

Project plan

Physicians' experiences of the decision-making process regarding decisions to withhold/discontinue life-sustaining treatment in children cared for in intensive care units in Sweden

NCT

Document date January 27 2026

Background and question

Every year, we have between 3-4000 cases of care in Swedish intensive care units for children younger than 15 years. Of these, between 60-80 die during their stay in the intensive care unit. And the total 90-day mortality rate in children who have been in intensive care is almost 4%.

¹Caring for patients who are life-threateningly ill with heavy life-support treatment requires that one constantly assesses whether the patient is benefiting from the healthcare provided. Sometimes the best thing for the patient is not to receive as much healthcare as possible without prioritizing other values. Although good nursing and full symptom-relieving treatment are an obvious part of modern Swedish intensive care, the quality of life during intensive care is affected. Deciding to adapt the strategy and goals of care in this way is called a breakpoint decision. A breakpoint decision often includes decisions about treatment limitations. Treatment limitations in intensive care usually involve decisions to withhold and/or interrupt one or more life-support treatments.

These types of decisions are complex and depend on both the acute and underlying illness, prognosis and ethical and religious values. It is further complicated by the fact that it should take place with shared decision-making between several different stakeholders, different treating physicians, guardians and sometimes the patient himself. How these complex decision-making processes work has been partly studied internationally but not from a Swedish perspective. ²³Given the complexity and the element of cultural values in this issue, the validity of studies from other countries must be considered with great caution.

Purpose

The aim is to explore doctors' experiences of the decision-making process regarding decisions to withhold or discontinue life-sustaining treatment in children cared for in the ICU .

Questions

What is the experience of being the one who participates in decisions to withhold or discontinue life-sustaining treatment?

How does the decision-making process for a decision to withhold or discontinue life-sustaining treatment work? What facilitating or aggravating circumstances are there?

What management strategies can a decision-maker use when different stakeholders have different opinions on an issue?

Method

The questions will be examined through semi-structured individual interviews of doctors who work with children in ICUs . There will be both intensive care doctors and doctors from other specialties, pediatricians in particular. Recruitment will be carried out by contacting the four pediatric clinics in Sweden and seeking volunteer study participants. At the same hospital, the pediatric clinics will also be contacted to get in touch with volunteers. Recruitment will then take place with repeated contact and snowballing , with interviewees helping with the recruitment.

An interview guide will be designed and a pilot on three people will be conducted for validation. The interview guide will then be updated.

The interviews will be conducted on link with verbatim transcription using speech recognition that will be corrected by the interviewer directly in connection with the interview. Analysis will be done in Nvivo ®with Qualitative Content Analysis according to Granhem and Lundman, based on narrative theory.

Importance

Knowing the attitudes of intensive care physicians towards and experiences with decisions to withhold/withdraw life-sustaining treatment in children is a first step in understanding the process behind this type of decision. From international literature, we know that ⁴complex decisions regarding life-sustaining treatment have variability between centers that cannot be explained by purely medical quantitatively measurable values. It is an assessment of many factors where not everything is easily measurable, which results in variability in the decisions that can be linked to which center the patient is cared for at. It has also been shown that this variability affects survival. The process leading up to these decisions needs to be studied in more detail in order to better describe and understand the qualitative values that influence the process. Even if the patient group is small, their quality of life, access to palliative care, the right to decide about their final days and in a few cases, it can affect the availability of organs for transplantation activities by how and when decisions of this type are made.

¹Swedish Intensive Care Register <https://portal.icuregswe.org/utdata/2013-2023>

² Zhong Y, Cavolo A, Labarque V, Gastmans C. Physician decision-making process about withholding/withdrawing life-sustaining treatments in pediatric patients: a systematic review of qualitative evidence. *BMC Palliative Care*. 2022 Jun 24;21(1):113. doi : 10.1186/s12904-022-01003-5. PMID : 35751075; PMCID : PMC9229823.

³ Zhong Y, Cavolo A, Labarque V, Gastmans C. Physicians' attitudes and experiences about withholding/withdrawing life-sustaining treatments in pediatrics: a systematic review of quantitative evidence. *BMC Palliative Care*. 2023 Sep 29;22(1):145. doi : 10.1186/s12904-023-01260-y. PMID : 37773128; PMCID : PMC10540364.

⁴ Malhotra AK, Shakil H, Smith CW, Sader N, Ladha K, Wijeysundera DN, Singhal A, Kulkarni AV, Wilson JR, Witiw CD, Nathens AB. Withdrawal of Life-Sustaining Treatment for Pediatric Patients With Severe Traumatic Brain Injury. *JAMA Surg*. 2023 Dec 20 236531. doi : 10.1001/jamasurg.2023.6531. Epub ahead of print. Erratum in: *JAMA Surg* . 2024 Jan 24;: PMID : 38117514 ; PMCID : PMC10733846.