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**Citation for published version:**

Kean, S, Donaghy, E, Bancroft, A, Clegg, G & Rodgers, S 2021, 'Theorising survivorship after intensive care: A systematic review of patient and family experiences', *Journal of Clinical Nursing*.  
<https://doi.org/10.1111/jocn.15766>

**Digital Object Identifier (DOI):**

[10.1111/jocn.15766](https://doi.org/10.1111/jocn.15766)

**Link:**

[Link to publication record in Edinburgh Research Explorer](#)

**Document Version:**

Publisher's PDF, also known as Version of record

**Published In:**

Journal of Clinical Nursing

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## REVIEW

# Theorising survivorship after intensive care: A systematic review of patient and family experiences

Susanne Kean PhD, MSc, Dip Education and Management, RN, Lecturer<sup>1</sup>  | Eddie Donaghy PhD, BSc (Hons), Research Fellow<sup>2</sup> | Angus Bancroft PhD Sociology, Lecturer<sup>3</sup> | Gareth Clegg MB ChB, BSc, MRCP, PhD, FCEM, Clinical Senior Lecturer, Honorary Consultant in Emergency Medicine<sup>4</sup> | Sheila Rodgers PhD, MScR, BSc (Hons), RN, Senior Lecturer (University of Edinburgh), Hon. Nurse Consultant in Critical Care (NHS Lothian)<sup>1</sup>

<sup>1</sup>Nursing Studies, School of Health in Social Science, The University of Edinburgh, Edinburgh, UK

<sup>2</sup>Usher Institute of Population Health Sciences and Informatics & Edinburgh Critical Care Research Group, The University of Edinburgh, Edinburgh, UK

<sup>3</sup>School of Social and Political Science, University of Edinburgh, Edinburgh, UK

<sup>4</sup>Deanery of Clinical Sciences, Centre for Inflammation Research, Edinburgh BioQuarter, University of Edinburgh, Edinburgh, UK

## Correspondence

Susanne Kean, Nursing Studies, School of Health in Social Science, The University of Edinburgh, Teviot Place, GB-Edinburgh EH8 9AG, UK.

Email: Susanne.kean@ed.ac.uk

## Funding information

This work was funded by the Chief Scientist Office, Scotland. Reference number: CGA/17/50

## Abstract

**Aims and Objective:** This systematic literature review explores and maps what we know about survivorship to understand how survivorship can be theoretically defined.

**Background:** Survivorship of critical illness has been identified as a challenge for the 21st Century. Whilst the use of the term 'survivorship' is now common in critical care, it has been borrowed from the cancer literature where the discourse on what survivorship means in a cancer context is ongoing and remains largely descriptive. In the absence of a theoretical understanding, the term 'survivorship' is often used in critical illness in a generic way, limiting our understanding of what survivorship is. The current COVID-19 pandemic adds to an urgency of understanding what intensive care unit (ICU) survivorship might mean, given the emerging long-term consequences of this patient cohort. We set out to explore how survivorship after critical illness is being conceptualised and what the implications might be for clinical practice and research.

**Design:** Integrated systematic literature review. The review protocol was registered with PROSPERO International Prospective Register of Systematic Reviews. PRISMA guidelines were followed and a PRISMA checklist for reporting systematic reviews completed.

**Results:** The three main themes around which the reviewed studies were organised are: (a) healthcare system; (b) ICU survivors' families; and (c) ICU survivor's identity. These three themes feed into an overarching core theme of 'ICU Survivorship Experiences'. These themes map our current knowledge of what happens when a patient survives a critical illness and where we are in understanding ICU survivorship.

**Conclusion:** We mapped in this systematic review the different pieces of the jigsaw that emerge following critical illness to understand and see the bigger picture of what happens after patients survive critical illness. It is evident that existing research has mapped these connections, but what we have not managed to do yet is defining what survivorship is theoretically. We offer a preliminary definition of survivorship as a

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process but are aware that this definition needs to be developed further with patients and families.

#### KEYWORDS

critical care, critical illness, integrated systematic review, intensive care, survivorship

#### What does this paper contribute to the wider global community?

- This integrated systematic review maps our current evidence on post-critical illness sequelae.
- Developing a theoretical understanding of survivorship following critical illness is essential for developing health and social care interventions for this patient cohort and their families, policies and research.
- The current COVID-19 pandemic will increase the need of post-critical illness interventions for this cohort and their families and thus there is some urgency in developing this work.

## 1 | BACKGROUND

It was a decade ago that Iwashyna (2010) wrote, 'survivorship will be the defining challenge of critical care in the 21st Century' (p 204). Subsequently, Palakshappa and Christie (2016, p 1423) noted that 'with over 300 publications in this arena over the past 15 years, we are rising to the challenge of studying survivorship'. Yet what is actually meant by the term survivorship in a critical care context remains poorly developed. In reality, whilst use of the term survivorship in critical care is now common, the term has effectively been borrowed from cancer literature stretching back to Mullen (1985). As Iwashyna (2010, p 204) commented,

One way to begin grappling with the needs and hurts of critical illness survivors may be to learn from the experience of cancer survivors. Survivors of both critical illness and cancer emerge from a highly technical acute hospitalization..... Both are discharged alive but face profound existential uncertainties and, often, an alienated relationship with their own bodies.

However, discourse on what survivorship means in a cancer context is still ongoing (Surbone et al., 2013) and remains largely descriptive. In reporting and describing events following an ICU patient's recovery from critical illness, the term 'survivorship' is often used in a generic and colloquial way in the literature, with no clear definition and theoretical underpinning of the term.

We believe that it is important to investigate this lack of theoretical grounding given the increasing recognition in general healthcare research of having a theoretical basis in reporting and describing phenomenon such as the patient and family experiences and to be vital in underpinning intervention development (Moore et al., 2015). As Alderson (1998) noted, theories, whilst frequently under-recognised, are fundamental to healthcare practice, promotion and research. Theories influence the way practitioners and researchers gather and interpret evidence. They can take the form of clear hypotheses to working models and frameworks of thought about

perceptions of reality. Theory in health care is therefore important in understanding phenomenon.

Consequently, in this systematic review, we aimed to uncover whether, in the context of critical care research and literature, the commonly used term survivorship has a theoretical grounding and if not, to argue why it is crucial to develop a theory of survivorship following critical illness.

The current COVID-19 pandemic adds to the urgency of understanding what intensive care unit (ICU) survivorship might mean given the emerging long-term consequences of this patient cohort and, to an extent, their families. However, the post-intensive care syndrome (PICS) many COVID-19 survivors are now facing is not new.

### 1.1 | The growing interest in survivors of critical illness

Even prior to the COVID-19 pandemic and the rise in admissions to intensive care units (ICU), it was evident that an increased uptake in ICU services, coupled with advances in technology and therapeutics, had resulted in growing numbers of ICU patients (approximately 80%) surviving a critical illness (Brinkman et al., 2013; Vincent & Creteur, 2015). However, the burden of surviving critical illness can be high, with physical and psychological disability common (van Beusekom et al., 2019; Davydow et al., 2009; Desai et al. 2011; Jackson et al., 2014). Disruptions to everyday social circumstances are frequent (Norman et al. 2016; Cuthbertson et al., 2010) and, as a recent systematic review found, many patients who were previously employed do not return to work, even one year later (McPeake et al. 2019). The multi-dimensional disabilities and impairments that follow critical illness have been termed 'post-intensive care syndrome', PICS (Needham et al., 2012), although there is a significant range and severity of PICS disability (Hashem et al., 2017; Marra et al., 2018). Recent research on survivors of critical illness has identified the importance of a number of factors on ICU survivors' recovery experiences; socio-economic status, pre-existing health (notably chronic

illness and frailty), age and resilience (Griffith et al., 2018; Jones et al., 2019; Kheir et al., 2018; Maley et al., 2016; Marra et al., 2018; Muscedere et al., 2017).

The impact of critical illness is also significant for families and carers in both social and psychological domains (Davidson et al., 2012; Fumis et al., 2015; Haines et al., 2015; McPeake et al., 2016). The urgent need for interventions to address both ICU survivors and family/carers support needs as they change across the illness and recovery trajectory have been emphasised by King et al., (2019) and Herridge (2017). Survivors of critical illness and their families/carers describe the need for, and value of, a range of interventions and informational supports to adjust to new disabilities, work, relationship and lifestyle change and to re-engage with everyday life (Agård et al., 2019; Cutler et al., 2013; Deacon, 2012; Olsen et al., 2017). This indicates that ICU survivors' needs are complex and multi-factorial, extending beyond biomedical models of care (McPeake & Mikkelsen, 2018; Mehlhorn et al., 2014).

Further, survivors of critical illness have been shown to have high ongoing healthcare costs (van Beusekom et al., 2018; Lone et al., 2013). Consequently, attention has begun to focus on health solutions to improve post-intensive care outcomes (Major et al., 2016; NICE, 2017; Reay et al., 2014). Whilst some consensus on ICU survivors' and families/carers' needs has developed (Azoulay et al., 2017), the development and implementation of models of care post-ICU remain 'in their infancy' (Howard et al., 2019). Haines et al., (2019) note that evidence is lacking regarding implementation of novel strategies such as follow-up clinics and peer support groups to reduce the burden of PICS. Similarly, a lack of evidence exists to determine whether ICU follow-up services are effective in identifying and addressing the unmet health needs of ICU survivors (Schofield-Robinson et al., 2018). As Herridge (2011) observed, progress in designing successful post-ICU interventions are hindered by the heterogeneity of patients' needs, with uncertainties over which ICU survivors need specific interventions, and the timing, length, nature and purpose of the interventions. Additionally, understanding of post-critical illness sequelae in primary care services is limited (Kiernan, 2017; Wong & Wickham, 2013).

We conducted this systematic review to map and explore how survivorship is theoretically defined in critical care literature and examine how we can move beyond current descriptive knowledge and accounts of survivorship to inform innovative future research. Developing a theoretical understanding of survivorship following critical illness is essential to (i) develop research that is theoretically grounded; (ii) address the needs of survivors and their families/carers; (iii) guide the development of complex interventions across health and social care services by drawing on a shared theoretical understanding of survivorship and in turn; and (iv) inform policy.

Our review questions were the following:

- I How is survivorship after critical illness defined and understood in the current literature?
- II What are the key issues regarding support needs of critical care survivors and their families?

III What are the important outcomes for survivorship following critical care for patients and families?

## 2 | METHODS

### 2.1 | Design

This integrative review was directed by Whittemore and Knaf's (2005) framework; problem identification, literature search, data evaluation, data analysis and presentation. Both qualitative and quantitative studies were included in gathering and synthesising the current evidence (Torraco, 2005; Whittemore & Knafi, 2005). The identified, included and excluded literature is presented in the flow diagram form using the Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA, 2009) (Appendix S1; Figure 1). The review protocol was registered with PROSPERO International prospective Register of Systematic Reviews (Donaghy et al., 2018).

