THE UNIVERSITY OF HULL

Understanding Patients' Psychological Experience of Critical Care: Patient and Outreach Nurse Perspectives

Being a thesis submitted in partial fulfilment of the requirements for the degree

of

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In the University of Hull

By

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A. Acknowledgements

To begin, I would like to express my profound gratitude towards the individuals who participated in this research. Not only did you volunteer your spare time, but you openly and generously shared your experiences and stories with me — in the middle of a global pandemic, no less. I also wish to acknowledge how much I admire and applaud the work you do professionally. I greatly valued your commitment to this project, during unprecedented and difficult times, and sincerely hope that the findings reflect a meaningful interpretation of your collective experiences. Without you, this research would not exist.

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B. Overview

This portfolio thesis is comprised of three parts: a systematic literature review, an empirical paper and supporting appendices.

Part one, the systematic literature review, focuses on patients' psychological experiences of critical care across the illness-recovery process. Overall, 16 articles were critically reviewed, evaluated and quality assessed. Narrative Synthesis allowed for a coherent, underlying narrative shared among the articles to be elucidated. Themes derived from the synthesis included, "Losing and Striving to Regain Self-Determination and Independence", "A Journey of Dynamic Psychological Challenges & Emotions", "A Deep Desire for Humanisation: Acknowledging the Person within the Patient", and "Transformation, Existential Realisations, & Re-Evaluation". The narrative which emerged from the synthesis was summarised and discussed in the context of future implications for clinical practice and recommendations for future research.

Part Two is an empirical research paper which used a qualitative methodology, Interpretative Phenomenological Analysis, to explore outreach nurses' experiences and perceptions of how critical care psychologically influences ICU patients. The following superordinate themes were constructed, "It Alters Thinking & Perception: Confusing & Surreal", "Powerlessness and Dependency", "It Can Be Traumatic", "Reorientation: Disrupting Life Narratives" and "Psychologically Impactful: An Individual Journey"; each superordinate theme was comprised of two or three subordinate themes. Participants perceived that patients exhibit a range of responses and emotions as a consequence of ICU experiences and critical illness, some of which connect to the ways in which patients are cared for across their critical care journeys. Consequently, participants experienced difficult professional dilemmas, strong emotional reactions, and incongruence with dissonance between participants’ desire to help patients psychologically and their perceived inability to enact helping behaviours around patients’ psychological difficulties. The research findings are discussed in the context of previous literature, implications for future research and implications upon clinical practice.

Part three contains the supporting appendices for both the systematic literature review and the empirical paper. Included within the appendices, is a reflective statement which highlights the researcher’s experiences of the research process. Also included, is an epistemological statement to provide further context to the thesis portfolio.

Total word count: 26,513 (excluding tables, appendices and references).

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Part One: Systematic Literature Review

Part One: Systematic Literature Review

This paper is written in the format ready for submission to the

Health Psychology Review journal.

Please see Appendix C for submission guidelines.

What is the Psychological Experience and Influence of Critical Care? Patient Perspectives Across the Illness-Recovery Process: A Systematic Literature Review

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Abstract

Critical care significantly psychologically influences patients. Whilst qualitative research providing an understanding of patients' psychological experiences of critical care accumulates, only one previous non-systematic review has examined and synthesised the literature (from 1967-2011). However, the findings were limited in detail and resembled a scoping review. The authors additionally advocated for further explication of patients' experiences from illness to recovery (the illness-recovery process). The current review therefore critically reviewed and systematically synthesised recent findings from 16 qualitative studies, between 2011-2021, exploring patients' psychological experiences of critical care across the illness-recovery trajectory. A Narrative Synthesis approach was utilised. Four main themes were outlined: "Losing and Striving to Regain Self-Determination and Independence", "A Journey of Dynamic Psychological Challenges & Emotions", "A Deep Desire for Humanisation: Acknowledging the Person within the Patient", and "Transformation, Existential Realisations, & Re-Evaluation". Data synthesis indicated that a strong narrative of commonalities across patients' psychological experiences of critical care exists, internationally. Implications for clinical practice have been detailed. Future research should a) continue investigating staff perspectives of how critical care psychologically influences patients, b) further explore psychological experiences of recovery itself, and c) investigate how psychological experiences of critical care are understood at specific moments within the illness-recovery process.

Keywords: Narrative Synthesis, Critical Care, Intensive Care, ICU, Patients' Psychological Experiences, Patients' Perceptions.

Introduction

Increasingly aging populations have contributed to heightened worldwide demand for critical care services (Atramont et al., 2019). Equally, medical advancements and increasingly skilled healthcare workforces have generated exponential growth in the survival rates of critical care patients, leading to heightened expectations for survival (Anderson et al., 2015; Clancy et al., 2015; Hillman, 2006; Kim et al., 2019; Scheunemann et al., 2020). However, there are multitudinous psychological consequences of a critical care stay (Bizek & Fontaine, 2013; Rose et al., 2019; Scragg et al., 2001). To inform preventative measures and improve care provision, the need to fully understand patients' lived experiences exists (Kelley et al., 2013; National Health Service (NHS), 2013). Whilst increasing evidence demonstrates post-traumatic growth following critical care (Barskova & Oesterreich, 2009; Johnston, 2014; Jones et al., 2020; Salick & Auerbach, 2006; Sheikh, 2004), evidence illustrating the negative psychological consequences of critical care is well established and proliferating (Clancy et al., 2015; Colbenson et al., 2019; Jónasdóttir et al., 2018; Oeyen et al., 2010; Pattison, 2005; Righy et al., 2019; Svenningsen et al., 2015; Wade et al., 2015).

To inform best practices (e.g., NICE, 2009; NICE, 2017), recent research has highlighted the value of exploring patients' lived experiences of critical care to fully understand factors linked with both negative and positive psychological outcomes (Kean & Smith, 2014; Stelfox et al., 2015; Topçu et al., 2017). Whilst quantitative research can clarify associations between aspects of critical care and specific mental health outcomes, it can only offer restricted insight into the subjective influence of critical care. Subjective lived experiences of critical care, in comparison, have remained a lesser explored topic but are crucial in deepening the insight needed to obtain a holistic and patient-centred picture (Alexandersen et al., 2019; Ewens et al., 2018; Pattison, 2005; Wermström et al., 2016). Such research has important implications for improving the patient experience, i.e., by bettering quality of care and informing preventative measures used to ameliorate negative mental health outcomes (Palesjö et al., 2015; Topçu et al., 2017).

Existing relevant reviews have a narrow focus. For example, Tsay et al. (2013) only reviewed extant literature pertaining to the experiences of adult ventilator-dependent patients. A subsequent review was equally limited through exploration of patients' ICU experiences solely within Nordic studies (Egerod et al., 2015). Topçu et al. (2017) explored patients' psychological experiences of ICU, but only briefly within a wider review of research into physical health experiences and ICU memory recall; additionally, articles published between 1998-2013 were exclusively explored. Furthermore, the latter two reviews did not include wider experiences within other critical care environments, e.g., high dependency units (HDUs).

Cutler et al. (2013) conducted the first broad review of qualitative literature, aiming to understand patients' experiences and understandings of critical illness and critical care, without eliminating geographical areas or specific patient groups. "Structured analysis" was the named method used to outline explicit themes across 26 articles' findings, as well as implicit themes developed by the reviewers (see Table 1). However, these themes were not supported by verbatim participant quotes; justification for this was unclear. Moreover, the review was not systematic and the unclear methodology for synthesising the findings led to a descriptive and categorical account. At the time of the review, the articles spanning from 1967-2011 offered little focus regarding the whole illness-recovery process; most studies explored patient experiences very soon (hours to days) after patients' critical care discharge. Many of these articles also placed greater emphasis on patients' ability for memory recall, as opposed to patients' deeper lived experiences. This shortcoming specifically prompted further research into experiences of the critical illness-recovery process (Palesjö et al., 2015).

Table 1

Previous Reviews' Themes

Review	Themes
Cutler et al. (2013)	Transformation of Perceptions: Unreal Experiences and Dreams Proximity to Death Transformation and Perception of the Body in Illness Transformation and Perception of Time The Critical Care Environment: Technology and Dependence Care, Communication and Relationships with Healthcare Professionals The Support of Family and Friends and Desire for Contact Transfer from Critical Care and Recovery from Critical Illness

Cutler et al. (2013) suggested that whilst there is a growing body of research informing the physiological basis for treating critical illness, patient experiences of critical care remain less well understood. Palesjö et al. (2015) reiterated that it is imperative for healthcare professionals to understand and attend to critical care patients' experiences, including their existential concerns, 'unreal' experiences, fear, panic, and emotional pain. Arguably, a paucity of qualitative research exploring patients' lived experiences of critical care remains — especially regarding psychological experiences. Despite the currently limited literature base, there has been sufficient research published within the last decade to warrant a further review.

The current review aimed to critically review and synthesise qualitative research findings, published between 2011-2021, pertaining to patients' psychological experiences of critical care. Articles already included within the previous review, Cutler et al. (2013), were not considered. First-hand patient experiences and perspectives across any stage of the illness-recovery process were sought to address a previously established gap within existing reviews. The following review question was addressed: what is the psychological experience of critical care across the illness-recovery trajectory?

Materials & Method

Search Strategy

Articles were sought which indirectly or directly explored psychological experiences of critical care — whether at an acute stage, during recovery, or both.

A database search of the literature was conducted between December 2020 and February 2021 using the platforms EBSCOhost and Web of Science. The following databases were included: CINAHL Complete, ERIC, MEDLINE, APA Psych Articles, APA Psychinfo, and the Core Collection of the Web of Science database. Therefore, psychological, general, and medical databases were searched, exploring an extensive pool of research to enhance the detection of all relevant articles. Applied search terms included:

Patient* OR survivor* OR individual* OR "critical care patient*"

AND

Experience* OR stor* OR "life experience*" OR "patients' experience*"

AND

"Critical care" OR ICU OR HDU OR "high dependency unit" OR "intensive care" OR "critical illness"

Wide-ranging terms were utilised, given variation in definitions of critical care and differing critical care contexts, to avoid inadvertently eliminating relevant literature. Asterisk truncations were applied after root words to encompass all word variations, broadening appropriate search results. Quotation marks ascertained specific terms/ phrasing of interest. To procure a wider range of suitable articles while still targeting factors relevant to the research question, the Boolean operators OR and AND were utilised.

Selection Strategy

Retrieved articles were screened by title to evaluate their relevance and remove duplicates. All identified articles of interest were then collectively screened by their abstracts. If deemed suitable, they were read in full and assessed against the inclusion and exclusion criteria (see Table 2 and Table 3). Finally, the included articles' reference lists were perused but no further pertinent articles were identified. Figure 1, below, demonstrates the article search and selection process (including article numbers) guided by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement (Moher et al., 2009).

Table 2

Inclusion Criteria and Rationales

Inclusion Criteria	Rationale
Peer reviewed	Peer reviewed articles' potential contribution to the scientific community is evaluated against their quality, resulting in reliably better-quality articles (American Psychological Association, 2018).
Written in English language	Due to limited resources, translation services were inaccessible. For analysis and synthesis purposes, a requirement for articles to be written in English was set; English is the native language of the researcher.
Qualitative methodology only	The current review sought to synthesise data aimed at understanding in-depth experiences of participants. Qualitative methodologies allow for the richness of lived experience to be captured.
Adults – participants aged 18 +	Children's and adolescents' experiences, relating to critical illness and critical care, likely differ from adults' experiences; care environment differences also exist (Lykkegaard & Delmar, 2013).
First-hand patient experiences of critical illness and critical care	To enable the synthesis of data grounded in gaining the depth and understanding of lived experience through each patient's lens.
Articles including data in the form of narratives, personal accounts and dialogue between researcher and participants	To ensure that original data sets were collected directly by researchers through interactions with the participant groups. Potentially, increasing the reliability and validity of findings by offering data more accurately reflecting participants' experiences. This criterion also excluded literature reviews.
Published between 2011- 2021	To build upon the existing work of a previous review, Cutler et al. (2013), without redundantly repeating previous findings.
Studies with an overarching focus on, or including underlying themes relating to, patients' psychological experiences of critical care at any stage of the illness-recovery process (e.g., acute, early post-discharge, or further into recovery)	To explore patients' psychological experiences of critical care, aligning with this review's aim, across the whole illness-recovery trajectory; consideration of this entire trajectory requires further exploration (Cutler et al., 2013).

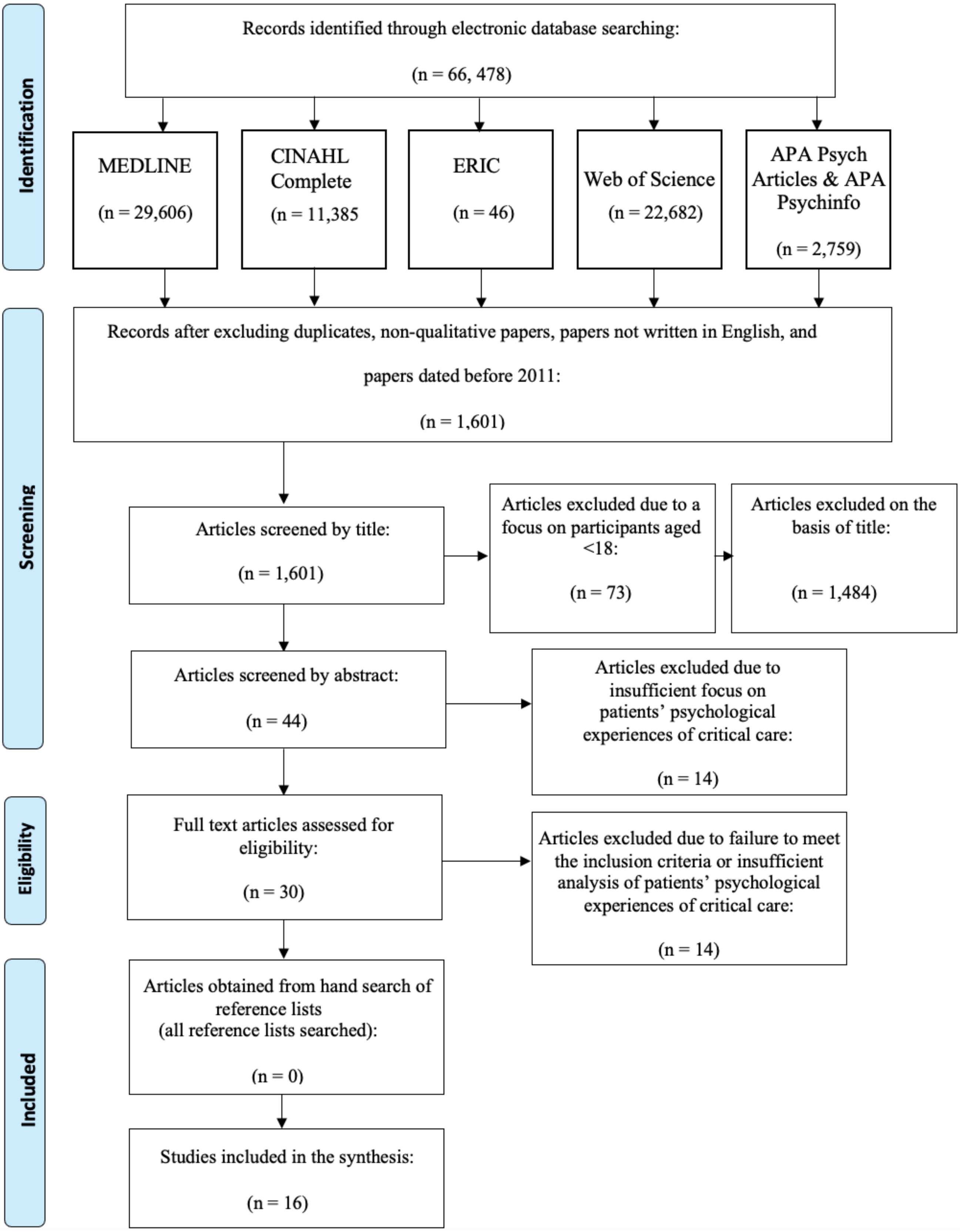
Table 3

Exclusion Criteria and Rationales

Exclusion Criteria	Rationale
Quantitative and mixed-method approaches	To ensure that the synthesised data answers the review question aimed at understanding lived experience; quantitative methodologies do not capture the in-depth or subjective nature of lived experience. Arguably, mixed-method approaches do so in much less detail than qualitative approaches.
Systematic review papers	Systematic reviews have already been interpreted second-hand, from first-hand original sources; this review aimed to stay as close to the original data as possible.
Studies which do not broadly encapsulate critical care patients' experiences, e.g., which focus on non-patient groups or an overly specific patient group, such as 'delirium patients' (recall difficulties are also limiting within this group)	To understand first-hand, lived experiences broadly pertaining to the general population of critical care patients. To limit the influence of recall difficulties, e.g., where a significant period of delirium existed.
Articles focused on participant groups aged <18	Paediatric ICUs differ from adult ICUs, likely resulting in different experiences. Additionally, there are differences between adults', children's and adolescents' expression of their experiences.
Articles heavily focused on a particular aspect or component of critical care deemed too far removed from the review question and aim, e.g., patient experiences of technology or factual memory recall within ICU	To adequately explore the breadth of patients' psychological experiences of critical care.
Articles heavily focused on a highly specific critical care context, e.g., neurosurgical / neurological ICU	To reduce context bias; highly specific critical care contexts, with varying levels of care provision and context-specific resources, may greatly alter patients' experiences — including their psychological experiences of critical care.

Figure 1

Article Selection Process



Note. Figure adapted from "PRISMA 2009 Flow Diagram" (Moher et al., 2009).

Data Extraction

Direct quotes were extracted to support key themes. DEFs detailed articles' research aims, participant demographics, recruitment settings, methodologies, key findings, limitations, and conclusions. The principal investigator (HH) extracted salient information from each article individually using a data extraction form (DEF) (example in Appendix A).

Quality Assessment

All selected articles used qualitative methodologies. Therefore, the NICE Quality Assessment Checklist (NICE, 2012) was utilised to assess methodological quality across 14 domains (see Appendix B for checklist ratings' meaning). This checklist was selected over other suitable checklists, e.g., the Critical Appraisal Skills Programme Qualitative Checklist (CASP, 2018), as it is arguably more thorough and aptly suited the review's aims. As a reliability check of the initial quality assessment ratings, the checklist was independently completed by a peer reviewer for three of the articles under consideration. These articles were strategically selected; the lowest rated paper (+), a mid-high rated paper (+/++), and a higher rated paper (++). Discussions around minor disagreements led to a 100% rating consensus. After which, given the high degree of agreement, the remaining papers were assumed to be reliably rated. Final quality ratings are listed within Table 4.

Data Synthesis

A Narrative Synthesis (NS) (Popay et al., 2006) was conducted upon 16 papers. NS was selected as it can appropriately synthesise data sets with varying qualitative methodologies, focuses, frames of reference, and dissimilar reporting styles to create an overarching 'story' within research findings; thus, connecting 'common threads' within articles (Popay et al., 2006; Ryan, 2013). This was done by carefully reading the texts, attending to language use, to develop textual descriptions of every article and then develop a preliminary synthesis of findings within each article (including provisional themes and subthemes). ‘Vote-counting’ similar types of findings within the data set helped to group studies with similar comparisons or conclusions; qualitative data ‘vote-counting’ is essentially frequency counting, resulting in grouped themes and findings allowing for the development of initial descriptive patterns of the entire data set. Original themes and subthemes were tabulated first (see Appendix C) and ‘vote-counted’, followed by ‘vote-counting’ of the researcher’s devised themes and subthemes; this also helped to explore and highlight emerging relationships across the data set and led to the refinement of final broader themes and subthemes. Lastly, the robustness of the synthesis was assessed. This involved re-referring to the methodological quality of included articles and assessing the trustworthiness of the synthesis based on multiple factors, e.g., the quality and quantity of the synthesis’ pool of studies, the degree of information provided to the reviewer to adequately judge that the selected articles met the inclusion criteria, and an analysis of the relationships between studies to assess the strength of the evidence supporting the NS’ conclusions.

Researcher’s Position

The researcher conducting the NS is a White British female from a northern city within England, was a Trainee Clinical Psychologist when this review was undertaken, has a keen interest in this topic, and has personal lived experience of an ICU admission and critical illness. Therefore, several preconceptions demanded attention, e.g., ICU experiences predominantly negatively psychologically influence patients and are individually unique. To aid reflection upon such preconceptions, regular supervision and reflective journaling was utilised. Within supervision, the researcher also acknowledged her ethnic and cultural background in relation to preunderstandings and assumptions around families’ and individuals’ responses to critical illness, the context of varying critical care settings, and the context of critical care within the NHS; this was important whilst dealing with an international body of literature. This aimed to reduce researcher bias. However, the researcher believes that it is impossible to fully 'bracket off' one's own experiences within the process of data interpretation and synthesis. For further context, peruse the researcher's reflective statement (Appendix D) and epistemological/ ontological statement (Appendix E).

Results

Characteristics of the Included Studies

In total, 212 participants were recruited within the 16 studies included (see Table 4). All articles were published between 2012-2019. Two studies (Lykkegaard & Delmar, 2013, 2015) shared the same three participants; this sample was counted once within the total. Of the 212 participants, 97 self-identified as female, 96 self-identified as male, and the genders of 19 participants were unreported. Sample sizes across papers ranged from 3-35 participants. Divergence was observed within critical care settings. Notably, some settings were unreported. Included articles reported the following settings: general ICU (5), medical/surgical ICU (3), cardiac ICU (1), unreported context (2), seven surgical ICUs and four cardiac ICUs (1), mixed ICU (1), one thoracic ICU and five general ICUs (1), two medical/surgical combined ICUs/HDUs (1), and one medical/surgical ICU and one thoracic trauma ICU (1).

All articles employed qualitative methodologies appropriate to their research aims. Articles' varied focuses can be gathered from their titles (see Appendix F). The most common analytic approaches were phenomenological-hermeneutic/ hermeneutic approaches (*n* = 4) and Content Analysis (*n* = 4), followed by Thematic Analysis (*n* = 3), Grounded Theory (*n* = 2), and Interpretative Phenomenological Analysis (*n* = 2). Not all articles, (*n* = 1), disclosed which specific type of qualitative analytic method was used; however, the latter study was a secondary analysis and was deemed to possess good methodological quality overall, scoring the highest quality checklist rating (++).

The studies were conducted across various geographical locations including the United Kingdom (*n* = 3), South Africa (*n* = 1), Australia (*n* = 1), Korea (*n* = 1), and several Nordic countries (*n* = 9). One article collected data online.

Significant variation was observed within and between studies with regard to when in the illness-recovery trajectory data was collected. Equally, dissimilarities existed in how clearly this was reported. For instance, some studies did not specify a data collection timeframe in relation to participants' position within the illness-recovery process, or omitted timeframe information altogether, e.g., Deacon (2012). Six studies included participant interviews conducted during what could be considered as participants' acute stage of illness (during their hospital stay) or, subjectively, very early recovery (4 days to 8 weeks post-critical care discharge) (Corner et al., 2019; Kang & Jeon, 2018; Kisorio & Langley, 2019; Lindberg et al., 2015; Olsen et al., 2017; Wermström et al., 2018). Ten articles included interviews conducted during participants' arguably early recovery (3-12 months post-critical care discharge) (Alexandersen et al., 2019; Alpers et al., 2012; Ewens et al., 2018; Kang & Jeon, 2018; Lykkegaard & Delmar, 2013, 2015; Moen & Nåden, 2015; Olsen et al., 2017; Ramsay et al., 2014; Stayt et al., 2015), three papers covered participants' mid-recovery timeframe (18-24 months post-critical care discharge) (Alexandersen et al., 2019; Kang & Jeon, 2018; Palesjö et al., 2015), and two papers interviewed during participants' later stages of recovery (25 months to 12 years post-critical care discharge) (Kang & Jeon, 2018; Palesjö et al., 2015). One paper specifically focused on experiences of being in an illness-recovery process (Palesjö et al., 2015).

Considerable variance was also noted within reported duration of interviews. Similarly, discrepancies were present in the richness of participant quotes offered. Within some articles, reported interview durations ranged between 12-97 minutes, with a median of 54 minutes (Lindberg et al., 2015), and between 20-60 minutes (Moen & Nåden, 2015).

Wermström et al. (2016) also reported interviews being shortened due to participants in hospital becoming “overwhelmingly tired”. Moreover, the results section of another article is brief and lacking in participant quotes (Lykkegaard & Delmar, 2015); full diversity of perspective and content may therefore not have been adequately explored. Without reflective statements, it is not clear what influenced the selection of presented quotes — including shorter quotes.

Table 4

An Overview of the Included Studies

	Author (Year)	Location	Method	Participants & Timing of Interviews	Critical Care Context & Participants' Length of Critical Care Stay	Main Findings	Quality Rating
1	Alpers, Helseth & Bergbom (2012)	Norway	Hermeneutic Approach – Open-ended interviews	6 (3 Females, 3 males) 3-6 Months post-hospital discharge	Specific context of critical care unreported 14-56 Days	1. To Have the Support of Next of Kin 2. The Wish to Go on Living 3. To Be Seen 4. Signs of Progress	++
2	Deacon (2012)	Online Study	Thematic Analysis – Open-ended survey questions	35 (5 Males, 30 females) This online study did not capture how long-ago participants were discharged from hospital or critical care	Multiple types of unreported critical care contexts 4 Days – 4 months	1. Personal Support 2. Assessment and Therapy 3. Information and Education	++ /+

3	Lykkegaard & Delmar (2013)	Denmark	Interpretative Phenomenological Analysis – Semi-structured interviews	3 (2 Females, 1 male) 6-12 Months post-ICU discharge	A high-technology intensive care unit - medical and surgical patients 21 Days - 3 months	1. With Dependency and Critical Illness, the Relation to the Self Is Changed a. To Be Dependent on Care Influences Self-Understanding b. It Is Associated With Shame to Receive Help for Care c. You Feel Powerlessness During Critical Illness	++
4	Ramsay, Huby, Thompson & Walsh (2014)	United Kingdom	Undisclosed qualitative data analysis – Semi-structured interviews	20 (9 Females, 11 males) Up to 6 months post-hospital discharge	Two medical/ surgical combined ICUs/HDUs Presented with a median figure and interquartile ranges – 35 (24, 47) days	"Meleis et al.'s work has resonance in terms of explicating intensive care patients' experiences of psychosocial distress throughout the transition to general ward–based care". "The putative origins of participants' psychosocial distress are encapsulated well within… disconnectedness as the most pervasive characteristic of the transitional process".	++
5	Lindberg, Sivberg, Willman & Fagerström (2015)	Sweden	Content Analysis – Semi-structured interviews	11 (7 Males, 4 females) 1-7 Weeks post-ICU discharge	One thoracic ICU & five general ICUs 2-28 Days	1. Acknowledged Dependence a. Feeling Trust b. Surrendering c. Losing Control d. Accepting Dependence 2. Being Recognised as a Person a. Being Noticed b. Being Asked c. Being Listened to d. Being Shown Respect	++

						e. Being Given Information 3. Invited Participation a. Being Encouraged b. Being Invited to Initiate Care Activities c. Being Part of the Care Relationship 4. Becoming a Co-Partner in Care a. Participation in Decision-Making b. Exerting Active Influence on Care c. Experiencing Independence d. Taking Personal Responsibility	
6	Lykkegaard & Delmar (2015)	Denmark	Phenomenological Hermeneutic Approach – Semi-structured interviews	3 (1 Male, 2 females) 6-12 Months post-ICU discharge	A high-technology intensive care unit - medical and surgical patients 21 Days - 3 months	1. The Relationship to the Care Staff is Ambivalent a. Being Dependent on Care Can Mean You Are Violated b. The Relation to Staff is Personal and Caring c. There is a Deep Gratitude Linked to the Dependency	+
7	Moen & Nåden (2015)	Norway	Interpretative Phenomenological Analysis – Open-ended interviews	7 (4 Males, 3 females) 5-12 Months post-ICU discharge	Specific type of ICU unreported – “average-sized ICU” Unreported. Describes as “varied”. Participants	1. Being Heard and Seen 2. Letting the Carers Take Over 3. Frustration About Inability to Speak 4. Being Respected 5. Feeling violated	++

					stayed in ICU for at least 5 days		
8	Palesjö, Nordgren & Asp (2015)	Sweden	Phenomenological Hermeneutic Approach – Semi-structured interviews	7 (3 Males, 4 females) At least 2 years post-hospital discharge	ICU for patients requiring close monitoring/ advanced treatment - organ failure and surgical patients 3-28 Days	1. To Create Meaning and Coherence a. Between the Real and Unreal b. A Struggle to Understand c. Lacking Mutual Understanding 2. To Recover in an Unfamiliar Body a. Altered Sensations and a Disobedient Body b. Having Motivation and a Vital Force c. Exposed in Vulnerability 3. To Strive for Reconciliation a. To Live in the Very Moment b. Learning to Live in a Changed Body c. A Struggle to Return to Ordinary Life	++
9	Stayt, Seers & Tutton (2015)	United Kingdom	Thematic Analysis – Semi-structured interviews	19 (Gender not reported) 3-7 Months post-ICU discharge	General ICU 7-28 Days	1. Making Sense of It a. Why Am I Here? b. Filling in the Gaps c. Sorting the Real From the Unreal d. Searching for Familiarity	++
10	Olsen, Nester & Hansen (2017)	Norway	Content Analysis – Semi-structured interviews	29 (19 Males, 10 females) Interview 1 was conducted on the ward post-ICU	“Mixed ICU” Unreported. States that patients were mechanically ventilated for a minimum of 48	1. Being on an Unreal Strange Journey a. Floating Between Facts and Delusions b. To Understand and to be Understood 2. Normalising the Abnormal a. Back to the Future b. Valuing Family c. Doing It My Way	++

				discharge. Interview 2 took place 3 months post-hospital discharge	hours – likely within ICU		
11	Wermström, Ryrlén & Axelsson (2017)	Sweden	Content Analysis – Semi-structured interviews	8 (3 Males, 5 females) During patients stay within the cardiac ICU	Cardiac ICU Unreported. Reports the duration of invasive monitoring and treatment (1-6 days)	1. Sense of Powerlessness and Striving to Regain Control a. To Be Exposed b. Loss of Empowerment c. To Surrender d. To Endure e. To Feel Hope f. Resting From the Illness g. To Participate	++
12	Ewens, Hendricks & Sundin (2018)	Australia	Thematic Analysis – Interviews & Diaries	6 (4 Females, 2 males) 4 Months & 2 weeks post-hospital discharge	General ICU 3-21 Days	1. Life Changing 2. Recovery Confusion 3. Absent Support 4. ICU Dreaming 5. Private Memories 6. Learning to Reflect	++
13	Kang & Jeong (2018)	Korea	Grounded Theory – Semi-structured interviews	13 (6 Females, 7 males) 1 Month – 12 years post-	Seven surgical ICUs & four cardiac ICUs 3-40 Days	1. Embracing the Vulnerable Self a. Being Vulnerable b. Struggling for Recovery c. New Crisis d. Being Devastated e. Mobilising Internal/External Resources	++

				hospital discharge		f. New Perspective on Normality	
14	Alexandersen, Stjern, Eide, Haugdahl, Paulsby, Lund & Haugan (2019)	Norway	Phenomenological Hermeneutic Approach – Semi-structured interviews	17 (13 Males, 4 females) 6-18 Months post-ICU discharge	General ICU 8-75 Days	1. No Doubt About Coming Back to Life a. Strong Connectedness to Life; Feeling Alive and Present b. Meaning and Purpose; Feeling Valuable to Somebody 2. How to Ignite and Maintain the Spark of Life a. Practical Solutions, Coping Skills from Previous Life Experiences b. Provocative and Inspiring Experiences c. Vivid Dream Experiences That Ignite the Willpower 3. Exhaustion, Weakness and Discomfort a. Physical Challenges b. Mental Discomfort 4. Tiring Delusions a. Living in the Worst Horror Movie b. Feeling Trapped	++
15	Corner, Murray & Brett (2019)	United Kingdom	Grounded Theory – Semi-structured interviews	15 (11 Males, 4 females) No specific timeframe given – "The interviews were carried	Medical/ surgical combined ICU 5-150 Days	1. Recalibration of the Self a. From Prior Self to Current Self b. From Current Self to Construction of the Future Self	++

				out either in the hospital or in the community after ICU discharge”.			
16	Kisorio & Langley (2019)	South Africa	Content Analysis – Semi-structured interviews	16 (9 Females, 7 males) On the ward at least 4 days post-ICU discharge.	Cardio-thoracic, trauma, medical & surgical ICUs 4-15 Days	1. Being in Someone’s Shoes 2. Communication 3. Presence 4. Religion and Spirituality	++

Note: Alphabetic letters represent subthemes and secondary categories.

Methodological Quality

According to the standardised quality appraisal, the overall methodological quality of included articles was good; 14 of 16 papers scored the highest quality rating score (++) on the NICE Quality Assessment Checklist (NICE, 2012). One paper scored the highest/ mid-level rating (++/+) and only one paper received a mid-level rating score (+); none were categorised with the lowest rating score (-) (see Table 4). However, these are broad overall quality ratings and the following quality issues were identified within and across selected articles.

