

Shared Decision-Making with a Surrogate for Life-Sustaining Treatment of Critically Ill Patients: A Scoping Review Protocol

Yoshiyasu Ito, Mika Moriyama, Akemi Nasu, Keiko Kamitani, Shimpei Hayashi, Satoko Ono, Yasuko Sumida, Keiko Matsumoto, Misae Ito

Submitted to: JMIR Research Protocols
on: August 31, 2025

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Abstract

Background: Shared decision-making (SDM) is a collaborative process that incorporates patients' values and preferences into healthcare decisions. In ICUs, critically ill patients often lack decision-making capacity, requiring surrogates to make complex choices regarding life-sustaining treatment (LST). While SDM is essential in supporting surrogates and ensuring patient-centered care, evidence on its application in this context remains unclear.

Objective: This scoping review aims to clarify the extent and type of evidence on SDM involving surrogates for LST of critically ill patients.

Methods: This scoping review will follow the JBI methodology and the PRISMA-ScR reporting guidelines. Studies will be included if they examine shared decision-making involving surrogates of adult critically ill patients regarding life-sustaining treatment decisions in ICU settings. SDM is defined using four criteria: participation of both healthcare professionals and surrogates; mutual information sharing; consensus-building; and agreement on treatment based on the patient's values and preferences. A comprehensive search will be conducted across PubMed, CINAHL, PsycInfo, CENTRAL, and Ichushi-Web for English and Japanese studies published from 2016 to 2025. Eligible study designs include quantitative, qualitative, and mixed-methods research. Title and abstract screening and full-text selection will be conducted independently by two reviewers using Rayyan. Data will be extracted on study characteristics, SDM definitions, participant roles, and key findings. Results will be mapped descriptively and presented in tables and narrative summaries to identify gaps and inform future research.

Results: As of June 13, 2025, the literature search has been completed. A total of 2,899 citations were identified through the specified database searches, of which 527 duplicates were removed. Title and abstract screening is currently in progress, and full-text review is expected to be completed by September 2025.

Conclusions: This scoping review will be the first to systematically map evidence on SDM with surrogates for LST in critically ill patients. By synthesizing diverse studies, it will clarify healthcare professionals' roles, identify interventions, and highlight challenges surrogates face. The findings will inform future interventions and policies, and advance patient- and family-centered care in critical care.

(JMIR Preprints 31/08/2025:83284)

DOI: <https://doi.org/10.2196/preprints.83284>

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Original Manuscript

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Authors

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Running Title

Scoping Review of Surrogate SDM in Critical Care

Keywords

ICU, life-sustaining treatment, protocol, scoping review, shared decision-making

Word Count

Main text: 2451 words (excluding abstract and references)

No. of tables/figures: 0/0

No. of references: 21

Data Availability

Data sharing is not applicable as no datasets were generated and/or analyzed for this study.

Funding Information

This study was supported by research funds from the Tsuruga Nursing University.

Author Disclosure Statement

The authors declare that they have no conflicts of Interest.

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Abbreviations

ICU: Intensive Care Unit

SDM: Shared decision-making

LST: Lie- Sustaining Teatment

JB: Joanna Briggs Institute

PRISMA-ScR: Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews

ABSTRACT

Background: Shared decision-making (SDM) is a collaborative process that incorporates patients' values and preferences into healthcare decisions. In ICUs, critically ill patients often lack decision-making capacity, requiring surrogates to make complex choices regarding life-sustaining treatment (LST). While SDM is essential in supporting surrogates and ensuring patient-centered care, evidence on its application in this context remains unclear.

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Rayyan. Data will be extracted on study characteristics, SDM definitions, participant roles, and key findings. Results will be mapped descriptively and presented in tables and narrative summaries to identify gaps and inform future research.

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Conclusions: This scoping review will be the first to systematically map evidence on SDM with surrogates for LST in critically ill patients. By synthesizing diverse studies, it will clarify healthcare professionals' roles, identify interventions, and highlight challenges surrogates face. The findings will inform future interventions and policies, and advance patient- and family-centered care in critical care.

