

# BMJ Open Patients' experiences of cognitive impairment following critical illness: a scoping review protocol

Anette Bjerregaard Alrø <sup>1,2</sup>, Helene Korvenius Nedergaard,<sup>3</sup> Helle Svenningsen,<sup>4</sup> Hanne Irene Jensen,<sup>3</sup> Pia Dreyer<sup>1,2</sup>

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<sup>1</sup>Intensive Care, Aarhus University Hospital, Aarhus, Denmark

<sup>2</sup>Institute of Public Health, Section of Nursing, Aarhus University, Aarhus, Denmark

<sup>3</sup>Anesthesiology and Intensive Care, University of Southern Denmark, Odense, Denmark

<sup>4</sup>Department of Nursing, Faculty of Health Sciences, VIA University College, Aarhus N, Denmark

## Correspondence to

Anette Bjerregaard Alrø; [anetnl@rm.dk](mailto:anetnl@rm.dk)

## ABSTRACT

**Introduction** Critical illness and admission to an intensive care unit (ICU) can affect patients for months or years following discharge as many suffer from cognitive impairment. Long-term cognitive impairment affects patients' quality of life and ability to adapt to everyday life. Exploring their experiences on how and which cognitive impairments are affecting their everyday lives facilitates planning of relevant research on interventions that may serve to alleviate the burden of post-ICU cognitive impairment. The objective of this scoping review is to map the existing research on patients' experiences of cognitive impairment following critical illness.

**Methods and analysis** The methodology will follow the Joanna Briggs Institute guidelines for scoping reviews. The databases MEDLINE, CINAHL, PsycINFO and Embase will be searched to identify studies appropriate for inclusion. Any peer-reviewed original studies meeting the inclusion criteria and include statements from adult patients about how they experience cognitive impairment following critical illness and ICU admission will be considered. Studies published in English and Scandinavian languages will be included, with no further geographical or cultural limitations. The included studies will be screened by two independent researchers using a standardised data extraction tool and the Mixed Methods Appraisal Tool will be used for critical appraisal. The results will be presented in a tabular form, and data will be supported by narrative descriptions or a narrative summary.

**Ethics and dissemination** Since the scoping review methodology aims at synthesising existing research on patients' experiences of cognitive impairment following critical illness, the scoping review does not require ethical approval. The results will be disseminated through a peer-reviewed publication in a scientific journal.

## INTRODUCTION

In recent decades, survival of critically ill patients in intensive care units (ICUs) has improved owing to advances in technology and critical care medicine.<sup>1</sup> The ICU is a hospital facility providing specialised treatment, care and 24-hour intensive monitoring of seriously ill patients needing life support.<sup>2</sup> Worldwide, millions of critically ill patients are being admitted to ICUs annually, needing treatment, care and monitoring for days,

## Strengths and limitations of this study

- The present protocol is for a scoping review of patients' experience of cognitive impairments following critical illness based on their own descriptions or mention.
- This is the first scoping review to identify and map the existing research on patients' experiences of cognitive impairment following critical illness.
- The Joanna Briggs Institute methodology provides a systematic approach to undertaking and reporting this scoping review.
- This scoping review will assess quality using the Mixed Methods Appraisal Tool.

weeks or months.<sup>3</sup> However, critical illness and admission to an ICU may affect patients several months or years following discharge.<sup>4</sup> Specifically, ICU admission may be associated with both mental, physical and cognitive impairments—also known as postintensive care syndrome (PICS). PICS refers to new or worsening multidimensional impairments following critical illness that persist beyond ICU discharge.<sup>1 5</sup> Fried *et al* investigated treatment preferences among critically ill patients, finding that patients were often willing to accept a relatively high burden of treatment if they could expect a favourable outcome regarding physical and cognitive function. However, if severe impairments were expected after treatment, many patients would choose not to accept the treatment, that is, many patients rated cognitive function higher than mere survival.<sup>6</sup>

Cognitive impairment is defined as impairments in memory, attention, executive function, mental processing speed and visuospatial ability.<sup>7 8</sup> Depending on the subgroup, impairments of cognitive function have been found in up to 100% of ICU survivors at hospital discharge and in approximately 50% 1 year later.<sup>9</sup> Some patients have even been



found to experience long-term cognitive impairments up to 5 years after discharge.<sup>9</sup>

