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Perspectives and insights of critical care clinicians, patients and families from culturally and linguistically diverse backgrounds around end-of-life care in an ICU: a scoping review protocol

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ABSTRACT

Objective Protocol to explore what is known about communication between critical care providers and patients and families from culturally and linguistically diverse backgrounds (defined as people who are either from minority ethnic groups, non-English-speaking backgrounds who may have diverse cultural, linguistic, spiritual and religious affiliations and opinions) about death, dying, end-of-life care and organ donation in the intensive care unit (ICU).

Introduction Patients from culturally and linguistically diverse backgrounds experience barriers to optimised care when admitted to the ICU. These barriers appear to derive from differences in language, cultural, societal and ethical expectations between patients, their families and healthcare professionals. These barriers may significantly impact the delivery of end-of-life care to patients from culturally and linguistically diverse backgrounds. Therefore, this has the potential for inadequate management of medical, psychological and existential distress.

Inclusion criteria Studies of all designs reporting for adult (age ≥18 years) patients and family members from culturally and linguistically diverse backgrounds at end-of-life in the ICU setting will be included. Studies that report results for patients aged <18 years or that are based outside the ICU will be excluded.

Methods Relevant sources will be retrieved, and their citation details will be imported into the Joanna Briggs Institute (JBI) System for the Unified Management, Assessment and Review of Information. This scoping review was guided by the JBI methodology for scoping reviews and reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews guidelines. A systematic search was conducted in EBSCOhost, Web of Science, PubMed Central and SciELO, OVID Medline, CINAHL, and Scopus, limited to English-language publications, without date limitation. Key study characteristics and findings will be extracted using a data extraction tool developed by the reviewers. Anticipating heterogeneous study designs, findings will be presented as a thematic synthesis.

Ethics and dissemination This is a protocol for a scoping review, formal ethics approval from the Human Research Ethics Committee (HREC) of the Local Health Network will be obtained for research projects that could potentially stem from this review and will then be subsequently disseminated through proper channels.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ End-of-life care in the culturally and linguistically diverse patient population (CALD) in the intensive care unit has not been well researched previously and this review will identify signals that can be further studied.
- ⇒ The scoping review encompasses key areas of palliative care and organ donation as they all are patient-centred issues, intricately linked with end-of-life care that need to be evaluated.
- ⇒ The review will help uncover some of the practical and logistic issues that influence the management of critically ill patients and families from a CALD background, and this will be of interest to clinician administrators.
- ⇒ Barriers and facilitators for effective and efficient communication with caregivers and critically ill patients of CALD background will be elucidated.
- ⇒ Reviewing non-English language studies or databases is outside the scope of this review and this may be considered a potential limitation.

INTRODUCTION

The term culturally and linguistically diverse (CALD) can be used to describe people who are either from minority ethnic groups, were born in a nation where the majority language is not English, do not speak English at home[1] or have diverse cultural, linguistic, spiritual and religious affiliations and opinions.[2 3]

There are significant differences in the definitions of CALD that are used in research, policy and government papers across the country, which makes it challenging to compile a unifying entity.[4] Previous research has demonstrated that patients from CALD backgrounds are less likely to have advanced care directives and more likely to die while receiving full life-sustaining therapy.[5–10] Patients and their families did not engage in conversations with the medical professionals about end-of-life care (EOLC), which compromised the quality of EOLC and resulted in suboptimal experiences for this group of patients and their families.[9 10] Furthermore, a lower standard of care and unfulfilled care expectations were linked to inadequate organisational structures to foster cultural safety, policies to support training and staff cultural awareness while managing CALD patients with limited English proficiency.[9 10]

Language challenges, a lack of awareness about the health system and consumer rights, and a lack of available resources have all contributed to this predicament.[11 12] Furthermore, patients from CALD backgrounds were less likely to have documentation about their EOLC and advanced care preferences expressed in family conferences.[10] Also, there is evidence[13 14] that language discordance results in poorer assessment and management of pain and distress of patients and relatives, from ethnically diverse backgrounds and in the elderly. This parallels some of the issues that have afflicted the care delivery for patients from an indigenous background in an Australasian context.[15–17] Also, the patient's inability to communicate their suffering, as they are likely to be on organ support, further compounds the problem. This may result in missed recognition of attempts by patients to communicate or misinterpretation of communication attempts by healthcare staff.[10]

