ABSTRACT

Introduction Increasing numbers of patients are surviving critical illness, leading to growing concern about the potential impact of the long-term consequences of intensive care on patients, families and society as a whole. These long-term effects are together known as post-intensive care syndrome and their presence can be evaluated at intensive care unit (ICU) follow-up consultations. However, the services provided by these consultations vary across hospitals and units, in part because there is no validated standard model to evaluate patients and their quality of life after ICU discharge. We describe a protocol for a scoping review focusing on models of ICU follow-up and the impact of such strategies on improving patient quality of life.

Methods and analysis In this scoping review, we will search the literature systematically using electronic databases (MEDLINE - from database inception to June 15th 2020) and a grey literature search. We will involve stakeholders as recommended by the Joanna Briggs Institute approach developed by Peters et al. The research will be conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews guidelines.

Ethics and dissemination This study does not require ethics approval, because data will be obtained through a review of published primary studies. The results of our evaluation will be published in a peer-reviewed journal and will also be disseminated through presentations at national and international conferences.

INTRODUCTION

Better understanding of disease pathophysiology, improvements in medical technology, and greater attention to the process of care have helped improve survival rates for intensive care unit (ICU) patients. However, ICU survivors can experience lifelong consequences of their critical illness, with survival just the start of a long challenging path of rehabilitation. After discharge, patients may have to cope with weakness, cognitive impairment, and psychological distress and the secondary effects of these sequelae, including burn-out, dependency and unemployment.

In 2012, a task force from the Society of Critical Care Medicine acknowledged the need to create post-intensive care syndrome (PICS). PICS is defined as worsening mental, cognitive and physical status that persists beyond the acute hospitalisation and impacts a patient’s quality of life. The prevalence of post-ICU disabilities varies across studies largely because of the heterogeneity of the tools used to assess patients. However, more than 50% of survivors will present one or more disabilities during the first year after ICU discharge. Cognitive impairments, including of global cognition and executive function, can affect up to 70% of ICU survivors. Psychological distress includes depression, anxiety and post-traumatic stress disorder (PTSD). Up to 50% of patients have anxiety after ICU discharge and up to 58% depression.

Because of the high risk that intensive care may compromise quality of life for survivors, PICS is a major concern for healthcare providers. Different models of ICU follow-up clinics have been established around the world aiming to address the problems associated with long-term disabilities of ICU survivors. However, the effectiveness of these clinics remains uncertain.

In 2012, a task force from the Society of Critical Care Medicine acknowledged the need to create post-intensive care syndrome (PICS). PICS is defined as worsening mental, cognitive and physical status that persists beyond the acute hospitalisation and impacts a patient’s quality of life. The prevalence of post-ICU disabilities varies across studies largely because of the heterogeneity of the tools used to assess patients. However, more than 50% of survivors will present one or more disabilities during the first year after ICU discharge. Cognitive impairments, including of global cognition and executive function, can affect up to 70% of ICU survivors. Psychological distress includes depression, anxiety and post-traumatic stress disorder (PTSD). Up to 50% of patients have anxiety after ICU discharge and up to 58% depression.

Because of the high risk that intensive care may compromise quality of life for survivors, PICS is a major concern for healthcare providers. Different models of ICU follow-up clinics have been established around the world aiming to address the problems associated with long-term disabilities of ICU survivors. However, the effectiveness of these clinics remains uncertain.
ICU survivors compared with standard care and showed that ICU follow-up could decrease PTSD symptoms.\textsuperscript{12} The published systematic reviews pooled highly heterogeneous data. A scoping review published by Lasiter \textit{et al} on critical care follow-up clinics had several limitations,\textsuperscript{13} including that only studies in English speaking populations were included, patients enrolled from burn units were excluded and other types of follow-up, such as phone calls, home visits and mailed questionnaires, were not assessed. One integrative review, also published in 2016, only analysed aspects of nurse-led follow-up.\textsuperscript{29}

To gain better knowledge about ICU follow-up, we, therefore, decided to conduct a new scoping review with broad eligibility criteria to identify features, advantages and disadvantages of all types of ICU follow-up. Given the methodological differences in the available studies on this subject, a scoping review will help better understand current practice and provide a basis for targeted research questions.\textsuperscript{30}

**OBJECTIVES**

The objectives of this review are to characterise the concept of an ICU follow-up service from a broad perspective, to clarify the implications of such a service for patient quality of life, to identify research gaps and to make methodological recommendations for future research.

