BMJ Open

Paediatric death after withdrawal of life-sustaining therapies: a scoping review protocol

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To cite: Francoeur C, Hornby L, Silva A, *et al*. Paediatric death after withdrawal of life-sustaining therapies: a scoping review protocol. *BMJ Open* 2022;**12**:e064918. doi:10.1136/bmjopen-2022-064918

► Prepublication history and additional supplemental material for this paper are available online. To view these files, please visit the journal online (http://dx.doi.org/10.1136/bmjopen-2022-064918).

Received 17 May 2022
Accepted 31 August 2022

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ABSTRACT

Introduction The physiology of dying after withdrawal of life-sustaining measures (WLSM) is not well described in children. This lack of knowledge makes predicting the duration of the dying process difficult. For families, not knowing this process's duration interferes with planning of rituals related to dying, travel for distant relatives and emotional strain during the wait for death. Time-to-death also impacts end-of-life care and determines whether a child will be eligible for donation after circulatory determination of death. This scoping review will summarise the current literature about what is known about the dying process in children after WLSM in paediatric intensive care units (PICUs).

Methods and analysis This review will use Joanna Briggs Institute methodology for scoping reviews. Databases searched will include Ovid MEDLINE, Ovid Embase, Cochrane Central Register of Controlled Trials via EBM Reviews Ovid, Ovid PsycINFO, CINAHL and Web of Science. Literature reporting on the physiology of dying process after WLSM, or tools that predict time of death in children after WLSM among children aged 0–18 years in PICUs worldwide will be considered. Literature describing the impact of prediction or timing of death after WLSM on families, healthcare workers and the organ donation process will also be included. Quantitative and qualitative studies will be evaluated. Two independent reviewers will screen references by title and abstract, and then by full text, and complete data extraction and analysis.

Ethics and dissemination The review uses published data and does not require ethics review. Review results will be published in a peer-reviewed scientific journal.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ This will be the first scoping review investigating what is known about the dying process in children after the withdrawal of life-sustaining measures (WLSM).
⇒ We will use a comprehensive search strategy and include and extensive body of literature to map the international literature around our topic of interest.
⇒ Results from our scoping review will be used guide clinical research related to the physiology of the dying process in paediatric intensive care units (PICUs).
⇒ We will only include articles in English and French and only focus on WLSM in PICUs and so may omit relevant evidence from other languages and exclude low-income countries.
⇒ We are using a scoping review methodology and to be congruent with our methods a quality appraisal of the included references will not be performed, but that may limit the applicability of our findings into clinical settings.

INTRODUCTION

Children die in different settings depending on many factors including geographical location, socioeconomic status and medical complexity.[1 2] Most paediatric deaths in high-income countries occur in hospital settings and the majority of these occur in pPaediatric intensive care units (PICUs).[2–5] The planned withdrawal of life-sustaining measures (WLSM) in many of these deaths in the PICU represents a transition from an invasive, interventional approach to a comfort and family-oriented approach. WLSM can be defined as the process in which medical interventions (eg, vasopressors and mechanical ventilation) are discontinued, which ultimately result in the patient's death from the underlying disease and/or complications.[6] Intensivists play a key role in facilitating this transition and the dying process before, during and after WLSMs. However, the physiology of the dying process following WLSMs is not well described in children. A retrospective study proposed a machine learning model that can reasonably predict death within 1 hour of WLSM in children,[7] but this model remains unvalidated and is not feasible for many institutions at this time.

The uncertainty around the timing of death among children after WLSMs can have negative impacts on family members, healthcare professionals and organ donation processes. Family members of children going through WLSM frequently report feelings of vulnerability and uncertainty during the

death process and the unpredictability of death timing can exacerbate these feelings.[8] In addition, the unpredictability of death timing for children after WLSMs can impact clinicians' ability to provide excellent end-of-life care, to counsel families through this difficult process, and to identify the children who will die within an acceptable timeframe to allow for controlled donation after circulatory determination of death (DCD).[9] The practice of controlled DCD has been increasing in recent years, and in this procedure, donation can be performed after circulatory DCD following a 5 min no-touch period after the WLSM.[10]

Donation after circulatory DCD represents a significant and growing proportion of donation in adults. In paediatrics, this proportion has been reported to be as high as 32.2%[11]; but in Canada, it remains small, accounting for only 10% of donors in 2019.[12] Although most paediatric deaths occur in the PICU,[3 13] a 2019 survey showed that several Canadian PICUs did not offer DCD.[12] In addition, a recent study estimated an active paediatric DCD programme could increase potential donations by 20%.[14] Therefore, there are recurrent missed opportunities for donation for both donors and recipients in Canadian PICUs.