During EOLC, there were disagreements between medical experts and families regarding the withdrawal of life-sustaining treatment. These disagreements were linked to the families' expectations of advanced medicine in the higher-resourced setting and their religious and cultural beliefs and values.[9 18] It is important for this patient population and personnel looking after this cohort to have comprehension and proficiency in cross-cultural communication.[19] There are inherent risks in linguistic misunderstandings[19] with both verbal and non-verbal communication. It has also been shown that the cultural and spiritual needs of this population are often overlooked or incorrectly assumed. This has the potential to widen the chasm in patient-centred care further.[20 21] There is evidence that affluent and highly educated patients and families are more likely to lodge a medicolegal complaint than those from under-represented or lower socioeconomic groups. This perhaps reflects their distrust of the healthcare system and lower health literacy in CALD groups.[22]

An over-reliance on caregivers has further complicated some issues around communication with patients and caregivers from a CALD background to relay patient-sensitive information without using validated methods like interpreters and counsellors. The perspectives of clinicians in relation to this aspect of communication, particularly in a critical care environment, managing acutely unwell patients with high complexity, acuity and severity of illness has not been fully elucidated and remains a knowledge gap that needs to be addressed. It has also been shown that patients and caregivers from a CALD background have been under-represented in previous quality and safety initiatives.[19] Consequently, their voices have not been heard in promulgating key initiatives around EOLC planning. One of the most important things that needs to be done is to encourage the use of advance care directives within the CALD community to provide dignified EOLC for this patient population.

Discussion around facilitating organ donation when feasible and appropriate is considered an integral aspect of good EOLC.[23 24] Given the high-stress, high-stakes environment, conversations concerning organ donation are frequently quite delicate and call for explanations of a variety of intricate medical details.[25 26] It has also been shown that perceived empathy and compassion along with verbal and non-technical skills influence decision-making in the organ donation process. Communication, therefore, can be extremely challenging across cultural and language barriers. Adding to the complexity of this issue is the management of the triangular conversations between the clinician, the patient/caregiver and the interpreter. This triangulation can often be difficult, particularly as interpreters may not be available after hours, and this might interrupt the continuity of communication, and as a result, inadvertently breed resentment and mistrust. It has also been shown that family members of non-English-speaking backgrounds are less likely to consent to organ donation.[26] Decision-making regarding EOLC is noticeably different for intensive care unit (ICU) patients with a low English language command.[27] There are several recognised obstacles in making high-quality decisions regarding EOLC for ICU patients and their families who have inadequate English proficiency.[28–32] It is possible that raising awareness of these factors[28–32] will make it easier to implement treatments that will improve the quality of decision-making that is compassionate and culturally sensitive for patients and families from a CALD background.

Review question(s)

This scoping review aims to explore and critically synthesise existing empirical research exploring communication between critical care providers and patients and families from CALD backgrounds, in the context of EOLC in an intensive care setting.

In the ICU, EOLC will be defined as the period beginning with the creation of medical consensus that the patient needs EOLC and that the intention to cure them is not feasible. EOL refers to the period of a person's life in which they are living with and being affected by a condition that will ultimately result in death, even if the prognosis is uncertain or impossible to predict.

Palliative care: Individuals who are living with and dying from an illness that will eventually be fatal and for whom the primary purpose is to improve their quality of life are eligible to receive palliative care, which is a specialised kind of medical treatment.

Care provided to patients at the end of their lives: EOLC is a comprehensive collection of health and community services that are provided to patients who are nearing the end of their lives. Strong networks involving providers of specialised palliative care, primary generalist providers, primary specialists and support care providers, as well as the community, are necessary to provide quality EOLC. These networks must collaborate to satisfy the requirements of individuals who require care.

