longitudinal data on post-traumatic stress in children and parents (reported here), and on self-reported health related quality of life in this sample (see Chapter 3).

2.2.2 Design of the 'PTSD Study': The aim of the 'PTSD Study' was to assess the rates of self-reported symptoms of PTSD in child-parent pairs at 3 months and 12 months after the child's discharge from PICU. Measures used were the SPAN,[87] a subset of the Davidson Trauma Scale[88] made up of the four items referring to: **S**tartle, **P**hysical Arousal, **A**nger and **N**umbness); the Hospital Anxiety and Depression Scale (HADS);[89] the Intensive Care Unit Memory Tool (ICUM)[90] and the Children's Revised Impact of Event Scale (CRIES-8).[91] Brief instruments were chosen to minimise burden on participants and to test the feasibility of their potential clinical use if follow up became more routine in future

TABLE 3. EXAMPLES OF CHILDREN'S HALLUCINATIONS

"I was certain that I got here on a yellow train."
"I was hanging out of the window and someone dropped a van on my head."
"They put me in a glass box and sealed it."
(girl, aged 17 yr)

"Dad was fighting, people were getting killed."
(boy, aged 15 yr)

"A monster wanted to eat me—to eat me to bits."
(boy, aged 7 yr)

"I thought I was awake—I could see this man in my room. I had to call the bell and shout I don't want to share my room with a man."
"I could see children at the bottom of my bed; they were laughing at me."
(girl, aged 12 yr)

"A cat bleeding on the ceiling."
"A woman who looked like my mum but her eyes were different."
(girl, aged 14 yr)

"See-through scorpions—on my feet and on the walls."
(boy, aged 9 yr)

"Rats in cups moving across the wall."
(boy, aged 16 yr)

"(I remember thinking) 'These aren't my hands! This isn't my head!'"
(boy, aged 14 yr)

"I thought my friend's mum was in the secret police."
"People being hurt, voices saying scary things."
"A man who looked like my dad, a woman who looked like my mum."
"All my friends jumping out of the window."
"Loads of massive spiders—we had to throw stones at them."
"Men were running after me—I had to run into the sunlight."
"Hornets, desert beetles, scorpions, bees."
(boy, aged 9 yr)

Figure 2.2: Examples of children's hallucinations (reprinted with permission from American Journal of Respiratory and Critical Care Medicine[61])

Children aged 7 to 17 years, and one parent, were interviewed at home or in the hospital depending on family preference, at 3 months. At 12 months follow up data was obtained by telephone interview or postal questionnaire. Associations between clinically significant levels of PTSD symptoms, socio-demographic information and medical data such as length of stay and severity of illness were examined.

2.3 Main findings

The principal finding was that significant proportions of children and parents scored above the clinical cutoffs for PTSD at both timepoints and that their rates of PTSD were clinically significant.[92,93] Children's scores at 12 months were associated with their 3 month scores and illness severity,[94] but were no longer associated with the report of delusional experiences during admission, as they had been at 3 months.[61] Parents' scores at 12 months were associated with their own previous anxiety, emergency admission and with avoidance symptoms in the child at 3 months.

Parents' mean group PTSD score decreased over time but there was no change in the children's mean score. However further examination of individual symptom patterns over the year showed that there were instances of child and parent scores increasing over the year, whilst the scores of others decreased or stayed the same. Furthermore, there were examples of cases of children and parents whose scores moved up from the non-clinical to the clinical range over the year, suggesting they may have experienced delayed PTSD in relation to their experiences on PICU (see Appendix 10.2.3).

2.4 Limitations

2.4.1 Age of the children studied: Another limitation of the study was that it only explored the experiences of children aged over 7 years. This age limit was determined by age ranges of the measures administered. It was important to get self-report data directly from them given the evidence that parents risk both over- and under-estimating children's acute stress symptoms,[95] but as has been outlined in Chapter 1, the majority of children admitted to PICU are very young.

Newly extended measures of child PTSD[96,97] which now cover children as young as 3 years, may be useful in future research with this population but the issue of the potential influence of parental symptomatology would still apply, as these rely on parental report.

2.4.2 Representativeness of sample: There was low representation in this study of fathers who only made up 12% of the parents in the child-parent dyads. This is a longstanding issue in paediatric and child psychology research. Future research could adopt some measures which have been suggested as likely to increase fathers' participation, such as writing separately to both parents, stressing the value of gathering perspectives from fathers as well as mothers, rather than relying on the mother as gatekeeper to the father's research participation.[98]

The only study in this field that has focused exclusively on the experience of PICU fathers (n=15)[74] found that they experienced more distress acutely than fathers of children admitted to general wards. The experience of fathers in relation to *neonatal* intensive care has, in contrast, been explored in more detail.[99]

In other respects, however, the sample was more representative of lower socio-economic groups and ethnic minorities than most of the literature in this field, which is important as both groups are more likely to be admitted to PICU[100] but are less well supported.[101]

2.4.3 Pre-morbid and peri-traumatic factors: No assessment was made of peri-traumatic appraisals or experiences (apart from the child's hallucinations), pre-existing mental health problems or trauma history in parents or children, all of which have been found to predict PTSD.[102-104] Obviously it is not possible to pre-emptively measure pre-morbid factors because so many PICU admissions are emergencies, but one way around this problem could be to enquire retrospectively about pre-admission factors. A recent study has shown an association in PICU survivors between lower pre morbid quality of life and acute stress during admission,[105] which subsequently correlated with higher PTSD scores at follow up.[106]

2.4.4 PTSD screening measures used: The choice to use brief screening instruments was made to limit burden on participants and to test their feasibility for future use. Both instruments had satisfactory psychometric properties[91,107] and their brevity may have contributed to the retention of a decent sized sample at 12 months, but on reflection they may have been too short.

The CRIES-8 does not contain any items relating to hyperarousal. A subsequent longer version, the CRIES-13,[91] has since been found to discriminate better in a study validating both versions against a gold standard clinical interview in PICU survivors.[108]

The SPAN[87] too has its limitations. It comprises 3 items measuring hyperarousal and one measuring avoidance but none measuring re-experiencing. It was useful to be able to examine associations with symptoms of avoidance and intrusion separately in the children, but this level of granularity was not possible for the parents' scores.

2.4.5 Definition of delayed PTSD: Another issue concerns the DSM-IV[109] definition of delayed PTSD which requires that new symptoms should emerge at least 6 months after trauma. As data were not available between 3 and 12 months, it is possible that some apparently 'delayed reactions' would not meet this definition. Also it was not possible to cast light on potential explanations for the increase in distress seen in some cases, because of this absence of information in the intervening period. Nevertheless the fact that 26 children and 18 parents became *more* symptomatic between timepoints is still noteworthy and has clear clinical implications.

2.5 Contribution to the field

This study, together with the previous paper on this cohort,[61] were the largest reporting on symptoms of PTSD in PICU survivors, at the time of publication. Only two other studies provided contemporaneous

information on symptoms in children and parents,[58,63] and only one other study reported longitudinally on a larger number of children, but this relied on parent report of symptoms and did not use a PTSD scale.[62]

In relation to length of follow up, this study also stands out in that it collected data for a year after discharge when most studies had only provided data at a much earlier timepoint. Although one other study[63] did collect data *up to* 12 months, this interval varied from 6 to 12, making the results difficult to interpret.

One of the main strengths of this study, apart from length of follow up and the fact that the sample was heterogeneous, was that it examined distress in child-parent pairs – in doing so respecting the 'inseparable dyad'[110] in which members' wellbeing is so interdependent[36] – and rather than reporting group differences in a dwindling number of participants, it examined a sample with data at both timepoints and provided information about individual family trajectories.

This paper also added to the literature by demonstrating evidence suggestive of delayed PTSD reactions and by providing new information on the different perspectives of parents and children, in relation to what had been the worst aspect of their experience.

Also the finding that early avoidance in children was predictive of later distress in parents was new for this population, although consistent with the wider literature on traumatic stress in children,[111]and has clear implications for intervention.

2.6 Evidence of impact

2.6.1 Citations: Impact data, on the database dimensions.ai, demonstrate the growth in citations for this paper over time (see Figure 2.3) and show that 37% of citations were made in the last two years making it 'extremely highly cited' with approximately 12 times more references made to it than to other papers in this field.

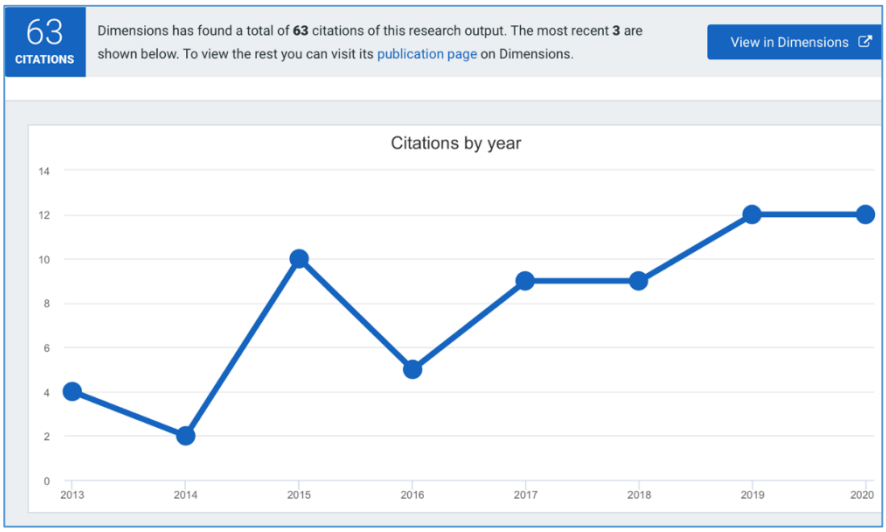


Figure 2.3: Citations 2013 - 2020 for Colville and Pierce (2012) (dimensions.ai accessed 9/5/21)

In order to further assess the impact of this paper, citations were examined in more detail, with reference to two further online databases: National Library of Medicine (pubmed.gov) and Google Scholar (scholar.google.com). In total, after removing duplicates and unpublished theses, 76 separate peer reviewed citations referencing this paper (including 6 papers with Colville as first author and 4 as co-author) were found in the nine years since publication including three in a journal with an impact factor of 14.

Articles were predominantly published in medical and nursing journals covering the field of intensive care (see Figure 2.4) and included 24 reviews of the field, one of which was published in the Cochrane Database of Systematic Reviews;[112] 16 prevalence studies; 7 qualitative studies; 6 intervention studies and 5 research protocols. A further 3 papers were more theoretical in their orientation, describing variously a model of symptom evolution in intensive care over time;[113] a model of how PICS manifests in paediatric patients and their family members[36] and guidance on ethical factors to consider in relation to prognosis after paediatric brain injury.[114] Other formats included book chapters and journal editorials.

2.6.2 Other types of impact: The publication of this paper was also subsequently associated with a number of invited presentations, at the annual meetings of SCCM in 2014 and 2017, the European Society of Paediatric and Neonatal Intensive Care (ESPNIC) in the World Federation of Pediatric Intensive Care Societies (WFPICCS) in 2014 and 2016 and the Société de Réanimation en Langue Française and British Congenital Cardiac Association in 2019. Furthermore this work led to invitations to write a commissioned review[115] and two book chapters on this topic.[116,117]

2.7 Implications for future research and clinical work

2.7.1 Research since publication: Tables 3 and 4 in Appendix 10.1 summarise studies published since this paper which have collected quantitative data on distress in children and parents from heterogeneous samples. They draw on three recent reviews[39,118,119] and the author's wider reading. Encouraging developments in this field include larger samples, analysis of trajectories of PTSD symptoms over the first year after discharge[120]; an emerging focus on 'family outcomes',[121] using standardised measures

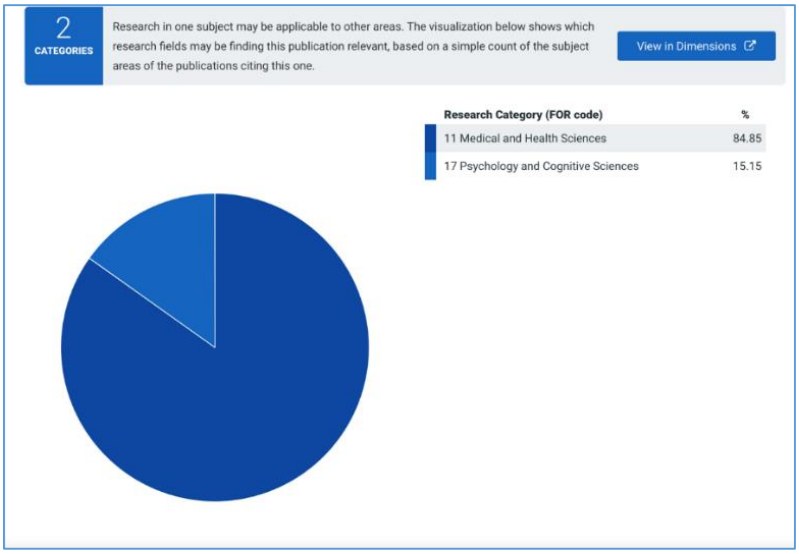


Figure 2.4: Research category for citations 2013 – 2020 for Colville and Pierce (2012)[40] (dimensions.ai accessed 9/5/21)

such as the PedsQL Family Module[122] and the application of 'big data' to these questions[123]. In addition there is evidence of increasing interest in pre-morbid factors such as resilience in parents[124] and pre-admission quality of life and previous trauma[105] in children.

More widely there have also been a number of studies on the psychological impact on particular subgroups on PICU such as bereaved parents[125], families of children with sepsis[126] and those on cardiac units[127], as well as those with chronic complex conditions[128-130], who make up an increasing proportion of admissions.

However there still remains a dearth of information in the literature on the direct experience of children. Although it is acknowledged that these studies are not easy to do[131], the mounting evidence PTSD is 'alarmingly common' in adult ICU survivors[132], which has emerged since the concept of PICS[35]

was first articulated, suggests that identifying PTSD in children should be important clinical priority, as well as a focus for further research.

2.7.2 Implications for screening: The associations found with later PTSD symptoms for particular aspects of experience, such as hallucinations for children, and early child avoidance and parental anxiety for parents' symptoms, warrant further examination in future research.

Other pre-morbid and peri-traumatic factors in parents, such as the belief that the child could die[49] could also be incorporated in future longitudinal research, in order to build up a more comprehensive picture of those who are most likely to require additional support. Recent associations found between a resilience measure and longer term adjustment in parents[124] and between early parental PTSD symptoms and the child's PTSD trajectory,[120] are also worth investigating further.

Furthermore there is some evidence that higher PSS:PICU scores are associated with a worse longer term outcome (see 'Follow up Clinic Study'[43] discussed in Chapter 4) but other candidate screening measures that may be useful in further prospective research and in clinical settings, are the Psychosocial Assessment Tool[154] developed for use with families of children with cancer; the Posttraumatic Adjustment Scale[155] which has been adapted for and trialled with this population[156] and the Acute Stress Disorder Scale.[157]

2.7.3 Trajectories and delayed responses: The variability in psychological outcome in relation to PICU admission a) over time; b) between different patients and c) between patients and their parents, was a noteworthy finding in this study. So too was the implication, from the individual trajectories, that delayed reactions are not unusual. This phenomenon of the emotional impact of the admission catching up with families after the child has largely recovered medically, has clear clinical implications and is consistent with subsequent qualitative work[158] in which families reported that they could only

fully adapt psychologically once the child had recovered physically. Further longitudinal research could confirm whether these apparently delayed reactions are found in other samples and establish whether there are any specific features of the child's or parent's experience which explain this.

Finally, units considering monitoring families for distress post-discharge should consider doing so for longer than 3 months, given these findings, and future research should ideally aim to use PTSD screening measures which cover the full gamut of symptoms necessary for a formal diagnosis.

2.7.4 Interactions between symptoms in parents and children: The findings at 3 months confirmed those of other studies,[58,63] that parent and child scores were moderately correlated, but the fact that this correlation no longer held at 12 months is worthy of further investigation. It is consistent with other paediatric research which found that mothers' and fathers' PTSD scores were more strongly correlated with each other than with those of their children,[159] and implies that family members are impacted differently over time. More in-depth research into the evolution of symptoms and better documentation of intervening stressors, would be helpful in relation to unpacking these associations.

2.7.5 Different perspectives: Despite going through this experience at the same time, parents and children had different perspectives on their time in PICU. This emphasises the importance of asking, rather than assuming, what is troubling someone and is further confirmation of the number of PTEs[20] in this setting. It also echoes a surprise finding elsewhere in the field of Paediatric Psychology, whereby children who were interviewed about their distress associated with undergoing Magnetic Resonance Imaging, were found to be more upset by the blood test they had just beforehand.[160]

2.7.6 Implications for intervention: The finding that the level of avoidance symptoms in children at 3 months was predictive of higher PTSD scores in parents at 12 months, has important clinical

implications too, if replicated. It suggests that by intervening to help the parent address the child's avoidance in the early months, it might be possible to reduce symptomatology in both. This hypothesis is consistent with the results of one of the few intervention studies with families in this situation, which had a specific aim to facilitate communication between parent and child.[161] Another approach, which has been used clinically and recently manualised, is the preparation of individualised storybooks for children who have been through intensive care.[162]

Also, interestingly, in relation to the interdependence of child and parent, Scheeringa has described how successful treatment for PTSD of young children after Hurricane Katrina led to a reduction in trauma symptoms in their caregivers, without the parents' symptoms being formally addressed.[163]The assumption is often made that parental reactions after traumatic events upset children, but another study which followed up families two years after a bushfire in Australia,[164] also found that high levels of symptoms in children predicted a worsening in *parents'* symptoms over time.

2.7.7 Conclusion: In summary, the main theme highlighted by this research is the enduring nature of distress, in children and parents, associated with PICU admission. Although there have been important developments in this field since this paper was published – most notably in relation to trying to achieve consensus on outcomes[165] and in the adaptation of the concept of PICS to this population[36] – more research is still needed on how to identify families most at risk of poorer psychological outcomes, on the direct experience of children and on how and when to intervene preventatively, to reduce symptoms where possible.

CHAPTER 3: The Child's Quality of Life after Discharge

Health is a *"state of complete physical, mental and social well-being, and not merely the absence of disease and infirmity"*

World Health Organisation, 1947[166]

PAPER 2 The 'Quality of Life Study': Colville GA, Pierce CM. Children's self-reported quality of life after intensive care treatment.
Pediatric Critical Care Medicine 2013;14:e85-e92

PAPER 3 The 'Fatigue Study': Colville GA, Pierce CM, Peters MJ. Self-reported fatigue in children following intensive care treatment.
Pediatric Critical Care Medicine 2019;20:e98-e101

3.1 Measuring quality of life in children after treatment on PICU

Concerns about an increase in morbidity[31] in PICU patients, associated with the recent decrease in mortality rates, have prompted greater interest in the measurement of long-term outcomes in PICU survivors. A number of different measures of functioning had been used in outcome studies published prior to the papers discussed here, but these were typically focused on physical health and completed by the doctor or parent (see Table 1 in 'Quality of Life Study' paper).

Meanwhile a number of more nuanced instruments had begun to appear in the wider literature on quality of life in children which, importantly, recognised the World Health Organisation (WHO)'s comprehensive definition of HRQoL as encompassing psychological, social and cognitive/academic aspects, as well as physical functioning and lack of pain and fatigue.[166]

3.2 The PedsQL™ scales

One particularly promising HRQoL measure for children is the Pediatric Quality of Life Inventory Generic Core Scales 4.0,[18] also known as the PedsQL™. It has been identified as having good psychometric properties[167] and is recommended for use with children after major trauma.[168] In addition to being brief, it offers the possibility of obtaining self-report information directly from children aged over 5 years, as well as parent proxy report for those aged from 1 month[169] to 18 years, whilst maintaining the same format. It has been normed on large community samples in the US,[170] as well as an ever growing number of condition specific groups (eg diabetes,[171] cancer[172] and asthma[173]). More recently norms have also become available for samples of healthy children and those with a range of medical conditions in the UK.[174]

3.3 Design of the studies

This chapter describes the findings of two studies which examined HRQoL in children in the year following their discharge from PICU, using the generic PedsQL™[18] and an additional PedsQL™ scale measuring fatigue,[172] as part of a larger project funded by the Health Foundation (see section 2.1).

3.3.1 Quality of Life Study: The aim of the first study was to collect self-report data directly from a heterogeneous group of children aged 7 to 17 years, in relation to their HRQoL, over the year following their PICU stay and to examine associations between HRQoL and medical variables, such as length of stay and illness severity, and PTSD symptoms at 12 months. The tool used for the collection of this data was the PedsQL™.[18] The PTSD screen used was the CRIES-8.[91] Children completed both measures at 3 months and 12 months post-discharge. The 3 month data was collected face-to-face and the 12 month data via postal questionnaire or telephone, depending on family preference.

3.3.2 Fatigue study: The aim of the second study was to collect information on fatigue directly from the sample at 3 months post-discharge, using the PedsQL™ Multidimensional Fatigue Scale.[172] Fatigue has been identified as a debilitating aspect of recovery in adult ICU survivors[175-177] but had not previously been examined in PICU survivors. It was hypothesised that cognitive fatigue would be highest in the subgroup with traumatic brain injury (TBI).[178]

3.4 Main findings

3.4.1 'Quality of Life Study': The main findings of the 'Quality of Life Study' were that the PICU sample reported lower total PedsQL™ scores than healthy controls at 3 months, but scores improved by 12 months, to the point where this difference was no longer statistically different. Physical HRQoL scores however continued to be lower than those of healthy controls, although they did improve.

Interestingly there was no systematic association between HRQoL and objective measures of illness during admission (such as mortality risk,[94] length of stay, length of time on sedation or lowest level of consciousness on the Glasgow Coma Scale (GCS)[179]) but HRQoL was significantly negatively correlated with PTSD score at 12 months.

There were also a couple of surprise findings, given the tacit assumption that PICU survivors would report lower HRQoL. The group admitted electively reported significantly *higher* emotional wellbeing at both timepoints than healthy children. They also reported a significant improvement in social functioning between 3 months and 12 months, which was not seen in the rest of the sample (see Appendix 10.3).

3.4.2 'Fatigue Study': The children's responses on the fatigue scale at 3 months indicated that they experienced more cognitive fatigue than their healthy counterparts, but similar general and sleep-related fatigue. The hypothesis that cognitive fatigue would be commoner in children with TBI was not however upheld. Furthermore the TBI group reported less sleep-fatigue than healthy controls.

As was the case for the generic PedsQL™ measure, there was no association with objective measures of illness, except that for the children in the elective subgroup there was a significant inverse relationship between debility on admission and fatigue at follow up, in that the worse their medical condition was pre-operatively, the better their fatigue post-operatively.

3.5 Limitations

3.5.1 Exclusion of younger and cognitively impaired children: As the main focus in these studies was self-reported HRQoL, a child needed to have a developmental age of at least 7 years to take part. This inevitably meant that a large proportion of children discharged over the study period were not eligible

for interview. In addition, many others have pre-existing developmental delay or neurological deficits[25] and so were not able to complete the questionnaires for this reason. There are clearly additional challenges posed in relation to determining HRQoL in these excluded groups.

3.5.2 Separate reporting of the fatigue data: It could be argued that the fatigue data should have been incorporated into the main 'Quality of Life Study' paper rather than being reported on separately, and indeed the decision to discuss them both in one chapter reflects the fact that they are, clearly, closely linked conceptually. However, at the time of writing the first paper, there was very little information available regarding healthy norms for the fatigue scale. Only one sample of healthy controls had been described[172] and comparisons with this sample (which, at n=52, was smaller than the 'Fatigue Study' sample of n=97) were not statistically significant. For that reason and the need to keep within journal wordcount limits, and given that the data on fatigue had only been collected at one of the timepoints studied, it was not included in the first paper.

Later, when further information became available on a larger group of healthy controls (n=209),[180] a re-run of the statistics yielded more interesting results and the decision was taken to submit the fatigue data separately for publication. It was felt that this data was worth highlighting given a) the dearth of information on fatigue in this population, b) the recognition of the need for new ways to assess the impact of 'early mobilisation'[181] in PICU, which was expected to promote recovery, and c) increasing interest in researching outcomes more generally.[182]

3.5.3 Determining difference from norms: In the past, papers describing the assessment of functioning in PICU survivors seemed to embody the implicit assumption that it was normal to be in complete health. Measures in use at the time[183,184] classified children as being 'in full health' or having a 'normal' quality of life on the basis of a cutoff score. The PedsQL™ scales are more nuanced, in that they express

HRQoL along a continuum of 0-100% and examine physical and psychosocial wellbeing separately. PedsQL™ data gathered from large community samples of healthy children have demonstrated that they rarely rate any of the HRQoL subscales at 100%.[171] Furthermore, their self-report scores for emotional HRQoL are more widely distributed (SD=17.9) than those for their physical HRQoL (SD=11.6).[173]

However this higher level of granularity, whilst offering a more subtle picture of a child's functioning, presents problems in relation to how best to compare PICU survivors with their healthy peers. The approach taken in these two studies was to compare mean group scores with published norms, following other studies using these measures.[169-173]

It should be acknowledged, however, that there are other ways to quantify differences between groups which may have yielded different results. One approach is to apply a 'minimal clinically important difference' (MCID) score, which is based on the standard error of measurement and has been calculated for each subscale for a community sample of over 10,000 children in California.[169]

Another approach, used by a study using the PedsQL™ fatigue scale in children with TBI,[177] is to establish the proportion of children scoring two standard deviations below the mean, referred to as having 'abnormal fatigue'. This strategy has been criticised as overly conservative[184] in a recent longitudinal study,[185] as it is equivalent to applying a difference score over three times the MCID mentioned above. Although it was useful in the 'Fatigue Study' as a way of providing complementary information, as it showed there was a group of badly affected children, (nearly 1 in 10 with TBI), who were not picked up by the mean group comparisons.

Finally, another option could have been to use the cutoff scores recommended in the literature, based on either a) one standard deviation below mean score[169] or b) on the proportion identified by parents as belonging to an 'at risk' category in relation to their health needs.[186]

3.5.4 Lack of baseline comparison data: Another pertinent issue regarding changes in HRQoL over time, relates to the importance of first ascertaining pre-admission functioning, something which was not done in either of these studies. As Killien et al (2018)[184] summarise elegantly, in a graphic of a range of hypothetical trajectories shown in Figure 3.1, it is only possible to make full sense of a child's self-reported HRQoL by referring to their usual HRQoL.

Furthermore, it is important to guard against the assumption that pre-admission HRQoL was 'normal'. The findings of a recent study, which specifically examined retrospectively collected, pre-admission psychosocial factors, demonstrated that HRQoL in PICU patients was lower than average, prior to admission.

3.6 Contribution to the field

3.6.1 Self-reported HRQoL after PICU: In 2007 Knoester et al[186] outlined a number of gaps in the literature on child outcomes following critical care treatment. In particular, they identified the dearth of self-report data. This is an important consideration given the lower congruence found between child and parent report for emotional wellbeing[188,189] and for social functioning in technology-dependent children with chronic conditions.[190]

Another weakness in this field relates to the multiplicity of instruments used to assess HRQoL in this population. Some measures only have norms for one country and some groups report the use of several different measures for different age groups in the same study, making comparisons between studies

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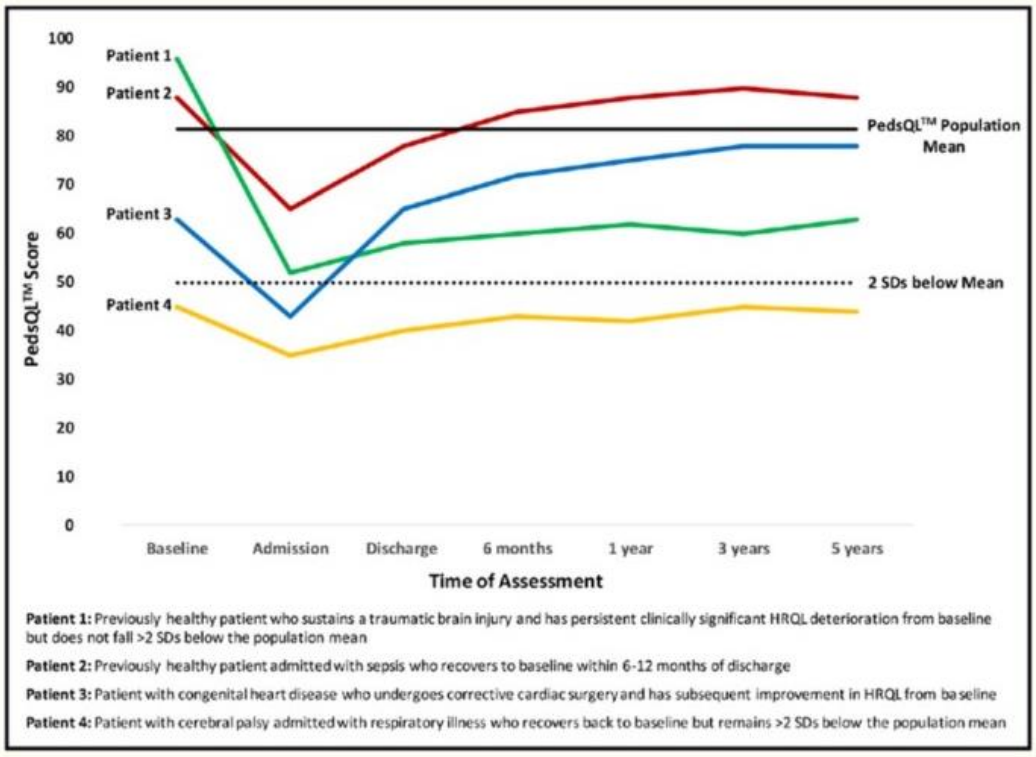


Figure 3.1: Graphic illustrating a range of hypothetical HRQoL trajectories following critical illness (reprinted with permission from Intensive Care Medicine[184]).

difficult. Recognition of these limitations has led to calls for more attention to be given to the collection of self-report data directly from children and for more research on heterogeneous samples, rather than on particular disease groups, such as the previously healthy[191] or those with sepsis.[192]

The 'Quality of Life Study' represented a significant addition to the literature in that it was, at the time of publication, the largest study of self-reported HRQoL in a heterogeneous sample of PICU survivors. The 'Fatigue Study' also made a separate, and important, contribution in that it provided standardised self-report data on an aspect of HRQoL not previously described in paediatric patients, although

recognised in their adult counterparts as a common consequence of ICU-acquired weakness, due to immobilisation and depleted nutrition. It also demonstrated a distinctive profile of increased cognitive fatigue in this group of patients.

3.6.2 Choice of measures: The 'Quality of Life Study' was also the first to use the self-report form of the generic PedsQL™ with a heterogeneous group of PICU survivors. Only two other studies had previously reported using the PedsQL™ scales with PICU patients – one was on a smaller sample (n=70), used the parent-proxy version of the scales and only assessed children who had been admitted for over 28 days,[193] and the other was a 4 year follow up of children with TBI who had been treated on PICU.[194] The 'Fatigue Study' also, and for the first time, presented the Multidimensional PedsQL™ Fatigue Scale as a viable instrument to use with children in this situation.

The growth in popularity of the PedsQL™ scales (which are now available in over 160 languages and encompass a number of new disease-specific modules which can be used to supplement the core generic scales[19]) is illustrated below, in Figure 3.2.

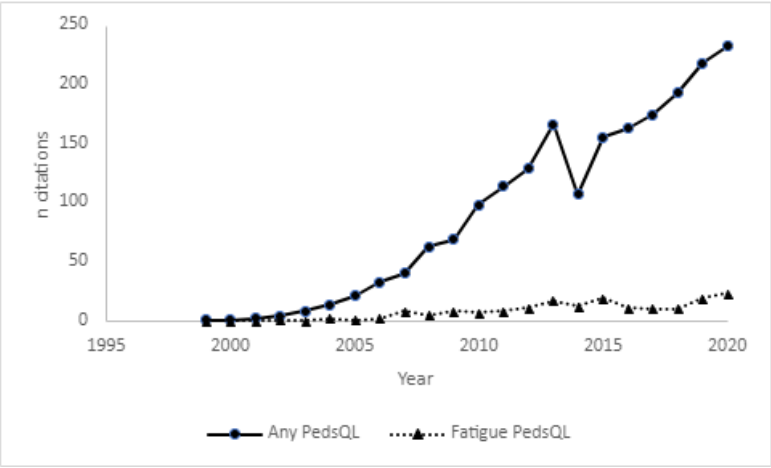


Figure 3.2: Annual growth in number of citations of papers referencing the PedsQL™ scales between 1999 and 2020 (pubmed.gov accessed 17/1/21)

3.6.3 Summary: This pair of studies has made a significant contribution to the literature on outcomes in children after PICU treatment, by presenting the PedsQL™ self-report scales as a viable option for assessment, both in outcome research and for potential use in clinical screening batteries.

3.7 Evidence of impact

3.7.1 Citations: Impact data (using sources described in section 2.6, accessed 9/5/21) showed that 39% of the citations of the 'Quality of Life Study' paper were made in the last two years, making it 'extremely highly cited', with nearly 10 times more references made to it than to other papers in this field.

In total, after removing duplicates and unpublished theses, 55 separate peer reviewed citations referencing this paper were found in the seven years since its publication, including 3 papers with Colville as first author and 3 as co-author. Articles included 18 reviews of outcomes; 17 HRQoL prevalence studies; 7 editorials; 5 qualitative studies and 2 research protocols.

The 'Quality of Life Study' paper was reviewed by Aspesberro et al (2015),[195] who sought to establish the extent to which HRQoL was a meaningful concept in this population and how best to measure it. The reviewers concluded that the PedsQL™ was one of only four measures deemed appropriate for use in follow up studies with this population and later went on to demonstrate its construct validity for use with PICU survivors.[196] It was also specifically recommended, subsequently, as a measure that should be considered for inclusion in a core outcome measure set.[165]

The 'Fatigue Study' paper was published more recently, in 2019, so fewer impact metrics were available, but as of 9/5/21, it had been cited 7 times including in an editorial;[197] in a book chapter on the impact of PICU care on the quality of children's sleep;[198] in a prevalence study of sleep-wake disturbance in

children after PICU[199] and in a narrative review emphasising the importance of measuring fatigue as a post-discharge outcome, across all ages.[200]

3.7.2 Other types of impact: Both papers were deemed to be of sufficient interest to the PICU community that they warranted separate editorials,[197,201] both of which framed the results as highlighting the resilience of children, in the context of research which shows that clinicians are prone to underestimating patients' quality of life.[202] Morrison (2013)[193] argued that it was important to hear directly from the children themselves as 'key stakeholders'. She also described the HRQoL data as 'much needed', pointing out that many children are not just surviving but also 'thriving' and referred to this work as 'an important first step' in obtaining children's opinions.

The editorial on the 'Fatigue Study' paper[201] described the size of the sample described as 'a remarkable strength' for a study of this type and argued that this data was 'groundbreaking' and indicated a need for health professionals to consider their obligations to their patients as reaching beyond PICU discharge.

This work also led to Invitations to present at workshops on PICU outcomes internationally at the ESPNIC and WFPICCS conferences in 2014 and 2016 and the Paediatric Intensive Care Society (PICS UK) 2017 annual meeting; to contribute to a paper on research priorities;[182] to consult on two ongoing UK research projects[203,204] and to take part in a Delphi study on a proposed core outcome set for use with PICU survivors.[165]

Finally, this work prompted an invitation to join an international research team as a co-investigator on a 5 year longitudinal follow up study, funded by the National Institute of Health (ref NIH R01HD098269)

which has adopted both of these PedsQL™ measures in its screening battery and is currently recruiting from over 30 centres in the US.

3.7.3 Summary: These studies have added to a growing literature on the measurement of outcomes in this population and have influenced the choice of outcome measures in three large multi-centre longitudinal follow up studies, as well as contributing valuable information to a recent outcome scoping exercise.

3.8 Implications for future research and clinical work

3.8.1 Lack of association between illness and HRQoL: The finding that objective measures of severity of illness were not predictive of later HRQoL has important implications for assumptions about who might need longer term support. This was also a feature of the fatigue data, in that there was no association between initial GCS score in the TBI group. This finding was consistent with another study of children with TBI[198]) and with the PTSD data in Chapter 2, and is indicative of the need for ongoing monitoring, in order to identify children who are struggling in their recovery.

On the other hand, the finding that the electively admitted group (many of whom had chronic conditions and underlying disabilities) rated emotional HRQoL at significantly *above* average, challenges the notion that poorer physical HRQoL is necessarily associated with poorer psychosocial functioning. It demonstrates that, even if they are not able to do everything their peers can do physically, there are some children who report as good, or better, psychosocial functioning than age matched controls, after PICU treatment.[197]

3.8.2 Link between HRQoL and distress: The link between lower HRQoL and PTSD has also been found in children with burns[205] and suggests that, if a child is found to have poorer HRQoL than expected at

follow up, it may be worth further exploring the psychological impact of admission, or the trauma precipitating it, in order to establish whether they also have PTSD.

Two recent prospective studies, which also used the PedsQL™, found links between delirium during admission and reduced HRQoL at follow up,[206] and between *pre-morbid* HRQoL and symptoms of acute stress during admission.[105] This is further evidence of the value of measuring this construct, pre- and post-admission, in order to determine which children may be at the greatest risk of poorer outcomes.

3.8.3 Different perspectives: Just as was the case in the previous chapter, where children and parents experienced the same admission differently, it is important to acknowledge the different perspectives of individual children in relation to HRQoL and fatigue. For some previously healthy children who sustained a serious accident or experienced a sudden critical illness, the year involved a gradual return to health, albeit sometimes incomplete. For others, however, PICU treatment was associated with significantly better psychosocial functioning, despite their continuing physical limitations.

3.8.4 Establishing baseline functioning: Killien et al (2018)[185] point out that it is only truly possible to make sense of a child's self-reported HRQoL after PICU discharge if information on their previous functioning is available, in order to establish whether or not they have returned to what is normal functioning for them, and to 'target interventions accordingly to improve outcomes in future'. Theoretically it would be possible to obtain information on baseline functioning as a matter of course, using a measure such as the PedsQL™, before any child is admitted for an elective procedure. In the case of an emergency admission this data could be collected *retrospectively* - an approach being used increasingly in longitudinal research.[105,207]

3.8.5 Measuring fatigue: Recognition of the significance of fatigue in adult ICU survivorship has led to calls for greater consistency in its measurement.[208] A screening measure such as the PedsQL™ Multidimensional Fatigue Scale could be useful both in research and clinically, as a tool for monitoring this aspect of the wellbeing of children after discharge from intensive care.

a) Sleep quality after PICU treatment: The quality of sleep is known to be impacted during admission, with the result that clinicians are increasingly making efforts to titrate sedation in order to facilitate a more normal sleep pattern as soon as this is feasible.[209] Little is currently known however about the longer term impact on sleep, although one study has found evidence of sleep disruption in a significant proportion of children at follow up.[139] The PedsQL™ fatigue scale contains a subscale addressing sleep-related fatigue specifically and might therefore prove a useful screening measure in this regard. This is also an important aspect of recovery to review in relation to children who have sustained brain injuries.[210] The apparently paradoxical finding in the 'Fatigue Study' that children with TBI were sleeping better than their peers at 3 months is worthy of further investigation, as it may indicate a pathological level of sleepiness, rather than a sign of enhanced wellbeing.

b) Impact of early mobilisation: The realisation of the extent of ICU-acquired weakness, through lack of movement and weight bearing, in combination with compromised nutrition, has influenced the new approach to 'early mobilisation'[211] which is now being evaluated in a number of paediatric centres.[212-214] Outcomes relating to HRQoL and fatigue will clearly be relevant to the evaluation of this new practice, in the longer term.

*c) Cognitive impairment screening***:** The impact of intensive care treatment on cognitive functioning has been identified in adult patients.[215,216] Iatrogenic effects of medication (such as delirium), hypoxia related to unstable blood pressure or cardiac arrest, infective processes and injury can all potentially

give rise to neurological sequelae. Data on children's neuropsychological functioning after discharge are now starting to emerge for particular condition-specific groups, such as those who have suffered cardiac arrest[217] or septic shock.[218] Full neuropsychological assessment takes time and can only be carried out by qualified personnel, but screeners such as the 6-item cognitive subscale of the PedsQL™ fatigue scale and the 5-item School Functioning subscale in the generic PedsQL™, might be helpful in determining which children might benefit from further formal assessment.

3.8.6 Core outcome set: Following the adoption of the term PICS[35] to describe the long term morbidities associated with ICU treatment in adults, it was realised that a consensus was needed regarding the measurement of outcomes, so that different centres could compare data and that interventions could be evaluated with similar tools.[219]

In relation to PICU outcomes, a recent scoping review[220] of 407 articles measuring outcomes in parents and children between 1970 and 2017, has revealed the startlingly high number (n=366) of different outcome instruments currently in use for assessing children's outcomes (see Figure 3.3). The authors rightly argue that greater consensus is needed, as research is being hindered by this multiplicity of instruments, and particularly stress the need for agreement on how best to measure cognitive status, HRQoL and family functioning, in particular.

Progress has been made in terms of defining the key domains of PICS in paediatric settings.[36] A Delphi study, involving over 300 participants, has concluded that four global domains (cognition, emotional status, physical functioning and overall health) should be assessed along with four specific outcomes (child HRQoL, pain, communication and survival).[221] The next stage in this process is to achieve further consensus on a set of instruments, just as has been achieved recently in the adult ICU literature.

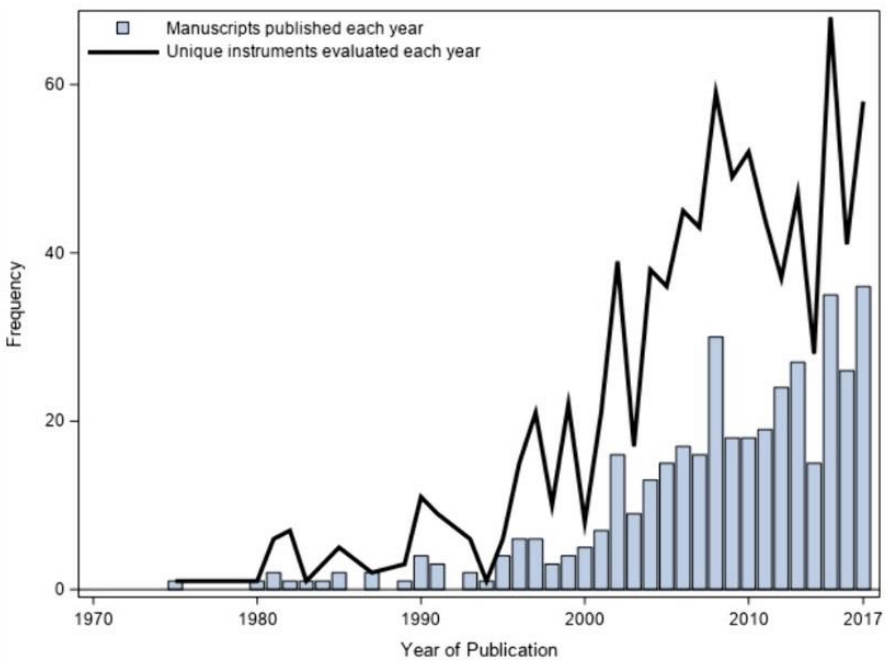


Figure 3.3: Number of manuscripts examining outcomes in PICU survivors together with number of unique instruments evaluated, by year of publication (reprinted with permission from Critical Care Medicine[220])

3.8.6 Conclusion: Merritt et al (2018)[220] report that parents and health professionals alike rate HRQoL as the most important outcome to track in children after discharge from PICU. Researchers also regard this aspect of recovery as important to study[182] and are working together to find and agree on suitable brief tools to use with this population.