It is essential to evaluate the current knowledge of the dying process in children, including timing of death and the impact on families, healthcare workers and the organ donation process. A better understanding of the physiology of dying may improve time of death prediction, empower clinicians, improve counselling for families and increase donor identification.[9] Insight into the experiences of families and treating team members may also provide the means necessary to better tailor counselling and end of life management in the PICU.

After conducting a preliminary search on MEDLINE, the Cochrane Database of Systematic Reviews and Joanna Briggs Institute (JBI) Evidence Synthesis, we did not identify any reviews on time of death prediction nor on its potential impact on families, clinicians and the organ donation system. However, we identified a meta-synthesis[15] and a scoping review,[16] evaluating parental experience of the death of children in the PICU, but these did not review the specific question of physiology nor time of death prediction, nor did they explore the perspective of healthcare providers. Therefore, this scoping review will aim to collate and summarise the current literature about what is known regarding the dying process in children after the WLSM in PICU.

The overarching question of this scoping review is: What is known about the process of dying in children after WLSM in PICU settings worldwide? The subquestions are: (1) What evidence exists that explores the physiological process of dying after WLSM in children? (2) What tools are available to help predict the timing of death after WLSM in children? (3) What is the impact of time of death (or prediction) after WLSM in children on healthcare workers and the organ donation process? (4) What is the evidence on the process of dying after WLSM in children in the family's experience of death?

METHODS AND ANALYSIS

This protocol and the proposed scoping review follow the JBI methodology for scoping reviews.[17]

Eligibility criteria

Participants

This scoping review will consider references that include children (0–18 years of age) going through WLSM. However, if the study focuses on newborns in neonatal intensive care unit (NICU), the reference will be excluded as premature infants have physiology that is distinct from term babies and children and thus, we believe that studies focused in NICU should be studied separately. In addition, if the study report on mixed data (eg, adult and paediatric patients), the results for paediatric patients need to be reported separately for the reference to be considered for inclusion. Our goal is to complete our review during the period from May to October 2022.

Concept

The main concept of interest in this review is the process of dying in children after WLSM, including aspects such as the physiological process of dying and time to death prediction. In addition, if the reports focus on the impact of the dying process in children after WLSM on families, healthcare workers and organ donation processes, the report will also be included. However, if the reference only reviews the incidence of autoresuscitation or transient resumption of cardiac activity in children, or if it focuses only on paediatric donation after circulatory death then the report will be excluded as these are not exclusively related to WLSM, and therefore, go beyond the scope of this review; as well as these areas have recently been explored and reported in other literature reviews.[18 19]

Context

References will be considered if they are focused on any paediatric intensive care settings worldwide. If the research is based in the NICU setting then the reference will be excluded for the reasons explained above. In addition, WLSM in settings other than PICU (eg, renal services, oncology units and ambulatory settings) will not be considered for inclusion.

Types of Sources

This scoping review will consider both experimental and quasi-experimental study designs including randomised controlled trials, non-randomised 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. In addition, references from systematic reviews will be screened to ensure no relevant references were missed in our search strategy. Text and opinion papers will also be considered for inclusion in this scoping review. We will not exclude references based on date of publication, but only articles in English and French will be considered.