**METHODS**

**Protocol**

The study will be conducted according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension (PRISMA) for Scoping Reviews guidelines.\textsuperscript{31} The protocol was registered in the Open Science Framework on 30 January 2020.\textsuperscript{32} Important protocol amendments will be registered on that webpage.

**Study design**

A scoping review was considered the most appropriate method for the aims of this study. In developing this protocol, we applied the approach developed by Peters \textit{et al},\textsuperscript{33} based on the framework proposed by Arksey and O’Malley,\textsuperscript{34} already improved by Levac \textit{et al} and the Joanna Briggs Institute (JBI).\textsuperscript{35} The five stages proposed by this approach are:

1. Identification of the review question(s).
2. Identification of relevant studies.
3. Study selection.
4. Charting the data.
5. Collating, summarising and reporting the results.

**Review questions**

We used the population, concept and context approach suggested by Munn \textit{et al} to guide our question development.\textsuperscript{37} Our review targets the following research questions:

- **Main questions:**
  - What types of ICU follow-up were reported?
  - What was the impact of the ICU follow-up on patient quality of life?

- **Secondary questions:**
  - For whom was the ICU follow-up suggested?
  - Was the effectiveness of the ICU follow-up assessed and, if so, how?

**Search strategy and eligibility criteria**

The search will use two sources: (1) electronic bibliographic database and (2) grey literature.

The electronic bibliographic database that will be searched is the Medical Literature Analysis and Retrieval System Online (MEDLINE). The proposed search strategy for MEDLINE via PubMed is detailed in Table 1. No date limits will be applied to this review. The search string will include as filters human species, adult patients and language. We will include studies published in English, French, Italian, Portuguese or Spanish. Articles related to any type of patient follow-up after discharge from an ICU, including burn units, will be considered. There will be no limitations for the duration of ICU follow-up or outcome measures. Primary research studies, letters, abstracts and guidelines will all be included, but reviews and meta-analyses will be excluded. The reference lists of all included articles will be checked to identify additional eligible documents.

The grey literature search will include general and targeted website searching. General website searching will use Google as the search engine and the following search terms: ICU follow-up; after intensive care; rehabilitation after ICU. All the results from each of the Google searches will be examined. The targeted websites will include the Society of Critical Care Medicine and the European Society of Intensive Medicine homepages and subpages.

**Study selection**

We will screen all documents in two phases. Two authors will independently evaluate the titles and abstracts of documents identified in the search, followed by full-text screening of potentially eligible articles for final inclusion. Any disagreements on study eligibility will be resolved through debate or by discussion with a third author. The citation management software used to manage the selection process will be EndNote X9 (Clarivate Analytics, Pennsylvania, USA). The reference lists of eligible documents will be imported into the JBI’s System for the Unified Management, Assessment and Review of Information (JBI SUMARI; The JBI, Adelaide, Australia). The results of each step of the planned search, including reasons for exclusion, will be given in detail in the final report and presented in a PRISMA flow diagram.

**Data charting**

Using the JBI Data Extraction Form for Experimental/Observational Studies, data will be extracted independently by two authors, because additional unforeseen
Prevedello D, et al. BMJ Open 2020;10:e037725. doi:10.1136/bmjopen-2020-037725

Open access

Data may be usefully identified in this manner. The results will be cross-checked. Any disagreements on data extraction will be resolved by a third reviewer. The following information will be extracted for each study: title, year of publication, first author, the country where the study was conducted, type of study, underlying diseases and any outcomes that fit into the conceptual framework of the study. Authors of the primary studies screened will be contacted in case of missing relevant data. The data extraction process will be referred to as ‘charting the results’. The authors will keep careful records to enable identification of each study.