The data in the papers discussed in this chapter support the use of the PedsQL™ scales with children after PICU. They are brief, available in many languages, cover many of the key domains established as most important in determining quality of recovery and are available across the age range. Although the parent proxy versions of these scales will be required for use with the majority, given their median age of under 2 years,[25] the self-report versions are also available for monitoring and screening over time, both clinically and in longitudinal outcome research.

CHAPTER 4: Intervention with Parents: Evaluation of a PICU follow up Clinic

"Life can only be understood backwards; but it must be lived forwards"
Søren Kierkegaard 1843[222]

PAPER 4 The 'Follow up Clinic Study': Colville GA, Cream PR, Kerry SM. Do parents benefit from the offer of a follow-up appointment after their child's admission to intensive care?: an exploratory randomised controlled trial. Intensive and Critical Care Nursing 2010; 26: 146-153

4.1 Support for the relatives of intensive care patients

4.1.1 Intervention with PICU parents**:** The culture of care on PICU has for some time embraced the importance of involving and supporting family members in relation to a patient's treatment. This is both in acknowledgement of the 'inseparable dyad'[110] of parent and child in hospital and in recognition of the child's unique level of dependency on their parents from a normal developmental perspective.

Family centred care (FCC),[223] the fundamental aim of which is to work in partnership with families, has been core to the philosophy of paediatric nursing for many years and has led to important policy changes in PICU. These have included 24 hour visiting and the option of parents being present during resuscitation.[224] However the definition of FCC has been criticised as being open to many different interpretations in practice and the evidence base for it remains weak.[225]

Prior to the publication of the 'Follow up Clinic Study', there was very little evidence regarding the impact of interventions with parents beyond their child's discharge from PICU. However, during admission a nursing programme which prioritised improved communication and support for families was found to be associated with decreased stress,[226,227] as measured by the PSS:PICU.[68] The provision of sleeping facilities for parents located nearer the child was also found to be associated with lower anxiety,[228] as was the provision of information.[230]

At the time of publication, the only example of an RCT of an intervention aimed at parents post-discharge examined the use of a programme entitled 'Creating Opportunities for Parent Empowerment' (COPE)[161] which provided parents with guidance designed to facilitate communication with the child about what had happened on PICU. This study found evidence that both parents and children did better psychologically if they had been allocated to the intervention condition.[231]

There is more evidence of the impact of parental intervention in neonatal units (NNU), with a recent review suggesting that psychoeducation, group support and trauma focussed cognitive behavioural therapy (TF-CBT) have a positive impact on parental wellbeing.[232] However the situation on NNU is different to PICU in that patients are much more homogeneous in relation to medical condition (usually complications of prematurity) and age, and their longer length of stay affords more opportunity for support. Patients on PICU in contrast, stay for less than 4 days on average,[25] so parents are harder to recruit to interventions and less likely to provide informal support to each other than parents on NNU. Patients on PICU also tend to be much more heterogeneous in terms of age and range of medical conditions, further adding to a 'lack of a collective identity' which has been identified as a barrier to intervention.[233]

4.1.2 Interventions with relatives of adult ICU patients: The evidence base for intervention with relatives of adult patients was similarly slim at the time of publication. In practice there had been less involvement with families on adult units, with fewer than 20% allowing unrestricted visitation.[234] Also on an adult unit, the fact that the patient has the legal power to consent to or refuse treatment clearly has implications for the involvement of family members in decision making. Even if the patient is incapacitated, their wishes, as expressed in a 'living will' when well, will trump the wishes of family members.

There had however been some pioneering work in the UK by Jones and Griffiths,[235] which led to increasing interest in the value of speaking with adult ICU patients after they left hospital. Feedback from patients at these early ICU follow clinics revealed that they continued to suffer a number of significant difficulties directly related to their critical care treatment, most notably intense fatigue and highly disturbing 'delusional memories' which were associated with the development of PTSD symptoms.[86] Similar forms of distress in relatives also became apparent in clinic appointments.[236] By

2006, nearly a third of adult units in the UK had set up an ICU follow up clinic.[237] The Liverpool group also went on to make a significant contribution to the subsequent NICE guideline on rehabilitation after ICU treatment,[238] which advocated ICU follow up clinics and recommended that both patients and relatives should be monitored for psychological distress after discharge.

Internationally the gradual accumulation of information on long term sequelae in adult ICU patients[239] and their relatives[240] gave rise to the adoption of the term PICS,[35] which was later extended to cover family members (PICS-F[37]). The hope expressed by the group of stakeholders who came up with this new nomenclature was that the articulation of these two related concepts would stimulate more research and, ultimately, better service provision for this population.

However, before this study, only one evaluation of an adult ICU follow up clinic had been published. It found no evidence of an impact on patient wellbeing and did not present any data on their caregivers.[241]

4.2 Design of study

Given the interest in follow up clinics in adult ICU settings and the fact that, in a survey of PICU parents, 74% indicated that they would have been interested in attending one,[73] it was decided to trial a PICU follow up clinic service, offered at random to a cohort of parents of children admitted to PICU at a London teaching hospital.

The hypotheses were that those who were more distressed acutely would be more likely to attend[73] and that the intervention group would derive psychological benefit from having a formal opportunity to discuss their child's treatment on PICU, consistent with qualitative work with adults who have described a need to discuss this unique experience with specialist staff.[242]

In this exploratory study, parents of children admitted consecutively to the PICU were invited to take part in a study evaluating a follow up clinic. They were recruited during the child's admission and completed the PSS:PICU[68] within 48 hours of discharge. They were then randomly allocated to the intervention (offer of a clinic appointment 2 months later) or control condition (no appointment). Both groups were followed up by post at 5 months, when they completed the Impact of Event Scale (IES)[243] and the HADS.[89] They were also asked for written feedback as to whether the appointment had been helpful; why they had not attended, if this was the case, or whether they would have attended, had an appointment been offered. The intervention and control groups were then compared statistically, in relation to psychological outcomes.

4.3 Main findings

The main finding was that there was no difference between the groups with regard to the psychological outcomes examined.

However subsequent post-hoc analyses suggested that there was an effect in favour of the intervention for parents who were the most distressed acutely. When outcomes for those with PSS:PICU scores above median (termed 'high risk') were considered separately, those who were offered an appointment reported significantly lower rates of PTSD and depression symptoms at follow up than control 'high risk' parents (see Figure 2 in the 'Follow up Clinic Study' paper).

In contrast, there were no significant differences in the proportions above cutoff for any of the outcomes studied when analyses were confined to 'low risk' parents, (ie those who scored below median on PSS:PICU).

Another important finding was that only a minority (25%) of the families who were offered an appointment actually attended. The hypothesis that those with higher acute stress would be more likely to attend was however upheld.

From the written feedback provided by both groups, it emerged that only 22% of the control group would have actually attended if they had been given the opportunity, and that a significant number of families either did not want or feel they needed an appointment, although there were some parents who could not attend for reasons relating to work or childcare and a few families reported that they would have liked a telephone appointment, if this had been possible (see Appendix 10.4.3).

4.4 Limitations

4.4.1 Post-hoc analyses: Although less weight may be attributed to the post-hoc analyses, they were informed by previous research findings which had shown that PSS:PICU scores were associated with higher PTSD scores[244] and with wanting follow up.[73] They also had sufficient statistical power to detect differences in categorical outcomes (see Appendix 10.4.2) and if replicated, warrant further investigation.

4.4.2 Validity of intervention: Criticism could also be levelled at the idea that a follow up clinic constitutes a psychological intervention. The format of the appointment was loosely defined, in that the proforma questions were quite general so that families could raise the issues of most importance to them, but all appointments included the presence of a psychologist in addition to a PICU nurse and a member of the medical team.

The main reason for choosing this format as an intervention worth evaluating was that this type of service was being widely adopted in the adult ICU context, and being formally recommended,[238] but

practice had outstripped the evidence, in that very little was known about the impact of these clinics on the wellbeing of patients or relatives, let alone about what the active ingredients might be. Also, the thinking behind the provision of such an appointment did have theoretical support from a psychological perspective in that it provided an opportunity for parents to clarify and take stock of what had happened to their child. This, together with the requirement to return to the hospital, would have re-exposed them to reminders of what, at least in part, may well have been quite a traumatic experience, and could therefore reasonably be expected to promote emotional processing of what had happened.[245]

Another criticism which could be made was that, in practice, the intervention that was actually evaluated in most cases turned out to be the *offer* of an appointment, rather than the provision of an appointment as, in this real world clinical setting, the majority of those offered did not attend and both the main analyses and the post-hoc analyses were carried out on an intention to treat basis. However, some families commented that they were glad of the offer, even if they had decided not to take it up. It could therefore be hypothesised that the possibility of being able to meet up with the PICU team again was experienced as containing in itself, psychologically.

4.4.3 Poor take up of intervention: The take up of this intervention was lower than expected from a previous parental survey,[73] and from reports of high satisfaction levels in adult ICU settings,[237] but this is exactly why it is important to do proper evaluations of service developments, with all the associated resource implications. At the time of publication, there was little consensus on how ICU follow up clinics should be run or who should attend them, either in terms of patient group or staffing, and technically there was no evidence that they were associated with improvements in outcome.

Obviously there are sound arguments for following up medical patients after a critical illness. However, it is also theoretically possible that people could be re-traumatised by having to relive their experiences at such an appointment. A recent illustration of good intentions not always translating into reduced distress in ICU relatives was provided by a study evaluating the provision of protocolised sympathy letters after the patient's death on adult ICU, which found that the intervention group reported *more* PTSD symptoms than controls.[246] This is an ethical issue about using evidence based practice and adhering to the fundamental tenet of medicine 'primum non nocere' (ie 'first do no harm').[247]

4.5 Contribution to the field

4.5.1 The evidence base on intervention: As discussed above, the evidence base for intervention with parents after a child's PICU admission was minimal at the time this study was published, and continues to be very small.[248,249] This study represented a significant contribution to this literature in that it provided longitudinal information on a reasonably large sample of parents followed up for 5 months, when many previous studies had only examined the impact of PICU on parents for a few weeks at most (see Table 2.2). In doing so it added to the growing evidence on the extent and persistence of parents' distress in this situation and, in addition, offered a potential method for screening them acutely to identify those at greater risk of poorer adjustment in its novel use of the PSS:PICU. It also set a benchmark for rigour in relation to the use of an RCT design, standardised measures of psychological distress and the collection of feedback from those who did and did not take up the intervention.

4.5.2 The impact of follow up clinics: More specifically, this study also constituted the first attempt to evaluate a *PICU* follow up clinic and the first to evaluate impact of a clinic on the wellbeing of the *relatives* of intensive care patients. It was also only the second example in the literature at the time of a formal evaluation using an RCT design,[241] despite the prevailing NICE guidance[238] recommending clinics should be routine.

The provision of real world attendance data and feedback (see Appendix 10.4.3) were also important strengths of this study and likely to be of use to other PICUs considering offering this new service. An intriguing finding that those who lived further away from the hospital were *more* likely to attend than those who lived nearer, is counter-intuitive but may be related to the fact that some very seriously ill children need to be 'retrieved' from local hospitals to the PICU hospital base, some distance away. Nevertheless, it is important to acknowledge, since it suggests that distance alone should not necessarily be assumed to be a barrier to attendance.

As might have been expected, parents who had suffered greater acute stress, and those whose children were sicker, were more likely to attend, but these data suggest that routine provision of appointments for all would be an inappropriate use of resources.

It was however instructive to learn that people reported being grateful to have had the chance of an appointment, even if they did not take it up. Gratitude was also a feature of the motivation to attend for some, who explained that part of the reason they had attended was to thank the team for caring for their child, without necessarily needing further support from them.

4.5.3 Summary: This study provided valuable information about the feasibility of a follow up clinic for parents after PICU and underlined, again, the persistence of distress associated with the admission. It also added to the existing literature in two further important respects, in that it suggested that this distress might be both predictable and - tantalisingly - modifiable.

4.6 Evidence of impact

4.6.1 Citations: Impact data in the online databases described in section 2.6 (accessed 9/5/21) show that 33% of the citations referencing this paper were made in the last two years, which is higher than would be expected for a paper published 10 years ago, and suggests it is 'currently receiving a lot of interest', with more than 4 times as many references made to it than to other papers in this field.

The most high profile citation of the 'Follow up Clinic Study' paper was its inclusion in the most recent update of the NICE guideline on PTSD treatment, in the section on evidence in relation to the organisation and delivery of care.[7]

A further 27 other citations were found referencing this paper (including two papers with Colville as first author and two as co-author) after removing duplicates and unpublished theses. Articles included 11 reviews; 5 qualitative studies; 3 prevalence studies; 3 editorials; 3 intervention studies and 2 book chapters.

4.6.2 Other types of impact: A conference presentation on the provisional findings at an annual meeting of the British Psychological Society generated press coverage[250] in the society's official monthly publication, which has over 50,000 subscribers, and prompted a request for a commissioned review on the role of psychology in ICU settings by the editor. [251]

The 'Follow up Clinic Study' also prompted a funded replication at another centre, which tested out the recommended strategy of offering this intervention to 'at risk' families. This replication study used a different measure of acute distress,[155] which incorporated a number of known risk factors for PTSD and depression.[102,103] Whilst it also encountered problems relating to attrition, power and attendance, it

confirmed the potential value of screening, in that it found an association between screening score and later psychopathology.[156]

4.6.3 Summary: This study added to a small but growing literature on interventions with families affected by ICU/PICU admission. The results extended the literature on ICU follow up clinics by applying this approach to a paediatric setting and evaluating its psychological impact on caregivers. Although ostensibly confirming the overall null result found in the only formal evaluation of an adult clinic available at the time,[26] it provided additional post-hoc data that suggest this mode of intervention might be better targeted at those who are most distressed acutely, a proposition further investigated by a replication study.[156] These findings together with the low attendance rate reported, since replicated in two further reports,[156,252] were important to disseminate because of the resource implications of setting up a multi-disciplinary clinic and the moral obligation to invest in services which have an evidence base.

4.7 Implications for future research and clinical work

The past decade has seen a growth in the appreciation of the psychological impact of an intensive care admission not only on patients, but on their relatives, who were the subject of this study. Professional guidelines devised by SCCM, which focussed on 'patient-centred' care,[253] have been updated with recommendations on how to offer 'family-centred' care.[254] The PICU community has in turn embraced this new terminology by coming up with a further variation of PICS, namely 'PICS-p'[36] wherein the unique interdependence of a child on its parents and the need to consider developmental issues have been added to the mix. However whilst there is ample evidence of long term distress in relatives in both adult[255] and paediatric[39] ICU settings, the evidence for intervention with them is still very limited.[248,256]

The findings of the 'Follow up Clinic Study' raise a number of possible fruitful avenues which could usefully be pursued in relation to this continuing gap in knowledge, in relation both to the potential

value of follow up clinics, but also more generally to screening and targeting 'at risk' groups for more support.

4.7.1 ICU follow up clinics: The provision of follow up clinics has grown in the past 10 years, particularly with adults in Europe[257,258] but also at adult centres in the US, most notably at Vanderbilt, which following groundbreaking research into the assessment and morbidity associated with ICU delirium,[251] has developed a dedicated ICU rehabilitation programme involving neuropsychological and pharmacological monitoring of patients for months after they leave critical care.[260] These clinics are being used mainly as a vehicle for maintaining contact with patients, rather than as an intervention in themselves, but even in relation to this, the evidence that they are associated with better outcomes still lags behind the enthusiasm with which some proponents advocate their use. It is therefore important that new adopters continue to monitor their effectiveness.[261]

However even if they are found to be effective for adult patients, on the basis of attendance rates in this and other studies,[156,252] they may not be a feasible option for paediatric patients.
Also the inevitable and necessary focus on the patient's physical wellbeing, particularly in the early weeks after discharge,[262] may limit the ability of some parents to make use of such a setting for considered reflection on their own emotional state.

4.7.2 Screening and monitoring: This study provided useful data on the potential feasibility of a screener, the PSS:PICU, in that it appeared to detect those parents who were more likely to respond to an intervention, 2 months later. The PSS:PICU was widely used in the 1990s, but mainly acutely and by nursing research teams only (see Appendix 10.1). It is 32 items long but has recently been shortened for use with parents of children admitted to a Spanish PICU[147] and found to have acceptable psychometrics and to be prospectively associated with later distress.

National guidelines on the treatment of PTSD recommend screening 'at risk' populations so that interventions can be targeted at those most likely to benefit.[7] A recent study demonstrated the impact of a simple 'Distress Thermometer' used during admission to identify families who might benefit from acute support and found that its use was associated with improvements in parental satisfaction with care and reduced requirement to involve security services when disagreements with families got out of hand.[263]

The PSS:PICU scale has salience with parents clinically, as well as in a research context, in that it lists a number of potentially traumatic events regularly encountered on PICU (such as intubation, resuscitation and suction), but importantly from a theoretical point of view, it does not address appraisals or acute emotional reactions or ask about known risk factors for the development of PTSD, such as previous mental health problems or a history of trauma. Other candidate screeners, which have been trialled with PICU parents,[49,156] and which derive from the wider literature on PTSD, are the Acute Stress Disorder scale[157] and the Posttraumatic Adjustment Scale.[155]

An alternative model for addressing long term parental distress could be to make more use of such standardised screeners at discharge. These could be used to determine who to refer on to appropriate support, rather than trying to establish a 'one size fits all' intervention based at the hospital.

4.7.3 Alternative interventions: Other interventions described in the adult ICU literature since the publication of this study which show some promise include a 'sense-making' approach to acute care;[264] encouragement to get more involved in the care of the patient;[265] the provision a telephone support package post-discharge;[266] and the provision of ICU diaries, which have impacted both on the wellbeing of patients and that of their relatives.[267]

There has already been some interest in using diaries in the PICU setting, with qualitative[268] and quantitative[269] evidence that parents find them helpful and a recent survey in the UK demonstrating that a number of PICUs have started to use them routinely.[270] Theoretically the provision of a coherent narrative for the family might facilitate communication about what happened as the patient recovers physically. This is something that has emerged as an important task for families in qualitative research,[158,262] which generated the development of a leaflet for families (see Figure 4.1 and Appendix 10.5) which was later adapted to form part of a psychoeducational intervention.[271]

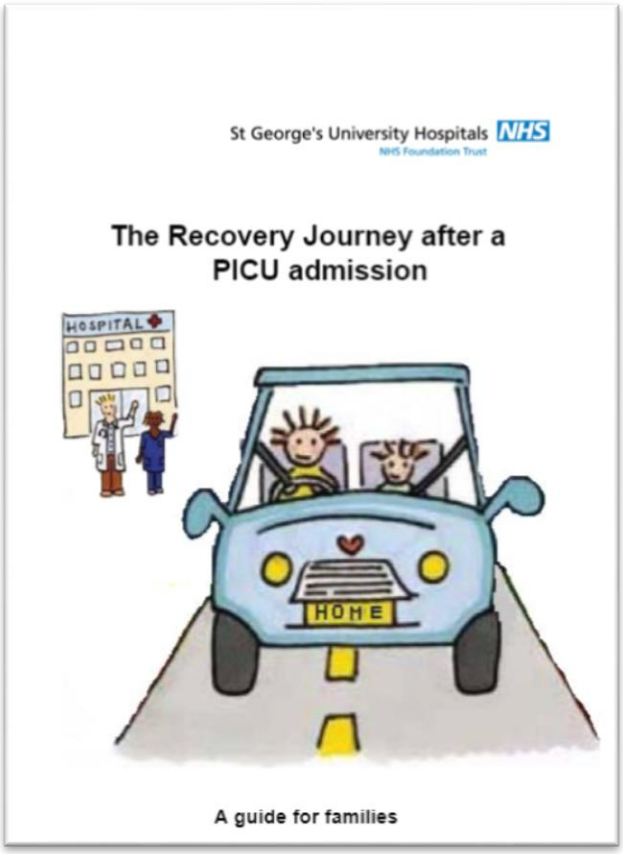


Figure 4.1: A leaflet summarising findings of qualitative research with families about their psychological recovery over the year following the child's discharge from PICU[158,262]

The potential value of facilitating communication about the PICU admission within the family after discharge would also be consistent with the findings of the impact of the COPE intervention[161] and the observation in the 'PTSD Study' that parents were more distressed at 12 months if their children were avoiding talking about what had happened on PICU, at 3 months.

Another more traditional approach to supporting parents after discharge would be to resource more dedicated psychology provision in intensive care settings, ideally with the capability to provide post-discharge support to patients and families when indicated. There is surprisingly little discussion about this option in the literature but in the next chapter the role of a clinical psychologist allocated to PICU is illustrated with respect to the treatment of PTSD in parents. (See also Chapter 8 for further discussion of this point).

CHAPTER 5: Narrative Exposure Therapy with Parents after PICU

"*The joys of parents are secret; and so are their griefs and fears.*
They cannot utter the one; nor they will not utter the other.
Children sweeten labours, but they make misfortunes more bitter;
they increase the cares of life, but they mitigate the remembrance of death"

Francis Bacon, 1612[272]

PAPER 5 The 'NET Study': Colville G. Narrative Exposure Therapy with parents who have been traumatized in paediatric settings: a case series.
Clinical Practice in Pediatric Psychology 2017;5(2):161-169

5.1 Psychological treatment for Post-traumatic Stress Disorder (PTSD)

The main psychological approaches recommended for the treatment of PTSD include TF-CBT[273] and prolonged exposure (PE) therapy,[274] which both involve exposure to reminders of traumatic events and exploration of the thoughts and feelings that this evokes. EMDR (Eye Processing Movement Desensitization and Reprocessing),[275] in which there is more focus on distressing images, also has a growing evidence base.

However most of the evidence for the effectiveness of these treatments is based on studies of single event traumas; they are not as effective for 'complex trauma' in which multiple traumas have been experienced, sometimes over a long period of time, eg during an abusive childhood.[276] In the light of the lower effectiveness (and acceptability) of existing therapies for this group and observations that it is 'inhumane'[277] to expect a patient to single out a 'worst' event to work on in therapy in this context, there has been increased recognition of the need for a different approach to 'complex' trauma.[276] This in turn has led to updated diagnostic[6,278] and treatment guidance.[7]

Recently a new, more integrative approach to treating the sort of traumas encountered by people in war–torn countries, such as the Congo and Rwanda, has been developed, termed Narrative Exposure Therapy (NET).[277] This focuses on the development of a coherent narrative, which helps to contextualize and integrate the traumatic material into the client's whole life story.

5.1.1 Narrative Exposure Therapy: NET was developed by Schauer, Neuner and Elbert[277] for use with groups of refugees, and others affected by war and organized violence, who had experienced multiple traumas and were poorly served by mental health services, because of the limited resources available in the low income countries where they lived. The aim of the initial research programme utilising this approach was to develop and evaluate a brief therapy package which could be rolled out, via local

volunteers, to large numbers of traumatised people in groups, with very little requirement for additional resources.

NET draws on three therapeutic approaches (TF-CBT, witness testimony therapy[279] and narrative therapy,[280]) together with recent research on autobiographical memory[281] and the importance of fear networks in the maintenance of traumatic reactions.[282] It aims to assist the traumatised individual to integrate their traumatic experiences into their wider life narrative, by first establishing their life context and then revisiting the traumatic events they experienced, over the course of 6-10 immersive sessions, ideally over a period of less than a month. The therapy culminates with the construction of a physical 'Life Line' using symbolic rocks and flowers to represent difficulties and joyful events that have occurred over the time examined and the production of a written account of the person's story.

A review of six published studies using NET with adults in 2010[283] showed that the evidence base was mounting for its effectiveness, and that many had benefited from treatment, even when their lives continued to be affected by political instability and the risk of conflict. A further review in 2014, comparing 15 NET studies to 32 Prolonged Exposure (PE) studies,[284] concluded that NET was a promising new brief therapy, with comparable efficacy to PE and better treatment drop out rates (5% v 27%), but cautioned that it had yet to be demonstrated as a useful approach in developed countries with populations who had experienced trauma types other than those associated with war or being a refugee. Consequently, at this stage NET was only formally recommended for use with refugee populations.

5.1.2 Applicability of NET to PICU parents: There were a number of reasons it was decided to trial NET clinically with parents who had significant levels of PTSD symptoms after PICU. Their traumatic experiences were usually multiple (eg repeated serious deteriorations in the child's condition). Also

previous research had shown that, as a group, they found it difficult to isolate one worst PTE,[285] with many replying 'everything' when asked what was the 'worst thing' about their experiences on PICU (see Chapter 2). As a brief intervention it was also hoped that it would be more likely to be acceptable to this population, who have numerous work and caring commitments. The idea of helping people put their story together was also inherently appealing, as this seemed to meet a clinical need in a group that had been overwhelmed by the need to take in large amounts of new medical information, in an emotionally loaded situation, over a short time. The potential of NET was also consistent with the wider context of ICU patients reporting being troubled by their 'memory gaps'[286] and qualitative research, in which the need to construct a narrative had emerged as a compelling theme for PICU families.[262]

5.2 Design of the study

This study reports on the psychological treatment for PTSD of a case series of four parents of children who had been admitted to PICU over the previous two years. All the children had survived, but one was left with a severe level of disability and two had ongoing medical issues. In each case a diagnosis of PTSD was established by a combination of score on the Posttraumatic Diagnostic Scale (PDS)[287] and clinical interview. Parents provided baseline data on the PDS and on the HADS[89] before treatment was commenced, as well as 1 month and 6 months after the completion of treatment. Treatment was guided by the NET developer's manual[277] and the clinical psychologist delivering it had also received formal training in this approach.

5.3 Main findings

All four parents remained in treatment throughout and experienced reductions in symptoms of PTSD, anxiety and depression that were clinically significant and continued beyond the end of the treatment period. Effect sizes for the reduction in scores between baseline and 6 month follow up for the group were large for PTSD (*d*=2.37), anxiety (*d*=2.15) and depression (*d*=1.01).

In terms of treatment fidelity, the clinician managed to complete therapy within the number of sessions specified in the manual and at the frequency recommended for full immersion in the emotional processing, which has been deemed necessary for a coherent and meaningful narrative to emerge (ie mostly twice a week and never less than weekly).

Parents also reported concomitant improvements in their general functioning following treatment, in relation to their ability to enjoy life and handle new stressors, and particularly appreciated being provided with a copy of their 'Life Line' (see Figure 1 in the 'NET Study' paper).

5.4 Limitations

5.4.1 No control group: As there was no control group, it was not possible to tell just how much this group's symptoms might have reduced spontaneously without treatment. There is only limited information available on the natural trajectory of parents' PTSD symptoms after PICU (see Chapter 2) but given the length of time since PICU discharge for this group (6 – 19 months) it seems unlikely that their symptoms would have abated naturally, given research that PTSD symptoms can persist for years if untreated.[164,288]

Repeated within-case baseline measures before treatment would have strengthened the findings. Alternatively, a design including waiting list controls would have lent the findings more weight.

However, this treatment was provided as part of a clinical service and the timing of the sessions necessarily depended on the readiness of the participants, in terms both of their psychological safety (related to the health of their child) and in relation to other commitments, given the number and length of sessions they needed to attend in a short time period. In practice they also needed to make time to recover from sessions and to think about them, as they made new sense of what had happened,

recalled new details and made new links between memories, cognitions and feelings, from the vantage point of now knowing how things had turned out.

5.4.2 Self selection: Another obvious criticism of this study is that the participants self-selected for this treatment. It was offered to other parents with significant symptom levels, but half of those declined to proceed after being provided with further information. It may be that NET does not suit everybody, but it is also well known that people suffering from PTSD are ambivalent about treatment,[289] whether because of perceived stigma or reluctance to experience additional short term distress, since all evidence based treatments involve a degree of exposure to traumatic memories and confrontation with painful material.

5.4.3 Clinician's previous contact: As stated in the 'NET Study' paper, two of the four parents had already been seen by the treating clinician, during the child's admission, and their PTSD symptoms were being monitored. It could be, therefore, that in these cases the pre-existing therapeutic relationship played an important part in the success of the treatment – and, it was certainly associated with earlier identification of their difficulties. However, in the other two cases, the parents were not known at all to the clinician and yet both made a good recovery after treatment, despite having symptoms which had persisted for 12 and 19 months respectively.

Another aspect of the treatment that may have had a direct bearing on the results, was the location. Parents needed to return to the hospital where their child had been treated on PICU in order to access this psychological input. This meant that they needed to retrace their steps in relation to driving to the hospital; parking the car; entering the building; waiting for the lift etc, and in doing so were likely to have been re-exposed to numerous reminders of their previous traumatic experiences. It is therefore possible that this additional re-exposure enhanced the impact of the treatment.

5.4.4 Resource implications: Although NET is a brief treatment, in the sense that it is designed to be delivered over the course of a month, it entails attendance at a similar number of sessions as other treatments.[284] This has resource implications in relation to the training of the clinician and their availability, not only for twice weekly sessions but also to assemble and edit the written account between sessions. The construction of the 'Life Line' is also quite labour intensive as it requires the re-reading of the final transcript and the placing of stones and flowers and labelling of events on the time line, which in practice required the help of an additional assistant.

However the fact that an inexpensive manual is freely available and that NET was designed to be used in settings with limited resources, means that it compares favourably in financial terms with other treatments which can only be delivered after extensive formal training and a set number of hours of practice.[290,291]

5.5 Contribution

5.5.1 Evidence base for interventions: As discussed in Chapter 4, the evidence base for intervention with parents after PICU is very small and has focused to date on the provision of universal intervention packages,[161,271] with only one study reporting on a more targeted approach.[156] The 'NET Study' is a reminder that the traditional approach of referral to a mental health professional when an individual's symptoms are persistent and affecting their functioning, is another way to address long-term parental distress associated with a child's PICU admission.

In this case series a novel brief therapy was effective in reducing symptoms of PTSD, anxiety and depression, over a short time period. The findings suggest that, for the parents concerned, being able to access therapeutic input at the hospital where their child had been treated provided continuity and facilitated the degree of re-exposure to traumatic material necessary for comprehensive emotional

processing of events. The data also contribute more widely to a field where the length of follow up is usually shorter,[292] and demonstrate an apparent continuing impact of the therapy for several months after the cessation of treatment, which has also been described by others using NET.[293]

5.5.2 Evidence base for NET: This study also added to the evidence base for the effectiveness of this relatively new approach, which at the time of publication was recommended for use only with refugee populations, because of the dearth of studies on other groups.[283,284]

The fact that it examined a new trauma type, namely witnessing a child's critical illness, and reported on outcomes other than PTSD, added to the existing literature.[283] It was also, at the time, the first treatment report on NET in the UK.

5.5.3 Summary: This study illustrated that NET could be applied successfully in a Western medical setting, that it was well received and that its use was associated with lasting improvements in parents' wellbeing.

5.6 Evidence of impact

5.6.1 Citations: Interrogation of the online databases described in section 2.6 revealed five citations for this paper. These included two self-references, two references to recent academic theses (one on the impact of trauma work on clinicians and the other on the application of NET to community psychiatric samples) and most significantly, one systematic review of the evidence for NET, which pooled the results of over 50 studies and reported large group effect sizes in favour of the treatment in meta-analyses.[293]

5.6.2 Other impacts: The publication of the paper led to invitations to speak about the treatment of PTSD in parents after PICU at two annual international meetings, of the European Society of Traumatic Stress Studies in 2017 and the WFPICCS in 2018. The latter presentation in turn led to a request to collaborate on a paper examining post-traumatic growth in bereaved PICU parents, which is in preparation.

The apparent feasibility and acceptability of the treatment also led to increased interest in NET as an option for addressing paediatric medical trauma in parents and children more widely in the author's clinical service, the upshot of this being that four other members of the team have now trained in NET and are delivering it to patients and family members.

Arguably, though, the greatest impact of this work was the personal impact on the parents treated and their families. As outlined in the paper, parents described a new and more nuanced understanding of what they had been through and were grateful for a new appreciation of the parts of their PICU experience that had actually gone well. They were also relieved to find they could face subsequent challenges with greater equanimity following NET treatment, even where these were related to their child's health problems.

5.6.3 Summary: This work had an important beneficial impact on the parents involved, influenced other clinical psychologists to seek training in this particular brief treatment and in adding to a growing evidence base, strengthened the data supporting its wider adoption.

5.7 Further clinical and research implications

5.7.1 NET as a treatment for PTSD: NET was initially only recommended for a limited group of trauma types. However the growth in evidence for both the effectiveness of this approach (see Figure 5.1), and

for its acceptability in terms of lower drop out rates than for other established treatments,[284] has been associated with its recent inclusion in guidelines in the UK[7] and the USA[294] as a recommended treatment for PTSD.

Additional analyses by Siehl et al[293] have demonstrated a large overall effect size for NET in a meta-analysis of studies which followed up patients for more than six months. This is consistent with the developers' claims that the impact of the treatment is not confined to the period over which the sessions are delivered. This review also represents the first report on NET in which the number of studies examining non-war related traumas, such as earthquakes, floods and cancer, exceeds the number of studies involving organized violence and displacement.

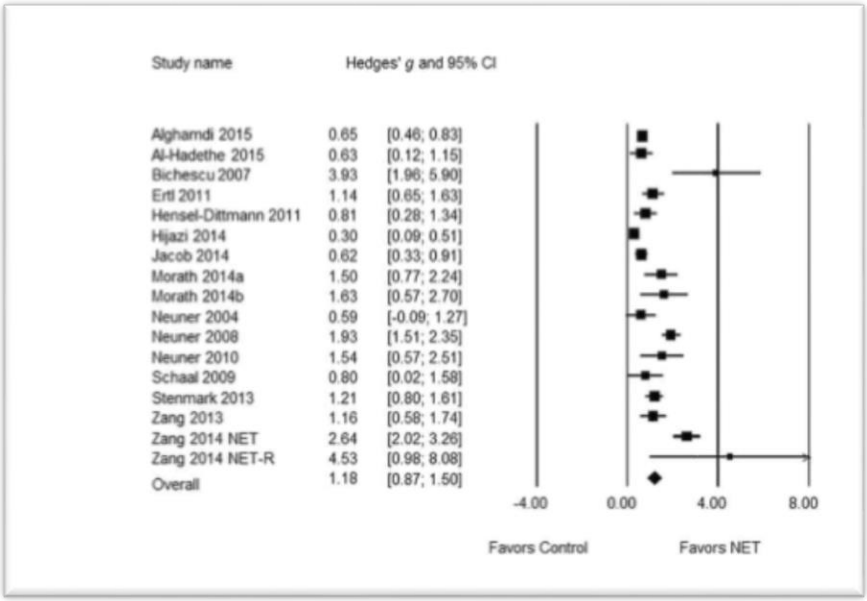


Figure 5.1: Mean effect sizes of narrative exposure therapy (NET) (reprinted with permission from European Journal of Psychotraumatology[295] http://tandfonline.com

Although the ordeals of asylum seekers, who have witnessed terrible conflict and suffering, may seem to have little in common with the experiences of people living in peaceful, affluent settings with access to good medical facilities, the latter may witness repeated sudden painful and life threatening deteriorations in their child and can suffer debilitating psychological symptoms as a result. NET appears to be a potentially useful treatment for parents in this situation and is currently also being trialled with adult ICU survivors.[296]

5.7.2 Treating children: Despite the fact that there are now a number of reports testifying to the presence of a significant level of PTSD in children following their treatment on PICU,[52] there is only one case report in the literature pertaining to their treatment.[297] Alongside other existing recommended options,[7] there is a version of NET available for use with traumatised children (KidNET[298]) which might be helpful with children after PICU or in other medical situations associated with higher rates of PTSD such as cancer,[285] and burns.[57]

5.7.3 Further comparative research: Most studies of NET to date have been undertaken in Europe or developing countries, with only one reported on a population in the USA and only one other study based in the UK.[295] Further research could also establish the potential applicability of NET in a wider range of countries and with a wider range of trauma types. Also given that the bulk of the RCT studies to date compare NET with no treatment,[293] there is a need for more research comparing NET to other established treatments.[295]

5.7.4 Monitoring at risk groups: This study also highlights the potential value of monitoring parents for PTSD symptoms after PICU discharge, in order to identify sooner those who might benefit from treatment. Two of the parents in the case series were being followed up by the psychologist and were consequently offered treatment at an earlier stage than the other two parents. The expansion of

routine monitoring of parental wellbeing after PICU could potentially facilitate earlier treatment, in accordance with mounting evidence in favour of early intervention, which has led to an update in national guidance on the treatment of PTSD, replacing the previous 'watchful waiting' advice.[7]

5.7.5 The role of the psychologist: Finally these findings are a powerful illustration of the potential role for psychologists in addressing the emotional fallout, in family members, of a child's admission to PICU. One way forward for units who wish to facilitate the provision of support for distressed families would be to set up a system of monitoring those at greatest risk of problematic long term reactions and referring on those with persisting symptoms, via primary care, to an appropriate local mental health service. But there is evidence from the adult ICU literature that patients find it difficult to explain what they have been through to health professionals outside the world of critical care.[242]

Another approach, therefore, which offers the potential for more preventative work, by normalising early reactions, facilitating coping and aiding emotional processing acutely,[20] by patients and their caregivers, is to resource more clinical psychology posts in medical settings, such as PICU.[251] This option would provide better continuity of care when the child is re-admitted (an increasingly frequent occurrence for children with chronic complex conditions[299]) and once the child is moved to the general ward - a transition many parents find very difficult emotionally.[230] Furthermore, with sufficient funding, a clinical psychologist could also provide input beyond discharge if needed, including the offer of a period of stabilisation sometimes necessary before trauma work can be undertaken.[300] They could also offer bereavement support to this population, who are known to be at heightened risk of complicated grief reactio

PART TWO: The Impact on Staff

CHAPTER 6: Burnout and Post-Traumatic Stress in Staff

"There is no such thing as work-life balance.
Everything worth fighting for unbalances your life."

Alain de Botton 2010[302]

PAPER 6 The 'Staff Stress Study': Colville G, Smith JG, Brierley J, Citron K, Nguru NM, Shaunak P, Tam O, Perkins-Porras L.
Coping with staff burnout and work-related posttraumatic stress in intensive care.
Pediatric Critical Care Medicine 2017; 18(7): e267-e273

6.1 Work-related stress in healthcare settings

Over the past decade there has been growing concern internationally about the level of work-related stress reported by healthcare staff. A large study in the US found that doctors reported significantly higher levels of 'burnout' than members of the general public in 2011, and that these symptoms worsened and were associated with a decrease in satisfaction with work-life balance, over the following three years.[303] The same metrics in the general population indicated lower rates of 'burnout' and higher job satisfaction (see Figure 6.1).

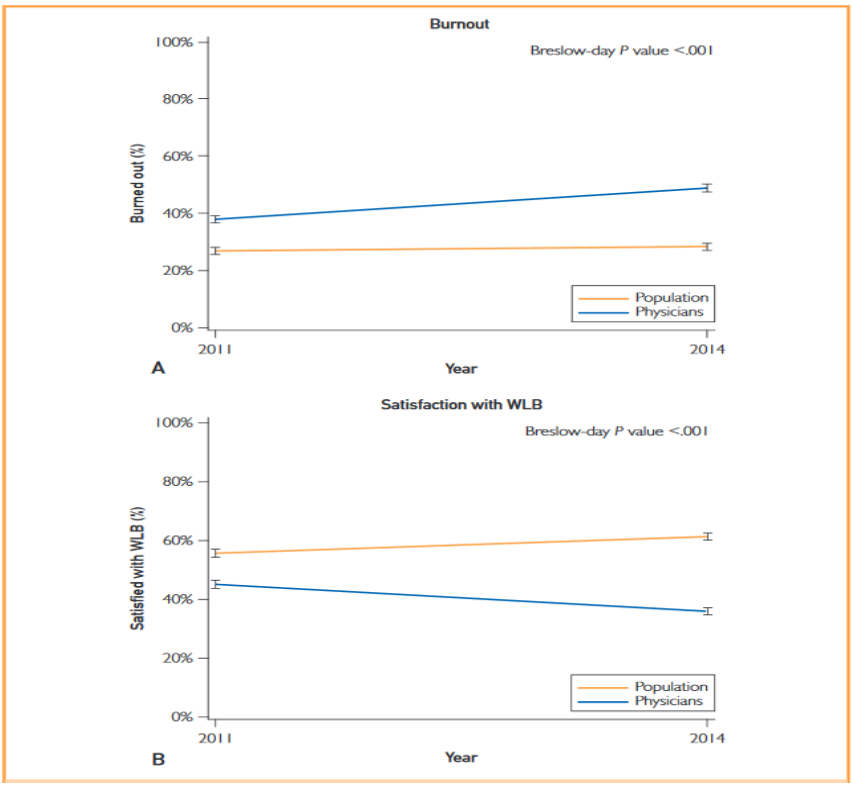


Figure 6.1: Burnout and satisfaction with work-life balance (WLB) in physicians (n=5313) and the general population (n=5392), between 2011 and 2014 (reprinted with permission from Mayo Clinic Proceedings under Creative Commons License[303])

Furthermore, rates of 'burnout' reported by doctors[304] and nurses[305] working in intensive care settings appear to have become particularly elevated, leading to a call for more research on this topic by a number of professional organisations representing staff in this field.[34]

The literature on occupational stress is heavily influenced by the Job Demands-Resources Model,[306] which posits that stress is a function of the mismatch between the demands of a job and the resources available, whether these be tangible (ie staff and equipment), physical, cognitive or emotional. In the case of intensive care workers the form of work-related stress most often measured in quantitative studies is 'burnout', but increasingly other forms of distress, relating to the potentially traumatic nature of the work and the difficult moral decisions that need to be made in these settings, are being examined.

6.1.1 'Burnout' in ICU staff: 'Burnout' as a term was first used in fiction in the 1960s.[307] Freudenberger then adopted it, in 1974,[308] to mean the sense of being depleted by work demands, but it is not a formal psychiatric diagnosis. Although it has recently been included in the International Classification of Diseases (ICD-11),[278] this has been with the stipulation that it should be regarded as an 'occupational phenomenon' rather than a medical condition.

It is most commonly measured using the Maslach Burnout Inventory (MBI),[309] which comprises three subscales measuring 'Emotional Exhaustion', 'Depersonalisation' and 'Personal Accomplishment'. However, there are many different approaches to the interpretation of MBI scores,[310] with some studies classifying a person as 'burned out' if they have a 'high risk' score on at least one subscale, and others only using this classification for those with 'high risk' scores on all three subscales. There is also a long running debate in the field about the extent to which 'burnout' may simply be a manifestation of depression.[311]

Notwithstanding these issues, there are now a number of studies demonstrating associations between 'burnout' and both suicidality and medical errors,[312] which have provided a rationale for its assessment. 'Burnout' has also proved to be a salient concept within the healthcare community. The result of this has been that the number of 'burnout' prevalence studies has continued to proliferate, despite the evidence base for intervention remaining small.[34]

6.1.2 PTSD in ICU staff: The diagnostic criteria for PTSD were expanded, in 2013, to include traumatic experiences arising in the course of someone's work role, even if the person concerned did not experience a direct threat to their own life or integrity.[6] This development has been associated with increased interest as to whether PTSD symptoms are more common in healthcare staff, particularly those working in emergency departments and ICU. Evidence has emerged that PTSD symptoms are reported by healthcare workers involved in critical incidents[313] and are more common in ICU nurses than other nurses.[314,315] However at the time of the publication of the 'Staff Stress Study', little was known about how PTSD and 'burnout' were associated, or how common PTSD was in ICU staff.

6.2 Design

The main aims of this cross-sectional survey were a) to collect prevalence data on 'burnout' and PTSD in ICU staff, and b) to examine the relationships between these forms of work-related stress and demographics, occupational factors, resilience and coping strategies.

Participants were surveyed anonymously using the following standardised questionnaires: the abbreviated Maslach Burnout Inventory (aMBI);[316] the Trauma Screening Questionnaire (TSQ);[317] the Brief Resilience Scale (BRS)[318] (and, for participants at one site, the HADS[89]). A checklist of coping strategies and types of organisational support was also included in the survey. Main hypotheses were

that the different forms of distress would be intercorrelated and that distress would be negatively associated with resilience.

