INTRODUCTION

The purpose of life sustaining treatments (LST) is to support and treat vital organ failure so that critically ill patients can return to a meaningful life. However, when the treatment is no longer beneficial for the patient, decisions to withdraw or withhold LST must be considered.\textsuperscript{1,2} This decision-making process is complex and challenging.\textsuperscript{3-6}

A decision to withdraw or withhold LST is based on information about the patient’s medical prognosis regarding acute disease and any comorbidities. Furthermore, the patient’s expected quality
of life after being critically ill needs to be considered. Above that, ethical grounds including the patient’s autonomy, maleficience, beneficence and justice are part of the decision-making process. Variability in end-of-life (EoL) decision-making among intensive care physicians (hereafter called intensivists) has been reported by several authors. Factors such as geographic areas, religions, cultures, juridical matters and the personality of the physician, including attitudes, have been suggested as factors that influence the decision-making.7,8 However, a deeper understanding of conceptions and attitudes in the decision-making process is still to a large extent, lacking. Patient factors that contribute to variabilities in EoL decisions include the patient’s medical condition, the diagnosis, advanced age, poor baseline functional status and female sex.9-17

In Sweden, the Swedish National Board of Health and Welfare stipulates regulations about LST and EoL decisions. Physicians are obliged to (a) respect patient autonomy, (b) consult at least one other health professional with a license to practice, prior to making a decision regarding withholding or withdrawing LST and (c) provide detailed documentation of the reasons for the decision. Furthermore, it is stated that the patient or the patient’s family is to receive adequate information, and it is of particular importance that the physician makes sure that the presented information is understood.18 It is essential that views of other members of the medical team, the patient and the family are taken into consideration. However, in the end, physicians are solely responsible for making the decision.

There are guidelines from the Swedish Association of Anaesthesia and Intensive Care on how to approach decisions regarding limitations on LST (Data S1). The guidelines are readily available online, but it is unclear if they are commonly used in daily practice.

The primary aim of this qualitative study was to address Swedish intensivists’ experiences, beliefs and attitudes regarding the decision-making process pertaining to the withdrawal or withholding of LST. Second, we aimed to identify underlying factors that may contribute to variability in the decision-making process. 

2 | METHODS
2.1 | Study design and setting
This is a descriptive study with a qualitative approach that adheres to the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines.19

Semi-structured interviews with a prepared interview guide consisting of informally grouped topics and questions were chosen as the method for the study. The interview guide was tested in three recorded pilot interviews, and feedback was provided by the other authors. Adaptations were made, and the pilot interviews were excluded from the results.

The study was conducted in general intensive care units in two university hospitals, two midsize hospitals and one smaller county hospital in Sweden. The hospitals were selected to ensure a mix of hospitals of different sizes as well as different ICU levels and geographic locations. No specialized intensive care units (paediatric, neurological or thoracic surgery) were included.

2.2 | Participants
At each of the selected hospitals, the ICU medical director was asked in an informative letter to find four consultants with different levels of experience and genders who were willing to participate in the study. Those agreeing to participate were supplied with further written information about the study. After obtaining signed consent, the interviewer arranged for a face-to-face interview. Seventeen of the nineteen respondents did not know the interviewing researcher, two had only brief professional acquaintance.

2.3 | Data collection
The semi-structured interviews took place from 1 February 2017 to 31 May 2017. During the interviews, a dialogical validation was performed, ie, similar questions were asked in different contexts to ensure that intensivists’ views were fully and correctly captured. The interviews took a median of 49.5 (range 33-68) minutes, and they were all recorded and transcribed verbatim.

2.4 | Analysis
The interview content was analysed based on principles for thematic analysis.20-22 The transcribed interviews were read by all authors. Primarily, the thematic analysis was carried out by two of the researchers (ANS, ÅÅ). During the initial coding process, informative data related to the aim and interest of the study were searched for, such as respondents’ experiences, beliefs, attitudes and illustrative phrases. These “meaning units” were attached by code labels to facilitate the sorting and further analyses. Individual variation, decision-making process, shared responsibility and ethical considerations were examples of codes assigned to data with similar content. Throughout the coding the data were reread repeatedly to refine the analysis. In order to improve the credibility and reliability of the results the whole research group met at three occasions.
Similarities and inconsistencies in the interpretations of the text were discussed and considered in open dialogue. Consensus was reached regarding the themes and presentation of the results.

2.5 | Short description of educational and critical care organization

All intensivists in Swedish hospitals are specialists in anaesthesiology and intensive care. During working hours specialists in anaesthesiology and intensive care with different levels of experience are present. During on-call hours, there are residents and/or specialists in anaesthesiology and intensive care present in the ICU, and there is always a more experienced specialist available for consultation. Organization in participating ICUs did not differ from the organization of other Swedish ICUs.