Collating, summarising and reporting the results

We will summarise quantitative results as frequency counts for concepts, populations and outcomes. Table 2 reports a descriptive and logical summary of the results that will be reported. An assessment of the quality of the included studies will not be performed. For qualitative studies, we will perform a descriptive qualitative content analysis, using NVivo software.38

**DATA STATEMENT**

The datasets generated during the current study and the analytical methods (including preprocessing and eventually the analysis code) will be available from the corresponding author on reasonable request.

**PATIENT AND PUBLIC INVOLVEMENT**

Involvement of patients and the public has been planned as proposed by the original framework of Arksey and O’Malley.34 We will contact critical stakeholders to identify

| Study | Design date of publication first author country of origin no of centres |
|-------|---------------------------------------------------------------------|
| Participants Demographic data | No mean age sex educational level employment status previous mental-cognitive status severity score at ICU admission |
| Clinical data | ICU admission category |
| | ICU length of stay hospital length of stay inclusion criteria exclusion criteria use of ICU support (mechanical ventilation, haemodialysis, sedation, ECMO, organ transplant) characteristics at discharge (including mental-cognitive status, need for life support) |
| Intervention | Characteristics of ICU follow-up consultation or rehabilitation programme: healthcare providers involved time point of the intervention number of attended consultations GP report (general practitioner report) alternative approach (hypnosis, music therapy, virtual reality) ICU diary |
| Outcomes | Primary and secondary outcomes if specified and collected pos-intensive care syndrome |

ECMO, extracorporeal membrane oxygenation; GP, general practitioner; ICU, intensive care unit; JBI, Joanna Briggs Institute.

Table 1 Search strategy on PubMed search conducted on 15 June 2020

| Search | Query | Records retrieved |
|--------|-------|-------------------|
| #1     | ((("critical care"[MeSH Terms] OR "critical"[All Fields] AND "care"[All Fields]) OR "critical care"[All Fields]) OR "critical care"[MeSH Terms] OR "critical"[All Fields] AND "care"[All Fields]) OR "critical care"[All Fields] OR "intensive care"[All Fields]) OR "intensive care units"[MeSH Terms] OR ("intensive"[All Fields] AND "care"[All Fields] AND "units"[All Fields]) OR "intensive care units"[All Fields] OR "icu"[All Fields]) OR ("therapy"[Subheading] OR "therapy"[All Fields]) OR "treatment"[All Fields]) OR "therapeutics"[MeSH Terms] OR "therapeutics"[All Fields]) OR "burns"[MeSH Terms] OR "burns"[All Fields] AND (follow-up [All Fields] OR ("rehabilitation"[Subheading] OR "rehabilitation"[All Fields] OR "consultation"[All Fields]) OR ("referral and consultation"[MeSH Terms] OR ("referral"[All Fields] AND "consultation"[All Fields])) OR "stress disorders, post-traumatic"[MeSH Terms] OR ("stress disorder", "post-intensive care syndrome") OR ("post-intensive care syndrome"[All Fields]) OR ("post-intensive"[All Fields] AND care[All Fields] AND ("syndrome"[MeSH Terms] OR "syndrome"[All Fields]))) | 73 805 |
| Limited to human species, adult patients and languages (English, French, Italian, Portuguese and Spanish) | 37 347 |
supplementary references for inclusion. The stakeholders chosen are members of the European Society of Intensive Care Medicine, the Belgian Society of Intensive Care and the Society of Critical Care Medicine.

ETHICS AND DISSEMINATION
This paper does not require ethics approval, as data will be obtained through a review of published primary studies. The results of our evaluation will be published in a peer-reviewed journal and will also be disseminated through presentations at national and international conferences. Patients’ associations, such as THRIVE ICU, Patients Like Me and Patient Opinion, will be contacted to disseminate the results through online material. Finally, team members will use their networks to ensure broad dissemination of the results.