Participants and the Role of the Researcher: Lack of Clarity

Six research papers, Alexandersen et al. (2019), Alpers et al. (2012), Corner et al. (2019), Lykkegaard and Delmar (2015), Palesjö et al. (2015), and Wermström et al. (2016), clearly described the role of the researcher(s) in relation to participants beyond simply commenting that a good rapport was built. Some omitted discussion of consent and anonymity (Kang & Jeon, 2018). Most articles did not relay how the research was presented to participants, other than stating when it was presented. None of the articles included an explicit reflexivity or reflective statement. This may link to the stringent word counts of peer-reviewed papers. However, reflective and reflexive considerations are key in demonstrating rigour and competence in qualitative research (Mortari, 2015). Despite this, several papers, Alexandersen et al. (2019), Alpers et al. (2012), Deacon (2012), Kang and Jeong (2018), Lykkegaard and Delmar (2015), Moena and Nåden (2015), Stayt et al. (2015), and Wermström et al. (2016), referred to the importance of researchers reflecting upon the significance of power, biases, pre-assumptions, and pre-understanding in relation to analysis and data interpretation.

Bypassing Ethical Approval

Two of the studies reported that they did not seek approval from an ethics committee (Lykkegaard & Delmar, 2013, 2015). The rationale behind a lack of ethical approval was the exclusion of biomedical aspects within these studies. It is arguably not common practice to bypass ethical approval on such grounds. However, regional and geographical differences must be considered; Danish law does not stipulate that qualitative studies require approval from a research ethics committee (Bruun et al., 2018).

Participant Selection and Sampling Strategy Issues

Few studies gave theoretical justification for both their selection of participants and sampling strategy, with the exception of Deacon (2012), Kisorio et al. (2019), and Lykkegaard and Delmar (2013). Ewens et al. (2018) gave justification for their sampling strategy and partial justification for participant selection. Alpers et al. (2012) partially justified their participant selection but not their sampling strategy, as did Corner et al. (2019), Lindberg et al. (2015), and Lykkegaard and Delmar (2015). Justification of sampling strategy alone was described by Kang and Jeong (2018) and Wermström et al. (2016). Other studies failed to acknowledge a rationale for either. There was a common inclusion criterion that participants must have experienced respirator or ventilator treatment with little explanation of the rationale for this.

Limited Participant Involvement

Only three studies (Corner et al., 2019; Ewens et al., 2018; Kang & Jeong, 2018) outlined the involvement of participants in the process of data interpretation or feedback. However, Stayt et al. (2015) offered justification as to why participants were not invited to validate the research themes. One further article by Ramsay et al. (2013) collected participant feedback as part of a larger study.

Quality Summary and Consideration of Strengths

Irrespective of these limitations each of the articles stated their research aims explicitly, although not all studies presented explicit research questions, and utilised methodological approaches which were appropriate. Research aims were derived from relevant theory and literature in every instance, with articles demonstrating the need for their research to be undertaken. Data collection and analysis methods were largely rigorous and suitably reported. However, it was unclear how systematic data collection and record keeping was; only two studies reported both systematic data collection and record keeping (Ewens et al., 2018; Kisorio & Langley, 2019). Recruitment settings were clearly defined across each study, but interview settings were invariably not reported. Findings were transparent and convincing, but several papers, Ewens et al. (2018), Lindberg et al. (2015), Lykkegaard and Delmar (2015), and Palesjö et al. (2015), could have solidified themes more effectively with additional participant quotes. Notably, Wermström et al. (2018) reported limited depth and diversity of perspective with few participant quotations, which were also brief.

Synthesis of Findings

Emergent themes and subthemes represent how patients experienced critical care at varying timepoints across the illness-recovery process (see Table 5). Ellipses, within quotations, represent short pauses as presented within original papers or removed text to illustrate points succinctly and accurately. The timing of data collection may have significantly influenced patients’ responses in terms of their insight, memory, and level of emotional and psychological processing.

Table 5
Major Themes and Subthemes

Main Themes	Subthemes	Papers Including Specific Subthemes
1. Losing and Striving to Regain Self-Determination and Independence	*1.1 Voicelessness & Violation of Personal Boundaries*	Corner et al., 2019; Kisorio & Langley, 2019; Lindberg et al., 2015; Lykkegaard & Delmar, 2013, 2015; Moen & Nåden, 2015; Ramsay et al., 2013.
	1.2 Dehumanising, Exposing, & Isolating	Corner et al., 2019; Ewens et al., 2018; Lindberg et al., 2015; Lykkegaard & Delmar, 2013, 2015; Moen & Nåden, 2015; Olsen et al., 2017; Palesjö et al., 2015; Ramsay et al., 2013; Wermström et al., 2018.
	1.3 Powerlessness & Dependency	Alexandersen et al., 2019; Corner et al., 2019; Kang & Jeong, 2018; Lindberg et al., 2015; Lykkegaard & Delmar, 2013; Moen & Nåden, 2015; Palesjö et al., 2015; Ramsay et al., 2013; Wermström et al., 2018.
	1.4 Passivity & Regression	Alexandersen et al., 2019; Corner et al., 2019; Lindberg et al., 2015; Lykkegaard & Delmar, 2013; Ramsay et al., 2013; Wermström et al., 2018.
2. A Journey of Dynamic Psychological Challenges & Emotions	*2.1 Shock & Denial*	Kang & Jeong, 2018; Lykkegaard & Delmar, 2013; Ramsay et al., 2013.

	2.2 Guilt & Self-Blame	Alexandersen et al., 2019; Corner et al., 2019; Ewens et al., 2018; Ramsay et al., 2013.
	2.3 Anger & Frustration	Alexandersen et al., 2019; Corner et al., 2019; Ewens et al., 2018; Kang & Jeong, 2018; Kisorio & Langley, 2019; Lykkegaard & Delmar, 2013; Moen & Nåden, 2015; Olsen et al., 2017; Stayt et al., 2015.
	2.4 Conviction to Recover, Willpower, Hope, & Positive Beliefs	Alexandersen et al., 2019; Alpers et al., 2012; Kang & Jeong, 2018; Kisorio & Langley, 2019; Lindberg et al., 2015; Olsen et al., 2017; Palesjö et al., 2015; Ramsay et al., 2013; Wermström et al., 2018.
	2.5 *Acceptance and Adjustment Challenges*	Alexandersen et al., 2019; Deacon, 2012; Ewens et al., 2018; Kang & Jeong, 2018; Olsen et al., 2017; Palesjö et al., 2015; Ramsay et al., 2013.
3. A Deep Desire for Humanisation: Acknowledging the Person Within the Patient	*3.1 Gratitude, Learnt Trust, & Comfort in Familiarity*	Alpers et al., 2012; Corner et al., 2019; Kisorio & Langley, 2019; Lindberg et al., 2015; Lykkegaard & Delmar, 2013, 2015; Moen & Nåden, 2015; Palesjö et al., 2015; Stayt et al., 2015.
	3.2 Feeling seen and heard as an Individual	Alpers et al., 2012; Corner et al., 2019; Deacon, 2012; Kang & Jeong, 2018; Kisorio & Langley, 2019; Lindberg et al., 2015;

		Moen & Nåden, 2015; Olsen et al., 2017; Palesjö et al., 2015; Ramsay et al., 2013.
	3.3 Shared Understandings: Doing With, Not Doing To	Deacon, 2012; Lindberg et al., 2015; Lykkegaard & Delmar, 2015; Moen & Nåden, 2015; Olsen et al., 2017; Palesjö et al., 2015; Wermström et al., 2018.
4. Transformation, Existential Realisations, & Re-Evaluation	*4.1 Reorientation of Self-Identity & Knowing the 'Unknown Body'*	Alexandersen et al., 2019; Corner et al., 2019; Ewens et al., 2018; Kang & Jeong, 2018; Lykkegaard & Delmar, 2013, 2015; Palesjö et al., 2015; Ramsay et al., 2013.
	4.2 A Haze Between the Real, Unreal, & Bizarre: Changed By the Unforgettable	Alexandersen et al., 2019; Corner et al., 2019; Ewens et al., 2018; Olsen et al., 2017; Palesjö et al., 2015; Ramsay et al., 2013; Stayt et al., 2015.
	4.3 Coming to Terms With Loss, Grief, Distress, Hopelessness, & Devastation	Alexandersen et al., 2019; Deacon, 2012; Ewens et al., 2018; Kang & Jeong, 2018; Lykkegaard & Delmar, 2013; Moen & Nåden, 2015; Olsen et al., 2017; Palesjö et al., 2015.
	4.4 A Mission for Understanding and Meaning	Alexandersen et al., 2019; Corner et al., 2019; Deacon, 2012; Ewens et al., 2018; Kisorio & Langley, 2019; Olsen et al., 2017; Palesjö et al., 2015; Stayt et al., 2015.

	4.5 Reappraisal of the Future & Existential Questions and Realisations	Alexandersen et al., 2019; Alpers et al., 2012; Corner et al., 2019; Ewens et al., 2018; Kang & Jeong, 2018; Palesjö et al., 2015; Wermström et al., 2018.

1. Losing and Striving to Regain Self-Determination and Independence

This theme accentuates the loss of self-determination and independence resulting from a critical care stay, including participants' other psychological experiences across the included articles associated with these losses. Within this theme, the struggle to regain self-determination and independence is explored; for some, independence was not fully regained at the point at which the studies' authors undertook data collection.

1.1 Voicelessness & Violation of Personal Boundaries

Within seven articles (see Table 5), voicelessness and violation of personal boundaries were discussed. Psychological experiences of both figurative and literal voicelessness within critical care were frequently relayed. For some, it felt challenging to complain about any aspect of care; psychologically, this evoked a sense of fear and disempowerment. One participant linked this to hospital experiences, generally:

> *"I said, "don't rock the boat, because I'm still here". You know, you are actually scared to complain because the power is with them (the nurses). I think that happens a lot in hospitals" (Ramsay et al., 2013, p. 610).*

Literal voicelessness within critical care led to frustration, annoyance, and was described as psychologically "difficult":

> *"I was so much in pain and they were nowhere to be seen. They would take years to come, and I would get so frustrated. I thought I was going to die. I could not move or talk, and they cannot pick up that you are in pain unless you tell them" (Kisorio & Langley, 2019, p. 395).*

An underlying theme of violation was expressed within multiple articles. Some papers explicitly discussed participants' psychological experience of critical care in relation to violation, resulting in fear and anger. Often, violation was connected to the infringement of personal boundaries:

> *"It was actually a doctor who did something bad… with the best of intentions. They wanted to see if I could breathe unaided, so they reset the ventilator… without telling me… or the staff and then they left the room… I was afraid and then I became angry, realising what had happened. It was a tremendous violation" (Lindberg et al., 2015, p. 299).*

1.2 Dehumanising, Exposing, & Isolating

Ten articles (see Table 5) detailed findings relating to experiences of isolation, feeling exposed, and dehumanisation within critical care. Isolation was experienced both in the presence and absence of nursing staff. Isolation was heightened when participants felt others could not understand their situation or when their reliance existed upon staff with wavering availability. Dehumanised care linked to a loss of perceived dignity and engendered shame, as did feeling exposed:

> *"The doctors do not think about the patients' dignity… there I was, with no clothes or trousers and the doctors just came in and threw off the duvet to take a look. They did not think of pulling the curtain. I felt like dirt" (Moen & Nåden, 2015, p. 289).*

Within these ten articles, participants reflected on the fundamentally isolating and lonely aspect of critical care, irrespective of others' presence:

> *"It is a very lonely experience even if the nurses are around, I know, I have experienced it and… the nurse cannot be there all the time" (Kisorio & Langley, 2019, p. 395).*

Isolation was further experienced through diminished human connection to staff, scarce availability of staff, and dehumanising care experiences causing psychological distress:

> *"Mostly, they will not be around; they will only appear when they have to do something otherwise you don't see them. You feel horrible, you feel neglected, and you are hopeless" (Kisorio & Langley, 2019, p. 395).*

> *"It was very transgressive when they touched me all the time. A lot of different people… I didn't feel that anybody considered me as a person. It was just a body lying there that they had to get going again" (Lykkegaard & Delmar, 2015, p. 5).*

1.3 Powerlessness & Dependency

Two articles specifically focused on the topic of dependency. One study explicitly explored a powerlessness-control continuum. Including these, nine articles (see Table 5) overtly spoke of powerlessness, dependency, vulnerability, and helplessness; these topics were also more implicitly discussed within other reviewed papers. Nine articles' participants discussed significant psychological difficulty adjusting to the role of a critical care patient, which is inherently coupled with dependency. These topics were emotionally and cognitively associated with anger, upset, shock, decreased confidence, and diminished dignity:

> *"You know, it is a chapter of its own (to be dependent on care). I am stubborn and I have always wanted to manage myself. And then, just like that you are dependent on others in a very annoying way" (Lykkegaard & Delmar, 2013, p. 7).*

> *"Experiences that demote dignity are that you are nursed, fed, and given medication. It's a clear sign that you can't take care of yourself. It doesn't boost confidence" (Moen & Nåden, 2015, p. 290).*

Powerlessness was experienced in the absence of an ability to complete previously taken for granted actions. Powerlessness was most evident when participants' lack of independence was starkly noticed. Loss of agency, power, and control were experienced intensely and unfavourably:

> *"I could not lift my arm to dry away the tears. The powerlessness was that I needed someone to dry away a tear. It was just a small thing that, that, I under normal circumstances would*

never have given a thought… I had to deal with everything and let others take care of me. I hope I will never experience this again" (Lykkegaard & Delmar, 2013, p. 8).

Powerlessness was also framed around lost freedom and diminished control:

"I feel so not free, everyone is doing what they want. I'm like a puppet and I hate that" (Corner et al., 2019, p. 7).

Reflecting on the powerlessness previously experienced with dependency, the importance of regaining independence was commonly contemplated:

"Maybe it took me 25 minutes to tie a shoelace, but I would do it myself. It was also a counter reaction to me having been so dependent on others" (Lykkegaard & Delmar, 2013, p. 8).

1.4 Passivity & Regression

Six papers (see Table 5) touched upon experiences of passivity and perceived regression within critical care. Experiences of child-like reliance were disclosed, and therefore regression, while being cared for. Discomfort and negative emotional responses towards child-like reliance were emphasised:

"The worst was not being able to get to the toilet yourself. It is tragic… being a grownup and you must… poop in the bed. That is not… something that you like!" (Alexandersen et al., 2019, p. 3999).

"I felt like a little baby when I needed help to eat, get washed and get rid of my excretions" (Lykkegaard & Delmar, 2013, p. 8).

Psychological passivity was also a reoccurring subject. Experiences comprised of willingly handing responsibility to care professionals, being compliant, losing the ability to care, and tolerating others' decisions:

"I didn't think of anything. No. I put up with it… I just let them decide" (Lindberg et al., 2015, p. 298).

"I was so ill when I arrived that I didn't really care. Things then simply progressed" (Wermström et al., 2016, p. 1069).

Some actively fought passivity within critical care, reflecting on its negative connotations:

"It's important to see that you can manage yourself. Otherwise, you might become very passive — that's not fun" (Wermström et al., 2016, p. 1069).

2. A Journey of Dynamic Psychological Challenges & Emotions

This theme reflects shifting emotional and psychological challenges arising from a critical care stay, over time. A spectrum of emotions were recounted by included articles' participants: guilt, self-blame, shock, denial, anger, frustration, willpower, and hope. Some endeavoured to find conviction to recover, drawing strength from positive beliefs.

2.1 Shock & Denial

Four articles (see Table 5) demonstrated accounts of shock and denial, arguably experienced before guilt and self-blame. The four articles' participants confirmed the shocking implications of critical care upon their physical abilities. However, participants' mentality changed during recovery; some participants later reported being shocked by their progress and reclaimed abilities. Shock was also experienced through family members' reactions to participants' illness and critical care journeys. It appeared that this type of shock was highly evident in participants who experienced gaps in memory whilst in critical care:

"My wife cried, you know. I did not understand why. What is going on? …When my brother came… he was crying too! … I had no feeling of ever having been in danger for my life!" (Alexandersen et al., 2019, p. 3997).

> *"Well, I was shocked at how little I could do, but now, it's the other way, I'm actually shocked at how much I can do" (Corner et al., 2019, p. 8).*

The psychological processing of the critical care experience was, for some, initially too challenging resulting in denial. In some instances, there was an absence of desire to understand what had happened in critical care. Other articles emphasised participants' deliberate attempts to deny and avoid painful psychological experiences associated with critical care:

> *"I dunno if... well, maybe a part of me switched off. Maybe I didn't want to know… I asked, eventually, and all they said was, "you've been very unwell"". (Ramsay et al., 2013, p. 609).*

> *"Painful things that I knew I should talk about were placed in a mental drawer, although I knew the importance of talking about these things. My mental drawer helped me getting through, day-by-day" (Alexandersen et al., 2019, p. 3997).*

2.2 Guilt & Self-Blame

Within three articles (see Table 5), participants divulged feelings of guilt and self-blame in connection to their experience of critical care. The strongest emphasis on guilt arose from Kang and Jeon's (2018) paper; notably, this paper scored the highest quality checklist rating. The influence of cultural differences within western and eastern countries, e.g., collectivist vs. individualist societal values, should be considered here — particularly in connection to health and illness and how individuals relate the consequences of their ill-health to their wider context (Alden et al., 2017). In some instances, the experience of self-blame was directly associated with inadequate information giving from healthcare professionals whilst in critical care:

> *"Your body feeds off your muscles (in ICU). I just thought, "I'm not trying hard enough". Had I have had this knowledge, it would've been… easier for me to accept" (Ramsay et al., 2013, p. 611).*

> *"I thought I was a failure… I couldn't do it" (Lykkegaard & Delmar, 2013, p. 8).*

Guilt frequently resulted from feeling burdensome to others; several comments on guilt in connection to how the critical care experience, and critical illness, impacted family members arose:

> *"I used to be the breadwinner…. now, I need the full help of my wife. I am so sorry for my wife. I used to think that I could do anything before… now I wonder what I can do" (Kang & Jeon, 2018, p. 47).*

2.3 Anger & Frustration

Nine papers (see Table 5) demonstrated findings of anger and frustration; frequently, critical care evoked anger and frustration in connection to loss of functioning and ability, dependency, and in connection to the outcome of staff care and decision-making:

> *"Once they called me the lightening because I was fast, and suddenly the lightening is out. Oh, by God it is annoying… damn it, it's difficult" (Lykkegaard & Delmar, 2013, p. 7).*

> *"I still feel very angry . . . they saved me one way but they . . . kind of damaged me in another" (Ewens et al., 2018, p. 1557).*

2.4 Conviction to Recover, Willpower, Hope, & Positive Beliefs

Critical care also elicited positive psychological responses from included studies' participants. Two articles, both scoring the highest quality checklist rating, wholly focused on patients' experiences of inner strength. Including these, nine articles (see Table 5) presented findings relating to positive experiences of hope, willpower, motivation, positive attitudes, strength, and conviction to recover:

"My attitude… is very important for my care… I believe that… to recover you also need the desire to recover… you have to decide!" (Lindberg et al., 2015, p. 300).

"Even though the doctors told me that my spine was broken, and I would not be able to move my legs again, I thought, "I have to make the best out of my situation"…. The doctors were quite clear - we cannot get your legs fixed... "We'll see! I am going to do whatever it takes to make them move again"... A message like this makes me even more motivated to disprove it!" (Alexandersen et al., 2019, p. 3998).

"What was it that gave me strength? It is, I think, a will to live" (Alpers et al., 2012, p. 154).

Markedly, the critical care experience also led some to focus on hope connected to spirituality and religious beliefs:

"I used to see groups of people coming to pray… it was good… many people are religious and if we receive such services, we get that hope" (Kisorio & Langley, 2019, p. 396).

2.5 Acceptance & Adjustment Challenges

Seven studies (see Table 5) presented findings which related to participants' struggle with acceptance and adjustment, particularly psychological adjustment. Acceptance and self-awareness were outlined as significant hurdles to overcome:

"The most difficult hurdle to overcome, I believe… is self-awareness – that you have to accept this is what the situation is like right now" (Lykkegaard & Delmar, 2013, p. 7).

The challenge of psychological adjustment, in the context of accepting help from others, was deemed exceptionally difficult for some:

"I cannot ask anyone for my mental suffering; so, I'm just hanging on"

(Kang & Jeon, 2018, p. 48).

In some cases, the experience of critical care led to losses which could not be regained. The lasting impact of critical care and the importance of 'successful' psychological adjustment and acceptance was recognised:

"I do not think it seems to have returned to me as it was. I am not trying to go back to the past, but I want to be the one that adapts as much as I can at this moment" (Kang & Jeon, 2018, p. 48).

"There are sick people all over the world. I just accept my illness and live with it" (Kang & Jeon, 2018, p. 47).

3. A Deep Desire for Humanisation: Acknowledging the Person Within the Patient

This theme accentuates recurring findings relating to the need to receive individualised, person-centred care, and the desire to be recognised as a person — not simply a patient. Gratitude, learnt trust, and comfort in familiarity were interconnected with these topics.

3.1 Gratitude, Learnt Trust, & Comfort in Familiarity

Nine articles (see Table 5) presented findings relating to gratitude, learnt trust, and comfort in familiarity. When humanised care was experienced within critical care, gratitude and trust followed. Gratitude for life was also a prevalent experience for participants:

"I am so grateful I survived! I don't feel sad at all, just happy" (Olsen et al., 2017, p. 64).

"In the beginning I was so sick. I felt grateful that there was someone to make the decisions for me! ... I mean, it was incredibly nice. And, I felt that it was part of... my recovery" (Lindberg et al., 2015, p. 297).

Additionally, familiarity offered further grounding in reality appeared to provide psychological comfort and promote hope:

"The fact that friends and family visited reassured me… It made it feel more normal, like life goes on. Life isn't confined to the weird environment" (Stayt et al., 2015, p. 229).

"My family do come and even if they don't do anything practically for me, they cheer me up, enlighten my emotions… Talk to me freely and encourage me. I put my hope to what they tell me"

(Kisorio & Langley, 2019, p. 395).

3.2 Feeling Seen and Heard as an Individual

Numerous accounts of critical care evoking a strong desire to be seen and heard unfolded; this was the most prominent theme across the papers. Such accounts were expressed within 10 articles (see Table 5). When participants felt seen and heard as an individual, they experienced this positively and it held significance for participants:

"It was good to be in intensive care. Whenever I had a question, I was heard immediately" (Moen & Nåden, 2015, p. 288).

"And then the staff ask you questions all the time. How you feel. If it is good in this way or that, or if you want it another way, and all the time you can say what you think" (Lindberg et al., 2015, p. 298).

"At the ICU, it was so good, the love I felt there I haven't got from anybody in my life. They fought for me, so I would survive. I felt that" (Palesjö et al., 2015, p. 3498).

Other participants' need to be seen and heard as an individual were met within critical care, but not within general ward care:

"In the intensive care unit, I was seen as a person but not in the general ward" (Moen & Nåden, 2015, p. 288).

Some findings highlighted experiences of hatred in relation to being treated like a patient by family and friends. This too highlights participants' need to be seen, including the person within the patient:

> *"I hate that my family and friends treat me like a patient" (Kang & Jeon, 2018, p. 47).*

3.3 Shared Understandings: Doing With, Not Doing to

Seven papers (see Table 5) included findings focused on participants' desire to acquire shared understandings with healthcare professionals; although, this includes two articles which failed to obtain the highest NICE (2012) quality assessment rating (Deacon, 2012; Lykkegaard & Delmar, 2015). This subtheme has not been illustrated with participant quotations from the lowest rated paper. Overall, the experience of critical care gave rise to strong beliefs that respectful care should be administered collaboratively and centred around informed consent. When these expectations were met, a sense of dignity and happiness was experienced:

> *"You feel more dignity if they give you information continuously, and maybe repeat it too. Because it's important that you're part of the team. That you're not just an interesting case lying there" (Moen & Nåden, 2015, p. 289).*

> *"Every time they gave me an injection, they told me this injection is for whatever. If they wanted to do something they just told me, and I was happy with the way they treated me" (Kisorio & Langley, 2019, p. 395).*

The absence of shared understandings with healthcare professionals was also reported. The psychological influence of this was emphasised; it appeared that stress could be alleviated through information sharing, which was sometimes lacking:

"Knowing what's ''normal'' relieves a lot of stress... No one ever tells you the negative side of treatment. They warn you of ''side effects'', but never really tell you what's going to happen (pain, the real details). Knowing the truth is helpful, good or bad"

(Deacon, 2012, p. 118).

4. Transformation, Existential Realisations, & Re-Evaluation

This theme spotlights the transformations critical care provokes. Across the findings of several studies, participants found themselves redefining their perception of 'normal' including the process of accepting and living with memories of hallucinations, delusions, and confusion between what they believed to be real and 'unreal' whilst in critical care. Participants' 'new normal' also included coming to terms with their loss, grief, distress, hopelessness, and devastation caused by the critical care experience; for some participants, these psychological experiences endured beyond discharge from critical care. In addition, participants commonly reported reinventing, or reorienting themselves to, their sense of self-identity. Moreover, regaining familiarity with an 'unknown body' was paramount to participants; the experience of critical care plausibly weakened participants' sense of connection with the physical self. Participants' explorations and transformation of meaning are also represented within this theme. Some findings related to tackling acceptance and adjusting psychologically to a 'new normal' and a 'new self'. This theme also considers how participants re-evaluated their life in relation to the future and existential crises, questions, and realisations stemming from the experience of critical care.

4.1 Reorientation of Self-Identity & Knowing the 'Unknown Body'

Eight papers (see Table 5) noted how the critical care experience psychologically changed participants, leading to reorientation of their self-identity, both physically and mentally:

"I just happened to catch sight of my whole body (in the mirror) and I nearly died. I thought; "that doesn't resemble the person that I am" (Corner et al., 2019, p. 5).

"I look at things different now… I think of the consequences, where before I wouldn't think and just do it… I think too much now! I'd rather be my old me than me as I am now" (Ewens et al., 2018, p. 1558).

Participants discussed feeling estranged from their bodies, perceived psychologically as 'strange' and hard to grasp — especially in combination with physical limitations:

"I was caught in… a strange experience… no power in my torso. I was not able to rise or anything. I wanted a cup of coffee… I saw the cup, but I was not capable of reaching it!" (Alexandersen et al., 2019, p. 3999).

"The body didn't obey me, I was weak in my arms and legs and I couldn't climb the stairs" (Palesjö et al., 2015, p. 3498).

4.2 A Haze Between the Real, Unreal, & Bizarre: Changed by the Unforgettable

Seven studies (see Table 5) featured vivid participant quotes pertaining to fused experiences of the real and 'unreal'. Critical care, for many of the participants, masked perceptions of time and included hallucinations, delusions, and a blurring of reality. This was reportedly experienced across the seven studies as chaotic, horrifying, confusing, difficult, and extraordinary:

"It was like glitter floating in the air; I tried to catch it with my hand. Everything was in complete chaos. I had no sense of day or night" (Olsen et al., 2017, p. 63).

"Certainly, those first days, I was in the twilight zone" (Ramsay et al., 2013, p. 608).

"Even now I have memories, but I don't know whether they are real or not. And some of them are so bizarre, I don't bother mentioning them… So, it is difficult finding out the reality and

the dream world… trying to distinguish the two was the hardest thing for me" (Stayt et al., 2015, p. 228).

"In the moment when it smacked, I became unconscious. Before I woke up, three people who have been very close to me came to see me on a mountain. We were elevated together in four pillars of light into heaven - they explained to me, that this life was over, and I had to choose where to live my next life! However, suddenly I was in the ICU, looking down on myself for a moment, and suddenly I was inside myself again! - An extraordinary experience!" (Alexandersen et al., 2019, p. 3998).

4.3 Coming to Terms With Loss, Grief, Distress, Hopelessness, & Devastation

Eight articles (see Table 5) highlighted hopelessness, devastation, and general distress linked to critical care experience. Such feelings were often powerful and too challenging for some to cope with, leading participants to continue feeling drained, sad, hopeless, and trapped:

"Should I say… ruined mentally? Confidence disappears, and I keep thinking this is useless" (Kang & Jeon, 2018, p. 47).

"I felt trapped in a sad way" (Moen & Nåden, 2015, p. 290).

"I feel emotionally drained" (Olsen et al., 2017, p. 64).

"My spirit is desolate…. I, myself and my family, are all devastated" (Kang & Jeon, 2018, p. 47).

Critical care and illness were so distressing for some participants, that it quashed their will to live:

"I have to be honest, there was a time during my stay at the intensive care unit where I thought that if I needed an injection of some kind… couldn't they just give me a proper dose and then I was gone (crying)" (Lykkegaard & Delmar, 2013, p. 9).

Others reflected on what had been missing in their experience of care provision in connection to this:

‘‘Definitely visits with a psychologist. About a year after the ICU, I suffered from PTSD and became almost non-functioning. No-one prepared me for what to expect in the days, months and years following hospitalisation” (Deacon, 2012, p. 119).

4.4 A Mission for Understanding and Meaning

Eight papers (see Table 5) highlighted their included participants’ desire for understanding and meaning making. In order for sense making of critical care experiences, recognition was given towards the helpfulness of others filling the gaps within participants’ memory:

“So I don’t remember all the details, just snippets. My wife has told me some things… filled me in on all the odds and ends. So, [wife] has helped a lot, she has been able to clarify the details” (Stayt et al., 2015, p. 228).

“I could not remember most of the things; I needed somebody to explain to me what was going on, what had happened to me” (Kisorio & Langley, 2019, p. 395).

The lack of first-hand memory of critical care was too taxing for some to fully comprehend their critical care situation, posing a threat to understanding and meaning making:

“The pictures help a little, but I still cannot understand it is me in that hospital bed” (Olsen et al., 2017, p. 65).

Critical care was experienced as a catalyst for change and transformation for many, resulting in re-evaluation of life meaning and personal values:

"I used to say to myself: If you have been so close to death, as they say you were, shouldn't you take care of your relations now?" (Palesjö et al., 2015, p. 3499).

4.5 Reappraisal of the Future & Existential Questions and Realisations

The findings of seven articles (see Table 5) were comprised of themes of an existential nature and considered participants' altered perceptions of time and the future. Critical care frequently prompted a reappraisal of the future. Some lost focus of the future, feeling forced to concentrate on the 'here-and-now' in order to cope and prevent further burnout:

"When you go through these situations you don't think… you don't think forward… you don't think about what may happen, and tell yourself to take this moment, and see what happens" (Wermström et al., 2016, p. 1069).

"I had enough by just being at that time, I was not able to think any further" (Alexandersen et al., 2019, p. 3999).

Critical care also evoked a fear of the future. Mostly, fear resided with thoughts that a future critical care experience and acute illness may emerge. Alternatively, fear was connected to continuing pain. Some consequently felt hopeless, losing sight of a positive future altogether:

"The fear has been always around me. I might be hospitalised again, and everything might become more complicated" (Kang & Jeon, 2018, p. 47).

"I had severe pain… I did not see any future" (*Alexandersen et al., 2019, p. 3998*).

Existential questions and realisations were omnipresent among participants, considered to be psychologically difficult. Some wondered why they survived and appeared disappointed towards their survival:

"Why did I survive? Why didn't they let me go?" (Palesjö et al., 2015, p. 3499).

The articles' participants frequently realised the vulnerability of the human condition, reflecting on their altered beliefs. The critical care experience arguably challenged their notion of invincibility; one participant reflected that this increased hesitance and cautiousness:

"I thought I was a bit invincible but now I know I'm not, I'm a lot more hesitant now . . . It's made me take a step back and reassess everything in life . . . I think too much now!" (Ewens et al., 2018, p. 1558).

Existential realisations were also contrasted against desires for the future, re-evaluation of life values, and the desire to live:

"My husband and grandchildren. I want to see them grow up… I am not ready to leave life yet. We shall be travelling, that was what I thought about. I want to live longer… I could not give up" (Alpers et al., 2012, p. 155).

Critical care was commonly perceived as psychologically distressing because it led to a direct confrontation with mortality, emphasising the inevitability of death. Many participants experienced their proximity to death as "terrible" and "horrible". Thoughts concerning these matters were evident for participants both in the acute stages of illness and during recovery:

"I woke up. I heard the voice of people… my body was not moving at all. I just felt like I was going to die. You cannot even imagine how terrible it was… I felt so close to death at that time. Even these days, I keep thinking about it; it is so horrible" (Kang & Jeon, 2018, p. 47).

Conversely, there were positive existential realisations driven by critical care experience from which positive psychological outcomes followed, e.g., increased confidence.

However, these were sparsely reported. Some plausibly re-evaluated life as precious, and valued their ‘second chance’ to live life to the fullest:

> *“Never been such a confident, able person ever… To realise that I could have died, and I didn’t; so, I should just go out there and do it…. throw caution to the wind to a degree” (Ewens et al., 2018, p. 1558).*

Discussion & Implications

Overview of Findings

This review critically synthesised findings, published between 2011-2021 spanning various timepoints of the illness-recovery trajectory, pertaining to patients’ psychological experiences of critical care. The review highlights a multi-dimensional spectrum of both positive and negative psychological experiences of critical care. Additionally, this NS highlights patients’ experiences over time on a wider scale; although, no single included article focused on the entire illness-recovery trajectory.