6.3 Main Findings

The proportion of participants scoring above cutoffs for 'burnout' and work-related PTSD were 37% and 13% respectively and, as expected, resilience was negatively associated with both forms of distress.

In the subset of the sample who also completed the HADS, clnically significant scores for anxiety (13%) and PTSD (11%) were more common than those for depression (4%). 'Burnout' was the most commonly endorsed form of work-related distress endorsed overall, as well as being positively associated with all other forms of distress and was reported more often by doctors than nurses

Personal coping strategies were used more often than organisational ones, but the most often used strategies were not necessarily the most effective, in terms of being associated with lower 'burnout' or PTSD (see Appendix 10.5 for univariate associations).

After controlling for resilience, 'attending debriefs' was a coping strategy specifically associated with lower 'burnout' scores. 'Speaking with manager' and having 'hobbies outside work' were associated with lower PTSD scores. Venting and increased alcohol intake were negatively associated with wellbeing.

Finally, in relation to a question enquiring which forms of organisational support participants would like to access in future, debriefing and reflective practice were the most highly endorsed.

6.4 Limitations

6.4.1 Different data collection periods: Data for the 'Staff Stress Study' was collected over a two year period by a group of medical students, in partial fulfillment of a coursework assignment. This meant that the data from the seven units surveyed was provided in different years, although in all cases between November and December. It is possible that some other extraneous factors, such as the prevalence of certain diseases, or changes in treatment approaches over time, may have influenced participants' responses.

6.4.2 Short screening instruments: Brief screening instruments were used in the survey to minimise burden on participants, and hopefully maximise participation. The rates of symptoms cannot therefore be taken to be strictly diagnostic. Furthermore, the PTSD screening instrument, the TSQ,[317] covered symptoms of hyperarousal and re-experiencing but not avoidance or negative mood. It was however recommended as a valid screening instrument for PTSD at the time.[107]

6.4.3 Definition and scoring of 'burnout': One of the main weaknesses in the literature on 'burnout' is the wide variation in its definition and scoring.[310] In this study the decision was made to employ the working definition used by Shanafelt and colleagues,[303,319] according to which 'burnout' is regarded as present if the score on either the 'Emotional Exhaustion' or the 'Depersonalisation' subscale is found to be in the 'high risk' range in the MBI manual[309] (ie in the top third). Although this decision is open to debate, it was made on the basis of research which demonstrated that these two dimensions of 'burnout' have been found to be much more closely associated with a clinical assessment of 'burnout'[320] than the third subscale, which assesses reduced 'Personal Accomplishment'.[321]

6.4.5 Coping measure: Another limitation of this study was the use of a non-standardised list of coping strategies, which was based on earlier findings from a focus group at one of the units surveyed. An

alternative strategy, would have been to make use of a standardised measure of coping, such as the Coping Orientation to Problems Experienced (COPE) Inventory.[322] This has recently been used in a study examining PTSD symptoms in ICU staff,[323] which found that the most common coping strategies they used were adaptive, and included acceptance and positive reframing.

6.5 Contribution to the field

6.5.1 PTSD in ICU staff: This study is believed to be the largest to report on PTSD symptoms in ICU staff, at the time of publication, illustrating the multi-faceted nature of work-related stress in this setting. Also, although it could not have been known at the time, this data proved to be relevant to the assessment of the psychological impact on staff of the ongoing COVID-19 pandemic. A survey of 709 ICU staff in the UK, determined that over 40% were suffering clinically significant levels of PTSD symptoms in relation to this work,[324] and contrasted this with the lower rates reported in a conference abstract on the 'Staff Stress Study',[235] in acknowledgment of the limitation that they had not assessed PTSD in their sample, prior to the pandemic.

6.5.2 Overlap between burnout and depression: The fact that 'burnout' and depression are associated has prompted a debate as to whether 'burnout' might be more parsimoniously explained by a diagnosis of depression.[326] Research has found that staff on sick leave with high levels of 'burnout' symptoms also report clinically significant levels of depression,[327] but it does not necessarily follow than healthy staff at work who report 'burnout' are also depressed. [321]

The 'Staff Stress Study' made a useful contribution to this debate,[328-330] in that it provided contemporaneous data on depression and 'burnout' and showed that 'burnout' was five times as common as depression, confirming a similar finding in a study of General Practitioners in Austria.[331]

This seems to be evidence that, although the two are associated, they are not interchangeable and suggests that 'burnout' should probably be regarded as a sub-clinical condition. It is also one which, importantly, staff may be more inclined to endorse, as it is less associated with stigma. Pragmatically, therefore, the monitoring of 'burnout', whether at the individual or the institutional level, may provide early identification of those in need of more rest or support, given its associations with alcohol abuse, suicidality and medical error.[332,333]

6.5.3 Evidence favouring particular coping strategies: The fact that particular coping strategies were associated differentially with specific types of distress is also novel and worthy of further investigation, particularly as these associations were independent of gender, role and resilience.

Furthermore, an editorial[333] commended this study for providing evidence of the importance of intervention at the organisational level, rather than promoting the idea that individuals should be held solely responsible for the maintenance of their own resilience. It also described as particularly 'intriguing' the finding that the coping strategies most favoured by staff were not the ones most strongly associated with their wellbeing.

6.5.4 Summary: The 'Staff Stress Study' provided information on the prevalence of 'burnout' PTSD, anxiety and depression, in a mixed group of ICU staff in the UK, and demonstratied that 'burnout' was the most common. The finding that certain coping strategies were independently associated with wellbeing could usefully inform future interventions.

6.6 Evidence of impact

6.6.1 Citations: Interrogation of online citation databases, as described in 2.6, revealed 72 separate peer reviewed citations in the four years since publication (including six papers with Colville as first author and one as co-author), after removing duplicates, webpage articles and unpublished theses.

Of the articles identified, 31 were symptom prevalence studies; 14 were editorials or commentaries; 13 were reviews of the field and 6 were intervention studies. Other formats included a book chapter, a qualitative study and a trial protocol. One third of citations addressed PTSD as well as burnout and 8 were written with specific reference to the current COVID-19 pandemic.

Data from the Dimensions database (accessed 9/5/21) demonstrated that 75% of these citations were made in the last two years, suggesting that this paper was currently 'receiving a lot of interest' and 'extremely highly cited', with approximately 20 times more references made to it than to other papers in this field, over the same period.

6.6.2 Impact on professional role: In relation to the author's clinical role, the dissemination of this research prompted a request from the Manchester PICU team following the terrorist attack at the Manchester Arena in 2017, for consultation regarding staff support in the aftermath of this trauma. This involvement led the author to develop an online screener for 'burnout' and PTSD, the 'stresscheckericu'[334], using the screening instruments employed in this study, which was made available to all staff at the hospital.

Other impacts of this line of research include the holding of a conference by the author In 2019 on 'Staff Stress and Wellbeing – The Role of the Psychologist', which was attended by over 40 clinical

psychologists and was subsequently associated with the development of a new PICU staff support post at Birmingham Children's Hospital.

Furthermore the author's reputation as a psychologist with a research interest in staff support has also led to a number of formal requests for specialist clinical supervision from newly appointed psychologists with a PICU staff support remit, variously employed by Manchester Children's Hospital; Alder Hey Children's Hospital in Liverpool; Birmingham Children's Hospital and Children's Health Ireland at Crumlin in Dublin, since the publication of this study.

6.6.3 Other types of impact: A conference abstract on the data in this study won a Star Research Award (ie scored as being in the top 10% of abstracts received) at the prestigious annual meeting of the SCCM in Hawaii, in 2017.[335] The publication of this paper was also subsequently associated with invitations to present on the topic of staff stress at the annual meetings of PICS UK, WFPICCS and ESPNIC, in 2018, 2020 and 2021 respectively.

The publication of this work also prompted a number of invitations to peer review articles on staff stress, and to write a text book chapter[336] and three editorials[337-339] on this topic.

6.6. Summary: In addition to providing prevalence information on 'burnout' in ICU settings in the UK, this study raised the profile of work-related PTSD symptoms in staff and led to a number of requests for consultation and supervision related to this field, as well as invitations to present and write on this topic.

6.7 Implications for staff support and further research

In considering the implications of these findings for future research and for the provision of staff support, it is necessary to acknowledge a growing resistance to the proposition that all that is needed to combat dissatisfaction at work is to increase personal resilience. There is evidence that even highly resilient staff are 'burned out'[340] and that staff exhaustion is often clearly related to short staffing. For this reason 'resilience' has become something of a 'dirty word',[341] with the president of the Royal College of Physicians recently questioning the validity of individual 'burnout'as a concept, arguing that the real problem here is a socio-political one.[342]

The proposition that definitions of work-related distress are inadequate without reference to moral aspects is a powerful one,[343-345] particularly in the current situation of high demand on this professional group in relation to the pandemic, and is explored further in the next chapter.

However, it seems misguided to abandon the concepts of resilience and 'burnout' altogether, given that both appear to demonstrate a significant amount of explanatory power in this field. A more constructive way forward would seem to be to find a way adequately to capture all of these aspects of psychological functioning in relation to working on ICU, so that appropriate interventions can be developed, evaluated and integrated into practice.

6.7.1 Monitoring distress: Although there are a number of valid instruments for measuring 'burnout', there is a lack of evidence on how best to address it. This has led some to argue that it is inappropriate to measure it at all,[346] while others have argued that it may be helpful for individuals, but worry about how this information might be used by organisations, if it is not anonymised.[347,348] Ultimately though there is a persuasive argument that you cannot change something if you do not measure it.[349] There is also interesting evidence that just by arming healthcare staff with feedback about how their wellbeing

compares to that of peers, it is possible to prompt them to make spontaneous efforts to improve their work-life balance.[350]

Future research could examine whether the provision of information on how to self-monitor symptoms of work-related distress might, in itself, promote better self-regulation and self-care. More longitudinal studies are also clearly needed - the fact that those who attended debriefs in this study were less burned out could be evidence that debriefs reduce 'burnout', but it could also be evidence that it is only the people who are less burned out who have the energy to attend.

6.7.2 Evaluating interventions: Reviews of the literature on staff stress unanimously emphasise the need for more longitudinal studies and for more evaluation of interventions in this field.[34,351] There is now ample evidence of work-related distress in ICU – but still very little on what can be done about it. Much of the small literature on intervention focuses on changes at the individual level, (eg conflict management[352] and mindfulness[353]). However, the results of meta analyses[354] in this field indicate that interventions are most effective if they are conducted at the organisational level, a finding echoed in the preferences expressed in this study for greater provision of debriefing and reflective practice.

Fatigue is an occupational hazard in ICU, and is likely to exacerbate emotional exhaustion, if not addressed.[355] In relation to this, it has been demonstrated that simple adjustments to rotas can be associated with immediate improvements in reports of 'burnout' and job satisfaction.[356] These findings are important because they show that 'burnout' symptoms 'ebb and flow', as the authors put it, and can be influenced by relatively straightforward practical adjustments.

Other potentially preventative unit level interventions could be designed, in which more time and space are made available to recover from the most demanding situations and to reflect on them with

colleagues.[357] If the predominant symptoms relate to PTSD however, it is important to be in a position to facilitate access to an established trauma focused treatment,[7] if distress persists.

6.7.3 The COVID-19 pandemic: There is currently a plethora of papers on the recent increase in 'burnout' and PTSD on ICU in relation to the global pandemic. This is understandable but it is also important to be aware of the high pre-existing levels of these symptoms in healthcare workers who were psychologically depleted before these new demands were placed on them.

At the same time, it is important not to over-pathologise normal reactions in an extraordinary situation[358] and to remember that, as a group, healthcare staff are resilient[340] and are, by and large, not showing higher levels of anxiety or depression than the general population at this time.[358]
Obviously it is important to ensure that staff who develop serious mental health problems as a result of their pandemic-related experiences, are able to access timely support, but the expert advice is that, with informal peer support, adequate leave and rest and a sympathetic ear from their supervisors, the majority will regain their equilibrium.[359]

In the meantime, psychoeducation about how to recognise different forms of distress, together with the provision of time and space to reflect together on what they have been through, are likely to be helpful. Hopefully in time they will be better able to articulate what was so difficult about this unprecedented challenge, but also to acknowledge what they have learned from it.

6.7.4 Moral aspects of distress: Finally, another type of work-related stress, which is not adequately covered by the concepts of PTSD or 'burnout', is moral distress,[343,344] which has been consistently found to be associated with 'intention to quit' ICU, in a number of studies.[345,360] Although they may co-exist, they are likely to require different interventions, on the assumption that these different forms of

distress have different causes. In this context, the final study in this portfolio, discussed in the next chapter, reports on the prevalence of moral distress in ICU staff.

It is hoped that future research will be able to examine in more detail a) the degree to which these three main forms of work-related distress overlap in individuals; b) which situations are most likely to cause each of them and c) how best to prevent and address them in the workplace.

CHAPTER 7: Moral Distress

"The body keeps the score"

van der Kolk, 2014[361]

PAPER 7 The 'Moral Distress Study': Colville GA, Dawson D, Rabinthiran S, Chaudry-Daley Z, Perkins-Porras L.
A survey of moral distress in staff working in intensive care in the UK. Journal of the Intensive Care Society 2019;30:196-203

7.1 Moral distress

The first recognised description of moral distress in a healthcare context is the definition by Jameton in 1984,[362] which centres on the discomfort felt when someone is required to act in a way which violates their professional or personal moral code. Much of the early literature on this topic was qualitative and focused on the experiences of nurses, but the development of a scale to measure it, by Corley in 2001,[363] has influenced research on this topic more recently and helped to demonstrate the consistent finding that this type of work-related distress is associated with the 'intention to quit',[345] particularly in ICU settings.

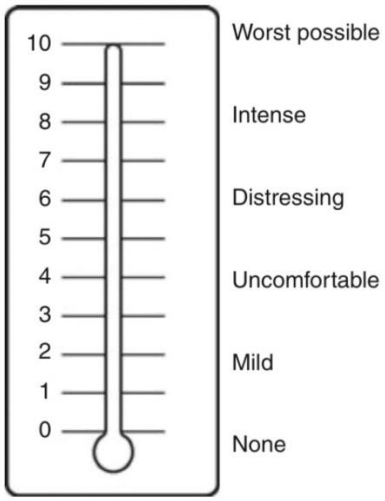
It is important to recognise that symptoms of moral distress are not, in themselves, signs of mental illness. They signify that a person has values and standards, which they ordinarily strive to attain, and are aware when this 'moral code' is under threat. However, if this form of distress is left unaddressed it can lead to psychopathology.

7.1.1 Measurement: Corley's original Moral Distress Scale (MDS)[363] was devised for use with adult ICU nurses. It contained 38 items describing situations which could theoretically cause moral distress, with respondents required to rate each situation for intensity, and again separately for frequency.

A subsequent revision of the MDS, the Moral Distress Scale-Revised (MDS-R),[364] was shorter (21 items) and issued in a number of adapted formats for doctors and nurses, working in paediatric and adult settings. Research using this measure has consistently indicated that moral distress is higher in intensive care settings and in nurses, and is associated with considering leaving work.[345]

An alternative simpler way to measure moral distress is the 'Moral Distress Thermometer' (see Figure 7.1) on which staff rate their moral distress on a scale of 0 to 10. Research has shown that scores of

above 3.5 are associated with a significant impact on functioning and are indicative that further discussion to is likely be needed in relation to the source of the distress.[365]



The Moral Distress Thermometer is available at www.fairbankscenter.org under the Nursing Ethics section.

Figure 1 Moral Distress Thermometer. Moral distress is a form of distress that occurs when you believe you know the ethically correct thing to do, but something or someone restricts your ability to pursue the right course of action. Please circle the number (0–10) on the thermometer that best describes how much moral distress you have been experiencing related to work in the past 2 weeks including today. [Correction added after online publication 11 July 2012: copyright notation for the instrument has been changed to make it possible for others to appreciate and have access to the work of Drs. Cook and Hoas and for individuals to access the Moral Distress Thermometer.]

Figure 7.1: The Moral Distress Thermometer (reprinted with permission from Journal of Advanced Nursing[365])

7.1.2 New sources of moral distress: In addition to the many sources of moral distress already outlined in the literature (eg unsafe staffing ratios[366]), a number of new strains on healthcare staff have been identified in recent years.

Technological advances in medicine have meant that more people are surviving what used to be fatal conditions, but their recovery is not always complete and there is evidence, in paediatrics particularly, that mortality has been replaced by morbidity.[31] A growing cohort of technologically dependent children, with complex conditions, are now surviving into adulthood and requiring repeated re-admission to intensive care.

Public expectations of treatment are high and families are less inclined to accept the team's decision regarding withdrawal of treatment in cases deemed futile, with parents increasingly turning to social media and the courts, in their efforts to pursue alternative treatment strategies.[367]

There is also a groundswell of frustration in relation to increased bureaucratic demands. This is underpinned by moral distress at the resultant reduction in time available for direct clinical work.[368]

At the time of publication of the 'Moral Distress Study' there were no published data on moral distress in ICU staff in the UK, but a study from Iran suggested that the association between 'burnout' and moral distress in ICU staff was significant.[369]

7.2 Design

This was a cross-sectional survey which was delivered online to all permanent members of staff on three adult ICUs, at one hospital site. The survey comprised a section on demographic and occupational factors; the Patient Health Questionnaire-4 (PHQ-4),[370] which is a brief screen used regularly in primary care to assess symptoms of anxiety and depression, and the MDS-R.[364]

The MDS-R requires participants to rate a list of 21 scenarios, in terms of the intensity of the moral distress they cause and the frequency with which they have encountered these situations in the course

of their work. Frequency and intensity scores are then multiplied to arrive at a composite score for each item, which are then added to make up the total score.

It was hypothesised from the literature that nurses would report higher scores than doctors and that moral distress would be associated both with other forms of distress and with intention to quit.

7.3 Main Findings

The main finding of the 'Moral Distress Study' was that the mean MDS-R score for this UK adult ICU sample was similar to that reported in other samples internationally. Staff rated the intensity of their moral distress as highest for items related to scarcity of resources and 'end of life' care, and rated frequency highest for items related to communication problems and 'end of life' care. The top three most morally distressing items were the same for doctors and nurses and all concerned the provision of life support in situations of futility.

Regression analyses showed that, after controlling for female gender, there were no other significant associations with occupational or demographic factors. As hypothesised, participants with higher scores were more likely to be considering leaving their job but the associations with other mental health symptoms (which were not particularly elevated) was weak, and only significant in the case of depressive symptoms.

7.4 Limitations

Aside from the limitations outlined in the 'Moral Distress Study' paper in relation to response rate, the use of brief measures and the fact that causation cannot be inferred from association in a cross-sectional survey, there are also a number of potential criticisms that could be levelled specifically at the MDS-R, as a measure. The concept of moral distress clearly has salience with staff, who can be troubled

about this aspect of their work without being exhausted, traumatised or depressed, but there are a number of issues with the MDS-R that pose problems when it comes to interpreting the scores.

7.4.1 The administration instructions*:* The MDS-R instructions require that the respondent considers how much distress they think a given situation would cause them irrespective of whether they have actually experienced the situation. Also there is no indication as to the time period to which the respondents should refer, when they complete it. The implication of this is that they should reflect on all their experience in that work setting in its totality. It is not clear therefore, how sensitive this measure is likely to be to the impact of an intervention, although there are examples of some intervention studies which have managed to demonstrate group differences using this measure (see section 7.7.2).

7.4.2 Omission of other key morally distressing situations*:* The developers of the MDS-R acknowledged that their list of potentially morally distressing situations was unlikely to be exhaustive and consequently invited respondents to add any other situations which they felt warranted inclusion. These suggestions have now been collated and added to a newly expanded 27 item version of the scale, the Measure of Moral Distress in Health Professionals (MMDHP),[360] which is otherwise administered and scored in the same way as the original MDS-R.

7.4.3 The scoring algorithm: If respondents rate the frequency or intensity of an item as '0', the composite score for this item is also rendered '0' since it is a multiple of the frequency and intensity score. This means it contributes nothing to the total score. Although mathematically useful, since this reduces the risk of a skewed distribution of total scores, it is not clear that the multiplication of intensity and frequency makes sense psychologically, or that adding scores from different situations makes sense either. It is also far from clear that being extremely morally distressed about just one or two items is

necessarily psychologically equivalent to being a little distressed by several items, yet these patterns of response may result in the same score.

In addition, the total score is effectively more influenced by the number of items relating to 'end of life care' (6 items) than those reflecting concerns about 'unethical behaviour' in others (2 items). This problem could be eliminated by reporting mean item scores, either for subgroups of items (as has been done in Figures 1 and 2 in the 'Moral Distress Study' paper) or for the scale as a whole.

7.4.4 The lack of an established cutoff: There is no agreed way to interpret MDS-R scores, as there is no cutoff for levels of moral distress that could be regarded as pathological. One research group has observed that scores over 90 are associated with a significant impact on functioning,[371] but there are currently no replications of this finding available. Without this, it is difficult for different organisations to make sense of different group mean scores or to use this scale in a meaningful way, as a quality benchmark.

7.4.5 Situations versus emotions and appraisals: Finally, a further criticism which could be levelled at the MDS-R is one which has been applied to early measures of moral injury[372] (see section 7.7.3). This limitation relates to the fact that the MDS-R is a list of *situations* rather than a list of *emotions and appraisals* triggered by morally distressing events. Just as exposure to a traumatic experience does not irrevocably lead to pathological levels of PTSD in everyone – it follows that the same is likely to be true of morally distressing situations.

7.5 Contribution to the field

7.5.1 Provision of new data: This study is believed to be the first study to use a standardised scale to measure the phenomenon of moral distress in ICU staff in this country. It was commended for raising

the profile of this aspect of work on ICU, which was described as hitherto 'under-researched', and for providing a 'valuable insight' into the sources of moral distress.[373]

In addition, by collecting data on symptoms of anxiety and depression in this staff group, it also provided the valuable contextual information that mental health problems were not particularly elevated in this sample, confirming the findings of the 'Staff Stress Study' in this regard.

7.5.2 Controlling for gender: Many studies of moral distress have found higher scores in nurses than doctors, leading to a number of speculative suggestions that this might relate to hours by the bedside (higher for nurses) or decision making latitude (higher for doctors). However these studies have not controlled for gender in their analyses. In the case of this dataset the difference first evident between professions was no longer statistically significant, once gender was controlled for. This begs the question as to whether the apparent difference between doctors and nurses may in fact have a more prosaic explanation, in that it might relate more to female response styles when completing psychological questionnaires.

7.5.3 National PICU survey: The choice of questionnaires to measure moral distress in this survey, and' burnout' and PTSD in the 'Staff Stress Survey', informed the methodology of a subsequent national survey of PICU staff, which was supported by PICS UK.[374] This large survey (n=1656) found further evidence of the salience of the concept of moral distress in a paediatric setting and added to the literature, in that it provided information on the overlap between moral distress, PTSD and 'burnout' in this staff group (see Figure 7.2). It also found an association between larger unit size and moral distress, which might explain the finding that one tertiary PICU in Canada[375] reported higher levels of moral distress than other units in that country.[371]

7.5.4 Summary: The 'Moral Distress Study' was the first in the UK to assess moral distress in adult ICU staff and went on, together with the 'Staff Stress Study' to inform the methodology of a national survey of wellbeing in PICU staff.

7.6 Evidence of Impact

7.6.1 Citations: Interrogation of online databases, as described in 2.6, revealed 25 separate peer reviewed citations, in the 18 months since publication (including one with Coville as co-author) after removing duplicates, webpage articles and unpublished theses. Of the articles identified, 12 were symptom prevalence studies; 5 were editorials or commentaries; 4 were reviews of the field and 3 were qualitative studies. Other formats included a description of a staff support service [376] and an intervention study.[377] Three papers were written with specific reference to the impact on staff wellbeing of the current COVID-19 pandemic.[378–380]

7.6.2 Online attention: Field citation ratios were not available on the Dimensions citation database because the paper was less than two years old, but its Altmetric Attention Score, which is an index of online interest, was high at 52. This placed it in the top 3% of over 17 million research outputs tracked by that database and in the top 6% of outputs *of a similar age* across all journals (altmetric.com accessed 9/5/21).

7.6.3 Other types of impact: The author's expanded understanding of the multi-faceted nature of staff stress on ICU, derived from the 'Moral Distress Study', informed a subsequent consultation aimed at improving the support offered to a staff group who had been adversely affected by their involvement in a very difficult and prolonged, high profile court case. As a direct result of this work the author was then also invited to contribute to a multi-disciplinary consultation exercise by the Nuffield Council on

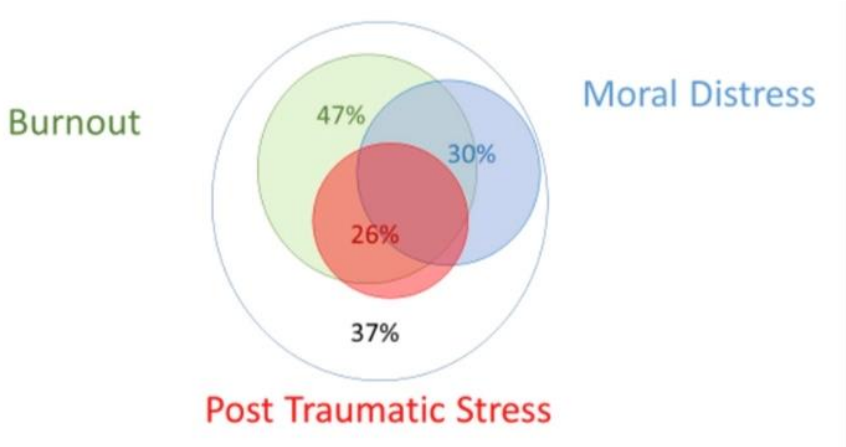


Figure 7.2: Overlapping symptoms of PTSD, 'burnout' and moral distress in a sample of 1656 staff working in PICU in the UK (reprinted with permission from Archives of Disease in Childhood[374])

Bioethics which culminated in the publication of a briefing note on handling disagreements about the care of critically ill children.[381] The publication of this work also led to an invitation from the PCCS to speak on moral injury in relation to the pandemic in 2021 and an invitation to write a chapter on this topic in a text book on bioethics.[382]

7.6.4 Summary: In addition to providing prevalence information on moral distress in ICU staff in the UK, this study raised the profile of this aspect of work-related distress and led to a number of requests for professional input, including consultation, presenting and writing on this topic. It also garnered a notable amount of online attention which, whilst not necessarily predictive of journal references,[383] in this case was associated with a significant number of citations in under two years.

7.7 implications for staff support and further research

7.7.1 Validity of the concept of moral distress: The interest in this study and the burgeoning literature on moral distress in ICU staff, suggests that this is a meaningful concept which adds to the wider understanding of occupational stress in this setting. It is therefore likely to be helpful to staff to be

informed about this aspect of work-related distress, so that they are able to distinguish it from 'burnout' or PTSD.

Some authors have even argued recently that the current 'plague' of 'burnout' in ICU staff would be more accurately conceived of as moral distress, in that it relates primarily to being overworked and under-resourced.[342,384] As described in the previous chapter, staff have grown resentful at the suggestion that they need to work on their resilience,[341] or try harder to 'find joy'[385] in their work. They can also now cite recent research that shows not only that doctors tend to be more resilient than most people, but also that they can also be 'burned out' even when they score at the top of the resilience scale.[340,386]

7.7.2 Evaluation of interventions: There are a few examples of interventions which have used MDS-R score as the main outcome. Wocial et al (2017)[387] evaluated a new style of working, termed 'PEACE communication rounds', which encouraged more regular and in-depth communication, both with families and within teams. Results indicated that the institution of this intervention was associated with lower moral distress in PICU staff and reduced length of stay for patients. Other promising interventions which appear to have had a positive impact on MDS-R scores include educational programmes which provide guidance on how to approach morally distressing stiuations.[388-390]

Another approach which provides a structured plan for targeting moral distress, is the 'Moral Distress Map'[391] (see Appendix 10.7). Future research could examine whether this model, when incorporated into a systematic intervention, might also lead to reductions in moral distress in participants.

However, as with 'burnout', the literature on moral distress is mainly cross-sectional and descriptive. There is clearly an important gap in terms of longitudinal and intervention research but realistically this

can only be breached once there is consensus on an appropriate way to quantify this phenomenon (see also sections 7.4 and 7.7.4).

7.7.3 Moral injury: The term 'moral injury' has been recently the subject of more attention, particularly in relation to the psychological impact of the COVID-19 pandemic on ICU staff. It was first used by Shay in 1994,[392] in relation to treatment-resistant Vietnam War veterans with PTSD. His definition of moral injury was similar to Jameton's definition of moral distress,[362] in that it addressed the strain engendered in a person when they felt they had acted in a way that was not consistent with their core values, but with a greater emphasis on the associated emotional impacts of anger, shame, guilt and a sense of betrayal.

Subsequent elaborations of this first definition[372,393] were followed by the development of a number of scales aiming to quantify this aspect of experience (see section 7.7.4). The two terms 'moral distress' and 'moral injury' are frequently used interchangeably, but Litz and Kerig (2019)[394] have suggested that they are better thought of as existing on a continuum, with moral injury being the most serious manifestation of reactions to a moral stressor (see Figure 7.3). The value of distinguishing between the two concepts is as yet unclear, but the adaptation of the concept of moral injury to health settings is a promising one, which seems deserving of further exploration.

7.7.4 Measurement options: The Moral Distress Thermometer,[365] described above, is the simplest example of a measure of moral distress that can be readily used by individuals or teams trying to gauge how much they have been affected by a difficult situation. The disadvantage of this measure, however, is that it presupposes that respondents are familiar with the definition of moral distress. A scale illustrating more clearly what is meant by this concept is likely to be necessary for future research in this field.

The scale used in this study, the MDS-R is the most commonly used scale for measuring moral distress in health professionals, with data on over 5000 staff now reported in the literature. It has, however, recently been updated, (see section 7.4.2). The result of this revision is that it is now more difficult to compare results on the new MMDHP[360] with those on the MDS-R, as previous items have been reworded and the revised scale includes new items, including one relating to clerical burden.[368]

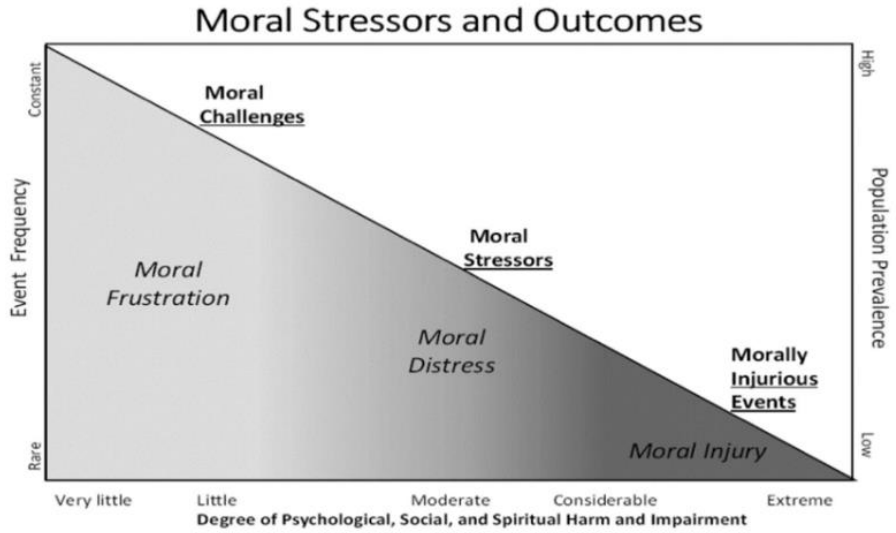


Figure 7.3: The continuum of moral frustration, distress and injury (reprinted with permission from Journal of Traumatic Stress[394])

A number of new scales have also been developed which measure moral injury in military samples. The first of these were similar to the MDS-R, in that their format was that of a list of potentially morally injurious situations encountered in military service,[395,396] but they have since evolved into shorter scales which place greater emphasis on the emotions and appraisals that these events evoke.[397-398] One in

particular, the Moral Injury Symptom Scale (MISS), has recently been adapted for use by health professionals,[399] and might be worth considering for use with ICU staff in future research.

7.7.5 Moral distress/injury associated with the pandemic: Finally, as stated earlier, the concepts of moral distress and injury have a particular salience in relation to the current global pandemic. A study of MDS-R scores in ICU staff, pre- and post- the first wave in the Netherlands, confirmed that moral distress levels increased significantly over this period.[400] Distress was particularly elevated in relation to inadequate resources and safety concerns associated with the competency of redeployed staff, who did not have ICU training, but were needed because of the extraordinary number of admissions. Furthermore, the fact that redeployed staff themselves have reported higher levels of distress in relation to their experiences of the pandemic,[401] may well be due to their own moral distress/injury about working beyond their normal competencies.

In another study of the impact of the pandemic in the UK, ICU staff were surveyed as to their 'burnout' and other psychological symptoms.[402] Although they were not surveyed directly about moral distress, their answer to a question about whether they needed more psychological support was very telling in this regard. They said they did – but for the patients and families, not for themselves. This strongly suggests that one of the main sources of moral distress for them was that they could not provide the level of support they wished to in this difficult situation, because of the external constraints of very high ICU occupancy combined with restricted family visitation policies.

Guidance in professional journals has repeatedly emphasised the moral aspects of the psychological impact on staff of this terrible and much protracted professional crisis,[378] and warned against over-pathologising normal reactions in an extraordinary situation.[358] Evidence of a high rate of PTSD symptoms in ICU staff has however already come to light,[345] with accompanying calls for additional

support to be made available to this staff group, once the crisis has passed. If the experiences of military psychiatrists trying to help war veterans are anything to go by, it may be important to encompass moral distress/injury in psychoeducation and, where necessary, clinical treatment, in order to optimise the chances of successful adaptation in this group, in the longer term.

CHAPTER 8: Conclusions

"When you can measure what you are speaking about,
and express it in numbers, you know something about it"

Lord Kelvin 1889[403]

8.1 Main themes

The body of work discussed in this commentary has illustrated three main themes, or 'golden threads', as they are referred to in relation to research synthesis.[404] These are a) the value of examining different perspectives in relation to admission to intensive care; b) the importance of using validated psychometric measures and statistics to measure these experiences and c) the potential role of the psychologist in this setting. Each of these threads is discussed below and illustrated with reference to the main findings of the studies described in the preceding chapters.

8.2 The value of examining different perspectives

The papers in this portfolio examined the experiences of three different groups – children admitted to intensive care, their parents and staff providing intensive care treatment, in both paediatric and adult settings. The child and parent studies found variability in psychological outcome: over time; between different groups of patients and between patients and their parents. The staff studies also showed how the experiences of health professionals compared with those of the families they care for. This rich harvest of data illuminated many important themes unique to each group, but also some commonalities, in relation to their experiences (see Figure 8.1).

8.2.1 Children: One of the most important strengths of this research is that it sought to obtain information on the PICU experience directly from those concerned including, importantly, children. Although this may seem an obvious thing to do, there was very little information available on how children experienced intensive care before these papers were written. This was likely largely due to the many methodological challenges in this work (see section 1.4), but may also have, in part, reflected a reluctance, in both parents and staff, to recognise children's distress, because they themselves find it painful to acknowledge. There is research evidence that parents are more inaccurate when reporting their children's socio-emotional quality of life than their physical quality of life,[188] and that parent proxy

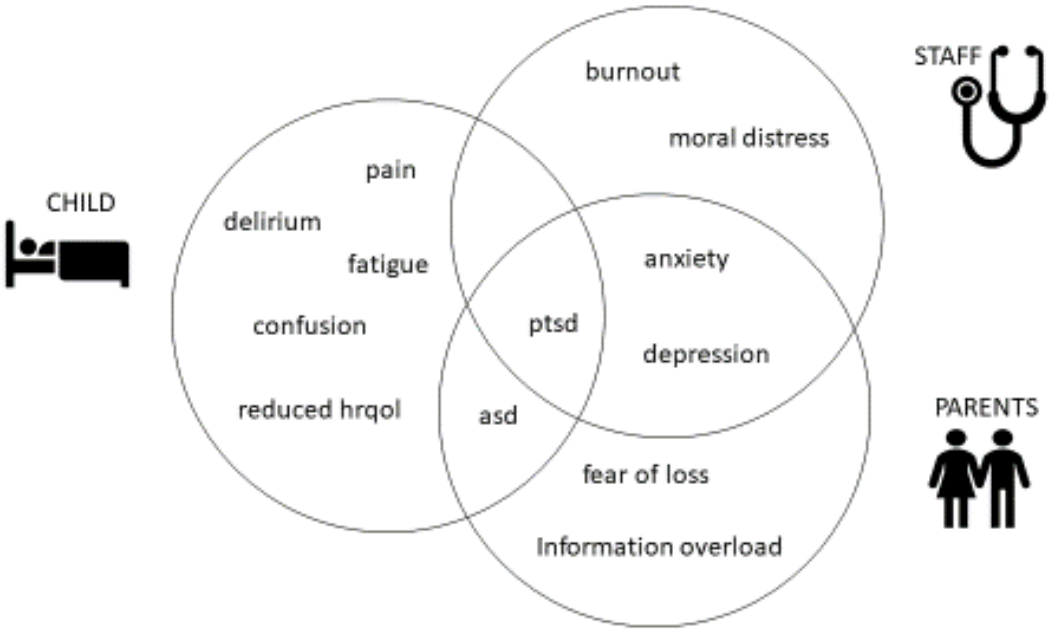


Figure 8.1: Psychological symptoms related to intensive care admission in children, parents and staff

report of acute stress in children is distorted by their own distress.[95] Furthermore, there is evidence that doctors tend to underestimate the HRQoL of children with disabilities.[197] For all these reasons, therefore, it is important to speak to children directly about their experience of PICU.

The research reported in Chapters 2 and 3 built on an initial groundbreaking study on the same sample by the author. This had shown definitively that children, like adults,[86] regularly report disturbing hallucinatory experiences after intensive care treatment,[61] that these are associated with length of time on sedation and predictive of PTSD symptoms at 3 months. Chapter 2 showed that, whilst these delusional memories were less strongly associated with longer term PTSD symptoms, these symptoms persisted and could be associated with events pre- and post-admission, as well as with the admission itself. These findings also highlighted the different perspective children had to their parents, who

continued to remain more preoccupied with the PICU admission, when asked to identify the worst aspect of their experience.

The quality of life data, reported on in Chapter 3, showed that although as a group, PICU survivors reported lower overall HRQoL on the PedsQL™[18] for many months after discharge, the subgroup receiving elective treatment reported *higher* emotional quality of life than their healthy peers and a significant improvement in social functioning over the year. Here a contrast was demonstrated in terms of the different perspectives of different subgroups of patients, challenging doctors' assumptions about children's HRQoL in recovery.

General fatigue levels in children at 3 months post-discharge were found to be similar to those of healthy controls, suggesting that child ICU patients are less troubled by this aspect of recovery than their adult counterparts.[200] However, the fact that their *cognitive* fatigue remained higher is one that warrants further investigation. Also the finding that the group's physical quality of life continued to lag behind their psychosocial quality of life, even a year on, is evidence of the importance of examining both these aspects of health separately.

8.2.2 Parents: A significant proportion of parents reported PTSD symptoms after their child's PICU discharge, but their answers to the anchoring question about what had been the worst thing about their experience, were very different. Unlike their children, they remembered only too well what had happened during the admission and were frequently unable to distinguish the impact of one terrifying event from another, during this ordeal.

A more detailed picture of the nature of the emotional impact on parents of having a critically ill child, emerged in Chapter 5, in which the treatment of a case series using NET was described. Over time, with

the therapeutic scaffolding provided by this approach, they were able to order their fragmented memories and even recall a richer range of experience, which also included positive aspects. These findings were illuminating and have implications for the future care of this population.

8.2.3 Staff: Another kind of distress, 'burnout', was reported by staff. Symptoms of emotional exhaustion were endorsed with the highest frequency in the study featured in Chapter 6, illustrating the strain of working in a high-stakes, life or death situation, where patients should have their whole lives in front of them. These results also highlight the perennial problem in the caring professions of how to maintain empathy, whilst also keeping a professional distance and protecting one's own emotional wellbeing.[337,405] An important finding in Chapter 6 concerned the different associations between particular coping strategies and the two main forms of distress studied, 'burnout' and post-traumatic stress. These findings persisted after personal resilience was controlled for statistically, and have clear implications for intervention.

Another unique form of distress, which had a moral dimension, was measured systematically for the first time in a UK group of ICU staff, in the paper critiqued in Chapter 7.

8.2.4 Commonalities of experience: All three groups reported symptoms of PTSD in relation to their experiences, although the triggers were different. There is a debate in the literature as to whether it is the ICU experience per se that confers this extra risk,[406,407] but what cannot be denied is that the two are significantly associated. The corollary of this is that, from a purely pragmatic perspective, ICU is a good starting point to begin monitoring the risk of developing PTSD, because of the increased exposure to potentially traumatising experiences it poses.

Also, in common with several other studies, no systematic association between objective indices of illness and subsequent distress was found for children in Chapters 2 and 3, or for parents in Chapters 2 and 4. These confirmatory findings bear repeating as they are counter-intuitive and have important implications for the identification of those at greatest risk of poor psychological adjustment.

Finally, although much has been made about differences between professions in relation to moral distress, in the study presented in Chapter 7 it emerged that doctors and nurses rated the same top three items as the most distressing, all of which related to 'end of life' care in situations of futility.

8.3 The importance of measurement

Throughout this portfolio, many examples have been provided of how the application of validated questionnaires has made a significant contribution to a clearer conceptualisation of the nature of distress experienced by the people most affected by an admission to intensive care.

Furthermore, by using statistics to examine repeated measures over time, and their associations, this research has mapped out trajectories of symptoms and identified possible risk factors for the development of distress, which could potentially inform the targeting of interventions at those who most stand to benefit.[7]

8.3.1 The child 's voice: As detailed above, there are many sound theoretical reasons for obtaining direct information from children about their experiences. The studies covered in Chapters 2 and 3 broke new ground in their use of a standardised psychological questionnaires not previously employed with this population. These included the CRIES-8,[91] the ICUM[90] and the PedsQL™ scales,[18] including the Multidimensional Fatigue Scale.[172]

This data extended the literature on the child's perspective on being critically ill, beyond the small number of qualitative studies available,[54,408] facilitating comparisons between units and between conditions.

8.3.2 Screening measures*:* The two intervention studies described in Chapters 4 and 5 also demonstrated that there was an important role for the use of standardised screening measures with parents. Chapter 4 showed that higher scores on the PSS:PICU[68] identified those parents who were more likely to respond well psychologically to the offer of a PICU follow-up clinic appointment. Standardised measures were also essential in relation to the assessment of baseline functioning, and therapy related progress, in the 'NET Study'.

The use of measures of common mental health problems, such as anxiety and depression, in Chapters 2, 4, 5, 6 and 7, also helped to characterise and contextualise the samples of parents and staff studied, in relation to community norms for these types of distress.

8.3.3 Associations between measures: This research also presented a host of examples of interesting statistical associations between variables. These include: the correlation between the child's early avoidance and longer term parental distress in Chapter 2; the negative association between PTSD symptoms and HRQoL in children 12 months after discharge in Chapter 3 and the association between high acute stress and subsequent positive impact on parents of an intervention in Chapter 4.

The data in the 'Staff Stress Study' in Chapter 6, also provided important data with which to refute the proposition that 'burnout' is basically the same clinical entity as depression. The extent to which the different types of distress overlapped in staff is also important to acknowledge going forward, given the different implications for intervention.

8.3.4 Repeated measures: Repeated measures were essential in order to establish the clinical effectiveness of the intervention outlined in Chapter 5, but were also important in the 'PTSD Study' in Chapter 2. Here they provided evidence of possible delayed trauma reactions in a substantial proportion of those parents and children deemed symptomatic at one year, underlining the importance of monitoring this population beyond the early months post-discharge.