Davydow *et al* reported that acute in-hospital stress symptoms are associated with an increase in cognitive impairments up to 12 months after discharge from the ICU.<sup>10</sup> Especially, the stressful environment with noise, ambient light, restriction of mobility and social isolation frequently experienced in an ICU is reported by patients as an important factor causing cognitive impairments.<sup>11</sup> Delirium during an ICU stay may also be associated with cognitive impairments following discharge.<sup>12</sup> Patients who develop delirium in general and severe delirium in particular also have higher rates of cognitive impairments.<sup>12 13</sup>

In recent years, a change of paradigm has occurred within critical care regarding the use of sedation. Focus is now on using less or even no sedation during critical illness.<sup>14</sup> This approach is especially prevalent in Denmark and other Nordic countries.<sup>15</sup> Less sedation increases the possibility to interact and communicate with the patient during his or her critical illness and provides the basis for active interventions, such as early mobilisation. However, non-sedation alone has not been found to improve cognitive function 3 months after ICU discharge, even though non-sedated patients were less delirious.<sup>16</sup>

The long-term cognitive consequences of critical illness can affect patients' quality of life, and adapting to everyday life can be challenging.<sup>17</sup> Cognitive impairments can also affect the lives of relatives, friends and colleagues. Therefore, a substantial burden is associated with critical illness in ICU survivors and it is a significant driver of healthcare costs.<sup>17 18</sup>

A relatively large body of the literature describes the mental and physical impairments associated with PICS. Likewise, a growing body of the literature has explored cognitive impairments. However, evidence describing how patients experience cognitive impairment following critical illness is relatively sparse.<sup>1</sup> Thus, patients' experiences of cognitive impairments are a frequently unrecognised post-ICU complication.<sup>19 20</sup>

A preliminary search of MEDLINE (PubMed), CINAHL, Embase, PsycINFO and the Joanna Briggs Institute (JBI) Database (of Systematic Reviews and Implementation Reports) was conducted to avoid evidence duplication.<sup>21</sup> No current or ongoing scoping reviews or systematic reviews concerning patients' experiences of cognitive impairments following critical illness were identified. Reviews focusing on interventions to reduce cognitive impairments and develop preventive strategies have been undertaken, although more effort should be devoted to producing evidence on recovery from cognitive impairments.<sup>22</sup>

The ageing population of the Western world and improved survival from critical illness mean that a growing number of patients will be suffering from cognitive impairment after their ICU discharge. Exploring their experiences on how and which cognitive outcomes are affecting their everyday lives is important to facilitate planning of relevant research into interventions that may

alleviate the burden of post-ICU cognitive impairments. Clinicians and researchers need to pay more attention to cognitive impairments during and after ICU admission, and patients and relatives need information as well as preparation for a time that may be marred by cognitive impairment.<sup>23</sup> Also, future research is warranted to determine which interventions may improve cognitive function for ICU survivors and when such interventions should be implemented.<sup>17</sup>

The objective of this scoping review is to review the literature on patients' experiences of cognitive impairment following critical illness.

## METHODS AND ANALYSIS

The scoping review will be conducted in accordance with the JBI methodology for scoping reviews.<sup>21</sup>

### Review question(s)

1. What is known about adult patients' experiences of cognitive impairment following critical illness?
2. Which cognitive impairments do patients describe following critical illness?

### Inclusion criteria

#### Participants

This scoping review will consider studies that include critically ill adult male and female patients >18 years who were admitted to an ICU >24 hours.

#### Concept

This scoping review will include studies that explore patients' experiences of cognitive impairments following critical illness. Studies containing specific descriptions or mention patients' descriptions will be included. To be included, studies need to report on more than quantitative questionnaire data.

#### Context

This scoping review will consider studies in which adult patients have been admitted to a general ICU >24 hours and assessed between discharge and 5 years after discharge. No restrictions will be applied in relation to geographical location or culture.