Topics which arose within this synthesis which were not explicitly named in the original articles’ themes and subthemes were shock, denial, anger, guilt, self-blame, hopelessness, passivity, regression, voicelessness, dehumanisation, isolation, and embarrassment; these themes were derived from careful re-interpretation of articles’ textual descriptions and the use of words and language used throughout the original articles, as previously described by the process stages of NS. All other elements of this review’s synthesis were also addressed within the original articles’ themes and subthemes (see Table 5 and Appendix C). Feasibly, these newly emergent themes did not materialise as themes within some of the included articles due to niche, or unrelated, conceptual focuses, e.g., some papers explored inner strength and willpower, story construction, and post-intensive care syndrome (Alexandersen et al., 2019; Alpers et al., 2012; Kang & Jeon, 2018; Stayt et al., 2015). For others, these topics were not dominant themes within single papers but connected to dominant/ recurring themes across other articles.

This NS revealed that participants' desire to feel seen and heard as an individual was most dominant, often stemming from experiences of powerlessness and dehumanisation. Comparable to Cutler et al.'s (2013) review, care experiences varied hugely between studies and most reported experiences of care were either extremely positive or extremely negative, reflected in the diverse findings of included studies. In another previous review (Tsay et al., 2013), only positive psychological experiences of healthcare staff support were reported. The current review illustrates that patients need to feel included in decision making around their care, they need to feel listened to, and wish to have care practices explained to them in order to avoid feeling neglected and hopeless. Feeling seen as an individual person and human being (not simply a patient) additionally helps patients to feel supported, which aids adjustment to dependency. When these needs are met, patients feel less dehumanised and are more inclined to feel connected and grateful towards healthcare staff. Patients' need for acknowledgement and connectedness was further linked to sustained dignity within one previous review of patients' ICU experiences in Nordic countries (Egerod et al., 2015); notably, Egerod et al's (2015) review shared two papers with the current review (Alpers et al., 2012; Lykkegaard & Delmar, 2013) although this finding related to four other papers not included here. The latter review also linked the critical care experience to participants losing their sense of being a person.

Topics within the following three subthemes were also frequently discussed and were the second most noted subjects: "Anger & Frustration", "Conviction to Recover, Willpower, Hope, & Positive Beliefs", and "Gratitude, Learnt Trust, & Comfort in Familiarity". Cutler et al.'s (2013) review connected anger and frustration to the influence technology had upon patients; however, the current review revealed that patients can experience anger in connection to a range of factors, e.g., dependency, staff actions, loss of ability and functioning (including communication difficulties), and self-directed anger associated with helplessness. In Tsay et al.’s (2013) review, anger was further linked to experiences of being ventilated, ineffective communication, and loss of control.

Interestingly, conviction to recover, willpower, hope, and positive beliefs were not represented within Cutler et al.’s (2013) review. Egerod et al. (2015) and Topçu et al. (2017) did not report upon these topics either. Trusting relationships with healthcare staff and significant others, and thoughts of becoming well in the future were linked to experiences of hope in Tsay et al.’s (2013) review. The current review revealed that such positive psychological experiences fuelled desire for recovery, enhanced motivation, cultivated inner strength, fostered both gratitude and happiness, and were connected to spirituality.

Cutler et al. (2013) reported patients’ sense of safety connected to the presence of familiar, trusted family members. Tsay et al. (2013) discussed gratitude only in the context of gratefulness for ventilator treatment to sustain life, they spoke of trust in connection to patients experiencing increased energy and ‘therapeutic effect’, whilst comfort in familiarity was not discussed. Topçu et al. (2017) only commented that trust is experienced by patients when caring attitudes of staff are more evident. Egerod et al. (2015) reflected on patients’ ambiguous state between trust vs. fear, gratitude was not evident as a topic within their review, but comfort in familiarity was present; tactile familiarity brought comfort to patients, and familiar faces or voices of family members were described as a lifeline to reality and the future (eight studies evidenced the latter point, one of which was also included within this review - Alpers et al., 2012). The latter review further highlighted instilled strength within patients through competent and compassionate nurses.

Similarly to Cutler et al.’s (2013) findings, ‘unreal’ experiences and dreams were also highly evident within this synthesis, highlighting how patients’ grasp of reality and sense of what is happening to them transforms during a critical care stay. The previous review suggested that such experiences may be distressing, but not demonstrably through participant data. The current review included participant quotes, offering patients' descriptions of such experiences: chaotic, horrifying, confusing, difficult, and extraordinary. Other related reviews have also reported participants' frequent experiences of hallucinations and unreal experiences, but again in limited detail. For example, Egerod et al. (2015) summarised hallucinatory experiences and nightmares as simply "terrifying", Topçu et al. (2017) briefly described psychological discomfort in connection to patients' experiences of hallucinations, and Tsay et al. (2013) only stated that hallucinations occur. However, it is well documented within the wider literature that critical care evokes 'unreal' experiences, unusual dreams, and hallucinations which can lead patients to experience paranoia, fear, confusion, an increased sense of isolation, anxiety, spiritual connectedness, and 'pleasant' feelings (Darbyshire et al., 2016; Granberg et al., 1999; Lennart et al., 2006; Whitehorn et al., 2015).

Proximity to death, also explored within Cutler et al.'s (2013) review, emerged strongly in the current review and was connected to perceived and actual closeness to death, experienced as psychologically distressing and traumatic. Critical care may cause a threat to the self because it strongly confronts people with the reality of their own mortality. Across studies, proximity to death appeared linked with a loss of perceived invincibility and reappraisals of the future, with a risk of experiencing hopelessness. Following trauma, existing literature describes a common sense of 'the world as a safe place' becoming a shattered illusion (Lilly et al., 2011). Different trajectories appear possible with respect to these experiences. For some patients, proximity to death may generate deeper existential questions and despair regarding reasons for survival. In others, it seems to strongly ignite the desire to go on living. Arguably, existential crises and realisations were intense experiences which led patients to reappraise their future and reconsider their life values and meaning.

Notably, this can be connected to post-traumatic growth (Barskova & Oesterreich, 2009). Fear of death and existential threat arose within each of the aforementioned previous reviews too, indicating this is a significant challenge for patients (Egerod et al., 2015; Topçu et al., 2017; Tsay et al., 2013).

Transformation in perception of the body was a dominant topic across the current and previous reviews, highlighting experiences of reorientation of self-identity. The current review demonstrates that patients' perceptions of a changed body is part of this and is experienced as difficult to comprehend, requiring significant psychological adjustment. Moreover, the body is felt to be "disobedient", suggesting a perceived disconnect between mind and body. When the physical body no longer represents patients' view of 'the self', self-identity may be wholly questioned. Tsay et al. (2013) also reported patient experiences of disconnection from the "strange" and "unfamiliar" body, causing emotional distress and disconnectedness from reality. An altered bodily state was also shown to engender disconnectedness within Egerod et al.'s (2015) study, as well as causing perceived regression.

Limitations

Participant quotes were extracted from each included article. However, certain papers were more heavily referenced than others due to limited quotations within some articles (Deacon, 2012; Lykkegaard & Delmar, 2015). Deacon's (2012) article only offered nine participant quotes, many of which were unrelated to the psychological influence of critical care; the objective of Deacon's (2012) paper was to explore former ICU patients' views on what the key components of a post-ICU rehabilitation programme should be. Although most of this review's themes and subthemes were supported within multiple articles (see Table 5), some subthemes were less salient. For example, the subtheme "Guilt & Self-Blame" was only represented by three papers; notably, quotes within this theme were derived from the same paper as the chosen data illustrated the essence of the theme most clearly. Nonetheless, it is difficult to conclude that guilt and self-blame are likely to be consistent experiences for critical care patients on the basis of three papers.

Whilst heterogenous samples, varied critical care contexts, and disparate geographical settings within the included studies could lend support for generalisability of this NS' findings, such variation highlighted a broad range of different psychological experiences. It is consequently difficult to comment on which psychological experiences are most dominant across 'typical' critical care settings; although, the need to feel seen and heard appeared dominant. However, geographical variations could still heavily influence and shape patients' psychological experiences. For example, critical care within the UK primarily exists within the context of the NHS which consists of distinct NHS hospitals with differing critical care capacities, focusing on dissimilar levels of critical care need and, sometimes, specific patient groups (Anandaciva, 2020). Additionally, the NHS contends with stretched funding (McDonnell et al., 2017; Montgomery et al., 2017) potentially adversely impacting staffing resources and staff-to-patient ratios (Lawless et al., 2019). Conversely, a recent survey contrasting European and Nordic intensive care units (ICUs) suggested that Nordic countries often have smaller ICUs with higher patient-nurse ratios (Egerod et al., 2013); nine of the papers in the current review were conducted in Nordic countries.

It was not possible to specifically discern how participants' perceived psychological experiences of critical care could change over time due to variation and lack of clarity across studies as to when in the illness-recovery process data was collected. Some studies conducted interviews across a very diverse timeframe, e.g., Kang & Jeong's (2018) timeframe spanned from 1 month to 12 years.

How participants psychologically experience critical care may be influenced by events preceding their critical care admission, e.g., how critical care interrupted participants' life stages and stages of psychosocial development (Erikson, 1950; Erikson, 1994; Erikson &

Erikson, 1997), and by the nature of the hospital admission itself, e.g., reasons for the admission and whether it was planned or unexpected. Similarly, patients' physical, mental, and cognitive health status prior to ICU admission may contribute to psychological perceptions of their critical care stay (Geense et al., 2020). The influence of such factors upon this review are unknown. Potentially, experiences may be perceived more negatively when the disruption to participants' life trajectories is deemed to be greater.

Despite the included articles utilising qualitative designs, which entails reflexivity on the part of researcher, none of the selected articles offered a reflective/ reflexivity statement. This limits a comprehensive view of the original researchers' perspectives during data analysis; multiple researcher biases could therefore have influenced research findings, e.g., confirmation bias, prejudicial bias, or anchoring bias. Although, recurring reflection was applied to researchers' descriptions of how they reduced the impact of power, biases, pre-assumptions, and pre-understanding upon their interviewing methods, data analyses, and interpretations – despite the nature of the researchers' biases and pre-assumptions not being outlined. However, this review offers transparency through explicitly discussing articles which excluded any form of reflection in their write-up.

A fundamental issue exists through the reviewer interpreting the work of other researchers who have already interpreted, through their own lens, participants' experiences; participants' experiences are themselves subjective interpretations. However, rigour is achieved within qualitative reviews by strengthening and assessing the trustworthiness of the synthesis (Popay et al., 2006). Whilst the quantity of articles within the synthesis was sufficient to draw meaningful conclusions from and the reviewer had adequate information to ensure that the articles met the inclusion criteria, methodological quality issues were observed. For example, some studies failed to report their own limitations or did so meagrely, two studies did not obtain approval from an ethics committee, dissimilarities were evident in a few studies' interview durations, many studies only partially justified their sampling strategy and participant selection, most studies omitted explanations of the specific information presented to participants for recruitment, and the implications of some articles were sparsely summarised. In particular, varying interview durations may have prevented the full breadth of certain participants' experiences from being explored.

A further group of potential participants' experiences may have been inadvertently overlooked within this review, due to the researcher being limited to English language papers; this paper may consequently be predominantly representative of critical care experiences in the context of Western culture. However, little was known about participants' cultural backgrounds.

Implications for Future Research and Practice

Understanding and acknowledging the need patients have to feel seen and heard as an individual, a salient finding of this review, holds numerous implications for clinical practice. Emphasis must be placed upon individualised, person-centred care. Practices which enhance humanising care should be actively employed within critical care settings, reflected within previous research (Nin Vaeza et al., 2020; Wilson et al., 2019). Healthcare staff must be cognisant of methods which reduce power imbalances within the patient-carer relationship. Simple methods of reducing this power imbalance may involve explicitly giving patients a voice, e.g., encouraging feedback and requests during care interactions, while creating a safe atmosphere to do so, and ensuring continuous patient understanding (Berry et al., 2017; Ringdal, 2017). Alternatively, when patients cannot physically voice their wishes and feelings, family input and patient advocates must be accentuated and utilised. Failure to reduce these power imbalances has observably negative effects (Henderson, 2003). Explicit empathy, and holding in mind the person within the patient, may additionally help patients to feel humanised; increasing staffs' skills in enacting empathy and compassion results in heightened perceptions of needs being met for both patients and their families (Moghaddasian et al., 2013; Roze des Ordons et al., 2019).

Barriers to employing empathy, compassion, and humanising practices must also be addressed. Avoiding humanisation of patients, and evading deeper personal interactions with them, may reflect defensive and protective mechanisms to avoid trauma and distress in the context of high patient mortality rates within critical care (Mealer et al., 2007; Moss et al., 2016). Emotional disconnectedness in healthcare staff working in critical care has been likened to a form of emotional armour (Sholtz et al., 2016). Research also demonstrates that humanising patients' suffering positively predicts symptoms of burnout in healthcare staff (Vaes & Muratore, 2012). Notwithstanding this, the current review highlights patients' sensitivity towards perceptions of dehumanised care and being treated only as a 'body lying there'. Reports of patients feeling dehumanised by being treated like 'objects' exist within other recent research endeavours too (Basile et al., 2021; Kompanje et al., 2015). Prioritising staff support is therefore equally crucial; inadequate peer support and staff debriefings act as blocks to nurses' empathy and compassion in intensive care, according to some nurses themselves (Jones et al., 2016). A compassionate workplace culture must be created which formally recognises and supports the psychological and peer support needs of critical care staff (Dixon-Woods et al., 2014; Farr & Baker, 2017; Jones et al., 2016). The context of the current COVID-19 pandemic particularly elucidates the imperativeness of providing psychological support for staff (Bates et al., 2020; Greenberg et al., 2021).

Review findings suggest that further qualitative research exploring how healthcare staff experience and perceive the psychological influence of critical care upon patients, broadly, is warranted. Understanding reasons why patients may not feel seen and heard as individuals from a staff perspective, in the context of their broader views on psychological influences of critical care, could be imperative for improving clinical practice and better understanding the patient experience, staff experience, and patient-carer dynamics. Equally, understanding how clinical practice currently addresses such patient experiences is important as these experiences still appear common for critical care patients. Further future research focusing on psychological experiences of the illness-recovery process, in itself, post-critical care is also justified. Future research should define a clearer relationship between the point of participants' experience recall and their temporal experiences of the illness-recovery process.

Conclusion

Despite the heterogeneous nature of the synthesised articles in their focus, geographical locations, methodologies, critical care contexts, sample sizes, and frame of reference, this review indicates commonalities in psychological experiences of critical care across an international body of qualitative literature. These experiences are diverse and complex. However, some contrasting findings also emerged from the pool of reviewed papers; responses were compared and contrasted across articles making similarities and differences explicit. One overarching finding is that critical care patients have complex psychological needs, particularly in relation to being seen and heard as individuals and not merely patients, which may not be immediately apparent or recognised by staff treating them. Such experiences may resonate with general patients, more broadly, too. However, it is perhaps more pertinent within critical care environments where the primary focus is on keeping people alive; the relative helplessness of critical care patients, and the potential need for staff to keep emotional distance from critically ill patients, is plausibly heightened. Future research should further investigate staff perspectives and experiences of how critical care psychologically influences patients. Further investigation into how psychological experiences of critical care are understood at explicitly differing points across the illness-recovery trajectory is also recommended.

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Part Two: Empirical Paper

This paper is written in the format ready for submission to the

International Journal of Qualitative Studies on Health and Well-Being

Please see Appendix C for submission guidelines.

How Do Outreach Nurses Experience and Perceive the Psychological Influence of Critical Care Upon ICU Patients?

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Abstract

Purpose: This research aimed to provide insight into outreach nurses' perceptions and experiences of the psychological influence of critical care upon intensive care unit (ICU) patients; outreach nurses' views and experiences of this topic were lacking within extant literature. Comprehension of outreach nurses' experiences can inform clinical practice and improve staff and patient support, promoting wellbeing. Additionally, exploration of wider relevant factors occurred within the research interviews, e.g., perceptions of patients' experiences and outreach nurses' experiences of the system in place supporting psychological distress arising from ICU experience.

Methods: Through purposive sampling, six outreach nurses working across two hospital sites within a northern NHS acute hospital in England were recruited. Qualitative data was gathered via semi-structured interviews and analysed using Interpretative Phenomenological Analysis (IPA) (Smith et al., 2009, 2012).

Results: Emergent superordinate themes included "It Alters Thinking & Perception: Confusing & Surreal", "Patients Experience Powerlessness & Dependency", "It Can Be Traumatic", "ICU Engenders Reorientation: Disrupting Life Narratives", and "ICU is Psychologically Impactful: An Individual Journey".

Conclusion: This research highlights that outreach nurses may perceive the psychological influence of critical care upon patients to be primarily negative, multifaceted, and complex. Implications for shaping critical care services, relating to psychological support for both staff and patients, and for improving staff training emerged.

Keywords: Interpretative Phenomenological Analysis, Critical Care, ICU, Nurses' Experiences, Psychological Experiences

Introduction

In addition to physical ramifications, patients experience multitudinous psychological consequences of acute illness and critical care admission (Colbenson et al., 2019; Jones et al., 2020; Rose et al., 2019; Scragg et al., 2001; Vincent, 2019). The National Institute for Health and Care Excellence (NICE) (2009, p. 58) proposes that "the care of a critically ill patient is not complete without some consideration of the psychological consequence(s) of the illness". Published research predominantly acknowledges the negative psychological repercussions of an intensive care unit (ICU) stay, e.g., depression, anxiety, delirium, intrusive memories, hallucinations, flashbacks or Post-Traumatic Stress Disorder (PTSD), cognitive dysfunction, reduced quality of life, and nightmares (Brück et al., 2018; Capuzzo & Bianconi, 2015; Clancy et al., 2015; Guttormson, 2014; Magarey & McCutcheon, 2005; Pattison, 2005; Righy et al., 2019; Svenningsen et al., 2015; Wade et al., 2012; Wade et al., 2013; Wade et al., 2015). Further consideration of patients' critical care journey is therefore essential to appreciate precipitants of these psychological repercussions, and to understand patients' wider psychological experiences in greater depth. Insight could foster better psychological support for patients, advance person-centred care, and improve patient-staff interactions; such potential improvements are pertinent due to reports of dehumanising ICU care, which neglects and denies individuality and humanness (Nin Vaeza et al., 2020; Vaes & Muratone, 2013; Wilson et al., 2019).

Optimal psychological support can only be offered by comprehending how staff involved in patients' care perceive and make sense of ICU patients' psychological needs and experiences connected to critical care (Chen et al., 2017). Appreciation of the interplay between staff and patient perspectives may also have wider implications, e.g., enhanced understanding of similarities and divergence between staff and patient perspectives, and improved staff training. Enhancing healthcare staffs' skills may nurture better patient perceptions of care; patients' mood within intensive care (IC) can be influenced by how care is interpreted, broader patient-staff interactions, and by how staff respond to and explain acute stress reactions, intrusive memories, and delusions (Bizek & Fontaine, 2013).

A holistic, deeper understanding must therefore be gained by investigating the psychological influence of ICU from every angle, e.g., exploring the breadth and richness of patients' and healthcare staffs' lived experiences and perspectives. Literature has increasingly explored the patient perspective (Alexandersen et al., 2019; Alpers et al., 2012; Ewens et al., 2018; Hofhuis et al., 2008; Kang & Jeong, 2018; Kisorio & Langley, 2019; Lindberg et al., 2015; Lykkegaard & Delmar, 2013, 2015; Moen & Nåden, 2015; Olsen et al., 2017; Palesjö et al., 2015; Russell, 2001; Samuelson, 2011; Stayt et al., 2015). Equally, exploration of a portion of healthcare staffs' experiences and perspectives exists (Karnatovskaia et al., 2017; Price, 2004; Turnock, 1989; Weare et al., 2019; Zamoscik et al., 2017). However, outreach nurse viewpoints remain unexplored despite their involvement with ICU patients across patients' acute illness-recovery trajectory. i.e., initial ward-based care, ICU, and step-down care (NICE, 2018).

Across this trajectory, outreach nurses witness the possible impact of IC, e.g., decreased communicative capacity, confusion, impaired recall, pain, diminished privacy and control, and adjustment towards dependency (Enger & Andershed, 2017; Pang & Suen, 2008; Puntillo et al., 2018; Ramsay et al., 2014), but research reporting how they experience and interpret the psychological influence of such experiences upon patients is absent. Similarly, outreach nurses' views of which patient experiences engender psychological difficulties or promote psychological growth remain unknown. Further questions concerning how outreach nurses shape their clinical practice around their perceptions also exist. Outreach nurses' voices should be amplified, as a thorough understanding of this subject matter may also improve staff support.

As NICE Clinical Guideline 94 (2018) highlights, outreach nurses possess a unique role within critical care; they help to identify and treat deteriorating patients within ward-based care to prevent ICU admission or ensure that ward-to-ICU transitions are smoother and timelier. Outreach nurses are involved in patients' ICU and hospital discharge, aiding patients' recovery by sharing critical care skills with general ward staff.

Prior to hospital discharge, outreach nurses complete follow-ups to assess patients' progress — primarily physically, but also emotionally (Chellel et al., 2006; Department of Health (DOH), 2000). However, the scope of their emotional support training is unknown; it is equally vague, within relevant resources and guidance, as to what this support typically entails (LHCH, 2021; NICE, 2007; SEWCCN, 2009). Outreach nurses' remit further extends to active participation within the resuscitation team, assisting with cardiac/ respiratory arrests and medical emergencies; outreach nurses therefore carry personal beepers and can be redirected from other duties when responding to emergencies (Hyde-Wyatt & Garside, 2019; NICE, 2018). This is noteworthy as outreach nurses may need to leave patients mid-follow-up, not excluding times when emotional and psychological matters are being discussed.

The development of the outreach nurse role highlights the need for continuity of care across patients' acute illness-recovery trajectory; how patients are managed and treated pre-post ICU admission significantly influences patient outcomes, physically and psychologically (Vincent, 2019). Additionally, evidence suggests that general ward staff sometimes lack insight into patients' unique care requirements arising from ICU experience (Bodley et al., 2019; De Grood et al., 2018; Häggström et al., 2009). Hence, nurses must work within a critical care setting, e.g., an ICU, for at least three years before being appointed as an outreach nurse (National Outreach Forum, 2020; Nursing Times, 2007). Consequently, outreach nurses are well positioned and appropriately experienced to comment on patient experiences of the entire critical care journey. Outreach nurses might offer a more holistic account of how critical care potentially psychologically influences ICU patients comparative to other staff groups — particularly as their evolved role includes attending to patients' emotional state (NICE, 2007).

How, and to what extent, outreach nurses understand and make sense of ICU patients' psychological experiences may differ depending upon numerous factors, e.g., their level of psychology-informed/ mental health training, perceived ability to manage and work with patients' psychological distress, supervisors' level of openness to address interpersonal difficulties relevant to such matters, personal experiences of ICUs, personal attachment styles, and degree of willingness to consider patients' psychological distress (Cross et al., 2012; Khodabakhsh, 2012). Additionally, outreach nurses may contemplate psychological experiences of critical care in the context of how they perceive ICU patients are treated by wider healthcare professionals, e.g., ICU staff.

Extant literature, across healthcare and ICU settings, demonstrates the existence of patient dehumanisation (Basile et al., 2021; Nin Vaeza et al., 2020; Vaes & Muratone, 2013; Wilson et al., 2019). Care which inadvertently dehumanises patients could serve a clear purpose: to act as a protective defense mechanism, allowing staff to avoid acknowledgement of patients' psychological distress and high mortality rates, preventing burnout and vicarious trauma (Haslam, 2006; Pompili et al., 2006; Vaes & Muratore, 2013). Based upon this phenomenon, Speering and Speering (2021) explicated a model of dehumanisation relating to dementia care where staff sometimes exercise positive and negative dehumanisation. Positive dehumanisation refers to 'added' factors to a person's perceived identity, associated with either children, the deceased, or non-human entities, e.g., objects and animals. Examples include emotional inertness, lack of intelligence, or child-like cognitive capacities. Conversely, negative dehumanisation refers to the 'removal' of humanising factors from a person's perceived identity. Examples include values (autonomy, privacy, dignity), attributes (intelligence, sophistication, self-awareness), and emotions (love, despair, fear). Individuals can be the subject of positive and negative dehumanisation simultaneously. This model might apply to critical care contexts. However, other perspectives require deliberation; research highlights the profound commitment, curiosity, care, and deep reflection some staff members show towards ICU patients (Olausson et al., 2014). Present research also demonstrates nurses' consideration and support of person-centred values and beliefs, e.g., patients' spiritual needs, contradicting dehumanising practices (Abu-El-Noor, 2016).

Current understandings of psychological experiences of IC, from ICU nurses' perspectives, outline patients' dehumanisation through loss of identity, lack of normality inducing demotivation, common experiences of depression and withdrawal, and suggest that the 'real' psychological needs of patients may be deliberately avoided through sedation use (Price, 2004). Within one ICU nurse group, only 10.3% (n = 4/39) perceived that their ICU training afforded them the adequate skills to handle patients' mental health difficulties; all respondents emphasised a requisite to be better prepared to assist patients psychologically (Weare et al., 2019). Additionally, Zamoscik et al. (2017) found that nurses recognise the regularity of ICU delirium but sometimes consider it to be a low priority issue (Zamoscik et al., 2017); this study also underlined certain ICU nurses' perception that the provision of psychological care often results in feelings of guilt and being 'judged' about not helping busier colleagues.

Several pertinent findings arose from a further survey of 43 physicians and 55 nurses (Karnatovskaia et al., 2017): 65% of respondents consistently acknowledged each patient's psychological state in decision-making, 56% desired more communication time with patients, and 77% consistently spent additional time at patients' bedsides providing reassurance. Salient factors perceived to contribute towards psychological distress within ICUs were also delineated: patients' 'underlying' psychological profiles, helplessness, diminished autonomy, isolation and disconnection, fear of the unknown, nightmares, financial concerns, and being sedated enough to cause confusion "but not enough to ease darkness" (Karnatovskaia et al., 2017, p. 108). However, survey responses limit deeper exploration of such perceptions. The current study may provide deeper insight into why staff hold specific beliefs, elucidating the complexity of outreach nurses' individual experiences.

Research Aims

The current study, to address gaps in the existing literature, aimed to understand outreach nurses' experiences and perceptions of ICU patients' psychological experiences. Through gaining these understandings, this study aimed to consider support for staff and ICU patients with clear proposals for clinical practice and future research. Therefore, the following research question was developed: how do outreach nurses experience and perceive the psychological influence of critical care upon ICU patients?

Method

Design

Semi-structured interviews were utilised to obtain qualitative data relating to the subjective lived experiences of outreach nurses, sampled at one particular point in time. Analysis was undertaken using Interpretative Phenomenological Analysis (IPA) (Smith et al., 2009).

Participants

Purposive sampling enabled identification of an appropriate, homogeneous sample. The inclusion criteria were as follows: NHS outreach nurses in continuous employment across the two hospital sites of interest, 2+ years of outreach nurse experience, and 3+ years of previous experience working within critical care, e.g., an ICU. Continuous employment and 2+ years of outreach nurse experience were thought to guarantee a wide enough range of experiences for participants to draw from. Previous experience within critical care, 3+ years, is simply required to be an outreach nurse.

Altogether, six participants were recruited. Whilst there is no ‘correct’ sample size for IPA studies (Smith et al., 2009), it is suitable to recruit between 4-10 participants for professional doctorates (Clarke, 2010; Noon, 2018). All participants were aged between 41-50 years of age; three participants were between the ages of 41-45, and three participants were aged between 46-50. The timeframe participants had held their current job role for ranged from 34 months-15 years, with a mean of 9.5 years. Some demographic details have been deliberately omitted to protect participants’ anonymity. Key participant details can be viewed below (Table 1):

Table 1

Participant Pseudonyms and Self-Identified Genders

Name (Pseudonym)	Self-Identified Gender
Bekki	Female
John	Male
Christine	Female
Lindsey	Female
Janet	Female
Gill	Female

Ethics

Ethical approval was granted by the Faculty of Health Sciences Research Ethics Committee at the University of Hull (REF: FHS245; Appendix J). The study’s information sheet (Appendix K), permission to be contacted slip (Appendix L), consent form (Appendix M), demographic information sheet (Appendix N), debrief sheet (Appendix O), interview schedule (Appendix P), and poster (Appendix Q) were reviewed and approved during this process.

Confidentiality was upheld by anonymising data and using pseudonyms in place of participants' true names. Some participants selected pseudonyms themselves, as research demonstrates the value participants may attribute to pseudonym selection (Allen & Wiles, 2016). Identifiable information was additionally anonymised within quotations, further protecting participants. Audio recordings were deleted after data transcription was finalised. Participants gave informed consent by reading and signing online consent forms, after being informed of their right to withdraw. No incentives were offered for participation. Precautions were exercised regarding post-interview support; participants received contact details for their team lead, a confidential emotional support telephone helpline, details of a local counselling service, contact information for pastoral and spiritual support, and details of two relevant occupational health departments. Additionally, the contact details of the lead researcher were given to answer follow-up questions relating to the study.

Procedure and Data Collection

After establishing a connection with a lead outreach nurse within a northern NHS acute hospital in England, via a field supervisor, contact with the participant group was secured; interest from potential participants was sought by distributing recruitment material (see Appendix I), including a study information sheet (see Appendix K). After receipt of signed permission to be contacted slips, by email, participants were approached to arrange virtual one-to-one interviews; face-to-face interviews were not possible due to the COVID-19 pandemic.

Six semi-structured interviews, lasting between 60-70 minutes, were conducted by the principal investigator (HH). With participants' consent, an NHS laptop audio recorded participant interviews; interviews were later transcribed verbatim. Participant data was stored securely, and relevant data protection principles were adhered to. The interview schedule, guided by principles of IPA, served as an aid and contained broad open-ended questions to allow participants to consider their experiences without being guided by the researcher; participants ultimately directed discussions. Each interview began with the same opening question: "based on your experiences, how do you think ICU patients emotionally and psychologically experience critical care?". The question was precisely worded to allow for both positive and negative experiences to be discussed.

Methodological Analysis

Analysis was undertaken using Interpretative Phenomenological Analysis (IPA), following appropriate guidance (Pietkiewicz & Smith, 2012; Smith et al., 2009), owing to IPA's ability to gather the richness of participants' lived experiences. Equally, IPA suited the novel nature of the research and the inherent homogeneity of the participant sample. IPA's appropriateness to, and history with, health-related psychology research also influenced the researcher's methodological selection. IPA, within this study, was underpinned by a multi-layered hermeneutic process; patient understandings of the subject have likely been communicated to participants, participants interpret patient accounts and draw conclusions from their own lived experience, participants then interpret the researcher's questions and offer their understandings. Finally, the researcher attempts to make their own interpretations, trying to understand each participant's life world and 'persons-in-context' (Braun & Clarke, 2013). It was therefore important for the lead researcher to consider the influence of their own pre-conceptions and biases upon data interpretation. Consequently, the researcher remained reflexive and reflective throughout the research process. This involved keeping a reflective journal and liaising with research supervisors about such matters within supervision. During data analysis, the reflective journal helped the researcher to revise personal biases and preconceptions until an ability to develop new projections of meaning was formed (Peoples, 2021).

In line with Smith et al.'s (2012) advised steps the lead researcher commenced an idiographic analysis, initiated by several readings of the transcripts. Salient quotations, from the researcher's perspective, were highlighted within each transcript. Note annotations were then made within individual transcripts (see Appendix R for an example). These annotations were completed in stages, comprised of three levels: a content descriptive level, a linguistic level appertaining to each individual participant's language use, and a conceptual level concerned with further probing to reach deeper meanings. Through abstraction, emergent themes were drawn from the data to develop superordinate themes. Subordinate themes were then constructed, and superordinate themes refined, accounting for convergent themes present across the data set.

Participants did not validate the themes, as this study integrated unique idiosyncratic participant accounts; generalisability was not aimed for. However, convergences and divergences were highlighted within the data set. Additionally, research supervisors were liaised with to review and validate themes. Furthermore, participants were offered the opportunity to feedback on the data following dissemination of the findings.

Lead Researcher's Position

The primary researcher is a White British female from North East England, a Trainee Clinical Psychologist, has been interested in this topic for many years, and has personal lived experience of ICU admission and critical illness. Accordingly, several preconceptions required contemplation: critical care experiences are idiosyncratic and transformational (ICUs therefore psychologically influence individuals varyingly), ICUs more commonly psychologically influence patients negatively than positively, and staff may not always have the resources or willingness to consider psychological aspects of patient care depending upon multifarious factors. Regular supervision and reflective journaling aided reflection upon these positions, the researcher's lived experience, and potential interaction between these positions and the research; thus, reducing bias. These processes also assisted the researcher in acknowledging the influence of her ethnic and cultural background upon her pre-understandings and assumptions regarding individuals' responses to illness, and the context of ICU within the NHS and within a Northern city. Similarly, the researcher reflected upon her gender in relation to the gender of participants, considering the impact of difference and similarity upon the participant-researcher dynamic. Research supervision additionally enabled access to a deeper level of critique unhindered by the researcher's preconceptions; the researcher endeavoured to stay close to participants' true accounts, taking steps to acknowledge and differentiate participants' experiences from her own. Equally, the researcher's stance is that the two cannot be entirely separated; preconceptions were consequently worked with, and utilised, in an effort to evolve understanding rather than merely bracketing them off. For further context, peruse the researcher's extended reflective statement (Appendix A) and epistemological/ ontological statement (Appendix B).