In relation to the child data, the repeated measures in the 'Quality of Life Study' provided a more comprehensive picture of the nature of the recovery of PICU survivors, in relation both to different subgroups and with reference to healthy controls, over time.

8.4 The role of the psychologist in intensive care

This PhD by Publication demonstrates, throughout its contents, the added value of a psychological lens to the care of intensive care patients, their families and the staff who treat them. A psychologist has access to a number of useful conceptual frameworks which can be applied to the experiences of families and staff in this unique situation. Furthermore, their ability to measure this distress, in a consistent and validated way, means they are well placed both to monitor patients referred to them, and to compare groups and evaluate interventions, in research studies.[251]

From a clinical perspective, the psychologist has the knowledge and professional training to make careful observations of the people they encounter, in this highly stressful situation, and to put together complex psychological formulations, explaining the reasons for the development and maintenance of their distress. They are thus well placed to support families acutely, when they are trying to make sense of a mass of new information amidst bewilderingly intense emotional reactions. Later on the psychologist can also assist with the construction of a more coherent narrative, which may facilitate the

family's re-integration back into an (albeit 'new') normal life.[158] Their training also equips them for a role encompassing the provision of psychoeducation and support of staff, if resources allow.

8.4.1 Conflicting roles and traditions within the ICU community: As outlined in Chapter 1, there is no tradition of follow up in intensive care, reflecting the fact that it is an emergency specialty. Clinical responsibility for the patient is relinquished by the ICU team, once the patient leaves the unit, even though they may remain in hospital for months. It is for this reason, and because of the necessary primary focus on life saving, that even the nature of patients' physical recovery (let alone their psychological recovery) was not well understood by ICU staff, until relatively recently.

Now though, with mortality rates falling to below 5% on PICU,[25] and also on adult ICU, albeit from a higher baseline,[409] there is more focus on long term morbidity and psychological sequelae,[35,36] although the involvement and support of family members on adult units still lags behind that traditionally found on paediatric units.[410,411]

This 'paradigm shift'[35] has not been welcomed by everybody working in ICU however, with one editorial acknowledging recently that some of this follow up data is 'uncomfortable' to digest.[412] Many in this specialty have self-selected for a highly technological, acute role and are constitutionally less inclined towards long term engagement with families of children who are being more frequently re-admitted with complex chronic conditions.[299,413] They are also uncomfortable with the sense that technological advancement is outpacing guidance on ethical practice, as evidenced by their responses in the 'Moral Distress Study' and the frequent refrain: 'This is not what I came into intensive care to do……'.

Nevertheless, there have been numerous calls within the professions of intensive care medicine and critical care nursing for a refocussing on outcomes in general, and psychological outcomes in

particular.[182] Editorials ask 'When is our job done?'[414] and argue that ICU/PICU teams have a moral obligation to monitor psychological sequelae in patients and families given the extent of data now available.[201,415]

Although some pioneering work has been undertaken, a degree of disillusionment has set in lately, after a number of large intervention trials directed at improving outcomes, have either been beset with recruitment problems or have struggled to demonstrate their effectiveness.[233,261] It is important to note, however, that for the most part these interventions have been nurse-led,[241,416] although interestingly a case-control study in Italy demonstrated that having an embedded psychologist on ICU was associated with lower rates of PTSD and psychotropic medication, in patients one year later.[417] Maybe, as Hodgson and Cuthbertson (2016)[418] put it, in an editorial addressing the paucity of data on effective interventions with ICU patients, 'the healthcare specialists with the most expertise at improving mental health outcomes are surely mental health specialists'?

8.4.2 Whose responsibility is psychological support?: There is a debate to be had about who is best placed to support patients and families and to what extent this responsibility should lie with ICU/PICU, particularly if their problems manifest some time after discharge, as was the case in several families described in chapters 2 and 5.

Responsibility for psychological follow up could pass to the specialist team taking over the patient's care after discharge, but the heterogeneity of these services could make consistency of approach difficult. Another option, could be to make primary care doctors routinely aware of the fact that a recently discharged patient might experience psychological sequelae related to intensive care. However neither of these options provide the family with continuity, something prized by adult ICU survivors,[242] valued

by parents in the 'Follow up ClInic Study' and associated with prompter resolution of distress in the 'NET Study'.

Another approach, would be to resource more clinical psychology posts in ICU settings, instead of expecting hard-pressed critical care staff to develop and offer novel psychosocial interventions alongside providing life-saving medical treatment.

8.4.3 Future psychology provision in intensive care: The research outlined in this commentary suggests a number of potential avenues for the future involvement of psychology in ICU settings: the link between early avoidance in children and later distress in parents in the 'PTSD Study' has implications for intervention, as do the findings of the 'NET Study' and the evidence in favour of certain coping strategies in the 'Staff Stress Study'.

To date however the role of the embedded ICU psychologist is still relatively rare. The small amount of information available on ICU psychologists in the US suggests that that their focus is mainly on rehabilitation,[419] although those in paediatric settings are reportedly more likely to provide acute input,[420] and has led to calls for consensus as to the professional competencies required in these settings.[421]

In contrast a survey of UK PICUs in 1996 found that 31% had access to a psychologist,[422] with this number rising to 64% (18/28) by 2021 (see Figure 8.2). The most recent UK PICS Quality Standards[423] specify that psychological support should be available to children, families and staff, but do not offer detailed guidance on how many posts are appropriate, per unit.

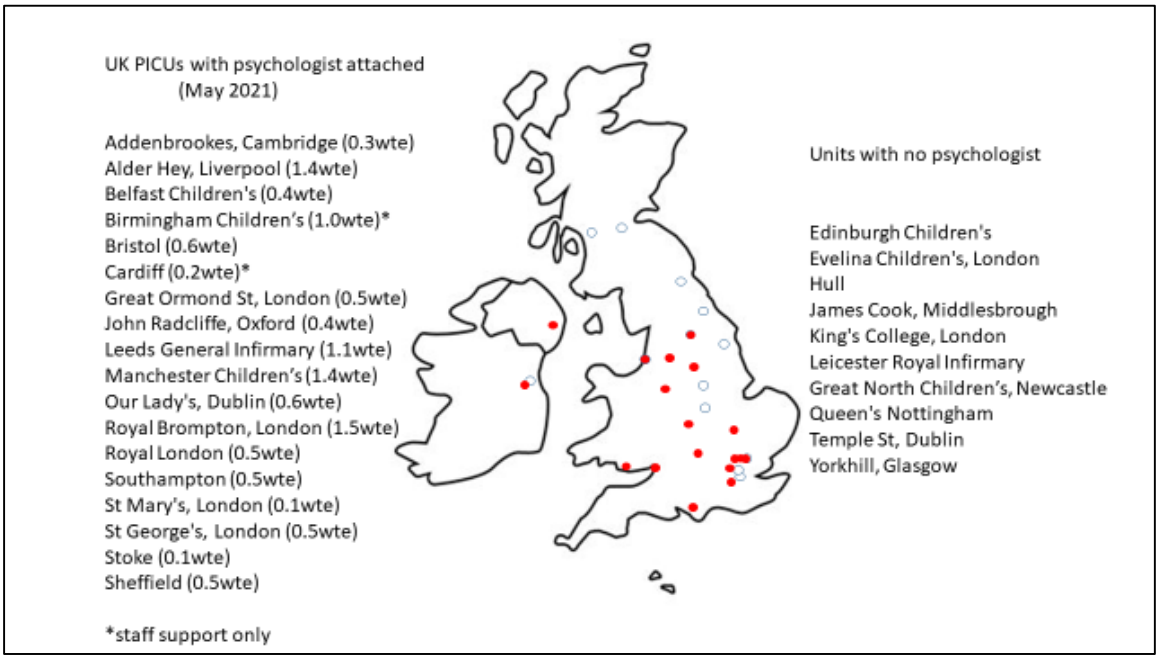


Figure 8.2: Map of UK PICUs which currently have embedded psychologists

(https://www.sgul.ac.uk/profiles/gillian-colville accessed 16/5/21)

A workforce survey of the 270 adult ICUs in the UK found that only 17% offered psychological support to patients and families,[423] but growing appreciation of the psychological impact of the pandemic on staff and families has led to more calls recently for ICU psychologists and may prove to be a catalyst for change.[424]

8.5 Future Directions

Although great strides have been made in relation to our understanding of the extent and nature of the psychological impact of the PICU experience on staff and families, there are still notable gaps in knowledge, particularly regarding screening and intervention. This portfolio, together with other recent literature in this field, has provided a number of pointers in terms of potentially useful brief measures

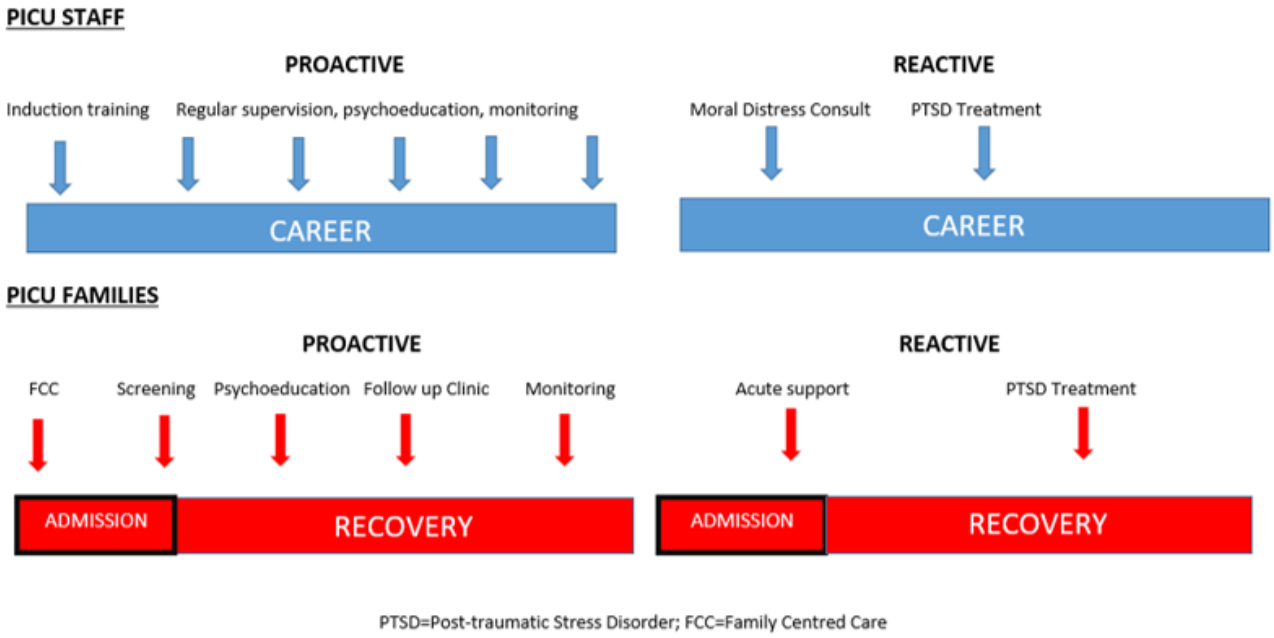
which could be included in screening batteries (see Table 8.1). It has also suggested a potential outline of how interventions, both proactive and reactive, might usefully be scheduled (see Figure 8.2), with good practice likely to include a combination of both and, in the case of staff, to involve regular screening and the provision of ongoing psychoeducation and support services, across the career span.

Future research is also needed to establish how different risk and protective factors, interacting over time, determine the extent to which people's wellbeing is affected by being in this challenging setting, whether they find themselves on PICU by accident or design. The framework depicted in Figure 8.4 outlines a number of candidate variables which deserve further exploration, drawing on this body of work and on three theoretical models (the PMTS model,[20] a conceptual model of post-ICU PTSD[113] and the Job Demands-Resources model[306]). It also acknowledges research findings from the wider trauma literature which have consistently found that PTSD risk is more related to intrapsychic variables, such as pre-trauma mental health problems and negative peri-traumatic appraisals, than to objective measures of trauma severity.[155]

Table 8.1: Measures for monitoring psychological wellbeing of PICU staff and families

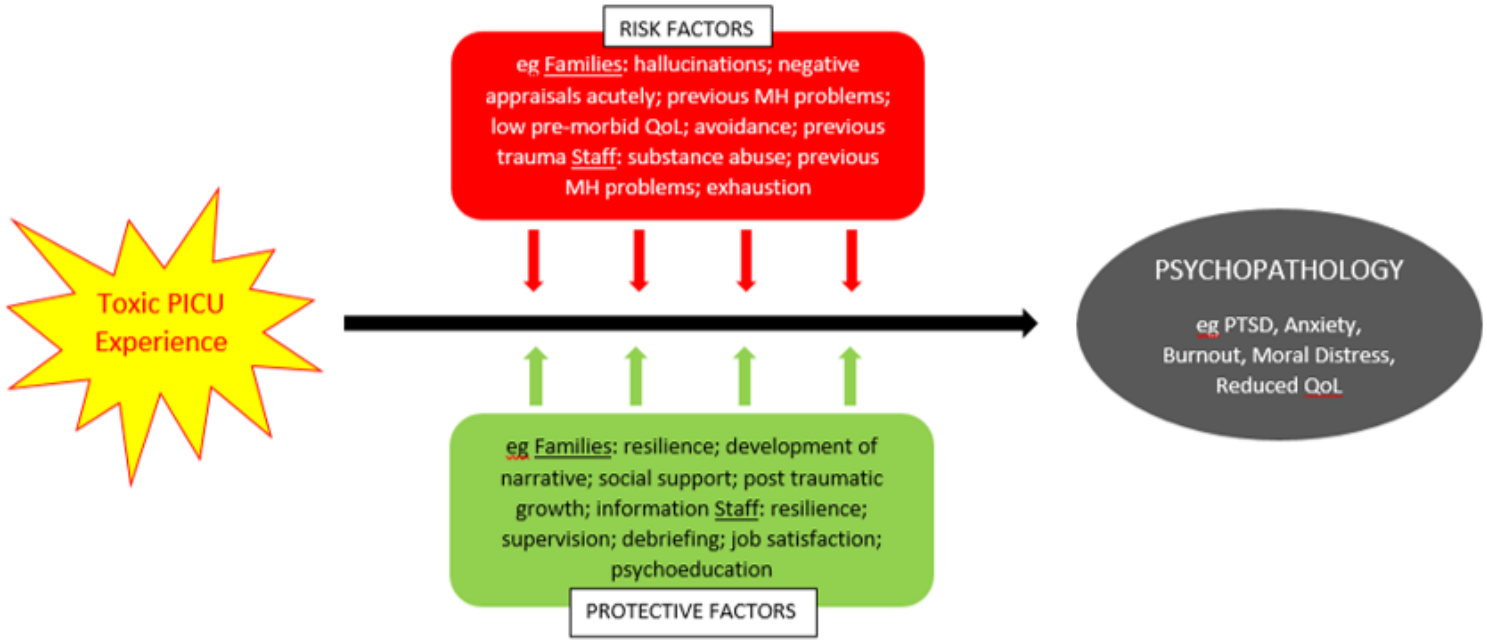
PICU Patients
• ICU Memory Tool[90] (Acute experience on PICU for age >7y) • CRIES-8[91](Post-traumatic Stress Disorder age >7y) • Young child PTSD Screen[96] (PTSD age 3-6y) • PedsQL Quality of Life Scale[18,19] • PedsQL Fatigue Scale[19,172]
PICU Parents
• Parental Stressor Scale:PICU[68;147] (Acute Stress related to PICU) • Posttraumatic Adjustment Scale[155] (Risk of PTSD/depression) • Trauma Screening Questionnaire[317](PTSD) • Hospital Anxiety and Depression Scale[89] • PHQ-4 (Anxiety and depression)[370] • Brief Resilience Scale[318] • PedsQL Family Module[19,122]
PICU staff
• abbreviated Maslach Burnout Inventory[316] (Burnout) • Trauma Screening Questionnaire[317] (PTSD) • Moral Distress Thermometer[365] • MMDHP[359] (Moral distress) • MISS-HP[398] (Moral injury) • Hospital Anxiety and Depression Scale[89] • PHQ-4[370] (anxiety and depression) • Brief Resilience Scale[318]

Figure 8.3: Proposed intervention schedule



PTSD=Post-traumatic Stress Disorder; FCC=Family Centred Care

Figure 8.4: Psychopathology after PICU: risk and protective factors



MH=mental health; QoL=quality of life; PTSD=Post-traumatic stress disorder

8.6 Conclusions

This portfolio illustrates what the discipline of clinical psychology can add to the conceptualisation and measurement of distress associated with the treatment of critically ill patients. In particular, it demonstrates the value of standardised psychological tools in helping to map out the territory of human experience in relation to this uniquely stressful situation, whether from the perspective of the family or staff. This body of work has influenced the research agenda and practice in this field, as evidenced by these papers' impact metrics (see Appendix 10.7) their contribution to the conceptualisation of PICS in children, as detailed in a co-authored paper,[36] which was the most cited aticle in 2018, in *Pediatric Critical Care Medicine,* the leading journal in the field and by the invitation to the author to act as co-investigator on a prestigious NIH grant examining long term outcomes after PICU.

The main findings of this research have a number of implications for clinical work and future research as detailed above. It is clear that there is much still to be learned about the ways in which families are affected by their experiences and more longitudinal studies are clearly warranted in this field. Also, from a staff perspective, the demands on health professionals working in intensive care settings - not least in the current pandemic - are also concerning. It will be important to continue to elicit risk and protective factors in this regard and to evaluate promising evidence-based interventions.

This thesis also provides an example of what can be learned by combining the two main professional stances of the author, namely that of clinician and researcher. Whilst there is an inevitable tension between these two positions, with some arguing that 'once a clinician, always a clinician',[9] it has been enormously helpful as a clinician, to be able to rely on relevant psychological theories and concepts and the rigour of psychometrics, as a way to maintain a scientist-practitioner perspective. At the same time, it has been humbling to be regularly 'at the coal face' clinically. This has mitigated against the danger of

the author getting carried away with theories and repeatedly brought up meaningful research questions from the front line.

There have also been personal rewards in finding and applying evidence-based ways to alleviate suffering and helping families and staff to label what they are experiencing, a simple act with very powerful consequences.[425]

In conclusion, although the main focus of this work has inevitably been distress, these papers have also identified a number of important positive aspects to people's experience of intensive care: in most cases children's HRQoL was restored in the year following their PICU stay; even a one off opportunity to speak with the PICU team was associated with a significant reduction in parental distress and for those with the most entrenched symptoms, a brief treatment was found to be effective and helped them remember the good things that had happened, not just the bad. And as regards staff, many had found ways to cope with the stress they encountered and only a minority reported significant problems. This is an emotionally demanding specialty to work in, whether as a nurse or a doctor – or even a psychologist – but as Schwingshakl puts it beautifully, the rewards of such a meaningful job are hard to rival.[426]

Finally, it is important to remember that human beings are built to adapt and the 'ordinary magic'[427] that comes into play at times of difficulty, helps to see them through, with most of those those who suffer also able to experience joy again. Indeed, the early work of Tedeschi and Calhoun on the phenomenon of post-traumatic growth,[428] has shown that those who report the greatest happiness in their old age are not those who have led especially contented lives, but those who have survived and learned to thrive after adversity, illustrating Nietzsche's dictum that for many 'what does not kill us, makes us stronger'.[72]

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10.0 APPENDIX

APPENDIX

10.1 Literature on distress in children and parents after PICU

Darker shading in Tables 1 and 2 indcates literature published between data collection and publication of 'PTSD Study'

Table 1: Comparisons with previous quantitative studies of psychological distress symptoms in *children* after PICU

First Author (date)	Country	n	Inc parent data?	Child self-report	Follow up	Standardised measure of PTSD	Control Gp?
COLVILLE 2012[40]	UK	66	✓	✓	3m; 12m	✓	x
ELISON 2008[59]	UK	16	x	✓	3-7m	✓	✓healthy
BRONNER 2008[58]	Netherlands	36	✓	✓	3m; 9m	✓	✓ fire
MURANJAN 2008[60]	India	17	x	✓	1m	✓	✓ gen ward
COLVILLE 2008[61]	UK	102	x	✓	3m	✓	x
SMALL 2006[62]	US	163	x	x	3m; 6m	x	x
REES 2004[63]	UK	19	✓	✓	6-12m	✓	✓
RENNICK 2004[64]	Canada	60	x	✓	6w; 6m	x	✓gen ward
RENNICK 2002[50]	Canada	60	x	✓	6w; 6m	x	x
YOUNGBLUT 1993[65]	US	9	x	x	4w	x	x
JONES 1992[66]	US	18	x	✓	T0	x	✓gen ward

Table 2: Comparisons with previous quantitative studies of psychological distress in *parents* after PICU

First Author (date)	Country	n PICU parents	Inc child data?	Follow up	Standardised measure of PTSD?	Control Gp?
COLVILLE 2012[40]	UK	66	✓	3m; 12m	✓	x
BRONNER 2010[71]	Netherlands	190	X	3m; 9m	✓	x
BRONNER 2009[70]	Netherlands	115	X	T0; 3m	✓	x
COLVILLE 2009[72]*	UK	50	X	T0; 4m	✓	x
BRONNER 2008[69]	Netherlands	247	X	3m	✓	x
COLVILLE 2006[73]*	UK	34	X	8m	✓	x
REES 2004[63]	UK	33	✓	6-12m	✓	✓gen ward
BOARD 2004[74]*	US	15	X	T0	x	✓gen ward
BALLUFFI 2004[49]	US	161	X	2-11m	✓	x

BOARD 2003[75]*	US	31	X	T0; 2w; 6w; 6m	x	✓gen ward
BOARD 2002[76]*	US	31	X	T0; 2w; 6w; 6m	x	✓ gen ward + healthy
TOMLINSON 1995[77]	US	20		1w; 9w	x	x
HAINES 1995[78]*	US	71	X	T0	x	x
LAMONTAGNE 1994[79]	US	22	X	T0	x	x
YOUNGBLUT 1993[80]*	US	18	X	T0; 2w; 4w	x	x
YOUNGBLUT 1992[81]*	US	29	X	T0	x	x
MILES 1991[82]*	US	28	X	T0	x	x
GRAVES 1990[83]	US	50	X	T0	x	x
MILES 1989[84]*	US	510	X	T0	x	x
JOHNSON 1988[85]*	US	41	X	T0	x	x

*used Parental Stressor Scale:PICU

Table 3: Quantitative studies of psychological distress symptoms in *children* after PICU, since publication of 'PTSD Study' in 2012

First Author (date)	Country	n	Inc parent data?	Child self-report	Follow up	Standardised measure of PTSD/ASD	Control Gp?
LONG 2021[133]	Australia	265	x	x	1m;3m;6m; 12m	✓	x
NELSON 2021[105]	US	111	x	✓	Pre;T0	✓	x
LE BROCQUE 2020[120]	Australia	272	✓	x	Pre;2m;3m; 6m;12m	✓	x
KYOSTI 2020[134]	Finland	753	x	x	>6y	x	x
KYOSTI 2019[135]	Finland	1105	x	x	>6y	x	x

NELSON 2019[106]	US	69	✓	✓	Pre;T0;1m; 3m	✓	x
DOW 2019[136]	Australia	95	x	✓	1m	✓	x
CASPANI 2019[137]	UK	71	✓	✓	3-6m	✓	x
VET 2016[138]	Netherlands	64	x	✓	2m	✓	x
ALS 2015[139]	UK	88	x	✓	5m	✓	x
STOWMAN 2015[140]	US	50	✓	✓	T0;6w	✓	x
DOW 2012[106]	Australia	55	x	✓	6m	✓	x

Table 4: Quantitative studies of psychological distress symptoms in *parents* after PICU, since publication of 'PTSD Study' in 2012

First Author (date)	Country	n	Inc child data?	Follow up	Standardised measure of PTSD/ASD	Control Gp?
ALZAWAD 2021[141]	US	81	x	Pre;T0	x	x
RILEY 2021[121]	US	88	x	1-3m	✓	x
LOGAN 2020[123]	US	95,070	x	Pre;6m	✓	x
ROTHSCHILD 2020[124]	US	232	x	Pre;T0;1m	✓	x
LE BROCQUE 2020[120]	Australia	215	✓	1m	✓	x
JARVIS 2019[142]	US	168	x	T0;3m;6m	x	x
RODRIGUEZ-REY 2019[143]	Spain	196	x	T0;6m	x	x

NELSON 2019[106]	US	69	✓	T0;1m;3m	✓	x
RODRIGUEZ-REY 2018[144]	Spain	196	x	T0;3m;6m	✓	x
STREMLER 2017[145]	Canada	118	x	T0	x	x
RODRIGUEZ-REY 2017[146]	Spain	143	x	6m	✓	x
RODRIGUEZ-REY 2016[147]	Spain	196	x	T0;3m	✓	x
STOWMAN 2015[140]	US	50	x	T0;6w	✓	x
MORTENSEN 2015[148]	Denmark	90	x	T0	✓	x
AAMIR 2014[149]	India	49	x	T0	x	x
POONI 2013[150]	India	100	x	T0	x	x
JEE 2012[151]	UK	100	x	T0	x	x
GLADSTON 2012[152]	India	182	x	T0	x	x

APPENDIX

10.2 Supplementary Information for Paper 1

Supplementary information on psychological measures, comparisons between recruits and non-recruits and comparisons between drop-outs and those families who remained in the study (supplied with original paper in Intensive Care Medicine 2012)

SUPPLEMENTARY INFORMATION

- Further information on psychological measures
- Table A: Sample characteristics of children from analysed and non-analysed families
- Table B: Comparison between the psychological scores of those children and parents who provided full data at one year and those who did not

10.2.1 Further information on psychological measures

1) The Children's Revised Impact of Event Scale

The Children's Revised Impact of Event Scale (CRIES-8)[S1] is derived from the adult Impact of Event Scale[S2] which is internationally the most widely used screening instrument for post-traumatic stress disorder in adults, although there are a number of reports of its use with children. It was modified by Yule who found, in large scale follow-up studies, that children regularly misinterpreted a number of the questions.[S3] He therefore proposed that a shortened version be used with children, using the 8 items which best reflected the underlying factor structure of the original. Items are scored 0-5 depending on the frequency with which they are experienced by the child and it is possible to calculate separate subscale score for symptoms of avoidance and intrusion. Scores range from 0-40 for the total scale and 0-20 for each subscale. The 8 item version of the questionnaire does not contain any items referring to symptoms of hyperarousal, which are required as part of any formal diagnosis of full PTSD but is reported to perform just as well as the longer 13 item version, which has an additional hyperarousal subscale, in terms of discriminating clinically significant levels of distress.[S4]

The CRIES-8 has not been used before, to our knowledge, with PICU survivors but has been used extensively with children after a wide range of other traumatic experiences including war, disaster and road accidents.[S3,S5,S6] Its criterion validity has been demonstrated by high correlations with the original Impact of Event Scale ($r=0.95$ $p<0.001$)[S3] as well as with an extended clinical interview, designed to elicit a diagnosis of post-traumatic stress disorder.[S1] It was chosen for its brevity, its well documented use with large samples of children, its criterion validity and its efficiency.[S4]

S1. Yule W. Anxiety, depression and post –traumatic stress in childhood. In: Sclare I, editor. *Child Psychology Portfolio*, Windsor, UK: NFER-Nelson; 1997. p. 35-38.
S2. Horowitz MJ, Wilner N, Alvarez W. Impact of Event Scale: a measure of subjective stress. *Psychosom Med* 1979; 41: 209-218.
S3.Yule W, ten Bruggencate S, Joseph S. Principal components analysis of the Impact of Event Scale in adolescents who survived a shipping disaster. *Pers Individ Dif* 1994; 16: 685-691.
S4. Perrin S, Meiser-Stedman R, Smith P. The Children's Revised Impact of Event Scale (CRIES): Validity of a screening instrument for PTSD. *Behavioural and Cognitive Psychotherapy* 2005; 33: 487-498.
S5. Smith P, Perrin S, Dyregov A, Yule W. Principal components analysis of the Impact of Event scale with children in war. *Pers Individ Dif* 2003: 34: 315-322.
S6. Stallard P, Velleman R, Baldwin S. Psychological screening of children for posttraumatic stress disorder. *J Child Psychol Psychiatry* 1999; 40: 1075-1082.

2) SPAN

The SPAN[S7] is a brief post-traumatic stress symptom screening questionnaire for use with adults which is made up of four items ('Startle', 'Physiological Arousal', 'Anger' and 'Numbness') from the Davidson Trauma Scale[S8] each of which are scored 0 = 'not at all distressing' to 4 = 'extremely distressing' with total scores ranging between 0 and 16. In studies validating this measure against a diagnostic clinical interview involving 243 patients who had endured a range of traumas including rape, combat related events

and natural disasters, a cut-off of ≥5 has been shown to classify correctly 88% of diagnosed cases of PTSD.[S7] Although very brief, it has been found to have acceptable psychometric properties and its overall efficiency is as good as that of longer, more complicated scales.[S9]

S7. Meltzer-Brody S, Churchill E, Davidson JRT. Derivation of the SPAN, a brief diagnostic screening test for post–traumatic stress disorder. *Psychiatry Res* 1999; 8:63-70.
S8. Davidson JR, Book SW, Colket JT et al. Assessment of a new self-rating scale for post-traumatic stress disorder. *Psychol Med* 1997; 27: 153-160.
S9. Brewin CR. Systematic review of screening instruments for adults at risk of PTSD. *J Trauma Stress.* 2005; 18: 53-62.

3) Hospital Anxiety and Depression Scale

The Hospital Anxiety and Depression Scale (HADS)[S10] is a self-report questionnaire, made up of two separate scales, one measuring anxiety (7 items) and the other measuring depression (7 items), with responses weighted 0-3 for frequency. It was originally designed for use with hospital patients suffering from physical health problems and for that reason does not include any somatic symptoms, but is now also frequently used in community samples as a screen for mental health problems. For each scale the authors suggest that scores of 8-10 indicate mild symptoms, 11-13, moderate symptoms, and ≥14, severe symptoms. It is widely used internationally, has demonstrated good levels of internal consistency (0.93 for anxiety and 0.9 for depression) and test-retest reliability (0.54 for anxiety and 0.79 for depression).[S11] and its factor structure has been confirmed in a number of different populations.[S12] A community survey (n=1792) in the UK recently found that 12.6% of the sample reported HADS anxiety subscale scores ≥11 and 3.6% scored at that level on the HADS depression subscale.[S13]

References

S10. Zigmond AS, Snaith RP. The Hospital Anxiety and Depression scale. *Acta Psychiatr Scand* 1983; 67: 361-370.
S11. Bjelland I, Dahl AA, Haug TT et al. The validity of the Hospital Anxiety and Depression Scale: an updated literature review. *J Psychosom Res* 2002; 52: 69-77.
S12. Moorey S, Greer S, Watson M et al. The factor structure and factor stability of the hospital anxiety and depression scale in patients with cancer. *Br J Psychiatry* 1991; 158: 255-259
S13. Crawford JR, Henry JD, Crombie C et al. Brief report: Normative data for the HADS from a large non-clinical sample. *Br J Clin Psychol* 2001; 40: 429-434.

10.2.2 Tables of sample characteristics

Table A: Sample characteristics of children from analysed and non-analysed families

	Analysed n=66 n (%) or median (range)	Non-analysed n=66 n (%) or median (range)	***p*[a]**
Demographics			
Age (years)	11.5 (6.8 - 16.9)	12.3 (6.9 - 18.1)	0.095
Male sex	38 (58%)	41 (62%)	0.594
Ethnic category (white UK)	40 (61%)	39 (59%)	0.859
Social Deprivation[b]	31 (47%)[c]	30[c] (45%)	0.860
Medical variables			
Length of stay (days):	2 (0 - 38)	2 (0 - 25)	0.077
Severity of illness (PIM)	4 (1 - 42)[c]	5.3 (0 - 30)[d]	0.159
Ventilated	61 (92%)	56 (85%)	0.170
Emergency admission	55 (83%)	52 (79%)	0.505

[a] Pearson's χ^2 or Fisher's Exact test used for categorical data; Mann Whitney U test used for continuous data; [b]Defined by proportion in the most deprived quintile, using the Townsend Deprivation Index ; [c]n=65;[d]n=63.

PIM, Paediatric Index of Mortality.

Table B: Comparison between the psychological scores of those children and parents who provided full data at one year and those who did not

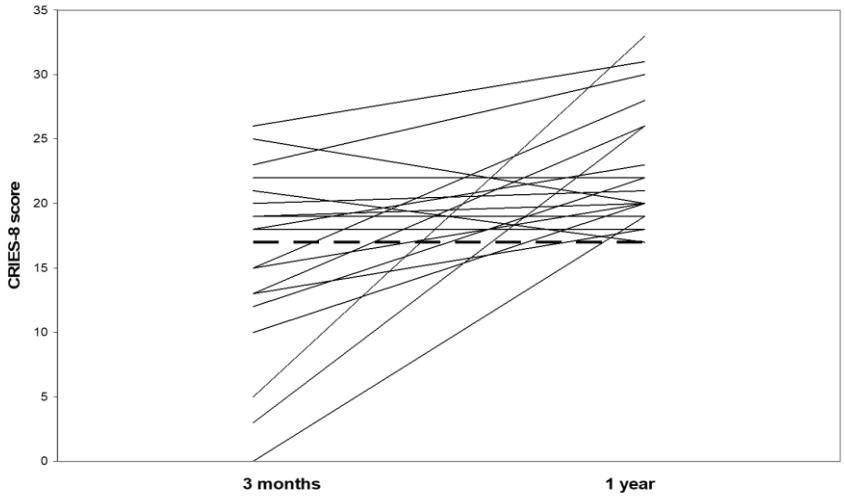
	Psychological scores at 3 months				
	Families with complete data at one year		Families who dropped out		
	median (range)	n	median (range)	n	***p*[a]**
Children:					
Post-traumatic stress (CRIES-8)	10(0-26)	66	7 (0-24)	30	0.137
Avoidance subscale (CRIES-8)	6 (0-18)	66	5 (0-18)	30	0.194
Intrusion subscale (CRIES-8)	4 (0-16)	66	3 (0-12)	30	0.243
Parents:					
Post-traumatic stress (SPAN)	4 (0-16)	66	4 (0-16)	34	0.714
Anxiety (HADS)	6 (0-18)	66	8 (0-18)	33	0.240
Depression (HADS)	2 (0-20)	66	3 (0-16)	33	0.503

[a]Mann Whitney U test.

CRIES-8, Children's Revised Impact of Event Scale; SPAN, abbreviated form of the Davidson Trauma Scale; HADS, Hospital Anxiety and Depression Scale.

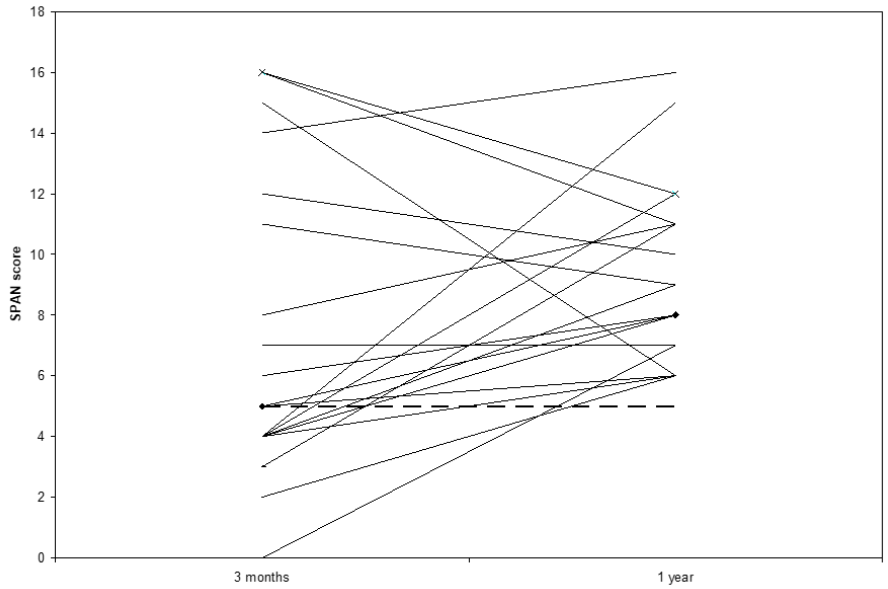
10.2.3 Trajectories of PTSD symptoms at 3 months and 12 months, for children and parents who scored above cutoff at 12 months

Figure 1a: Individual post-traumatic stress symptom trajectories for children scoring above cut-off (>=17) at 1 year (n=19/74)



CRIES-8, Child Revised Impact of Event Scale (8 item version)

Figure 1b: Individual post-traumatic stress symptom trajectories parents scoring above cut-off (>=5) at 1 year (n=21/72)



SPAN=short form of Davidson Trauma Scale

APPENDIX

10.3 Supplementary Information for Paper 2

10.3.1 Tables

Table S1. Comparisons between sample characteristics of recruited and non-recruited children

	Frequency n (%) or median (range)		
	Recruited n=102	Non-recruited n=30	*p* [a]
Demographics:			
Age (years)	11 (7 -17)	13 (9 - 18)	.003
Male sex	59 (58%)	20 (67%)	.39
Ethnic category (white UK)	58 (57%)	21 (70%)	.20
Social Deprivation[b]	50 (49%)	11 (37%)	.27
Medical variables			
Length of stay (days):	2 (0 - 38)	1 (0 -17)	.01
PIM	4 (0 - 42)	4 (0 - 22)	.13
Mechanically ventilated	93 (91%)	24 (80%)	.11

UK, United Kingdom; PIM, Paediatric Index of Mortality (20).

[a]Pearson's χ^2 or Fisher's Exact test used for categorical data, Mann Whitney used for continuous data; [b]proportion in the most deprived quintile as measured by the Townsend Deprivation Index (21)

Table S2. Comparisons between sample characteristics of children who provided data at 3 months only (n=25) with those who provided full data at 3 months and at one year (n=72)

	Frequency n (%) or median (range)		
	3 month data only n=25	3 month and one year data n=72	p^a
Demographics:			
Age (years)	11.5 (6.9 – 16.7)	11.2 (6.8 – 16.9)	.80
Male sex	15 (60%)	40 (56%)	.70
Ethnic category (white UK)	13 (52%)	41 (57%)	.67
Social Deprivation[b]	14 (56%)	35 (67%)	.56
Medical variables:			
Length of stay (days)	2.0 (0 - 20)	2.0 (0 – 38)	.32
PIM score	4.5 (1 - 30)	5.0 (1 – 42)	.72
Mechanically ventilated	23 (92%)	67 (93%)	1.00
Psychological variables at 3 months:			
CRIES-8 total score	7 (1 - 24)	10 (0 – 26)	.36
PedsQL total score	85.9 (26.4 – 100)	80.4 (34.8 – 98.9)	.22

UK, United Kingdom; PIM, Paediatric Index of Mortality (20); CRIES-8, Children's Revised Impact of Event Scale; PedsQL, Pediatric Quality of Life Inventory.

[a]Pearson's χ^2 or Fisher's Exact test used for categorical data; Mann Whitney used for continuous data;[b]proportion in the most deprived quintile as defined by the Townsend Deprivation Index (21).

Table S3. Children's self-reported health related quality of life in the year after discharge from intensive care: comparisons with norms for healthy children

Pediatric Quality of Life Inventory (PedsQL) [a]	Healthy UK Sample (n=1033) [b]	PICU Sample at three months							
		Whole Sample (n=97)		Elective (n=15)		Emergency (n=82)			
						TBI (n=36)		Other (n=46)	
	mean (SD)	mean (SD)	*p*	mean (SD)	*p*	mean (SD)	*p*	mean (SD)	*p*
Total Score	83.9 (11.8)	79.1 (14.9)	.003	72.0 (12.6)	.003	82.9 (13.7)	.656	78.5 (15.9)	.027
Physical Health Summary Score	88.5 (11.6)	73.8 (23.5)	<.001	55.2 (25.5)	<.001	80.6 (18.8)	.017	74.6 (23.4)	<.001
Psychosocial Health Summary score	81.8 (13.2)	82.5 (12.6)	.642	81.7 (9.8)	.964	84.6 (12.3)	.198	81.0 (13.7)	.709
Emotional Functioning Subscale score	78.5 (17.9)	84.7 (16.6)	<.001	91.0 (14.2)	.005	84.2 (18.2)	.071	83.0 (15.9)	.065
Social Functioning Subscale score	87.7 (16.5)	87.0 (14.6)	.684	80.0 (14.0)	.059	91.8 (12.0)	.050	85.5 (15.6)	.374
School Functioning [c] Subscale score	78.9 (15.9)	74.3 (17.9) $^{(n=76)}$	.035	71.7 (19.2) $^{(n=12)}$	.226	76.3 (17.0) $^{(n=28)}$	.429	73.8 (18.6) $^{(n=36)}$	.110

PICU, pediatric intensive care unit; TBI, traumatic brain injury.

[a]Scores range from 0-100, with higher scores indicating fewer problems; [b]Upton et al, 2008 (30); data were compared with norms for UK healthy sample using two-tailed Student's *t* test; [c]21 children had not yet returned to school 3 months after discharge and were therefore unable to complete this subscale at this time.

Table S4. Associations between post-traumatic stress symptom score and the Pediatric Quality of Life Inventory subscale scores at 1 year post-discharge from PICU (n=72)

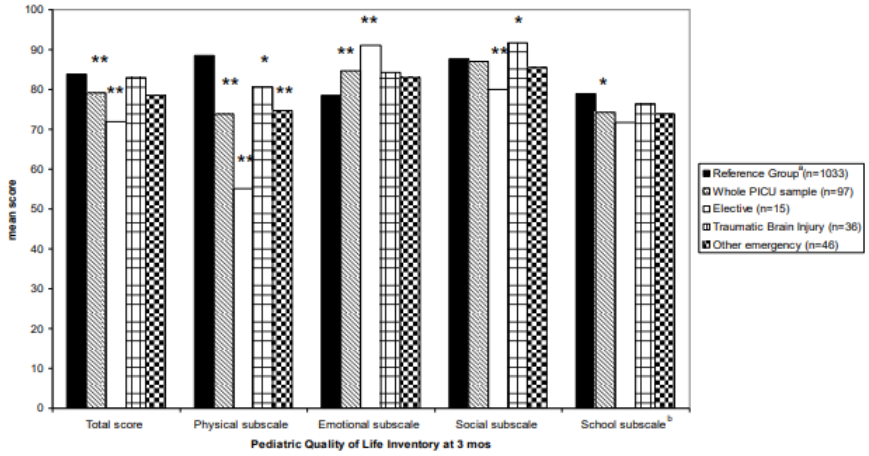
Pediatric Quality of Life Inventory (PedsQL) [b]	Spearman correlation with post-traumatic stress score [a] at 1 year							
	Whole Sample (n=72)		Elective (n=11)		Emergency (n=61)			
					TBI (n=27)		Other (n=34)	
	r	*p*	r	*p*	r	*p*	r	*p*
Total Score	-.40	.001	-.28	.408	-.56	.002	-.33	.055
Physical Health Summary Score	-.23	.054	-.24	.479	-.40	.038	-.21	.240
Psychosocial Health Summary score	-.41	<.001	-.01	.968	-.56	.003	-.38	.029
Emotional Functioning Subscale score	-.46	<.001	-.08	.825	-.60	.001	-.38	.029
Social Functioning Subscale score	-.18 $^{(n=71)}$	.142	.07	.835	-.26	.196	-.18 $^{(n=33)}$	.305
School Functioning Subscale score	-.40	<.001	.14	.680	-.57	.002	-.35	.041

PICU, pediatric intensive care unit; TBI, traumatic brain injury.