Introduction

Background

Historically, Intensive Care Unit (ICU) decision-making has favored a one-way model based either on patient autonomy or physician paternalism [1]. In the ICU, patients frequently lack the capacity to make decisions for themselves, so decisions regarding their health are delegated to surrogates. However, to achieve patient-centered care, shared decision-making (SDM) is imperative, even in circumstances involving surrogates. This new paradigm is recommended as the primary model for decision-making in the ICU [2]. The SDM in the ICU is defined as follows: "SDM is a collaborative process that allows patients, or their surrogates, and clinicians to make health care decisions together, taking into account the best scientific evidence available, as well as the patient's values, goals, and preferences [2]."

The process of surrogate decision-making in the ICU is frequently reported to be a highly challenging experience [3], with 19% of ICU patient surrogates experiencing moderate to severe long-term decisional regret [4]. Furthermore, such negative experiences with surrogate decision-making are known to increase the long-term risk of psychological impairment in surrogates [5,6]. SDM is known to improve patient satisfaction and the quality of care [7], but it is also expected to modify the negative experiences of surrogate decision-making in the ICU and serves as a crucial component in supporting surrogates [1].

SDM is not always necessary. When there is only one best option, as in the case of a patient with a gunshot wound to the abdomen who requires immediate surgery, SDM does not apply. It is only applicable when two or more reasonable choices exist [8]. ICU patients are critically ill, and there are few cases where there are multiple rational options, but in decision-making regarding life-support treatments (LSTs), SDM is applicable, as choices must be made among multiple available options.

Surrogates of critically ill patients are often required to make difficult decisions regarding LST, such as whether to withhold, withdraw, or escalate care. Decision-making about LST is highly complex and challenging, as it requires balancing the patient's best interests, the surrogate's values, and their understanding of the patient's wishes. Consequently, surrogates often experience strong feelings of regret regarding their decisions [4]. Considering the complexity and psychological burden of decision-making regarding LST, SDM plays a crucial role in carefully respecting patients' values, goals, and preferences. In the ICU, where medical decisions often carry profound ethical and emotional implications, SDM serves as an essential framework for aligning medical care with patients' wishes and supporting surrogates in making well-informed decisions. Particularly in discussions surrounding LST, SDM is a key approach to reduce decisional conflict and to guide surrogates through the process of making these difficult choices. More recently, a consensus framework has been developed to guide decision-making processes regarding the continuation or limitation of LST in ICU patients, and SDM has been increasingly recommended as an important process in such decision-making [9]. However, it remains unclear what information and evidence are available regarding SDM with a surrogate for LST of critically ill patients, and no systematic reviews or scoping reviews have been conducted on this topic.

Review Objectives

The aim of this scoping review is to clarify the extent and type of evidence on SDM with a surrogate for LST of critically ill patients, providing valuable insights into the current state of SDM in critical care treatment, identifying knowledge gaps, and suggesting directions for future research.

Review Questions

The research questions of this scoping review are as follows.

1. What study has been conducted on SDM with surrogates for LST of critically ill patients, and

what are the key findings?

2. What types of healthcare professionals' SDM interventions are there regarding LST for critically ill patients?
3. What are the roles of each healthcare professional participating in SDM with regarding to LST for critically ill patients?

Methods

This study is a scoping review. The proposed scoping review will be conducted in accordance with the JBI methodology for scoping reviews [10], and we will report the guidelines described in the Preferred Reporting Items for Systematic Reviews and Meta-analyses Statement extension for Scoping Reviews (PRISMA-ScR) [11]. This review protocol has been registered with the Open Science Framework (<https://osf.io/mf2ht/>).

Inclusion criteria

Population

This scoping review will include studies on SDM on surrogates who are involved in treatment and care decisions-making for adult patients aged 18 and older. Surrogates include not only the patient's family members, such as spouses, children, or parents, but also individuals who have been legally designated to make healthcare decisions on the patient's behalf, including legal guardians and those with durable power of attorney for healthcare.

Concept

This scoping review will include studies of SDM between healthcare providers and surrogates for

critically ill patients who lack decision-making capacity due to disease progression or functional impairment. The definition of SDM in critically ill patients is described as collaborative process that allows patients, or their surrogates, and clinicians to make health care decisions together, taking into account the best scientific evidence available, as well as the patient's values, goals, and preferences [2]. Additionally, the characteristics of SDM (1) that at least two participants-physician and patient be involved; (2) that both parties share information; (3) that both parties take steps to build a consensus about the preferred treatment; and (4) that an agreement is reached on the treatment to implement¹¹. Therefore, in this scoping review, SDM will be defined as meeting all the following criteria: at least two participants, patient's surrogates and healthcare professional, should be involved; both parties share information; both parties take steps to build a consensus about the preferred treatment based on the patient's values, goals, and preference; and an agreement is reached on the treatment to implement.