Results

Participants were asked to talk widely about their experiences, attitudes, perceptions, and beliefs. Participants' accounts were clustered around five superordinate themes, each with subordinate themes ($n = 14$) (see Table 2). Themes were phrased to directly answer the research question: how do outreach nurses experience and perceive the psychological influence of critical care upon ICU patients? Additional supporting quotations, and their interpretations, can be found for most subordinate themes within Appendix S.

Table 2

Superordinate Themes and Subordinate Themes

Superordinate Themes	Subordinate Themes
1. It Alters Thinking & Perception: Confusing & Surreal	1.1 Nightmares & ‘Unusual’ Experiences 1.2 Intrusive Thoughts: Difficult to Handle
2. Patients Experience Powerlessness & Dependency	2.1 Dependent on Access to Emotional Support: It Varies 2.2 Helplessness: Loss of Self-Worth and Autonomy 2.3 Difficulty With Being Misunderstood
3. It Can Be Traumatic	3.1 Proximity to Death 3.2 The Harsh Reality of Intensive Care: “Torturous”, Isolating, & Dehumanising 3.3 Flashbacks, Witnessing Trauma, & Re-Living Trauma
4. ICU Engenders Reorientation: Disrupting Life Narratives	4.1 The Need for Answers 4.2 Life Changing: Re-Evaluating the Future 4.3 Re-Establishing Connection & Seeking Reassurance
5. ICU is Psychologically Impactful: An Individual Journey	5.1 A Personal Adjustment Journey 5.2 It Depends: Individual Differences 5.3 A Diverse Rollercoaster of Emotions

All themes were substantiated with verbatim quotations from participant interviews. Within participant quotes, ellipses represent short pauses or removed text to illustrate participants’ points succinctly and accurately, bold text represents emphasised words, asterisks replace expletives, and upward arrows mark rising intonations within speech.

1. It Alters Thinking & Perception: Confusing & Surreal

This superordinate theme, comprising two subordinate themes, details participants' recognition of patients' confusing and surreal ICU experiences. Gill tentatively summarised, using the words "kind of" and "maybe", her perception of the nature and development of such experiences. This tentative description may be linked to speculation over another group of individuals' internal experiences which may have felt difficult to grasp:

> *"Patients don't know whether it's day or night, they don't know… where they are half the time… they're sleep deprived, they're over noise stimulated… we sedate them… they're in a world somewhere between sedation and being awake sometimes and… that part of a dream process that's… where your kind of nightmares and hallucinations and things maybe start" (Gill).*

1.1 Nightmares and 'Unusual' Experiences

Each participant heavily emphasised the psychological influence of nightmares and 'unusual' experiences within IC.

John outlined the nature of patients' 'unusual' experiences and described patients getting "worked-up" and upset. He relayed his perception of common gender and age differences in patients' ability to confide in others, initially, necessitating further probing. John implied that validation of patients' 'unusual' experiences is a useful and important technique:

> *"People… say that they thought that they were being abducted by aliens, or tested on, or in a concentration camp… being injected, and probed, and prodded… … you'll go to some people… "how are you feeling? Do you remember being on ICU? And they'll… and I*

suppose it is typically older males… they will… go, "yeah, no. I'm alright"… and then… you might ask how they're sleeping, and they'll start going, "oh, I have terrible nightmares"… "I've started seeing things on the walls and started grabbing at things"… you can see them getting really upset and worked-up about it… thinking, "I know this isn't normal, but I can't stop it"… but sometimes just saying to them, y'know, "you have just come out of intensive care, you've been through a lot"…" (John).

Within Janet's lived experience, some patients use humour to deflect from the distress, fear, and worry of surreal, or "bizarre", nightmares continuing. She reflected on her discomfort in dealing with patients' distress, past the point of normalisation, using the idiom a 'can of worms' to describe her perception of a challenging situation; this idiom is often used to represent complicated and difficult conversations or tasks which an individual believes are better left alone. Janet mirrors the fear that she perceives the patient to experience within her account below:

"He said, "the nightmares, you wouldn't believe the nightmares I'm having"… he went, "ohhh, I was on the Titanic and the wife drowned", and he went, "do you know what's funny about that?", I went, ↑ "nothing?", he went, "well I aren't even married!"… he was having the bizarrest of dreams, and then he ended up crying... erm… because he was actually really frightened by the nightmares but was making a joke of it… he was one of those examples of a can of worms 'cause then I was a bit like…. once I'd reassured him that you do get nightmares and stuff… and that they would get better, he was like… "what if they don't?", and then that, that's where I was like… uhhh, I don't know!" (says in a frightened voice) (Janet).

Bekki also reflected on patients' nightmares, expressing concerns about opening up a 'can of worms'. Bekki voiced her worries about making patients feel worse by "re-living" their experiences, pointing to an underlying belief that patient-staff interactions can heavily influence patients' psychological outcome. Her questions apparently represent a difficult dilemma around how to respond in the best interest of patients whilst fulfilling the emotional support aspect of the outreach nurse role, possibly causing ambivalence:

> *"Say there's a sleep problem… it might say from the previous visit… not sleeping very well, still having nightmares, but… do I really want to keep opening up that can of worms? Your nightmares… is it making it worse by reliving what they've already said?" (Bekki).*

Christine seemingly desires to reduce patients' concerns over 'unusual' experiences, to "put it to bed", through normalisation. However, Christine has experienced that normalisation is "enough" to reassure only some patients. Christine further emphasised patients' worry about others' perceptions of their mental status:

> *"Sometimes when we go, we can answer questions and put it to bed for them… y'know, "why… why did I think I was on a ship? Was I going mental?". That's what they think, "am I going mad? Am I going mad that I'm seeing things?"… but if you can try and just… explain the reasons why that would be happening, for a lot of people it is enough. For some people it isn't, and it will continue to stay on their mind" (Christine).*

Lindsey echoed experiences of patients' concern about others' perceptions of their mental status. Lindsey acknowledged the need for explicit conversations with patients about hallucinations and appeared to place value in offering patients the opportunity to talk. This held value, in accompaniment with Lindsey's quoted impressions of patients' perspectives, arguably demonstrates Lindsey's empathy with patients who experience worrying and distressing hallucinations:

> *"You sometimes hear them talk about things like… "oh I was on a spaceship", or "there were aliens", or "people were trying to do this to me", or "I was part of an experiment"... there's sometimes sort of paranoia in terms of people trying to hurt them or do things to them, but if they don't get an opportunity to verbalise it with somebody, if somebody doesn't actually ask them outright, "have you had any hallucinations?"... then they may not tell anyone because they don't want anyone to know that they're… a bit crazy — in their words. They think, "I've had enough go wrong with me, I don't want people thinking that I've, I've lost the plot and I'm crazy", y'know" (Lindsey).*

Gill reflected on her experiences of patients becoming "depressed" and "withdrawn" due to their 'unusual' experiences, as they no longer feel like themselves:

> *"They will say… "I've had these strange dreams and… I've had hallucinations and I don't feel like myself"... you can see some patients who get depressed and withdrawn and don't want to communicate" (Gill).*

1.2 Intrusive Thoughts: Difficult to Handle

One participant highlighted her experience of patients having dark and intrusive thoughts (IT), which can be difficult for patients to discuss. Gill described using normalisation, to "explain it away", and humour tentatively, "a little bit", to make patients feel better. This careful use of humour may represent Gill's perception of ITs as a difficult topic to broach, address, and normalise, plausibly in response to patients' reluctance to discuss ITs. Similarly, Gill's desire to "explain away" ITs may connect to a need to quickly move past such topics of discussion. However, it may represent Gill's wish to fully and swiftly alleviate the distress ITs cause patients:

> *"Some of them are… having like really dark thoughts of murdering people and going home and killing their husbands, or wives, or whatever… having bad thoughts about family… really just, just really intrusive thoughts that… they don't ever want to say anything about. I've had a few that have, erm, spoke about it and we've tried to explain it away in terms of… look when you've been in intensive care, we've given you lots of drugs, erm, and, and humoured it a little bit, y'know, "some people pay to have the drugs that you've had and we've just given you them for free, so to speak", erm… so er, so yeah… sometimes… they do find that… really, really difficult to speak about" (Gill).*

2. Patients Experience Powerlessness & Dependency

Within participants' accounts, a central issue was the powerlessness IC can engender for patients through general loss of autonomy and control, dependency on access to psychological and emotional support, and dependency on staff who may misunderstand ICU patients, all of which reinforce powerlessness.

2.1 Dependent on Access to Emotional Support: It Varies

All participants perceived patients to be dependent in their reliance on staff and services for recognition of their emotional needs, and for access to psychological support following ICU discharge. However, participants reported that access to support within their region varies depending upon ICU patients' admission pathway, "*if you're going to be ill… and you need psychological support, the best pathway to be on is the trauma one" (Gill), "the other service that does have some psychology support is… rehabilitation… so the long-term patients who need some further rehabilitation" (Lindsey).* Similarly, participants reported pitfalls in post-discharge services.

Participants also underscored the expectancy for them to provide emotional support for patients, relating to post-ICU psychological distress, which each participant experienced with difficulty as discomfort arose with uncertainty around how to provide emotional support, even when personally invested in purveying psychological support. Additionally, this responsibility evoked further difficult feelings —*"you can sometimes feel a bit helpless and feel that… you don't have any sort of qualification in psychological support as such, and… you, you kind of feel a bit inadequate at times, y'know, they struggle… it depends what your level of interest is as well so I, I have got quite an interest in trying to offer support, psychological support"* (Lindsey). Participants reflected on the psychological influence of this upon patients.

John and Janet both repeated the same idiom, a 'can of worms', describing fears of addressing patients' psychological and emotional experiences connected to IC. They linked their fears to not having enough time, training, or solutions to handle psychological matters. Janet alluded to the transforming remit of outreach nurses, with heightening expectancy to provide emotional support. The word "burden" arguably suggests that Janet experiences this additional expectancy to be taxing. John reflected on patients' emotional responses; the words "ditch and run" may imply that John fears patients feeling abandoned, adding to their upset. However, Janet also tentatively ("but, but, really") acknowledged the importance of patients being able to open-up, representing a dilemma; Janet discussed "good intentions" highlighting a desire to help, but acknowledged her perception of lacking “solutions”, plausibly causing dissonance:

“You get some who start to well-up, and get teary, and you’re like, “I’m, I’m not the person that you can talk to about this really”.... for many reasons… some of it is just about the time… you don’t want to open a can of worms knowing that your bleeps might go off and you might have to just ditch and run!... None of us feel confident in really… supporting them too much because we don’t want to open that can of worms… then think, “ohh, I can’t get out of this! I’ve got this patient that’s in floods of tears now, on the edge”…” (John).

“It’s almost added a burden to the job because now there’s a therapy, or a support, that these patients need that we never gave them before, and I don’t feel that we are properly trained. I think that… we go in with a good intention and sometimes we can open a whole can of worms... that we haven't got the solution to, but, but, really that can of worms did need opening” (Janet).

Christine stressed that the duality of the outreach nurse role is difficult to manage, comparing it with “trying to juggle”. Her use of the word “constantly” hints towards the perceived relentlessness of managing this duality. Christine arguably believes that this can also be disadvantageous to patients when they begin expressing strongly felt emotions — “pouring their heart out”:

“You’re constantly getting bleeped and trying to juggle with two roles at once, and I don’t think that does them any favours sometimes. If they’re in the middle of pouring their

heart out to you and then your bleep goes off, then they feel like you're not concentrating" (Christine).

Gill perceived discussion of patients' psychological difficulties to be outside of her "areas of expertise", particularly with reports of suicidality. This caused uncertainty for Gill, i.e., not knowing how to respond to patients. Additionally, Gill's specific use of consecutive questions may hint towards her view that psychological difficulties are complex. Finally, Gill suggested that 'root causes' are challenging to identify, strongly reemphasising her feeling of not knowing — "I don't know!":

"I think emotionally, erm, that becomes… an area where we maybe don't all feel like we've got the skills to discuss that, and if some of them are having issues, emotionally, psychologically… you think, "oh it's out of my area of expertise, I don't really know what, what to say". They're talking about, y'know, wanting to kill themselves and all sorts of stuff… and is that because they've been in intensive care? Or is that something that they were like before they came in? Or has intensive care changed their personality and their emotional state? I don't know!" (Gill).

Finally, one participant accentuated participants' dependency upon post-discharge services, highlighting her interpretation of limited services — "there's just nothing". Lindsey perceived that the psychological significance of this can be overlooked, evoking a feeling of 'uselessness' within Lindsey:

"There's just nothing for people… it feels… y'know, when you are seeing these people who feel quite helpless, you feel quite useless,… you have to ring your G.P., you may

> *be in a queue, y'know, people are sat in queues for 45 minutes… an hour, and… when you get through it's the receptionist you've got to deal with and… y'know, are somebody's mental health needs going to be… y'know, "I'm struggling a little bit to process what's happened to me when I was in intensive care"… is that hospital G.P. receptionist going to have any insight into… how huge that is for that patient and what they're experiencing? They're probably not. Y'know… then you're asking that the G.P. recognises that and understands… and again, that can be a big ask… if they haven't got any insight into critical care or critical illness" (Lindsey).*

2.2 Helplessness: Loss of Self-Worth and Autonomy

Four participants outlined their experiences and reflections of patients' helplessness, loss of autonomy, and loss of dignity arising from ICU experience. Christine emphasised the commonality, "a lot", of helplessness following an ICU stay:

> *"A lot of people just describe like feelings of helplessness" (Christine).*

Bekki defined her perception of the psychological influence of diminished autonomy and independence within ICUs, as "very frustrating" and "very upsetting". She perceives that patients are not afforded basic rights, almost likening this to a "prisoner". According to Bekki, heightened dependency is often experienced with longer ICU stays. Bekki highlighted how recognising dependency and loss of autonomy can motivate the desire to care:

> *"I think… I mean by being in hospital you, you seem to be… like a prisoner, no, you're not a prisoner but you haven't got your basic rights, have you? Like you would do normally… I mean some of the patients, especially if they've been there for a while, they*

> *can’t lift a finger never mind doing anything for themselves, and it is, it must be, very, very, upsetting, very frustrating for them … I try to spend… as long as I can, really, just trying to make it, make them feel a little bit better” (Bekki).*

One participant alluded to increased autonomy “maybe” making a positive difference to an ICU experience, by amplifying the patient’s voice. For Janet, this was relevant to conscious patients. However, Janet appeared to experience difficulty in expressing her interpretation over which group of patients have an ‘easier’ experience; similarly to other participants, Janet may approach speculation over another group of individuals’ internal experiences with caution and hesitance to avoid conjecture:

> *“I don’t know which patient it’s easier for, I couldn't tell you if it's easier for the unconscious patient but… I feel like, the conscious patient gets the explanation — it doesn't make the experience any less unpleasant, you know, nearly dying’s hideous anyway, isn’t it? But… maybe having that say in it, a bit of autonomy maybe makes a difference” (Janet).*

In Bekki’s experience, dependency also frequently leads patients to feel burdensome and to doubt their self-worth, possibly linked to loss of autonomy and length of illness — “can’t do an awful lot” and “poorly for so long”; for Bekki, this represents a “big” psychological impact:

> *“A lot of the same problems… feeling they’re a burden to everybody because they’re, they’re so incapacitated… the other’s self-worth really because they can’t do an awful lot because of… being poorly for so long. So, psychologically it has a big impact on them” (Bekki).*

2.3 Difficulty With Being Misunderstood

Five participants described their experiences of patients' heightened powerlessness and dependency when perceiving that ward staff misunderstand them, following ICU-ward transfer.

For some participants, patients' powerlessness and dependency links to the stark absence, *"there's just* ***nobody*** *actually there or present"* (Lindsey), of ward staff resulting in patients feeling abandoned and isolated. Lindsey empathised with the potentially "*really difficult*" experience of this and highlighted the importance of "*trying to then convey to… the ward staff… trying to let them understand what that patients' experience has been and how that must feel for them now*" (Lindsey).

Other participants accentuated the perceived impact of patients feeling misunderstood or not heard, describing patients as "frightened". Bekki additionally framed this fear around patients' isolation and lack of understanding around different care contexts (ward versus ICU care); Bekki appeared to strongly emotionally connect with the emotional needs of patients in response, as she feels compelled to spend "a lot of time" supporting patients with the "psychological transfer" from ICU to ward care to arguably make this process more bearable. John framed this fear around patients' powerlessness in dependency on ward staff when struggling to communicate their needs. In giving these descriptions, John identified and empathised with patient experiences by highlighting how he perceives other staff to view patients' critical care journeys; also, by imitating patients' thought processes with example quotes:

> *"I don't think it's always helped by staff on the ward, 'cause they don't appreciate what… what an ICU patient, they don't always appreciate what they've been through… now they're in a room by themselves… frightened, thinking "I've just been on ICU and now*

you've stuck me in a room in the middle of", y'know, with the door shut or whatever. They might be in a room by themselves, and they won't see anyone for a long time, and if that buzzer's just out of reach, or they haven't quite got the strength to press the buzzer to call for someone, and they need a drink or something doing, I think that's what can make it hard for them" (John).

"The psychological impact of going onto a normal ward… they find that very difficult to cope with. They feel… isolated and they're not being listened to… they're quite upset about… they've been pressing the buzzer for say… five minutes and nobody's responded to it straight away — that's really difficult for them to understand… they're feeling quite frightened and scared by it all…. so we do spend quite a lot of time talking to them about that… helping them with the psychological transfer from ICU to the wards" (Bekki).

3. It Can Be Traumatic

This superordinate theme describes participants' recognition of traumatic elements of ICU patients' critical care experience. According to participants, these factors include patients' proximity to death, the ICU environment and its potentially dehumanising nature, and patient experiences of trauma.

3.1 Proximity to Death

Two participants recounted their perceptions and experiences of distress associated with patients' proximity to death. For Gill, worry is prominently encountered suddenly ("hit them") when death has nearly been the patient's outcome. Similarly, Bekki arguably believes that a "close shave with death" is psychologically traumatic for patients, causing an emotive response when a near death experience is realised. Bekki also alludes to the precarious nature of survival — “fragile line between life and death”. It may be hard for Bekki to bear witness to such patient accounts, “they do talk about that”, while observing patients’ emotive responses. The phraseology “surreal feeling” may also point to Bekki’s belief that narrowly escaping death is a bizarre experience, blurring the line between life and death, which may be unusual and difficult for others, without this experience, to understand; Bekki seems to struggle to articulate patients’ experience herself — “it must be”:

“It’s… you’ve nearly died, y’know, and the worry and psychological impact of that can hit them” (Gill).

“It would affect him psychologically about, y’know, the close shave with death that he had. Erm… I think a lot of people feel that it’s that close shave that they’ve had, and they’ve actually survived it, particularly the cardiac patients, y’know, it’s erm… it must be a surreal feeling to get that close and then… y’know you survive it” (Bekki).

“They’re usually quite tearful about it all… they realise that they were very close to death and, erm…. they get quite emotional about that, that, erm… they was on the brink of death and, y’know, they managed to bring them back from that. They find, they find that quite traumatic… that fragile line between life and death and they do talk about that, erm, that they thought that they weren’t going to make it” (Bekki).

3.2 The Harsh Reality of ICUs "Torturous", Isolating, & Dehumanising

For three participants there was an awareness that ICUs can be isolating and dehumanising for patients. Bekki hinted at others' perception of 'the demanding patient' rather than seeing, as she does, a vulnerable person feeling neglected:

> *"Then you start seeing it from the patient's point of view… the patient's not demanding at all… they're just erm… they're just feeling very neglected, and you can understand why... patients say it, y'know, patients say on a frequent, a frequent basis… they feel as though they're neglected… it's difficult, y'know, when somebody is saying to you that they're feeling so, so unwell and so vulnerable" (Bekki).*

In Janet's experience, patients are stripped of their individuality and dignity which she frames as dehumanising. Janet arguably highlights her view that life-saving measures are more important than maintaining patients' dignity, but acknowledges the potential for psychological consequences — "knock-on effect":

> *"They all have the same gown on, there's nothing personal, you can't smell like yourself, you don't look like yourself, there's nothing of your own" (Janet).*

> *"See, the worst thing… for the majority of people is… it's the absolute worst thing that's ever, ever happened to them and their families and… the things that matter to you are different from the priorities of intensive care... if that makes sense. You know... that people are clean, and washed, and their bums are covered is important to the patient and the family but… we kind of don't, well we don't not care about it but, it's not important. Y'know, when we're struggling to keep somebody alive and they're sort of, they're stripped naked in the bed*

and there is no dignity, erm, but at that moment, it just isn't important, and I think that has a knock-on effect, doesn't it?" (Janet).

Similarly, Christine views ICUs as dehumanising linked to patients' total lack of independence — "take everything away". Christine likened the ICU environment to "torture" but acknowledged the essentialness of life-saving measures above all else. She reflected upon her view of the mental harm patients may experience. The phraseology "it's draining" may represent both Christine's and patients' feelings:

*"I kind of think of it as… they liken it to torture, don't they? What we do to people in ICU is… quite horrendous, but it's life-saving measures, so it is essential, but it also dehumanises the person, doesn't it? I think… it harms sort of people mentally because of what they have to go through, because we basically take everything away from them… as in, we breathe for them, we take their blood pressure for them, (*awkward laughter*) we go to toilet for them, y'know… everything… it's draining, and I think… well, y'know, a lot of people come out of it not… psychologically intact really" (Christine).*

Three participants also reflected upon their perceptions of ICUs as seemingly torturous, *"They also talk a lot about… they feel as though they were in a prison and they were being tortured and… they feel as though people were trying to kill them"* (Bekki), described as "mentally difficult" for patients by Gill; Gill also noted her discomfort with this, describing coping mechanisms to "live with" what has to be done to patients such as increasing patients' medication or sedation. However, Jon highlighted his belief that patients' altered perception of time and day can be "mind screwing", particularly for post-operative, septic, or sedated patients. John experiences ICUs as places people would not choose to go to:

"Sometimes… they will say that they remember nothing about being on intensive care whatsoever… and personally… I always say this to them… "d'ya know what? I think that's a good thing" because it's not a place that I think people would choose to go to… and actually… some of the things that they do in intensive care could be classed as torturous in a way… even things like… you don't get that perception of night and day, and… for patients that are coming out of big operations, or have been septic, and been pumped full of drugs… to not have that simple perception of night and day… can be a bit mind screwing, I think" (John).

"We need to have the monitors on… we need to put a tube in their throat, and sedate them, and put them on a ventilator and, y'know, we need to make them cough and clear their chest but sometimes that feels like, to them, that they're suffocating. So, it's a form of, a bit like a form of torture really, erm, but… these things are all done with their best interest… it's really difficult…. mentally difficult for them to, er, to live through that… you try and hope that they don't remember it. So, if you're going to do a procedure… or… you're going to be doing some cares on them, you will try and up their pain medicine or up their sedation a little bit so that they are not aware of it… I think that that's the easiest way to kind of live with what we do to these patients" (Gill).

Three participants discussed their views of the psychological influence of patients lacking insight into the harsh reality of the ICU environment and ICU interventions. One quote, in particular, starkly highlighted this while demonstrating Janet's held value in offering transparency to patients and giving them what she perceives to be a realistic account:

> *"Patients, I don't think, have a real understanding of what they're going to experience and it's like, talking about resuscitation with people… er, they need to know that actually, we're gonna cave your chest in, you're gonna sh*t yourself, you're going to inhale your own vomit, and it will be in your eyes because we haven't got time to wipe it out, erm, and you're probably going to die anyway as a result of it… and, you know, at least fifteen people are gonna be stood round your bed trying to get blood out of your femoral arteries" (Janet).*

3.3 Flashbacks, Witnessing Trauma, & Re-Living Trauma

Four participants acknowledged patients' psychological reactions to experiencing, re-living, and witnessing trauma. Janet recounted an experience of a patient who had witnessed trauma, resulting in the patient feeling frightened, traumatised, and upset — "sobbing". Janet reflected on her own emotive response to witnessing this patient's trauma, suggesting that she was drawn towards wanting to help the patient. Janet also wondered "how many other patients" exist "like her", possibly implying that the need to support such patients is overlooked which may present a professional dilemma around how to intervene. Pertinently, Janet reflected that ICU sometimes does "more harm than good", in her view:

> *"One good example… the woman who came, she had an overnight stay… she arrived on ICU… in the afternoon, and she went back to the ward… the next day… she was lucid… but she saw three people die… in the time she was there… she didn't physically see them die, she'll have heard the cardiac arrest next to her, and… heard the relatives coming in and all of that, y'know, people* ***know****, you know that somebody's died… even though we shut the*

curtains… and she didn't sleep for a week after that because she was terrified… she was sobbing and sobbing, she was that… traumatised by what she'd been through, almost to the point where she would've been better off not coming to ICU… so, you know, ICU did her more harm than good… I wanted to cry for her, she was so frightened, and thinking that, erm, you know, how many other patients like her have there been?" (Janet).

Christine simply noted that patients often relive ICU trauma, hinting that this can eventually cause PTSD. However, the repetition of her question "don't they?" may imply a lack of confidence in stating that ICU experience causes PTSD:

"I think every day they kind of relive… I think… they constantly relive it, don't they?... A lot of patients get PTSD, don't they?" (Christine).

Bekki has witnessed patients having flashbacks about IC; Bekki found this difficult to navigate, appearing to greatly doubt her skills in handling and responding to such situations:

"They'll start having flashbacks… about being on intensive care and although you can talk to them about "it wasn't real" and y'know… I just feel sometimes really out of my depth" (Bekki).

4. ICU Engenders Reorientation: Disrupting Life Narratives

Participant accounts described the disruption ICUs cause to patients' lives, necessitating reorientation and re-evaluation. For patients to reorient themselves and reconnect with their life narratives, participants experienced patients commonly seeking answers to questions regarding their experience. Participants also perceived patients to re-evaluate the future and consider changes to their lives. For better psychological outcomes, patients additionally seek to reconnect with family, reconnect with ‘normality’, and to forge connections with staff, according to participants. Lastly, participant experiences highlighted the commonality of patients seeking reassurance from staff.

4.1 The Need for Answers

Five participants expressed their perceptions of patients’ need for answers, both in relation to what happened to them within IC, and in relation to ongoing medical treatment and care.

Lindsey considered patients with gaps in their memories of the ICU; her use of successive imitated patient questions may represent patients’ confusion and the urgency that she feels these patients experience in their desire for answers. Equally, Lindsey appeared to emphasise the impact of patients having “a huge gap” in their life narratives. Lindsey likens patients’ patchy memories and confusion to having merely parts of a jigsaw puzzle or having the wrong picture altogether, awkwardly laughing at the harshly realistic nature of the statement (in Lindsey’s perception). Arguably, Lindsey often experiences being the person to correct the pieces of the jigsaw puzzle by providing patients with answers:

> *“They still have a huge psychological impact because they’ve got, y’know, a huge gap in their life. They don’t remember anything at all, they don’t know what’s happened to them… what did they look like? How sick were they? Did they nearly die? Erm… how were the family? How did it affect them? What went on in their own lives?... Normal lives if you like… without them… how did life go on when they were not there?... How’s this going to affect us financially?... Who’s looked after me? What’s happened? Was I naked?... often, they remember becoming ill at home… calling an ambulance and their journey in, and then it*

> *stops… there's a gap until they come out of ICU. Or sometimes they just have little parts… they might say "did this happen to me?" or "did… would this have happened? Is it possible that anyone said this to me?"… I always say it's a bit like a jigsaw puzzle, in that they've either got no pieces of the jigsaw puzzle there, or they've got a few little bits, or they've got the wrong jigsaw puzzle all together (*awkwardly laughs*) in their reality" (Lindsey).*

Christine reported that some patients cannot psychologically handle experiencing gaps in memory, causing rumination:

> *"They can't get their head around that they can't remember what happened to them… they just can't handle that… what they've actually been through… I think that plays on a lot of peoples' minds" (Christine).*

Janet illuminated her belief in the ability of ICU patient diaries to provide patients with strength and comfort, helping them understand the extent of their experience. She recounted one particular patient's experience of this, using this tool to demonstrate to him that he had "been through hell". Janet possibly found the outcome, it "put him right", rewarding as the patient reportedly became stronger and less self-critical:

> *"I can't stop reading it"... "yeah, no wonder I feel like sh*t!" and it was literally as easy as that... to kind of put him right… he did do well, and he got a lot stronger… once he was able to appreciate why he was so weak and stop... y'know… thinking of himself as pathetic… and, y'know, weak... thinking of himself as somebody that has been through hell… I think that did a lot of good for him" (Janet).*

However, in John’s experience, not all patients have a desire to find answers or restore gaps in memory. John frames this in a manner which indicates that patients may find such matters too difficult to discuss. The unpredictability of this variation may be unsettling or as john comments, “surprising”:

> *“I just think it’s so varied, ‘cause like I say… sometimes people surprise you and they don’t remember a thing, or they don’t want to remember a thing, and they’ll just tell you that… ‘cause they don’t want to talk about it” (John).*

Patients’ need for answers extends to understanding their ongoing care and physical health status, according to two participants. Bekki discussed this topic in terms of alleviating patients’ fears and experienced a mirrored sense of relief when successfully tapping into her ability to “mentally” help patients:

> *“Sometimes I feel relieved, y’know… you see that they’re scared to death, but then when you go in and explain exactly what it means... ‘cause talking to a lay person what intensive care means, they don’t really know they just think, a lot of them think, that they’re going to die when they see a lot of people running around, and then once you can actually tell them, and try and alleviate their fears erm… you can see the relief on their faces… you’re not only making them better physically… but mentally, you’re helping them as well” (Bekki).*

4.2 Life Changing: Re-Evaluating the Future

The topic of changed patient perceptions of the future was discussed by three participants. For Gill and Janet, it appears psychologically difficult for some patients when they have lost sight of a positive future, e.g., fearing future illness or worrying that their current situation won't improve:

> *"Their psychological problems will start holding them back. They're frightened, erm y'know, they're frightened of being ill again" (Janet).*

> *"A lot of it is to do with depression and just not thinking they're going to get anywhere, erm, they, they just think that they're going to be like this forever" (Gill).*

Christine reflected that she struggles to keep patients happy, confident, and motivated when a positive future and positive recovery progression are difficult to envisage; it appears difficult for Christine to witness patients' disappointment related to slow recovery. Christine states that this engenders patients' frustration, which is common — a "big thing":

> *"We try and drive, within the outreach team, trying to get them to keep focused on what they're aiming for… but when you tell them that's months and months away, it's really hard for them to… get their head around that, and they often get quite frustrated… frustration's a big thing for them, erm… they get quite withdrawn sometimes, y'know… they kind of reach a point where they don't want to interact... because... they don't feel like they're making any progress, because often the progress is just such small steps…, the day they stand up on their own and it's a big deal, but you can see in their faces that they're thinking "God, is that it? Is that all that I can do?". They just want to be able to get back to how they were… it's hard to keep them confident, and happy, and motivated" (Christine).*

4.3 Re-Establishing Connection & Seeking Reassurance

When discussing their experiences, four participants considered the importance of connection, reconnection, and reassurance for patients.

Lindsey advocated for patient diaries, suggesting that they can provide patients with personal connection to healthcare staff; consequently, providing “comfort” following ICU discharge. Lindsey’s account could be interpreted that staff also experience a heightened connection to patients through completing ICU diaries; possibly, these diaries help to humanise patients:

> *“But the diaries put, erm… put a name… to those people that have cared for them, and they provide connection as well so it’s, y’know, “hello, my name is… I’ve looked after you today” erm… and… you try to write it in a simple way… it’s about trying to tell them what’s happened, but that… people were behind that… and… I think it must offer some comfort to know that there’s been a combined team trying to get you better and that they’ve endeavoured to help you” (Lindsey).*

Similarly, John reflected that a connection, or lack of connection, with staff can directly influence ICU patients’ critical care experience shaping it as a “bad” or “positive” experience, from his perspective. John also hinted at the importance of reassurance and seemingly values nurses who are driven to “do their best” for patients; it could be interpreted that John endeavours to act in line with this value:

> *“If a patient had a bad experience or a positive experience, I think sometimes it is down to… the staff that are on ICU… if you’ve got someone who’s quite… … who’s good at their job, who’s reassuring, who’ll talk to the patients. So, sometimes you’ll get nurses who*

will just… it's almost just a job for them, they've got to do x, y, and z to get through their shift… … but other nurses they'll talk to the patients and… try and do their best for them" (John).

Two participants proposed that reorientation and reconnection to reality provides patients with a sense of 'normality' and independence. Lindsey suggested that an ICU stay is significantly far removed from patients' comfortable and familiar environments. Lindsey additionally framed this in the context of each individual's personal reality, accentuating her perceived value in re-connecting patients with their families:

"That is not normal, is it? That's not normal life for most people. Erm, y'know, for the majority… that is completely out of their comfort zone and their reality. So… it's trying to offer them… some comfort and connection to people, and to the real world, and to their real world as well. Talking about their family or… y'know, trying to connect them to their family in some way" (Lindsey).

5. ICU is Psychologically Impactful: An Individual Journey

Within all accounts, intensive care was described as psychologically impactful. Every participant framed patients' ICU experiences as varied, idiosyncratic journeys, *"every patients' journey is different, and their experience is different… and… it can be a huge range of experience they've got"* (Lindsey), comprised of several personal factors which influence how patients psychologically perceive their ICU experience, e.g., patients' personal adjustment journeys, patients' individual differences, and the unique 'rollercoaster of emotions' each patient experiences.