### Types of sources

This scoping review will consider original research within qualitative, quantitative and mixed methods study designs for inclusion. The scoping review will also consider descriptive observational study designs. Furthermore, qualitative studies with approaches such as phenomenology, ethnography, qualitative description, grounded theory and action research will be considered. Quantitative approaches such as cohort studies and case-control studies will also be considered for inclusion. Besides, we will go through reviews' references to search for relevant and eligible studies.

## Search strategy

The search strategy will aim to locate both published and unpublished original studies. An initial limited search of MEDLINE (PubMed) and CINAHL (EBSCO) was undertaken to identify articles on the topic. The text words contained in the titles and abstracts of relevant articles and the index terms used to describe the articles were used to develop a full search strategy for MEDLINE, which is shown in online supplemental appendix I. The search strategy, including all identified keywords and index terms, will be adapted as needed for each included information source. The reference lists of included studies will be screened for additional papers. Articles published in English and Scandinavian languages will be included in this scoping review.

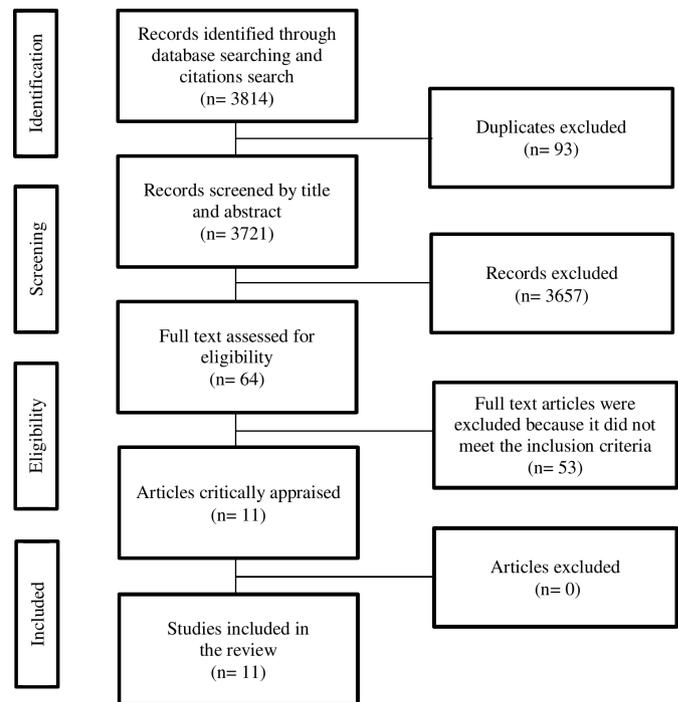
Articles published as from 1980 will be included. The databases to be searched include MEDLINE via PubMed, CINAHL EBSCO, PsycINFO via EBSCO and Embase via Elsevier. Unpublished studies and grey literature will be searched in Google Scholar.

## Study selection

Following the literature search, we will collect all identified studies, upload them to EndNote V.20 (Clarivate Analytics, Pennsylvania, USA) and remove duplicates. Titles and abstracts will then be screened by two independent reviewers (ABA and HKN) for assessment against the inclusion criteria. Potentially relevant studies will be retrieved in full text and assessed for eligibility. The full text of selected citations will be assessed in detail against the inclusion criteria by two independent reviewers (ABA and HKN). Reasons for exclusion of full-text papers that fail to meet the inclusion criteria will be recorded and reported in the scoping review. Any disagreements that might arise between the reviewers at each stage of the selection process will be resolved through discussion or by consulting a third reviewer (HS). The results of the search will be reported in full in the final scoping review and presented in a Preferred Reporting Items for Systematic Reviews and Meta-analyses for Scoping Reviews flow diagram (figure 1).<sup>24</sup>

## Data extraction

Data will be extracted from studies included in the scoping review by two independent reviewers (ABA and HKN) using a data extraction tool developed by the reviewers. The data extracted will include specific details about the population, concept, context, methods and key findings relevant to the review objective/question. A draft extraction tool is provided (online supplemental appendix II). The draft data extraction tool will be modified and revised as necessary during the data extraction process from each of the included studies. Modifications will be detailed in the full scoping review. Any disagreements that arise between the reviewers will be resolved through discussion or by consulting a third reviewer. Authors of papers will be contacted to request missing or additional data, where required. The Mixed Methods Appraisal Tool will be used for critical appraisal of the included studies.<sup>25</sup>



**Figure 1** Preferred Reporting Items for Systematic Reviews and Meta-analyses flow diagram of the systematic search strategy.

