Life after critical illness: a systematic review and thematic synthesis protocol

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Background

Survivorship following critical illness can be the beginning of a challenging and prolonged recovery. Patients, many of whom are elderly and frail (1), require supportive therapies such as ventilation, other organ support devices, sedation and experience immobility. These factors can contribute to long-term musculoskeletal impairments resulting in decreased exercise tolerance, loss of muscle strength, chronic pain, and shoulder impairment (2, 3). Subsequently, patients often experience functional impairments limiting their activities of daily living, and leading to a long-term reduction in health-related quality of life (HRQoL). This includes unemployment, increased healthcare utilisation and unplanned hospital readmissions (4). Inability to return to work persisted across a five-year follow-up period for 31% of patients with acute respiratory distress syndrome (5).

Beyond the physical impairments, the biopsychosocial impact of ongoing ill health can be an overwhelming burden for patients. Depression and post-traumatic stress disorder (PTSD) are the primary psychological symptoms that can lead to a long-term reduction in HRQoL. Mores so, psychosocial impairments are classified as an unacceptable patient-reported outcome following critical illness. Similarly, the consequences of the patients' ill

health also adversely impacts their families. This ranges from financial dependence, transitioning to the care giver role and their own psychological distress (6).

For healthcare professionals to deliver optimal rehabilitation services, it is essential to understand the patients' experiences of recovery from critical illness, and what it means to 'recover'. For example, what are the components of functional recovery that patients consider as important and therefore are likely to engage with? This will allow healthcare professionals to deliver patient centred care through their assessments and interventions which should be seen as fundamental to recovery. Given the profound and lasting impairments associated with critical illness, the impact of these need to be explored beyond the acute hospital, to include the transition and reintegration into the community setting (7). A qualitative evidence synthesis will help us to understand the experience of transition and reintegration into the community in order to improves outcomes and experiences following critical illness. To our knowledge, a systematic review on this topic has not been undertaken. Our findings will support future qualitative research focusing beyond hospital discharge to contribute to the development of a complex intervention to improve the long-term musculoskeletal health of survivors of critical illness, and shared decision making.

The search strategy tool of SPIDER (*sample*, *phenomenon of interest*, *design*, *evaluation*, *research type*) (Table 1) was used to develop and refine the key components of the review questions (8). Our systematic review questions are:

1 What are the experiences of critical care survivors living with physical impairments beyond hospital discharge?
2 What are the experiences of family and staff supporting critical care survivors living with physical impairments beyond hospital discharge?

Table 1: A SPIDER tool for these research questions.

S: sample	Patients, family or staff supporting
P of **I**: phenomenon of interest	Adult survivors of critical care
D: Design	Any qualitative design; or mixed methods with primary qualitative
E: Evaluation	Experiences, views, thoughts, perceptions
R: Research type	Qualitative

Objective

Our primary aim of this review is to identify and synthesise primary qualitative studies exploring the experiences of critical care survivors living with physical impairments beyond hospital discharge. Our secondary aim is to identify and synthesise primary qualitative research of experiences of family and healthcare staff supporting critical care survivors living with physical impairments beyond hospital discharge.

Methods

This protocol was prepared using the Preferred Reporting Items for Systematic Review and Meta-analysis Protocols (PRSIMA-P) (9). This systematic review has been registered with PROSPERO (the international prospective register of systematic reviews): CRD42022306578.

Eligibility

For inclusion, studies must explore experiences of adult (18 years or older) survivors of critical illness experiencing physical impairments beyond hospital discharge. Similarly, studies that explore experiences of families supporting or caring for; or staff signposting or providing rehabilitation services to adult survivors of critical illness experiencing physical impairments beyond hospital discharge will also be included. Staff groups are not limited to a specific profession. Studies will be excluded if any participants are under the age of 18 or adolescent; or if they are paid caregivers and relatives to this patient group. We will include primary qualitative research studies or mixed-methods studies using primary qualitative data. We will only include studies published in English.

Data source

Multiple databases will be searched, including Allied and Complementary Medicine database (AMED), Cumulative Index of Nursing and Allied Health Literature (CINAHL), Embase, PubMed and Physiotherapy Evidence Database (PEDro). Grey literature will also be searched including Open Grey, clinicaltrials.gov, pre-print servers and hand searching of Google Scholar.