5.1 A Personal Adjustment Journey

Personal psychological adjustment journeys were discussed by four participants in terms of several elements: adjustment and processing of the ICU experience itself, adjustment relating to differences in the ongoing physical impact of critical care and illness, and differences between pre-post quality of life which influences the degree of adjustment patients face.

Gill described her experience of patients' delayed psychological reactions, similar to Bekki, explaining that patients don't always consider the psychological influence of ICUs straight away; this again suggests a process of personal adjustment which may be hard to work with, e.g., patients' lethargy in sickness (falling asleep when approached) and Gill's worry over broaching psychological aspects of a patient's experience "too early". Additionally, the below quotes seemingly pertains to negative delayed psychological appraisals — "manifests itself":

> *"Sometimes they are falling asleep when they are talking to you, and you're thinking, "this is just not in their best interest"... sometimes it's too early to talk about the psychological and emotional sides of things because they've not even thought about that themselves yet, and I don't know whether we're the right ones to talk about those things with them too early on. Some people, some are very open and will tell you, but others maybe it's just, y'know, it manifests itself maybe a little bit later on… I think physically they have too much to deal with to maybe think about the emotional side of things when they're in hospital, and I don't think the environment helps" (Gill).*

> *"I think everything takes time to sink in, doesn't it?" (Bekki).*

Two participants discussed their perceptions of differences in the ongoing physical impact of ICUs and illness, entailing adjustment for patients. Christine reflected upon her experiences of ICU patients' lasting physical changes, appearance-wise, suggesting a process of adjustment with patients initially feeling "freaked out" towards physically changed selves. In Christine's view, a patient's 'normal life' is lost. Christine appears to psychologically struggle to accept the measures taken to save patients' lives in the context of difficult lasting consequences:

> *"They can come out looking different, very, very different… a lot of those ones that don't do well… you're like "hey, we saved your life! You're still here! Oh but by the way, you've got no feet left and your fingers fell off" and… I suppose deep down you have an expectation that they'll be grateful that they're still alive but then you think, "oh my God, we saved", you feel guilty almost, "we saved you, but you are not having a normal life again"… I think as a nurse sometimes you struggle with the, the lengths that they go to, to save someone's life… it isn't always, it isn't always right… you know…. they can come out of there, like, are all their muscles have wasted away and all their skin is saggy… they don't look like they used to and… some of them get quite freaked out by it" (Christine).*

Janet explained her view of the significance of patients' pre-post quality of life in connection to critical care, considering how this influences patients psychologically. For Janet, age and degree of premorbid functioning are factors to consider before a patient's admission to ICU. Janet appeared to feel guilty about being associated with medical teams who employ life-saving measures which inadvertently significantly reduce patients' functioning and quality of life:

"I have a sort of a personal viewpoint about very elderly people and there's always this thing about, erm, so say like they're in their 80s and 90s but they still live in their own home and people go, "oh he's a really good 80", and then I think, and so we should take him to ICU, but then I'm like… "no, that's worse!" because... you will never get him back to that… if your quality of life was so good beforehand, you have more to lose, don't you? And that must have a, ***I feel,*** *that must have a bigger psychological impact" (Janet).*

5.2 It Depends: Individual Differences

All participants described their perceptions of patients' individual differences, contemplating the influence of these upon patients' psychological experiences of an ICU stay.

Three participants have experienced individual differences within patients in terms of how they perceive the psychological influence of IC, and in relation to patients' desire to think more deeply about their ICU experience. John expressed concern for patients who do not wish to talk about their experience, questioning whether negative consequences will emerge later, whilst Gill highlighted that patients' individual differences intensifies her perceived difficulty in handling patients' psychological difficulties:

"Other times, people are just like… "I just want to get over it, and just move on" or forget about it… so, we do… see two, sort of, extremes to it sometimes…. but then sometimes, personally, I worry about those that don't want to say anything… because I think, "is something going to come and… bite them later on?" (John).

"Dealing with patients' psychological issues is not easy. There's not, y'know, one way fits them all – they're all different. Erm… it's difficult, it's a minefield really" (Gill).

Other participants placed emphasis upon individual differences in patients' mental health status prior to ICU admission. Janet perceived that patients may experience mental health difficulties post-IC if they already had a pre-existing mental health difficulty, 'making it worse'. She alludes to her perception that such patients require a higher level of psychological support than Janet perhaps feels equipped to offer:

"The ones that probably had mental health problems before they came in… you know, with a… a deep depression, or some sort of anxiety, erm… we, we can't really help them. We can offer them the simple things but, that is much deeper than… anything we can do. It's kind of like they couldn't be helped before this experience and now this will have made it worse" (Janet).

Comparably, John relayed his view that patients' previous life experiences vary and may influence patients' perceptions of ICU experience. John recounted one example of a woman who had already had a "really bad" ICU experience, which caused an avoidance of hospitals leading to a further ICU admission:

"I think people's perceptions obviously go by what their, what they've been through… in their lives normally. So, whether they've had, y'know, more than one stay on ICU… because I know, I've definitely seen people that have had more than one stay… I remember seeing one lady… she had a really bad ICU experience, the first time, and it actually prevented her from going into hospital the second time which meant that her... problem… got worse and worse until the point where she collapsed and had to come in" (John).

John re-emphasised the impact of individual differences in patients' life histories. However, he then reflected upon the impact of repeated exposure to patients' difficult circumstances and acknowledgement of their individuality over time. This arguably influences how, and to what extent, John may perceive the psychological influences of IC upon patients. John perceives a dilemma between choosing to be focused mentally or choosing to be in touch with patients emotionally:

> *"You don't know their histories and all the rest it, but… it's, that accumulation over time of seeing patient after patient and probably, at times, seeing quite tragic things happen it's going to get to you, isn't it? It's going to affect you, it's going to be emotive… sometimes…* ***personally*** *I try and put things, I know I put things, in boxes in my head… 'cause you are… just focused on doing your bit, and doing your bit to the best of your ability, erm… …. at that time I, whether I choose to, or I just do it, I don't let that emotional side come in because I think if it does… then it will start to effect, y'know, you'll start to get, it's already stressful enough, but you'll start to get more stressed and emotionally involved when you just need to be… mentally… on the ball and on the game and… doing what you need to do. Erm, I think emotionally… when you see connection, or you have that… "yeah, this is a real person"… you have to …. or I have to… try and block that out, because I just know I need to focus on what I need to do to try and support, y'know, get this child, or patient or whoever it is, through whatever's happening… I just… know that I need to be on it mentally… and I can't be on it mentally and on it emotionally at the same time, I don't think" (John).*

In Janet's experience, a range of individual differences can influence patients' perceptions of ICU. Janet's dismissed generalisation suggests that she has commonly experienced patients in their eighties to be noticeably brave:

> *"Personality type obviously comes into it, doesn't it? Some people are highly anxious, some people have... higher pain thresholds, some people have lower pain thresholds, there's sort of... cultural difference in people. I think there is a different between men and women, I do, and I definitely think there's an age thing; men and women in their eighties are the bravest people you'll ever meet, 'cause they just, they just are. I don't care if I'm generalising!" (Janet).*

Stark individual differences can be observed, within Lindsey's experience, between patients' focus on the emotional and psychological aspects of their ICU experience. Lindsey stated that some patients report feeling "completely lost", "hopeless", and "disconnected", describing them as "completely broken". However, it could be argued these patients focus on their psychological experiences more because they feel these emotions:

> *"Everybody will have different level of perhaps… knowledge… and they'll process it in, in a way that they're intellectually able… but also that they're comfortable with, y'know, some people may have a high level of intellectual level of knowledge but… "I don't really want to know much about it, thank you" and… so on an emotional level or psychological they don't really want to delve too deeply into how that impacted them. Whereas other people are much more, y'know, the emotional and psychological side is all that's happened to them… it's about how they're actually feeling. They're, y'know, really feeling emotional or… or weepy or… completely lost, disconnected erm… feeling hopeless erm… some people are just completely broken from the psychological impact" (Lindsey).*

Bekki has experienced that the duration of an ICU stay is not always a good indicator of whether or not a patient will be psychologically "affected" by their ICU experience, highlighting patients' individual differences. Bekki alludes to the uncertainty she may experience in "never" knowing what she is "actually going to find" until approaching patients:

> *"It's really difficult to judge because some people who have only been on the unit for a couple of days…will be not affected, and then other people who have been on a couple of days will be really affected. So, you never know what you're actually going to find until you start speaking to somebody" (Bekki).*

5.3 A Diverse Rollercoaster of Emotions

Three participants discussed the multitude of emotions that they have experienced ICU patients to feel, relevant to experiences of critical care. From Christine's perspective, this links to change. Christine's use of the word "everything" hints towards her perception that this change is inescapable:

> *"I suppose everything changes for them, doesn't it? And they must go through every emotion possible" (Christine).*

John talked about his experience of ICU patients who undergo planned operations, underscoring his perception that "some" patients experience concurrent emotions of relief and shock seemingly linked to the anticipation associated with planned operations:

> *"I think… it's a relief as well… 'cause they've either been gearing, y'know, if it's a planned operation, they've been gearing up for this operation for however long it is and*

> *actually to have it done and to come out of intensive care, they're, some of them are a bit relieved…. but also, probably a bit shocked" (John).*

Lindsey explicitly described patients' "roller coaster of emotion" post-ICU, heavily emphasising this theme within her account. She reflected that experienced emotions are idiosyncratic but seemed to believe that patients commonly experience extreme emotional shifts linked to realising their limited abilities. Lindsey's wording ("suddenly") suggests that she has experienced these shifts abruptly:

> *"It can vary for each patient, but they suddenly can feel… they go from this high to erm, such a deep low… from… "yay! I'm alive" to "oh my God, this is it now… and…. I can't do anything and… how am I going to get better if I can't do things for myself?"…" (Lindsey).*

Specific examples of Lindsey's experience of such emotional shifts were offered. Lindsey's use of the word "literally" emphasises the stark contrast in the patient's emotional state, experienced by Lindsey as the difference between "night and day":

> *"On the first visit, he was really quite buoyant… happy to be alive and "I'm great, just looking forward to getting a good night's sleep"… and I sort of said, "I'm going to come and see you tomorrow again and see what sort of a night you've had", and the difference the next day was… literally night and day. He'd had a terrible night, he couldn't sleep, he couldn't switch off… he felt really anxious… he got really frightened… he couldn't stop crying" (Lindsey).*

Lindsey's experience of this was then connected to changed role; Lindsey described her transformed perceptions of working solely within an ICU versus working as an outreach nurse. Lindsey articulated that patients' emotional and psychological difficulties have become more transparent to her as an outreach nurse — a shocking realisation for Lindsey, described as "sudden" and "striking":

> *"Certainly doing the outreach job… even after all that time, 17 years on the ICU and working from within, to seeing it on the other side and seeing how… how abandoned some patients can feel… y'know, sudden realisation… like nothing really, you sort of realise how much psych (*deliberately cuts off*)… y'know, how much people do seem completely normal when you leave them, and you wave them off, and they go off to the ward, and you think… "we've done a really good job"… because they're in that buoyant, "yeah! I'm okay, I'm alive"… but you, what you don't see is that rollercoaster of emotion then that they go through and… that feeling of abandonment and… erm, feeling hopeless and that long journey that they've got ahead of them. I think that was probably quite erm… a striking thing that I realised once I did the outreach job" (Lindsey).*

Discussion

Overall Findings

This research primarily aimed to understand outreach nurses' experiences and perceptions of how critical care psychologically influences ICU patients. Interestingly, participants mostly considered the negative psychological influence of an ICU stay.

Participants perceived several salient factors in patients' psychological experiences of intensive care: the confusing and surreal nature of ICUs — including hallucinations and nightmares, powerlessness and dependency, experiences of trauma, responses to impaired recall and gaps in patients' life narratives, and the individual journey of emotion and psychological adjustment believed to be influenced by patients' individual differences. For participants, patients exhibit a range of responses and emotions as a consequence of ICU experience and critical illness. Additionally, participants reflected on the range of emotions connected to ways in which patients are cared for across their critical care journeys. In response, participants experienced difficult professional dilemmas, strong emotional reactions, and incongruence with dissonance between participants' desire to help patients psychologically and their perceived inability to enact helping behaviours to mitigate patients' psychological distress.

In terms of how, and to what extent, outreach nurses understand and make sense of ICU patients' psychological experiences of critical care, the findings were illuminating. Participants arguably reflected deeply on the psychological influence of critical care upon ICU patients when interviewed. However, participants reported avoidance of reflecting too deeply on emotional and psychological matters with patients, due to participants' perceived lack of time and low level of training in psychological support. Another influential factor may relate to attachment styles within nurse-patient dynamics. Nurses' attachment styles, for example, may influence nurses' empathy; secure and insecure attachment styles have previously been found to have significant positive and negative correlations with empathy, respectively, in a group of student nurses (Khodabakhsh, 2012). Extant literature further suggests that patients' attachment style can impact upon patients' satisfaction with care (Kaya, 2012). The intricacies and complexity of each nurse-patient dynamic, in the context of attachment theory (Bowlby, 1969, 1973, 1980), may influence how and to what extent outreach nurses address patients' emotional and psychological needs, and how and what patients choose to disclose.

Interestingly, this group of participants used the same idiom repeatedly, a 'can of worms', to discuss their fears around offering psychological/ emotional support, potentially indicating that this topic has been jointly discussed and acknowledged with ‘in-group’ peer support. Additionally, the findings support that participants may fear the emotional impact of such work. For contrast, ICU nurses report a similar avoidance of patients’ psychological needs due to lack of time and feeling unsupported (Price, 2004; Weare et al., 2019). To some extent, participants were comfortable with normalising and validating ICU patients’ emotions and distressing experiences. Yet, some reported feeling more comfortable handling and acknowledging such matters than others; this may also depend on individual interest, as one participant accentuated.

Participants perceived an ongoing gap in psychological support for ICU patients within their region of England, with exception for ICU patients with complex rehabilitation needs or those admitted through the major trauma pathway; this arguably demonstrates inequity in access to psychological support. The existence of a ‘postcode lottery’, as to whether or not general ICU patients can access specialist psychology services, is evident when placing this finding in the wider context of national service provision too. A recent audit benchmarking psychological service provision for ICU patients (ICS, 2020), demonstrated regional variability in psychological service provision with only an estimated 19% of the United Kingdom’s (UK’s) ICUs (51/280) having access to ICU psychologists. Similarly, an even more recent UK national survey concerning recovery, rehabilitation and follow-up services after critical illness suggested that clinical psychology was the most frequently absent profession within critical care inpatient and outpatient services across the 176 hospital sites offering survey responses (Connolly et al., 2021). Commissioning and funding disparities must therefore be addressed to achieve equitable care and to ensure standardised national compliance with best practice recommendations and guidance (e.g., NICE, 2009; NICE, 2017). Additionally, where psychological support services are available to general ICU patients, further issues pertaining to referral failures may also exist. For example, in one audit of adult critical care rehabilitation processes in a UK district general hospital (Agarwala et al., 2011) it was found that referrals were not made for 10 of 19 patients who met the criteria to receive support from a psychologist; the authors concluded that a more robust system should be established to ensure psychology referrals are made when indicated.

A dominant discourse emerged, within participant accounts, around more specific psychological support being needed for ICU patients; outreach nurses appear involuntarily caught within this gap when specialist psychological support is lacking, often being the first professionals patients get the opportunity to discuss emotional and psychological matters with. Some participants framed this as disadvantageous for patients due to the duality of the outreach nurse role; that is, trying to acknowledge and assess patients' psychological and emotional concerns, whilst principally attending to medical aspects of the job which arguably take precedence within the outreach nurse role. Equally, one participant highlighted her views of existing difficulties with post-discharge psychological support, e.g., the onus falling on general practice surgeries to understand and appreciate the complexity of ICU patients' psychological experiences in relation to critical care. Other critical care professionals have noted this to be problematic too, emphasising the potentially limited exposure that GPs may have had to ICU patients (post-discharge) until recently due to COVID-19; improved collaboration and co-ordination of care, for post-ICU patients, is required between community and secondary and tertiary services to better support post-ICU recovery (The Faculty of Intensive Care Medicine (FICM), 2021). The notion of a 'postcode lottery' also exists in terms of routine access to post-discharge psychological support for ICU patients; critical care follow-up clinics only operate within some areas of the UK, and often do not include every recommended profession within multidisciplinary teams (NHS England, 2020). Despite psychologists being recommended to participate in ICU patients' follow-up reviews within the community and outpatient clinics (ICS, 2019; NICE, 2017), such input is lacking within certain areas of the UK (ICS, 2020).

It is important to consider a further participant's account of avoiding patients' emotions and acknowledgement of the person within the patient, hinting to moments of realising — *"yeah, this is a real person"*. Speering and Speering (2021) coined the term 'negative dehumanisation' to describe this; the 'removal' of humanising factors from a person's perceived identity, e.g., emotions. This participant's account raises the issue that some outreach nurses may, at times, struggle to connect with patients' emotions as a defence mechanism to prevent burnout and vicarious trauma 'in the moment', i.e., whilst caring for a patient. This is consistent with existing research on healthcare staff working with ICU patients (Haslam, 2006; Pompili et al., 2006; Vaes & Muratore, 2013). However, enacting explicit empathy and compassion, which involves connecting with patients' emotions, assists patients to feel humanised and heightens patients' perception that their needs are being met (Moghaddasian et al., 2013; Roze des Ordons et al., 2019). One study further evidenced that in order for patients to avoid feeling dehumanised, their 'routine suffering' must be addressed and highly personalised ways of improving their well-being must also be offered, e.g., honouring patients' wishes, learning about each patient as a person, and using appropriate touch such as holding a patient's hand (Basile et al., 2021). These acts can be so powerful, in terms of humanisation, that they are considered central tenets of giving a patient a 'good death' within palliative care practices (Mitchinson et al., 2021). Since human connection can be thought of as a basic need, and illness can cause the deterioration of human connection, it is essential that ICU patients regain a sense of connectedness (Hagerty & Williams, 2020; Soler-Gonzalez et al., 2017). However, in this participant's example, the removal of patients' emotions was reported to heighted this participant's ability to complete other tasks within the outreach nurse role and assisted with staying *"mentally on the ball and on the game";* this realisation may have arisen from deliberate reflection within the research interview. Relating to patients' emotions can seemingly put staff members in a vulnerable position, taking focus and energy away from staff when completing their day-to-day duties. This participant further commented on the accumulative negative impact of witnessing tragic things happen to patients over time. It is therefore argued that psychological support for staff is paramount and should be better integrated into critical care outreach teams; such integrated support was absent at the time these interviews were conducted. Improved staff support could also have a ripple effect, leading to better psychological outcomes for patients.

Participants' perceptions of experiences which engender psychological difficulties, and those which promote better psychological outcomes varied. Participants perceived patients' individual differences to play a role in this, including pre-post quality of life, previous life experiences, and patients' pre-existing mental health status. Increased patient autonomy, within ICUs, was tentatively linked to better psychological outcomes. Significance was also placed upon the ICU-ward transition; participants appeared to perceive greater psychological difficulties with more difficult ICU-ward transitions or when ICU patients are ill-prepared for what to expect from ward-based care. Similar to existing research, participants frequently perceived patients to be misunderstood by ward staff; Kean and Smith (2014) also described ICU patients 'fading into the background' following discharge from intensive care, with patients' special circumstances often being overlooked. Witnessing trauma and death were further elements of some patients' ICU experience which in participants' experience, cause significant psychological distress.

Some consideration was given to patients' gratitude for life. However, participants framed gratitude as a dwindling emotion as the full psychological impact of critical illness and critical care is realised. Post-traumatic growth was therefore not discussed by the participants within this study. Nevertheless, outreach nurses only see patients at the acute stages of illness and recovery; post-traumatic growth (PTG) may develop later during recovery. The phenomenon of PTG is well documented and accentuates the importance of time; inner strength development, integration of feelings and self-presentation, re-integration into society, and re-integration with the ‘new-self’ are reportedly gradual processes supporting PTG (Barskova & Oesterreich, 2009; Gill, 1997; Salick & Auerbach, 2006). A significant passing of time may therefore be required before patients develop acceptance and novel ways of viewing themselves, appreciating newly developed strengths arising from their hardships (Jones et al., 2020). Additionally, researched patient priorities following ICU discharge demonstrate an urgency for physical recovery before psychological processing and healing (Scheunemann et al., 2020). Furthermore, follow-up sessions post-ICU discharge offer the opportunity to clarify unclear information relating to patients’ ICU experience, with the potential to provide consolidation and closure; thus, facilitating PTG (Haraldsson et al., 2015).

Implications for Clinical Practice

The findings suggest that psychological services and psychologists should be integrated into critical care services for all ICU patients to reflect the recommendations of critical care guidance (NICE, 2009; NICE, 2017), with parity in access to support across all regions of the UK. These research findings support this, as the complex nature of patients’ varied psychological difficulties and needs were evident alongside the sustained pressure upon outreach nurses stemming from the dual nature of their role; equally discomfort and differing levels of personal drive to offer psychological/ emotional support were discussed. The Faculty of Intensive Care Medicine and the Intensive Care Society (FICM & ICS) (2019, p. 63) support that “patients should receive assessments and interventions for psychological as well as physical problems throughout the intensive care pathway. These should be delivered or supervised by qualified psychologists”. Additionally, research recommends that psychologists be integrated into ICUs staffing structure as part of ICUs ‘basic requirements’ (Valentin et al., 2011).

However, participants acknowledged that not every ICU patient wishes to discuss the psychological influence of critical care initially. Despite this, participants described numerous accounts of patients attempting to discuss such matters with them often due to frequent distress. One participant suggested that the need to discuss such matters may develop from ICU discharge to ward transfer — an observation more noticeable from an outreach nurse perspective. This suggests that patients would benefit from specific psychological support before longer-term follow-up appointments, potentially before hospital discharge; however, due to individual differences, this support may be required shortly after post-hospital discharge based upon participants’ reports of patients’ delayed psychological reactions. Research also demonstrates that patients who are not offered psychosocial support during the early illness-recovery trajectory eventually develop a greater need for follow-up sessions and support (Haraldsson et al., 2015).

As briefly highlighted previously, this research also demonstrates the need for better psychological support for staff — including outreach nurses. The findings clearly highlight difficult feelings arising for staff when working with critically ill patients, and with patients’ psychological distress. The impact of these difficult feelings may accumulate and be more difficult to experience over time. Imperatively, the current findings also demonstrate that dehumanisation may be linked to the psychologically taxing nature of this type of work. Within the context in which this was reported, the need for staff to receive their own emotional and psychological support transpired; staff support services should be integrated into hospital settings without exception in order for workplaces to be conducive to well-being (NHS Employers, 2018). It is already known that staff need and value such support, and that employers have a duty of care to support staff working within stressful environments where heavy workloads are common and burnout is pervasive (Costa & Moss, 2018; FICM & ICS, 2019; Zamoscik et al., 2017).

Linked to this, the findings of this study accentuate the great difficulty arising from the duality of outreach nurses' role. It is arguably not conducive to well-being, for staff or patients, when patients confide in outreach nurses about emotive topics while outreach nurses are on-call. Similarly, the duality of outreach nurses' role may decrease the likelihood of outreach nurses maintaining compassion satisfaction within their profession — similarly seen within some critical care nurses (Sacco et al., 2015). Healthcare staff well-being positively correlates with patient well-being and influences patients' outcomes (Hall et al., 2016). Causal models of staff thriving, and future role adaptations therefore require further contemplation (Zhu et al., 2021, in press).

The findings additionally emphasise aspects of how outreach nurses shape their clinical practice around their perceptions of how patients psychologically experience critical care. For example, one participant reported increasing patients' pain medication and sedation to spare patients from the negative psychological influence of remembering difficult healthcare procedures; this was also framed as a means of 'living with' what has to be done to ICU patients. This approach highlights the emotional and psychological experience of staff, linked to empathy and compassion, differing from reports within previous research which suggest that sedatives may be used to avoid patients' 'real' psychological needs or to "quieten" patients (Price, 2004). However, highly sedated patients often experience increased amnesia and delusions which can escalate patients' risk of PTSD and poorer psychological adjustment to illness (Griffiths, 2012; Kress, 2003). Additional staff training around PTSD and its causes may therefore be advantageous.

Outreach nurses may also wish for more extensive training in psychological support, beyond normalisation and validation techniques, e.g., psychological first aid. Additionally, guidance and job descriptions should more clearly specify the extent and nature of the emotional support outreach nurses are expected to offer. Regular staff and peer support, e.g., reflective practice groups and supervision from psychologists, could additionally enable the dissemination of psychological knowledge and assist staff to confidently offer more advanced emotional support (FICM & ICS, 2019). In benchmarking the provision of psychological services for staff and patients within critical care contexts ('units') across the UK, the ICS (2020) found that only 18 of 280 units (6.4%) reported the use of psychologist-led reflective practice groups for ICU staff. As peer support, reflective practice groups, and Schwartz Rounds (The Schwartz Centre, 2021), are recommended within NHS staff well-being frameworks (NHS Employers, 2018) to help staff to 'decompress', these pockets of good practice must become increasingly ubiquitous.

Existing research additionally emphasises that inadequate peer support and staff debriefings act as blocks to nurses' empathy and compassion in intensive care, which may hinder staffs' desire to offer psychological support to patients (Jones et al., 2016). However, psychological support is not the primary purpose of outreach nurses' role. The findings of the current study also highlighted participants' mixed levels of interest and ambivalence towards working with patients' psychological and emotional concerns, the impact of which should be considered for patients and outreach nurses. The psychological impact of the work may also mediate how 'available' staff are to offer such support. Existing research, however, supports the feasibility of a nurse-led intervention to prevent acute stress and long-term morbidity in critical care patients; although, the aim to significantly reduce depression, anxiety, and PTSD symptomology within patients was unmet (Mouncey et al., 2019; Wade et al., 2018).

Similarly, it appears that general ward staff may benefit from further training in understanding ICU patients' critical care journey and psychological experiences of critical care. This is especially pertinent as ultimately, holistically focused quality care should continue throughout ICU-ward transitions and this handover of quality care is argued to be the shared responsibility of both critical care and ward teams (FICM, 2021). Additionally, the ICU-ward transition is often a significant event for patients, often evoking strong emotions for both patients and their families (FICM, 2021). One participant highlighted that when patients try to communicate that they feel neglected whilst receiving ward-based care, some nurses interpret the patient as being demanding instead. Improving general ward staffs' understanding could therefore support improvements in person-centred care, patient-staff interactions, and healthcare staffs' skills. As nurses offer a frequent presence for patients, they may be appropriately positioned to identify early signs of psychological distress and prevent or improve patients' distress with increased support and training (Price, 2004). Importantly, this may improve patients' perception of the ICU-ward transition, experienced by participants in this study to have a marked influence on patients' emotional state. The reality of understaffed and under-resourced wards, however, must be addressed to allow general ward staff the room for such considerations (Connell et al., 2020; Glette et al., 2017). NICE specifically propose that, "staff working with acutely ill patients on general wards should be provided with education and training to recognise and understand the physical, psychological and emotional needs of patients who have been transferred from critical care areas" (NICE, 2007, p. 13). However, the current findings highlight that critical care patients still report feeling misunderstood by general ward staff — a potentially pre-existing perception within existing literature (Stein-Parbury and McKinley, 2000).

Implications for Future Research

Further research investigating staff perceptions of access to psychological support services for ICU patients, across England's regions, would be worthwhile. Concerning this topic, service provision guidance, audits, and national service data collection/ the benchmarking of psychological services (e.g., ICS, 2020; FICM & ICS, 2019) are of equal importance and should be continually updated in light of COVID-19; plausibly, the changing context of this pandemic continues to significantly shift and shape psychological service provision for staff and patients.

Supplementary investigation into staff perceptions of patients' psychological support needs, and staffs' opinions and lived experiences of the current psychological support offered to ICU patients across patients' entire illness-recovery trajectory would also strengthen the extant literature base. Similarly, ICU patients' lived experiences of inpatient-to-post-discharge psychological support across the illness-recovery trajectory should be further investigated. More research exploring in-depth lived experiences of dehumanisation within ICU and wider critical care contexts appears necessary, adding to existing literature, from both patients' and staffs' perspectives.

Due to COVID-19, the psychological influence of critical care upon ICU patients should be re-investigated to consider patients who experienced an ICU admission during the context of this pandemic. Similarly, emphasis should be placed upon staff experiences in connection to this; the current findings highlighted the pre-existing need for additional psychological support for outreach nurses, and staff training, prior to the impact of the COVID-19 pandemic materialising. Future research should consider the impact of potential burnout and diminished personal resources upon staff groups working across critical care settings during the timeframe of the pandemic.

Limitations

The participant sample was fairly homogeneous. Therefore, a more diverse sample of participants in age, gender, and job location may have yielded different results. Particularly in relation to location as there are disparities in the psychological services offered to patients across the UK, thought to be perpetuated by resource restrictions (FICM, 2019).

Outreach nurses only volunteered to participate in the study if they could offer spare time outside of working hours. Those who demonstrated interest may have represented a proportion of outreach nurses who are particularly invested in understanding ICU patients' psychological experiences or in offering these patients emotional support. This has the potential to limit the transferability of the findings.

This research gave little acknowledgement towards post-traumatic growth or positive psychological experiences within and post-ICU; these topics did not arise within participant accounts, and therefore within this study's findings. Possibly, this is due to the acute stage at which outreach nurses see patients.

The impact of the COVID-19 pandemic upon the research requires consideration. Interviews were originally planned face-to-face. However, it became necessary to utilise an online interviewing platform instead. This may have changed the dynamic and level of rapport built between the researcher and participants, potentially influencing participants' responses.

Conclusion

The study highlights multiple facets of how outreach nurses perceive and experience ICU patients to be psychological influenced by critical care, primarily negatively. These findings have implications for shaping critical care services, in terms of psychological support for both staff and patients, and for improving staff training.

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Part Three: Appendices

Appendix A: Reflective Statement

Background & Research Topic

There is a sense of not knowing how to begin this reflective statement. There is much I could say about the research journey — a journey which has been both inspiring and impossibly difficult. This thesis project has felt all-consuming for the past six months, it has resided in my thoughts for almost three years, but I am grateful for the opportunity afforded to me and for the knowledge I have acquired during the research process. I am equally proud of the skills I have strengthened by completing a project of this magnitude; conscientiousness, dedication, patience, and self-reflection were required.

I consider my route into the Clinical Psychology Doctorate as somewhat *unconventional*, linked to a gap in education resulting from my personal experience of critical illness and intensive care. I was unable to complete my college studies following discharge from intensive care, which consequently changed my life trajectory for several years. Embarking upon a thesis has therefore been a challenge, and a privilege, I never thought I would be faced with — acknowledgement of this has, in itself, been emotive. This thought has driven my commitment and determination to complete this project to the best of my ability, particularly while tackling the challenges of research during a pandemic.

Empirical Paper

When first considering selection of a research topic, I felt daunted by the prospect of the decision; pressure existed to make the *right* choice. For this project to feel *right* for me, I knew that I needed to select a subject which would contribute something worthwhile to the relevant fields of research, I also needed to perceive that my chosen topic was manageable and within my sphere of capabilities; I value completing tasks to the utmost of my abilities and additionally value integrity, including doing what you state you're going to do. I consequently didn't want to bite off more than I could chew, but equally suspected that I would need to keep Imposter Syndrome in check. Therefore, I consciously chunked the research into manageable pieces and progressively learned to trust the research process — including the strengthening of my research skills with progression of the project. Furthermore, it felt extremely important to choose a topic which would sustain my passion for research; I trusted that this would enable me to overcome challenges and barriers across the research process.

It is my personal experience of critical illness and ICU care, 14 years ago, which sparked my interest in the chosen research topic. My experiences were complex and significantly impacted my life; psychologically, I experienced intensive care and critical illness to be traumatic. I perceived that psychological support following ICU discharge was lacking, which partly shaped my motivations to complete the research project I chose; I wanted to provide support for change around the ways in which people are supported following critical care. However, my own difficult experiences eventually enabled me to reconsider my life values which facilitated positive growth. In thinking about this, I wondered how other patients had psychologically experienced critical illness and critical care and whether they needed, or had access to, psychological support. I also wondered how the staff caring for ICU patients experienced and perceived patients to be psychologically influenced by such experiences. This led to further curiosity around the implications of staff perceptions upon clinical practice and support for patients. These curiosities were my starting point.

Understanding the nuances and richness of subjective lived experience are where my natural interests lie. Upon reviewing the literature regarding the psychological influence of critical care, it became clear that the gaps in research also required a qualitative, exploratory approach which could illuminate the complexities of lived experience. Interpretative Phenomenological Analysis (IPA) therefore seemed to be a fitting methodology for the empirical paper. I knew that I would be required to research IPA thoroughly, as it was a novel methodology to me. I remember feeling apprehensive about the notion of doing the data justice and employing IPA correctly but reflected that these feelings were likely common. Consequently, I very consciously adjusted my interviewing technique during data collection to step into the role of an IPA researcher; I was cautious not to lead participants and carefully considered my interview schedule to be harmonious with IPA tenets. I was equally assiduous in completing data analysis thoroughly and accurately according to IPA guidance; I studied written examples to better grasp how to approach IPA. On reflection, I therefore think that these fears became strengths as they made me more conscientious towards data analysis.