Included studies will be interrogated to answer the following questions in this CALD/ICU/EOLC context:

What are the facilitators of effective communication, what preparation, resources and support do clinicians, patients, and families value?

What are the barriers to effective communication about death, dying, EOLC and organ donation?

Inclusion criteria

Participants

Studies of all designs will be included that meet the following criteria: the study populations include adult (age ≥18 years) patients and family members from CALD backgrounds at EOL in the ICU setting. Studies will be excluded that report results for patients aged <18 years or that are based outside the ICU setting.

Concept

This review will focus on patients from CALD communities and how clinicians (medical, allied health and nursing) deal with the expectations from these communities, mainly focusing on their perspectives and insights on care delivery at EOL (death and dying in the ICU).

Context

The context is EOLC in the critical care environment.

Types of sources

This scoping review will consider all empirical studies, including qualitative, quantitative and mixed-methods designs.

In addition, systematic reviews that meet the inclusion criteria will also be considered, depending on the research question.

Conference abstracts will not be considered for inclusion in this scoping review.

METHODS

The proposed scoping review will be conducted according to the Joanna Briggs Institute (JBI) methodology for scoping reviews[33] and in line with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR).[34] This protocol has been registered with the Open Science Framework.

Patient and public involvement

None.

Search strategy

The search strategy will aim to locate both published studies. A three-step search strategy will be used in this review. First, an initial limited search of MEDLINE (PubMed) will be 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 OVID Medline, CINAHL, Embase (OVID) and Scopus (see online supplemental appendix 1). The search strategy, including all identified keywords and index terms, will be adapted for each included database and/or information source. The reference list of all included sources of evidence will be screened for additional studies.

The search will be limited to studies published in English. There will be no limit on dates of study publication.

Study/source of evidence selection

Following the search, all identified citations will be collated and uploaded into read cube Papers (2021 Digital Science Research & Solutions) or COVIDENCE and duplicates will be removed. Following a pilot test, titles and abstracts will be screened by two or more independent reviewers for assessment against the inclusion criteria for the review. Potentially relevant sources will be retrieved in full, and their citation details will be imported into the JBI System for the Unified Management, Assessment and Review of Information (JBI, Adelaide, Australia).[35] The full text of selected citations will be assessed in detail against the inclusion criteria by two or more independent reviewers. Reasons for the exclusion of sources of evidence in full text that do not meet the inclusion criteria will be recorded and reported in the scoping review. Any disagreements that arise between the reviewers at each stage of the selection process will be resolved through discussion or with additional reviewers. The results of the search and the study inclusion process will be reported in full in the final scoping review and presented in a PRISMA-ScR flow diagram.[34]

Data extraction

Data will be extracted from papers included in the scoping review by two or more independent reviewers using the JBI data extraction tool.[33] The data extracted will include specific details about the participants, concept, context, study methods and key findings relevant to the review questions.

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/s. If appropriate, corresponding authors of papers will be contacted to request missing or additional data, where required.

Data analysis and presentation

The extracted data will be presented in tabular form and as a narrative summary that aligns with the aim of this scoping review. The table will report (1) the distribution of studies by countries of origin and study design; (2) participants/sample size; (3) perspectives and insights studied; (4) outcome measure and (5) a summary of findings. This table may be further refined at the review stage. Graphical representations may be used. A narrative summary will accompany the tabulated or charted results and describe how the results relate to the review's objectives.

Data statement

Technical appendix, statistical code and dataset are available in the Figshare repository.

Registration

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Contributors KS and ER collected data by reviewing the literature and preparing the manuscript. KS and RH performed the preliminary analysis plan and provided intellectual input in finalising the manuscript. RH, AS, NA and RAD assisted with data screening and collection, manuscript editing and administrative affairs related to this study. The above authors were collectively involved in the study design, protocol development and data management. KS, RAD, AS, NA and CP will complete the scoping review and finalise our data. All authors have read and approved the final manuscript. KS will be the guarantor for this project.

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