Search strategy

Search terms have been developed with a university librarian to produce the following search strategy which focuses on survivors of critical illness. The principal search terms will include (critical illness or intensive care or (ICU or ICUs or ITU) or adult respiratory distress syndrome or ARDS or critical* ill*) and (qualitative or 'mixed methods'). Accordingly, search terms or (Medical Subject Heading) MeSH terms will be utilised for individual databases as necessary.

Data selection

Outputs from searches of each database will be imported into Rayyan software (10), and any duplicate publications will be removed. Studies will be assessed for inclusion (against eligibility criteria) independently by two reviewers at title and abstract. Remaining studies will be independently assessed by two reviewers at full text. At both stages, if disagreements cannot be resolve through discussion, a third reviewer will add to the discussion. Data selection will be presented in a PRISMA flowchart (Figure 1).

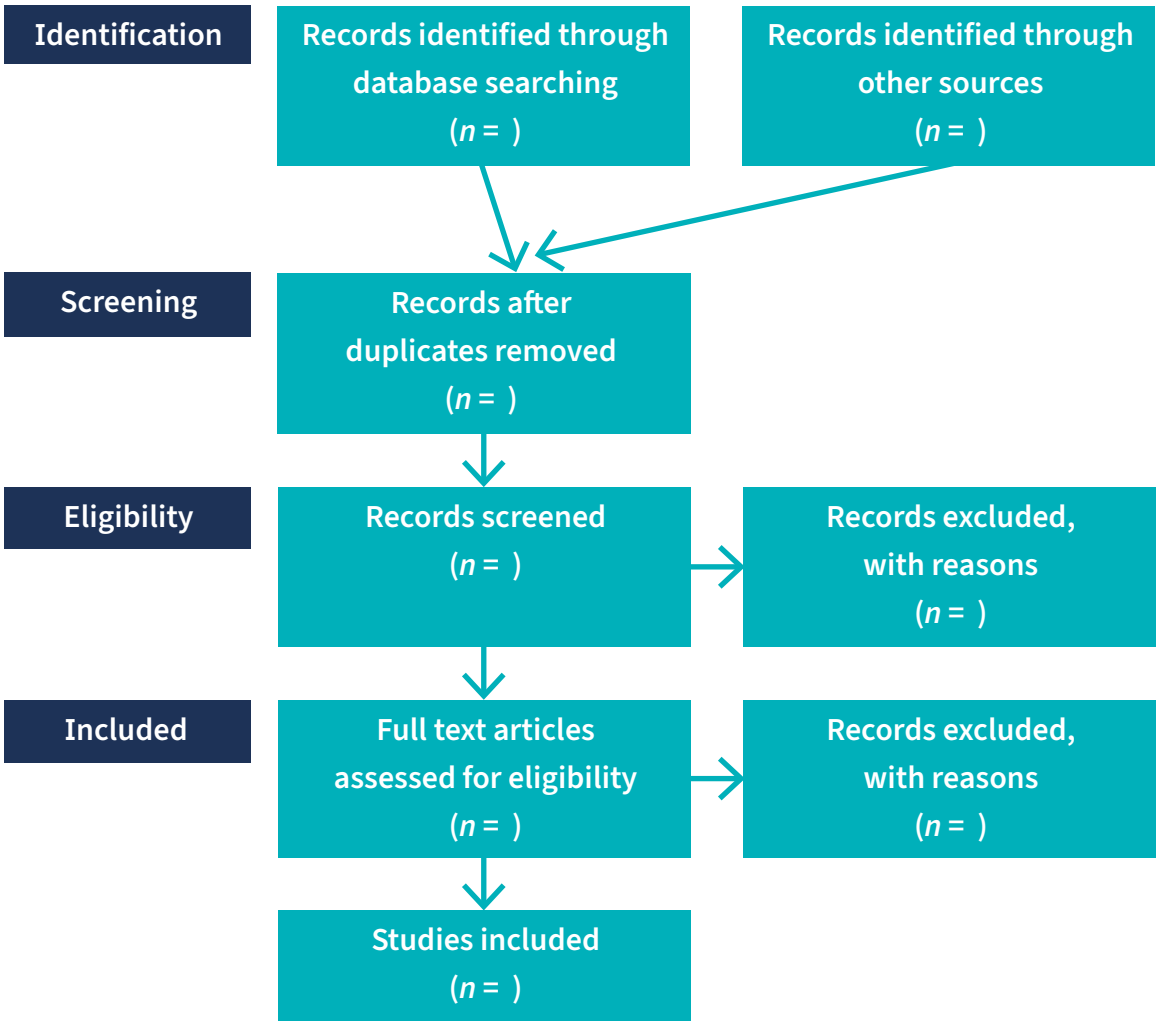

Figure 1: PRISMA flowchart.