Patient perspectives of this subject matter are increasingly being explored. Similarly, research on healthcare staffs' perspectives is increasing. However, there was a clear gap investigating outreach nurses' experiences and perspectives. My field supervisor also highlighted this gap and enabled me to gain access to my participant sample. Initially, I made the assumption that outreach nurses would be well positioned to discuss the psychological influence of critical care upon ICU patients owing to their prior ICU nurse experience, and due to their input across ICU patients' acute critical care journey. This assumption was more firmly cemented upon learning more about the outreach nurse role. Some of this learning occurred through shadowing multiple outreach nurses' shifts on several occasions, prior to the COVID-19 pandemic, enabling me to witness the complexity of their role. This also exposed me to the ICU environment again and prepared me for consideration of the types of experiences outreach nurses could potentially highlight within the research interviews. Although, I have realised that psychological processing may take time for a proportion of patients and outreach nurses only see ICU patients during the acute stages of illness and recovery; perhaps, explaining why post-traumatic growth did not emerge as a topic within the empirical findings.

Through my field supervisor's connections, it was fairly straightforward to recruit my participant sample and for this I am extremely appreciative. Initially, I was aiming for a sample of 6-8 participants. In the end, I feel the 6 recruited participants provided ample data to complete a thorough IPA analysis. Equally, I was impressed and thankful for the commitment my participants still demonstrated towards this project whilst the COVID-19 pandemic unfolded.

When approaching the point of interviewing, I remember feeling excited and hesitant. Whilst the process of recruitment was not taxing, the process of gaining ethical approval was. Although ethical approval is valuable and important, the process was arduous and lengthy. Therefore, I was excited when the opportunity for interviewing finally surfaced. Simultaneously, I felt cautious because I did not know, with certainty, what participants would bring-up; I had some concerns about participants raising topics which strongly resonated with my own lived experiences of critical illness and ICU care. Such topics were inevitably raised but hearing experiences of them through staffs' perspectives enabled me to distance myself from my own experiences, which preserved my own sense of well-being. I was distracted with being immersed in participants' emotional responses and concerned with their lived experiences of such topics at that time. Therefore, in hindsight, I thoroughly enjoyed the interviewing process even when difficult and emotive topics arose. I also remember being preoccupied with participants' well-being following the interviews, but I knew that a lot of time was spent considering how to offer participants appropriate sources of support. Later, the repeated re-listening to interview recordings took its toll on me at several points during data analysis. Accordingly, I took breaks away from the data when needed. I was mindful that descriptions of the ICU environment, patients' emotive responses, and staffs' emotive responses were all connecting with, or shifting my perspective of, my own experiences which increased the potential of impacting my analysis. My reflective research journal assisted in teasing apart participants' experiences from my own and helped me to stay close to participants' *true* accounts.

In terms of data analysis, I was eager to amplify the voices of the outreach nurses and to construct a meaningful analysis of their lived experiences. The amount of data obtained within the interviews was somewhat overwhelming, but I was enthusiastic about immersing myself in the data. Due to personal significance this research topic held for me, I attempted to tease apart the perceptions and experiences of the participants from my own. I didn't want my potential biases to heavily influence the analysis. Therefore, I re-visited my medical notes which detailed every aspect of my own ICU stay and used a reflective journal. This helped me to make further sense of my own experiences and reminded me of the topics I may be more sensitive or biased towards when interpreting the research data. At this time, my systematic literature review (SLR) had already been a source of learning - strongly linked to the focus of the empirical paper; it consequently felt important to consider the influence of the SLR findings upon the empirical analysis. Although, I also reflected on the knowledge that data interpretation would always be through my own unique lens.

While writing the empirical paper, I endeavoured to focus on each participants' unique use of language to edge closer to participants' meaning and experience. There appeared to be overlap between some of my own experiences and perceptions, and how participants made sense of and experienced the research topic. This created a sense of understanding the participants better, but I approached this notion cautiously to avoid assumptions. Staying anchored to participants' language use was therefore even more imperative, to reduce personal projections of meaning. Accordingly, feedback from my supervisors was welcomed and invaluable. The final stages of writing were tough; it was a demanding and time-consuming task, but a worthwhile and illuminating one. The process has provided foundations for future personal research endeavours, as I now fully appreciate a) what larger-scale research projects entail, and b) the importance of organisation. Additionally, this research taught me the reward of perseverance, and has tinted my 'own unique lens' a little more.

Systematic Literature Review

The SLR provoked a greater sense of anxiety within in me than the empirical paper. Development of a research question was a lengthy process, and I spent a significant amount of time feeling stuck about how to approach this element of the thesis project. Inevitably, this caused delays to the selection of a topic and the commencement of my SLR. In hindsight, the systematic and stringent procedural nature of the SLR was originally off-putting to me. This is possibly because the SLR process, of a project this size, was novel and provoked a feeling of uncertainty. I knew that the SLR process would demand a high level of rigour and attention to detail. However, I overcame this issue by stopping myself from overthinking or mentally overcomplicating the process; ruminating on my uncertainty was interfering with any progress. At this point, I developed a few tentative ideas and began to scope suitable literature bases. I quickly realised that whilst the psychological influence of critical care was increasingly being researched from the patient perspective, qualitatively, only one previous review had attempted to synthesise such research. This review, however, did not include research from the last decade and was published in 2013. There were other elements of the review which necessitated an updated systematic review of the literature. As soon as I recognised the feasibility of this project, I felt a shift in my attitude towards the SLR; I became passionate about the thesis project as a whole, which appeared to click into place, with both halves of the project complimenting each other well.

Upon reflection, I was not prepared for my reaction to reading through the literature base in connection to my SLR; I found the stories and experiences of others to be on a spectrum from harrowing to truly uplifting. I had assumed that the empirical research would be more difficult to sit with during data analysis. However, I was more touched than I had anticipated by others' research dealing with many patients' psychological experiences of critical care. Therefore, the need to acknowledge my own biases and lens heightened.

I was also ill-prepared for the laborious and iterative process of constructing my SLR. If asked to offer advice to other trainees, I would recommend getting started with this half of the project as early as possible without getting too caught up in securing a highly specific question to begin with. The quantity of data initially felt vast and overwhelming. My sense was that I had to learn through a hands-on approach by simply launching myself into the process. However, my choices, at every stage, were very deliberate and I learnt that I am meticulous in my approach towards research. Albeit, I found myself struggling to write concisely and to focus only on key areas of interest. To aid progress, I enhanced the standard of my work throughout by utilising the stages of Kolb's (1984) reflective model including abstract conceptualisation and active experimentation. This enabled me to gradually implement refined and upgraded techniques to assist the Narrative Synthesis, and to continuously review my approach and SLR drafts with a fresh perspective to seek out further improvements.

In the end, the writing of my SLR was a greater challenge than my empirical paper; this was both in terms of the technical procedures to follow and in persisting through an emotive journey. Despite this, to my surprise, a meaningful and coherent narrative was pulled from a large amount of data with varying focuses, methodologies, geographical locations and critical care contexts.

Final Thoughts

This research has also challenged my pre-existing beliefs. For example, that most, if not all, ICU patients wish to process and discuss their psychological experiences of critical care. Both papers, particularly the empirical paper, supported that some patients do not wish to acknowledge such experiences immediately (if at all). It has additionally emphasised, for me, the importance of supporting staff when asking them to deal with others' psychological and emotional difficulties. I was moved by participants' accounts of how difficult this may be for staff accumulatively, over time.

Additionally, this project fostered reflection around my personal views regarding researchers with lived experience of their topic of interest. I believe these researchers must deeply reflect, even more so than *usual*, on why they are completing their research and on how to carefully analyse their research findings, seeking guidance and support from colleagues when necessary. They must also explicitly consider and employ methods of maintaining their well-being throughout the research process, if the research is likely to evoke difficult emotions. However, it is my view that such researchers are a valuable resource with unique dual insight by being both professionals with research expertise (and sometimes professional experience of the subject area) and experts by experience.

Overall, I believe that both halves of the project offer something novel and consequential to the relevant fields of research and I am equally proud of both papers. It is my hope that I have represented the data in a way which speaks to the *truth* of the subjects' lived experience, across thesis project. At the very least, I am certain that I exercised all personal efforts and resources to develop this thesis project.

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Appendix B: Epistemological / Ontological Statement

Epistemology refers to the philosophy of knowledge (Willig, 2008). It is concerned with the nature of knowledge and methods of acquiring knowledge (how can something be known?), whilst ontology tackles questions of what actually exists in the world (what can be known?) (Willig, 2016). It is imperative for a researcher to understand and identify their own ontological and epistemological position, as these shape the researcher's basic beliefs and assumptions, influencing the entire research process including the nature of the research question. This statement provides a summary of the ontological and epistemological assumptions and beliefs which guided this portfolio thesis.

It can be argued that this research was informed by 'soft' (guiding, loosely held tenets) critical realist aspirations and an interpretative epistemological approach, which are argued here to be intertwined and not entirely contrasting. The following quote illustrates the usefulness of a more blended epistemological and ontological stance when using an interpretivist approach, "seeing emotions, beliefs, values, and so on as part of reality supports an interpretivist approach to understanding social phenomena without entailing a radical constructivism that denies the existence or causal relevance of a physical world" (Soini et al., 2011, p. 19). This position appeared appropriate when recruiting participants stemming from a medicalised, health context who are arguably familiar with physical, concrete, 'real world' consequences and exist within a socially influenced structure.

The researcher was drawn to better understanding lived experience but most importantly, a gap in the qualitative literature was identified in relation to lived experience. Therefore, a qualitative approach was deemed appropriate. In light of the research methodology and subject matter for the empirical paper, positivist and purely realist epistemological stances were thought to be too reductionist and concerned with objectifiable knowledge and discoverable truths (Braun & Clarke, 2013). However, the question, "how do outreach nurses experience and perceive the psychological influence of critical care upon ICU patients?", is realist in its hint towards a phenomenon, a shared experience, with ontological status; emotional, cognitive, and experiential structures existing irrespective of the researcher's efforts to acquire the participants' account of them (Willig, 2016). In addition, the researcher sought to understand implications of participants' experiences within the wider context; the external, outer, 'real' world. The empirical research question is additionally concerned with unique subjective experiences; the research sought to understand how meaning making is personally experienced and developed. Additionally, emphasis is placed in the researcher's interaction with the data, e.g., how a specific researcher interprets subjective experiences in order to learn more about participants' individual realities. In this way, the research aims are grounded in interpretative epistemology (Levers, 2013).

In order to gain the richness and depth of participants' lived experiences, whilst considering wider contextual factors, social phenomena, participants' language use, the role of the researcher, and some acknowledgement of a shared reality, Interpretative Phenomenological Analysis (IPA) (Smith et al., 2009, 2012) was considered to be an appropriate methodology to explore how outreach nurses experience and perceive the psychological influence of critical care upon ICU patients. Importantly, the research aims did not necessitate generalisation of the research findings, again making IPA a good methodological fit. Notably, IPA can be both a method and a methodology as it draws together ontology/ epistemology and methods within a research paradigm. However, it does so flexibly and varies across a relativist-critical realist dimension with different potential paradigms.

In terms of the systematic literature review, a Narrative Synthesis of qualitative studies was undertaken to construct a meaningful narrative of the included articles (Popay et al., 2006). A Narrative Synthesis is therefore concerned with story construction and is an appropriate methodology to encapsulate the findings of articles with varied focuses, geographical locations, methodologies, sample sizes, and frames of reference. An interpretative epistemological stance also extended to the systematic literature review, as studies attempted to understand and interpret participants' lived experiences with many of the articles acknowledging the role of the researcher in offering their own unique interpretation. Additionally, some of the methodologies within the synthesis were also aligned with critical realist aspirations, e.g., Grounded Theory (Glaser & Strauss, 1967), according to Willig (2016). Narrative Synthesis therefore arguably 'solved' the problem of varied epistemological and methodological positions, pulling together similar threads across research papers.

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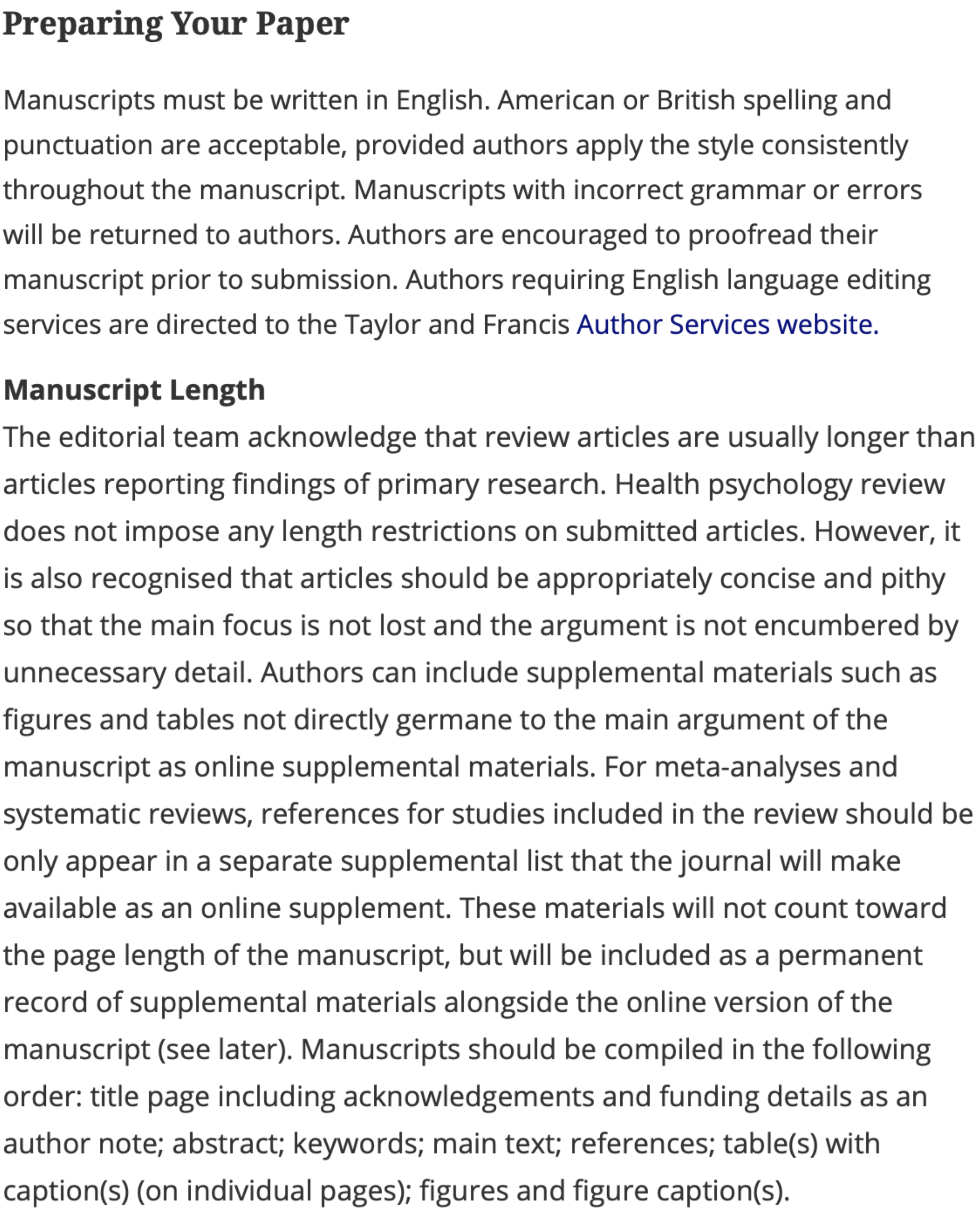

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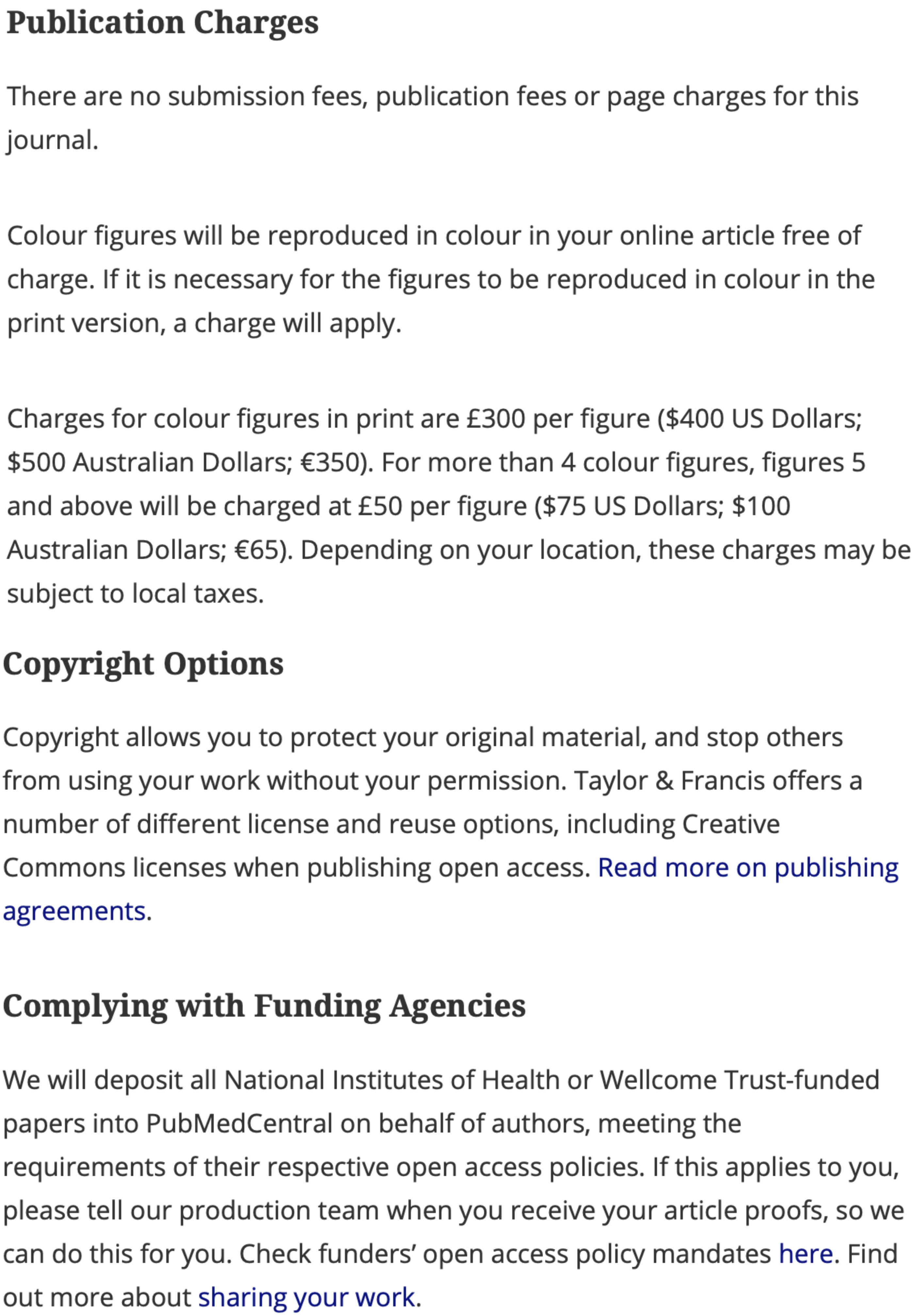

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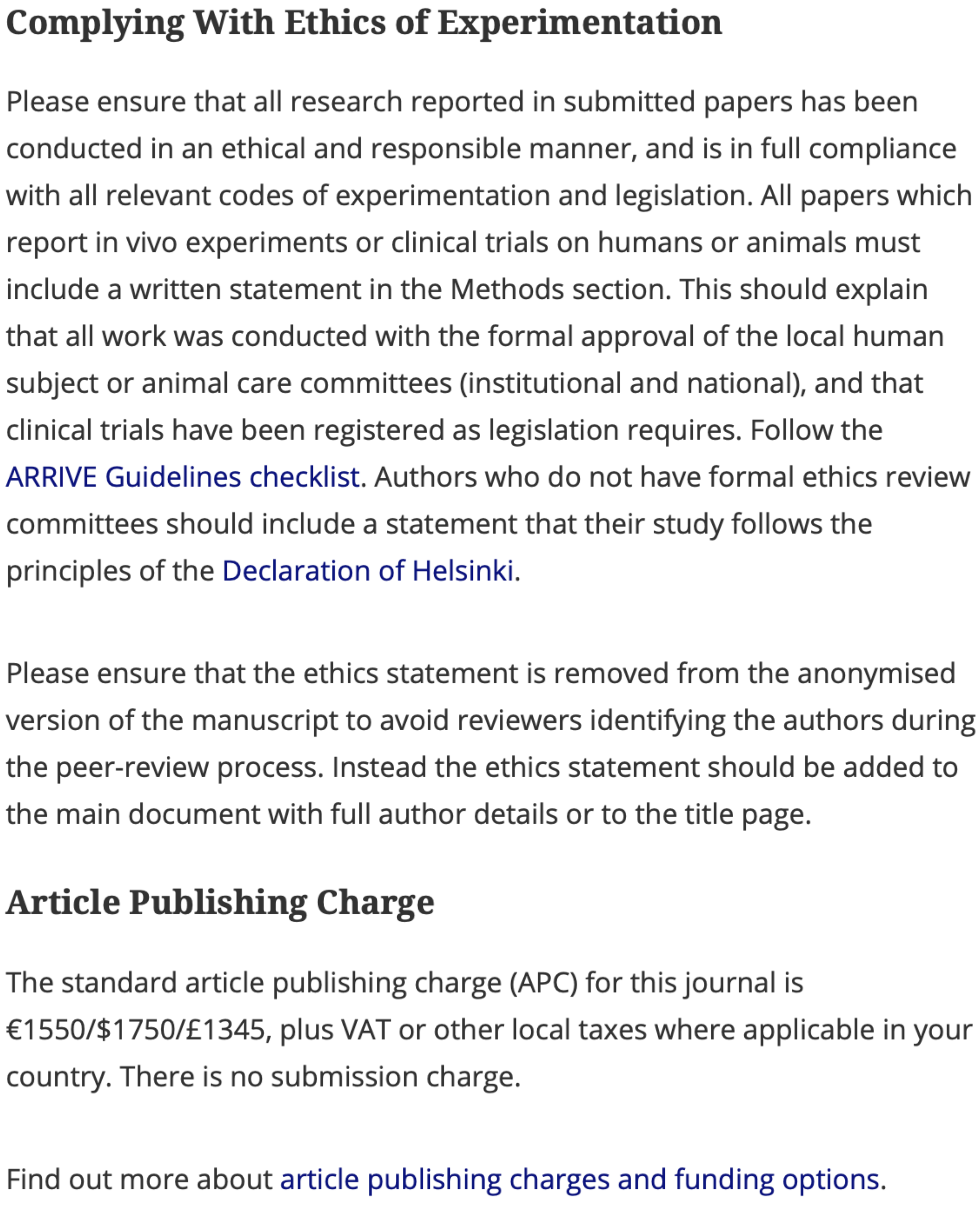

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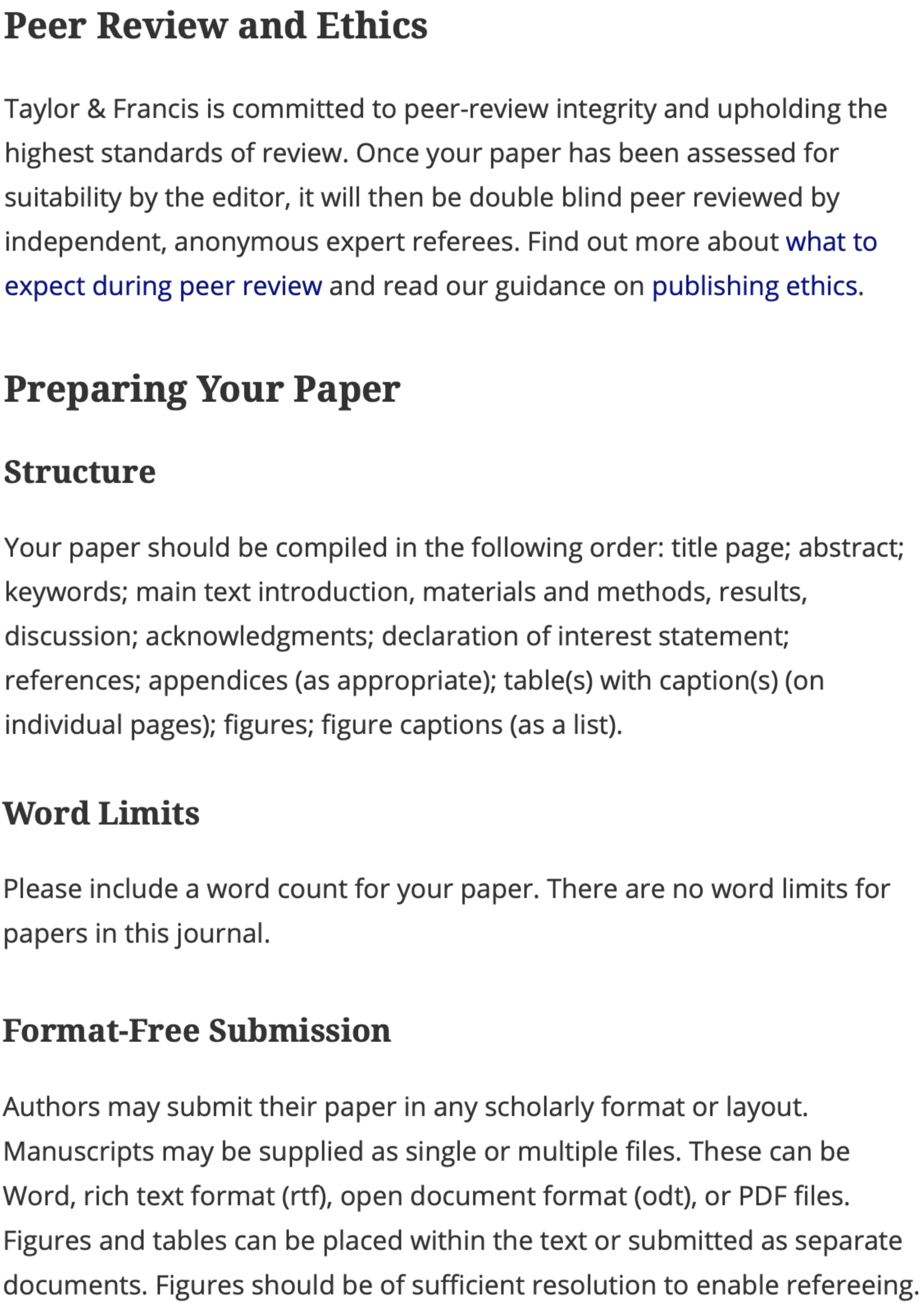

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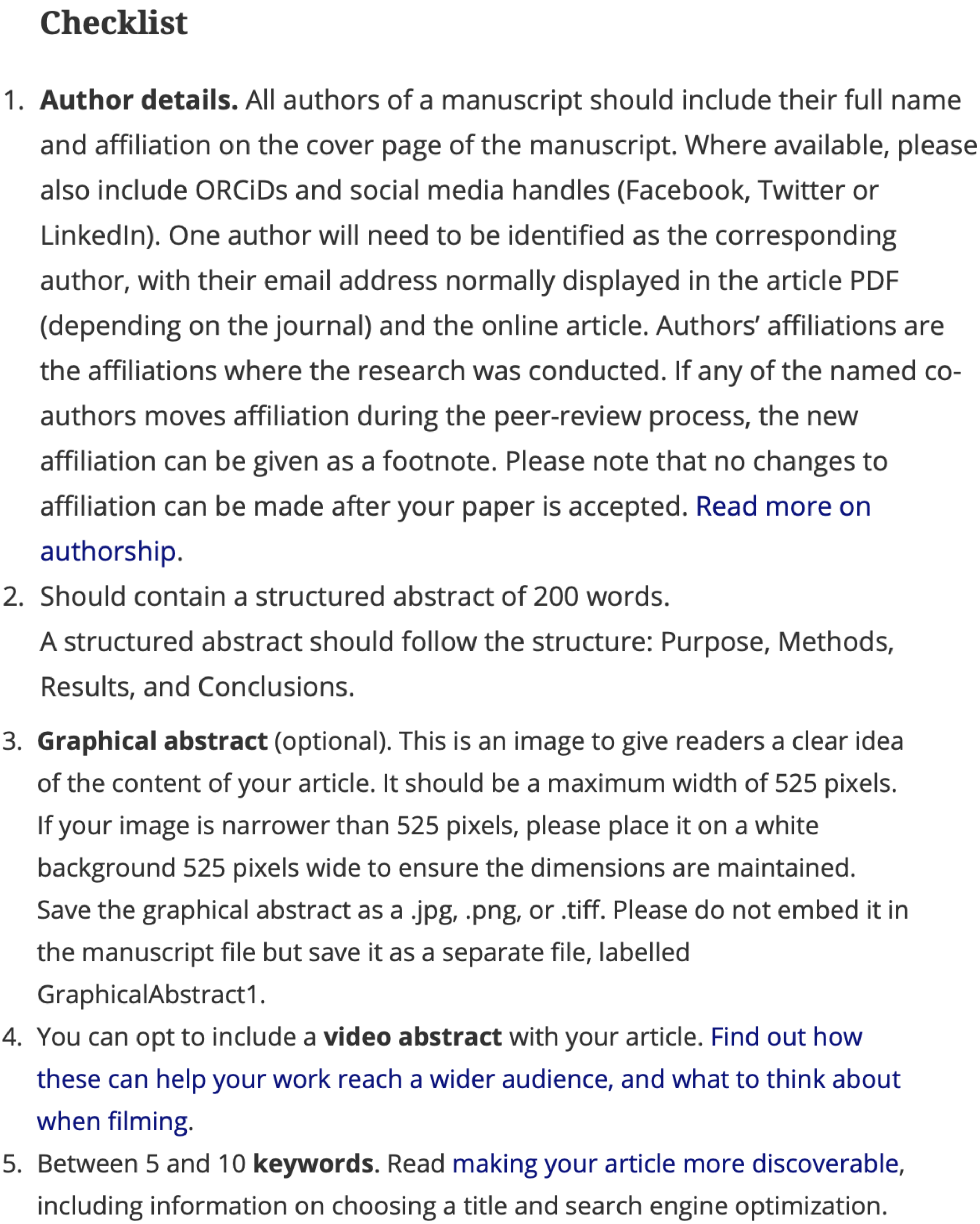

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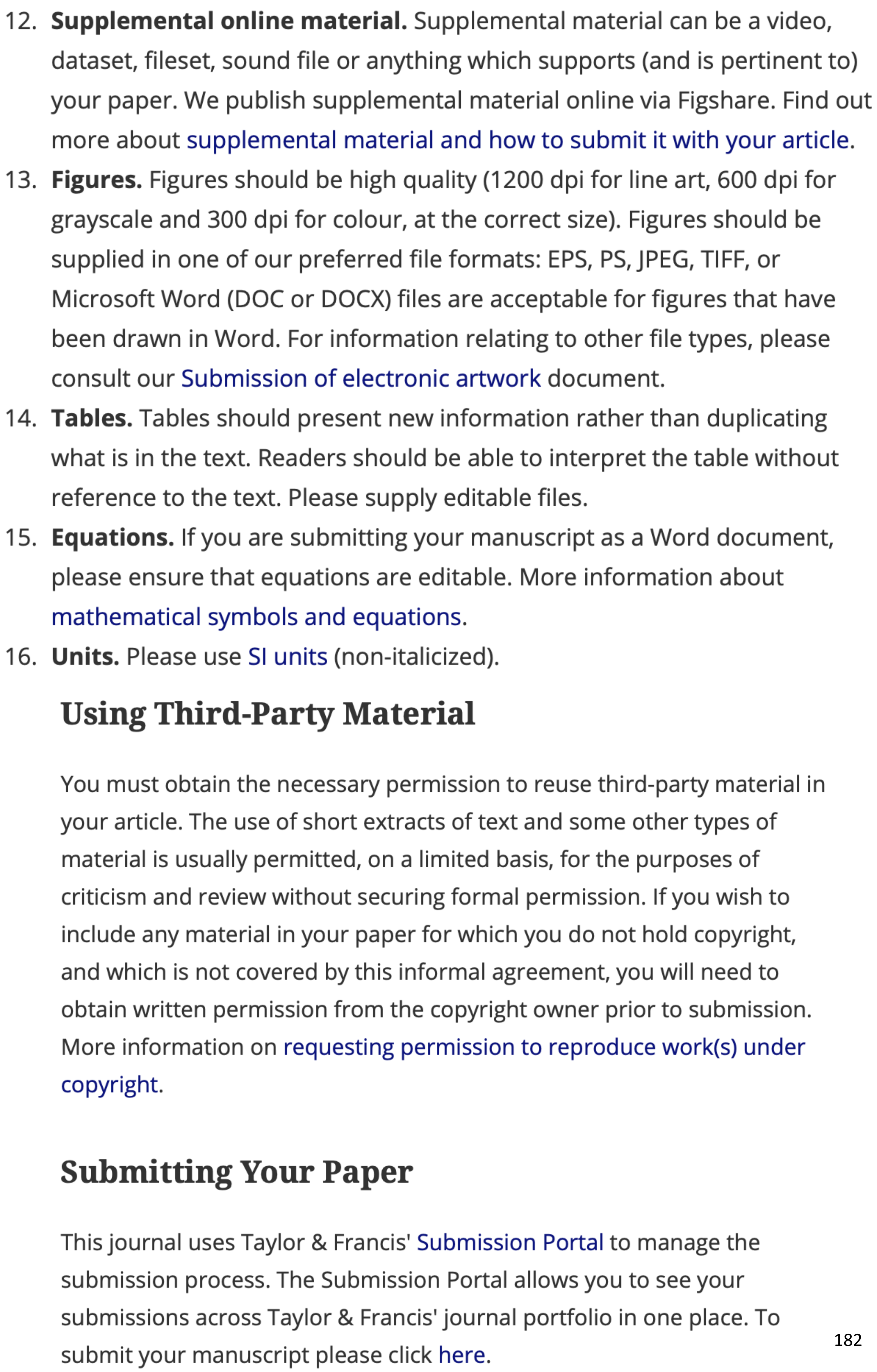

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Appendix D: Data Extraction Form Example

Study Title: Making Sense of It: Intensive Care Patients' Phenomenological Accounts of Story Construction.