## Data analysis and presentation

The software programme NVivo V.12.0 (QSR International, Victoria, Australia) will be used to manage the qualitative and quantitative extracted data. The extracted data will be presented in a tabular form in a manner aligned with the objective and the research questions of the scoping review. Data will be supported by narrative descriptions or a narrative summary. Themes concerning patients' experiences of cognitive impairments will be identified from the included studies. The themes will be presented in a separate column together with other relevant results and supported by narrative descriptions or a narrative summary.<sup>21 26</sup>

## Patient and public involvement

This scoping review is mapping existing research on patients' experiences of cognitive impairment following critical illness. Patients or the public will therefore not be directly involved in this scoping review. However, results from the scoping review as well as patient and public involvement will be used in ABA's PhD programme with further explorative qualitative interview and observational studies on patients' and relatives' experiences of cognitive impairments following critical illness in the ICU.

## ETHICS AND DISSEMINATION

Since the scoping review methodology aims at synthesising existing research on patients' experiences of cognitive impairment following critical illness, the scoping review does not require ethical approval.

The results will be disseminated through a peer-reviewed publication in a scientific journal. We anticipate that the results of this scoping review will provide a comprehensive overview of patients' experiences of cognitive impairment following critical illness, and therefore important for patients, relatives and improving healthcare. With regard to other dissemination activities, the results will be used in ABA's PhD programme in terms of teaching activities, qualify interviews as well as presentation at relevant conferences.

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**Contributors** The scoping review was planned and conceived by all authors (ABA, HKN, HS, HIJ and PD), based on a common wish to map the existing research on patients' experiences of cognitive impairment following critical illness. ABA was responsible for the initial research search, the design used throughout the manuscript, the drafting and reporting of the protocol manuscript. HKN contributed extensively to the drafting, editing and reporting of the manuscript. All authors (ABA, HKN, HS, HIJ and PD) have contributed to conducting the protocol manuscript with supervision and critical revision. All authors (ABA, HKN, HS, HIJ and PD) have approved the final protocol manuscript.

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#### ORCID iD

Anette Bjerregaard Alrø <http://orcid.org/0000-0001-9600-5006>

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**Appendix I: Search strategy**

MEDLINE (PubMed)

Search conducted April 28, 2021.

Search	Query	Records retrieved
#1	Search: ((((((((((cognitive impairments) OR (cognitive deficits)) OR ("Cognitive Dysfunction"[Mesh])) OR (cognitive function)) OR (cognitive defect)) OR (cognitive disorders)) OR ("Cognition Disorders"[Mesh])) OR (postintensive care unit syndrome)) OR (post intensive care unit syndrome)) OR (post-intensive care unit syndrome)) OR (post icu syndrome)) OR (pics)) OR (postintensive care syndrome)	462,479
#2	Search: ((((((((((patients experience) OR (psychology)) OR (psychology[Title/Abstract])) OR (perceived)) OR (perception)) OR (thoughts))) OR (opinion)) OR (stress, psychological)) OR (patient satisfaction)) OR ("Patient Satisfaction"[Mesh])	3,205,456
#3	Search: ((((((((((icu) OR (icu[Title/Abstract])) OR (intensive care units)) OR ("Intensive Care Units"[Mesh])) OR (intensive care unit*)) OR (critical ill)) OR (critical illness)) OR ("Critical Illness"[Mesh])	353,659
#3	#1 AND #2 AND #3	2,867
	Limited to language (English and Scandinavian), adults + 18 years	

**Appendix II:** Data extraction instrument. Extraction of findings from studies.

<b>Authors (year)</b>	<b>Aim/ purpose</b>	<b>Number of participants</b>	<b>Study population</b>	<b>Origin/ setting</b>	<b>Methods/ Methodology</b>	<b>Main results/ findings</b>	<b>Authors' conclusion</b>	<b>Summary of critical appraisal</b>