[a] Post-traumatic stress symptoms were measured with the Children's Impact of Event Scale (Revised) 8 item version; [b]Scores range from 0-100, with higher scores indicating fewer problems

10.3.2 Graphs

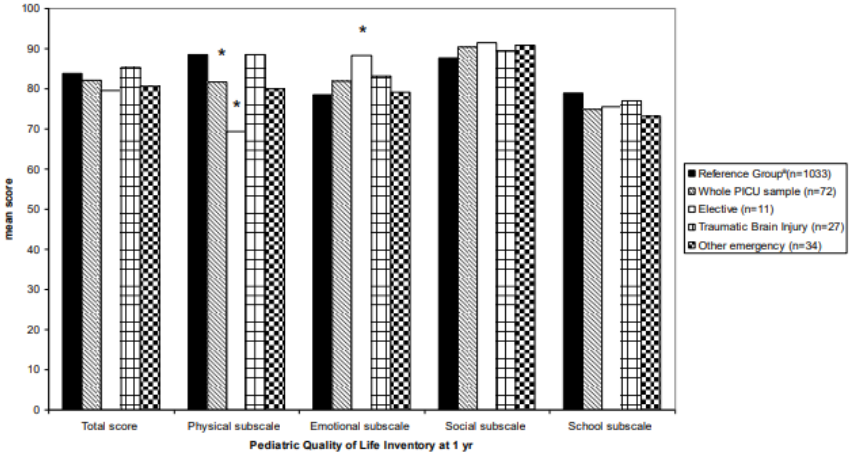
Supplemental Figure 1a: Children's Self-Reported Health-Related Quality of Life 3 Months After Discharge from Intensive Care: Comparisons with Norms for Health Children



[a] Data were compared with Reference norms for United Kingdom healthy sample (Upton et al [33]) using two-tailed Student's t test *p<0.05 **p<0.01

[b]21 children had not yet returned to school after discharge and were therefore unable to complete this subscale 3 mos

Supplemental Figure 1b: Children's Self-Reported Health-Related Quality of Life 1 Year After Discharge from Intensive Care: Comparisons with Norms for Healthy Children



[a] Data were compared with Reference norms for United Kingdom healthy sample (Upton et al [33]) using two-tailed Student's t test *p<0.05 **p<0.01

APPENDIX

10.4 Supplementary Information for Paper 4

ELECTRONIC SUPPLEMENTARY MATERIAL

1) Further information on psychological measures

2) Breakdown of parents' responses re non-attendance (intervention group) and the need for follow-up (control group)

3) Statistical power considerations

4) Table A: Baseline characteristics of the children of participating and non-participating families

5) Table B: Baseline characteristics of recruited families who provided outcome data at five months compared with those of families who did not

1) Further information on psychological measures

a) Parental Stressor Scale: Pediatric Intensive Care Unit

The Parental Stressor Scale: Pediatric Intensive Care Unit (PSS: PICU) is a 37 item Likert scale questionnaire which measures parents' perceptions of PICU associated stress on seven different dimensions: 'Child's appearance'; 'Sights and sounds'; 'Procedures'; 'Parental role'; 'Child's behavior'; 'Staff behavior' and 'Staff communication'. The total score is the mean of the seven subscale mean item scores and ranges between 1 ("not stressful") and 5 ("extremely stressful"). Items for inclusion in the early versions of this questionnaire were obtained from a number of sources including literature searches, parental observations and interviews and nurse consultation exercises [1]. Factor analysis was then used to reduce the length of the original instrument and to group items into meaningful dimensions. Finally the questionnaire was administered to a sample of 510 parents and further revised from 62 to the final 37 item version [2]. Construct validity was demonstrated for this version by the developers in terms of significant correlations (all p=0.0001) for all seven subscales with an established measure of anxiety (Spielberger's State–trait Anxiety Inventory [3]). The reliability of the original questionnaire has since been further confirmed in a number of studies [4-7], which report Cronbach alpha coefficients of between 0.90 and 0.96 for the total instrument, and between 0.72 and 0.99 for the individual subscales.

To date, The PSS:PICU has been used to establish he differences between the experiences of parents of intubated and non-intubated children on PICU [6] and to gauge the impact of interventions designed to improve the experience of caregivers [4,5,8]. It is available, and has been further validated, in both Spanish [9] and Chinese [10] versions but, prior to the present study, has not been used before to predict risk of subsequent psychopathology.

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[10] Yam BM, Lopez V, Thompson DR. The Chinese version of the PSS:PICU. Nurs Res 2004; 53(1): 19-27.

b) Impact of Event Scale

The Impact of Event Scale [1] is the most widely used measure of symptoms of Post-traumatic Stress Disorder (PTSD). It is made up of 15 questions about 8 symptoms of avoidance (eg not wanting to talk about what happened) and 7 symptoms of intrusion (eg flashbacks, nightmares), related to a specified traumatic event. Each question is scored according to the frequency with which the symptom is experienced, from 0 ('not at all') to 5 ('often'), with total scores ranging between 0 and 75. Although it was originally devised before the formal identification of the Posttraumatic Stress Disorder (PTSD) in 1980 [2], it has proved to be a useful screener of risk of both current and future development of PTSD [3], with a cut-off of 35 providing good overall efficiency (94%) in terms of identifying cases meeting full criteria in a diagnostic interview [4]. It has good split-half (0.86) and test-retest reliability (0.87), a number of studies have confirmed its factor structure and validity and a revised version, which includes an additional 7 items describing hyperarousal symptoms (eg irritability, exaggerated startle), is also available [5].

References

[1] Horowitz M, Wilner N, Alvarez W. Impact of Event Scale: a measure of subjective stress. Psychosom Med 1979; 41:209-218.
[2] American Psychiatric Association (1980) Diagnostic and statistical manual of mental disorders (3rd ed). Washington DC: Author.
[3] Sundin EC, Horowitz MJ (2002) Impact of Event Scale: psychometric properties. Br J Psychiatry 180:205-209.
[4] Neal LA, Busuttil W, Rollins J, Herepath R, Strike P , Turnbull G J (1994) Convergent validity of measures of post-traumatic disorder in a mixed military and civilian population. J Trauma Stress 7:447-455.
[5] Weiss DS, Marmar CR (1997) The Impact of Event Scale – Revised. In: Wilson JP, Keane TM (eds) Assessing Psychological Trauma and PTSD. NY: Guilford, pp 399-41.

c) Hospital Anxiety and Depression Scale

The Hospital Anxiety and Depression Scale (HADS) is a self-report questionnaire, made up of two separate scales, one measuring anxiety (7 items) and the other measuring depression (7 items), with responses weighted 0 to 3 for frequency [1]. It was originally designed for use with hospital patients suffering from physical health problems and for that reason does not include any somatic symptoms, but is now also frequently used in community samples

as a screen for mental health problems. For each scale the authors suggest that scores of 8 -10 indicate mild symptoms, 11-13, moderate symptoms, and >=14, severe symptoms, but in epidemiological studies a cut-off of >=8 has been shown to discriminate best between cases and non-cases [2]. It is widely used internationally, has demonstrated good levels of internal consistency (0.93 for anxiety and 0.9 for depression) and test-retest reliability (0.54 for anxiety and 0.79 for depression) [3] and its factor structure has been confirmed in a number of different populations [4].

References

[1] Zigmond AS, Snaith RP (1983) The Hospital Anxiety and Depression scale. Acta Psychiatr Scand 67:361-370.

[2] Hermann C (1997) International experience with the Hospital Anxiety and Depression Scale. J Psychosom Res 42: 17-41.

[3] Bjelland I, Dahl AA, Haug TT, Neckelmann D (2002) The validity of the Hospital Anxiety and Depression Scale: an updated literature review. J Psychosom Res 52(2):69-77.

[4] Moorey S, Greer S, Watson M, Gorman C, Rowden L, Tunmore R, Robertson B, Bliss J (1991) The factor structure and factor stability of the hospital anxiety and depression scale in patients with cancer. Br J Psychiatry 158: 255-259.

2) Statistical power considerations

As a result of the attrition between the collection of baseline and outcome measures, the power of the comparative statistics employed for the main analyses was reduced to <70%. However, despite the smaller size of the samples in the post-hoc analyses, the proportions found scoring above clinical cut-off for post-traumatic stress and depression within the 'high stress' group were such that the statistical tests employed to examine differences between intervention conditions had over 95% power to pick up a significant difference at $p<0.05$. Statistical comparisons relating to anxiety levels in 'high stress' parents and all three comparisons in 'low stress' parents had limited power (<40%) to detect a significant difference at $p<0.05$.

Reference

Uitenbroek DG. Binomial. SISA. 1997.
<http://www.quantitativeskills.com/sisa/calculations/power.htm>
(Accessed 2 Jan 2010)

3) Breakdown of parents' responses re non-attendance (intervention group) and the need for follow-up (control group)

Of the 54 families in the intervention group who did not attend the clinic offered, 33 cancelled the appointment and 21 did not reply or attend. Reasons for non-attendance were given by 30/54 families and fell into the following categories: did not feel they needed appointment (10); too busy with work or childcare commitments (8); never received appointment letter (5); lived too far from hospital (4); could not face returning to hospital (3).

In total, of the 61 families not offered an appointment (control group), 41 answered a brief question on whether they would have liked an appointment. Only 9/41 (22%) said they would have liked to have been offered an appointment, although one mother commented that this did not necessarily mean that she would have attended.

Of the 32/41 families who indicated that they would not have wanted an appointment, 10 gave specific reasons: they were happy with their child's care on PICU (4); they had concerns about their child's chronic condition, but not about the PICU experience per se (2); they were familiar with the intensive care setting because their child had been admitted before (1); their child's admission had been elective (1); they were being followed up elsewhere (1); the child had made a full recovery (1).

10.4.4 Baseline characteristics

Table A Baseline characteristics of the children of participating and non-participating families

	Participating families (n =133)	Non-participating Families (n = 31)	*p*[a]
Age, yrs[b]	2.5 (0 to 18.5)	4.5 (0 to 15.4)	0.166
Male[c]	82 (62%)	20 (65%)	0.767
White UK[c]	96 (73%)	12 (39%)	<0.001**
TDI [b,d]	0.3 (-4.8 to10.9)	2.9 (-4.0 to 9.9)	0.001**
Length of stay, days[b]	1.8 (0.5 to 42)	1.2 (0.6 to 11.8)	0.029*
Emergency[c]	93 (70%)	24 (77%)	0.406
Ventilation[c]	56 (42%)	7 (23%)	0.044**
PIM[b]	1.4 (0.2 to 18.4)	1.4 (0.2 to15.2)	0.707

TDI, Townsend Deprivation Index; PIM, Paediatric Index of Mortality
[a]Mann Whitney U test / Pearson's Chi-square; [b]median (range); [c]n (%); [d]positive scores indicate greater level of socio-economic deprivation
*p<0.05 **p<0.01

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Table B. Baseline characteristics of recruited families who provided outcome data at five months compared with those of families who did not

		Provided data at 4 months	Lost to follow up	*p*[a]
Children:		(n = 95)	(n = 38)	
	Age, yrs[b]	2.5 (0 to16.5)	2.5 (0 to 18.5)	0.236
	Male[c]	57 (60%)	25 (66%)	0.535
	White UK[c]	71 (75%)	25 (66%)	0.298
	TDI[bd]	- 0.1 (-4.8 to10.9)	1.5 (-3.7 to 8.0)	0.298
	Length of stay, days[b]	2.0 (0.5 to 42)	1.3 (0.5 to 29.6)	0.049*
	Emergency[c]	73 (77%)	20 (53%)	0.006**
	Ventilated[c]	46 (48%)	10 (26%)	0.026*
	PIM[b]	1.8 (0.2 to 18.4)	0.9 (0.2 to 10.7)	0.004**
Parents:		(n = 105)	(n = 49)	
	Fathers[c]	18 (17%)	16 (32%)	0.031*
	PSS:PICU score at 48 hrs[b]	2.5 (1.1 to 4.3)	2.4 (1.4 to 4.3)	0.363

TDI, Townsend Deprivation Index; PIM, Paediatric Index of Mortality; PSS:PICU, Parental Stressor Scale: PICU
[a]Mann Whitney U test / Pearson's Chi-square; [b]median (range); [c] n (%); [d] positive scores indicate greater level of socio-economic deprivation
*p<0.05 **p<0.01

APPENDIX

10.5 Parent leaflet

St George's University Hospitals NHS
NHS Foundation Trust

The Recovery Journey after a PICU admission

A guide for families

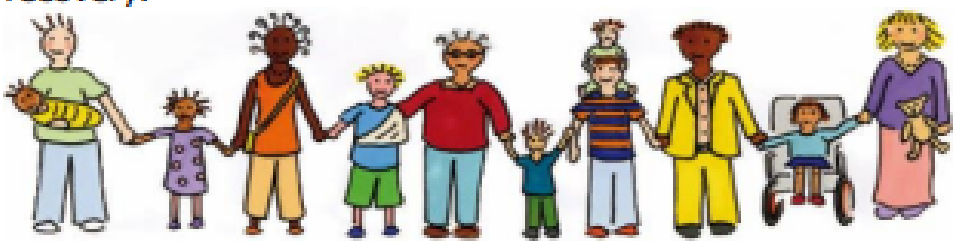
Introduction

This booklet has been written for parents and young people who have experienced a Paediatric Intensive Care Unit (PICU) admission. It explores the journey that you may experience after discharge.

We spoke to lots of families who have spent time on PICU. What we learned from them has helped us to make this booklet. For most families, discharge from PICU is a welcome relief, but we also learned that the year after discharge from PICU can be hard and the recovery journey may also raise unexpected challenges.

It is important to remember that everyone is different and there is not one right way to recover. Different families will cope in different ways. This may be influenced by the reasons for your PICU admission and your natural coping style. Families tell us that it can be helpful to know what to expect and what feelings and challenges you may encounter.

We hope that this booklet will help you think about the challenges you may face after a PICU admission. It is designed to give you some ideas about how to look after yourself and your family as you travel along the road to recovery.



What is recovery?

In hospital, there is often lots of talk about recovering and "getting better". By this we usually mean **physical recovery** – your child regaining full strength and fitness. Because your child has been so unwell, physical recovery is what many people including doctors, family and friends, will focus on. However, physical recovery is only one part of the recovery process.

There is also **social recovery** and **emotional recovery** to think about. Social recovery involves returning to normal life, for example getting back in touch with friends or returning to school. Emotional recovery involves thinking about what has happened, reflecting upon it and eventually moving on from the experiences in PICU. Both emotional and social recovery are just as important as physical recovery.

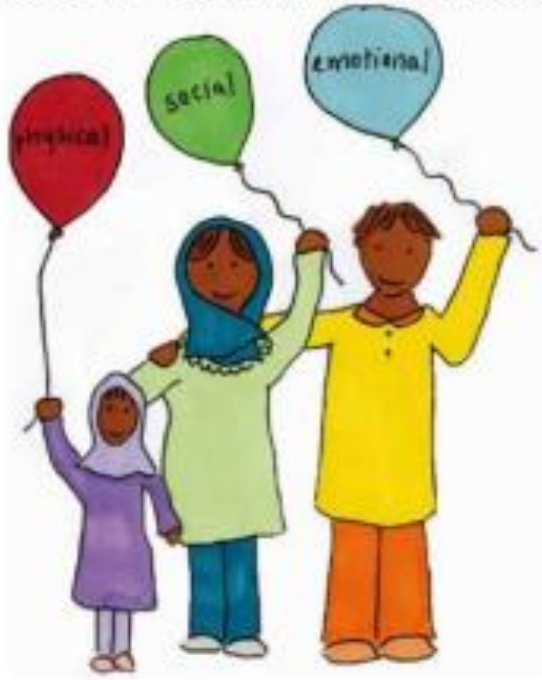
The road to recovery can be even more challenging if your child has ongoing difficulties such as continuing health problems or disabilities.

The effect on the family

It is helpful to keep in mind that a PICU admission does not just affect the child, but impacts on the whole family.

You may find that you also need some time to recover and often this process will be similar to your child's recovery. With your child on PICU, you may not have slept well or eaten regularly – getting back into a healthy routine will be part of your **physical recovery**.

Reconnecting with the wider world and perhaps returning to work may be part of your **social recovery.** Finally, having a child in PICU can be deeply upsetting for parents and family members so it is likely you'll need time for **emotional recovery** – just as your child will.



Straight After Discharge

The families we spoke to told us that after discharge from PICU, they wanted to focus on 'getting back to normal'. By this they meant being back at home and returning to what they usually did.

Many families said they needed coping strategies to deal with the demands of being back home after a hospital stay. Some families said that coping strategies like returning to old routines and 'just getting on with it' really helped in the short-term after discharge.

There are lots of other healthy coping strategies which can help you to feel better. These include getting enough sleep, taking gentle exercise, eating healthily, seeing supportive close friends and family and giving yourself time to readjust to the home environment. It may be tempting to use unhelpful coping strategies, such as comfort eating, or not eating enough, smoking or using too much alcohol. In the short term these behaviours can sometimes seem helpful, but in the long term they can be unhelpful and damaging to your health.

Adjusting to a 'New Normal'

Lots of families talked about wishing that things could return to how they were before the PICU admission. As time went on they realised that the illness and admission had changed them and their family. They noticed that things were different to how they were before.

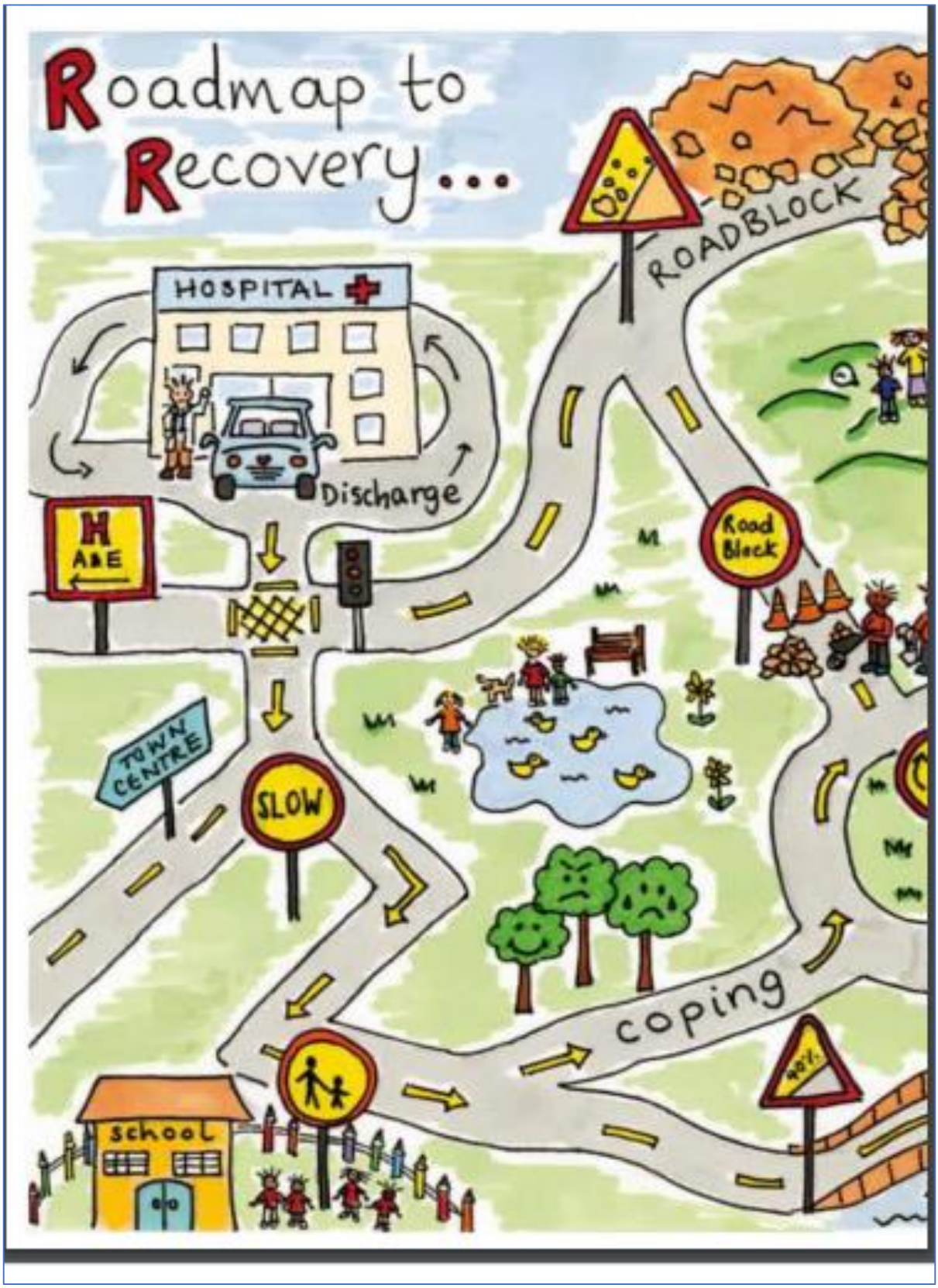
Some of these changes can be difficult to get used to, and may be upsetting. It is important to know that it is not unusual to feel sad, angry or scared about what happened or to feel upset by the new changes. Many families noticed positive changes too. These included having more perspective on what was important in life, focusing more on family life, or becoming a stronger person who is more able to cope with life's ups and downs.

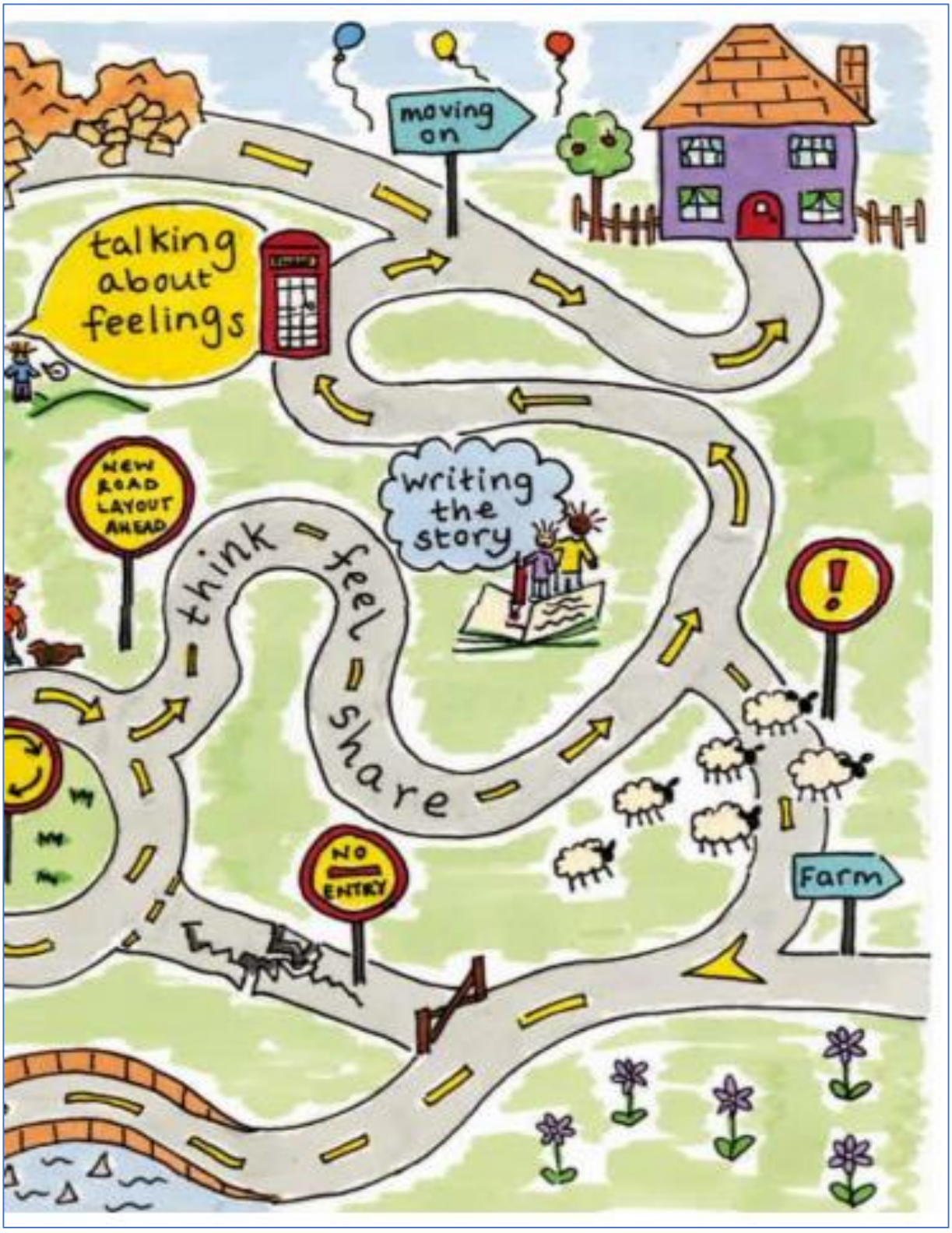
It is likely that you will experience a mix of changes, some positive and some which are more difficult to come to terms with. It is important to remember that **life changes anyway.** Even without the PICU admission, things would still be different. This can be helpful to remember if you find yourself wishing things would return to how they were before.

Building the story

As time passes families often find themselves thinking about what happened to them in hospital. For some families, certain images tended to stick in their minds, whilst for others it was the whole experience that they thought about. Thinking about what happened is a normal part of recovery from a serious illness or accident. In time it can be helpful for families to have a clear and complete 'story' about what happened to them and their child.

Building a story about what happened involves **thinking, feeling and sharing** the story with others. You might need to ask others about the missing bits of the story which you don't remember. You might decide to write it down or to share it with someone else to see what they think. Reliving and remembering the events of your child's admission can be painful. However, many families said it was important to go through this stage as it helped them to understand things better, and through this, to move on with their lives.


Roadmap to Recovery...
HOSPITAL
ROADBLOCK
Discharge
H
A&E
Road Block
TOWN CENTRE
SLOW
coping
School


moving on
talking about feelings
NEW ROAD LAYOUT AHEAD
writing the story
think
feel
share
!
NO ENTRY
Farm

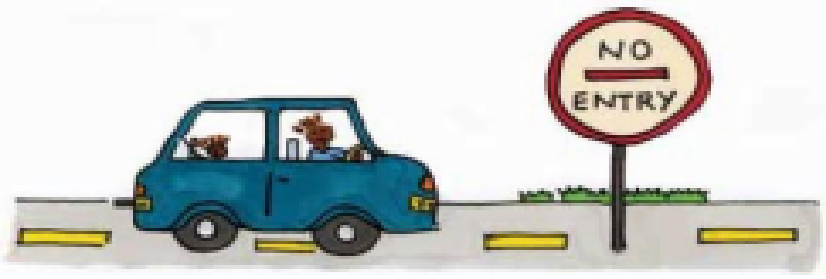
Roadblocks

The road to recovery is not always smooth and some of our families talked about obstacles, or 'road blocks' which can get in the way of recovery or slow it down.

- **Story-making too early and getting overwhelmed**

Being discharged from hospital can be overwhelming. Many families feel they need a break from thinking about their experiences. Giving yourself time off from thinking can allow your body and mind time to recover. In time you will find that you feel ready to address your thoughts and after a little 'head space' will find thinking about the admission easier and less painful.

- **Getting stuck in the story** Some people find that they cannot stop thinking about what happened and feel they are constantly preoccupied by worrying thoughts. This is not unusual as a PICU admission can be very traumatic and it can be hard to find someone who understands just what you've been through. It can help to talk it through with family, friends, or a professional, such as a psychologist or your GP. Other things that can help are writing the story down or having a change of scene or pace - such as having a holiday or going back to work. These things can help you to organise and make sense of your thoughts.



Roadblocks

- **Worrying you are not normal**

Families respond to a PICU admission in different ways – some are very distressed or overwhelmed, whilst others show little emotion.

The same is true for recovery – some families think about the experience a lot, whilst others focus only on physical recovery and think of little else.

Recovery takes time and operates at different speeds, so you may find that you or your child has recovered physically but that you are still putting together what happened or get upset when talking about it. Give yourself time, be patient with your feelings and remember there are lots of kinds of 'normal' – recovery is a highly individual and personal journey.

- **When your child won't talk**

Some children won't want or be able to talk about what happened in hospital. Sometimes these children may be covering up their feelings or memories as they don't understand them or because they arouse strong feelings which are difficult to manage. They might also worry about upsetting other people.

Roadblocks

Alternatively it may be the case that your child has very few memories about their admission and are not talking simply because they remember little and feel unaffected.

In either case, gently discussing the hospital experience from time to time can help your child to see that it is OK to talk about it and that it does not have to be overwhelming.

Parents can help by trying not to force their child to talk. Instead, try giving them lots of emotional support and simply letting them know that you are ready to listen when they are ready to talk.

It can help to sit down together and do an activity such as looking at photos from their admission. When a child does start to talk, make sure that you listen carefully and encourage them to talk about their feelings.

Roadblocks

- **When you don't know how to explain**

Children may ask questions which are difficult to answer. This may be because you don't know the answer or because you find it difficult and upsetting to talk about the PICU admission.

A psychologist or counsellor may be able to give you support with answering your child's questions and explaining what happened to them. If you are struggling to come to terms with the events, they may also be able to help you to understand and manage your own feelings.

Planning what you want to say to your child, using words they understand, will help you to explain things and help your child to form a 'story' of their experiences. Asking for help from a partner or close friend or using story books or toys can make it easier to explain.

Long Term Recovery

The families we spoke to all said that with time they were able to move on from the experience of a PICU admission. This meant they felt emotionally recovered and were less preoccupied with what had happened.

Long term recovery involves accepting that PICU was a part of your family's history. This may sound simple, but it can be a big step to recognise the impact that the experience had on your child and family and to accept that the experiences are now a part of who you have become.

At first it may feel as though the road to recovery is endless and that discharge is just the first obstacle of many, but be assured that with time, the recovery process does become easier. As time passes, life becomes a little less uncertain, and families tell us that they begin to know what the road ahead may look like. With courage, strength and support, and the PICU admission behind you, you can begin to make plans for the future. Having goals that you want to achieve can help you and your child to look forward to the future.

Further Support

Most families who have had a PICU admission are able to make the journey of recovery without additional help. However some families do find it more difficult and it's important to remember that you don't need to struggle alone. There are people on hand, with experience, who can help you.

Speaking to your GP, your child's nurse or doctor, or a psychologist may help smooth the road to recovery for you, your child and your family.

Contact Details at your hospital

The leaflet is based on research carried out
in conjunction with the University of Surrey

Produced by Ellie Atkins and Gillian Colville,
Paediatric Psychology Service, St George's Hospital.

Illustrations by Hannah Tetlow.

pdf available at PICUpsychology.net/leaflets

Ref: 0459tv3 Designed and produced **SGUL Media Services**

APPENDIX

10.6 Supplementary Information for Paper 6

Supplementary Table 1. Univariate analysis of associations between socio-demographics, occupational factors and resilience, and burnout and post-traumatic stress status

Variable	Burnout			Post-Traumatic stress		
	Yes *n* = 131	No *n* = 228	*p*	Yes *n* = 44	No *n* = 290	*p*
	n (%)	*n* (%)		*n* (%)	*n* (%)	
Socio-demographics						
Gender						
Male	26 (43)	34 (57)		7 (12)	50 (88)	
Female	105 (35)	194 (65)	0.228	37 (13)	240 (87)	0.827
Age group						
≤ 30y	46 (40)	68 (60)		14 (13)	93 (87)	
31-40y	53 (39)	84 (61)		19 (15)	104 (85)	
≥ 41y	29 (31)	65 (69)	0.327	10 (11)	81 (89)	0.635
Living arrangement						
With others	107 (38)	175 (62)		34 (13)	226 (87)	
Alone	22 (31)	48 (69)	0.311	8 (12)	60 (88)	0.773
Children at home						
No	78 (38)	126 (62)		24 (13)	167 (87)	
Yes	44 (32)	93 (68)	0.248	15 (12)	110 (88)	0.881
Occupational factors						
Professional role						
Doctor	36 (49)	38 (51)		7 (10)	63 (90)	
Nurse	95 (33)	190 (67)	**0.015**	37 (14)	227 (86)	0.377
ICU unit						
Adult	50 (31)	114 (70)		14 (9)	138 (91)	
Paediatric	81 (42)	114 (59)	**0.030**	30 (17)	152 (84)	0.050
	Mean (*SD*)	Mean (*SD*)	*p*	Mean (*SD*)	Mean (*SD*)	*p*
Years qualified	11.9 (9.2)	13.0 (9.5)	0.275	12.7 (9.8)	12.8 (9.5)	0.922
Years ICU	6.9 (7.1)	8.3 (7.7)	0.088	6.9 (6.9)	8.1 (7.8)	0.318
Personality						
Resilience (BRS;1-5)	3.28 (0.72)	3.60 (0.61)	**<0.001**	2.97 (0.78)	3.58 (0.62)	**<0.001**

Notes: Burnout was defined by the presence of high levels of emotional exhaustion as determined by subscale score ≥ 27 (prorated from aMBI) or depersonalization as determined by subscale score ≥10 (prorated from aMBI); post-traumatic stress was defined as scoring above the cut-off ≥ 6 for clinically significant level of symptoms on the Trauma Screening Questionnaire; aMBI = abbreviated Maslach Burnout Inventory; *SD* = standard deviation; *p* values were calculated using Chi-square tests for categorical variables and independent group *t*-tests for continuous variables (with bootstrapping employed where distributions did not follow an approximately normal distribution); significant group differences are highlighted in bold.

Supplementary Table 2. Univariate analysis of associations between coping strategies and burnout and post-traumatic stress status

Coping strategy	Burnout			Post-Traumatic Stress		
	Yes *n* = 127	No *n* = 224	*p*	Yes *n* = 44	No *n* = 288	*p*
	n (%)	*n* (%)		*n* (%)	*n* (%)	
Organizational strategies						
Talk to seniors	41 (33)	108 (48)	**0.004**	11 (25)	131 (46)	**0.011**
Attend teaching sessions	25 (20)	46 (21)	0.849	6 (14)	63 (22)	0.210
Attend debrief	13 (10)	47 (21)	**0.010**	5 (11)	56 (19)	0.197
Personal strategies						
Speak to people at work	97 (76)	179 (80)	0.438	33 (75)	227 (79)	0.567
Speak outside work	79 (62)	158 (71)	0.109	28 (64)	201 (70)	0.411
Try to be cheerful	80 (63)	153 (68)	0.311	28 (64)	194 (67)	0.625
Hobbies	64 (50)	142 (63)	**0.017**	20 (46)	182 (63)	**0.025**
Look for positives	68 (54)	128 (57)	0.514	20 (46)	167 (58)	0.119
Find solutions	56 (44)	138 (62)	**0.002**	21 (48)	163 (57)	0.270
Remember value of work	54 (43)	119 (53)	0.056	16 (36)	150 (52)	0.052
Keep home/work separate	58 (46)	115 (51)	0.307	20 (46)	142 (49)	0.634
Keep prof boundaries	56 (44)	104 (46)	0.673	19 (43)	133 (46)	0.710
Exercise	53 (42)	103 (46)	0.441	26 (59)	127 (44)	0.063
Keep busy	53 (42)	77 (34)	0.170	19 (43)	103 (36)	0.342
Use faith	43 (34)	82 (37)	0.621	17 (39)	95 (33)	0.480
Vent emotion	49 (39)	48 (21)	**0.001**	19 (43)	74 (26)	**0.016**
Ignore stress	40 (32)	51 (23)	0.073	16 (36)	71 (25)	0.100
Work harder	37 (29)	53 (24)	0.259	12 (27)	75 (26)	0.863
Relaxation	29 (23)	59 (26)	0.467	11 (25)	71 (25)	0.960
Drink alcohol	38 (30)	32 (14)	**<0.001**	13 (30)	52 (18)	0.074
Take time off	30 (24)	40 (18)	0.194	10 (23)	55 (19)	0.572

Notes: Burnout was defined by the presence of high levels of emotional exhaustion as determined by subscale score ≥ 27 (prorated from aMBI)) or depersonalization (DP; as determined by subscale score ≥ 10 (prorated from aMBI); post-traumatic stress was defined as scoring above the cut-off (≥ 6) for clinically significant level of symptoms on the Trauma Screening Questionnaire; aMBI = abbreviated Maslach Burnout Inventory; *p* values were calculated using Chi-square tests; significant group differences are highlighted in bold.

APPENDIX

10.7 Moral Distress Map

The ‘Moral Distress Map’ tool, outlined by Dudkinski (1) is summarised in the table below. In a situation of moral distress, feelings often run high with strong emotions engendered such as anger, blame and guilt. For this reason the ‘Moral Distress Map’ process requires that first these emotions are acknowledged and labelled. This advice is based on a well-established principle in psychology, whereby anxiety is reliably reduced by the simple action of naming emotion, or ‘affect labelling’ (2). The next step is to clarify what is causing the moral distress and consider what the obstacles to action and the various conflicting responsibilities are that make a decision about the preferred course of action difficult. Then by considering the implications of the different courses of action available, it is possible to make the best decision possible in the circumstances.

Case example: A nurse witnesses a colleague doing something she considers unethical but feels torn between reporting it and losing her colleague’s friend ship. She would first consider the strength of emotion she is experiencing which may include a sense of betrayal and also fear that she may lose the other person’s trust. If she reports it, her manager may be impressed and patient care will be best served but she may lose a friend. If she keeps quiet she will feel guilty. On balance she may therefore decide to encourage her colleague to admit their mistake and offer to accompany them to report the issue, in order to offer provide support. In this way she preserves her friendship but at the same time acts professionally, in the best interests of patients.