2.6 | Ethics

Ethics approval for the study was obtained from the Regional Ethical Review Board in Gothenburg, 2016-10-20, reference number 616-16. The study was performed in accordance with the Helsinki declaration.

3 | RESULTS

Nineteen semi-structured interviews with intensivists, nine women and ten men, from five different hospitals were performed. One intended respondent was absent and could not be rescheduled. All of the respondents except two were educated in Scandinavia. The participants had a median age of 43 years (range 35-61) and had a median length of experience as intensivists of 8.5 (range 1-27) years.

The primary aim of this qualitative study was to investigate Swedish intensivists’ experiences, beliefs and attitudes regarding decision-making concerning end-of-life decisions. The main themes that emerged are listed in Table 1.

3.1 | Sufficient information

A majority of the respondents stressed the importance of access to sufficient information to make well-grounded decisions based on adequate knowledge about the patients’ medical history, life situation and treatment preferences. All of the respondents’ main concern was the question of whether a LST could be considered beneficial for an individual patient. Another recurrent opinion emerging from the interviews was that decisions about LST should be a shared responsibility between the intensivists and physicians responsible for the patient outside the ICU, such as surgeons or cardiologists. However, in acute situations, especially during on-call hours, information and possibility to share responsibility are often lacking.

The majority of the respondents stressed the importance of access to sufficient information to make well-grounded decisions regarding withdrawing or withholding LST. However, in acute situations, information is often incomplete or unavailable. This was emphasized as a major factor affecting difficulties and uncertainty, especially for intensivists with less experience. There is a difference between making decisions based on adequate knowledge about the patients’ medical history, life situation and treatment preferences and making decisions with insufficient background information. Thus, the spectrum of the complexity of these decisions ranges from very easy to very difficult.

“Making decisions about life-sustaining treatments varies a lot. Sometimes it is very hard; sometimes it is very easy” (R 5).

The younger intensivists focused a great deal on the possibility of making a right or a wrong decision, with a clearly stated fear of being

| TABLE 1 | Primary aim- main themes that emerged from the interviews in end-of-life decision-making |
|---------|-----------------------------------------------|
| Quote examples | Code examples | Theme |
| “Making decisions about life-sustaining treatments varies a lot. Sometimes it is very hard; sometimes it is very easy” (R 5). | Uncertainty Complexity Well-grounded decisions | Sufficient information |
| “I actually feel that the most difficult part of my job is to decide whether or not the patient should be taken to the ICU at all?” (R5). | Right or wrong decision | Patient beneficence |
| “Decisions on LST for old and chronically sick patients in the wards should not be made by the intensivist in an emergency situation. It is really tiresome to have to assume this role, particularly when on-call” (R 14). | Joint decision Consensus | Shared responsibility |
| “If there is only the slightest uncertainty, it may feel hard to make a decision and therefore one chooses to defer it” (R4). | Lack of continuity Psychological reasons | Deferred decisions |
| “Within a clinic there will be extremes. Someone who is reluctant to make a decision right up to the very last. Someone else who makes decisions prematurely. It depends on the kind of persons we are” (R 14). | Personal variability Diurnal variation | Variability |

Abbreviations: ICU, intensive care unit; LST, life sustaining treatment.
subject to criticism and blame. One respondent, however, expressed a
more complex view of the matter.

“I used to feel like it was all up to my decision, making
it so irrevocable. Now I do not see it like that; it is more
of a process over time and my decision is just a smaller
fraction of the entire process”

(R13).

The fear of criticism was particularly an issue when information
was scarce or the medical prognosis was difficult to predict. In these
cases, several of the respondents preferred for the decision-making
process to be deferred.

Acquiring knowledge of the patient’s own preferences was
considered a decisive component in the decision-making pro-
cess. Many respondents strived for a consensus with the family in
making decisions to withdraw or withhold LST, and conflicts with
family were not a frequent or major problem. However, when they
did occur, they were emotionally demanding and stressful. The
respondents rarely experienced any disputes with nurses when it
came to opinions about LST for individual patients, but many had
experienced that nurses tended to be more critical of continuing or
prolonging LST earlier in the patient’s disease course than were the
intensivists. This was explained by nurses working more closely
with the patients and experiencing moral distress. Moreover, not
being responsible for the decision and its consequences proba-
bly makes it easier to suggest that treatment should be limited or
withdrawn.