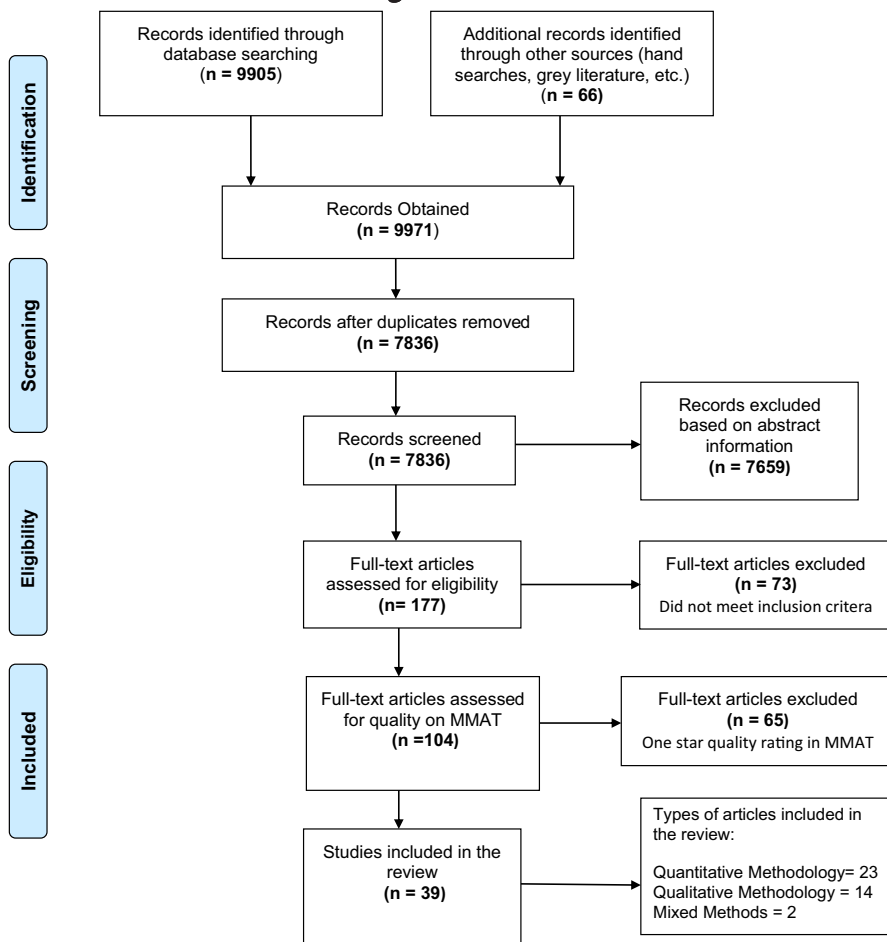
### 2.2 | Search methods

The search strategy was established in discussion with the University of Edinburgh's systematic review librarian to ensure that we secured all appropriate published (peer reviewed) and unpublished literature (including non-peer reviewed and grey literature) relating to survivorship in critical illness. Three approaches were used to identify literature: (i) searching the following electronic databases; MEDLINE, EMBASE, CINHAL, PsycINFO, SocINDEX, ASSIA, PROSPERO; (ii) we identified grey literature using the following resources; OpenGrey database; New York Academy of Medicine Grey Literature Report; Thesis and dissertations through the British Library Ethos service and ProQuest Dissertations and Thesis; and (iii) hand searching key journals. Our search strategy, including key terms, is available in Donaghy, Salisbury, et al. (2018).

One of the authors (ED) independently carried out the literature search using agreed search terms. Two reviewers (SR and SK) independently screened the title and abstracts for eligibility using our inclusion and exclusion criteria (Table 1). Full text articles were obtained and allocated to ED, SR and SK for further independent assessment. Subsequently, all reviewers met to discuss and compare recommendations for full text article inclusion or exclusion in the review.

### 2.3 | Quality appraisal and data extraction

The Mixed Methods Appraisal Tool (MMAT) was used to rate the quality of the studies since it has been accepted as a reliable tool and assesses the methodological quality of the studies rather than the reporting of them (Pluye et al., 2009). The current 2018 version was developed through findings from a literature review of critical



**FIGURE 1** Survivorship systematic review: PRISMA flow diagram. From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *PLoS Med* 6(7): e1000097. <https://doi.org/10.1371/journal.pmed1000097>

Inclusion	Exclusion
Published in English	ICU patients under 16 years.
Published between January 2000 and July 2019 Unpublished literature (including non-peer reviewed and grey literature).	Systematic reviews, literature reviews and meta-analyses.
All adult ICU patients aged 16 years and over	
Reported primary research using quantitative approach (experimental and/or observational study designs, including randomised control trial, case control and cohort study) and any qualitative approach (all study designs).	

**TABLE 1** Inclusion and exclusion criteria

appraisal tools, interviews with MMAT users and an eDelphi study with international experts (Hong et al., 2018). The MMAT provides for quality appraisal of quantitative and qualitative studies as well as mixed methods resulting in a quality rating of between one to four stars (\* to \*\*\*\*) with \*\*\*\* representing the highest possible quality. At least two reviewers independently rated all included studies using MMAT and subsequently agreed scores. Any studies with a score of one star were excluded since they were of very low quality.

Data extraction was completed by all reviewers using a standardised data collection form. All data extraction was reviewed and summarised by one reviewer (SR). Data extraction included the

following: Author (year and country), time frame of study, type of critical care patient, characteristics of participants, methodology, nature of any intervention, main findings, definition of survivorship, theory of survivorship and MMAT score.

### 3 | RESULTS

A total of 9,971 records were identified resulting in 7,836 once duplicates were removed which were screened by reading the abstracts. One hundred and four of the articles were full text reviewed for quality using the MMAT. Sixty-five articles were excluded as they did not meet

the required quality rating of \*\* or above in MMAT resulting in 39 studies remaining for inclusion. Of the final sample of 39 studies, 23 were based on quantitative methodologies, 14 on qualitative and two had a mixed-methods design (see Table 2). Studies were published between 2003 and 2019 and were derived from nine different countries (UK, USA, Canada, Sweden, Norway, Denmark, Australia, Hong Kong and South Korea). The number of participants in studies varied from six patients and five family members to 39,337,348 patients and 85 family members. The age range of participants was 18–89 years.

Studies focused on the experiences of critically ill patients with biomedical studies looking at physical and/ or psychological aspects post-critical illness, and qualitative studies focusing on the experiences of critical illness and/or recovery. However, none of the studies set out to look at survivorship as a process or attempted to define survivorship in the context of critical care, with the exception of those by Corner et al., (2019), Iwashyna et al., (2010), Kean et al. (2017), Lone et al., (2016) and Page, et al. 2019) as indicated in Table 2.

### 3.1 | Data analysis

One of the challenges in an integrated literature review relates to the dealing with the different epistemological stances of included studies. This challenge exists, irrespective of whether authors stated their original epistemological stance or not, since this impacts on the type of knowledge created. Yet, epistemology and one's epistemological stance is of major importance in research. As Hetherington (2012) points out, epistemology relates to our account of knowledge and how we know/ justify our knowledge. Data are not self-interpreting (Greenhalgh, 2018) and only become evidence through analysis (Becker, 2018). Constructionism guided this analysis. Constructivism emphasises that knowledge is not discovered but constructed and is a result of social interactions (Crotty, 1998; Flick, 2018; Schwandt, 2000). The emphasis of constructionism is on meaning making (Charmaz, 2014; Crotty, 1998), allowing the construction of survivorship as a shared lived reality.

Data analysis followed an inductive–abductive process using open and focused coding. Codes can either be concept-driven and therefore *a priori* codes are used when analysing, or data driven where open codes describing the data, are created (Gibbs, 2018; Guest et al., 2012). Analysis using open coding is a process that starts with describing a section of data which is then summarised in an open code. Subsequent analytical cycles see open coding summarised into higher levels of codes sometimes called themes, categories or index (Gibbs, 2018) in a move away from description to explanation. Higher levels of codes reveal the dimensions of an experience or phenomenon thus enabling an understanding of how things connect and may be interdependent.

Two reviewers (ED and SK) independently coded 10 articles before discussing and agreeing codes and definitions of these codes (see Figure 2 for an example) with the full team.

The initial analysis resulted in a coding book which is critical when working with more than one analyst to ensure rigour of the analysis (Guest et al., 2012). All data were uploaded into NVivo 12

and data coded and categorised to develop emergent themes as presented below.

## 3.2 | Themes

The three main themes emerged from the data analysis process as described above. The three main themes were developed from their sub-themes which in turn were developed from the categories. The three main themes feed into an overarching core theme of 'ICU Survivorship Experiences'. Themes, sub-themes and categories are presented in Table 3.

Relationships between the sub-themes, themes and core theme were in some cases inter-related and these relationships are presented in Figure 3.

We followed an inductive–abductive analysis process. Abduction is the process of making theoretical sense of findings by drawing on theoretical ideas, concepts or theories in relation to the findings (Atkinson, 2015; Reichertz, 2013). Therefore, the findings are presented alongside relevant theoretical concepts and a discussion against existing knowledge and research.

The findings are presented below according to the three main themes:

1. Healthcare system
2. ICU survivors' families
3. ICU survivor's identity

### 3.3 | Theme 1: Healthcare system

This theme relates to the context of the healthcare system that influences experiences of ICU survivors across the care continuum as they transition from tertiary to secondary to primary care settings. This theme has three dimensions: (1) classification system, (2) transition into the primary care services and (3) post-hospital discharge ICU follow-up clinics.

#### 3.3.1 | Classification system

There are numerous formal classification systems in health care such as the International Classification of Diseases (ICD). Bowker and Star (2000) argue that to classify is human. These classification systems have several functions one of which is effective and succinct communication between healthcare professionals. Post-Intensive Care Syndrome (PICS) is a classification used as a shorthand by healthcare professionals to describe what is, in reality, a complex picture of ICU survivors' health.

PICS is a relatively new term which can be defined as '*new or worsening impairment in cognition, mental health, or physical function after critical illness. Neuropsychological and physical impairment has been associated with medication non-adherence, an inability to return to*