Key stages of the Moral Distress Map (adapted from Dudkinski 2016)

1.	Label the emotions being felt that accompany a sense of moral distress
2.	Identify the source of moral distress
3.	List the internal and external constraints that apply to the situation
4.	Consider the conflicting responsibilities and values in the individual and/or team
5.	Generate a list of potential actions: a) to improve patient outcome; and b) to relieve the moral distress being experienced
6.	Decide on final action

1. Dudzinski DM. Navigating moral distress using the moral distress map. Journal of medical ethics. 2016;42(5):321-4. doi: 10.1136/medethics-2015-103156
2. Lieberman MD et al. Putting feelings into words: affect labeling disrupts amygdala activity in response to affective stimuli. Psychol Sci. 2007;18:421-428

APPENDIX

10.8 Author Contributions

Chapter 2 Post-traumatic stress in the child and parent

Paper 1: PTSD Study

Colville G, Pierce C. Patterns of post-traumatic stress symptoms in families after paediatric intensive care. Intensive Care Medicine. Intensive Care Med. 2012 ;38(9):1523-31

Professional Roles
GC Principal Investigator
CP Lead Clinician at research site (Paediatric Intensivist)

Contribution	**GC**	**CP**
Initial Design and Conceptualisation	✓	
Ethical submission	✓	
Delivering Intervention	N/A	N/A
Recruitment	✓	✓
Data Collection	✓	
Data Entry	✓	
Data Analysis	✓	
Initial Draft of Paper	✓	
Revisions	✓	✓
Approval of final draft	✓	✓

Chapter 3 The Child's Quality of Life after Discharge (2 papers)

Paper 2: Quality of Life Study

Colville GA, Pierce CM. Children's self-reported quality of life after intensive care treatment. Pediatric Critical Care Medicine 2013: 14(2); e85-e92

Professional Roles
GC Principal Investigator
CP Paediatric Intensivist - Lead Clinician at research site

Contribution	**GC**	**CP**
Initial Design and Conceptualisation	✓	✓
Ethical submission	✓	
Facilitate Recruitment		✓
Delivering Intervention	N/A	N/A
Data Collection	✓	
Data Entry	✓	
Data Analysis	✓	
Initial Draft of Paper	✓	
Revisions	✓	✓
Approval of final draft	✓	✓

Chapter 3 The Child's Quality of Life after Discharge (2 papers)

Paper 3: Fatigue Study

Colville GA, Pierce CM, Peters M. Self-reported fatigue in children following a PICU admission. Pediatric Critical Care Medicine 2018 e98-101

Professional Roles
GC Principal Investigator (Health Foundation : Leading Practice Through Research Award)
CP Paediatric Intensivist - Lead Clinician at research site
MP Paediatric Intensivist – Lead Academic/Clinician at research site

Contribution	**GC**	**CP**	**MP**
Initial Design and Conceptualisation	✓		
Ethical submission	✓		
Facilitate Recruitment		✓	
Delivery of Intervention	N/A	N/A	N/A
Data Collection	✓		
Data Entry	✓		
Data Analysis	✓		
Initial Draft of Paper	✓		
Revisions	✓	✓	✓
Approval of final draft	✓	✓	✓

Chapter 4 Intervention with Parents: Follow up Clinic

Paper 4: Follow up Clinic Study

Colville GA, Cream PR, Kerry SM. Do parents benefit form the offer of a follow-up appointment after their child's admission to intensive care?: an exploratory randomised controlled trial. Intensive Critical Care Nursing 2010; 26: 146-153

Professional Roles
GC Principal Investigator
PC Research Assistant
SK Statistician

Contribution	GC	PC	SK
Initial Design and Conceptualisation	✓		
Ethical submission	✓		
Recruitment		✓	
Delivering Intervention	✓		
Data Collection	✓	✓	
Data Entry	✓	✓	
Data Analysis	✓		✓
Initial Draft of Paper	✓		
Revisions	✓	✓	✓
Approval of final draft	✓	✓	✓

Chapter 5 Intervention with Parents: Individual Therapy

Paper 5: NET (Narrative Exposure Therapy) Study

Colville G Narrative Exposure Therapy with parents who have been traumatized in paediatric settings: a case series. Clinical Practice in Pediatric Psychology 2017; 5(2): 161-169

Professional Role
GC Clinician/Researcher

Contribution	**GC**
Initial Design and Conceptualisation	✓
Ethical submission	N/A
Facilitate Recruitment	✓
Delivery of Intervention	✓
Data Collection	✓
Data Entry	✓
Data Analysis	✓
Initial Draft of Paper	✓
Revisions	✓
Approval of final draft	✓

Chapter Burnout and Post-traumatc stress in staff

Paper 6 Staff Stress Study

Colville G, Smith JG, Brierley. J, Citron K, Nguru NM, Shaunak P, Tam O, Perkins-Porras L. Coping with staff burnout and work-related posttraumatic stress in intensive care. Pediatric Critical Care Medicine 2017; 18(7): e267-e273

Professional Roles
GC PI/Research Supervisor of Medical students
JS Senior Lecturer - Statistical advice
JB Paediatric Intensivist - Lead Clinician at second site
KC Medical student
NN Medical student
PS Medical student
OT Medical student
LP Senior Lecturer – PI/Research Supervisor of Medical students

Contribution	**GC**	**JS**	**JB**	**KC**	**NN**	**PS**	**OT**	**LP**
Initial Design and Conceptualisation	✓							✓
Ethical Submission	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Recruitment			✓	✓	✓	✓	✓	
Delivery of Intervention	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Data Collection				✓	✓	✓	✓	
Data Entry	✓			✓	✓	✓	✓	
Data Analysis	✓	✓						
Initial Draft of Paper	✓	✓		✓	✓	✓	✓	✓
Revisions	✓	✓	✓	✓	✓	✓	✓	✓
Approval of final draft	✓	✓	✓	✓	✓	✓	✓	✓

Chapter 7 Moral Distress

Paper 7: Moral Distress Study

Colville G, Dawson D, Rabinthiran S, Chaudry-Daley Z, Perkins-Porras L. A survey of moral distress in staff working in intensive care in the UK. Journal of the Intensive Care Society. 2019**;** 20: 196-203

Professional Roles
GC Clinical Psychologisty - PI
DD ICU Matron - Lead Clinician
SRMedical student
ZC Medical student
LP Senior Lecturer – PI/Research Supervisors of Medical students

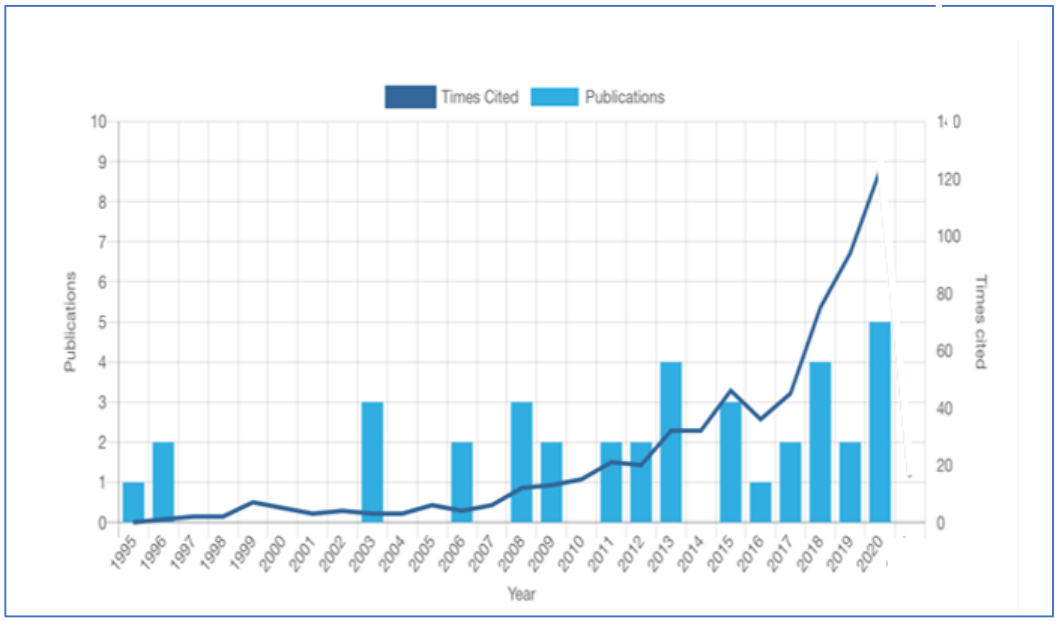
Contribution	**GC**	**DD**	**SR**	**ZC**	**LP**
Initial Design and Conceptualisation	✓				✓
Ethical submission	N/A	N/A	N/A	N/A	N/A
Recruitment		✓	✓	✓	
Delivery of Intervention	N/A	N/A	N/A	N/A	N/A
Data Collection			✓	✓	
Data Entry	✓		✓	✓	
Data Analysis	✓				
Initial Draft of Paper	✓		✓	✓	
Revisions	✓	✓	✓	✓	✓
Approval of final draft	✓	✓	✓	✓	✓

APPENDIX

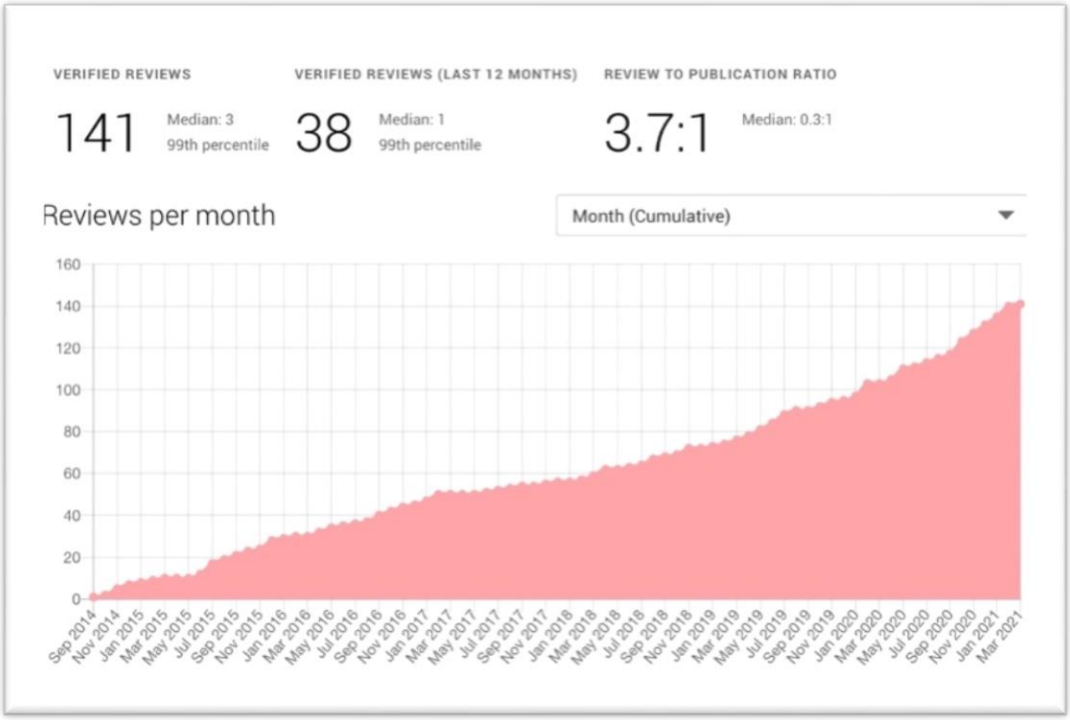
10.9 Impact Metrics

Publons.com Metrics

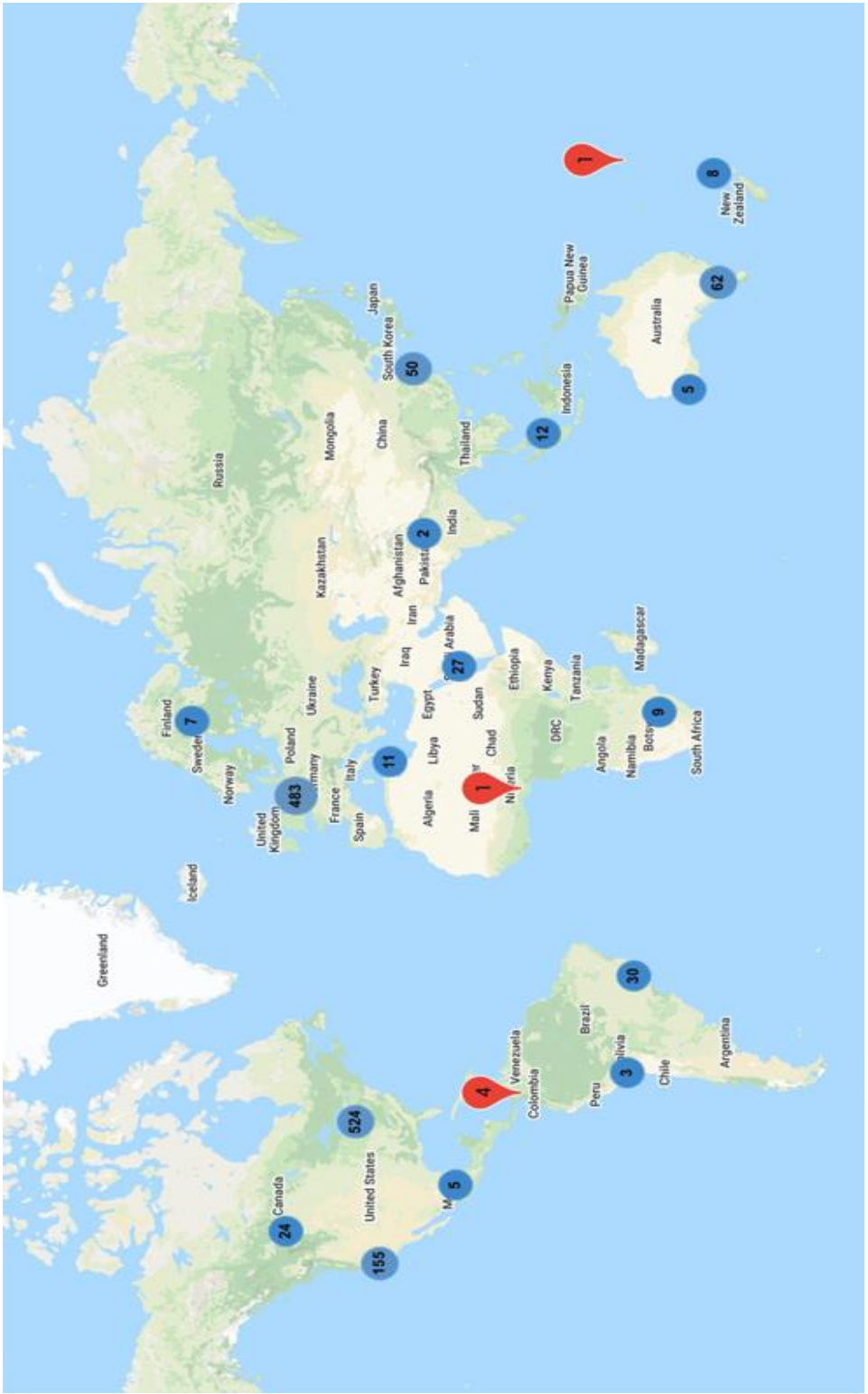
10.9.1 Author's publications and citations 1995 to 2020 (based on Web of Science outputs only, accessed 23/3/21)



10.9.2 Author's completed peer review requests 2014 to 2021 (accessed 23/3/21)



10.9.3 World map showing locations of institutions of citing authors (based on Web of Science outputs only, accessed 23/3/21)



APPENDIX

10.10 Questionnaires

10.10.1 Abbreviated Maslach Burnout Inventory (aMBI)

Abbreviated MASLACH BURNOUT INVENTORY

How often:	Never	A few times a year	Once a month or less	A few times a month	Once a week	A few times a week	Every day
	0	1	2	3	4	5	6
1) I deal very effectively with the problems of my clients and colleagues.							
2) I feel I treat some clients and colleagues as if they were impersonal objects.							
3) I feel emotionally drained from my work.							
4) I feel fatigued when I get up in the morning and have to face another day on the job.							
5) I've become more calloused towards people since I took this job							
6) I feel I'm positively influencing other people's lives through my work.							
7) Working with people all day is really a strain for me.							
8) I don't really care what happens to some people I deal with at work.							
9) I feel exhilarated after working closely with my clients and colleagues.							

In this section there are 9 statements of job-related feelings. Please read each statement carefully and decide if you ever feel this way about your job. Beside each statement, please tick the appropriate box which best describes how frequently you feel that way.

McManus IC, Gordon D, Winder BC: Duties of a doctor: UK doctors and good medical practice. Qual Health Care 2000; 9:14–22

10.10.2 Brief Resilience Scale (BRS)

BRIEF RESILIENCE SCALE

	Strongly Agree	Agree	Neutral or don't know	Disagree	Strongly diagree
1. I tend to bounce back quickly after hard times	**4**	**3**	**2**	**1**	**0**
2. I have a hard time making it through stressful events	**0**	**1**	**2**	**3**	**4**
3. It does not take me long to recover from a stressful event	**4**	**3**	**2**	**1**	**0**
4. It is hard for me to snap back when something bad happens	**0**	**1**	**2**	**3**	**4**
5. I usually come through difficult times with little trouble	**4**	**3**	**2**	**1**	**0**
6. I tend to take a long time to get over set-backs in my life	**0**	**1**	**2**	**3**	**4**

Smith BW, Dalen J, Wiggins K et al. The Brief Resilience Scale: Assessing the ability to bounce back. Int J Behav Med 2008; 15:194–200

10.10.3 Child Revised Impact of Event Scale (CRIES-8)

Revised Child Impact of Events Scale

Below is a list of comments made by people after stressful life events. Please tick each item showing how frequently these comments were true for you *during the past seven days*. If they did not occur during that time please tick the 'not at all' box.

Name: …… Date: ……

		Not at all	**Rarely**	**Some-times**	**Often**
1.	Do you think about it even when you don't mean to?	[ ]	[ ]	[ ]	[ ]
2.	Do you try to remove it from your memory	[ ]	[ ]	[ ]	[ ]
3.	Do you have waves of strong feelings about it	[ ]	[ ]	[ ]	[ ]
4.	Do you stay away from reminders of it (e.g. places or situations)	[ ]	[ ]	[ ]	[ ]
5.	Do you try not talk about it	[ ]	[ ]	[ ]	[ ]
6.	Do pictures about it pop into your mind?	[ ]	[ ]	[ ]	[ ]
7.	Do other things keep making you think about it?	[ ]	[ ]	[ ]	[ ]
8.	Do you try not to think about it?	[ ]	[ ]	[ ]	[ ]

Perrin S, Meiser-Stedman R, Smith P. The Children's Revised Impact of Event Scale (CRIES): validity as a screening instrument for PTSD. Behav Cogn Psychother 2005;33:487–498

10.10.4 Hospital Anxiety and Depression Scale (HADS)

Hospital Anxiety and Depression Score (HADS)

This questionnaire helps your physician to know how you are feeling. Read every sentence. Place an "X" on the answer that best describes how you have been feeling during the LAST WEEK. You do not have to think too much to answer. In this questionnaire, spontaneous answers are more important

Zigmond AS, Snaith RP. The hospital anxiety and depression scale. Acta Psychiatr Scand. 1983;67:361-370

A	**I feel tense or 'wound up':**	
	Most of the time	3
	A lot of the time	2
	From time to time (occ.)	1
	Not at all	0
D	**I still enjoy the things I used to enjoy:**	
	Definitely as much	0
	Not quite as much	1
	Only a little	2
	Hardly at all	3
A	**I get a sort of frightened feeling as if something awful is about to happen:**	
	Very definitely and quite badly	3
	Yes, but not too badly	2
	A little, but it doesn't worry me	1
	Not at all	0
D	**I can laugh and see the funny side of things:**	
	As much as I always could	0
	Not quite so much now	1
	Definitely not so much now	2
	Not at all	3
A	**Worrying thoughts go through my mind:**	
	A great deal of the time	3
	A lot of the time	2
	From time to time, but not often	1
	Only occasionally	0
D	**I feel cheerful:**	
	Not at all	3
	Not often	2
	Sometimes	1
	Most of the time	0
A	**I can sit at ease and feel relaxed:**	
	Definitely	0
	Usually	1
	Not often	2
	Not at all	3

D	**I feel as if I am slowed down:**	
	Nearly all the time	3
	Very often	2
	Sometimes	1
	Not at all	0
A	**I get a sort of frightened feeling like "butterflies" in the stomach:**	
	Not at all	0
	Occasionally	1
	Quite often	2
	Very often	3
D	**I have lost interest in my appearance:**	
	Definitely	3
	I don't take as much care as I should	2
	I may not take quite as much care	1
	I take just as much care	0
A	**I feel restless as I have to be on the move:**	
	Very much indeed	3
	Quite a lot	2
	Not very much	1
	Not at all	0
D	**I look forward with enjoyment to things:**	
	As much as I ever did	0
	Rather less than I used to	1
	Definitely less than I used to	2
	Hardly at all	3
A	**I get sudden feelings of panic:**	
	Very often indeed	3
	Quite often	2
	Not very often	1
	Not at all	0
D	**I can enjoy a good book or radio/TV program:**	
	Often	0
	Sometimes	1
	Not often	2
	Very seldom	3

10.10.5 Impact of Event Scale (IES)

IMPACT OF EVENT SCALE

Below is a list of comments made by people after stressful life events. Please mark each item, indicating how frequently these comments were true for you ***during the past seven days.*** *If they did not occur during that time, please mark the "not at all" column.*

Select only one answer per row.

		Not at all	Rarely	Sometimes	Often
1.	I thought about it when I didn't mean to.	0	1	3	5
2.	I avoided letting myself get upset when I thought about it or was reminded about it.	0	1	3	5
3.	I tried to remove it from memory.	0	1	3	5
4.	I had trouble falling asleep or staying asleep because of pictures or thoughts about it that came to my mind.	0	1	3	5
5.	I had waves of strong feelings about it.	0	1	3	5
6.	I had dreams about it.	0	1	3	5
7.	I stayed away from reminders about it.	0	1	3	5
8.	I felt as if it hadn't happened or was unreal.	0	1	3	5
9.	I tried not to talk about it.	0	1	3	5
10.	Pictures about it popped into my mind.	0	1	3	5
11.	Other things kept making me think about it.	0	1	3	5
12.	I was aware that I still had a lot of feelings about it, but I didn't deal with them.	0	1	3	5
13.	I tried not to think about it.	0	1	3	5
14.	Any reminder brought back feelings about it.	0	1	3	5
15.	My feelings about it were kind of numb.	0	1	3	5
		0	+___	+_____	+__ =___

Scoring: Total each column and add together for a total stress score.
For example, every item marked in the "not at all" column is valued at 0. In the "rarely" column, each item is valued at a 1. In the "sometimes" column every item marked has a value of 3 and in the "often" column each item is valued at 5. Add the totals from each of the columns to get the total stress score.

Horowitz M, Wilner N, Alvarez W. Impact of Event Scale: a measure of subjective stress. Psychosom Med 1979;41:209-218

10.10.6 Intensive Care Unit Memory Tool (ICUM)

ICU Memory Tool (ICUM)

1. Do you remember being admitted to hospital?
2. Can you remember the time in hospital before you were admitted to intensive care?
3. Do you remember being in intensive care?
4a. Do you remember all the stay clearly?
4b. What do you remember? (circle those things you remember)
Clearly Hazily Not at all
All of it Some of it Nothing
Yes/No Yes/No
Hallucinations Nightmares Dreams Panic
(please circle the appropriate answer)

Family Faces	Alarms	Breathing tube	Feeling down
Voices	Lights	Being uncomfortable	Feeling anxious/frightened
Suctioning	Darkness	Clock	Feeling that people were trying to hurt you
Tube in your nose	Ward round	Feeling confused	Pain

4c. If you had any feelings that someone was trying to hurt or harm you while you were in intensive care can you please describe these feelings below.
.....
.....
.....

4d. If you had nightmares or hallucinations while you were in intensive care could you please describe these:
.....
.....
5. Do you remember being transferred from intensive care to the general wards?
Clearly Hazily Not at all

6. Have you had any unexplained feelings of panic or apprehension?
Yes/No
6a. If yes: What were you doing when these feelings happened?
.....
.....
7. Have you had any intrusive memories from your time Yes/No in hospital or of the event that lead up to your admission?
7a. If yes to 7: What were you doing when these intrusive memories happened?
.....
.....
7b. If yes to 7: What did these memories consist of (e.g. frightening nightmares)?
.....
.....

8. Have you talked about what happened to you in intensive care with:-
 A member of your family
 A nurse on the ward
 A friend
 A doctor on the ward
 Your family doctor

C. Jones, G. Humphris, RD. Griffiths. Preliminary validation of the ICUM tool: a tool for assessing memory of the intensive care experience. Clinical Intensive Care. 2000;11(5):251-255.

10.10.7 Moral Distress Scale – Revised (MDS-R)

Hamric AB, Borchers CT, and Epstein EG. Development and testing of an instrument to measure moral distress in healthcare professionals. AJOB Prim Res 2012; 3: 1–9

10.10.8 Posttraumatic Diagnostic Scale (PDS)

Foa EB, Cashman L, Jaycox L, Perry K. The validation of a self report measure of posttraumatic stress disorder: The Posttraumatic Diagnostic Scale. Psychological Assessment. 1997;9:445–451

10.10.9 PedsQL™ Generic Scale

Varni JW, Seid M, Rode CA. The PedsQL: measurement model for the pediatric quality of life inventory. Med Care. 1999;37:126-139

(Available at http://www.pedsql.org)

10.10.10 PedsQL™ Multidimensional Fatigue Scale

Varni JW, Burwinkle TM, Katz ER, Meeske K, Dickinson P. The PedsQL in pediatric cancer: reliability and validity of the Pediatric Quality of Life Inventory Generic Core Scales, Multidimensional Fatigue Scale, and Cancer Module. Cancer 2002 1;94:2090-2106

(Available at http://www.pedsql.org)

10.10.11 Patient Health Questionnaire (PHQ-4)

PHQ-4: THE FOUR-ITEM PATIENT HEALTH QUESTIONNAIRE FOR ANXIETY AND DEPRESSION

Over the last two weeks, how often have you been bothered by the following problems?

	Not at all	Several days	More than half the days	Nearly every day
Feeling nervous, anxious or on edge	0	1	2	3
Not being able to stop or control worrying	0	1	2	3
Feeling down, depressed or hopeless	0	1	2	3
Little interest or pleasure in doing things	0	1	2	3

TOTALS
Total score is determined by adding together the scores of each of the 4 items. Scores are rated as normal (0-2), mild (3-5), moderate (6-8), and severe (9-12). Total score ≥3 for first 2 questions suggests anxiety.
Total score ≥3 for last 2 questions suggests depression.

Kroenke K, Spitzer RL, Williams JB, Löwe B. An ultra-brief screening scale for anxiety and depression: the PHQ-4. Psychosomatics. 2009;50(6):613-21

10.10.12 Parental Stressor Scale: PICU (PSS:PICU)

Carter MC, Miles MS. The Parental Stressor Scale: Pediatric Intensive Care Unit. Matern Child Nurs J. 1989;18:187-198

10.10.13 SPAN (short version of Davidson Trauma Scale)

Meltzer-Brody S, Churchill E, Davidson JR. Derivation of the SPAN, a brief diagnostic screening test for post-traumatic stress disorder. Psychiatry Res. 1999;88:63-70

10.10.14 Trauma Screening Questionnaire (TSQ)

TRAUMA SCREENING QUESTIONNAIRE

In this section consider the following reactions which sometimes occur after a traumatic event. This section is concerned with your personal reactions to the management of the high profile case on the unit earlier this year.

Please state briefly **the worst situation/event you experienced** in relation to your work:

When reading the following statements. Indicate (by circling 'yes' or 'no') whether or not you have experienced any of the following at least twice in the past week.

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

Scores>=6 are suggestive of possible PTSD

Brewin CR, Rose S, Andrews B et al. Brief screening instrument for post-traumatic stress disorder. Br J Psychiatry 2002; 181:158–162

APPENDIX

10.11 Personal Reflections

Personal Reflections on being a 'clinician-researcher'

"Research is of no use unless it gets to the people who need to use it"
Prof Chris Whitty 2016

Background/Career choice: I decided I wanted to be a psychologist when I was 12y. I had enjoyed documentaries about human behaviour on the television and requested a copy of a book called 'The Psychology of Childhood and Adolescence' when I won a book prize at the end of my first year of secondary school, which I found fascinating.

I enjoyed university in Newcastle upon Tyne – particularly in relation to applying my facility with numbers to human topics - and am still regularly teased, at home and at work, about my love of graphs to this day. I ran a psychology film club in my final year and showed a short features every week, which arrived in the post on old fashioned celluloid reels in circular tin boxes. Topics included Stanley Milgram's (literally) shocking experiments and the Robertsons' ground breaking observational work on the distress of children left on their own in hospital in the 1960s, which eventually led to the open visiting policies on paediatric wards which are now the norm.

I was surprised however to find that a psychology degree was at that time classed as a Bachelor of Arts (BA) at that university and managed to argue successfully that the modules I had chosen rendered it a BSc.

When I finished my degree I was initially more interested in research than in the idea of a clinical career. My first job after graduating was at the Addiction Research Unit at the Institute of Psychiatry next to the Maudsley Hospital in South London, now part of King's College, University of London. I worked on a smoking research project which entailed interviewing smokers and collecting their used cigarette butts and saliva for analysis. It was not exactly glamorous but I met some good colleagues I kept up with for many years afterwards and had a number of formative research experiences whilst there. The most powerful of these was in relation to a discovery I made of bias in what was meant to be a blinded RCT of a promising new smoking cessation intervention. I had offered to read an early draft of a paper, out of interest, but then noticed that many of the anomalous results in the intervention group were coded as successes when similar results in the control group were coded as failures. I raised my point with the team in a genuine spirit of intellectual curiosity but it did not go down well. The subsequent changes made to the analyses reduced the size of the effect but a principled statistician refused to attach his name to the paper unless the changes were made and I was acknowledged. There were lighter moments in this job though, such as our team's attendance at a snuff taking championship in the west country, where we measured nicotine blood levels and got a paper published in the process. And it was in this post that I first encountered SPSS statistical software – although in the 1980s data had to be prepared in the form of a set of hole-punched cards and it took 24 hours for each analysis to be completed on a large central computer!

At the Institute, I also began attending lectures on clinical topics and was particularly taken with Bill Yule's down to earth, but finely observed, talks about children, which helped me decide to pursue a clinical career.

At the time I then went on to train as a clinical psychologist at the Institute of Psychiatry the course was only two years long, although it still contained six placements, as is the current practice on the usual three year courses now. The clinical psychology qualification at that time was usually an MSc but at the Institute it was an MPhil – a master of philosophy – which I liked the sound of. These days people emerge from a three year training with a professional doctorate eg PsychD or DClinPsy.

It was fast and furious, switching setting every four months, but most placements were on the Maudsley site so there was little travelling and more continuity, in that I could regularly catch up with staff and students in the staff canteen. It was amazing to find yourself next to Rutter and Eysenck in the coffee break. In those days people had lunchbreaks and coffee breaks and a lot of useful discussion and sharing of ideas occurred informally at those times. I also learned something very important on my first child placement about how well a multidisciplinary psychosocial team could work. I was lucky to be on a particularly experienced and well functioning team whose senior members had enormous respect for each other – and this filtered down to the staff working under them who mirrored this regard, facilitating good working relationships and the smooth running of the team more generally.

I was clear from the start that I wanted to focus on child psychology and managed to arrange that four out of six of my placements were in a child setting: Maudsley Child Outpatients; Bethlem Child Learning Disabilities; Orchard Lodge Adolescent Forensic Unit and Maudsley Child Inpatient Unit. In addition, I did a core adult placement and a neuropsychology placement where I encountered Creutzfeldt-Jakob Disease (CJD) for the first time and which involved attending weekly 'brain cuts' (discussions of brain pathology results in front of shelves of brains in buckets of formaline). Toward the end of my second year I had my first baby which meant that I qualified a little later than expected.

First Exposure to Paediatrics: My first job was as a research psychologist working with Martin Bax, at the Community Paediatric Research Unit, attached to Westminster Children's Hospital (since closed). My job was to collate questionnaire data from around 300 families with a rare degenerative condition called Mucopolysaccharidosis and to visit some families to carry out cognitive assessments on a subsample of children around the country.

It was a nice team and we worked in a beautiful Georgian building looking on to Vincent Square, but the work was gruelling. I did not mind the travelling – I got to see Blackpool, Lowestoft, Salisbury and Glasgow for the first time – but it was heartbreaking to hear the families' stories and to be charged with measuring the evidence of their inevitable cognitive decline. There was no cure for the condition at that time, so although some children had milder variants, many with the severest form died in early childhood. Nowadays there is the option of bone marrow transplant to replace the gene they are missing, but early diagnosis is still difficult to make.

After the birth of my second child I found this work too painful to return to, but did eventually write the work up, albeit years later, and it is still read and regularly cited. One paper I managed to put together off my own bat, focused on what it was about the way the condition manifested early on that first made parents seek help, although on average it often took two or more years for a definitive diagnosis to be made. To my amazement (and long before the days of email and zoom) I once took a phone call from a lawyer in Wyoming who was requesting a copy of this paper on behalf of his client, a doctor being sued for not realising a child's diagnosis sooner.

I took some time off to be at home when I had my third child and then gradually returned to part-time work over the next five years. During this time I did some research interviewing for a project on health beliefs and behaviour of adolescents, with Anne Oakley at the Institute of Education, and worked as a locum child psychologist at the Sheldon Child Development Centre in Peckham.

First job in Paediatric Intensive Care: I then moved to Great Ormond St Children's Hospital (GOSH) where I was attached to the Metabolic/Gastroenterology ward and to the Paediatric Intensive Care Unit (PICU). It was the first time a psychologist had been allocated to PICU and I was therefore the

first person to instigate a psychosocial meeting in that setting, although they were a regular feature on other wards, where they frequently included the regular presence of a psychologist, a psychiatrist ant a social worker.

GOSH was a fascinating place to work. The clinicians there were ambitious and at the top of their game and there was enormous variety in terms of the children's conditions. There was also a strong culture of involvement of psychosocial personnel in ward work there, well ahead of practice elsewhere.

The hospital is very high profile in the UK, as evidenced by the scene in the opening ceremony of the London 2012 Olympics where nurses from GOSH were much celebrated. Appreciation for it in the national psyche that means that local shops and marathon runners across the country often raise money for the care provided there, when ironically their local units are much more cash-strapped and in need of support. I came across all sorts of serious, rare conditions in the three years I worked there including Rett's syndrome, Pervasive Refusal Syndrome and Munchausen by Proxy which is, shockingly, associated with a 10% mortality rate. I mistakenly thought that Dermatology might be a less dramatic specialty to take on (when I returned from leave after the birth of my fourth child) but had not bargained for ichthyosis (proliferation of foul smelling, fishscale-like skin growths which are constantly shed) or epidermolysis bullosa (a condition when the slightest knock can result in huge skin sores externally and internally, eg in digestive tract) which had a devastating impact on the quality of life of affected children and their families.

PICU was also a completely new world and also the part of the hospital with the highest mortality rate, which averaged 11% of admissions over the time I worked there (although nationally rates have now, 25 years on, reduced to around 4%). Not all staff were convinced about the need for psychology on the unit, but I gradually won most over, on a case by case basis, by showing how the provision of extra time and support for families to talk reduced their anxiety and freed up staff to concentrate on caring for the patient. In order to win the doctors' confidence in particular it was important to learn as much as I could about the children's conditions and treatment and an offer I made at one point to accompany them in bereavement reviews was sincerely appreciated. The development of a PICU Bereavement Clinic was also a springboard for me sending in my first conference abstract in this field to a Paediatric Intensive Care Society Annual Meeting in 1993 which was accepted as an oral presentation. At the end of my lecture, which was well received, I asked if there were any other psychologists in the audience – but there was a stony silence.

The admissions book contained many interesting entries including 'struck by lightning', 'choked on grape' and 'shrapnel injury' (in relation to a Bosnian refugee) and parent's occupation was once given as 'HRH heir to throne' when one of the royal princes was admitted for observation for a head injury related to being hit by a cricket ball. I loved the variety and the opportunity to learn so much. The first cases of HIV in infants were being diagnosed and were at that time inevitably associated with death soon afterwards of the child and often the mother, whose diagnosis only came to light as a result of the child's blood results. There were also regular deaths from meningitis. Now with the use of anti-retroviral drugs and caesarean birth, HIV is rarely transmitted from mother to child and children with HIV are living well into adulthood, with appropriate medication and specialist follow up. And numerous new vaccines, including those for pneumococcal meningitis, Hib meningitis and meningitis C, have virtually wiped this condition out – to the point where I now cannot remember the last time I heard a child had died of this on PICU.

The commuting to central London was hard though, and although I worked part-time, the days were long. The nature of the institution was also such that there was a high turnover of staff with many

people doing a training stint there but moving on, which meant that there was a constant requirement to form new working relationships with the team – particularly the nurses who could not afford to work in central London once they started to have children of their own.

So I started to monitor the job ads for a promotion. I was clear that I wanted to stay in paediatrics and preferably work in a teaching hospital nearer home that was big enough to have an intensive care unit. As luck would have it two jobs came up at the same time – both south of the river, one at Guy's and one at St George's – and I was offered both. I picked St George's in the end although it paid less, because of the attitude of the Head of Child Psychology at the time, Mike Berger, who gave me the space and time to make the decision at my own space.

This is a decision I have never regretted – and I am still at St George's more than 25 years later. I have been able to pursue my research interests, seen a huge variety of patients despite the PICU being smaller than the one at GOSH and have been able to build a new Paediatric Psychology Service that now employs 15 qualified staff, as well as being able to walk to work.

Early research ideas at St George's: My initial role at St George's included covering general outpatient referrals especially from gastroenterology and urology, but it also encompassed developing the inpatient role of our small team of three. There was an established presence of psychology on the oncology/infectious diseases ward and the general medical ward but no regular input to the surgical ward or the tiny two-bed PICU. I started by approaching the surgeons to suggest that we held a weekly psychosocial meeting (as I had been used to these at GOSH) but they were too busy to fit in an extra meeting. So I asked if I could join a ward round instead, once a week. They relented and so it was that a space opened up in which to consider, cursorily to begin with, psychosocial aspects of patient and family care in a formal setting. I knew I had got somewhere when a senior surgeon stopped me in the corridor to explain his Damascene moment. He told me he had just explained at some length to a mother what was wrong with her child, but was surprised to notice that she was still crying afterwards, so he thought of making a referral to psychology!

Initially I did not have much contact with PICU but, encouraged by my published abstract on the Bereavement Clinic at GOSH, I set about conducting a survey on the current position as regards psychosocial staffing of PICUs in the UK. The number of units was small enough to chase up non-responders by phone and I was pleased to have a paper accepted on the findings.
In my second year at the hospital the PICU was expanded to 8 beds and moved from what was known as 'the broom cupboard' to shiny new facilities further along the corridor on the first floor of the hospital. This is the 'business floor of the hospital where the most critical work happens and where a patient may need to be moved very quickly for life support from one area to another. It is where the labour ward, all the theatres and all the other intensive care units, including the neonatal ICU, general adult ICU, adult cardiac ICU and adult neurosurgical ICU, are sited.

The funds to build the newly expanded PICU had been raised by the hospital charity and included a significant amount of money which was specifically earmarked for research (10% of the total budget). I was alerted to this by the then head of paediatrics, Prof Dafydd Walters, who suggested I put a research proposal together and to my delight I received the lion's share of the research funding allocation.

My project represented an effort to find out more about how parents and children were affected psychologically in the longer term, by their experiences on PICU. I could find very little on this topic in either the psychological or intensive care literatures at this stage and was aware of a debate about the potential risks of debriefing, following the publication of a couple of studies which actually found

higher rates of distress in debriefed patients than controls, after traumatic experiences. I wanted to have a better sense of how, in retrospect, families construed their time on PICU and how they managed in the longer term. I hoped this would then inform my role as I tried to support new admissions acutely, keenly aware from the new research that there was also the potential for me to cause them harm.

The research grant enabled me to hire a research assistant and to backfill half of my clinical sessions, thus providing me with time to gather data, pore over it, read and write. I was also given a desk in the medical school, in the psychology department, which at that time was headed up by Andrew Steptoe and later Robert West (both of whom later moved to the Behavioural Unit at UCL). They were supportive although they did not have formal links with paediatrics in the hospital and provided me with sound guidance. I also realised anew how central research was to my professional identity and from then on protected my research time much more consciously, in the periods when I did not have funding for clinical cover. This was important as it was not easy to complete writing up within the grant periods with such a busy home and clinical life. The enormous comfort of having a permanent job, which included a notional minimum of 20% of my hours to be allocated to research in the job description, provided me with time for my ideas to brew at a natural pace, both in relation to new projects and how to interpret and do justice to my findings by applying them in practice.

At this point I was also asked to get in involved in a survey of parents across the South East who had been through the experience of having a child 'retrieved' from their local hospital to one of the London PICUs. The study was coordinated through Guy's who managed to collect data from over 200 parents but I helped design the survey and the analysis and write up also fell to me. It was meant to be a customer satisfaction survey but what emerged was a picture of distraught parents who did not remember being given a leaflet about the retrieval service (which the lead nurse assured me was provided to every family on their arrival at the local hospital) and who were devastated at not being allowed in the special PICU ambulance with their child during the transfer. I knew from some of my research interviews for the main study I had been working on just how far away some of these families lived from the capital. I had interviewed them at home, travelling by public transport and it had sometimes taken up to three hours to reach them, if for example they lived in rural Kent, which has no PICU nearer than South London. I found out later from a cleaner than many leaflets were discarded, unread, in the waiting room. Importantly, on the basis of these findings, the decision was taken at management level to allow one parent in the retrieval ambulance from then on, which earned me an honourable mention for good practice in a national NHS Improvement report. Parents now are astounded to hear that this was ever an issue and cannot imagine being separated from their child at such a terrible point.

Although I prefer doing quantitative analyses, I had also made a decision to audiotape the parent interviews from the previous project. After publishing the initial findings (which demonstrated that a significant proportion of parents were exhibiting clinically significant levels of distress and that many would have appreciated a follow-up appointment) I went about trying to make sense of their responses from a qualitative perspective. There was a large amount of data (52 interviews) so It was helpful to invest in some qualitative software which made it easier to search for particular terms and phrases. This all took time, more time than was funded, and so I needed to continue this work back in my day job, and finally published it a couple of years later.

One of the most valuable things I learned through these analyses was how often people spontaneously commented on positive aspects of their experience (eg their admiration of the NHS staff who cared for their child and for them and their new sense of what was important in life). This

prompted me to read more widely about a phenomenon known as 'post-traumatic growth' and later to include a measure of this aspect of experience in another project.
My confidence in presenting posters, and then oral submissions at conferences grew. It was exciting to travel to new places to attend international meetings and I began to strike up professional relationships with colleagues who were interested in the same issues. Over time I also began to be asked to contribute to symposia, as well as continuing to submit my own study findings.

My next project was an evaluation of a PICU follow-up clinic which is included in this portfolio. I had read about a pioneering adult ICU in Merseyside which was offering an opportunity for patients and family members to return to the hospital to clarify what had happened to them during admission and for referral on for additional rehabilitation or support if needed - I wondered whether this might be something that would appeal to the families of PICU patients. Obtaining ethical permission to carry out research projects was much less bureaucratic then and I was able to find a bit more funding to employ another research assistant, which made it possible to conduct a small randomised controlled trial on a shoestring.

We found some evidence that this intervention was helpful – but only for those parents who had reported high levels of acute stress at the time of the admission.

Shift of focus onto the child's experience: My focus then moved to what the children themselves made of their PICU experience, and particularly how they made sense of the hallucinations they were reporting in my clinical practice. Looking back now I am struck by how I spent roughly 10 years researching the parents' perspective, 10 years on the children's experience and, by the time I retire, I will have spent 10 years focusing on staff stress and its measurement.

I managed to secure funding from the Health Foundation for a new project via a Leading Practice Through Research Award, and was again in a position to employ backfill for half of my clinical post. I realised from some early pilot work that it would be difficult to recruit sufficient numbers of older children win a reasonable timeframe, given the fact that the majority of children admitted to PICU are aged under 3y, so I approached my former colleagues on the PICU at GOSH to ask if I could recruit instead from their larger unit.

This time I did the data collecting, entering and cleaning, as well as the analyses and write up with some help with logistic regression from a statistician, as I had no assistant. But on reflection I believe it was important that an experienced child clinician did the interviews. I managed to interview over 100 children twice in 18 months and uncovered some very rich data which formed the basis of a landmark paper on children's experience of deleriogenic hallucinations on PICU (previously only reported in adult intensive care patients), which is my most widely cited publication. I also later wrote up further papers on post-traumatic stress symptoms and quality of life and fatigue in this cohort, which also form part of this portfolio.

The impact on staff of the work they do: My current main interest now is on the impact of working in PICU on staff, a topic which is especially pertinent at the time of writing in the pandemic. There was however already pre-existing evidence that this group of staff were at elevated risk of burnout, PTSD and moral distress by virtue of the numerous traumatic events they witness over the course of their careers. Another aspect of their work that has been associated with increased stress levels has been the increasingly fraught context surrounding the difficult decisions they have to make regarding the many new treatment options afforded by the latest developments in medical technology, as greater proportions of children survive with significant levels of morbidity. As discussed in the thesis, I have published data on burnout, PTSD and moral distress in adult and

paediatric intensive care staff at St George's and GOSH and most recently have collaborated on a bigger national survey of PICU staff (n=1656) using the same instruments that were part of my original battery.

I have also continued to be involved in collaborations with others on longitudinal studies following the trajectories of distress in children and parents post-discharge. The paper I am probably most proud of, although it does not have the highest number of citations, is one I wrote combining my clinical and research expertise. It presents evidence of the efficacy of a brief treatment for PTSD in a case series of parents I have treated and has also been included in my PhD by Publication.

On re-reading my papers in the process of writing this thesis, I have been reflecting on how lucky I have been to get to go to so many conferences to present – which was not an aspect of the work I had expected to experience or to enjoy as much. Some of the most memorable places I have presented in on my work in humble Tooting are Hawaii, Copenhagen, Bergen, Montreal, Seattle, San Francisco, Singapore and Istanbul. I have been honoured to gain professional acceptance within PICS and SCCM, and as my experience and confidence have increased over the years, I have now moved through the whole gamut of conference-related research experiences from getting posters accepted to being asked to collaborate in symposia, leading to invitations to judge posters and chair sessions. This has recently culminated in me being able to put on my own study day, on the role of psychologists in supporting staff wellbeing, which was attended by psychologists from all over the country.

Balancing my research and clinical roles on PICU: Finally, despite calling myself a 'clinician-researcher', I am aware that in this account I have skated over my clinical work. It is harder to distil my thoughts about this while I am still working, although I realise I am likely to be reminded of many details when I begin an audit of 20 years of clinical referrals from PICU at St George's, which is the next project I plan to undertake.

I still struggle to decide whether my clinical persona or my research persona has the upper hand, in relation to my professional identity – but I am quite certain that my research has sustained me in relation to being able to continue with this challenging clinical work. Also on a personal level, I cannot imagine a more worthwhile area of study. The to-ing and fro-ing between the research world and the clinical world has, I have no doubt, kept my work relevant to the populations I have attempted to describe and has enhanced my ability to continue to support them in an evolving evidence-based way.

At this stage I feel it is too soon to have enough perspective on the many painful stories I have encountered over my career, or to reflect properly on my clinical contribution, but I hope that in retirement I will be able to do so, spurred on by the positive experience of taking formal stock of my research contribution, in this thesis.

Gillian Colville
25/10/21

PORTFOLIO OF PAPERS

PAPER 1 The PTSD study: Colville G, Pierce C. Patterns of post-traumatic stress symptoms in families after paediatric intensive care. Intensive Care Med. 2012;38:1523-1531.

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PEDIATRIC ORIGINAL

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Patterns of post-traumatic stress symptoms in families after paediatric intensive care

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Abstract *Purpose:* To establish longitudinal rates of post-traumatic stress in a cohort of child–parent pairs; to determine associations with poorer outcome. *Method:* This was a prospective longitudinal cohort study set in a 21-bed unit. In total 66 consecutive admissions aged 7–17 years were screened with one parent at 3 and 12 months post-discharge. Measures used were the Children's Revised Impact of Event Scale (CRIES-8) and the SPAN (short form of Davidson Trauma Scale). *Results:* In total 29 (44 %) child–parent pairs contained at least one member who scored above cut-off 12 months after discharge, with scores increasing over time for 18 parents and 26 children. At 3 months, 28 (42 %) parents and 20 (32 %) children scored above cut-off; at 12 months the rates were 18 (27 %) parents and 17 (26 %) children. Parents scoring above cut-off at 12 months were more likely to have had a child admitted non-electively (100 % vs. 77 %, $p = 0.028$); had higher 3-month anxiety scores (11.5 vs. 4.5, $p = 0.001$) and their children had higher post-traumatic stress scores at 3 months (14 vs. 8, $p = 0.017$). Children who scored above cut-off at 12 months had higher 3-month post-traumatic stress scores (18 vs. 7, $p = 0.001$) and higher Paediatric Index of Mortality (PIM) scores on admission (10 vs. 4, $p = 0.037$). *Conclusions:* The findings that (a) nearly half of families were still experiencing significant symptoms of post-traumatic stress 12 months after discharge; (b) their distress was predicted more by subjective than by objective factors and (c) many experienced delayed reactions, indicate the need for longer-term monitoring and more support for families in this situation

Keywords Post-traumatic stress · Paediatric intensive care · Longitudinal · Outcomes · Parents

Introduction

Recent guidelines on the management of post-traumatic stress disorder (PTSD) [1] have endorsed a move away from the provision of blanket interventions, recommending instead that at risk populations are monitored for a period before evidence-based interventions are offered to those with significant or persistent symptoms. Such an approach depends on the use of validated screening instruments [2] but, in practice, routine screening for post-traumatic stress after traumatic events is rare, outside the research context. This situation is partly related to the small number of psychologists and psychiatrists working in medical settings, but is also the result of the lack of awareness of suitable validated screening instruments on the part of health professionals who are most likely to be

in contact with families in the aftermath of traumatic medical events.