General Article Information

Author(s): Stayt, L. C., Seers, K., & Tutton, L.

Year of Publication: 2016

Research Aims: “The aim of this article is to examine the process of story construction in people's phenomenological accounts of being a patient in the technological environment of intensive care”.

Participants

Sample Size: 19

Sample Demographics: >18 Years (aged between 32-86). All white, English participants. Participants were in the ICU for 4 or more days (average length of stay was 2.1 weeks… ranging from 1 to 4 weeks). “Average time since discharge from the ICU at the time of the interview was 4.3 months (±0.8 months) and ranged from 3 to 7 months”.

Recruitment Setting: “The research was conducted in a university teaching hospital in the south of England in a general ICU”.

Methodology

Method of Data Collection: “Semi-structured interviews, lasting 45–90min”.

“From 2009 to 2011, **convenience samples** of these patients were invited by letter to participate in an interview either before or after their scheduled appointment”.

Theoretical Approach and Data Analysis: The “design of this study was informed by Heideggerian phenomenology”. The study used thematic analysis.

Quality Checklist Score: ++

Findings and Conclusions

Main Findings:

Main Theme: “Making sense of it”.

Sub-Themes: “Why I am here?”, “filling in the gaps”, “sorting the real from the unreal" and "searching for familiarity".

Other Main Findings: "Participants invariably started their story by describing the events leading up to their critical illness". "All participants… had a clear idea of the physical reasons that had led to their ICU admission".

"Some participants appeared to emphasise the chronology of events and spent time making sure that the chronology was correct, often referring to a picket diary or verifying with their relatives". "The complete, chronological account of events leading up to their ICU admission appears to be important to participants. Together with an understanding of their physical ailments".

"All participants describe having patchy memories and often expressed frustration at not having the complete picture". "The importance of having somebody, most commonly a family member, fill in the gaps".

"Just as participants can describe a definite time when clear memories disappear, most participants can distinguish a time when they are suddenly aware that they are full conscious". "In between these two-time frames… memories are hazy, some are based in reality and others are based on their dream-like state or their distorted perception of events at the time". "Spent a lot of time trying to distinguish which memories were real and which were part of their dream world". "Reality and unreality were intermingled and sometimes inseparable". "Many relied upon family members to help them sort the real from the unreal".

"Frequently, a participant's real memories were of specific events or interventions". "Participants appeared to be unable to accurately recall their environment or recall and details or memories of the people caring for them".

"Relied upon familiar factors… such factors primarily included a sense of time and routine, familiar people and activities". "Often unable to distinguish night from day". "Knowing the time was important as it gave them a sense of orientation".

"Familiar people and activities provided a sense of reassurance and normality and helped them situate their personal experiences".

Limitations:

The study spoke about context bias and its own limitations acknowledging that this was a "single centre study in the UK with the sample only consisting of white Europeans. The findings may therefore not reflect other regions within the UK and abroad". "Only patients who attended follow-up clinics were recruited; participation of patients, who potentially may have made rich contributions to the data but did not want to attend the clinics, may have been inadvertently restricted". "The self-selecting nature of the recruitment process meant that those who felt that they had memories of the ICU and were willing and able to share them may be more inclined to participate than those with limited memories or those too traumatized to share their experiences. The process of constructing a story may be different in these two groups". However, the methodology and aims of the study were not centred around generalising the findings.

Doesn't explicitly discuss justification for sampling techniques.

Doesn't fully justify selection of cases/ sampling strategy.

Relationship between the researcher and participants isn't clearly defined.

Research describes how the study was presented to the participants but not how it was explained.

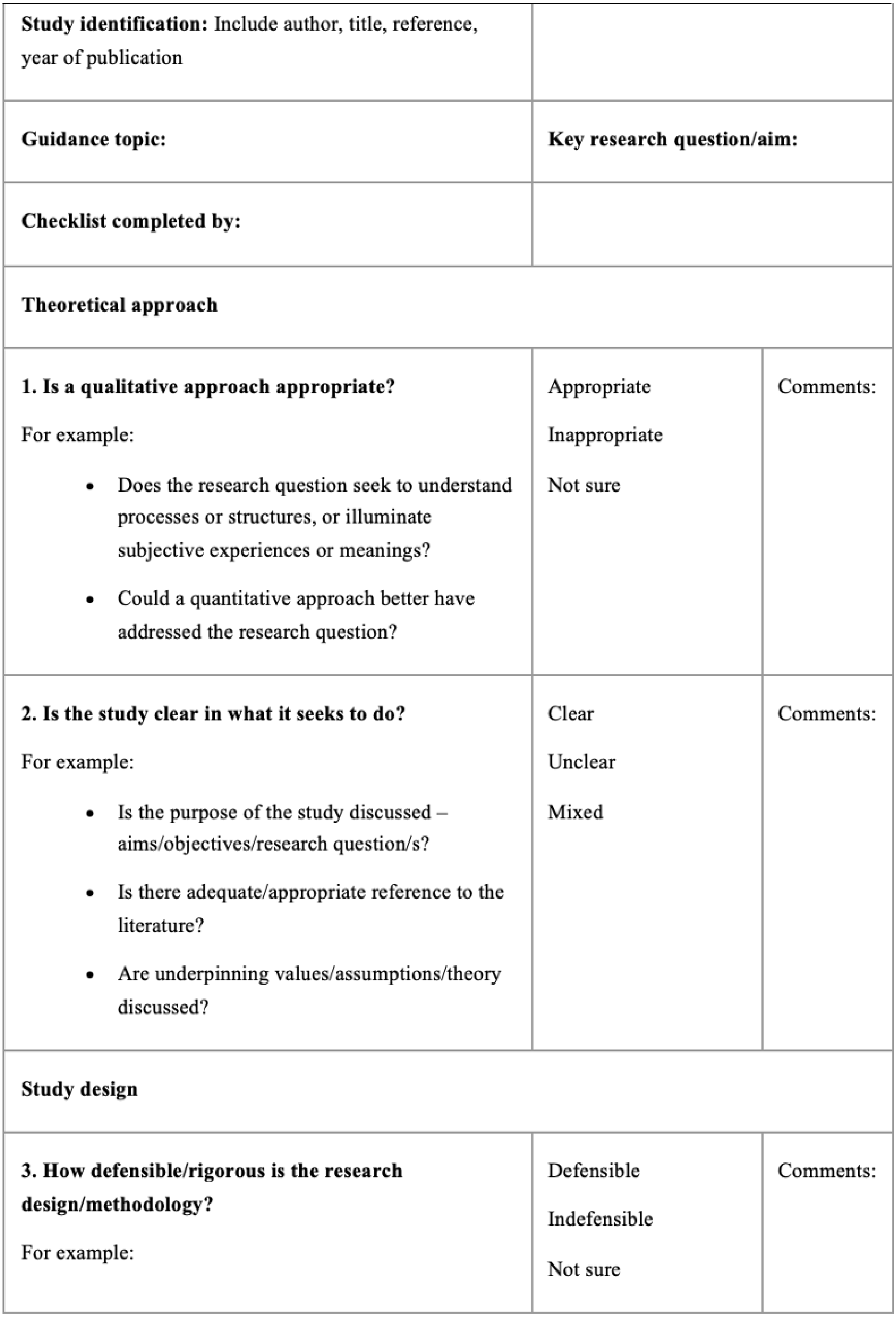
Participants' gender not reported.

There isn't much in the way of contrasted responses within groups. Unsure if the diversity of perspective and content has been explored.

Conclusions:

"The importance of early support from health care professionals to facilitate patients' story construction is highlighted. The study also emphasizes the role families play in supporting patients while they make sense of their experiences and the associated psychological recovery process. Further research to evaluate methods of facilitating story construction, such as nurse-led debriefing and patient diaries, is recommended. In addition, an investigation of families' perceptions of their role in assisting patients construct their story may facilitate the development of strategies by health care professionals to effectively support families in their role".

Appendix E: NICE Quality Assessment Checklist



Study identification: Include author, title, reference, year of publication		
Guidance topic:	**Key research question/aim:**	
Checklist completed by:		
Theoretical approach		
1. Is a qualitative approach appropriate? For example: • Does the research question seek to understand processes or structures, or illuminate subjective experiences or meanings? • Could a quantitative approach better have addressed the research question?	Appropriate Inappropriate Not sure	Comments:
2. Is the study clear in what it seeks to do? For example: • Is the purpose of the study discussed – aims/objectives/research question/s? • Is there adequate/appropriate reference to the literature? • Are underpinning values/assumptions/theory discussed?	Clear Unclear Mixed	Comments:
Study design		
3. How defensible/rigorous is the research design/methodology? For example:	Defensible Indefensible Not sure	Comments:

• Is the design appropriate to the research question? • Is a rationale given for using a qualitative approach? • Are there clear accounts of the rationale/justification for the sampling, data collection and data analysis techniques used? • Is the selection of cases/sampling strategy theoretically justified?		
Data collection		
4. How well was the data collection carried out? For example: • Are the data collection methods clearly described? • Were the appropriate data collected to address the research question? • Was the data collection and record keeping systematic?	Appropriately Inappropriately Not sure/inadequately reported	Comments:
Trustworthiness		
5. Is the role of the researcher clearly described? For example: • Has the relationship between the researcher and the participants been adequately considered? • Does the paper describe how the research was explained and presented to the participants?	Clearly described Unclear Not described	Comments:

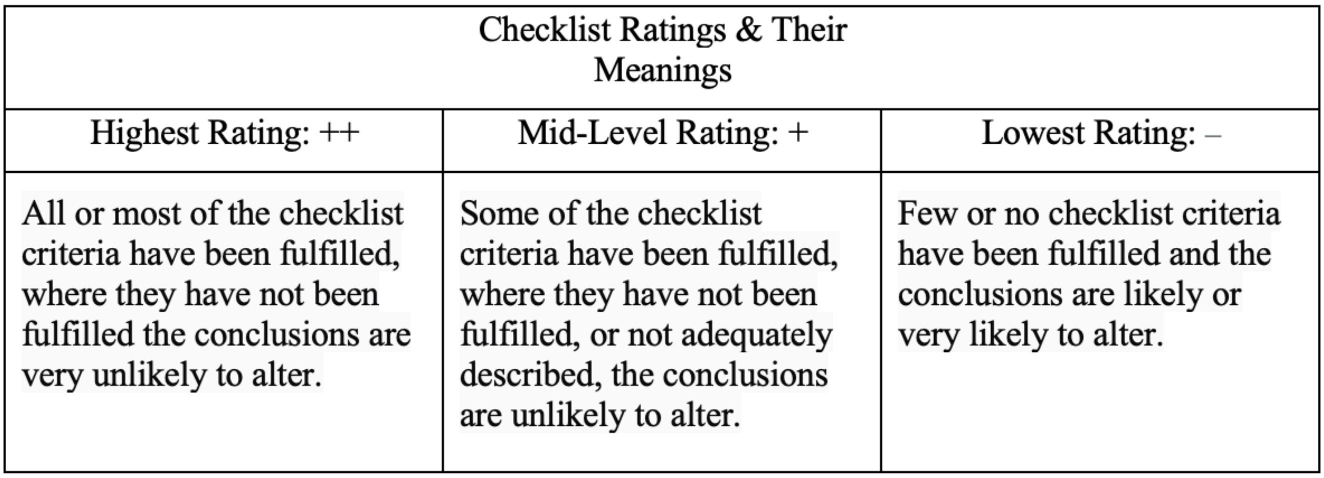
6. Is the context clearly described? For example: • Are the characteristics of the participants and settings clearly defined? • Were observations made in a sufficient variety of circumstances • Was context bias considered	Clear Unclear Not sure	Comments:
7. Were the methods reliable? For example: • Was data collected by more than 1 method? • Is there justification for triangulation, or for not triangulating? • Do the methods investigate what they claim to?	Reliable Unreliable Not sure	Comments:
Analysis		
8. Is the data analysis sufficiently rigorous? For example: • Is the procedure explicit – i.e., is it clear how the data was analysed to arrive at the results? • How systematic is the analysis, is the procedure reliable/dependable? • Is it clear how the themes and concepts were derived from the data?	Rigorous Not rigorous Not sure/not reported	Comments:
9. Is the data 'rich'?	Rich	Comments:

For example: • How well are the contexts of the data described? • Has the diversity of perspective and content been explored? • How well has the detail and depth been demonstrated? • Are responses compared and contrasted across groups/sites?	Poor Not sure/not reported	
10. Is the analysis reliable? For example: • Did more than 1 researcher theme and code transcripts/data? • If so, how were differences resolved? • Did participants feedback on the transcripts/data if possible and relevant? • Were negative/discrepant results addressed or ignored?	Reliable Unreliable Not sure/not reported	Comments:
11. Are the findings convincing? For example: • Are the findings clearly presented? • Are the findings internally coherent? • Are extracts from the original data included? • Are the data appropriately referenced? • Is the reporting clear and coherent?	Convincing Not convincing Not sure	Comments:

12. Are the findings relevant to the aims of the study?	Relevant Irrelevant Partially relevant	Comments:
13. Conclusions For example: • How clear are the links between data, interpretation and conclusions? • Are the conclusions plausible and coherent? • Have alternative explanations been explored and discounted? • Does this enhance understanding of the research topic? • Are the implications of the research clearly defined? **Is there adequate discussion of any limitations encountered?**	Adequate Inadequate Not sure	Comments:
Ethics		
14. How clear and coherent is the reporting of ethics? For example: • Have ethical issues been taken into consideration? • Are they adequately discussed e.g., do they address consent and anonymity? • Have the consequences of the research been considered i.e., raising expectations, changing behaviour?	Appropriate Inappropriate Not sure/not reported	Comments:

- Was the study approved by an ethics committee?		
Overall assessment		
As far as can be ascertained from the paper, how well was the study conducted? (see guidance notes)	++ + –	Comments:

Appendix F: Quality Assessment Checklist Ratings



Checklist Ratings & Their Meanings		
Highest Rating: ++	Mid-Level Rating: +	Lowest Rating: –
All or most of the checklist criteria have been fulfilled, where they have not been fulfilled the conclusions are very unlikely to alter.	Some of the checklist criteria have been fulfilled, where they have not been fulfilled, or not adequately described, the conclusions are unlikely to alter.	Few or no checklist criteria have been fulfilled and the conclusions are likely or very likely to alter.

Appendix G: Original Articles' Themes & Subthemes

Dependence & Violation

- With Dependency and Critical Illness, the Relation to the Self is Changed
- Being Dependent on Care Can Mean you are Violated
- To be Dependent on Care Influences Self-Understanding
- Accepting Dependence
- Feeling Violated
- Letting the Carers Take Over
- Acknowledged Dependence
- There is a Deep Gratitude Linked to the Dependency
- Surrendering
- Feeling Trapped
- It is Associated with Shame to Receive Help for Care

Understanding & Meaning

- A Trajectory Towards Partnership in Care Depending on State of Health and Mutual Understanding
- A Struggle to Understand
- Lacking Mutual Understanding
- To Understand and to Be Understood
- To Create Meaning and Coherence
- Making Sense of It
- Meaning and Purpose; Feeling Valuable to Somebody

Humanising Care / Being Seen as a Person

- To Be Seen
- Being in Someone's Shoes
- Being Recognised as a Person
- Being Noticed
- Being Asked
- Being Listened to
- Being Shown Respect
- Being Respected
- Being Given Information
- Information and Education
- Communication
- Bring Encouraged
- Being Heard and Seen

Independence & Partnership in Care

- Invited Participation
- Becoming a Co-Partner in Care
- Being Invited to Initiate Care Activities
- Being Part of the Care Relationship
- Participation in Decision Making
- Exerting Active Influence on Care
- Experiencing Independence
- Taking Personal Responsibility
- To Participate
- Doing It My Way

Recalibration of the Self / Changed Identity

- To Recover in an Unfamiliar Body
- To Strive for Reconciliation
- Altered Sensations and a Disobedient Body
- Learning to Live in a Changed Body
- Recalibration of the Self
- From Prior Self to Current Self
- Back to the Future
- From Current Self to Construction of the Future Self
- A Struggle to Return to Ordinary Life

Powerlessness & Loss of Control

- Sense of Powerlessness and Striving to Regain Control
- Losing Control
- You Feel Powerlessness During Critical Care
- Loss of Empowerment
- To Surrender

Unusual Experiences & Living Between the Real and Unreal

- Between the Real and Unreal
- Disconnectedness
- Searching for Familiarity
- Tiring Delusions
- ICU Dreaming
- Filling in the Gaps
- Vivid Dream Experiences That Ignite the Willpower
- Being on an Unreal Strange Journey
- Sorting the Real From the Unreal
- Normalising the Abnormal
- New Perspectives on Normality
- Floating Between Facts and Delusions
- Religion and Spirituality

Exposed & Vulnerable

- Exposed in Vulnerability
- Embracing the New Vulnerable Self
- Being Vulnerable
- To Be Exposed

Existential Questions, Issues & Realisations

- Why Am I Here?
- The Wish to Go on Living
- Strong Connectedness to Life; Feeling Alive and Present
- How to Ignite and Maintain the Spark of Life
- New Crisis
- To Live in the Very Moment
- Life Changing
- Having Motivation and a Vital Force
- Mobilising Internal/ External Resources
- No Doubt About Coming Back to Life

The Experience of care

- Feeling Trust
- The Relationship to the Care Staff is Ambivalent
- Absent Support
- Personal Support
- Assessment and Therapy
- The Relationship to Staff is Personal and Caring

Connectedness to Others

- Valuing Family
- To Have the Support of Next of Kin
- Presence

Ambivalent Emotions & The ICU Journey

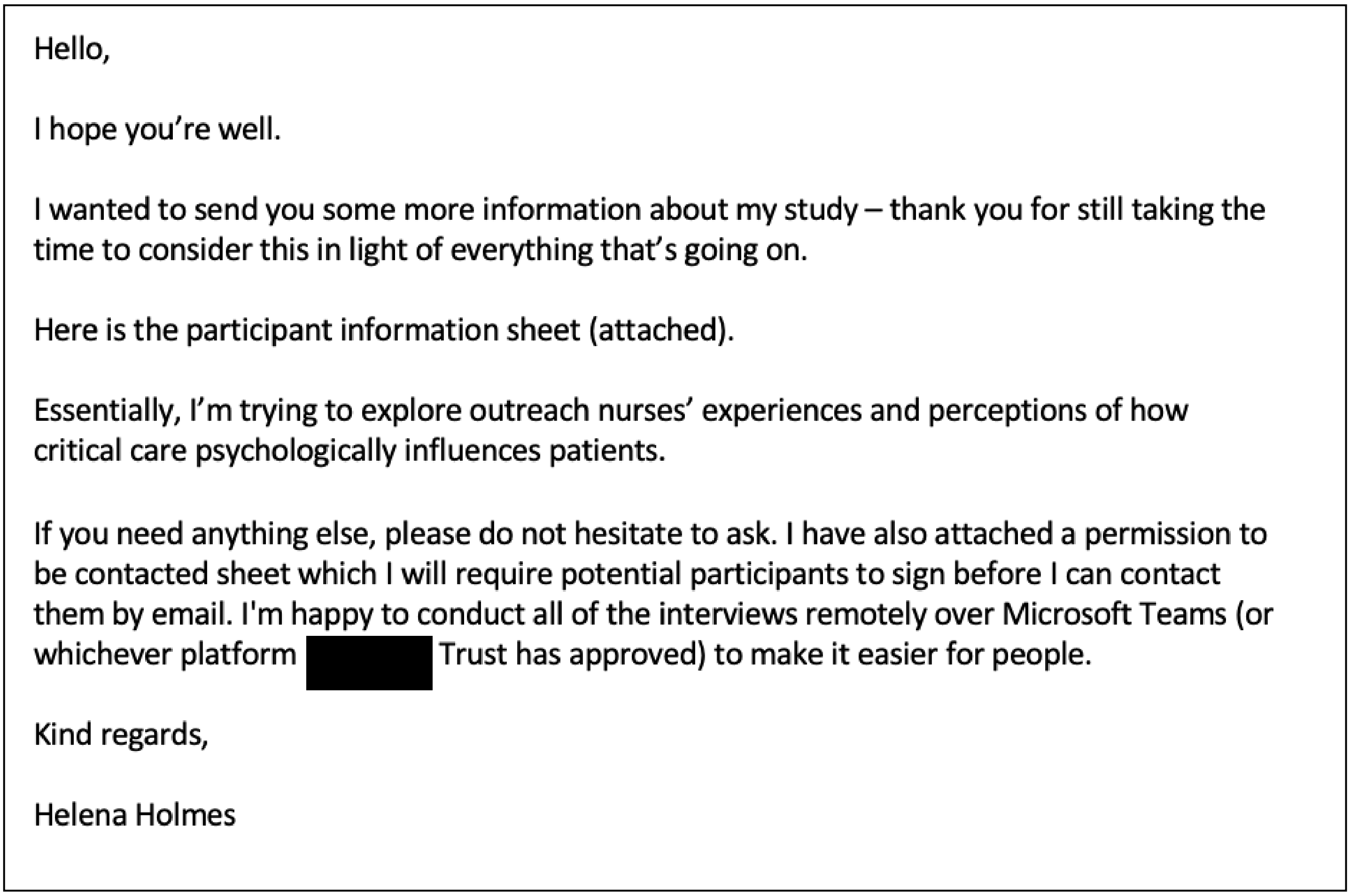
- To Endure
- To Feel Hope
- Being Devastated
- Frustration About Inability to Speak
- Struggling for Recovery
- Living in the Worst Horror Movie
- Resting From the Illness
- Physical Changes
- Mental Discomfort
- Recovery Confusion
- Signs of Progress
- Practical Solutions, Coping Skills From Previous Life Experiences
- Provocative and Inspiring Experiences
- Exhaustion, Weakness and Discomfort
- Private Memories
- Learning to Reflect

Appendix H: Original Articles' Titles

Article Author(s)	Article Title
Alpers, Helseth & Bergbom (2012)	Experiences of Inner Strength in Critically Ill Patients—A Hermeneutical Approach.
Deacon (2012)	Re-Building Life After ICU: A Qualitative Study of the Patients' Perspective.
Lykkegaard & Delmar (2013)	A Threat to the Understanding of Oneself: Intensive Care Patients' Experiences of Dependency.
Ramsay, Huby, Thompson & Walsh (2014)	Intensive Care Survivors' Experiences of Ward-Based Care: Meleis' Theory of Nursing Transitions and Role Development Among Critical Care Outreach Services.
Lindberg, Sivberg, Willman & Fagerström (2015)	A Trajectory Towards Partnership in Care—Patient Experiences of Autonomy in Intensive Care: A Qualitative Study.
Lykkegaard & Delmar (2015)	Between Violation and Competent Care—Lived Experiences of Dependency on Care in the ICU.
Moen & Nåden (2015)	Intensive Care Patients' Perceptions of How Their Dignity is Maintained: A Phenomenological Study.
Palesjö, Nordgren & Asp (2015)	Being in a Critical Illness-Recovery Process: A Phenomenological Hermeneutical Study.
Stayt, Seers & Tutton (2015)	Making Sense of It: Intensive Care Patients' Phenomenological Accounts of Story Construction.

Olsen, Nester & Hansen (2017)	Evaluating the Past to Improve the Future – A Qualitative Study of ICU Patients’ Experiences.
Wermström, Ryrlén & Axelsson (2017)	From Powerlessness to Striving for Control – Experiences of Invasive Treatment While Awake.
Ewens, Hendricks & Sundin (2018)	Surviving ICU: Stories of Recovery.
Kang & Jeong (2018)	Embracing the New Vulnerable Self: A Grounded Theory Approach on Critical Care Survivors’ Post-Intensive Care Syndrome.
Alexandersen, Stjern, Eide, Haugdahl, Paulsby, Lund & Haugan (2019)	"Never in My Mind to Give up!" A Qualitative Study of Long-Term Intensive Care Patients' Inner Strength and Willpower - Promoting and Challenging Aspects.
Corner, Murray & Brett (2019)	Qualitative, Grounded Theory Exploration of Patients' Experience of Early Mobilisation, Rehabilitation and Recovery After Critical Illness.
Kisorio & Langley (2019)	Critically Ill Patients' Experiences of Nursing Care in the Intensive Care Unit.

Appendix I: Recruitment Material



Hello,

I hope you're well.

I wanted to send you some more information about my study – thank you for still taking the time to consider this in light of everything that's going on.

Here is the participant information sheet (attached).

Essentially, I'm trying to explore outreach nurses' experiences and perceptions of how critical care psychologically influences patients.

If you need anything else, please do not hesitate to ask. I have also attached a permission to be contacted sheet which I will require potential participants to sign before I can contact them by email. I'm happy to conduct all of the interviews remotely over Microsoft Teams (or whichever platform [redacted] Trust has approved) to make it easier for people.

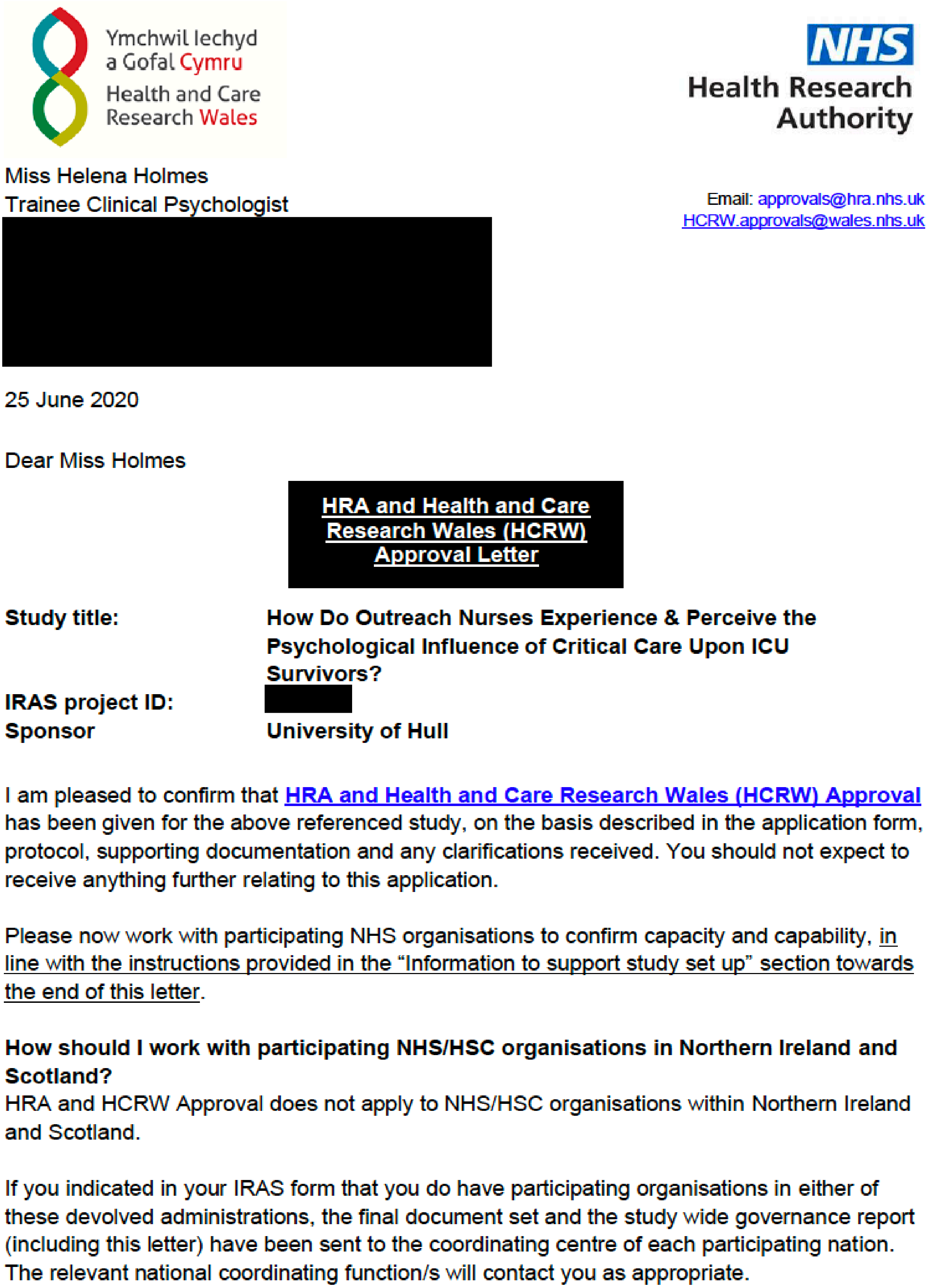
Kind regards,

Helena Holmes

Additional context:

This was not the first time contact had been made with the lead outreach nurse of the team participants were recruited from; the lead outreach nurse already had information about the study and the lead researcher's role. Notably, this email was also sent in the context of the COVID-19 pandemic – "in light of everything that's going on".

Appendix J: Documentation of Ethical and R&D Approval



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

Miss Helena Holmes
Trainee Clinical Psychologist
[redacted]

25 June 2020

Dear Miss Holmes

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**How Do Outreach Nurses Experience & Perceive the Psychological Influence of Critical Care Upon ICU Survivors?**
IRAS project ID:	[redacted]
Sponsor	**University of Hull**

I am pleased to confirm that HRA and Health and Care Research Wales (HCRW) Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The *"After HRA Approval – guidance for sponsors and investigators"* document on the HRA website gives detailed guidance on reporting expectations for studies with HRA and HCRW Approval, including:

- Registration of Research
- Notifying amendments
- Notifying the end of the study

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

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is [redacted] Please quote this on all correspondence.

Yours Sincerely
Beverley Mashegede

Email: approvals@hra.nhs.uk

Copy to; Dr David Richards, Sponsor Contact

UNIVERSITY
OF HULL

University of Hull
Hull, HU6 7RX
United Kingdom
T: +44 (0)1482 463336 | **E:** e.walker@hull.ac.uk
w: www.hull.ac.uk

PRIVATE AND CONFIDENTIAL
Helena Holmes
Faculty of Health Sciences
University of Hull
Via email

8th April 2020
version 1.0

Dear Helena

REF [redacted] How Do Outreach Nurses' Experience & Perceive the Psychological Influence of Critical Care Upon ICU Survivors?

Thank you for your responses to the points raised by the Faculty of Health Sciences Research Ethics Committee.

Given the information you have provided I confirm approval by Chair's action.

Please refer to the Research Ethics Committee web page for reporting requirements in the event of any amendments to your study.

I wish you every success with your study.

Yours sincerely

Professor Liz Walker
Chair, FHS Research Ethics Committee

UNIVERSITY
OF HULL

Liz Walker | Professor of Health and Social Work Research |
Faculty of Health Sciences
University of Hull
Hull, HU6 7RX, UK
www.hull.ac.uk
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@UniOfHull /UniversityOfHull universityofhull

From: [redacted]
Sent: 07 July 2020 10:12 AM
To: HOLMES, Helena (HUMBER TEACHING NHS FOUNDATION TRUST) <helena.holmes@nhs.net>
Cc: [redacted]
Subject: [redacted] Confirmation of Capability and Capacity [redacted]

Dear Miss Holmes

Confirmation of Capacity and Capability at [redacted]

(Please retain a copy of this email as this confirms NHS permission for this site)

IRAS: [redacted]
LOCAL ref:
EDGE ID:
REC ref: N/A Staff as Participants

Full Study Title: How Do Outreach Nurses Experience & Perceive the Psychological Influence of Critical Care Upon ICU Patients?
PI: Miss Helena Holmes
Academic Supervisors: Dr Jo Beckett / Dr Christopher Clarke
Sponsor: University of Hull
[redacted] **Local Collaborator:** [redacted]

This email confirms that [redacted] Trust has the Capacity and Capability to deliver the above referenced study.

It is noted that all internal and regulatory approvals are in place. It is noted that you currently hold the appropriate contract of employment with the Trust

Given the current pandemic situation, you must ensure you take the appropriate steps to protect yourself and any staff member that may agree to participate by adhering to the Government and Trust guidelines regarding Social Distancing and where appropriate the wearing of PPE

Please liaise with your contact within the Trust to arrange a suitable start date and inform me of the actual date the research activity commences.