TABLE 2 Survivorship review articles and MMAT scores

Author & Country	Methodology and Data Collection	Setting / Sample	Participants (age, gender, LoS, Socio-economic status)	Main Finding	MMAT
Ågård et al. (2012) Denmark	Grounded theory study. Interviews with patients and their partners at 3 and 12 months post-ICU discharge	Five ICUs in Denmark, four general, one neurosurgical. Adult ICU patients mechanically ventilated >96 hours; patients with a cohabiting partner.	Patients n = 17 Partners n = 16 Gender: 11 male, 7 female Age: 35–70 years	'The ICU survivors struggled for independence and focussed chiefly on "recovering physical strength," "regaining functional capacity," and "resuming domestic roles." The first year of recovery evolved in three phases characterised by training, perseverance and continued hope for recovery. The ICU survivors did not seem to worry about traumatic experiences. Rather, their focus was on a wide range of other aspects of getting well'. P.105	***
Allum et al. (2018) UK	Qualitative exploratory study.	ICU survivors recruited from a charity and a patient and public involvement group. Patients with an ICU stay of at least 48 hours in the last 10 years.	Patients n = 12 Gender: 5 male, 7 female Age: 25–75 yrs Time since ICU <1 yr to 9 yrs	'Survivors of critical care should be equipped with information about their critical care stay, ongoing health issues and recovery and should be provided with holistic care at home. Critical care follow-up was an effective way of meeting many of these needs, but this needs to be flexible to be useful to attendees. Peer support groups (face-to-face and online) provided information, reassurance, a social network and an avenue for those who had longer-lasting problems than current services provide for'. P.316	***
Bäckman et al (2017) Sweden	Qualitative descriptive design.	One ICU in Sweden. Age 18+, ICU stay of 96 hours or more in last 3–18 months.	Patients n = 17 Gender: 12 male, 5 female Age: median 67 (39–81) yrs ICU stay: median 17 (5–47) days Ventilator days: median 14 (0–45) Hospital stay: median 37 (19–131) days	Former ICU patients participated in two group meetings to review ICU experiences. Patients wrote feelings in a notebook after each group meeting. Eleven patients were also interviewed. 'Meeting others revealed to the former patients new dimensions of being critically ill, and they both gave and received strength from each other. The meetings were meaningful as they gained insight into other patients' lives, and realised what it meant to survive intensive care'. p86. One sub-theme—Understanding the meaning of surviving intensive care	****
Bagshaw et al. (2015) Canada	Prospective multi-centre observational cohort study.	ICUs in six hospitals in Alberta, Canada. Patients aged 50+ staying in ICU for >24 hours.	Patients n = 421 Gender: 258 (61.3%) male, 163 (38.7%) female Age: Frail mean 69.0 yrs, Not frail mean 66.2 yrs. Frail: n = 138 (33%) Less than high school education: Frail=28.9%. Not frail =19.4%	Multi-variable analyses used to evaluate factors independently associated with frailty. Follow-up at 6 and 12 months post-ICU. Frailty defined as a score ≥5 on the Clinical Frailty Scale before hospitalization. ICU survivors identified as frail before index were more likely to have poor quality of life and poorer functional outcomes at 6 and 12 months after discharge. Previously frail patients are at higher risk of survivorship problems (pain, depression, anxiety). Previously frail patients need follow-up for physical, psychological and emotional support.	****

(Continues)

TABLE 2 (Continued)

Author & Country	Methodology and Data Collection	Setting / Sample	Participants (age, gender, LoS, Socio-economic status)	Main Finding	MMAT
Bagshaw et al. (2016) Canada	Sub-study of a prospective cohort study selecting out those aged 50–64.9 years.	ICUs in six hospitals in Alberta, Canada. Patients aged 50+ staying in ICU for >24 hours.	Patients $n = 197$ Gender: 125 (63%) male, 72 (37%) female Age: mean 58.5 (SD 4.1) years, Three or more co-morbid illnesses $n = 143$ (73%) Frail: $n = 55$ (28%)	Multi-variable analyses used to evaluate factors independently associated with frailty. Follow-up at 6 and 12 months post-ICU. Frailty defined as a score $\geq 5$ on the Clinical Frailty Scale before hospitalization. 'Pre-hospital frailty is common among younger critically ill patients and was associated with higher mortality, and rehospitalization at 1 year. Frailty needs to be recognized and integrated into management of selected younger patients admitted to the ICU, and not just the elderly'. p184	***
Chiang (2011) Hong Kong	Grounded Theory. Participant observation and interviews.	One adult ICU unit, hospital wards that patients were discharged to from ICU, Hong Kong. Adult ICU patients with ICU stay >48 hrs	Patients $n = 6$ Family members $n = 5$ Gender: 5 male, 6 female Age: 51–77 years Length of stay: 3–18 days	'A substantive theory emerged and it illustrated and described the dynamic actions and interactions between critically ill patients and their main family carer during the process of recovery. Three categories, 1) being there with, 2) coping and 3) self-relying, comprise the essential components of this theory'. P.317	***
Choi et al. (2012) USA	Longitudinal descriptive study.	One medical ICU in the USA. Adult ICU patients with mechanical ventilation for 4 days or more, age >21 yrs. Caregivers were non-professional unpaid carers aged 21+.	Patients $n = 47$ Family caregivers $n = 50$ Gender: Caregivers female 74% and 26% male, Patients male 66%, 34% female. Age: Caregivers mean =52.3 years (SD 11.8), Patients mean =55.5 years (SD 16.7).	Caregivers assessed for depressive symptoms, burden and health risk behaviours during ICU, at ICU discharge and at 2 months after ICU discharge. Two trajectory groups emerged: 1) caregivers who had clinically significant depressive symptoms during ICU admission that remained high at 2 months post-ICU discharge (high trajectory group, 56%); and 2) caregivers who reported scores that were lower during ICU admission and decreased further at 2 months post-ICU discharge (low trajectory group, 44%). High trajectory group caregivers tended to be younger, female, an adult child living with financial difficulty, and less likely to report a religious background or preference. They reported greater burden and more health risk behaviours at all time points; patients tended to be male with poorer functional ability at intensive care unit discharge. P.2	****
Corner et al. (2019) UK [Th]	Exploratory Grounded Theory with semi-structured interviews.	One adult medical/surgical ICU in London, UK. Patients with ICU stay >72 hrs, aged 18 yrs +, documented intensive care unit acquired weakness so received rehabilitation interventions.	$n = 15$ Gender: 11 male, 4 female Age: range 30–89 Median length of ICU stay: 19 days (IQR 8–33) Median length of hospital stay: 63 days (IQR 34–107) Median time between ICU discharge and interview: 56 days (IQR 36–80)	The central phenomenon grounded in these data was recalibration of the self. There were two themes contributing to this temporal model of recovery: the transition 'from prior self to current self' and the transition 'from current self to construction of the future self'. 'Recovery from ICUAW is a complex process that often begins with survivors exploring and adapting to a new body, followed by a period of recovering autonomy. Rehabilitation plays a key role in this recalibration period, helping survivors to reconstruct a desirable future'. P.1	**

(Continues)



TABLE 2 (Continued)

Author & Country	Methodology and Data Collection	Setting / Sample	Participants (age, gender, LoS, Socio-economic status)	Main Finding	MMAT
Cuthbertson (2005) Scotland, UK	Prospective cohort study of quality of life	One ICU in Scotland, UK.	n = 300 Gender: male 59%, female 41% Age: median 60.5 years APACHE II score: median 18 Mean length of stay: 6.7 days	SF-36 and EQ-5D at 3, 6 and 12 months post-ICU admission. 'SF-36 physical component scores decreased from pre-morbid values at 3 months ( $p = .05$ ) and then returned to pre-morbid values at 12 months ( $p < .001$ ). The mean physical scores were below the population norm at all time points but the mean mental scores were similar or higher than these population norms. Patients who died after intensive care discharge had lower quality of life scores than did survivors (all $p < .01$ ). Poor pre-morbid quality of life was demonstrated and appears to reduce after ICU discharge. For survivors there was a slow increase in physical quality of life to pre-morbid levels by the end of the first year but these remained lower than in the general population. ICU patients experience a considerable longer-term burden of ill health'. P.332	***
Cuthbertson et al. (2013) Scotland, UK	Prospective cohort study. Mortality and quality of life measured at 3.5 and 5 years after severe sepsis.	26 adult ICUs in Scotland UK.	n = 439 recruited. 85 respondents at 3.5 years and 67 at 5 years. Gender: 53% male, 47% female Age: median 58 (45 to 67) APACHE II: median 23 (17 to 28) Simplified Acute Physiology Score (SAPS II): median 41 (30 to 54)	'Patients with severe sepsis have a high ongoing mortality after severe sepsis with only 61% surviving five years. They also have a significantly lower physical QOL compared to the population norm but mental QOL scores were only slightly below population norms up to five years after severe sepsis. Mortality and QOL outcomes were broadly similar to other critically ill cohorts throughout the five years of follow-up. The majority of severe sepsis survivors were satisfied with their current QOL and all patients would be willing to be treated in an ICU again if they become critically ill despite many having unpleasant memories and recall of ICU events'. P.6	****
Davydow et al. (2013) USA	Prospective cohort study.	Non-trauma ICU patients in one ICU in USA. Patients with >24 hour stay in ICU, no pre-existing cognitive impairment.	n = 120 completed at 12 months (150 recruited). Gender: 51 (42.5%) female, 69 (57.5%) male Age: mean 49.0 (SD 14.6) 86% graduated from high school ICU LOS: median 5 days (IQR 3–9) SAPS II: median 23.0 (IQR 13.0–37.0)	Measured in-hospital stress symptoms were assessed before hospital discharge and cognitive status assessed at 12 months after discharge with some having follow-up interviews. Patients with high acute stress symptoms before hospital discharge are more likely to have greater cognitive impairment at 12 months post-ICU.	****

(Continues)

TABLE 2 (Continued)

Author & Country	Methodology and Data Collection	Setting / Sample	Participants (age, gender, LoS, Socio-economic status)	Main Finding	MMAT
Donaghy, Salisbury, et al. (2018) Scotland, UK	Mixed methods study. Focus groups and semi-structured interviews.	Adult ICU patients from three Health Board regions in Scotland, UK. Patients with early unplanned hospital readmission within 90 days of hospital discharge, mechanical ventilation for >48 hours, age>18 years.	Patients $n = 29$ ; Family members $n = 29$ Gender (patients): Male 18 (62%) Female 11 (38%) Age: range 18 to 65+ Social deprivation status, $n$ (%) Most deprived 13 (45%), Mid-deprived 10 (34%), Least deprived 6 (21%) Multi-morbidity: 18 (62%) Polypharmacy: 21 (72%) Drug and/or alcohol misuse: 8 (28%) Treatment for depression and/or anxiety: 13 (45%) Major mobility problems: 10 (34%)	'A "complex health and psychosocial needs" context occurred in patients with multi-morbidity and polypharmacy, who frequently also had significant psychological problems, mobility issues, problems with specialist aids/equipment and fragile social support. These patients typically described inadequate preparation for hospital discharge, poor communication between secondary/primary care, and inadequate support with psychological care, medications and goal setting.' P.1	****
Eakin et al. (2017) USA	Descriptive qualitative study. Semi-structured telephone-based interviews.	Adult survivors of ARDS and ARF recruited from other studies recruiting across 41 hospitals in the USA.	Patients $n = 48$ Gender: Female 26 (54%), Male 22 (46%) Age: mean 53 (SD15) yrs Ethnicity: White 39 (81%) Prior residence: home independently 42 (88%) APACHE III score: 100 (SD 34) Duration of mechanical ventilation: 9.8 (SD 10) days ICU length of stay: 13 (SD 10) days Hospital length of stay: 22 (SD 17) days	Major themes identified were: "physical health, mental health, and social health. These aspects were particularly prominent: mobility impairments, pulmonary symptoms, fatigue, anxiety and depression symptoms, and decreased ability to work and participate in valued activities. Impacts on overall well-being and on relationships with friends and family members varied among the survivors. Some survivors reported gratitude, increased appreciation of life, and closer relationships to loved ones. Other survivors reported boredom, social isolation, and wishing they had not survived." P.456	***
Egerod et al. (2011) Denmark	Qualitative, multi-centred using some grounded theory approaches to explore diary use.	Two ICU's in Denmark. Patients receiving a nurse written diary following an ICU stay were interviewed, some along with a relative.	Six individual patient and 13 paired (patient and relative) interviews conducted ( $n = 32$ ). Patients $n = 19$ , Relatives $n = 13$ Gender: Patients Female 9, Male 10; Relatives Female 9, Male 4. Age: mean 55.4 (18–76) years APACHE score: mean Site I = 26, Site II = 18. Mean days in ICU: Site I = 13, Site II = 15. Mean days mechanical ventilation: Site I = 9, Site II = 12.	The central phenomenon (core category) of the study was constructing the illness narrative. "Main categories within the patient perspective were information acquisition and gaining insight, and the main categories within the relative perspective were supporting the patient, supporting oneself, and negotiating access.... Post-ICU patients need to construct their illness narrative and that intensive care diaries are among the sources of information they use." P.1922	**