Children admitted to a Pediatric Intensive Care Unit (PICU) are theoretically at increased risk of the development of PTSD since they are, by definition, at increased risk of death. There is cross-sectional evidence that they report higher rates of post-traumatic stress symptoms than children admitted to general wards and that their symptoms are positively correlated with those of their parents [3] and more common in children who recall delusional experiences during admission [4]. However, little information is available on how children's symptoms, or those of their parents, who are at even higher risk [5, 6], develop or resolve in the longer term. The authors of a recent review of psychological outcome studies [7] conclude that PICU patients exhibit significant psychiatric morbidity and that there is a need for more research in this area on how their symptoms change over time and interact with parental psychopathology.

Furthermore, recent guidelines on rehabilitation of adult intensive care survivors [8] have identified these patients and their relatives as needing regular psychological monitoring in recognition of the evidence of psychopathology in these groups [9, 10]. It could be argued that the need to monitor family members is even more pertinent in paediatric settings where patients are particularly dependent on their parents for their medical care and emotional well-being.

The main aim of this exploratory study was to use brief screening instruments to monitor the levels of post-traumatic stress symptoms in child–parent pairs at 3 and 12 months post-discharge. In doing so we hoped that it would be possible to establish more information about the natural history of these symptoms in this population. In recognition of the limited information available currently on which aspects of the intensive care experience are found to be most traumatic [11], participants were asked to state the 'worst thing' that they had experienced. Finally, associations with post-traumatic stress status 12 months after discharge were examined.

On the basis of previous research it was hypothesised that a significant minority of participants would score in the clinical range and that, in the majority of adults, symptoms would reduce over time [12]. It was less clear how the children would fare owing to the limited longitudinal evidence available, although there is some research suggesting that children may be more prone to delayed reactions [13] and a recent epidemiological study has shown that post-traumatic stress symptoms take longer to remit naturally after childhood trauma [14].

Method

Participants

Participants were children aged 7–17 years and their primary carers. All children had been consecutively admitted over an 18-month period to a tertiary centre 21-bed PICU and had previously been interviewed about their experiences of PICU, 3 months after discharge. Principal exclusion criteria were significant learning difficulties and readmission during the study period. The lower end of the age range of the children in the sample was determined by the requirements of the original study [4], which focused on the nature of children's memories of PICU and how these were associated with sedation and distress.

Procedure

Ethical permission for the original study and this follow-up study was granted by the Great Ormond Street/Institute of Child Health Research Ethics Committee and written informed consent obtained. Demographic and medical data were obtained from the child's medical record. Illness severity in the first 24 h of admission was measured using the Paediatric Index of Mortality (PIM) [15]. Level of social deprivation was quantified using the Townsend Deprivation Index (TDI) [16].

Three months after discharge from PICU, in the course of an interview about their memory for events during their admission [4], each child had completed a post-traumatic stress screening questionnaire. One parent or primary carer (referred to as 'parent' throughout the text for clarity) also completed a post-traumatic stress screen at this point, as well as a brief measure of symptoms of anxiety and depression, but these data have not been published previously.

As the 1-year anniversary of discharge approached, permission was sought from the family's general practitioner to re-contact the family by post. If the questionnaires were not returned after a second mailing, participants were given an opportunity either to complete them over the telephone or in person, when the child was next due to be reviewed in the outpatient clinic. All families were offered referral on for further support if their scores were above clinical cut-off at 12 months.

Psychological measures (see online supplement for further information)

The questionnaires used were selected on the basis of their brevity, as well as their validity, in order to minimise the burden on the participants in the clinical setting where full psychiatric interviews are impractical.

1. *Children's Revised Impact of Event Scale* (*CRIES-8*): Children's post-traumatic stress symptoms were measured using the eight-item version of the Children's Revised Impact of Event Scale (CRIES-8). This is a self-report measure developed for use with children

aged between 7 and 18 years, with established reliability and validity [17]. A total score of 17 or more has been found to classify correctly over 80 % of children with a diagnosis of PTSD [18].

2. *SPAN*: The SPAN is a brief post-traumatic stress symptom screener for adults, made up of four items ('Startle', 'Physiological Arousal', 'Anger' and 'Numbness') from the Davidson Trauma Scale [19], which is reported to have as good psychometric properties as other longer screening instruments [20]. Scores of 5 or more have been shown to classify correctly 88 % of diagnosed cases of PTSD [21].
3. *Hospital Anxiety and Depression Scale*: The HADS is a self-report questionnaire for use with adults with good internal consistency and reliability [22], made up of two separate scales, one measuring anxiety and the other measuring depression. Scores of 11 or more on either scale indicate a 'moderate/severe' level of symptoms, which is regarded as clinically significant [23].

Statistical analyses

Non-parametric statistics were used, as not all variables were normally distributed. The Wilcoxon signed-rank test was used to make paired comparisons for the same participant at the two screening timepoints. Differences between subgroups were analysed using the Mann–Whitney *U* test for continuous variables and Pearson's χ^2 or Fisher's exact test for categorical data. Finally Spearman rank correlations were computed to examine the association between parents' and children's post-traumatic stress scores. Analyses were performed using the SPSS 16.0 software (SPSS, Inc., Chicago, IL).

Results

Recruitment and retention (see Fig. 1)

Of the 132 families approached to take part in the original study [4], 102 (77 %) agreed to take part. Families of surviving children ($n = 99$) were re-contacted for the present study and of these, 81 (82 %) provided some follow-up data at 12 months. Given the focus of this study, statistical analyses were confined to the 66 child–parent pairs [50 % of original potential sample ($n = 132$) but 67 % of those approached ($n = 99$)] who provided complete post-traumatic stress data at both timepoints. Statistical comparisons showed no systematic differences, regarding baseline patient characteristics, between the children in recruited and non-recruited families, or between those who stayed in the study and those who dropped out between 3 and 12 months (see Tables A and B in the online supplement). Sample characteristics of the 66 child–parent pairs with complete post-traumatic stress data are given in Table 1.

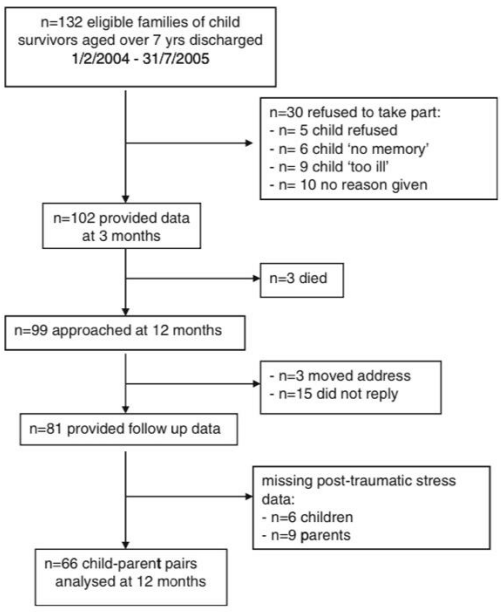

Fig. 1 Study flow diagram

Prevalence of post-traumatic stress symptoms

Children

Children's group median (range) score on the CRIES-8 did not change significantly between the timepoints studied [10 (0–26) at 3 months vs. 7.5 (0–33) at 12 months, $p = 0.218$]. Similarly there was little difference between the proportion of children scoring in the clinical range at 3 months and 12 months [20 (32 %) vs. 17 (26 %), $p = 0.561$]. On an individual level, however, seven children scoring below cut-off at 3 months, later scored in the clinical range at 12 months (Fig. 2).

Parents

Parents' group median (range) score on the SPAN fell significantly between 3 months and 12 months from 4 (0–16) to 2 (0–16), $p = 0.017$. In total 28 (42 %) parents scored in the clinical range at 3 months. This number fell to 18 (27 %) at 12 months ($p = 0.067$). However, these group level analyses concealed individual differences in the opposite direction. There were eight examples of

Table 1 Baseline sample characteristics of child–parent pairs with full post-traumatic stress data at 3 and 12 months after discharge from the PICU ($n = 66$)

Variable type	Median (range) or *n* (%)
Demographics	
Child age (years)	11.2 (6.8–16.9)
Male child gender	38 (58 %)
Social deprivation[a]	31 (47 %)[b]
White UK ethnicity	40 (61 %)
Parent/carer	
Mother	57 (86 %)
Father	8 (12 %)
Grandmother	1 (2 %)
Parent/carer age (years)	39 (27–57)
Admission related	
Length of stay on PICU (days)	2 (0–38)
Emergency admission	55 (83 %)
Severity of illness (PIM)[c]	4 (1–42)[b]
Reason for admission	
Respiratory	3 (5 %)
Neurological	5 (8 %)
Medical other	15 (23 %)
Traumatic brain injury	26 (39 %)
Surgical emergency	6 (9 %)
Elective surgery	11 (17 %)

TDI Townsend Deprivation Index, *PIM* Paediatric Index of Mortality, *PICU* Paediatric Intensive Care Unit

[a] Defined as proportion in the lowest quintile using the TDI

[b] $n = 65$

[c] Higher scores indicate higher risk of mortality

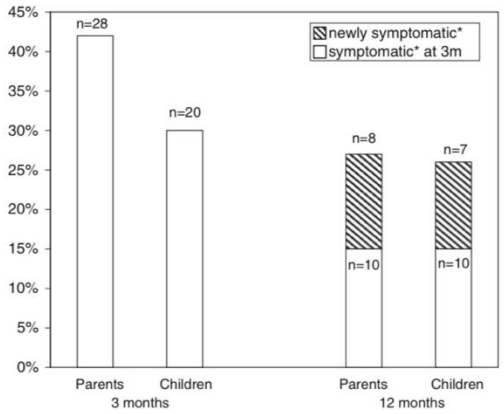

Fig. 2 Proportions of children ($n = 66$) and parents ($n = 66$) scoring above cut-off on post-traumatic stress screening measures at 3 months and 12 months following the child's discharge from the PICU. *Symptomatic defined as score above recommended clinical cut-off: for children ≥17 on the CRIES-8; for adults ≥5 on the SPAN

parents who had scored below the clinical range at 3 months who later scored above cut-off at 12 months (Fig. 2).

Child–parent pairs

The proportions of families affected by significant levels of post-traumatic stress at 3 months and 12 months are illustrated in Fig. 3. Clinically significant symptom levels were evident in at least one member of 29 (44 %) child–parent pairs a year after discharge, and there were nine examples of families where *both* the child and the parent were significantly symptomatic. In total, post-traumatic stress scores *increased* over time in the cases of 26 children and 18 parents.

The 'worst thing' about the PICU experience

In the process of completing the post-traumatic stress screening instruments, children and parents were asked to state the 'worst thing' that they had experienced in relation to the child's intensive care admission. Responses to this question were examined for the 20 children and 28 parents scoring in the clinical range at 3 months.

Children

Many children reported a specific distressing event on PICU as the worst thing they remembered, such as waking up and not knowing where their parents were ($n = 5$); vomiting ($n = 3$); having hallucinations on PICU ($n = 2$) and choking on the ventilator tube ($n = 1$). Some could not isolate a particular event, describing the whole PICU experience as traumatic ($n = 3$). However, in 7 (35 %) cases children specified an event which had occurred *outside* the PICU as the worst part of their experience. This was most commonly related to the accident or deterioration that had precipitated their admission.

Parents

In comparison only 4 (14 %) parents gave a pre-admission event as the most traumatic. The majority stated that the time on PICU was the most stressful from their perspective, with 13 parents citing a particular low point (such as seeing the child attached to the machines for the first time, receiving a life-threatening diagnosis or realising their child could die) and 11 parents responding to the question in general terms, such as 'the whole thing' or 'everything—I will never forget it'.

Associations with post-traumatic stress status 12 months after discharge

Children (see Table 2)

Children scoring above cut-off at 12 months had higher post-traumatic stress scores at 3 months and higher

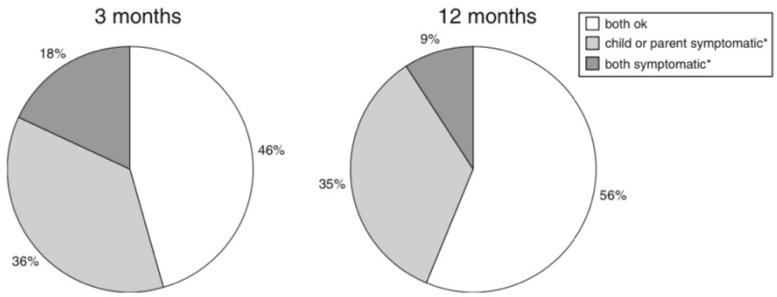

Fig. 3 Proportions of child–parent pairs ($n = 66$) exhibiting clinically significant levels of post-traumatic stress symptoms at 3 months and 12 months post PICU discharge. *Symptomatic defined as score above recommended clinical cut-off: for children ≥17 on the CRIES-8; for adults ≥5 on the SPAN

Table 2 Associations with children's post-traumatic stress scores 12 months after discharge from intensive care ($n = 66$)

	Children's post-traumatic stress score on CRIES-8		
	Normal range $n = 49$	Above clinical cut-off (≥17) $n = 17$	p[a]
Demographics			
Child age (years)	11.2	11.1	1.000
Male child gender	–	–	0.904
Parent age (years)	39	40	0.924
Female parent gender	43 (88 %)	15 (88 %)	1.000
Social deprivation[b]	25 (52 %)[c]	6 (35 %)	0.234
White UK ethnicity	29 (59 %)	11 (65 %)	0.688
Admission-related variables			
Length of stay on PICU (days)	2	2	0.885
Emergency admission	38 (78 %)	17 (100 %)	0.053
Severity of illness[d] (0–100)	4[c]	10	0.037*
Child's memory of PICU			
Any factual memory	29 (59 %)	10 (59 %)	0.979
Any delusional memory	17 (35 %)	7 (41 %)	0.632
Child post-traumatic stress score at 3 months			
Total score (0–40)	7	18	0.001**
Avoidance subscale score (0–20)	6	9	0.033*
Intrusion subscale score (0–20)	3	6	0.042*
Parent psychology scores at 3 months			
HADS anxiety (0–21)	6	9	0.393
HADS depression (0–21)	2	4	0.393
SPAN post-traumatic stress (0–16)	4	4	0.870

Data are given as median or number with percentage in parenthesis as appropriate
CRIES-8 Children's Revised Impact of Event Scale, *SPAN* abbreviated Davidson Trauma Scale, *PICU* Paediatric Intensive Care Unit, *HADS* Hospital Anxiety and Depression Scale
* $p < 0.05$, ** $p < 0.01$

[a] Pearson's χ^2 or Fisher's exact test used for categorical data; Mann–Whitney U test used for continuous data
[b] Defined by proportion in the most deprived quintile using the TDI
[c] $n = 48$
[d] Measured by PIM

mortality risk (PIM) scores on admission. Their status was not however associated with any demographic variables or with parental psychopathology at 3 months. Also, although the child's report of delusional experiences during admission was associated with post-traumatic stress symptoms at 3 months in the original study [4], this association was not significant at 12 months, in this subsample.

Table 3 Associations with parents' post-traumatic stress scores 12 months after discharge from intensive care ($n = 66$)

	Parents' post-traumatic stress score on SPAN		
	Normal range $n = 48$	Above clinical cut-off (≥5) $n = 18$	p[a]
Demographics			
Child age (years)	11.8	10.1	0.407
Male child gender	27 (56 %)	11 (61 %)	0.722
Parent age (years)	40	37	0.247
Female parent gender	41 (85 %)	17 (94 %)	0.430
Social deprivation[b]	24 (51 %)[c]	7 (39 %)	0.379
White UK ethnicity	31 (65 %)	9 (50 %)	0.280
Admission-related variables			
Length of stay on PICU (days)	2	3.5	0.669
Emergency admission	37 (77 %)	18 (100 %)	0.028*
Severity of illness[d] (0–100)	4[c]	7	0.144
Child's memory of PICU			
Any factual memory	27 (56 %)	12 (67 %)	0.443
Any delusional memory	17 (35 %)	7 (39 %)	0.794
Child post-traumatic stress score at 3 months			
Total score (0–40)	8	14	0.017*
Avoidance subscale score (0–20)	6	11	0.017*
Intrusion subscale score (0–20)	4	3.5	0.627
Parent psychology scores at 3 months			
HADS anxiety (0–21)	4	3.5	0.001**
HADS depression (0–21)	2	6	0.092
SPAN post-traumatic stress (0–16)	2.5	5	0.297

Data are given as median or number with percentage in parenthesis as appropriate
CRIES-8 Children's Revised Impact of Event Scale, *SPAN* abbreviated Davidson Trauma Scale, *PICU* Paediatric Intensive Care Unit, *HADS* Hospital Anxiety and Depression Scale
* $p < 0.05$, ** $p < 0.01$

[a] Pearson's χ^2 or Fisher's exact test used for categorical data; Mann–Whitney U test used for continuous data
[b] Defined by proportion in the most deprived quintile using the TDI
[c] $n = 47$
[d] Measured by PIM

Parents (see Table 3)

Parents scoring above cut-off at 12 months had higher anxiety scores at 3 months and were more likely to have had their child admitted non-electively. Furthermore, at 3 months their children had reported higher post-traumatic stress scores, and in particular more symptoms of avoidance, than the children of parents who scored in the normal range for post-traumatic stress symptoms 12 months after discharge

The correlation between child and parent post-traumatic stress scores was significant at 3 months ($r = 0.32$, $p = 0.008$), but not at 12 months ($r = 0.01$, $p = 0.920$).

Anxiety and depression in parents

The numbers of parents scoring in the 'moderate/severe' range on the HADS (subscale score ≥ 11) for anxiety were 19 (29 %) at 3 months, and 17 (26 %) at 12 months. For depression, the numbers were 5 (8 %) and 4 (6 %), respectively.

Discussion

This study a group of children, whose recollections of PICU and post-traumatic stress symptoms at 3 months have been reported on previously [4], were followed up together with their parents, 12 months after discharge.

Rates of post-traumatic stress were similar to those found in other studies [3, 5, 6]. However, although parents' and children's scores were significantly associated at 3 months, as has been found in another cross-sectional study [3], this association was no longer significant at 12 months after discharge, suggesting that different factors influenced their psychological outcome as time went on. Also, in relation to the change in symptoms over time, whilst there was a significant reduction in parents' group median score over the year, the same was not true for children. This finding is consistent with those of a small number of studies of children followed up for a year or more after injury, which have shown strikingly little change in rates of post-traumatic stress levels [24, 25]. Furthermore, although the qualitative findings relating to parents' experiences of PICU were similar to those described by

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ORIGINAL ARTICLE

Do parents benefit from the offer of a follow-up appointment after their child's admission to intensive care?: an exploratory randomised controlled trial

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KEYWORDS
Post-traumatic stress;
Depression;
Intervention;
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Summary
Objective: The study aim was to evaluate the psychological impact on parents of the provision of a paediatric intensive care follow-up clinic.
Design: Exploratory randomised controlled trial. Families were allocated to intervention (follow-up clinic appointment two months after discharge) or control (no appointment) condition.
Setting: An eight-bed Paediatric Intensive Care Unit (PICU) in an inner city teaching hospital.
Measurements: Parents' baseline stress was assessed using the Parental Stressor Scale: PICU. Post-traumatic stress, anxiety and depression were assessed at five months using the Impact of Event Scale and the Hospital Anxiety and Depression Scale.
Results: Only 18/72 families (25%) in the intervention group chose to attend the clinic. Outcome data were provided by 55/82 parents in the intervention group and 50/72 in the control group. Although no significant differences were found between the groups as a whole, parents with higher baseline stress reported lower rates of post-traumatic stress ($n = 8/32(25\%)$ vs. $n = 13/23(57\%)$, $p = 0.018$) and depression ($n = 6/32(19\%)$ vs. $n = 12/23(52\%)$, $p = 0.009$) at five months if they had been offered an appointment than if they had not.
Conclusions: Whilst these results do not justify routine follow-up for all, they suggest that, for the most traumatised parents, rates of long-term distress could be reduced by this intervention.

The new guideline on rehabilitation after intensive care (NICE, 2009) stresses the need for continued monitoring and support of patients and their families following intensive care treatment. Furthermore, adult intensive care survivors report that, if they feel they need it, they value having an opportunity to meet with staff as outpatients, both to review their recovery and to give feedback about what they

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regard as a unique experience, which they do not feel is understood by other health care professionals (Prinjha et al., 2009). The United Kingdom, in response to Department of Health recommendations (Department of Health, 2000), has led the way internationally in setting up intensive care follow-up services. Yet despite the fact that as many as 30% of adult units now offer follow-up clinic services (Griffiths et al., 2006), we still do not have an evidence base for this form of intervention and therefore cannot say who is most likely to benefit. Also there is no consensus on how these services should be delivered, although many units restrict services to patients who live nearest to the hospital or have been admitted for a certain number of days (Williams and Leslie, 2008).

The only randomised controlled trial of a nurse-led intensive care follow up programme has found no significant effect on patient physical or psychological outcomes at one year (Cuthbertson et al., 2009). However the authors concede that the need to adhere to a standardised research protocol may have detracted from the potential impact of this form of intervention and they may have underestimated the need to address the complexity of the role of relatives in patients' recovery. Commentators on this study have also suggested that a more individualised approach with a greater focus on the changing support needs of survivors may yield more promising results for follow-up services (Lee et al., 2009).

Little information is available about the impact of follow-up clinics on relatives, who suffer significant distress in their own right (Azoulay et al., 2005), although when they attend follow-up clinics, they often raise the issue of the impact of their loved one's critical illness on their own mental health (Hall-Smith et al., 1997; Jones et al., 1994).

Another gap in the literature in this area relates to the provision of follow-up services in *paediatric* settings. Given that 47% of patients in paediatric intensive care are aged under 12 months (Paediatric Intensive Care Audit Network, 2005), such services need to be aimed primarily at parents. There is a growing body of evidence that parents report significant levels of distress relating to their child's intensive care admission (Balluffi et al., 2004; Board and Ryan-Wenger, 2003; Bronner et al., 2008; Colville and Gracey, 2006; Colville et al., 2009; Rees et al., 2004) and, in a recent survey, two thirds of parents indicated that they would have appreciated a follow-up clinic appointment to discuss their child's admission (Colville et al., 2003) but to date only one paediatric intensive care follow-up clinic has been described in the literature (Bronner et al., 2008).

The main aim of this study was to evaluate whether the offer of an follow-up clinic appointment would have an impact on parents' psychological well-being. It was hypothesised that the provision of an opportunity for parents to discuss their child's admission would result in more complete emotional processing of events (Ehlers and Clark, 2000) and thereby lead to reduced levels of post-traumatic stress symptoms and associated distress.

Two secondary aims of this study, which concerned the control data only, were to establish whether parents' baseline stress was predictive of their longer term distress and whether parents in this situation report post-traumatic growth. The results of these two nested studies are reported on separately (Colville and Cream, 2006, 2009).

Method

Design

An exploratory randomised controlled design was adopted in order to determine whether the offer of a follow-up appointment would be associated with a reduction in psychological distress over and above that which might naturally occur over time. Ethical permission for the project was granted by the Local Research Ethics Committee and parents were required to provide written consent.

Participants

Participants were parents of children admitted consecutively to an eight-bed Paediatric Intensive Care Unit (PICU) in a teaching hospital in an inner city area, who were available to give consent within 48 h of the child's discharge. Families were excluded if the child had been admitted for >12 h as it was logistically difficult to make contact with this group but otherwise there were no further exclusions relating to length of stay or distance. Parents were however excluded if staff felt it was inappropriate to approach them (e.g. non-accidental injury), or if the child had died, since these families were followed up routinely in any case.

Procedure

Parents were asked to complete a baseline stress measure on discharge from PICU (see below). Demographic and medical variables, including the child's Paediatric Index of Mortality (PIM) score (Pearson et al., 2001), were extracted from the child's medical record and the family's level of socio-economic deprivation was estimated using the Townsend Deprivation Index (Townsend et al., 1988).

Participating families were then randomised to either the intervention or control condition, using the sequentially numbered, sealed opaque envelope method.

Those in the intervention group received a letter inviting them to the PICU Follow-up Clinic, which was scheduled two months later, in accordance with parents' stated preferences in a previous survey (Colville and Gracey, 2006). The letter indicated that there would be a PICU consultant, a senior PICU nurse and a psychologist available to discuss their child's care during admission and that attendance was optional. Families were given the option of rescheduling and asked to confirm whether they would be attending. Staff were blind as to parents' baseline stress scores. The child was not examined but the medical record was available for consultation. During the appointment parents were encouraged to provide feedback on the admission, to ask any questions they had arising from it and to reflect on how they had been affected emotionally by their experiences.

Four months after discharge, parents in both groups were sent three questionnaires by post (see below). In addition, parents in the intervention group were asked to state whether they had found the appointment helpful or to give reasons for their non-attendance and parents in the control group were asked whether they would have liked an appointment. If they did not return the questionnaires

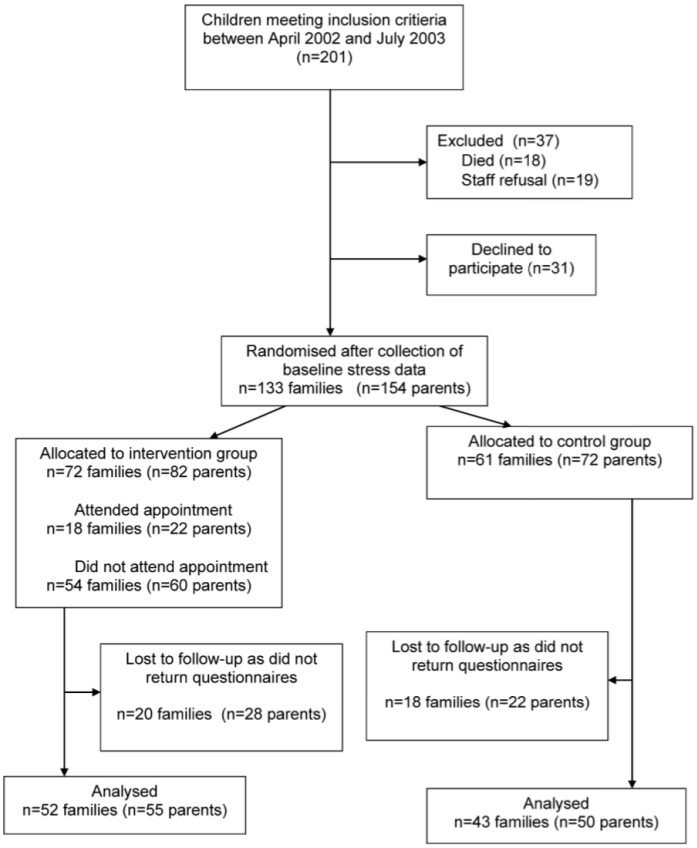

Fig. 1 Study flow diagram.

after a second mailing, parents were given a telephone reminder.

Psychological measures *(see ESM for more information)*

Parents' baseline stress was measured using the Parental Stressor Scale: PICU (PSS:PICU), which measures parents' perceptions of PICU related stress on seven different dimensions (Carter and Miles, 1989). The total score is the mean of the seven subscale mean item scores and ranges between 1 ('not stressful') and 5 ('extremely stressful'). The developers have demonstrated construct validity for this measure, in terms of strong correlations with an established measure of anxiety, and good internal reliability for the main scale and the subscales, confirmed by subsequent research by other teams (Curley and Wallace, 1992; Haines et al., 1995; Seiderman et al., 1997). Since its development the PSS:PICU has been used to determine the impact of short-term nursing interventions on parents' stress levels during admission (Curley and Wallace, 1992; Smith et al., 2007), but has not been used previously to predict risk of longer term psychopathology.

The primary outcome measure was derived from parents' scores on the Impact of Event Scale (IES) (Horowitz et al., 1979) which is a widely used, self-report measure of specific responses to trauma, with good psychometric properties (Sundin and Horowitz, 2002). Total scores of 35 or above are regarded as suggestive of a high risk of post-traumatic stress disorder (Neal et al., 1994), although the scale should not be used as a diagnostic tool in isolation.

Parents' anxiety and depression levels were also measured using the Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith, 1983). This is a self-report questionnaire, made up of two separate scales measuring anxiety and depression, with scores of 8 and above, on either scale, shown to discriminate best in terms of risk of psychiatric 'caseness' (Hermann, 1997). It is widely used internationally and has been shown to have good internal consistency and reliability (Bjelland et al., 2002).

Table 1 Baseline characteristics of intervention and control group families who provided outcome data at 5 months.

	Intervention group	Control group
Children	($n=52$)	($n=43$)
Age, years[a]	2.3 (0 to 16.2)	2.8 (0 to 16.5)
Male[b]	30 (58%)	27 (63%)
White UK[b]	41 (79%)	30 (70%)
TDI[a,c]	−0.1 (−4.0 to 9.9)	0.05 (−4.8 to 10.9)
Length of stay, days[a]	2.0 (0.5 to 26.6)	2.9 (0.5 to 42)
Emergency[b]	38 (73%)	35 (81%)
Respiratory	10	13
Sepsis	8	9
Trauma	3	4
Neurological	5	3
Other	12	6
Elective[b]	14 (27%)	8 (19%)
Plastic surgery	3	3
Oncology surgery	3	4
Other surgery	8	1
Ventilated[b]	22 (42%)	24 (56%)
PIM[a]	1.6 (0.2 to 18.4) ($n=55$)	2.1 (0.2 to 7.6) ($n=50$)
Parents		
Fathers[b]	7 (13%)	11 (22%)
PSS:PICU score at 48 h[a]	2.6 (1.1 to 4.3)	2.4 (1.1 to 4.3)

TDI, Townsend Deprivation Index; PIM, Paediatric Index of Mortality; PSS:PICU, Parental Stressor Scale: PICU
[a] Median (range).
[b] *n* (%).
[c] Positive scores indicate a greater level of socio-economic deprivation

Statistical analysis

Statistical comparisons were made on the basis of the original group allocation to the intervention (offer of appointment) or control (no appointment) conditions. The primary outcome measure was the proportion of parents scoring above the cut-off for probable post-traumatic stress disorder (IES $\geq$ 35). Proportions scoring above clinical cut-offs for anxiety (HADS Anxiety $\geq$ 8) and depression (HADS Depression $\geq$ 8) were also examined. Group comparisons were made using non-parametric statistics (Mann Whitney U-test/Pearson's Chi-square test) using SPSS version 16.0 (SPSS Inc, Chicago IL). Power calculations indicated that a sample of 128 would be sufficient for 80% power to pick up a medium-sized difference (i.e. 0.5 SD) in IES score at $p<0.05$ (Uitenbroek, 1997). Assuming an attrition rate of 20%, the aim was therefore to recruit between 150 and 160 parents.

Results

Recruitment, attrition and randomisation (Fig. 1).

Of the 164 families approached to take part in the study, 133 consented (154 parents), representing a recruitment rate of 81%. The children of those who declined to take part were less sick in terms of admission length and ventilation status and were more likely to belong to an ethnic minority and live in a socially deprived area but were otherwise comparable (see ESM Table A).

The baseline characteristics of the families who supplied outcome data ($n=95/133$ (71%)) were similar for the intervention and control groups and are provided, together with the main medical diagnoses of children, in Table 1. Rates of attrition were similar in both the intervention (30%) and control (28%) groups, with fathers and parents whose children were less sick statistically more likely to drop out (see ESM Table B).

Impact of intervention on psychological outcomes

Parents completed the postal questionnaires a mean (SD) of 5.33 (1.49) months after their child's PICU discharge. The prevalence rates for each psychological outcome examined and results of statistical comparisons between intervention and control groups are provided in Table 2. Although parents in the control group reported higher levels of all three forms of distress, these differences were not statistically significant

Further exploratory sub-group analyses were then performed in order to examine whether parents' stress at the time of their child's discharge from PICU had any bearing on their response to the offer of a follow-up appointment. Parents were classified 'high stress' or 'low stress' according to whether they had scored above or below median score (2.48) on the PSS:PICU. The proportions of 'high stress' and 'low stress' parents in each intervention condition scoring above clinical cut-offs at five months are illustrated in Fig. 2(a)−(c).

'High stress' parents who were offered an appointment reported lower rates of post-traumatic stress ($n=8/32$ (25%) vs. $n=13/23$ (57%), $\chi^2=5.63$, $p=0.018$) and depression ($n=6/32$ (19%) vs. $n=12/23$ (52%), $\chi^2=6.79$, $p=0.009$).

Table 2 Psychological outcomes at 5 months for parents in the intervention and control groups (whole sample analyses).

	Intervention group, *n* (%) *n* = 55	Control group, *n* (%) *n* = 50	*p*[a]	OR (95% CI)
Post-traumatic stress[b]	12 (22%)	16 (32%)	0.239	0.59 (0.25 to 1.42)
Anxiety[c]	26 (47%)	26 (52%)	0.628	0.83 (0.38 to 1.78)
Depression[c]	9 (16%)	15 (30%)	0.097	0.46 (0.18 to 1.16)

OR, Odds Ratio; CI, Confidence Interval.
[a] Pearson Chi-square.
[b] Impact of Event Scale Scale ≥ 35.
[c] Hospital Anxiety and Depression Scale ≥ 8.

Table 3 Baseline characteristics of intervention group families who attended the follow-up clinic compared with those of families who did not.

	Attenders (*n* = 18)	Non-Attenders (*n* = 54)	*p*[a]
Children			
Age, years[b]	1.2 (0 to 9.5)	3.0 (0 to 18.5)	0.416
Male[c]	12 (67%)	31 (57%)	0.488
White UK[c]	13 (72%)	43 (80%)	0.513
TDI[b,d]	0.4 (−4.0 to 9.9)	0.9 (−4.0 to 9.7)	0.630
Distance from hospital, miles[b]	18.2 (1.7 to 79.7)	5.7 (0.6 to 55.1)	0.042*
Length of stay, days[b]	4.3 (0.8 to 15.4)	1.2 (0.5 to 26.6)	0.001**
Emergency[c]	15 (83%)	33 (61%)	0.083
Ventilated[c]	11 (55%)	17 (31%)	0.068
PIM[b]	3.6 (0.2 to 18.4) (n = 22)	1.3 (0.2 to 11.0) (n = 60)	0.087
Parents			
Fathers[c]	4 (18%)	13 (22%)	0.730
PSS:PICU score at 48 h[b]	2.7 (1.1 to 4.0)	2.6 (1.1 to 4.3)	0.040*

TDI, Townsend Deprivation Index; PIM, Paediatric Index of Mortality; PSS:PICU, Parental Stressor Scale: PICU
[a] Mann Whitney *U*-test/Pearson's Chi-square.
[b] Median (range).
[c] *n* (%).
[d] positive scores indicate greater level of socio-economic deprivation.
* $p < 0.05$.
** $p < 0.01$

than 'high stress' parents in the control group. Comparisons relating to anxiety levels in the 'high stress' parents were not statistically significant (intervention $n = 18/32$ (56%) vs. control $n = 16/23$ (70%), $\chi^2 = 0.83$, $p = 0.362$).

For 'low stress' parents the proportions scoring above cut-off were as follows: post-traumatic stress: intervention $n = 4/23$ (17%) vs. control $n = 3/27$ (11%), $\chi^2 = 0.05$, $p = 0.823$; depression: intervention $n = 3/23$ (13%) vs. control $n = 3/27$ (11%), $\chi^2 = 0.05$, $p = 0.823$; anxiety: intervention $n = 8/23$ (35%) vs. control $n = 10/27$ (37%), $\chi^2 = 0.03$, $p = 0.869$). (see ESM for relevant power calculations).

Demand for follow-up clinic

Of the 72 families in the intervention group who were offered an appointment, only 18 (25%) families attended but, of these, 17 indicated they found it helpful. They commented in particular on the importance of being able to provide feedback and on having a formal opportunity to thank staff for their care as well as having a chance to clarify information and reflect on how they had been affected emotionally by their experiences.

Attendance at the clinic was positively associated with distance between home and hospital, length of stay and higher baseline stress (Table 3). 'High stress' parents were significantly more likely to attend the appointment ($n = 15/40$ (38%)) than 'low stress' parents ($n = 7/42$ (17%), $\chi^2 = 4.53$, $p = 0.033$).

Of the 41 families *not* offered an appointment who provided feedback, only 9 (22%) stated that they would have attended, given the opportunity and 10 explicitly stated they did not need follow-up *(see ESM for further information on parents' comments)*.

Discussion

In a recent editorial, Querques (2009) has proposed that a follow-up clinic meeting may be psychologically beneficial to adult intensive care survivors. The results of this study appear to support the contention that such a meeting might be also be beneficial to some relatives.

Parents in this study who had reported high levels of baseline stress, reported lower rates of post-traumatic stress and depression 5 months after discharge, if they had been

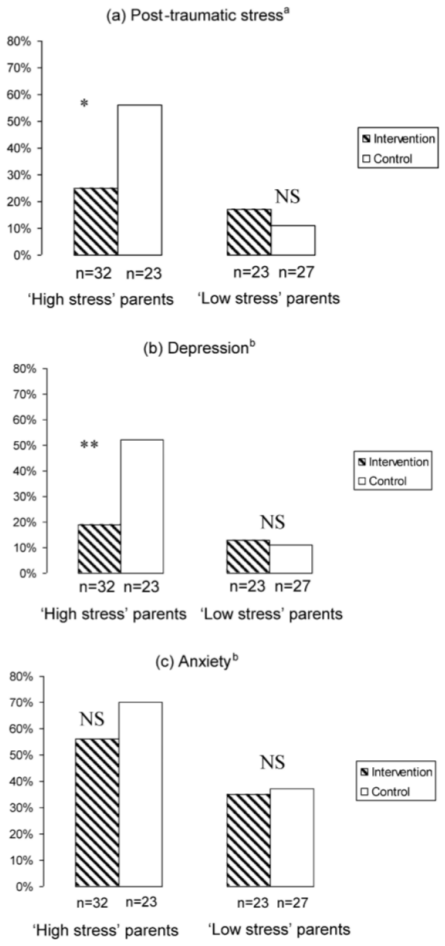

Fig. 2 Proportions of parents in the intervention and control groups scoring above clinical cut-offs at 5 months, by baseline stress levels. Parents were grouped as either 'high stress' ($n = 55$) or 'low stress' ($n = 50$) on the basis of whether they had scored above or below median (2.48) on the Parental Stressor Scale: PICU at the time of the child's discharge. Comparisons using Pearson's Chi-square test showed that 'high stress' parents who were offered an appointment reported lower rates of post-traumatic stress and depression but similar rates of anxiety, to those who were not offered follow-up. For 'low stress' parents, differences in psychological outcome between the intervention (appointment offered) and control (no appointment) conditions were not statistically significant. [a]Impact of Event Scale ≥ 35. [b]Hospital Anxiety and Depression Scale ≥ 8. *$p < 0.05$; **$p < 0.01$; NS = non-significant statistical difference.

offered a follow-up appointment than if they had not been offered an appointment. This finding, which was masked by initial whole group analyses, was both clinically and statistically significant.

The overall level of demand for follow-up from parents in this prospective study, however, was low. Only one in four intervention families who were offered an appointment chose to attend and a similarly small proportion of the control group stated that they would have attended if they had been offered an appointment.

However, the fact that parents with higher baseline stress were more likely to attend appears to indicate that parents self-selected for the appointment on the basis of their experiences during admission. This would be consistent with the finding that parents with higher post-traumatic stress scores 8 months after PICU discharge are more likely to say they would have liked follow-up (Colville et al., 2003) and with qualitative research that has found that adult patients only attend follow-up if they feel they need it (Prinjha et al., 2009).

The fact that families who attended the clinic lived significantly *further away* from the hospital than those who did not, is likely to be explained by the fact that the sickest children were often retrieved from some distance in this study. This is interesting finding, nevertheless, since it shows that distance from the hospital was not necessarily a barrier to attendance, although it is often given as an exclusion criterion by adult intensive care clinics (Williams and Leslie, 2008).

Strengths and limitations

To our knowledge, this is the first randomised controlled trial of a paediatric intensive care follow-up clinic, and is also the first to examine the link between parents' scores on the PSS:PICU at the time of admission and their longer term distress. The recruitment rate of over 80%, the measurement of parents' baseline stress and the collection of information on their views about follow-up were all strengths of this study.

However, the lower participation rates for those in ethnic minority and socially deprived groups are a concern given the evidence that these parents suffer higher levels of stress in relation to PICU (Balluffi et al., 2004) and that non-English speaking relatives receive less emotional support from ICU staff than other relatives (Thornton et al., 2009).

The low attendance rate at the clinic was disappointing, but a previous survey (Colville et al., 2003) had suggested that a higher proportion of families would attend. The only other PICU follow-up clinic in the literature reported a higher attendance rate at 69%, but they recruited a lower proportion of families at the outset and restricted their clinic to families of ventilated children and/or those admitted for over a week (Bronner et al., 2008). Williams and Leslie (2008) report that attendance rates at adult clinics vary, with the sickest patients being more likely to attend.

The attrition rate between baseline and the collection of outcome measures was higher than anticipated and reduced the power of the main analyses. Other researchers have reported similar problems retaining intensive care families in longitudinal studies (Balluffi et al., 2004; Melnyk et al., 2004). It is possible that telephone contact in between

assessments (Scott et al., 2006), would have resulted in lower rates of attrition, but this might also have had a therapeutic impact, which would have been difficult to disentangle from that of the intervention. Fathers were contacted separately to mothers in order to maximise their involvement (Phares et al., 2005), but were underrepresented.

A further limitation was that screening measures were used to establish rates of psychopathology rather than full diagnostic interviews, which would have been more definitive, but more costly.

Research implications

The results of this study must be regarded as preliminary, since they derive in part from post-hoc analyses, but they are worthy of further investigation. Further research on a larger sample could target parents judged to be at highest risk of poor outcome, in accordance with recent guidelines on post-traumatic stress disorder (NICE, 2005). Also, research on adult services might usefully consider examining the impact of intensive care clinics on relatives, given the increasing acknowledgement of the importance of the caregiver's role in the recovery of patients (Cameron et al., 2006).

Conclusions

Despite repeated recommendations in scholarly reviews (Board and Ryan-Wenger, 2000; Shudy et al., 2006), there are very few reports of intervention studies in this field, possibly because of the inherent problem of engaging potentially traumatised populations who, by definition, often avoid experiences that remind them of the traumatic event (Weisaeth, 1989). However, it is only by systematically testing out interventions that researchers will be able to advise on their effectiveness and feasibility in the clinical setting (Kazak et al., 2007).

These results appear to show that, for some parents, the chance to attend a follow-up clinic has a significant beneficial impact on psychological well-being. The high prevalence of distress in parents in this study serves as a reminder that more research on psychological intervention with families in this situation is urgently required.

Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at doi:10.1016/j.iccn.2010.02.005.

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PAPER 5 The NET Study: Colville G. Narrative Exposure Therapy with parents who have been traumatized in pediatric settings: a case series. Clin Pract Pediatr Psychol 2017;5:161–169

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Narrative Exposure Therapy With Parents Who Have Been Traumatized in Pediatric Settings: A Case Series

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There is increasing evidence that a significant number of parents are affected by symptoms of posttraumatic stress and anxiety for many months after their children's serious illnesses or accidents. It is important, therefore, that psychological treatments for use with this population are tried and evaluated for effectiveness with this population. The application of a new brief treatment, narrative exposure therapy (NET), is described here in relation to a case series of 4 parents who met criteria for posttraumatic stress disorder following their children's intensive care treatment. This approach, which has shown promise with other samples of people who have suffered repeated traumas, was associated with significant symptom relief (Cohen's *d*s = 1.01–2.37). The main themes that emerged in therapy are discussed, along with other treatment considerations.