Studies involving decision-making support, such as decision coaching, decision support, and question prompt sheets, will be included if they are interventions that form part of SDM meeting the four criteria mentioned above. Studies that do not meet the SDM definition criteria or studies related to SDM when the patient has decision-making capacity will be excluded.

Context

This scoping review will include studies of the decision-making process surrounding LST for critically ill patients. This includes not only decisions regarding the initiation of LST but also those related to the withholding or withdrawal of such treatments. The context of these decisions typically takes place in ICUs, where patients are critically ill, often requiring advanced medical interventions to sustain life. The reason the ICU is central to these decisions is that time for decision-making is often limited, and the choices made can have profound consequences on the patient's survival. These decisions are critical and extremely difficult, as they involve determining whether to continue life-

sustaining interventions or to cease them, which directly impacts the patient's life or death. Studies involving treatments and care other than LST, environments other than the ICU, or multiple contexts (e.g., ICU and surgical wards) will be excluded.

Types of Sources

This scoping review will consider both experimental and quasi-experimental study designs including randomized controlled trials, non-randomized controlled trials, before and after studies and interrupted time-series studies. In addition, analytical observational studies including prospective and retrospective cohort studies, case-control studies and analytical cross-sectional studies will be considered for inclusion. This review will also consider descriptive observational study designs including case series, individual case reports and descriptive cross-sectional studies for inclusion. Qualitative studies will also be considered that focus on qualitative data including, but not limited to, designs such as phenomenology, grounded theory, ethnography, qualitative description, action research and feminist research. Studies published in English or Japanese scientific literature from 2016 to 2025 will be included. Review articles, protocol papers, opinion papers, letter, editorial, commentary, and grey literature (such as conference, governmental, and institutional websites) will be excluded.

Search Strategy

A 3-step search strategy will be used. An initial limited search of PubMed was performed to identify relevant articles. The text words contained in the titles and abstracts of the relevant articles, and the index terms used to describe the articles, were used to develop a full search strategy (S1 Table). Specific keywords and index terms from each database and information source were incorporated into the search strategy. The databases searched included PubMed, CINAHL Ultimate (EBSCO), PsycInfo (EBSCO), Cochrane Central Register of Controlled Trials in the Cochrane Library

(CENTRAL), and Ichushi-Web of the Japan Medical Abstract Society. Studies published in English or Japanese were included, and all studies published from 2016 to 2025 will be considered. The database searches were conducted on June 13, 2025.

Study Selection

Following the search, all identified citations will be collated and uploaded to Rayyan software and duplicates will be removed. Following the pilot test, titles and abstracts were screened by two independent reviewers to assess the inclusion criteria. Furthermore, potentially relevant sources were retrieved completely, and their citation details will be imported into the Rayyan software. Two independent reviewers will assess the complete texts of the selected citations in detail against the inclusion criteria. The reasons for excluding sources of evidence that did not satisfy the inclusion criteria will be recorded and reported. Any disagreements between the reviewers at any stage of the selection process will be resolved through discussion or consultation with additional reviewers. The results of the search and study inclusion processes will be reported using the Preferred Reporting Items for Systematic Reviews and Meta-analyses 2020 flow diagram [13]. The source of evidence selection is scheduled to be conducted between June and August 2025.

Data Extraction

Data will be extracted using a data extraction tool developed by the reviewers. cite the tool to be used or append the data extraction tool. The extracted data will include evidence source details and characteristics of the citation details, country, study design, purpose, definition of SDM, types of healthcare professionals participating in SDM, context/settings, participants, methodology, and main results. A draft extraction form is provided (S2 Table). The draft data extraction tool will be modified and revised as necessary during the process of extracting data from each included evidence source. Modifications will be detailed in the scoping review. Any disagreements that arise between the

reviewers will be resolved through discussion, or with an additional reviewer. Data extraction is scheduled to be conducted between September and October 2025, after the completion of the source of evidence selection.