CONCLUSION
This scoping review will identify existing literature related to all types of ICU follow-up services. With its broad eligibility criteria, our results will help better understand the advantages and disadvantages of ICU follow-up, and guide future research and practice.

Acknowledgements We would like to thank Karen Pickett who provided English medical edition.

Contributors DP and MF mainly wrote this study. JC and JCP supervised the written and revised the protocol. All authors gave final approval of the version to be published and agreed to be accountable for all aspects of the work.

Funding The authors have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors.

Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not required.

Provenance and peer review Not commissioned; externally peer reviewed.

Open access This is an open access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited, appropriate credit is given, any changes made indicated, and the use is non-commercial. See: http://creativecommons.org/licenses/by-nc/4.0/.

ORCID ID
Danielle Prevedello http://orcid.org/0000-0003-3945-0757

REFERENCES
1 Luhr R, Cao Y, Söderquist B, et al. Trends in sepsis mortality over time in randomised sepsis trials: a systematic literature review and meta-analysis of mortality in the control arm, 2002–2016. Crit Care 2019;23:1–9.
2 Maca J, Jor O, Helub M, et al. Past and present ARDS mortality rates: a systematic review. Respir Care 2017;62:113–22.
3 Harvey MA. The truth about consequences—post-intensive care syndrome in intensive care unit survivors and their families. Crit Care Med 2012;40:2506–7.
4 Elliott D, Davidson JE, Harvey MA, et al. Exploring the scope of Post–Intensive care syndrome therapy and care. Crit Care Med 2014;42:2518–26.
5 Kress JP, Herridge MS. Medical and economic implications of physical disability of survivorship. Semin Respir Crit Care Med 2012;33:339–47.
6 Hopkins RO, Girard TD. Medical and economic implications of cognitive and psychiatric survivorship. Semin Respir Crit Care Med 2012;33:348–56.
7 Norman BC, Jackson JC, Graves JA, et al. Employment outcomes after critical illness. Crit Care Med 2016;44:2003–9.
8 Needham DM, Davidson J, Cohen H, et al. Improving long-term outcomes after discharge from intensive care unit. Crit Care Med 2012;40:502–9.
9 Angus DC, Carlet J, 2002 Brussels Roundtable Participants. Surviving intensive care: a report from the 2002 Brussels roundtable. Intensive Care Med 2003;29:368–77.
10 Lowry DW, Eid MP, Sobolynsky A, et al. Quality of life in adult survivors of critical illness: a systematic review of the literature. Intensive Care Med 2005;31:611–20.
11 Myhren H, Ekeberg Olvind, Stokland O. Health-Related quality of life and return to work after critical illness in general intensive care unit patients: a 1-year follow-up study. Crit Care Med 2010;38:1554–61.
12 Jensen JF, Thomsen T, Overgaard D, et al. Impact of follow-up consultations for ICU survivors on post-ICU syndrome: a systematic review and meta-analysis. Intensive Care Med 2015;41:763–76.
13 Lasiter S, Oles SK, Mundell J, et al. Critical care follow-up clinics: a scoping review of interventions and outcomes. Clin Nurse Spec 2016;30:227–37.
14 Marra A, Pandharipande PP, Girard TD, et al. Co-Occurrence of Post-Intensive care syndrome among 406 survivors of critical illness. Crit Care Med 2018;46:1393–401.
15 Bienvenu OJ, Colantuoni E, Mendez-Tellez PA, et al. Cooccurrence of and remission from general anxiety, depression, and posttraumatic stress disorder symptoms after acute lung injury: a 2-year longitudinal study. Crit Care Med 2015;43:642–53.