Keywords: intervention, posttraumatic stress disorder (PTSD), pediatric intensive care unit (PICU), anxiety, depression

The possibility of being traumatized by the suffering of another has been more widely acknowledged since the extension of the criteria necessary for a diagnosis of posttraumatic stress disorder (PTSD) to include vicarious trauma (American Psychiatric Association, 1994). One example of a situation in which a person may be severely traumatized, without actually being at risk physically themselves, is that of a parent witnessing the suffering of a child in a hospital context in the event of an accident or serious illness. There is a growing literature on the prevalence of posttraumatic stress symptoms in parents in pediatric settings and in particular, those whose children's conditions require admission to intensive care (Balluffi et al., 2004; Bronner, Knoester, Bos, Last, & Grootenhuis, 2008; Colville & Pierce, 2012). As many as 20% of parents in this situation report clinically significant rates of PTSD (Nelson & Gold, 2012), and research has shown that they are aware that they have a tendency to be overprotective for many months after their children's discharge (Colville et al., 2009). Furthermore, the evidence that children take longer to recover emotionally when their parents report a high number of posttraumatic stress symptoms (Landolt, Ystrom, Sennhauser, Gnehm, & Vollrath, 2012) suggests that it is important to find ways to help such parents, not just for their sakes, but also in the interests of promoting their children's psychological well-being.

Narrative Exposure Therapy (NET)

Traditional evidence-based treatments for PTSD have, for the most part, addressed single traumas and commonly focus on exposure to the most traumatic event experienced, but a novel, manualized approach, NET, focuses instead on the value of integrating multiple traumatic experiences into the client's wider life story (Schauer, Neuner, & Elbert, 2011). NET was originally designed for use with survivors of multiple traumas, such as those experienced in situations in which support services are in short supply, for instance, during war and after natural disasters, and it is informed by testimony therapy, narrative therapy, and cognitive–behavioral exposure therapy. In a

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recent review comparing the results of 15 studies using NET and 32 studies using prolonged exposure therapy, Mørkved et al. (2014) found that NET was comparable in terms of effectiveness and had better drop-out rates. On the basis of this evidence, the authors have called for more research evaluating NET's use with a wider range of populations and trauma types.

NET treatment is considerably intensive in that it is usually scheduled at the frequency of two 60–90 min sessions a week, but it is similar in overall length to other established PTSD treatments (National Collaborating Centre for Mental Health, 2005). In the first session, the client is asked to relate a summary of his or her life up until the trauma. In subsequent sessions, clients are encouraged to talk through the most difficult parts of their experiences in detail, paying attention to the thoughts, emotions, and physical sensations they felt at the time, with the aim of helping them to uncover the "fear network" of associations linked with their trauma memories (Schauer et al., 2011). The therapist takes detailed notes during each session and then reads them back aloud to the clients at the start of each new session. This serves three functions: (a) re-exposing them to the material, (b) giving them the chance to correct any mistakes or add additional details, and (c) providing them the opportunity to reflect on and create new meanings in relation to their experiences, which can then be incorporated into the latest version of the account. Finally, with the help of the therapist, the clients use their latest account versions to construct their individual lifelines, illustrating the most notable high and low points in their life stories with symbolic flowers and stones (see Figure 1). At the end of treatment, clients are given copies of their accounts and lifelines to keep.

It was decided to try this approach with parents who had been referred for trauma symptoms in relation to their children's pediatric treatment on the basis that (a) NET was developed for use with people who have suffered repeated traumas (Schauer et al., 2011), as is often the case with parents whose children have been critically ill; (b) its focus on the whole story, as opposed to the worst event, might be more conducive to helping parents both *process* the wider context of the child's illness and better *integrate* previous traumatic events, which they are more likely to have experienced than nonsymptomatic parents (Ozer, Best, Lipsey, & Weiss, 2003); and (c) it is reported to be well-tolerated, with lower drop-out rates than other forms of therapy for PTSD.

Four traumatized parents participated in this study following their children's PICU admissions, and NET was used and provided the framework for the description of these parents and their experiences. The impact of this treatment approach on parents' psychological symptoms and the main themes that emerged in the work are examined and clinical implications for therapists are discussed.

Method

Setting

The setting was an inner city teaching hospital within the United Kingdom's National Health Service (NHS stands for National Health

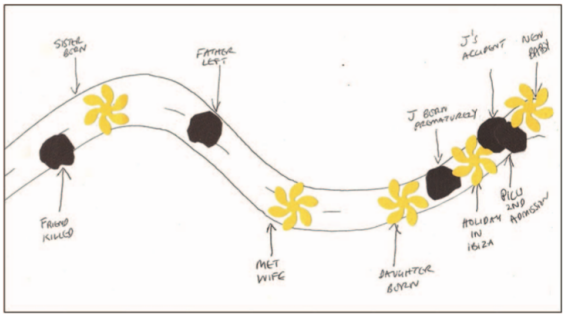

Figure 1. Steve's NET lifeline. Traumatic events are indicated by stones and particularly positive experiences by flowers. See the online article for the color version of this figure.

Service; NHS), which has an embedded pediatric psychology service of 8.8 clinical psychologists and a 12-bed PICU. The psychologist, who covers PICU on a half time basis, sees 40–60 referrals a year, with treatment costs covered by the hospital, as part of NHS public health provision. The nature of the referrals is comparable to that recently described in a similar context in a United States unit, by Tunick, Gavin, DeMaso, and Meyer (2013), but both the mortality rate (4% in UK vs. 2.7% in U.S.) and the proportion of PICU admissions referred to psychology (10% in UK vs. 5% in U.S.) were higher on the UK unit.

The clinical psychologist who delivered the treatment described below attended a training workshop organized by the developers of NET (Schauer et al., 2011) at the University of Konstanz in Germany. (Further details of training workshops in the United States and elsewhere are available at http://www.nvivo.org/).

Participants

Four parents of children who had been treated in the PICU were referred for support. They all met *DSM–IV* (APA, 1994) criteria for PTSD on the basis of their questionnaire results and agreed to try NET as a way to address their ongoing distress. In two cases, the parents had not been seen by the psychologist before (Cases 1 and 2) but the other two parents had been seen while their child was an inpatient and their symptoms were being monitored after discharge. The series comprised one father and three mothers, all of white Caucasian ethnicity. Main sample characteristics are given in Table 1. Reasons for referral to PICU and length of stay and were comparable to UK national data for this population, the majority of whom are aged under 5 years (Paediatric Intensive Care Audit Network, 2015).

Measures

Posttraumatic stress symptoms were assessed using the 49-item Posttraumatic Diagnostic Scale (PDS; Foa, 1996), which establishes whether an individual meets the *DSM–IV* (APA, 1994) criteria for PTSD and measures the severity of their key symptoms of avoidance, reexperiencing, and hyperarousal in relation to this diagnosis. Total scores, which range from 0–51, are categorized in terms of severity as follows: >35 = *severe*, 21–35 = *moderate/severe*, 11–20 = *moderate*, and 1–10 = *mild*. The PDS is reported to demonstrate high internal consistency (.92) and good test–retest reliability (.83), as well as showing good agreement (83%) with an independent PTSD diagnosis based on clinical interview (Foa, Cashman, Jaycox, & Perry, 1997).

The Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) is a frequently used self-report questionnaire in community samples as a screener for mental health problems. It is made up of two separate scales, one measuring Anxiety (seven items) and the other measuring Depression (seven items), with responses weighted 0 to 3 for frequency. For each scale, scores of 8–10 indicate *mild* symptoms, 11–13, *moderate* symptoms, and ≥14, *severe* symptoms. The HADS has been widely used internationally, has demonstrated good levels of internal consistency (.93 for Anxiety

Table 1
Main Sample Characteristics

Case	Age		Reason for referral to PICU	PICU stay	Hospital stay	Discharge to treatment	Number of NET sessions
	Parent	Child					
Case 1	39 years	18 months	Acute infection	48 hr	2 weeks	19 months	6
Case 2	32 years	5 months	Acute infection on top of chronic hematological condition	12 hr	20 months	12 months	7
Case 3	36 years	8 months	Chronic respiratory condition	4 months	12 months	9 months	10
Case 4	40 years	4 years	Acute respiratory condition	24 hr	4 weeks	6 months	6

Note. PICU = pediatric intensive care unit; NET = narrative exposure therapy.

and .90 for Depression) and test–retest reliability (.54 for Anxiety and .79 for Depression) (Bjelland, Dahl, Haug, & Neckelmann, 2002), and its factor structure has been confirmed in a number of different populations (Moorey et al., 1991).

Analysis Plan

The analysis plan was to assess all three outcomes at baseline and again 2 and 6 months after treatment was completed. Visualization of the parents' symptom trajectories was used to determine whether a treatment effect had been detected, as evidenced by a sustained drop in psychometric scores from the clinically significant to the nonsignificant range (Ernst, Barhight, Bierenbaum, Piazza-Waggoner, & Carter, 2013). Further supporting anecdotal information, in the form of feedback regarding any changes parents noticed since treatment, was also sought. The sample size precluded formal statistics, but effect sizes were computed using Cohen's *d* (0.2–0.5 = small effect; 0.5–0.8 = medium effect; >0.8 = large effect).

Illustrative Case Study

Background. Johnny, a 4-year-old boy, was crossing the road on the way to school with his mother when he was hit by a van, sustained a serious fracture to his leg, and briefly lost consciousness. He was airlifted to the hospital and his mother was escorted there by the police. She telephoned Steve, Johnny's father, from the back of the police car, distraught, and he then made his own way, by bus, to the hospital to join them. (This case study was a composite designed to illustrate the NET approach and the issues that commonly arise in treatment, drawing on the experiences of the four parents seen.)

Hospital admission. Johnny was sent for X-ray on arrival. He was very distressed and confused initially but was relieved when his parents arrived. He spent a week on PICU recovering from surgery and was then moved to the surgical ward. Steve stayed overnight with Johnny, as his wife was heavily pregnant. In the 2nd week, however, Johnny's condition deteriorated and he needed to be transferred back to PICU for 48 hr. In the following 2 weeks on the ward, he had to undergo numerous painful procedures, which were distressing for him and his parents to witness, in relation to the management of his wounds. At the bedside nurse's request, therefore, the psychologist met with the family twice for support. The focus of the intervention at this stage was on promoting Johnny's parents' coping resources (Kazak et al., 2006) and teaching Johnny distraction techniques to help him manage his dressing changes.

Rereferral. Six months after Johnny's discharge, Steve mentioned in his son's orthopedic review appointment that he himself was regularly experiencing flashbacks, finding it hard to concentrate at work and had noticed his heart racing whenever he heard an ambulance siren or the phone rang. He was therefore rereferred to the PICU psychologist who found on subsequent assessment, at a separate appointment, that his levels of posttraumatic stress and anxiety were clinically significant.

Narrative exposure therapy. Steve was seen for six twice-weekly sessions of NET. In the first session, he revealed that he had lost a classmate in a road accident when he was a child and that he had been fearing that Johnny, who had been born prematurely, would die. When Steve's distress rose in sessions, he was encouraged to use simple grounding strategies, such as rising to a standing position in the room, to bring his immediate anxiety down before continuing the account. In the final session, with the help of the therapist, he drew up a lifeline based on the final account (see Figure 1).

Follow-up. Steve's symptoms were monitored at regular intervals over the following year. Two months after treatment, his symptoms were significantly improved, in that he was sleeping much better and no longer met criteria for PTSD. At 6 months, he reported that he felt closer to his son and was grateful for a new appreciation of the way in which recent events had triggered memories of earlier traumatic experiences. He was discharged at 1 year.

Results

Quantitative Data

Three parents completed their NET treatments within seven sessions. In the remaining case (Case 3), the therapy took 10 sessions because of the high number of traumatic events

that had occurred over the course of this parent's child's lengthy hospital stay. All parents completed questionnaires pretreatment and 2 months posttreatment at follow-up appointments. Additional scores were obtained from three parents at 6-month follow-up. (Case 1 did not attend, but later reported that symptoms had continued to reduce steadily after treatment). Significant and sustained improvements in symptoms were reported, particularly in relation to posttraumatic stress and anxiety (see Figure 2). Mean (*SD*) scores fell between baseline and 2 months posttreatment as follows: from 20.75 (9.46) to 9.25 (7.27) for posttraumatic stress, (d = 1.36), from 14.25 (4.27) to 8.25 (3.59) for anxiety (d = 1.52), and from 5.25 (3.69) to 3.75 (3.77) for depression (d = 0.40). They reduced further by 6 months, as compared with baseline, to 3.67 (1.52) for posttraumatic stress (d = 2.37), 5.00 (d = 2.15) for anxiety (d = 2.15), and 1.33 (2.31) for depression (d = 1.01), such that by this stage, none of the parents' scores were in the relevant clinical range. (The relatively smaller change in depression scores may relate to the fact that these symptoms were not particularly elevated at baseline, unlike these parents' symptoms of posttraumatic stress and anxiety.)

Parents' Comments

The quotations used in this section were taken verbatim from parents' NET accounts, but to protect their identities, have not been directly attributed to them. Parents found it difficult to organize their memories initially, but expressed relief when they had completed their accounts, consistent with the recent conceptualization of PTSD as primarily a disorder of memory (Yule, 2014). The most striking aspect of their accounts was the powerful and particularly visceral nature of the feelings they articulated having at the time of their traumatic experiences: "In the ambulance I had the most painful and overwhelming feeling I have ever had in my life. It felt like being belted in the guts five or six times over—the feeling that I should have kept [child] safe." In addition, all four parents expressed the strong fear that their child could have died: "I really thought [child] could die. I felt it physically. I felt a sort of internal shaking which was terrifying but which for some reason did not show on the outside. This is a feeling I have had since." This subjective perception of risk has been found to be more predictive of later posttraumatic stress symptoms than measures of objective risk to the child (Balluffi et al., 2004).

Parents appreciated being provided a concrete illustration of events in the form of the lifeline at the end of NET treatment, and spoke of a new understanding of the links between the traumatic events they had described and other events in their lives, such as the serious illnesses or deaths of loved ones in the past. They also commented on the value of recognizing that good things had happened during their children's time in the hospital as well as bad, suggesting that they, like others in this kind of situation, may have

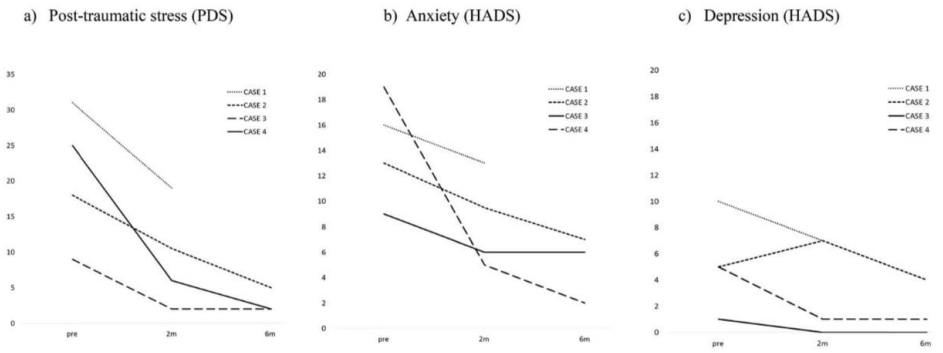

Figure 2. Parents' individual pre- and post-treatment scores. PDS = Posttraumatic Diagnostic Scale; HADS = Hospital Anxiety and Depression Scale.

experienced a degree of posttraumatic growth (Colville & Cream, 2009). Finally, at follow-up, parents gave examples of situations they were able to tolerate with much less anxiety than before, such as traveling abroad with their families and managing their children's minor illnesses.

Discussion

The traumatized parents described in this case series had witnessed repeated examples of their children suffering sudden, life-threatening deteriorations and numerous painful, treatment-related ordeals. The provision of NET was associated with prompt and significant reductions in their symptoms of posttraumatic stress. Furthermore, the available evidence suggests that, as Schauer et al. (2011) reported, their symptoms continued to reduce in the months after treatment. Large treatment effects were seen both at 2-month and 6-month follow-ups, compared with baseline scores. These findings also illustrate the importance of assessing comorbid problems in traumatized patients, as they suggest that this treatment, which targeted posttraumatic stress, also had a positive impact on symptoms of anxiety and depression.

Previously, the evidence base for this approach has related mainly to its use with refugees or war-torn samples in developing countries (Robjant & Fazel, 2010). This study adds to a growing body of literature suggesting that NET (Schauer et al., 2011) might be applicable to a wider range of trauma types than previously reported (Alghamdi, Hunt, & Thomas, 2015; Campbell et al., 2016; Zang, Hunt, & Cox, 2014).

Therapist Considerations

In line with recent evidence favoring high-frequency contact in therapy for PTSD (Gutner, Suvak, Sloan, & Resick, 2016), the developers of NET recommend twice-weekly sessions, arguing that a frequency of less than weekly is unlikely to bring about the degree of immersion in the relevant traumatic memories that they believe necessary for the technique to be effective (Schauer et al., 2011). This level of intensity may not suit everyone, but there is evidence that patients who are offered intensive therapy report that the high pressure and pace improves their motivation and engagement, despite their initial misgivings about being overwhelmed (Bevan, Oldfield, & Salkovskis, 2010). Although it has been our experience that only approximately half of those offered this or other forms of trauma-focused therapy have ultimately agreed to formal input, to date no parent has dropped out of NET treatment. It remains to be seen whether this success will be maintained in a larger sample but it is consistent with evidence that NET is better tolerated than more traditional exposure therapy (Mørkved et al., 2014) and contrasts with the experience of other trauma therapists working in real-world settings (Kehle-Forbes, Meis, Spoont, & Polusny, 2016).

In relation to treatment fidelity, broadly speaking it was possible to maintain the frequency of sessions advised in the NET manual, although 3 of the total 29 treatment sessions offered needed to be rescheduled. However, although the developers recommend limiting the discussion of previous life events to the first session only, in practice this part of the treatment took two sessions in two cases (Case 3 and Case 4), because of the number of traumatic events experienced in the past.

Trauma work is generally acknowledged to be emotionally demanding and particularly challenging for therapists (Zoellner et al., 2011) but in relation to NET specifically, there are additional challenges in terms of scheduling, both for the patient and for the therapist. Although no homework is set with this approach, patients needs to clear their weekly timetables sufficiently to focus on the therapeutic work *during* sessions and to have time for reflection on it *between* sessions. In addition, the therapist needs to allocate sufficient time between sessions to prepare the latest version of the narrative account, so that it is ready to be read out at the following session. This task, which can often take an hour or more after the first few sessions particularly, is more demanding than the simple transcription of session notes because the client's account is often very jumbled initially. The therapist needs to use his or her clinical judgment regarding the saliency of particular thoughts, events, and feelings to decide what to include and what to leave out. In this way therapists help clients to construct narratives that are both coherent and meaningful.

In relation to the wider implications for clinical practice, the length of time between parents' traumatic experiences and their treat-

ment is worthy of further comment here. The parents in this case series had been symptomatic for many months, but had not received help earlier. This was partly because they had hoped their symptoms would reduce over time, but also because they needed to adjust to the new demands placed on them by their children's medical conditions, consistent with research suggesting that biological and social concerns need to be tackled before a parent has the energy to attend to his or her own psychological adjustment after a PICU admission (Atkins, Colville, & John, 2012). However, the fact that the two cases who were already in contact with the psychologist were seen sooner suggests that ideally this group should be monitored routinely after discharge, particularly if they are found to be at high risk of developing PTSD (Samuel, Colville, Goodwin, Ryninks, & Dean, 2015).

Decisions regarding whether and when to embark on an intervention such as NET require that the therapist establishes first that the parent's life situation is sufficiently stable for her or him to have the emotional space, as well as the time, available to confront any traumatic memories (Lab, Santos, & de Zulueta, 2008). In pediatric practice settings, this means that the timing of this intervention is dependent on the stability of the child's medical condition; therefore, treatment can usually only take place some time after the child has been discharged from the hospital.

Finally, an argument could be made that this work might be more appropriately undertaken by local adult therapists with experience in treating trauma. Indeed, even in cases in which the hospital reimbursement system allows for long-term follow-up, the distance a parent lives from the hospital may make regular appointments difficult to attend, in which case it may well be more appropriate to refer them to an appropriate local service. However, it is our experience that parents often report that their experiences are not well-understood beyond the acute setting in which their children were treated, and that they very much appreciate being offered this continuity of care. Provision of follow-up care such as this also reflects the "systems-orientation" of pediatric psychology (Ernst et al., 2013), in that it recognizes the dependency of children in these "inseparable dyads" on the emotional well-being of their caregivers (Davidson, 2012).

Limitations and Future Directions

It is necessary to acknowledge the limitations of this small case series. First it may not generalize to other populations of parents of critically ill children. Second, the fact that two parents had had previous contact with the psychologist when their child had been an inpatient may have contributed to their positive outcomes. Third, the lack of a control group meant that it was not possible to be certain that the improvements seen were attributable to the treatment provided. However, the length of time parents had been symptomatic and the promptness and enduring nature of the reduction in their symptoms suggest that further evaluation of this technique with larger samples is warranted.

In terms of implications for clinical work in the future, although this study focused on the experience of parents of children who had been admitted to PICU, it is clear from the literature in this field that persisting symptoms of posttraumatic stress are also often seen in the *children* themselves, after critical care treatment (Colville & Pierce, 2012; Nelson & Gold, 2012). KidNET (Neuner et al., 2008), a version of NET that has been adapted for use with younger patients, might be useful to try with symptomatic children, perhaps as part of a more general support package aimed at helping them understand their conditions.

This approach might also be helpful with other groups who have reported high rates of posttraumatic stress in pediatric settings, such as the families of children with cancer (Alderfer, Cnaan, Annunziato, & Kazak, 2005; Bruce, 2006) and other life-threatening conditions, or when the idea of incorporating traumatic events into the person's wider life story seems particularly appropriate or appealing.

Also, the finding that delayed reactions are common in this population (Colville & Pierce, 2012) suggests that families should be monitored for some time and might benefit from flexible services, which they can access when the time is right for them. Even in situations in which there are insufficient resources available to provide therapeutic outpatient support for parents at the base hospital, pediatric psychologists could monitor parents by postal questionnaire after discharge and refer those found to be symptomatic to appropriate

local services or alert their primary physicians to their psychological difficulties.

In conclusion, although it has been apparent for some time that PICU parents often suffer significant distress as a result of their traumatic experiences related to their children's treatment in the PICU, there is a dearth of information on how best to help them. This study adds to a small body of literature on intervention in this field, and in doing so, has made some headway toward meeting psychologists' moral obligation to provide services that better address their psychological needs (Hoehn, 2014).

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PAPER 6 The Staff Stress Study: Colville GA, Smith JG, Brierley J et al. Coping With Staff Burnout and Work-Related Posttraumatic Stress in Intensive Care. Pediatr Crit Care Med. 2017;18:e267-e273 doi: 10.1097/PCC.0000000000001179

PAPER 7 The Moral Distress Study: Colville GA, Dawson D, Rabinthiran S, Chaudry-Daley Z, Perkins-Porras L. A survey of moral distress in staff working in intensive care in the UK. J Intensive Care Soc. 2019;20:196-203

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A survey of moral distress in staff working in intensive care in the UK

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Abstract

Elevated rates of burnout and post-traumatic stress have been found in staff working in critical care settings, but the aspect of moral distress has been harder to quantify until a recent revision of a scale previously designed for nurses, was adapted for use with a range of health professionals, including physicians. In this cross-sectional survey, $n = 171$ nurses and physicians working in intensive care in the United Kingdom completed the Moral Distress Scale-Revised in relation to their experiences at work. Mean (SD) Moral Distress Scale-Revised score was 70.2 (39.6). Significant associations were found with female gender (female 74.1 (40.2) vs. male 55.5 (33.8), $p = 0.010$); depression ($r = 0.165$, $p = 0.035$) and with intention to leave job (considering leaving 85.5 (42.4) vs. not considering leaving 67.2 (38.6), $p = 0.040$). These results highlight the importance of considering the moral impact of work-related issues when addressing staff wellbeing in critical care settings.

Keywords

Moral Distress Scale-Revised, staff stress, depression, ethics, futility

Technological advances in critical care medicine have led to dramatic improvements in patient survival but have also been associated with a number of unforeseen negative consequences for staff, beyond the inevitable challenges inherent in keeping up with such a fast-moving, highly technical specialty. Paradoxically, given that technology is supposed to make life easier, there is evidence that health workers are increasingly overloaded by the clerical burden related to electronic record keeping and feel guilty about the time it requires them to be away from the bedside.[1] Also, the increased survival of intensive care patients has sometimes come at a significant cost to the quality of that survival, particularly in paediatric settings.[2] These factors have led to staff feeling demoralised and at times questioning why they do what they do. Furthermore, this anxiety has recently been amplified by the intense public scrutiny of their clinical decision-making afforded by 24/7 social media,[3] to which they are unable to respond directly for reasons of patient confidentiality.

Growing appreciation of the stress critical care staff are under has led to calls for more research in this area[4] and there are a number of well-validated tools available to measure the symptoms of burnout and post-traumatic stress that staff experience,[5–7] but distress related to more existential concerns about meaning and purpose[8] is harder to quantify.

Jameton[9] first used the term 'moral distress' in 1984 to identify this aspect of work-related distress, defining it as 'when one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action',[9] differentiating it from having an 'ethical dilemma', where the best treatment option is unclear or 'emotional distress', which does not necessarily have a moral component. Specifically, moral distress involves 'a perceived violation of one's core values and duties'.[10] This original concept has been further elaborated by observations that it may build up cumulatively with repeated exposure which leaves behind a 'moral residue',[11] which is then added to, over time, by subsequent similar events, in what has been described as 'the crescendo effect'.[10]

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The UK literature on moral distress is limited but recent studies have shown that medical students are able to habituate to it, to some degree, if they are able to see that coping with a morally distressing situation contributes to their learning[12] and that critical care nurses feel conflicted, among other things, about the discrepancy between the way they talk about patients in the course of their work and the way they feel they *ought* to talk about patients.[13]

In relation to the quantification of moral distress, a scale developed in 2001 to measure it in adult critical care nurses[14] has recently been shortened and adapted to cover a wider range of potentially distressing situations and for use with a range of health professionals[15] and is now known as the Moral Distress Scale-Revised (MDS-R).[16] It has been validated in a number of different staff groups both in intensive care and general hospital settings.[17–20]

The main aim of this study was to add to the literature by using this scale to establish levels of moral distress in a sample of physicians and nurses working in adult ICU settings in the United Kingdom. Secondary aims were to examine associations between MDS-R scores and socio-demographic factors, scores on a brief mental health screening instrument and intention to leave the job. It was hypothesised that staff would report moral distress associated with their work to varying degrees, with nurses[17,20–22] and those with more experience of working on ICU[17,23] reporting higher levels than others. It was also expected that intention to leave the job would be correlated with total moral distress scores.[16,17,19,22]

Method

Ethics approval was obtained from the Joint Research and Enterprise Office for the hospital and university. External ethical approval was not required. The anonymous survey was cross-sectional and took place over two four-week periods in October 2015 (General Intensive Care Unit) and 2016 (Neuro-Intensive Care Unit and Cardiothoracic Intensive Care Unit). Informed consent was assumed by the completion and return of the surveys, which were provided in both electronic and paper form and took less than 10 min to complete. Participants were also provided with an information sheet about the purpose of the study and details of local support services.

Measures

The questionnaire comprised a section on socio-demographic and occupational information (e.g. marital status, gender, length of time qualified) and two standardised measures – the MDS-R and the Patient Health Questionnaire-4 (PHQ-4).

The MDS-R[16] is a revision of the Moral Distress Scale[14] which comprised 38 items and was designed for use with adult critical care nurses. The updated version, MDS-R, was adapted to include a wider range of potentially distressing situations and shortened to 21 items. It was also made available in a number of different versions, such that it could be completed by a range of health professionals, working in adult or paediatric healthcare settings.

It contains items relating to a range of situations which would be expected, from the literature in this field, to engender a sense of moral distress. These include six items about end of life care; five items on limited staffing and resources; four items about communication between staff and with families; four items on the way decisions are made and two items relating to the witnessing of unethical behaviour. Respondents are asked to rate each item in terms of how frequently they have come across the situation in their work and again, in terms of how disturbing they would find the situation. Responses are scored on a Likert scale from 0 to 4 for both frequency and intensity of disturbance. Composite scores for each item are then generated by multiplying the relevant frequency and intensity scores and these are summed to provide an overall composite moral distress score ranging from 0 to 336. The MDS-R also contains a final section consisting of a series of short questions exploring the respondent's attitude to the idea of leaving their position as a result of moral distress.

The scale has been shown to have good content validity[16] and reliability (Cronbach's alpha 0.84 to 0.90) across a number of different samples.[18–20] It has also been used in a number of different hospital settings.[19,24] Questionnaires were included in the analyses in this study as long as there were no more than three missing data points on the MDS-R[20] and where missing data were included in the calculation of the total composite score, they were scored conservatively as equivalent to zero.

The PHQ-4 is a validated four-item screening measure for rating psychological distress over the previous two weeks.[25] It has good psychometric properties[26] and was developed by combining the PHQ-2 and the GAD-2, which are brief screens for the core criteria of depressive disorders and generalised anxiety disorder, respectively, and have been shown to be excellent population screening tools.[27,28]

Responses for each of the four items are scored using a Likert scale: 0 = 'not at all' to 3 = 'nearly every day'. Subscale scores are obtained by summing scores for questions 1 and 2 for depression, and questions 3 and 4 for anxiety, resulting in total scores that range from 0 to 6 for each subscale. A score of $\geqslant 3$ on the relevant subscale is regarded as suggestive of depression or anxiety and worthy of further assessment, although not definitively diagnostic.

Statistical analysis

Statistical analyses were carried out using the IBM Statistical Package for the Social Sciences (SPSS) version 25. Descriptive data are given in the form of

mean (SD) and percentages. As the distribution of MDS-R scores was negatively skewed (i.e. non normal), non-parametric statistics were employed: Mann–Whitney U and Kruskal–Wallis H tests for between-group comparisons, Spearman's rho to establish correlations between continuous variables and Fisher's exact test for categorical group comparisons. Linear regression analysis was performed to ascertain the degree to which any socio-demographic variables which emerged as significantly associated with moral distress explained variance in the total MDS-R score. A p value of 0.05 was applied to determine statistical significance throughout.

Results

In all, 190/408 (47% response rate) questionnaires were returned; 157 on paper and 33 online. Nineteen surveys contained too many missing responses for a composite moral distress score to be calculated, resulting in a final sample of $n = 171$ for the main analyses. The sample characteristics of this group are provided in Table 1.

Prevalence of distress

MDS-R total composite scores ranged from 0 to 182, with a mean (SD) of 70.2 (39.6), and no significant differences between units (General 76.7 (44.1), Cardiothoracic 62.8 (32.0), Neuro-intensive 68.5 (37.9); Kruskal–Wallis $H = 2.514$, $p = 0.285$). The reliability of responses was good (Cronbach's alpha = 0.87). In general, staff reported the highest *intensity* ratings for the items relating to scarce resources and issues arising in the context of end of life care (Figure 1), but in practice the causes of moral distress cited with the highest *frequency* related to end of life care and communication problems, with unethical behaviour rarely reported as a problem (Figure 2). The two professional groups rated the same three situations as most distressing overall (Table 2) and all of these related to the provision of end of life care in situations of futility.

Mean item scores relating to the intensity of disturbance associated with the MDS-R items ranged from 1.71 out of a possible total of 4 for item 14 'Increase the dose of sedatives for an unconscious patient that I believe could hasten the patient's death' to 2.89 for item 21 'Work with levels of nursing or other care provider staffing that I consider unsafe'. Mean item scores relating to the frequency with which the situations described in the questionnaire were actually encountered in practice were lower, ranging between 0.46 and 2.09 out of a possible total of 4. The majority of items were rated as occurring infrequently with only two items rated at a mean above 2 for frequency ('sometimes'/'frequently'). These were item 3 'Follow the family's wishes to continue life support even though I believe it is not in the best interest of the patient' and item 4 'Initiate extensive life-saving actions when I think they only prolong death'.

As regards the intention to quit, 12/171 (7%) reported they had left a previous job for this reason; 44/171 (26%) had considered leaving one in the past and 28/170 (16%) were currently considering leaving because of their feelings of moral distress.

The mental health screening tool PHQ-4 identified 26/163 (16%) of staff as reporting clinically significant levels of anxiety and 13/164 (8%) reporting clinically significant levels of depression. These levels are consistent with community norms.[29]

Table 1. Sample characteristics ($n = 171$).

Variable	*n* (%) / mean (SD)	*n*
Profession:		
Physician	26 (15%)	
Nurse	145 (85%)	171
Intensive care unit:		
General (18-bed)	74 (43%)	
Neuro-intensive (14-bed)	50 (29%)	
Cardiothoracic (18-bed)	46 (27%)	170
Age (years)	36.4 (9.2)	163
Female	132 (77%)	168
Married/cohabiting	101 (59%)	169
Live alone	27 (16%)	168
Children living at home	59 (35%)	168
Full-time worker	144 (84%)	166
Years qualified	11.5 (8.6)	163

Associations with moral distress

Initial analyses of the relationship between socio-demographic variables and MDS-R scores indicated significant associations with nursing profession, female gender and length of time since qualification (see Table 3). However, a linear regression model incorporating the three socio-demographic explanatory variables, although statistically significant ($F = 3.103$, adjusted $R^2 = 0.037$, $p = 0.028$), explained less than 4% of the variance in scores and found gender to be the only significant predictor (standardised beta = 0.174, $p = 0.037$). This suggests that socio-demographic factors are not strongly predictive of moral distress and that the difference initially found between professional groups was most likely accounted for by the higher proportion of female responders in the nursing group as compared with the physician group (85% vs. 44%).

Moral distress scores were, however, associated with the participant currently considering leaving their job (85.5 (42.4) vs. 67.2 (38.6), $p = 0.04$); with them having left or considered leaving a job for this reason in the past (86.9 (43.9) vs. 62.1 (34.7) $p < 0.001$)

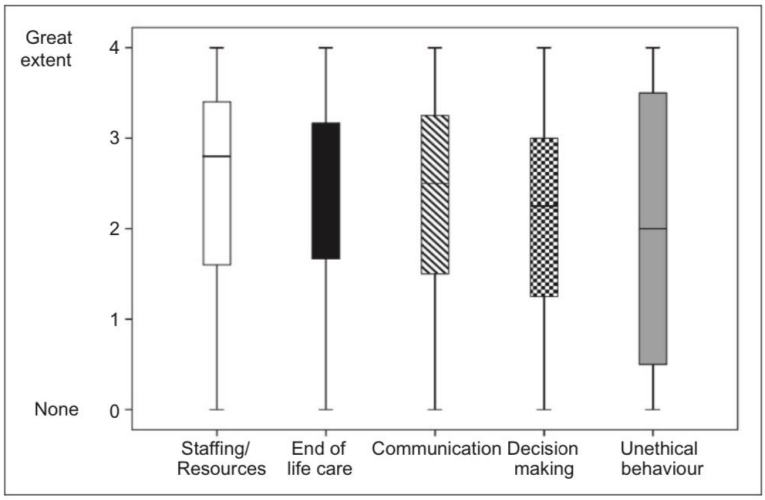

Figure 1. Main causes of moral distress on the Moral Distress Scale-Revised by mean item score for *level of intensity of disturbance* ($n = 171$).
Note: Data spread is indicated by box and whisker plots, illustrating median, interquartile range and range of scores, excluding outliers.

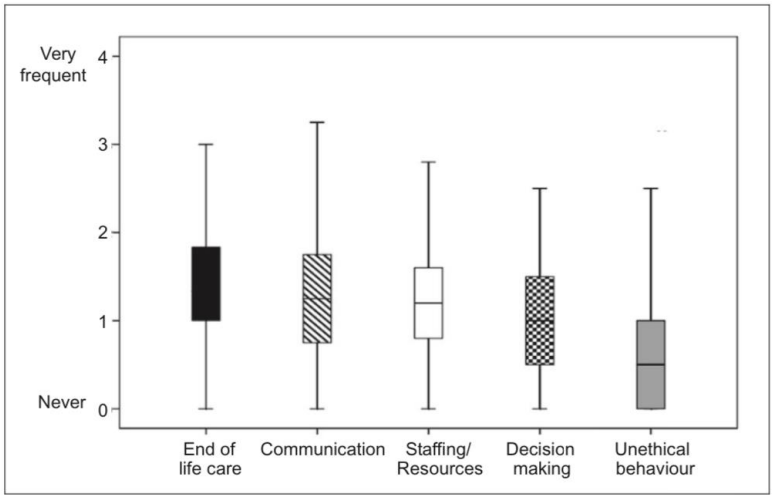

Figure 2. Main causes of moral distress on the Moral Distress Scale-Revised by mean item score for *frequency* ($n = 171$).
Note: Data spread is indicated by box and whisker plots, illustrating median, interquartile range and range of scores, excluding outliers.

and with a higher depression score on the PHQ-4 ($r = 0.165$, $p = 0.035$), but not with a higher anxiety score ($r = 0.122$, $p = 0.122$).

Discussion

The mean MDS-R score of 70.2 in this sample was comparable with those for adult ICU professionals reported in the international literature, which range from 57 to 92[16–19] but was lower than that reported recently in a sample of 206 staff working in a paediatric ICU setting[20] where the mean MDS-R score was 102. Further investigation is warranted as to whether this finding is representative of other paediatric ICU staff groups as it may be that there are moral issues particularly relevant to the care of critically ill

Table 2. Top five ranking items on the Moral Distress Scale-Revised (MDS-R) for physicians and nurses.

Item no.	Distressing situation	Physicians ($n = 26$) Mean (SD) composite score[a]	Rank	Nurses ($n = 145$) Mean (SD) composite score[a]	Rank
3.	Follow the family's wishes to continue life support even though I believe it is not in the best interest of the patient	5.73 (5.01)	1	6.52 (4.16)	1
4.	Initiate extensive life-saving actions when I think they only prolong death	5.04 (4.08)	2	6.13 (4.32)	2
7.	Continue to participate in care for a hopelessly ill person who is being sustained on a ventilator, when no one will make a decision to withdraw support	4.58 (3.72)	3	5.98 (4.69)	3
2.	Witness healthcare providers giving 'false hope' to a patient or family	4.04 (3.78)	4	3.91 (3.64)	(8)
20.	Watch patient care suffer because of lack of continuity	3.46 (4.10)	5	4.09 (4.46)	(7)
21.	Work with levels of nursing or other care provider staffing that I consider unsafe	3.12 (3.57)	(8)	5.61 (4.68)	4
17.	Work with nurses or other healthcare providers who are not as competent as the patient care requires	2.77 (2.96)	(11)	5.31 (4.68)	5

[a]MDS-R composite score (range 0–16) = frequency score (range 0–4) × intensity score (range 0–4)

Table 3. Socio-demographic associations with Moral Distress Scale-Revised (MDS-R) composite scores.

Categorical variables	*N*	MDS-R composite Mean (SD) Yes	No	p[a]
Nurse profession (v physician)	171	**72.5 (39.4)**	57.4 (36.7)	**0.040**
Female gender	168	**74.1 (40.2)**	55.5 (33.8)	**0.010**
Married/living with partner	169	70.2 (41.6)	71.1 (36.8)	0.706
Lives alone	168	67.4 (41.6)	71.3 (39.5)	0.517
Children living at home	168	71.4 (42.0)	69.6 (38.2)	0.855
Full-time worker	166	69.0 (40.4)	76.9 (34.0)	0.255
Continuous variables	*n*	Correlation coefficient		p[b]
Age	165	0.099		0.209
Years qualified	165	**0.180**		**0.021**

[a]Mann–Whitney *U* test.
[b]Spearman's rho test. Significant results are indicated in bold.

children. The recent dramatic reduction in child mortality has been associated with a significant increase in the numbers of children surviving with serious disabilities, leading one editorial to suggest that moral distress in paediatric and neonatal intensive care settings is 'inevitable'.[2]

The expected associations with past and present intention to leave the job were confirmed, lending further support to the argument that employers would be wise to address moral distress in their staff if they wish to retain them.[30] However, in this sample, neither profession or length of service were significantly related to moral distress, after controlling for female gender. Although a number of studies have found higher moral distress scores in nurses, and have speculated that this might be because they spend more time at the bedside or have less say in clinical decision making,[19] they have not always controlled for gender in their analyses and there are examples of other studies that also found higher levels of moral distress in female staff[31,32] reflecting a tendency for women to report higher rates of symptoms more generally.[33]

The lack of a clear relationship with age or length of service did not support the notion that moral distress is cumulative. However, given the association across the literature with intention to quit, it is

possible that staff with the highest moral distress in these occupations self-select out of the workforce, leaving behind staff with lower moral distress. This might explain why, in addition to studies which found an association with higher moral distress, there are examples of studies which found experience was associated with *lower* moral distress.[22] Nevertheless, the finding that rates of mental health problems in this sample were not significantly elevated or strongly related to moral distress is consistent with the idea that moral distress is conceptually different, as has also been found with burnout, which is more prevalent in this population than anxiety or depression.[7]

As in previous studies, the nature of the situations engendering the highest levels of moral distress was similar across profession and often concerned aggressive treatment in situations where care was felt to be futile. This illustrates the impact on staff of the strain of the new ethical dilemmas that have arisen as a direct result of recent technological advances in this field of medicine, which often involve balancing the wish to preserve life with the obligation to consider the impact on quality of life and on the limited resources available. Interestingly, and consistent with other studies, there was less evidence of moral distress in relation to *withholding* potential treatment.[16,21]

There are a number of limitations to this study. The response rate was moderate although comparable to or better than that of other studies in this field.[17,19,24] Also the fact that the survey was anonymous meant that it was not possible to determine how representative the sample was of the total staff group. Finally, the fact that it was cross-sectional and based on one site meant that it was not possible to infer causality from the associations found or draw conclusions about their wider generalisability.

These findings add to a body of literature on this newly revised measure and confirm its applicability in another country. The development of a measure such as this is helpful not only in terms of helping health professionals and institutions better understand the causes of work-related distress, but also in relation to the evaluation of interventions designed to address this aspect of working in these demanding healthcare settings. The literature on intervention to reduce moral distress is small but growing.[34] In a recent editorial on this topic, Perni [35] has stressed the need for more open discussion about 'the disconnect between our ideals and the realities of medical practice' and Hamric and Blackhall[21] have observed that successful interventions tend to share common attributes in that they improve communication between members of staff and with patients and families, thereby enabling people to understand the perspectives of others better. In an example, one such intervention, which used the MDS-R as an outcome measure, the 'PEACE communication rounds' were not only shown to be associated with a reduction in staff members' moral distress scores but also with a shorter length of stay for patients.[36] Several studies have identified that conflict in relation to the recognition of futility is associated with poor communication about prognosis and end of life planning and that conversely, efforts to reach agreement about care strategies make acceptance of the prognosis by families more likely.[37,38] Recently, there has been a move towards ensuring that there is more discussion and documentation of treatment escalation plans in relation to the management of frail, co-morbid patients where CPR or escalation to ICU may be both futile and traumatic.[39,40] These developments may be associated with a reduction in moral distress in ICU staff. Other organisational strategies, which might usefully be considered, include the increased provision of mentoring, which is now recognised as a valuable asset across the whole lifespan of a career,[41] and the development of an institution-wide Moral Distress Consultation Service.[42]

In conclusion, it is likely that some degree of moral distress is inevitable in this work and indeed some discomfort of this kind may be a sign that staff are retaining the ability to think critically about what they are doing. However, if this form of work-related stress builds to a level where a staff member's emotional wellbeing is seriously compromised, it is likely to have an impact on the quality of care of patients, as well as on unit morale and staff turnover. Interventions designed to help staff to make sense of the more difficult aspects of their experiences at work together and find a way to work through them, are therefore to be welcomed and a measure such as the MDS-R provides a potentially useful tool with which to evaluate their impact.

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