Data Analysis and Presentation

In this review, data will primarily be presented in tabular form, but other formats that better illustrate the results will also be considered. Each study will be classified into multiple domains according to its study purpose. A detailed mapping will be conducted by describing each study within each domain in terms of country, study design, purpose, setting, participants, methodology, and key findings. In addition, when there will be more than two studies on a domain, the findings will be summarized narratively, and the evidence was mapped descriptively. Data analysis and presentation will be conducted after the completion of data extraction, between November and December 2025. The results of this scoping review are expected to be published from January 2026 onwards.

Results

As of June 13, 2025, the literature search has been completed. A total of 2,899 citations were identified through the specified database searches, of which 527 duplicates were removed. Title and abstract screening (conducted by YI, MM, AN, KK, SH, SO, YS, KM, and MI) is currently in progress, and full-text review is expected to be completed by September 2025.

Discussion

In the ICU, critically ill patients frequently lose the capacity to make healthcare decisions, and responsibility often falls to surrogate decision-makers [2, 14]. While SDM has been endorsed as the

preferred framework for aligning medical treatment with patient values, its application in surrogate decision-making for LST is limited [15]. Previous research has highlighted the complexity of surrogate decision-making, including decisional conflict, regret, and psychological burden [16-19], yet evidence on how SDM processes specifically mitigate these challenges in the ICU is fragmented. To our knowledge, this scoping review will be the first to systematically map the extent and type of evidence on SDM with surrogates for LST of critically ill patients.

This review will clarify how SDM has been conceptualized and operationalized in the ICU setting, identify the types of healthcare professional interventions that have been applied, and delineate their roles within SDM processes. In the ICU, shared decision-making has been implemented as an interprofessional process involving collaboration among physicians, nurses, and other healthcare professionals [20, 21]. This study will further contribute to advancing SDM by clarifying the specific roles of each profession within these processes. Furthermore, by synthesizing diverse study designs and methodologies, this review will provide a broad overview of the current state of knowledge and highlight areas where empirical evidence is lacking. The findings are expected to inform the development of interventions aimed at improving surrogate support and strengthening the integration of SDM in critical care practice.

The results of this scoping review will contribute to both clinical practice and research in several ways. First, by mapping existing interventions and roles of healthcare professionals in surrogate SDM, the review will provide valuable insights into multidisciplinary approaches that may alleviate decisional burden. Second, it will help identify which elements of SDM are most effective in improving surrogate experiences, such as structured communication tools, decision aids, or family conferences.

A key strength of this review is the use of the JBI methodology and adherence to PRISMA-ScR guidelines [10, 11], ensuring a systematic and transparent approach to evidence mapping. The

inclusion of a broad range of study designs, including both quantitative and qualitative research, will allow for a comprehensive understanding of the topic. In addition, by incorporating literature published in both English and Japanese, this review may capture cultural and contextual variations that enrich the interpretation of findings.

However, some limitations should be acknowledged. Restricting the search to publications from 2016 onwards may exclude earlier but potentially relevant studies on SDM. Similarly, limiting to English and Japanese literature could omit findings from other cultural contexts where SDM practices may differ. Another limitation is that, as a scoping review, this study will not assess the quality or risk of bias of included evidence, which may limit the strength of conclusions regarding intervention effectiveness. Despite these limitations, the review will provide an essential first step in consolidating current evidence and identifying gaps for future systematic reviews or interventional studies.

Conclusion

Overall, this scoping review will be the first to systematically investigate the scope and characteristics of evidence regarding SDM with surrogates for LST in critically ill patients. By synthesizing findings across diverse studies, it will clarify the roles of healthcare professionals, identify existing interventions, and highlight the challenges surrogates face during LST decision-making. The knowledge gained will not only inform the design of future interventions and policies but also support the advancement of patient- and family-centered care in critical care settings.

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Supplementary Files

Multimedia Appendixes

S1 Table. Preliminary search strategy for the PubMed.

URL: <http://asset.jmir.pub/assets/6d13f74c35b70652c2374e6f3d84b2af.docx>

S2 Table. Data extraction instrument.

URL: <http://asset.jmir.pub/assets/83e13b5a191f2744ac9295d753a3efe6.docx>

CONSORT (or other) checklists

Untitled.

URL: <http://asset.jmir.pub/assets/6483ac335cf39631c52af565d1eb42a0.pdf>