(Continues)

TABLE 2 (Continued)

Author & Country	Methodology and Data Collection	Setting / Sample	Participants (age, gender, LOS, Socio-economic status)	Main Finding	MMAT
Griffith et al. (2018) Scotland, UK	Prospective nested cohort study within a randomized controlled trial.	Two adult ICUs in Scotland, Adult ICU survivors, mechanical ventilation >48 hours.	Patients: from sample of 240 recruited in ICU $n = 197$ at 3 months, $n = 165$ at 6 months, $n = 155$ at 12 months. Gender: Male 137 (57%), Female 103 (43%) Age: mean 60 (SD 14) years Deprivation category: Most deprived 33 (14%) Least deprived 54 (23%)	Explored HRQoL 12 months after ICU. Mean Physical Component Score and Mental Component Score were reduced at all time points. Increasing pre-ICU co-morbidity count was strongly associated with lower HRQoL and more severe self-reported symptoms. APACHE II score and mechanical ventilation days were not associated with HRQoL. Older age and lower social deprivation were associated with better Mental Component Score health-related quality of life. $P.594$ Many patients failed to experience clinically important improvement in HRQoL between 3 and 12 months. Pre-critical illness co-morbidities rather than features of the critical illness were the strongest predictors of survivors' HRQoL and self-reported physical symptoms during the 3–12 months following ICU discharge. $P.600$	***
Griffiths et al. (2013) UK	Multi-centre questionnaire-based study	22 UK ICUs. Patients >48 hours of level 3 dependency care. Age 16+	Patients: $n = 293$ Gender: Male 192(66%) Female 101(34%) Age: median 62 (IQR 52–71) APACHE II: $>18 = 127$ (43%) LOS ICU: median 8 (IQR 5–16) days LOS Hospital: median 29 (IQR 17–47) days Ethnicity: British 257(88%)	Social and economic outcomes and HRQoL were measured at 6 and 12 months after ICU discharge. Negative impact on family income with a 50% reduction in patients reporting employment as sole source of income at 12 months. One quarter of patients reported themselves in need of care assistance at 6 months and 22% at 12 months. The majority of care was provided by family members for half of whom there was a negative impact on employment. Mobility problems nearly doubled between pre-admission and 6 months (32% to 64%). 73% reported moderate or severe pain at 12 months and 44% remained significantly anxious or depressed. $P.1$	****
Haines et al. (2018) Australia	A prospective, observational follow-up study.	Adult ICU. Patients were longer-stay (median ICU admission of 7 days).	$n = 56$ Gender: Male 34 (61%) Age: mean 59 (SD 14.1) at recruitment LOS ICU: 7 (IQR 5–11) days LOS Hospital: 19 (IQR 11.3–29.5) days	Evaluated 4- to 5-year outcomes. Mean six-minute walk distance increased, depressive symptoms were low, mean levels of post-traumatic stress symptoms were low, no change in SF36 Physical and Mental Component Scores was seen. Outcomes were varied across settings. Survivors achieved a high level of recovery for physical function and health-related quality of life with low psychological morbidity at follow-up.	****
Hanifa et al. (2018) Denmark	Focused ethnography of a nurse-led post-ICU follow-up consultation.	One Adult ICU, post-ICU patients at follow-up.	$n = 10$ Gender: Male 3, Female 7 Age: 32 – 84 years LOS ICU at least five days Mechanically ventilated for at least 24 h during hospitalisation.	Content and setting of the consultation were of utmost importance. Revisiting the unit and experiencing the setting in person played a huge role in coping with post-intensive care syndrome. Involving relatives was essential, as they were an important part of the patient's rehabilitation. $P.85$	****

(Continues)

TABLE 2 (Continued)

Author & Country	Methodology and Data Collection	Setting / Sample	Participants (age, gender, LoS, Socio-economic status)	Main Finding	MMAT
Hatch et al. (2018) UK	Prospective multi-centre follow-up study of ICU survivors for psychopathology.	Patients from 26 ICUs in the UK who were 16 years of age or older	n = 4,943 Male: 57%, Median age: 64 (52–73 IQR) years ICU LOS: 3 (2–6 IQR) days LOS Hospital: 15 (9–28 IQR) days	Over half reported significant symptoms of anxiety, depression or PTSD. When symptoms of one psychological disorder are present, there is a 65% chance they will co-occur with symptoms of one of the other two disorders. Depression following critical illness is associated with an increased mortality risk in the first 2 years following discharge from ICU.	***
Herridge et al. (2003) Canada	Longitudinal cohort follow-up study	Four ICUs. ICU patients with ARDS	n = 109 Male: 66 (56%) Median Age: 45 (36–58 IQR) years ICU LOS: 25 (15–45 IQR) days LOS Hospital: 48 (27–77 IQR) days Mechanically ventilated 21 (12–40 IQR) days	Evaluated patients at 3, 6, and 12 months after discharge from ICU. Patients were interviewed and underwent a physical examination, pulmonary-function testing, a six minute-walk test, and a quality-of-life evaluation. Median scores on SF36 physical health and the six minute walk test increased at 12 months but were lower than predicted. Most patients had persistent extrapulmonary conditions and muscle weakness.	***
Herridge et al. (2011) Canada	Longitudinal cohort follow-up study	Four ICUs. ICU patients with ARDS	n = 64 at 5 years Male: 33 (52%) Median Age: 44 (35–57 IQR) years ICU LOS: 26 (16–49 IQR) days LOS Hospital: 49 (29–72 IQR) days Mechanically ventilated 24 (12–41 IQR) days	At five years, ICU survivors still had exercise limitations. Younger patients had a greater rate of recovery but none recovered to normal. Patients reported social isolation, sexual dysfunction, job loss, dispute over disability claims and insurance claims in qualitative interviews. Those with more coexisting illnesses had greater persistent issues at 5 year follow-up.	****
Iwashyna et al. (2010) USA [D]	Prospective cohort study	Survivors of severe sepsis compared to those surviving non-sepsis hospitalization.	516 survived severe sepsis and 4,517 survived a non-sepsis hospitalization to at least 1 follow-up survey are included in the analysis. Less than half of sepsis survivors had an ICU stay.	Assessed functional disability and cognitive impairment. The odds of acquiring moderate to severe cognitive impairment were 3.3 times higher following an episode of sepsis, with an additional mean increase of 1.5 new functional limitations per person.	***
Iwashyna et al. (2012) USA	Retrospective cohort study	All short stay inpatients in the United States 1996–2008 extracting those with severe sepsis, age 65+	1996, 34,782,442 Medicare beneficiaries aged 65 and above were examined (Median age 73 (IQR 68 to 79); 59% were female; 2008, 39,337,348 Medicare beneficiaries were examined. (Median age 73 (IQR 68 to 80); 57% were female.	Number of survivors of severe sepsis and rates of severe sepsis both increased from 1996 to 2008. The increase in survivorship resulted from more new diagnosis and not a change in case fatality. Sepsis survivorship, which carries with it substantial long-term morbidity, is a common and rapidly growing public health problem for older Americans. There has been little change in long-term case fatality, despite changes in practice.	****

(Continues)

TABLE 2 (Continued)

Author & Country	Methodology and Data Collection	Setting / Sample	Participants (age, gender, LoS, Socio-economic status)	Main Finding	MMAT
Jones et al. (2003) UK	RCT	Three UK hospitals. 126 consecutively admitted ICU patients who had been ventilated.	n = 126 (69 Intervention, 57 control) Intervention group— Male: 37 (58%) Mean Age: 57 (SD 17) years ICU LOS: 14 (SD 20) days Control group— Male: 33 (54%) Mean Age: 59 (SD 16) years ICU LOS: 13 (SD 18) days	Evaluated a rehabilitation program—a self-help rehabilitation manual in aiding physical recovery and reducing depression. Intervention group had higher SF36 physical function scores at 8 weeks and 6 months and lower rate of depression at 8 weeks. No difference found in levels of anxiety and PTSD-related symptoms. Patients with delusional memories from the ICU, may need further psychological care to reduce the incidence of anxiety and PTSD-related symptoms.	****
Kang and Jeong (2018) South Korea	Classic grounded theory approach,	Adult ICU survivors who had experienced physical, mental or cognitive changes after discharge. Time since discharge varied between 1 month and 9 years.  Recruited by 'public announcements' and referring medical staff.	n = 13 Male 7; Female 6 Age range 20–82 years ICU LOS: 3–40 days	Individual interviews on ICU survivors' experiences of post-intensive care syndrome (PICS). Findings revealed 6 categories: Being vulnerable; Struggling for recovery; New crisis; Being devastated; Mobilising internal/external resources; New perspective  on normality. These categories were incorporated into the core category 'Embracing the New Vulnerable Self'. Survivors who were discharged from ICUs were physically, mentally, cognitively or socially vulnerable.	**
Kean et al. (2017) UK [D, Th]	Longitudinal qualitative and constructivist grounded theory.	Two ICUs in Scotland. Adult ICU survivors experiencing >48 hours of mechanical ventilation.	n = 17 patients Total of 47 interviews at four time points; before hospital discharge, 4 to 6 weeks post-discharge, 6 months and 12 months post-discharge.	Aimed to theorise ICU survivorship. ICU survivorship describes the unscheduled status passage of falling critically ill and being taken to the threshold of life and the journey to a life post-critical illness. Surviving critical illness goes beyond recovery. Transitioning from critical illness to ICU survivorship took four general directions: (1) survivorship, (2) recovery towards survivorship, (3) survivorship towards new-onset disability and (4) survivorship towards palliation	****
Khandeival et al. (2018) USA	Secondary analysis of RCT participants as a cohort.	Five hospitals in the USA. Adult ICU patients experiencing >48 hours of mechanical ventilation and their families. Eligible family members were age 18 years + and expected to provide significant post-discharge assistance. One family member for each patient if available.	Patients n = 175 (86 coping skills training group, 89 education group) Male: 57% Mean Age: 52 (SD 13.8) years ICU LOS: Median 8 (IQR 5–13) days Family members n = 85 (39 coping skills training, 47 education) Mean age: 51 years (SD 15), Male: 20%	Prevalence of financial stress described within 2 weeks of arriving home and at 3 and 6 months post-discharge. Serious financial stress high at both 3 and 6 months and was highest at 6 months (42.5%) among patients and at 3 months (48.5%) among family members. Factors associated with financial stress included female sex, young children at home, and baseline financial discomfort. Experiencing financial stress had direct effects on symptoms of anxiety and depression. Financial stress after critical illness is common and associated with symptoms of anxiety and depression.	***

(Continues)

TABLE 2 (Continued)