3.2 | Patient beneficence

The respondents’ main concern was the question of whether an
LST could be considered beneficial for an individual patient. The re-
pondents expressed that it can be difficult even for an experienced
intensivist to know with certainty whether an individual patient will
benefit from a specific LST. This uncertainty concerning medical
prognosis in individual cases was the core element in ethical con-
siderations concerning the withdrawal or withholding of LST for all
respondents.

Some respondents argued that it is more difficult to withdraw
treatments for patients once they had been accepted into the inten-
sive care unit than it was to not offer patients intensive care at all.

A trend towards treating elderly patients with several comorbid-
ities in the ICU was noticed by the more experienced intensivists. A
majority of the intensivists stated that there was no justification for
treating patients in a high-tech environment such as an ICU for an
extended period if they do not benefit from the treatment.

“I actually feel that the most difficult part of my job is to
decide whether or not the patient should be taken to the
ICU at all”

(R5).

Respondents did not acknowledge variability in EoL decisions
caused by a shortage of beds or resources, although they admitted to
an increased level of stress when resources were scarce.

3.3 | Shared responsibility

A recurrent opinion emerging from the interviews was that decisions
about LST should be a shared responsibility between the intensiv-
ists and physicians responsible for the patient outside the ICU, such
as surgeons and cardiologists. Making joint decisions and reaching
consensus was also considered an important strategy to make well-
grounded decisions.

Several of the intensivists reported that it was common for phy-
sicians from other specialties to have different opinions regarding
whether LST should be withheld or withdrawn at the ICU. Several
respondents claimed that patients were commonly subjected to fu-
tile or unnecessary treatment due to disagreements between the
intensivists and other physicians.

Possible explanations were that other physicians often had deviant
expectations of outcomes and that they tended to focus more on a
particular organ than on the overall clinical assessment of the patient.

Another view that emerged was that sometimes other physicians
had a prior long-standing personal relationship with patients and
families and therefore had a stronger emotional attachment.

A common opinion among the respondents was that physicians
representing other medical specialities in charge of patients suf-
fering from underlying chronic diseases had a responsibility to
consider limitations in LST and to discuss their patients’ treatment
preferences. Criticism was directed at the lack of documentation
regarding limitations in LST in patients’ medical records. For on-
call intensivists, this lack of support from clear documentation
imposed an extra burden and responsibility. Having access to ad-
vanced directives in emergency situations to facilitate the decision
about appropriate level of care for a patient was desired by the
respondents.

“Decisions on LST for old and chronically sick patients
in the wards should not be made by the intensivist in an
emergency situation. It is really tiresome to have to as-
sume this role, particularly when on-call”

(R 14).

3.4 | Deferred decisions

Some respondents experienced that the lack of continuity among
senior intensivists at the ICU was a reason for deferring decisions
and increased the risk that decisions were changed, often drifting
towards a more active strategy. A few comments were made on the
fact that younger patients and patients with complications related
to surgery and other iatrogenic damages may lead to unnecessary
overtreatment in the ICU for psychological reasons.
“If there is only the slightest uncertainty, it may feel hard to make a decision and therefore one chooses to defer it.”

(R4).

3.5 | Variability

The secondary aim of this study was to identify underlying factors that may contribute to variability in the decision-making process. All of the respondents experienced a great deal of variability in the decision-making process. The reasons for the variability could be divided into three main categories; physician-related variability, patient-related variability and circumstance-related variability, listed in Table 2.

Many respondents reported that the intensivist’s personality played a major role in how and when decisions to limit LST were made. In fact, subjectivity and variability were regarded as inevitable. Clinical experience, the ability to communicate, strategies to address inherent medical uncertainty and the level of fear of making a decision that could be challenged by others were examples of explanations as to why personality creates variability in the decision-making process. Some respondents argued that there was generally no reason to question a colleague’s clinical judgement and that different views might even be beneficial when forcing oneself and others involved to clarify standpoints and justify proposals.

“Within a clinic there will be extremes. Someone who is reluctant to make a decision right up to the very last. Someone else who makes decisions prematurely. It depends on the kind of persons we are”

(R 14).

Patient-related factors for variability in EoL decisions were mainly described as medical prognostication, age and patient’s preferences. Furthermore, all respondents recognized variability in how decisions were processed during working hours compared with on-call hours.

The variability was generally accepted and explained by the lack of competence and experience among the physicians on call at the hospital and the lack of sufficient support from their senior colleagues.

4 | DISCUSSION

Swedish intensivists’ experiences, beliefs and attitudes emerging from the interviews showed that intensivists wish to make EoL decisions that are well-grounded, based on sufficient amounts of information and based on a medically certain prognosis. Furthermore, there is a wish for consensus with the patient, family, staff and other intensivists.