If you haven't already, you will shortly receive an email requesting you to set up your account on the EDGE system. The study is on the EDGE database www.edge.nhs.uk and can be found using the R&D reference, IRAS number, EDGE ref or the study title all shown above. You will need to ensure the study is updated on EDGE with the following;

- All recruitment data. Via the patient tab.

If you need any further support from R&D, please do not hesitate to contact me.

With best wishes for a successful study.

Kind regards

Appendix K: Participant Information Sheet

UNIVERSITY OF HULL | FACULTY OF HEALTH SCIENCES

Version number: 2.0

24.06.2020

Participant Information Sheet

IRAS Research Project ID: [redacted]

We would like to invite you to take part in a research study. Before you decide, we would like you to understand why the research is being done and what it would involve for you. ***Please read the information below. If you have any questions, please ring the number at the end of this form.***

Title: "How Do Outreach Nurses Experience & Perceive the Psychological Influence of Critical Care Upon ICU Patients?"

Background

It is important to conduct this study as research proposes that ICU patients are a highly vulnerable population; these individuals have experienced significant difficulties with their physical health and are also at higher risk of developing mental health difficulties. It is also important to give outreach nurses a voice in sharing their own experiences and to allow them to communicate how they perceive ICU patients to be psychologically influenced by critical care – including the experience of patients receiving care from outreach nurses. To date, to the best of the researcher's knowledge, this has not yet been done.

What is the purpose of the study?

To explore outreach nurses' experiences and perceptions of ICU patients' psychological experiences of the critical care journey (ICU admission, ICU & step-down care).

To highlight outreach nurses' experiences to gain insight into how they make sense of the psychological influence of critical care.

The aims will be achieved by conducting an hour-long interview with each participant.

Why have I been invited?

If you are an outreach nurse with three years (or more) of experience within your current job role and you are working at [redacted] then you are invited to take part in this study because you can provide vital information which fills a gap within the current literature on ICU patients' psychological experiences.

Do I have to take part?

No, it is up to you to decide whether or not you want to take part. This information will tell you what is involved in the study. Whether or not you take part will not affect your work in any way.

What will happen if I decide to take part?

If you decide to take part, you should:

- **Email the researcher confirming that you are happy to be contacted** to discuss the study further – please email helena.holmes@nhs.net within two weeks of receiving this information sheet.

The researcher will then get in touch with you in April/ May 2020, and if you are still happy to proceed, arrange a date and time to conduct an interview; this interview will last approximately 60 minutes and can be conducted either face-to-face in person or over a video conferencing platform such as Microsoft Teams.

What are the possible disadvantages and risks of taking part?

Taking part in this study requires some of your time, but the interview can be undertaken at a time that suits you. This study may also mean that you are asked to think about some sensitive issues (the psychological impact of being in ICU) which have the potential to be upsetting, however, you will be fully debriefed at the end of the study and given contacts of sources of support. In addition, you are free to withdraw from the study at any point before data analysis.

Additionally, this study will take up to 60 minutes to complete.

What are the possible benefits of taking part?

You may become more aware of your views and feelings around this topic, you may be more likely to discuss matters arising from the research in supervision (seeking more support) and the research will provide insight into the current system in place for psychological support for ICU patients as well as fill an important gap within the literature (offering a better understanding of how critical care may psychologically influence ICU patients).

What will happen if I decide I no longer wish to take part?

If before, during or after the interview you decide you no longer wish to take part, you may contact the researcher and we will arrange for the data to be destroyed. This will only be possible up to the point of transcription of the data in preparation for the study write-up. The timeframe between interview dates and transcription will be roughly 4-5 months.

If you decide not to take part, you do not need to do anything; we will assume you do not wish to participate.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researcher; the research will gladly answer your questions. If you remain unhappy and wish to complain formally, you can request to speak to the researcher's supervisors whose contact details are at the bottom of this form.

Will my taking part in this study be kept confidential?

All data will be handled according to ethical and legal practice. All information which is collected about you during the course of the research will be anonymised. Your completed interview transcript will be given a code number which will be used throughout the analysis of the results. The coded data will be stored securely on University Departmental premises for five years after completion of the study.

What will happen to the results of the study?

The results will be written up and submitted for publication in a scientific journal. A report regarding the findings of the study will also be made available to the participants of the project should they wish for such a report to be compiled. Information about the results will be available in April/ May 2021 and the researcher is happy to provide feedback before the publication/ formal submission of the study to the University of Hull for partial requirement of completing and acquiring a doctorate in clinical psychology (ClinPsyD).

Who is organising and funding the research?

This research is being undertaken at the University of Hull in collaboration with [redacted]

Who has reviewed the study?

All research in the NHS is looked at by external professionals in the process of gaining ethical approval to commence data collection; this is to protect your safety, rights, wellbeing and dignity. This study has also been peer reviewed by the researcher's supervisors and other psychologists at the University of Hull. The research project received a favourable review from the Faculty of Health Sciences Research ethics committee (University of Hull).

Data handling and confidentiality

Your data will be processed in accordance with the General Data Protection Regulation 2019 (GDPR). You should be made aware of the following data protection procedures:

- Audio recordings will be recorded on an NHS Humber Teaching Foundation Trust laptop which has several layers of security - personal login and password required, kept in a bag with a combination code lock, kept in a secure place (out of sight).

- Signed consent forms will be kept in a separate locked bag within a locker cabinet at the University of Hull (in the researcher's supervisors' office). Only the researcher will have access to all of the above, and if and when necessary so will the primary researcher's supervisors.

- The only personal data held will be with regards to:

    - Job role, age, email addresses, gender and years of experience (roughly). Your name will be additionally be recorded on the permission to be contacted sheet (and on this sheet only). This information will be kept separately from electronic recordings and consent forms. This information will be kept in a locked bag within a separate filing cabinet of the researcher's supervisors' office within the University of Hull. The data disposed of (paper information shredded) after data write-up.

- Pseudonyms will be used to quote participants within the final research write-up.
- Personal data will be retained for less than 3 months after the study has ended. Research data will be retained for 10 years, after the study has ended, on secure network drives (belonging to the project supervisors) at the University of Hull.
- Data will only be shared within the research team, consisting of the researcher and the researcher's supervisors.

Data Protection Statement

The data controller for this project will be the University of Hull. The University will process your personal data for the purpose of the research outlined above. The legal basis for processing your personal data for research purposes under GDPR is a 'task in the public interest' You can provide your consent for the use of your personal data in this study by completing the consent form that has been provided to you. Information about how the University of Hull processes your data can be found at https://www.hull.ac.uk/choose-hull/university-and-region/key-documents/data-protection.aspx.

You have the right to access information held about you. Your right of access can be exercised in accordance with the General Data Protection Regulation. You also have other rights including rights of correction, erasure, objection, and data portability. Questions, comments and requests about your personal data can also be sent to the University of Hull Data Protection Officer [dataprotection@hull.ac.uk]. If you wish to lodge a complaint with the Information Commissioner's Office, please visit www.ico.org.uk.

Further information and contact details

If you have any further questions or queries, please contact the researcher

- Miss Helena Holmes: email - helena.holmes@nhs.net, Telephone: [redacted]

Or contact the researcher's supervisors:

- Dr Jaswinder Moorhouse: email - Jaswinder.Moorhouse@hey.nhs.uk
- Dr Jo Beckett: email - Jo.Beckett@hull.ac.uk
- Dr Chris Clarke: email - C.Clarke@hull.ac.uk

*Note: Some information redacted to ensure anonymity of specific hospital sites.

Appendix L: Permission to Be Contacted Slip

Date: 24/06/2020
Version Number: 2.0
IRAS ID: [redacted]

Title of Study: ***How Do Outreach Nurses Experience & Perceive the Psychological Influence of Critical Care Upon ICU Patients?***

If you are interested to take part in the study, please leave your contact details on the space provided below. You will be contacted by the researcher to arrange a meeting at a convenient place and time.

Name:

....

Email Address:

....

....

....

....

Telephone Number:

....

Mobile Phone Number:

....

Are there any times of the day that you prefer to be contacted?

....

Do you have any further comments?

....

....

Signature:...

Date:...

Thank you very much for your interest!

Appendix M: Online Participant Consent Form

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Version number: 1.0

Date: 09.01.2020

IRAS ID: [redacted]

CONSENT FORM

Title of study: “How Do Outreach Nurses Experience & Perceive the Psychological Influence of Critical Care Upon ICU Patients?”

Name of Researcher: Helena Holmes

Please initial boxes

1. I confirm that I have read the information sheet dated 24.06.2020 (version number: 2.0) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my job role or legal rights being affected. I understand that once data analysis has taken place in preparation for research publication, that I cannot withdraw my anonymised data. I understand that the data I have provided up to the point of withdrawal will be retained. ☐
3. I understand that the research interview will be audio recorded and that my anonymised verbatim quotes may be used in research reports and conference presentations but that I will not be personally identifiable from this information. ☐
4. I understand that the research interview will be audio recorded and that my anonymised verbatim quotes may be used in research reports and conference presentations. ☐
5. I give permission for the collection and use of my data to answer the research question in this study. ☐
6. I agree to take part in the above study. ☐

☐	☐	☐
Name of Participant	Date	Signature
____________	____________	____________
Name of Person Taking Consent	Date	Signature

Appendix N: Online Demographic Information Sheet

Date: 23/02/2020
Version Number: 1.0
IRAS ID: [redacted]

UNIVERSITY
OF HULL

Demographic Information

This information will be held confidentially and destroyed after the research has been completed.

Job Role:

....

Number of Years and Months in Current Job Role:

....

....

....

....

Gender:

....

Age – Please tick the appropriate box:

☐	☐	☐	☐	☐	☐	☐	☐
25-30	31-35	36-40	41-45	46-50	51-55	56-60	61+

Date:..

Appendix O: Debrief & Sources of Support Sheet

*Note: Key contact details redacted to ensure anonymity of specific hospital sites.

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Debriefing Sheet

Version 1.0

20.02.2020

IRAS Research Project ID: [redacted]

Debriefing Information for participants

Title: "How Do Outreach Nurses Experience & Perceive the Psychological Influence of Critical Care Upon ICU Patients?"

Name of Chief Investigator and Researcher: Helena Holmes

Thank you for taking part in this study. What I want to find out from this research is to better understand staff experiences (outreach nurses) and to gain insight into how outreach nurses perceive and make sense of the psychological influence of critical care upon ICU patients. A further aim within this, is to try and better understand patients' psychological experiences of critical care too. As a result of gaining these understandings, this study aims to consider how best to support both staff and critical care patients and potentially propose further research in relation to this.

Methodology & Design:

This is a qualitative study, data (direct quotes) will be analysed using interpretative phenomenological analysis (IPA); this methodology is suitable for making sense of peoples' experiences.

After completing your participation in this research:

If you would like further information about the study or would like to know about what my findings are when all the data has been collected and analysed then please contact me (Helena Holmes) on:

Telephone: [redacted]
Or email: helena.holmes@nhs.net.

If taking part in this study has raised any specific concerns about the emotional impact participation has had on you, then please read the information providing sources of support on the page below.

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Sources of Support and Information

Your line manager/ team lead [redacted] can offer supervision and support:
Telephone: [redacted]
Or email: [redacted]

Confidential helplines can also provide emotional support, e.g.,
Samaritans:
Free Phone: **116 123**

Counselling service [redacted] **Let's Talk** can offer advice, information and support:
[redacted]
or text TALK to 61825.
Telephone: [redacted]

Counselling service [redacted] can
offer advice, information and support:
[redacted]
Email: [redacted]
Telephone: [redacted]

Should you have any specific issues due to taking part in this study, then you can call the **researcher (Helena Holmes)** on:
Telephone: [redacted]
Or email: **helena.holmes@nhs.net**

If you still have concerns having spoken to the researcher, you may also wish to call **Occupational Health;** Occupational Health can provide an in-house counselling, or they can offer an external agency counselling service (**Focus Counselling Service**). For either option, please contact Occupational Health on:

[redacted] Hospital Site Telephone: [redacted]
or On-Site Extension Number: [redacted]

[redacted] Hospital Site Telephone: [redacted]
or On-Site Extension Number: [redacted]

24-hour out of hours number
(Pastoral Care Service) provided by the Chaplaincy Department:
[redacted] Hospital Site Telephone: [redacted]
Hospital Site Telephone:
Email: Chaplaincy.team@[redacted]
or for urgent support via the trust switchboard.

You may alternatively wish to seek advice from your GP

Appendix P: Interview Schedule

Interview Schedule

Version 1.0

11/04/2020

It may be useful to explicitly mention to participants that the interview questions are aimed at getting more of an overview pre-COVID-19.

Main Questions:

- "Based on your experiences, how do you think patients emotionally and psychologically experience ICU?"

  "Keeping in mind patients' psychological experiences of ICU, what's your overall experience of working with these patients?"

    - Prompt/ sub-question: "Thinking about this, can you tell me about your most prominent memory or experience of working with these patients in critical care?"

- "In your experience, is there anything that you think might influence patients' experience of ICU?"

Prompts:

"Can you share any specific examples?".

"What was that like for you at that time?" / "what is that like for you?".

"How does that shape your experience of working?".

"How do you think your colleagues would answer that question?".

"What do you think has shaped this particular view/ belief of yours?".

"How do you think this makes patients feel?" and "how did (or do) you feel about that?".

"How did that influence you?".

"Could you elaborate a little more?".

Appendix Q: Research Poster

UNIVERSITY OF HULL | FACULTY OF HEALTH SCIENCES

How Do Outreach Nurses Experience & Perceive the Psychological Influence of Critical Care Upon ICU Patients?

Helena Holmes, Supervised by Dr Jo Beckett, Dr Christopher Clarke and Dr Jaswinder Moorhouse Department of Clinical Psychology. Faculty of Health Sciences.

For more information contact H.J.Holmes-2018@hull.ac.uk

BACKGROUND

Research mostly acknowledges the negative consequences of critical care for ICU patients, e.g., greater risk of depression, anxiety and poorer quality of life compared to the general population (Capuzzo & Bianconi, 2015; Wade et al., 2012), intrusive memories of hallucinations or delusions connected to intensive care (Wade et. al., 2014) and an increased likelihood of experiencing post-traumatic stress disorder (PTSD). A common perception may be that ICU patients do not fully contemplate the psychological influence of ICU until post-discharge; hence the phenomenon known has post-intensive care syndrome (PICS) (Maley et al., 2016). This may explain the clear gap in the literature focusing on psychological experiences of ICU across the critical care journey (admission, ICU and step-down care), both from patient and staff perspectives.

OBJECTIVES

This study aims to explore the lived experiences of Outreach Nurses (ONs) in relation to their perceptions of how ICU patients are psychologically influenced by critical care. This study also aims to better understand, and gain the richness and complexity of, ICU patients' psychological experiences of critical care via the lens of ONs. It is important to fully comprehend ONs' experiences to understand how to best support staff and patient wellbeing.

The broad questions put to ONs could allow for discussion around positive or negative psychological interpretations of critical care.

Research Question

How Do Outreach Nurses Experience & Perceive the Psychological Influence of Critical Care Upon ICU Patients?

METHOD

Semi-structured interviews will take place with 7-8 ONs, currently working across two major hospitals in [redacted]

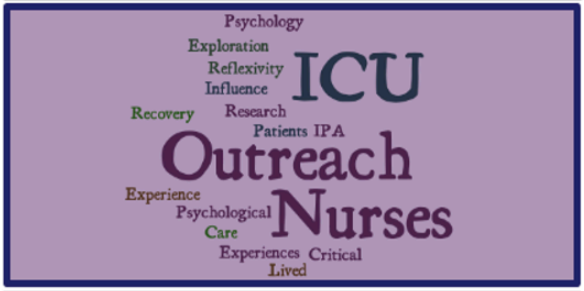
Data analysis will be undertaken using Interpretative Phenomenological Analysis (IPA). IPA aims to explore individuals' lived experiences with the aim of capturing in-depth, rich accounts of the participants' experiences. It explores singular, personal accounts of an experience and makes no attempt to generalise or categorise others' experiences too broadly. The approach encourages the researcher to explore their own position within the research, e.g., how the researcher's experiences and beliefs influences their interpretation and interaction with research data (Smith, 2003).

RESULTS/PROGRESS SO FAR

So far, five ONs have been interviewed and the recordings transcribed. Two more interviews are arranged and an additional ON has also show interest in the research. Analysis is yet to commence. Recruitment was made possible by identifying a potential participant group early on, through connections the field supervisor already had with this particular team. The team was contacted by the researcher to arrange face-to-face meetings to introduce the research; this was done as early in the research process as possible. Information sheets and permission to be contacted slips were sent to the lead of the team and distributed via email on the researcher's behalf. Upon receipt of permission to make contact, the researcher individually emailed each participant and made arrangements to conduct interviews virtually; face-to-face interviews are no longer possible due to COVID-19 / pandemic restrictions. Demographic information sheets and consent forms were sent directly to participants by email prior to the interviews commencing.

Hints and tips:

With help from my field supervisor, I initiated contact with the team's lead outreach nurse early on. I spent time shadowing a few ONs during their shifts too. Consequently, I was a familiar face, the team were aware of my research at an early stage and I gained a good grasp of the ON job role. Investing time in developing good relationships with the team made recruitment a much smoother process.



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Appendix R: Example of an Annotated Transcript

Emergent Themes	Interview Transcript	Exploratory Comments
		Level One: Descriptive Comments (Normal Text) Level Two: Linguistic Comments (Red Italics) Level Three: Conceptual Comments (Blue & Underlined)
	Researcher: So yeah, I guess the main question is… based on your experiences, how do you think ICU patients are emotionally and psychologically influenced by their experiences of critical care?	
Patients' Individual Psychological Journeys Confusion & Altered Reality	**Participant:** Erm, I think in different ways actually, I think, I think it does impact… every patients' journey is different, and their experience is different, erm, and that… it can be a huge range of experience they've got ranging from not remembering anything… to… thinking that what they recall is reality when it's been an altered reality, erm, and then that obviously then domino effects and impacts them it sort of takes them down a different path and, and their experience is different. Y'know… somebody who doesn't remember anything… they still have a huge psychological impact because they've got, y'know, a huge gap in their life - they don't remember anything at all, they don't know what's happened to them. Who's looked after them? What did they look like? How sick were they? Did they nearly die? Erm… y'know… what… how were the family? How did it affect them? What went on in their own lives?... Normal lives if you like… without them… y'know… how did life go on… When they were not there? So I think, y'know, for those patients who don't remember anything there's huge impact and then… you have the group of people who… erm… who… perhaps have an altered reality maybe linked to the sedation… and those patients, y'know, they might have had really	*Repetition of "I think" and "a huge range of experience" – Is the participant experiencing difficulty articulating something this emotive and complex? Perhaps a feeling of not knowing where to start?* Patients report a range of differing psychological experiences linked to memory recall, perceived reality, and the disruption of their lives. The participant believes each patient has different lived experience of ICU and their 'journeys' are therefore unique. What does it mean to have a gap in your life narrative which you can only fill with others' perceptions and recall of your own experiences? Participant reports this to have a "huge impact".

Disruption of ‘Normal’ Life and Life Narrative Sedation: Paranoia and ‘Unreal’ Experiences & Perceptions	vivid dreams, erm, they might recall, erm y’know, situations you, you sometimes hear them talk about things like, y’know, “oh I was on a spaceship” or “there was aliens” or “people were trying to do this to me” or “I was part of an experiment” or, erm y’know, there’s sometimes sort of paranoia in terms of people trying to hurt them or do things to them and that impact is.. then goes on forward in their recovery because y’know they’ve come out of ICU you can see they’re sort of looking about, they’re scared, they’re paranoid, they don’t quite trust what people are telling them or they don’t quite trust, y’know... what’s… who do I believe here? Who do I trust? And… it can be difficult for those patients. Some people do… remember some parts, so it might be that they’ve got just little snippets of things that happened. Sometimes, often they remember becoming ill at home and calling an ambulance and their journey in and then it stops and there’s a gap until they come out of ICU. Or sometimes they just have little parts or, or they might say “did this happen to me” or “did… would this have happened, is it is it possible that anyone said this to me” or “is it possible that..” erm… y’know, it can be simple things like being turned or, y’know, when they’re sedated and… it… it can be quite a disorientating experience if you can imagine being laid on an air mattress and you’re under sedation… … y’know… you perhaps have some faint awareness of noise around you people talking to you and then suddenly you’re being rolled and moved and you might experience pain and… dizziness, and disorientation just from a simple, a really simple task like giving somebody a bed bath or changing the sheets.	“Thinking that what they recall is reality when it’s been an altered reality”. The participant is suggesting inaccurate recall. What are the implications of participant accounts being different from the accounts of those around them in terms of perceived ‘reality’ and the psychological influence of this? Participant believes in one ‘true’ reality? “Then you have a group of people” – indicates common experiences of vivid dreams and ‘unreal’ experiences. Participant links to sedation. The participant believes that patients have unanswered questions they often want others to address. The participant has experienced that patients consider the impact of their ICU stay upon family members. “Who’s looked after them? What did they look like?” Does the participant think that patients are concerned with others’ perceptions of them in sickness? What is this linked to? Dignity? Vulnerability? Loss of independence? “How sick were they? Did they nearly die?” Does the participant believe that patients are psychologically influenced by proximity to death or by future implications of how sick they’ve been?

Seeking Unknown Answers		If the participant believes that paths are pre-determined by patient perceptions of reality, does the participant believe that pre-determined paths can be changed? Can staff meaningfully intervene?
		"A huge psychological impact" – the word huge (repeated several times) emphasises the significance of the psychological impact.
Disorientation and Faint Awareness		"How did life go on?" Implies a disruption in life. Signifies that life does goes on in the external world, but patients' internal worlds were altered and frozen within ICU. *Use of the word "how" – do patients want to know specific details? Or know how life could possibly go on in their absence?*
		Is paranoia linked to fear of being harmed, confusion, and 'unreal' experiences? Participant links paranoia to a lack of trust.
		"Journey" - Indicates a process involving stages (with a start and an end?).
		"Their experience is different" (repeated) and "ranging from" – emphasis on differing individualistic experience on a spectrum?
		"Domino effects", "then goes on forward in their recovery" and "takes them down a different path" – Butterfly effect? Pre-determined paths? Does the participant believe specific events make

other events more likely to occur , e.g., knock on effect?

Participants' belief that events interconnect and one element of an individual's experience goes onto influence future experiences and 'paths'.

"They don't know what's happened to them. Who's looked after them? What did they look like? How sick were they? Did they nearly die?" Consecutive questions representing the vast number of things patients want answers to. Possibly represents the urgency of wanting answers or the flooding feeling of a need for information when awake and lucid again?

"They just have little parts" & "just little snippets of things that happened"- Does the use of the words "just" and "little" emphasise that patients don't remember enough? Just = insufficient?

"Normal lives" implies that the participants perceives that ICU disrupts, and changes, lives abnormally.

"Oh I was on a spaceship", "there was aliens, "people were trying to do this to me", "I was part of an experiment", "paranoia in terms of people trying to hurt them or do things to them" – the participant threads together patient accounts using language to suggest 'unreal' experiences of patients feeling probed or exposed and in danger.

Repetition of "they're" and "they don't" – patients as 'others'/ specific out-group.

Repetition of "y'know" – linguistic filler? Emphasising statements? Encouraging agreement on the part of the researcher?

"Dizziness, and disorientation just from a simple, a really simple task like giving somebody a bed bath or changing the sheets" – Even small actions may have an influence upon patients including disorientation. *Use of the word "simple" in context = trivial or seemingly harmless in staffs' eyes? Simple tasks to medical professional.*

"Or they might say "did this happen to me" or "did… would this have happened, is it is it possible that anyone said this to me" or "is it possible that..." erm… y'know" & "often they remember becoming ill at home and calling an ambulance and their journey in and then it stops and there's a gap" – Emphasises common experiences of gaps in memory, even patients who do remember some things. Participant is highlighting patients' frequent desire for sense-making. *Repetition of "or" and "they" – grouping common patient questions?*

Appendix S: Additional Supporting Quotations for Subordinate Themes

Additional Supporting Quotations for Subordinate Themes

Subordinate Theme	Participant Quotations	Quotation Interpretations/ Context
1.1 Nightmares & Unusual Experiences	"What I've seen in many of the survivors… and I'm generalising… but, men, older men, who will say that they're fine and they never… bring up anything psychological that's happening to them… if you just ask the question "are you having nightmares?"… I could tell you three men now, off the top of my head, that have gone, "ohh God, yeah, you wouldn't believe the nightmares that I'm having"… that is often a… really good opening question because then a load of other stuff will come out… that's the door to open to get to other problems because talking about your sleep is… slightly different to talking about your mental health, isn't it?" (Janet).	Janet has experienced gender and age differences in patients' willingness to report unusual experiences or psychological concerns; Janet's use of the word "never" implies her perception that older males demonstrate extreme reluctance. The importance of conversing about sleep and nightmares was stated, as Janet experiences that these conversations initiate deeper discussion around patients' psychological well-being, hinting towards her belief that the topic of mental health is more difficult to discuss. The wording "survivors" may emphasise Janet's consideration that IC is a difficult experience that some do not survive.
2.1 Dependent on Access to Emotional Support: It Varies	"I do struggle with the psychological needs… if we do get a problem then you're thinking "oh right, now I've opened up a can of worms, what do I do with this can of worms?"… y'know, you're finally getting somebody to talk to you about their problems and you say, "oh well actually, I can't help you with that… I'll have to get somebody else to talk to you", and then they've got to try and form that, erm, trust with somebody else then. I think psychological input needs to be somebody who's better trained… they know how to handle situations… I know if I had a problem, and then I opened-up to somebody, and… they couldn't handle it… I'd feel… not quite	Bekki reflected upon her perception of the challenge patients face in building trust to discuss psychological difficulties, post-ICU, without continuity of support; feasibly, this represents Bekki's recognition of lack of services. However, Bekki also described fears over discussing patients' psychological distress with the same expression as her colleagues, i.e., a "can of worms". Beliefs in not being able to appropriately help and inadvertently diminishing patients' trust, whilst valuing the opportunity for patients to 'open-up' (the word "finally"

	prepared to open-up again… I think it would be better for them if they had that continuity" (Bekki).	emphasises importance), appeared to engender Bekki's fear. She made reference others not being able to "handle it", possibly representing her own feelings.
2.2 Helplessness: Loss of Self-Worth and Autonomy	"You can only think… how would I feel if that was me? Erm… I think… what must that be like for a patient who's been in intensive care? It's, it's the loss of control — I wouldn't like that. I wouldn't like losing control and not knowing what was happening to me. Being unconscious, not… y'know, it's not a normal state for anybody, is it? To be completely incapacitated. Not everybody is unconscious, some people are awake… but you still, you have no control; if you're critically ill you can't get up and walk around and live your life as normal… y'know. It's all the personal care bits that you need, which… you obviously want people to look after you and wash you, but it still must be a really strange… erm… strange experience to know that that's happened, and you've not been aware of that" (Lindsey).	Lindsey explicitly expressed the difficulty experienced in stating how patients psychologically experience IC. Lindsey acknowledged that she could only try to empathise with patients' circumstances and consider how she would feel. Through empathising and identifying with patient experiences, Lindsey may have touched upon her own vulnerabilities adding to difficulty in expression — Lindsey described factors she "wouldn't like". Loss of control, lack of understanding, and being dependent on others for personal care were all salient considerations for Lindsey. Lindsey reflected on the potentially "strange" experience of lacking awareness of some of these experiences.
2.3 Difficulty With Being Misunderstood	"Once they leave ICU, going back to the ward, they struggle… they get shut away. So, they're isolated, and they don't have a nurse… it's a big step from having a nurse there at your bedside continuously to going to a ward, and you press your buzzer, and nobody comes for twenty minutes… erm, and I think a lot of them struggle with that… that has a big impact on their mental health" (Christine).	Christine highlighted the "big step" in forming shared understandings in expectations for care between patients and ward staff, also empathising with patients' "struggle".
3.2 The Harsh Reality of Intensive Care:	"I don't know if it's that they maybe weren't told orrr… they maybe didn't...	John highlighted patients' shock associated with such experiences,

"Torturous", Isolating, & Dehumanising	understand what the consequences of their operation and their stay on intensive care was going to involve... so, actually when they come out and they're like, "I can't move, I can't eat", or "I can't swallow", or whatever, then... I think sometimes that's a bit of a shock for them" (John).	demonstrating his uncertainty over what contributes towards this shock — "I don't know".
3.3 Flashbacks, Witnessing Trauma, & Re-Living Trauma	"Often, for the ICU patients, they'll have gone through the majority of what a trauma patient goes through… it's just the mechanism of how they've ended up on hospital is different. So, they might have had a sepsis they might have had an overwhelming infection… but that's still traumatic. Being ill is still a traumatic thing" (Lindsey).	Lindsey considers severe illness in itself to be traumatic for ICU patients; she reflected that the trauma of illness can be overlooked and less obvious with certain patient groups.
	"They may witness… upsetting or traumatic… y'know, they may be aware of… although we, we try to maintain privacy and curtains are generally closed if anything, y'know, dramatic is going on… if there's a cardiac arrest, or someone's deteriorating… the curtains are pulled around, but depending on how lucid they are… they may pick up signs that something's not… very good with that person, or the staff seem a bit anxious here or… they may see patients who are… agitated or shouting or… babbling, erm, y'know… sick people react in different ways and… if you've got an agitated patient on a unit who's… shouting or swearing, then that must be really frightening for everybody else, for other patients who are a bit more lucid" (Lindsey).	Lindsey considered the possibility of lucid patients experiencing more trauma, whilst describing difficulty staff experience with maintaining privacy and shielding patients from secondary trauma.
4.1 The Need for Answers	"I've seen a few people relieved to be told the truth and accepting" (Janet).	Janet re-emphasised her perceived value in transparency, while discussing her view that it is

		imperative to alleviate patients' fears.
	"It must be absolutely terrifying when they wake up… in a different place, erm, y'know, coming out of sedation it must be absolutely terrifying not knowing where they are, how long they've been asleep for… we have had patients who have talked about it, and they're worried that there's this big chunk in their life… missing… they do appreciate the patient diaries so that we can actually sit and talk to them about, y'know, what happened, why it happened, how long each episode, erm… how long was they out for and erm… it is a very frightening thing for them… I can't imagine what they go through, bless them, it must be awful… erm, a lot of it is… why was they put to sleep erm, y'know, what, what have we done to them? Why have they got a sore throat? Why, why does something hurt them so much?" (Bekki).	Bekki attempted to put herself in patients' shoes, describing the likely "terrifying" nature of waking-up in an unknown place with unanswered questions. She explained that some patients find this frightening and worrying, also emphasising the "big chunk" missing in a patient's life narrative. Bekki has experienced ICU patient diaries to be useful and valuable in supporting patients to regain understanding:
4.2 Life Changing: Re-Evaluating the Future	"They can't see the light at the end of the tunnel – I think that's a big thing for them" (Bekki).	Bekki's perception parallels other participants' views, illustrating that a hindered view of a positive future and recovery is "a big thing" for patients to psychologically handle.
4.3 Re-Establishing Connection & Seeking Reassurance	"Some patients get their mobile phones quite early, old people don't use mobile phones and they don't use 'Facebook'. So, they don't know what day it is. So, we would get them a newspaper, probably… and then they can reorientate themselves… they can see for themselves what the date is, what's been going on" (Janet).	Janet reflected on the different methods of providing reconnection she provides, dependent on a patient's age cohort, demonstrating a person-centred approach:
5.1 A Personal Adjustment Journey	"They're overwhelmed… when they come out of ICU… the impact of their illness… is going to hit them at some point. Even if they don't remember anything about being in ICU, you're suddenly realising that you were really	Lindsey has similarly experienced patients' delayed psychological reactions, linked to a period of adjustment. Initially, Lindsey believes that patients are too

	sick you were in intensive care, y'know, and that may have been for days, or weeks, or months. So, that in itself can… that impact is going to hit them at some point" (Lindsey).	"overwhelmed" to consider psychological implications.
	"They've got image things to deal with as well, haven't they? If you end up with a colostomy or, even a tracheostomy, or you need a feeding line, or something like that, and you, you're different, and your life's limited… but you're well. I think that's the difference, isn't it? You could still go to work with a colostomy, but you can't go swimming and… you can't have a curry, can you (awkward laughter)? And four pints of larger. So, I think they probably…. miss out" (Janet).	Janet proposed that patients with long-term medical needs, requiring the use of external medical equipment, may be more limited and Janet perceives that they may 'miss out' on certain life experiences.
	"Not everyone is doom and gloom about the psychological impact and sometimes it's just the fact that they're just not quite ready to open-up, and then you'll go back and see them a week later, and they'll be a lot better because their anxiety levels are reduced" (Gill).	According to Gill, some patients eventually process the psychological influence of IC well. She seemed to describe a period of adjustment, with time successfully reducing patients' anxiety:
5.2 It Depends: Individual Differences	"It is really, really broad. Some people just… they just deal with it fine, y'know, they nearly died, and they're not bothered, they're still here, d'you know what I mean? And they do really well, and they go home and then others… just don't" (Christine).	Christine has experienced individual differences within patients in terms of how they perceive the psychological influence of intensive care.