Author & Country	Methodology and Data Collection	Setting / Sample	Participants (age, gender, LoS, Socio-economic status.)	Main Finding	MMAT
Langerud et al. (2018) Norway	Exploratory, longitudinal cohort study	Two ICUs in one hospital in Norway. Adult ICU survivors with a length of ICU stay of >48 hours.	n = 118 Mean age: 55.1 (SD 14.4) years LOS ICU median: 9 (IQR 9–15) days Mechanically ventilated 6 (IQR 3–12) days	Investigated the prevalence of anxiety, depression, fatigue, sleep disturbance and post-traumatic stress symptoms (PTSS) among intensive care survivors at 3 months and 1 year post-ICU. ICU survivors with pain reported more symptoms than those ICU survivors without pain. Symptoms included anxiety depression sleep disturbance, PTSS, and fatigue.	***
Lone et al. (2016) Scotland, UK [D]	Matched cohort study using national whole population data	All adult general ICU patients in Scotland (2005) surviving to hospital discharge matched to similar hospital control subjects.	n = 5,259 ICU patients (almost all with matched controls) Male: 55.4% Median age: 60 (IQR 44–72) years Mechanically ventilated 61% ICU LOS Median 2 days (IQR 1–5) 27.2% from most deprived SIMD	5 years after hospital discharge ICU survivors had a higher 5 year mortality, and increased resource use than non-ICU patients and both excess mortality and resource use were greater for younger patients. Factors present before ICU admission (co-morbidities/pre-ICU hospitalizations) were stronger predictors of hospital resource use than acute illness factors. P.198	****
Maley et al. (2016) USA	Mixed Methods pilot study	Two medical adult ICUs. Patients surviving with an ICU length of stay >2 days.	n = 43 Male: 18 (41.9%) Mean age: 59 (SD 15) years Mechanically ventilated: 20 (46.5%) ICU LOS: 5.1 (IQR 2.5–11.3) days Hospital LOS: 14.1 (IQR 6.9–24.1) days	Resilience was inversely correlated with neuropsychological impairment, pain, and difficulty with self-care. PICS was present in most survivors of critical illness, and 54% reported neuropsychological or physical function to be worse, yet resilience was normal or high in most survivors.	***
Norman et al. (2016) USA	Prospective cohort study	Medical and Surgical ICUs in two hospitals. Previously employed patients from the BRAIN-ICU study who survived a critical illness due to respiratory failure or shock.	n = 113 Male: 69 (61%) Mean age: 53 (IQR 44–60) years	Baseline and in-hospital clinical data were collected with follow-up for global cognition and employment status at 3 and 12 months. There was a reduction in employment after ICU in the majority of survivors, approximately half of which was new unemployment. Delirium at either 3 or 12 months was not a predictor yet cognitive function at 12 months was a predictor of subsequent employment status.	****
Olsen et al. (2017) Norway	Qualitative exploratory study	One hospital ICU in Norway. Adult ICU survivors experiencing >48 hours of mechanical ventilation in ICU, living at home with no nursing homecare services.	n = 29 Age median range 60–69 Male: 19 (65.5%)	Two main themes emerged: "Being on an unreal, strange journey" and "Balancing between who I was and who I am". Patients' recollection of their intensive care stay differed greatly. Continuity of care and the nurse's ability to see and value individual differences was highlighted. The information pamphlet helped intensive care survivors understand that what they went through was normal. Participants with a chronic illness or disability before their ICU stay were pleased with their health condition and quality of life three to four months after the stay. They accepted a lower standard of "good health" and did not expect to be symptom free after ICU.	***

(Continues)



TABLE 2 (Continued)

Author & Country	Methodology and Data Collection	Setting / Sample	Participants (age, gender, LoS, Socio-economic status.)	Main Finding	MMAT
Page, Simpson & Reynolds (2019) UK [D]	Constructivist grounded theory study	ICU in one UK hospital. Adult ICU survivors and their family members.	Patients $n = 16$ Male: 10, Female = 6 Age: mean 61 (range 42–75) Duration of time in ICU 4–40 days Duration from discharge to interview 4–11 months Family members $n = 15$ 5 interviewed during ICU admission 10 interviewed 4–11 months after discharge	In-depth interviews were undertaken with survivors of critical illness and their family members. Perspectives of survivors and their family members do not always coincide. The transitional period to a new normal following physiological survival requires support from practitioners and family members. Regaining family homeostasis can be a challenging journey for both survivor and family member. Survivors of critical illness, together with family members, experience challenges when endeavouring to readjust to life post-critical care. This study identified a middle range theory of dualistic worlds between and within the survivor and family member experiences. Exploring the dynamic interplay between intrapersonal, and societal factors provided theoretical insights with practice implications in relation to surviving critical illness. P.603	****
Pattison et al. (2015) UK	Mixed method longitudinal study	One ICU set in a tertiary referral cancer hospital. Patients surviving with an ICU length of stay >48 h.	$n = 77$ for Survey data Male 50% Age: 59.03 (SD 12.94) years APACHE II: Mean 15.44 (SD 5.37) ICU LOS: Mean 90.58 hours (3.77 days) Sub-sample for email interviews $n = 22$ Mean age 59.2 years Male 8 (36.4%) ICU LOS: Mean 137.6 hours	Data was collected at 2 weeks, 6 months, 12 months using the ICE-q, HADS, EQ-5D triangulated with clinical predictors. In-depth qualitative email interviews completed at 1 month and 6 months. Mean EQ-5D utility scores and HADS scores improved from 2 weeks to 6 months ( $p = <0.001$ ), but between 6 and 12 months, there was no change suggesting improvements level off. These variations were reflected in qualitative data themes: rehabilitation/recovery in the context of chronic illness; impact of critical care; emotional and psychological needs (including sub-themes of: information needs and relocation anxiety). The overarching core theme related to adjustment of normality. P213	**
Prinjha et al. (2009) UK	Qualitative study	ICU survivors from across the UK who were admitted to the ICU as an emergency. Time lapsed since ICU stay when data was collected was not reported	$n = 34$ Male: 20, Female: 14 Age: range 23–76 years ICU LOS: 4 days- to 5 weeks	Patients valued ICU follow-up services, which had made an important contribution to physical, emotional and psychological recovery in terms of continuity of care, receiving information, gaining expert reassurance and giving feedback to ICU staff. Continuity of care included having tests and being monitored, referrals to other specialists and ICU follow-up appointments soon after hospital discharge. Information about physical, emotional and psychological recovery was particularly important to patients, as was information that helped them make sense of their ICU experience. Those without access to ICU follow-up care often felt abandoned or disappointed because they had no opportunity to be monitored, referred or get more information. P.46	***

(Continues)

TABLE 2 (Continued)

Author & Country	Methodology and Data Collection	Setting / Sample	Participants (age, gender, LoS, Socio-economic status)	Main Finding	MMAT
Tembo et al. (2015) Australia	Qualitative (phenomenological) study	One ICU in Australia. Adult ICU patients who had been mechanically ventilated and undergone daily sedation interruption for at least 48 hours	n = 12 Male: 5, Female: 7 Age: range 20 to 76 years ICU LOS: range 3 to 36 days	Used in-depth interviews to explore the lived experiences of patients in ICU in the context of daily sedation interruptions. Communication difficulties continue to affect patients up to eleven months after ICU hospitalisation. This leaves the people with a loss of identity and feelings of being in limbo, not knowing when their voice will come back. The overarching theme: 'Being in limbo' and sub-themes 'Being disrupted', 'Being imprisoned' and 'Being trapped' depict the main elements of the experience.	***
Wade et al. (2019) UK	Multi-centre, parallel group, cluster randomised clinical trial	24 ICUs in the UK. Adults ICU patients who regained mental capacity following level 3 intensive care.	N = 24 ICUs with 1,458 patients Intervention n = 12 ICUs, 669 patients Male: 59.4% baseline, 55.5% study Age: mean 59.5 baseline, 60.4 study Control n = 12 ICUs, 789 patients Male: 63.0% baseline, 60.1% study Age: mean 57.2 baseline, 57.2 study	The preventive, complex psychological intervention comprised promotion of a therapeutic ICU environment plus 3 stress support sessions and a relaxation and recovery program delivered by trained ICU nurses to high-risk (acutely stressed) patients. The primary clinical outcome was PTSD symptom severity among survivors at 6 months measured using the PTSD Symptom Scale-Self-Report questionnaire. The intervention did not significantly reduce patient-reported PTSD symptom severity at 6 months. These findings do not support the use of this psychological intervention.	****
Walsh et al. (2015) Scotland	Parallel group, randomized clinical trial with blinded outcome assessment	Two ICUs in Scotland, UK. Adult ICU survivors with mechanical ventilation for >48 hours.	N = 240 Intervention group n = 120 Male: 55.8% male, Age: median 62 (IQR 51–71) Mechanical ventilation: median 9 (IQR 5–16) days Social class 4 or 5: 45% Intervention group n = 120 Male: 58.3% male, Age: median 62 (IQR 53–69) Mechanical ventilation: median 8 (IQR 4–15) days Social class 4 or 5: 43.3%	Patients in the intervention group received rehabilitation that typically increased the frequency of mobility and exercise therapies 2- to 3-fold, increased dietetic assessment and treatment, used individualized goal setting, and provided greater illness-specific information. Intervention group therapy was coordinated and delivered by a dedicated rehabilitation practitioner. No difference in any outcomes measures following additional rehabilitation support on physical, psychological measures or symptom reporting. Patients did report greater satisfaction with care though.	****
Wunsch et al. (2010) USA	Matched, retrospective cohort study	Random sample of half of all patients aged >65 years who received intensive care and survived to hospital discharge in 2003 in the USA from Medicare records.	n = 35,308 ICU survivors n = 35,308 controls Male: 45.8% male, Age: mean 78 (SD 6.9) ICU LOS: 1 (IQR 0–3) days Hospital LOS: 5 (IQR 3–9) days	Two matched control groups were generated: hospitalized patients who survived to discharge (hospital controls) and the general population (general controls), individually matched on age, sex, race, and whether they had surgery (for hospital controls). There is a large US population of elderly individuals who survived the ICU stay to hospital discharge but who have a high mortality over the subsequent years in excess of that seen in comparable controls. The risk is concentrated early after hospital discharge among those who require mechanical ventilation.p.849	***

Abbreviations: D, definition of survivorship after ICU provided; Th, Theory of survivorship after ICU developed.

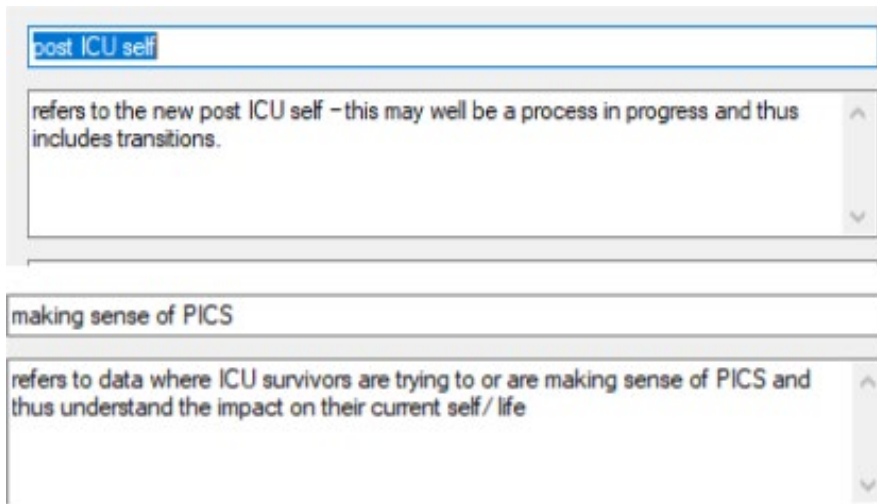


FIGURE 2 Examples of open code definitions

work, decreased quality of life, and functional disability. If unrecognised, these impairments could undermine long-term health and health-related quality of life' (Maley et al., 2016, p 1352). Research by Marra et al., (2018) found that more years of education was protective from post-intensive care syndrome problems highlighting the importance of considering the social determinants of health and well-being alongside recovery from critical illness (McPeake & Mikkelsen, 2018). Marra et al., (2018) also argue that future studies are needed to better understand the heterogeneous subtypes of post-intensive care syndrome.