Data extraction

For all studies, data will be extracted including study design (including qualitative methodology), qualitative data collection (for example, interviews or focus groups with participant numbers), participant characteristics (for example, patient, relative, staff), study aims, interview time point and reviewer's initial comments. This will be undertaken and recorded on data extraction tables within Microsoft Excel by the first reviewer and checked by second reviewer. Subsequently, NVivo (version 12), a qualitative data analysis software package will be used to allow for data extraction of study findings, concepts and contextual information; overaching themes will be defined in NVivo too, in order to allow for the inductive generation of codes and themes.

Quality appraisal of studies

All studies included within the review will be assessed for quality using the *Critical Appraisal Skills Programme – qualitative checklist* (11) independently by two reviewers. CASP – qualitative, which is endorsed by Cochrane Qualitative and Implementation Methods Group is the most commonly tool for quality appraisal in health-related qualitative evidence synthesis (QES) (12).

Data synthesis

Thematic synthesis is derived from thematic analysis which analyses primary qualitative research data. Thematic synthesis has three stages:

- The coding of text line by line.
- The development of descriptive themes.
- The generation of analytical themes (13).

The first reviewer will undertake all three stages of thematic synthesis with NVivo. This will be an iterative process and therefore developed in discussion with all authors. The preliminary themes will be further distilled until final themes are agreed.

Confidence in cumulative findings

Confidence in the findings of this review will be assessed according to GRADE CERQual (Confidence in the Evidence of Qualitative research) (14). GRADE CERQual assesses the confidence of findings from a review which is the extent of which the findings are a reasonable representation of the phenomenon. The 4 components for consideration are:

- Methodological limitations.
- Coherence.
- Adequacy of data.
- Relevance.

Confidence ratings are classified as high, moderate, low or very low.

Two reviewers in collaboration will undertake the assessment of GRADE CERqual due to the subjective nature of the judgements. The confidence ratings for each theme will be recorded in a table using the *GRADE CERQual Interactive Summary of Qualitative Findings* tool.

Reflexivity

As qualitative research risks elements of subjectivity; it is essential reflexivity is acknowledged. Reflexivity details how researchers demonstrate an awareness of their role across the research processes (15). Five authors are physiotherapists (Elizabeth King, Owen Gustafson, Sarah Vollam, Francine Toye and Mark Williams), including two who work within critical care (Elizabeth King and Owen Gustafson) and one author is a nurse, who is a critical care researcher (Sarah Vollam). One author (Francine Toye) is an expert in qualitative research. With particular care at times of key decision-making and analysis, time will be invested to discuss our pre-conceptions and work as a group on interpretation and analyses.

Discussion

This systematic review with thematic synthesis will explore the experiences of:

1 Adult survivors of critical illness, in particular those who experience physical impairment which might impact their participation in life.
2 Their family members and health workers involved in their care and rehabilitation.

This synthesis of qualitative research is likely to provide insight into a range of factors that have an impact on a person's recovery following critical illness at family and service provider levels.

Identifying the literature base is the initial element of the development phrase for designing a complex intervention (16). The findings of this review will synthesise the experiences of key stakeholders, and identify any gaps in the existing literature. This will contribute to the theoretical development stage whereby primary research can be undertaken through interviewing key stakeholders. A complex intervention is needed to optimise the rehabilitation for survivors of critical care as trials have yet to demonstrate intervention with fully understood endpoints. This is coupled with a lack of understanding of the experiences and motivators of patients to engage with the treatments.

Whilst exploring and identifying the literature, we believe this topic of interest is one of trustworthiness due to the significance of real world impact for patients, their families and staff. We will explore the credibility of the literature and similarly consider the transferability of the findings to the critical care populations nationally (17).

Key points

1 Functional impairments are commonly experienced following periods of critical illness.
2 These can negatively impact long-term reduction in health-related quality of life, unemployment, and lead to increased healthcare utilisation.

The synthesis of literature for survivors of critical illness beyond hospital discharge is yet to be undertaken.

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