The main ethical question was whether or not a particular LST is in the patient’s best interest. Further, the intensivists stressed that an EoL decision should be a shared responsibility between intensivists and other physicians responsible for the patient. A general opinion was that EoL decisions were processed differently during working hours compared to on-call hours.

Unfavourable circumstances for EoL decisions were concurrently scarce information, uncertain medical prognosis and lack of consensus. Furthermore, not knowing the patient's preferences was considered a major factor in complicating the decision-making process. There was also a clear frustration among intensivists when forced to make EoL decisions for rapidly deteriorating, hospitalized patients with far advanced chronic diseases.

In our study, younger intensivists involved in decisions regarding withholding or withdrawing LST generally discussed these questions from a "wrong or right decision" perspective. The respondents were worried about making a decision that could be challenged by others and stressed that preferably these decisions should be made with

| Factors contributing to variability in EoL decision-making | Improvements suggested by the respondents |
|----------------------------------------------------------|-------------------------------------------|
| Physician-related                                        | • Personality of the physician            |
|                                                          | • Communication skills                    |
|                                                          | • Clinical experience and competence      |
|                                                          | • Occurrence of iatrogenic damage         |
|                                                          | • Fear of criticism                       |
|                                                          | • None                                    |
| Patient-related                                          | • Medical prognostication                 |
|                                                          | • Age                                     |
|                                                          | • Preferences                             |
|                                                          | • Patients with chronic diseases should be given the opportunity to discuss their preferences prior to deterioration |
| Circumstance-related                                     | • On-call hours                           |
|                                                          | • Support from senior consultants         |
|                                                          | • Location (ward, emergency department, ICU) |
|                                                          | • Continuity by senior intensivists       |
|                                                          | • Improve continuity of attending senior consultants |
|                                                          | • Daily formalized small conferences      |
|                                                          | • Distinct and visible documentation      |

Table 2 Secondary aim- factors contributing to variability in EoL decision-making and improvements suggested to reduce variability

Abbreviations: EoL, end-of-life; ICU, intensive care unit.
as much information as possible and in shared consensus with other physicians.

Respondents conceded internal conflicts when decisions were about younger patients and patients with iatrogenic damage, which is in line with the results of other studies. Responses did not acknowledge variability in LST decisions caused by a shortage of beds or resources, although they admitted to ethical stress when resources were scarce. This is inconsistent; the ethical stress, recognized by the respondents, implies that a shortage of resources may have some impact on EoL decision-making, as previously reported by several other authors.

Underlying factors that may contribute to variability in the decision-making process can be summarized as consisting of physician-related factors, patient-related factors and circumstance-related factors. Nearly all of the respondents emphasized that there is a large variability in decision-making that primarily depends on the intensivist’s personality, which is in line with the results of previous studies. Generally, this was not considered a problem by the respondents. The unquestioned acceptance concerning the recognized impact of personality and preferences of the individual intensivist on EoL decisions found in this study have previously been described as problematic.

The recognized impact of personality and preferences of the individual intensivist on EoL decisions, and that only few of the respondents asked for a more structured approach needs further investigation.

The attempt to ensure diversity among the respondents in terms of gender, experience, education, geographic locations and ICU level strengthens the credibility of this study. The fact that all interviews were conducted by the same person during a period of four months eliminates to some degree, the possibility for data to change over time, and the consistency in answers given by the respondents provides some support that the opinions derived can be transferable to other Swedish intensivists.

We have made an effort to achieve trustworthiness by presenting our findings in a way that makes transferability possible. We believe that our findings could be applicable or generalized to other intensivists in Sweden.

However, in a qualitative study such as this, the opinions and thoughts presented originate from the interviews performed. It is also nearly impossible to eliminate the interviewer’s and the respondent’s impact on each other in each interview. Two of the respondents had brief professional acquaintance with the interviewer which may have caused some bias.

5 | CONCLUSION

The conclusion of this study is that Swedish intensivists’ wish to make EoL decisions based on sufficient amounts of information, a medically certain prognosis and in consensus with the patient, family, staff and other physicians. Furthermore, Swedish intensivists experience a great deal of variability in EoL decisions. The variability is generally accepted and not questioned.

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CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

AUTHOR CONTRIBUTIONS

Alma Nordenskjöld Syrous participated in planning, analysing, manuscript writing and conducting all of the interviews. Anders Ågård participated in planning, analysing and manuscript writing. Maria Kock Redfors participated in planning, analysing and manuscript writing. Silvana Naredi participated in planning, analysing and manuscript writing. Linda Block participated in planning, analysing and manuscript writing.

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**SUPPORTING INFORMATION**

Additional supporting information may be found online in the Supporting Information section.