Classifying has consequences for how we see the other. Terminologies like 'disability' or 'impairment' are not value neutral but point to something that is dysfunctional. For example, Herridge et al., (2011) investigated the functional disability of ICU survivors five years after an admission for acute respiratory distress syndrome (ARDS) and found that;

patients with ARDS had new or continued impairments related to a variety of physical and neuropsychological disorders between 2 and 5 years of follow-up. (Herridge et al. 2011, p 1295): p?)

Iwashyna et al., (2010) studied sepsis survivors and found;

the onset of disability is associated with worsened mortality and substantial increase in medical costs over subsequent years, including a disproportionate strain on Medicaid and Medicare. Both cognitive and physical disability impose yet further burdens on families and informal caregivers. (Iwashyna et al 2010, p 1787)

Since one of the functions of a classification system is communication, terms like 'disability' or 'impairment' are frequently used in reporting research (Berghs et al., 2016). To classify ICU survivors as having 'disabilities' or 'impairments' is describing ICU survivors' loss of former abilities. This classification of 'disability' can serve

a purpose, for example, legitimatising the application for disability benefits or determining physiotherapy interventions. However, these classifications primarily serve us as health and social care professionals reflecting our language and views or perspectives taken in a study and crucially, what we see as important interventions post-critical illness. These classifications may not necessarily represent how ICU survivors or family members perceive themselves. Any healthcare system aiming to be person- or patient-centred, therefore, needs to pay attention to these differences. Yet pathways of care have gained prominence in attempting to classify by disease and disorder and predetermine need.

### 3.3.2 | Transitions into primary care

Care pathways were developed to try and address the fragmentation of health and social care services to provide a smooth transition between acute and community care and thus meeting patients' anticipated needs. However, not only do these socially constructed tools assume that people will suitably follow predetermined pathways, they can be disempowering and marginalising for some where no pathway exists or is not meeting identified need and moreover disguise uncertainties that are a normal part of medical treatment (Checkland et al., 2019). Whilst the PICS literature identifies much of the needs of those recovering from critical illness, their survivorship needs, in terms of timing of interventions to meet those needs and the heterogeneity of patient need, is not accounted for. Given the heterogeneity of the critical care population, the heterogeneous subtypes of PICS and the need for person-centred care, there are significant challenges in single pathway approaches to ICU recovery and survivorship.

The appropriateness of single pathway approaches involving patients with complex care needs is addressed in other research studies. Grimsmo et al. (2018), highlighting the rise of multi-morbidity in the western world, found that the feasibility of disease-specific pathways in primary care is limited, both from a clinical and organisational perspective, for patients with complex needs. A view echoed by Barrett et al. (2012), who, following their epidemiological study of



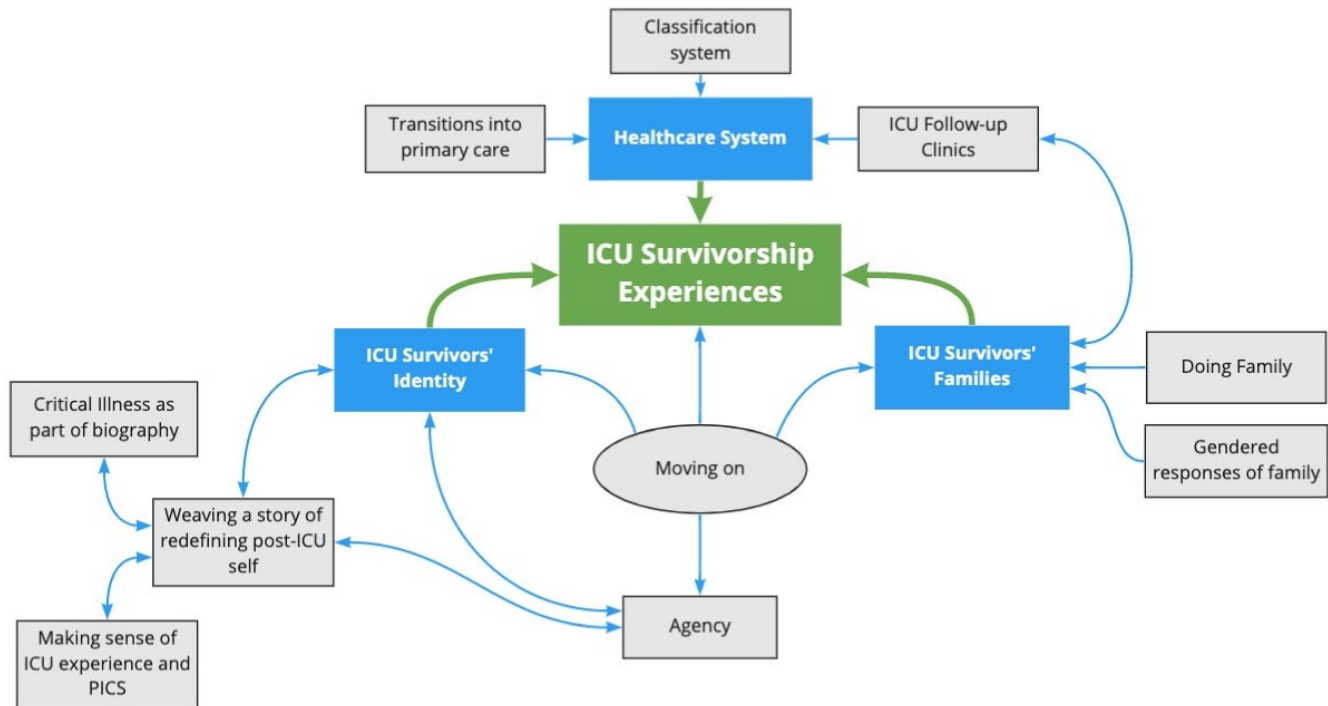


FIGURE 3 Model of ICU survivorship experiences

multi-morbidity in Scotland noted that multi-morbidity is becoming the norm rather than the exception, especially in areas of social deprivation and challenged the single-disease framework by which most health care, medical research and medical education is configured.

The fragmentation of services in the reviewed studies was evident when patients or carers reported that;

communication between hospital and community-based services had been poor around the time of their discharge, and community services were unaware they had been discharged and/or lacked relevant information. Community support was frequently perceived as reactive rather than anticipatory, despite poor health status at hospital discharge. When multiple services were needed, they were perceived by some to act independently without coordination. (Donaghy et al. 2018, p 6)

Lack of communication between services often resulted in a lack of understanding of the impact critical illness can have on patients and families. Allum et al., 2018, p 318), pointed out that;

whilst some of these participants sought reassurance from their GP, most suggested that the GP was not familiar with the speciality of critical care to adequately provide this role.

This experience was echoed by participants in other studies (Eakin et al. 2017; Dahle Olsen et al. 2017; Prinjha et al., 2009) where:

in the patients' experience, health-care professionals outside the ICU had little knowledge of the symptoms that occurred following a critical illness. (Hanifa et al 2018, p 88)

Given the overall small number of ICU survivors that individual GPs or other community healthcare professionals see, this is perhaps not surprising, but does highlight a need for education on ICU survival and its longer-term impact on patients and families. The need to address ICU survivors' health and psychosocial needs post-ICU has been recognised for some time by ICU healthcare professionals and some policy makers (NICE, 2009); nevertheless, we still need to develop models of care that incorporate follow-up care and ongoing support throughout the recovery and subsequent survivorship trajectory and that are person-centred (Allum et al., 2018; Prinjha et al., 2009; Tembo et al. 2015).

Recovery from critical illness and moving on to survivorship are complex and non-linear processes that including reversals and diversions (Kean et al. 2017). Single-disease care pathways do not account for the heterogeneity of the ICU population. Heterogeneity and pre-ICU health of ICU patients however are important factors impacting on ICU outcomes and the complexity of recovery (Griffith et al., 2018; Nielsen et al., 2019).

Lone et al., (2016, p 205) point out that they;

were surprised that the acute illness factors such as ICU admission illness severity and requirement for organ support had little or no influence on subsequent resource use. .... Our data indicate that

pre-illness factors, such as previous hospital resource use and comorbidity, most strongly influence subsequent hospital resource use.

The impact of pre-ICU health is starting to be recognised as a significant factor in recovery (Bagshaw et al., 2015; Griffith et al., 2018; Lone et al., 2016; Nielsen et al., 2019). Given the complexity of multimorbidities, pre-ICU health, and type and severity of critical illness, it must be questioned if there can be a predetermined standardised care pathway for recovering ICU patients and how such standardisation would align with person-centred care approaches (Scottish Government, 2010).

Though not part of an integrated care model in the above sense, ICU follow-up clinics were a frequently mentioned intervention in the reviewed studies.

### 3.3.3 | ICU follow-up clinics

Internationally, there is no agreed standard on what constitutes a follow-up clinic, and this is evident in the included literature. There is a rich literature on follow-up clinics which reports the inconsistency of provision, challenges that exist in delivering these services as well as the effectiveness of this intervention (e.g. Cuthbertson et al., 2007; Griffiths et al., 2006; Haines et al., 2018; Prinjha et al., 2009). However, in this review, we focused on insights in relation to survivorship and what these clinics might bring to survivorship.

The traditional form of follow-up clinic still appears to be a face-to-face meetings, either with an ICU consultant, a nurse or both, at a predetermined time point (Allum et al., 2018; Hanifa et al., 2018; Prinjha et al., 2009). Research under this heading looked to determining needs of ICU survivors post-discharge (Allum et al., 2018; Pattison et al., 2015; Prinjha et al., 2009) but also at interventions such as group meetings and/or ICU diaries (Bäckman et al., 2017; Chiang, 2011). These studies suggest that ICU survivors and their families need timely information throughout their recovery trajectory. Timely does not refer to a fixed time point set by the system, which is often the case in follow-up clinics, but to the shifting and changing needs of an individual ICU survivor during recovery and thus is an individually determined time point.

Some studies suggest that a more flexible model of service provision might improve accessibility, for example, follow-up occurring at different time points in recovery, offering more than one appointment (Prinjha et al., 2009) or occurring at a site away from the hospital, over the phone or via email (Pattison et al., 2015). Contact details for a critical care clinician during the interim wait time for a follow-up appointment was suggested (Pattison et al., 2015).

ICU patients recover and transition into survivorship at their own pace and this temporal dissonance between set organisational time frames and personal/body times of patients' needs to be taken into account in post-ICU support (Kean et al. 2017).