16 Patel MB, Morandi A, Pandharipande PP. What’s new in post-ICU cognitive impairment? Intensive Care Med 2015;41:708–11.
17 Jutte JE, Erb CT, Jackson JC, et al. Physical, cognitive, and psychological disability following critical illness: what is the risk? Semin Respir Crit Care Med 2015;36:943–58.
18 Hopkins RO, Wade D, Jackson JC. What’s new in cognitive function in ICU survivors. Intensive Care Med 2017;43:223–5.
19 Davydov DS, Gifford JM, Desai SV, et al. Depression in general intensive care unit survivors: a systematic review. Intensive Care Med 2008;35:796–809.
20 Rabiee A, Nikayin S, Hashem MD, et al. Depressive symptoms after critical illness: a systematic review and meta-analysis. Crit Care Med 2016;1–10.
21 Nikayin S, Rabiea A, Hashem MD, et al. Anxiety symptoms in survivors of critical illness: a systematic review and meta-analysis. Gen Hosp Psychiatry 2016;43:23–9.
22 Jackson JC, Pandharipande PP, Girard TD, et al. Depression, post-traumatic stress disorder, and functional disability in survivors of critical illness in the BRAIN-ICU study: a longitudinal cohort study. Lancet Respir Med 2014;2:369–79.
23 Prevedello D, Preiser J-C. Feasibility of Follow-up Consultations. In: Preiser J-C, Herridge M, Azoulay E, eds. Post-Intensive care syndrome. 1st edn. Berlin Heidelberg: Springer, 2019: 331–42.
24 Schofield-Robinson OJ, Lewis SR, Smith AF, et al. Follow-Up services for improving long-term outcomes in intensive care unit (ICU) survivors. Cochrane Database Syst Rev 2018;11:CD012701.
25 Cuthbertson BH, Rattray J, Johnston M, et al. A pragmatic randomised, controlled trial of intensive care follow-up programmes in improving longer-term outcomes from critical illness. The practical study. BMC Health Serv Res 2007;7:1–6.
26 Hernández RA, Jenkinson D, Vale L, et al. Economic evaluation of nurse-led intensive care follow-up programmes compared with standard care: the practical trial. Eur J Health Econ 2014;15;2:43–52.
27 Stelfox HT, Bastos J, Niven DJ, et al. Critical care transition programs and the risk of readmission or death after discharge from ICU. Intensive Care Med 2016;42:401–10.
28 Connelly B, Thompson A, Dourii A, et al. Exercise-based rehabilitation after hospital discharge for survivors of critical illness with intensive care unit-acquired weakness: a pilot feasibility trial. J Crit Care 2015;30:589–98.
29 Jönsson CG, Klinte CE, Jönsson CG, et al. Integrative review of nurse-led follow-up after discharge from the ICU. J Clin Nurs 2016;25:20–37.
30 Grant MJ, Booth A. A typology of reviews: an analysis of 14 review types and associated methodologies. Health Info Libr J 2009;26:91–108.
31 Tricco AC, Lillie E, Zarin W, et al. PRISMA extension for scoping reviews (PRISMA-ScR): checklist and explanation. *Ann Intern Med* 2018;169:467–73.

32 Prevedello D, Fiore M, Creteur J, et al. Intensive Care Units Follow-up: a scoping review [Internet]. 2020. Available: http://doi.org/

33 Peters MDJ, Godfrey CM, Khalil H, et al. Guidance for conducting systematic scoping reviews. *Int J Evid Based Healthc* 2015;13:141–6.

34 Arksey H, O’Malley L. Scoping studies: towards a methodological framework. *Int J Soc Res Methodol* 2005;8:19–32.

35 Levac D, Colquhoun H, O’Brien KK. Scoping studies: advancing the methodology. *Implementation Sci* 2010;5:1–9.

36 MDJ P G C, M P, et al. Scoping Review. In: Aromataris E, Munn Z, eds. Joanna Briggs Institute Reviewer’s Manual, 2017. https://reviewersmanual.joannabriggs.org/

37 Munn Z, Peters MDJ, Stern C, et al. Systematic review or scoping review? guidance for authors when choosing between a systematic or scoping review approach. *BMC Med Res Methodol* 2018;18:1–7.

38 QSR International Pty Ltd. NVivo qualitative data analysis software 2020.