Search strategy

The search strategy aimed to locate both published and unpublished papers. An initial limited search of Medline (OVID) was completed by an experienced information specialist with an analysis of the text words in titles, abstracts and index terms used to describe articles. The search strategy included controlled vocabulary (eg, MeSH) and text words for concepts: death processes, time to death predictions after WLSM and paediatrics. The strategy was created using an interactive process based on findings from initial searching, as well as the final searching strategy was reviewed using the Peer Review of Electronic Search Strategies for systematic reviews by a second experienced information specialist in medical research.[20] In addition, the primary information specialist designed and adapted all search strategies (online supplemental appendix I) for the following electronic databases: Ovid MEDLINE, Ovid Embase, Cochrane Central Register of Controlled Trials (CENTRAL) via EBM Reviews Ovid, Ovid PsycINFO, CINAHL (EBSCOhost) and Web of Science databases (Science Citation Index Expanded; Social Sciences Citation Index). The information specialist also searched Embase for meeting abstracts from the past 3 years and Web of Science Conference Proceedings Citation Indices, ProQuest Dissertations & Theses Global, and Google Scholar for any studies missed by the database searches. The search results were limited to human studies in English or French. No publication date or document type restrictions were applied to the search.

Study/source of evidence selection

Following the search, all identified citations will be collated and uploaded into Covidence (web-based systematic review platform) and duplicates removed. Following a pilot test, titles and abstracts will be screened by two independent reviewers in a blinded review process for assessment against the inclusion criteria for the review. Potentially relevant sources will be assessed in detail using the full text by two independent reviewers for final decision regarding inclusion/exclusion. Any disagreements that arise between the reviewers at each stage of the selection process will be resolved through discussion or with the input of a third reviewer. Reasons for exclusion of sources of evidence at full text that do not meet the inclusion criteria will be recorded and reported in the final report of this scoping review. The results of the search and the study inclusion process will be reported in full in the final scoping review and presented in a Preferred Reporting Items for Systematic Reviews and Meta-analyses extension for scoping review flow diagram.[21] The reference list of selected articles will also be searched for additional sources of information according to the same inclusion criteria.

Data extraction

Data will be extracted from the included reports by two independent reviewers using a data extraction tool that we developed for this review (online supplemental appendix II). The data extraction tool will be pilot tested at the beginning of the data extraction process, modified and revised as needed during the process. Any disagreements between the reviewers during the data extraction will be solved through discussion or with the input of a third reviewer. The data extraction tool includes specific details about the population, concept, context, study methods and key findings relevant to the review objective (eg, physiological process of dying after WLSM, tools to predict death, family experience, impact on organ donation process). If needed, authors of papers will be contacted to request missing or additional data.

Data analysis and presentation

After the data extraction process, the data will be collated and summarised quantitatively and qualitatively to respond to the objective and research questions of this review. For the quantitative part, we will use a descriptive numerical summary, and for the qualitative part we will conduct a content analysis using an inductive approach from the data extracted. In the descriptive numerical summary, we will use a simple numerical count to describe the characteristics of the included reports (eg, year of publication, design, country), and data from the content analysis will be presented in categories using a narrative format to discuss the current state of the literature on the dying process in children after WLSM. We will also develop charts and tables to help clarify the findings from this scoping review related to the evidence exploring the physiological process of dying after WLSM in children, tools available to predict the timing of death and the impact of time of death on family members, healthcare workers and the organ donation process. Also, a quality appraisal of the included literature will not be conducted to be in line with JBI scoping review methodology.

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Acknowledgements The authors would like to thank the Information Specialist, Robin Featherstone, for developing and executing the main electronic search strategies; and Dagmara Chojecki, for peer reviewing the search methods and strategy.

Contributors CF, LH, AS, NBS, MW and SD contributed to the design of this protocol, helped drafting the protocol and critically reviewed, read and approved the final version. CF is the guarantor of the review.

Funding This work was supported by a grant from Canadian Blood Services (no grant number is applicable). Canadian Blood Services is a national, not-for-profit charitable organisation that manages the supply of blood and blood products in all provinces and territories in Canada (with the exception of Quebec) and oversees the Canadian Blood Services Stem Cell Registry. In 2008, Canadian Blood Services became responsible for national activities related to organ and tissue donation and transplantation (OTDT), which includes national system development and

operation of interprovincial organ sharing programmes. Canadian Blood Services is not responsible for the management or funding of any Canadian organ donation organisation or transplant programme. Canadian Blood Services works with the organ and tissue donation and transplantation community to improve the system for all Canadians.

Competing interests LH is a paid research consultant for Canadian Blood Services.

Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication Not applicable.

Provenance and peer review Not commissioned; externally peer reviewed.

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