TABLE 4 Morgen's (2011) key characteristics of family practices

1. A sense of the active—family life is a set of activities; individuals can be seen as 'doing family'
2. A sense of the everyday—in relation to everyday but also including life events such as parenthood, partnering, looking after a sick family member, etc.
3. A sense of the regular—regular practices are part of everyday family life, for example school runs, annual family Christmas reunion, birthday routines and so on.
4. A sense of fluidity—family boundaries are fluid and it depends on who is defining 'family', practices can also be gendered practices, for example in caring situations
5. A linking of history and biography—neither family nor an individual exists in a vacuum, but they have a history and exist within a social context.

## 3.4 | Theme 2: ICU survivors' families

### 3.4.1 | Doing family

Family, whether defined in the narrow kinship sense or from a more inclusive family of choice perspective (Chambers, 2012), is often the context within which ICU survivors receive a considerable amount of care and support during their critical illness, the recovery period and the subsequent transition into survivorship.

That families play a crucial role in the recovery of ICU survivors across the critical care continuum into survivorship is not a new insight. Families and their contributions, whilst under-researched in this context, provide support and care needed for ICU survivors across the care continuum and this was evident in many studies (Ågård et al., 2012; Chiang, 2011; Choi et al., 2012; Eakin et al. 2017; Egerod et al., 2011; Griffiths et al. 2013; Maley et al., 2016; Page et al. 2019).

Families, and specifically the importance of families in critical illness, can be understood theoretically when drawing on Morgen's (2011) concept of 'family practices'. Family practices are those everyday activities that family members do with the intention of doing something for another family member (Cheal, 2002). Table 4 lists the key characteristics of 'family practices' as described by Morgan (2001).

We know from decades of international Critical Care Family Needs Inventory (CCFNI) studies that 'being there' is a fundamental need of family members (Alsharari, 2019; Bergboom & Askwall, 2000; Lam & Beaulieu, 2004; Leske, 1998). Open visitation policies allow family members to be at the bedside and this is the time frame within which many family members engage in different family practices. Within the reviewed studies these practices included writing diaries whilst the patient was still in ICU but also included sense-making and thus information giving post-ICU when ICU survivors had questions about their time in ICU.

Ewens et al. (2014), for example, draw attention to the usefulness of writing diaries for some family members. They argued that 'writing in the diaries enabled them to express their feelings to loved ones whilst they were in ICU, to share experiences, connect them



with normal family events, express emotions and maintain a connection with them' (Ewens et al. 2014, p 1409).

Maintaining a connection is also expressed in sense-making for and information giving to ICU survivors by family members as is evident in Page et al.'s (2019) study. Sense-making occurs often post-ICU when ICU survivors try and make sense of what has happened to them. Family members are often in a position of providing this information and at a pace that is right for the individual ICU survivors.

Family practices is characterised by reciprocity. Olsen et al. (2017), for example, reported that all participants valued their families and 'spoke positively about their family and the support they received during and after their ICU stay. Their family's presence, the fact that family members cared, meant a lot. They also highlighted the role of the family as information agents, especially after their ICU stay. They commented that having family members present during times they themselves could not remember made them feel safe' (p 64).

It is these links between family members and their practices in individual families that we need to pay attention to when caring for ICU survivors and their families. We therefore need to be sensitive to and cognisant of the fact that family members live through the whole episode of their family member's critical illness and that critical illness truly goes beyond the ICU patient and impacts on family members too. It is useful to think here of the 'dualistic world' ICU survivors and family members inhabit (Page et al. 2019). This is, for example, evident in the following excerpt from Page et al. (2019) expressed by participants such as Jenny who:

spoke openly and honestly about the enormous pressures of living with and through critical illness as a family member and provided a further insight into the different worlds experienced by patients and family members in critical care.

Jenny: I will be honest, because I have spoken about this to David, our two kids were superb and very supportive and the eldest son said, I've got to say something to you mum, and I knew what he was going to say, if Dad's going to die, let it happen now, don't keep putting us through...So from that side of it, I don't know if David to this day, will ever know what the family goes through, but there he is sitting there'. (Page et al 2019, p 607)

### 3.4.2 | Gendered responses

Another often neglected aspect in research is gender. Egerod et al. (2011) study raises the issue of a gendered response of family members to critical illness. It was evident in this study that women coped differently to men to a family member's critical illness. Egerod et al., (2011, p 1926) suggest that for their study participants that 'the women were eager to read the diary, whereas the men tried to avoid

the disease discourse. Some men wished to "put it behind them," whereas the women needed to "talk it through". This is an important insight since gender is one of the under-researched aspects in this area but would impact on any intervention design should this be confirmed.

## 3.5 | Theme 3 ICU survivors' identity

### 3.5.1 | Weaving a story of redefining post-ICU self

Recent ICU survivorship research has developed a deeper, more theoretical understanding of survivorship through a greater recognition and appreciation of self, biography and identity in those surviving critical illness. Kean et al. (2017), following longitudinal qualitative research on critical illness survivors, argued that survivorship goes beyond functional recovery (physical and psychological). For Kean et al. (2017, p 3121), 'surviving means "moving on" to life post-critical illness. "Moving on" incorporates a redefinition of self that incorporates any lingering intensive care unit legacies and being in control of one's life again'. Ewens et al., (2017), highlight the 'hidden disruption' to self that many survivors of critical illness experience which, they suggest, makes the interpretative biographical approach one way of studying and better understanding survivorship in critical care. In a similar vein Page et al. (2019), emphasise the importance of developing our understanding of the subjective experience of ICU survivors and their families arguing, 'the need to consider the legacy of critical care beyond physiological survival is imperative' (p 603). Corner et al. (2019) argue that if clinicians are able to assist patients in '*recalibrating to their new current self*' and the reconstruction of a '*compelling future self*', it may improve patient care and outcomes. Therefore, a definition of what is meant by the term survivorship in a critical care context requires urgent investigation.

When reviewing the included literature, it became evident to us that the bigger picture some of these studies drew attention to, was the changing and shifting sense of identity among many ICU survivors. Identity construction can be understood as a process that is fluid, multi-layered and dynamic (Jenkins, 2014). Scott (2015 p.1) points out that:

we may think we know who we are, but these ideas are constantly changing, shaped by our experiences, relationships and interactions: who I am now is not the same as who I was yesterday or who I will be tomorrow.

Importantly, identity is not just our internal self-identification but also subject to external categorisation (Jenkins, 2014). Whilst there is no single, overarching definition of identity (Lawler, 2014), the concept can be understood as 'a set of integrated ideas about the self, the roles we play and the qualities that make us unique' (Scott, 2015 p.2).

These integrated ideas about the self were reflected in the different dimensions that lead to a redefinition of an ICU survivor's

identity. Dimensions, such as 'having survived'; 'not recalling ICU'; 'having experienced critical illness' and 'making sense of PICS' are inter-related. The process of redefining one's self often starts with the acknowledgement that one had survived a critical illness (Eakin et al., 2017; Egerod et al., 2011; Kean et al., 2017; Page et al., 2019). Whilst this sounds trivial, it is by no means unusual and is linked to many ICU survivors being unaware of how sick they had been. For some ICU survivors this realisation came when reading their diary (Egerod et al., 2011), others reported participants' new appreciations of life's fragility (Eakin et al., 2017; Kean et al., 2017; Page et al., 2019) and for some participants the critical illness demarcated a turning point in their lives (Eakin et al., 2017).

Making sense of the critical illness experience is challenging given the heterogeneity of this population, especially when many patients do not recall having been in ICU. Our integrated ideas about our self and who we are (Scott, 2015) are challenged in these circumstances because the short- and long-term consequences of critical illness often forces ICU survivors to surrender their pre-illness self and identity to one that has yet to emerge post-critical illness (Kean et al., 2017). The mental image many patients have of themselves is the one pre-critical illness. An example of this is given in Egerod et al., (2011) study. In this case, Nina, one of their participants 'compared her hospital chart and diary and found that they told two different stories: "The diary and the chart could have described two different people...when they describe the scans...the dates are the same, but the person is not the same...but [the diary] is more personal and tries to tell me who was there and how I did"' (Egerod et al., 2011, p 1925). In essence, the mental image Nina had of herself post-critical illness was her pre-critical illness self and thus this did not match with the Nina that was described in her hospital charts.

This temporal mismatch between the pre-illness and post-illness self is further evident in Corner et al.'s (2019) study explaining that:

when questioned about early physical function, patients recalled a discrepancy at the time of recovering awareness between their current self, which incorporates their physical dependency, fatigue, clarity of mind and self-image and the mental representation of themselves, which is still consistent with their pre-admission self. [] Physical independence and function are core components of the concept of self. When physical ability deteriorates so unexpectedly, rapidly and without obvious causation (as in ICUAW), it comes as a shock to the patient blurring their sense of self. Physical rehabilitation aims to improve impairments and function by challenging patients' physical ability thereby, in this extreme context, inadvertently challenging their self-perception as well. (Corner et al 2019, p 5)

The person emerging post-critical illness can be indeed a different person. For ICU survivors making sense of these changes, information giving, either by healthcare professionals (Hanifa et al. 2018) and/

or family members, is essential. By providing information and filling in the blanks of what is not remembered by ICU survivors enables them to make sense of how these two different perceptions of the pre- and post-critical illness 'self' match up and thus supporting the process of redefining their identity. Providing information therefore is a supportive intervention that helps ICU survivors weaving their own stories of survival, underlining the co-constructive aspects of survivorship stories (Corner et al., 2019; Egerod et al., 2011; Kean et al., 2017; Page et al., 2019).

As Corner et al.'s (2019) excerpt makes evident, the post-critical illness 'self' reflected a person with physical dependencies, fatigue and cognitive challenges. Ågård et al., (2012) called this process 'a struggle for independence' and this striving for independence was also evident in a number of other studies (Bäckman et al 2017; Corner et al. 2019; Hanifa et al. 2018; Kean et al., 2017). This struggle involved the regaining of their physical and cognitive ability with the aim of resuming their previous roles and positions in life (e.g. family, work and wider society). However, the critical illness often required ICU survivors to realise that their post-critical illness lives differed, and at times, significantly from their pre-illness lives (Bäckman et al 2017; Kean et al., 2017; Page et al., 2019).

Coming to terms with their 'new' post-ICU self is therefore a common experience for many ICU survivors, especially for those with few previous health problems. We must also however consider recent research that has highlighted pre-existing poor health in ICU survivors' prior to an ICU admission, notably those with chronic illness, multi-morbidity and frailty and those from socially deprived backgrounds. For this group of ICU survivors it may be that their admission to ICU is a continuum of living with poor health and difficult social circumstances, albeit exacerbated by their experience of being critically ill. It could be argued that for this group of ICU survivors, rather than their critical illness being the single major acute life event with associated impact on self and identity, it is an accumulative experience as the self is constantly and progressively reconstituted throughout the prolonged experience of chronic illness or disease (Denzin, 1989; Frank, 1995). In this context we believe it is worth investigating what are the similarities and differences between those surviving a critical illness episode as part of an exacerbation of chronic illness/multi-morbidity and pre-existing frailty and those for whom severe illness is acute in onset in terms of surviving critical illness. We believe this is especially important given the diverse needs of those surviving critical illness and what is expected from health and social care services to meet these diverse needs.

We note however that research, particularly qualitative research involving ICU survivors with chronic illness, multi-morbidity, frailty and from socially deprived backgrounds prior to their critical illness remains in its infancy, perhaps because they are 'hard to reach' when conducting research studies (Boneveski et al., 2014).

### 3.5.2 | Agency

Adapting to a new lifestyle and/or a different set of challenges post-critical illness is one of the functions of ICU survivors weaving

their survivorship stories. Agency, the ability of the individual to make their own choices, was evident across a number of studies (Corner et al., 2019; Eakin et al., 2017; Kang & Jeong, 2018; Kean et al., 2017). Participants' agency was evident when participants reported that they 'started to think about motivating, getting myself to do the things that I need to do, get up and instead of using a walker just try to walk on my own' (Eakin et al., 2017, p 458) but also the realisation that they may have temporarily lost their agency when participants reported that they felt 'so not free, everyone is doing what they want, I'm like a puppet and I hate that' (Michelle), and feeling isolated: 'I don't think I had a voice at one point, which was probably one of the most difficult things to experience, because you can't talk to people' (Richard)' (Corner et al., 2019, p 7).

That pre-existing illnesses impacted on agency and how ICU survivors approached their recovery is evident in Kean et al.'s (2017) study. These participants had a better idea of what they needed in terms of support (e.g. physiotherapy) or occupational material post-discharge. As Griffith et al., (2018) point out, pre-hospital illness and its role in recovery post-critical illness is not well-understood. Reviewed studies examining Quality of Life of ICU survivors suggest that pre-existing co-morbidities are associated with a lower health-related quality of life and physical symptoms following a critical illness (Cuthbertson et al., 2005; Griffith et al., 2018).

In this context, frailty pre-critical illness is currently emerging as an important indicator on critical illness survivorship and readmission risks of this patient cohort (Bagshaw et al., 2016; Donaghy, Salisbury, et al., 2018). These studies suggest that ICU survivors with pre-existing chronic conditions, have a higher mortality and readmission rate and a lower quality of life. This is an important insight since this knowledge should trigger a screening for frailty to determine the intervention needed for a specific ICU survivors post-discharge to maximise recovery.

Considering pre-existing frailty and co-morbidities are therefore also important factors in relation to recovery expectations and the time it may take. ICU survivors recover at their own pace and this varies significantly. It was evident in several studies that some ICU survivors recovered relatively quickly whilst others needed a lot more time and hadn't recovered within the studies' timeframes (Ågård et al., 2012; Kean et al., 2017; Olsen et al., 2017). Again, information giving and what to expect after hospital discharge is crucial for ICU survivors. The impact of a lack of information and recovery expectation is, for example, evident in Donaghy, Salisbury, et al., (2018) study. In their study, participants made it clear that the discharge information given did not meet their needs of what to expect post-discharge. As one participant commented: 'When I was in the High Dependency Dr X said you will have to take things very easy, softly, slowly. Okay. I understand that. But I didn't have anybody come and say to me exactly what that meant. Like, 'look you're going to be feeling like this for this amount of time. That's normal. And this might happen and if it does you need to do this exactly if that happens. Things will be like this for the next 3–4 months so take these steps, do this to help you get better' type thing. But no. Back

home the GP didn't know I'd been in ICU' (Donaghy, Salisbury, et al., 2018, p 5).

### 3.5.3 | Moving on

'Moving on' is the ultimate goal of recovery and is expressed by, for example, a new sense of normalcy (Kean et al., 2017; Page et al., 2019). This process included the realisation that aspects of PICS are not restricted to oneself but, indeed, are common experiences among other ICU survivors. Hanifa et al. (2018), for example, report data in which participant 7 says that 'It was a relief to know. It really was. It was nice to know that I was not the only fool who dreamed such dreadful dreams because it—while it was happening—consumed me completely. It did'. Consultations or ICU follow-up clinics were often the mechanism in which ICU survivors were able to discuss their experiences, fears and hopes (Allum et al., 2018; Bäckman et al 2017; Hanifa et al., 2018; Olsen et al., 2017) and because this was either with ICU healthcare staff or support groups of ICU survivors, realised that their struggles are, to an extent, shared struggles.

We need to be mindful that not all ICU survivors wish to participate in any form of ICU specific follow-up or post-hospital discharge discussion. This is an individual choice and perhaps, as Egerod et al., (2011) and Hanifa et al. (2018) suggest has a gendered component. We have too little evidence that this is the case and future research should examine this dimension because, as argued earlier, this will have an impact on intervention development if men really need something different in support from women. This is true for ICU survivors as well as for family members.

The process of 'moving on' includes the appreciation of what family members do for the ICU survivor during their recovery as well as a realisation for some, what their family must have gone through during their time in ICU. This is where we come full circle and where the context in which care is being delivered by healthcare professionals or given by family member intersects with 'doing family' and the understanding of ICU survivors of their families and just what they did for them during a time of critical illness.

Hanifa et al. (2018), for example, report a participant explaining 'that seeing other relatives visiting their sick family members had given him insight into the concerns of his wife and daughter while he had been admitted to ICU' (p 88). Similar concerns for family members can be found in a number of other studies (Ågård et al., 2012; Chiang, 2011; Kean et al., 2017).

At the same time, ICU survivors described their families as important resource of support and care. Family members kept ICU survivors motivated when they were disillusioned with the time it took to recover (Ågård et al., 2012; Kean et al., 2017), they would accompany the ICU survivors to follow-up clinic appointments (Bäckman et al. 2017; Egerod et al., 2011; Hanifa et al., 2018) and generally looked after the recovering ICU survivors during their critical illness and after their discharge home (Ågård et al., 2012; Eakin et al. 2017; Kang & Jeong, 2018; Kean et al. 2017).

In essence, the insight from these studies has to be that the focus of delivering care to ICU survivors need to include the family. Not just because family members deliver care but because the critical illness experience impacts in a significant way on both: ICU survivors and their family members.

### 3.6 | Limitations of the study

This was a comprehensive systematic review without date limits which utilised a range of key electronic databases, grey literature and hand searching of key journals. However, there remains a small risk that some relevant studies may have been excluded. At least two reviewers completed the initial screen on all articles whilst at full text review stage, studies were reviewed initially independently and then subject to a panel discussion. It may be that the representations by the reviewers at these panels led to some bias in the selection process however discussion were robust and criterion based. During the coding process, a code was produced to aid analysis however this could have been open to misinterpretation. Any disagreements were resolved in discussion and a third independent reviewer attended these discussions to ensure consistency.

## 4 | CONCLUSION

Our review was nearing the end when the current pandemic with COVID-19 began. The pandemic catapulted the importance of intensive care and its treatments in managing critically ill patients' centre-stage in the global response to COVID-19. The major focus being on the urgent need to significantly increase ICU bed capacity and the urgent need to increase the stock of ventilators to address the surge in critically ill patients as a result of the pandemic.

The pandemic has led to a significant increase in ICU admissions and thus to an increase in the population of ICU survivors. The pandemic has also increased focus on critical care medicine and nursing.

This systematic review has mapped the different pieces of the jigsaw that emerge following critical illness in an attempt to understand and see the bigger picture of what happens when a patient survives a critical illness and where we are in understanding ICU survivorship. We have demonstrated that whilst existing research has mapped these connections, what we have not managed to do yet, is to theoretically define survivorship for this patient cohort and their families.

Whilst 'survivorship' is a commonly used phrase, apart from recent studies by Kean (2017), Ewens (2017) and Page (2019), which have adopted a more social science perspective to understanding critical illness survivors' experiences, there is little theoretical basis to the use of the term 'survivorship' in the critical care literature. It is evident from this systematic literature review that survivorship after critical illness is currently not well-understood

and, consequently, no agreed or well understood definition of it emerged from this review.

Despite none of the aforementioned studies (Ewens et al., 2017; Kean et al., 2017; Page et al., 2019) setting out to study survivorship theoretically, they found that this was a key feature in the outcome of their research. Further, these studies show that ICU survivors experienced changes in self, biography and identity. Bearing in mind that survivorship is a dynamic, transitional process, we offer the following preliminary definition:

ICU survivorship is a dynamic process which starts with the survival of a critical illness and incorporates changes in self, biography and identity based on the individual patients' experiences of critical illness and their families. These changes are captured in the process of 'moving on'.

It was evident to us, that survivorship is not an end stage but a transitional stage. There is life after survivorship. However, our preliminary definition needs to be explored with patients and families and developed further to ensure that any future definition of ICU survivorship reflects a shared understanding.

Some of the key issues regarding support needs of critical care survivors and their families emerged and were encapsulated in the three main themes presented here. Important outcomes for survivorship following critical illness for patients and their families were suggested particularly within the theme of ICU survivor's identity and the sub-theme of 'moving on' however the evidence in these areas is limited and requires further exploration. This, we argue, needs the active involvement of ICU survivors and their families and needs to be co-produced in future longitudinal research that captures the immediate, intermediate and long-term experiences, both clinically and socially, of what it means to be a survivor of critical illness.

Research funders need to urgently reflect on what it means for patients and families to survive critical illness and include in their funding streams social science research that enables us to understand the challenges and experiences of ICU survivors and their families so that we can develop interventions that enables this heterogeneous patient cohort and their families to live the best lives possible post-ICU.

## 5 | IMPLICATIONS FOR PRACTICE

The terms 'survivor' and 'survivorship' are used with little definition in current research. Survival is often considered in the short term and where longer-term survival is studied, it often relates to mortality rates. The experiences of people surviving critical illness experiences either as a patient or family member have been studied fractionally rather than holistically. Whilst those experiencing critical care are a heterogeneous group, they share a common experience of being critically ill and in many cases facing life-threatening and life-changing experiences.

This systematic review identifies a body of evidence clearly documenting the short and long-term physical and psychological consequences for ICU survivors and their families in relation to PICS and PICS-F (Simpson & Robinson, 2020; Stam et al., 2020). What we are currently lacking is a more informed understanding of ICU survivorship in terms of both, theoretical understanding of survivorship for this group and the economic and social dimensions of survivorship. The implications for practice could be highly significant if there was more substantive theoretically based research in this area. It is crucial for society, governments, policy makers, non-ICU healthcare professionals and ICU survivors and their families to understand the implications of surviving critical illness since the current pandemic has led to a significant increase in ICU admissions and thus to an increase in the population of ICU survivors.

We would be wise in paying attention to Stam's et al. (2020) warning in relation to COVID-19 patients, namely that:

the notion that patients surviving intensive care and mechanical ventilation for several weeks can be discharged home without further medical attention is a dangerous illusion' (p 2)

#### CONFLICT OF INTEREST

All authors declare that they have no conflict of interest.

#### AUTHOR CONTRIBUTIONS

All authors contributed to the design of the study and writing of this article. ED involved in literature search. ED, SK, SR, GC and AB contributed to analysis of data.

#### DATA AVAILABILITY STATEMENT

Data openly available in a public repository that issues datasets with DOIs.

#### ORCID

Susanne Kean  <https://orcid.org/0000-0002-3717-9740>

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## SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

**How to cite this article:** Kean S, Donaghy E, Bancroft A, Clegg G, Rodgers S. Theorising survivorship after intensive care: A systematic review of patient and family experiences. *J Clin Nurs*. 2021;00:1-27. <https://doi.org/10.1111/jocn.15766>