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Shared Decision Making in the ICU from the perspective of physicians, nurses and patients: A Qualitative Interview study

Nina Wubben, MSc[1], Mark van den Boogaard, RN, PhD[1], Johannes G van der Hoeven, MD, PhD[1], Marieke Zegers, PhD[1]

1. Radboud university medical center, Radboud Institute for Health Sciences, Department Intensive Care, Nijmegen, The Netherlands

Corresponding author: Dr Marieke Zegers

Institution where work was performed: the Department of Intensive Care Medicine of the Radboud University Medical Center in Nijmegen, the Netherlands.

Author email addresses

Nina Wubben nina.wubben@radboudumc.nl

Mark van den Boogaard mark.vandenboogaard@radboudumc.nl

Johannes van der Hoeven hans.vanderhoeven@radboudumc.nl

Marieke Zegers marieke.zegers@radboudumc.nl

Abstract

OBJECTIVE To identify views, experiences, and needs for Shared Decision Making (SDM) in the ICU according to ICU physicians, ICU nurses, and former ICU patients and their close family members.

DESIGN Qualitative study.

SETTING Two Dutch tertiary centers.

PARTICIPANTS 19 interviews were held with 29 participants: seven with ICU physicians from two tertiary centers, five with ICU nurses from one tertiary center, and nine with former ICU patients, of whom seven brought one or two of their close family members who had been involved in the ICU stay.

RESULTS Three themes, encompassing a total of 16 categories, were identified pertaining to struggles of ICU physicians, needs of former ICU patients and their family members, and the preferred role of ICU nurses. The main struggles ICU physicians encountered with SDM include uncertainty about long-term health outcomes, time constraints, feeling pressure because of having final responsibility, and a fear of losing control. Former patients and family members mainly expressed aspects they missed, such as not feeling included in ICU treatment decisions and a lack of information about long-term outcomes and recovery. ICU nurses reported mainly opportunities to strengthen their role in incorporating non-medical information in the ICU decision-making process and as liaison between physicians, and patients and family.

CONCLUSIONS Interviewed stakeholders reported struggles, needs and an elucidation of their current and preferred role in the SDM process in the ICU. This study signals an essential need for more long-term outcome information, a more informal inclusion of patients and their family members in decision-making processes, and a more substantial role for ICU nurses to integrate patients' values and needs in the decision-making process.

Keywords: Shared decision-making, Qualitative study, Interview study, Family, Patient experiences, Critical Care

Strengths and limitations of this study

- Strengths of our study contain the inclusion of diverse samplings of the three major stakeholder groups for SDM in the ICU, and interviews were held until data saturation was reached
- Thorough analysis lead to the identification of three overarching themes and corresponding categories
- A limitation is that clinician participants were recruited from two tertiary centers
- Views and articulations of experiences are influenced by culture and should be verified in more international qualitative studies

Background

Shared decision-making (SDM) has been endorsed as the most ethical and appropriate decision making approach (1, 2). SDM is defined as a cooperative process between clinicians and patients and, often in the Intensive Care Unit (ICU), their surrogates that enables a way of healthcare decision making that combines both the clinician's expertise as well as the patient's values and healthcare goals (3, 4).

SDM in the ICU is recommended when defining the overall goals of care and when making major treatment decisions that are preference-sensitive (2). The SDM process should contain as its three main ingredients information exchange, a deliberation period and making an eventual treatment decision. Research has shown that interprofessional SDM between physicians and nurses is associated with more accurate prognoses, reduction of moral distress and a more resilient team (5-9), signaling a need for a defined space for nursing staff along with physicians and patients and surrogates as the three pillars of ICU decision-making.

Though SDM has received a lot of attention by healthcare policy makers as a proponent of a patient's right to self-determination, there is a lack of evidence for associations between SDM interventions and patient outcomes (10, 11). Moreover, its implementation in healthcare settings is oftentimes not without difficulty. There is enormous diversity in care practices influenced by workplace culture and practice style (12, 13). Clinicians also interpret guidelines differently, and subsequently do not always follow the recommendations when it comes to information provision (14, 15). In practice, families might not be seen as decision-makers but rather as informants who should be protected from feeling responsible for choices made for a loved one (3).

While patients and families and clinicians do not always agree when it comes to treatment decision making (16), making family members feel involved in ICU care and treatment decision-making has been shown to reduce fear and anxiety and prepares them in aiding patients during their recovery process (17-21). SDM also increases the likelihood of patients forgoing aggressive care (22). SDM interventions are able to improve families' ratings of quality of communication and shorten the ICU length of stay (23).

By elucidating the views of the three main SDM stakeholder groups in current ICU care, it is possible to elaborate on current ideas about when to incorporate patient and family preferences, when these preferences should be overridden by clinicians and how clinicians can improve their own interprofessional SDM (5, 24-26). Therefore, the aim of this study was to explore the views, experiences, and needs for SDM in the ICU according to ICU physicians, ICU nurses and former ICU patients and their close family members.

Methods

Study design and setting

This is a qualitative interview study carried out between June 2019 and January 2020 in two tertiary centres. The Consolidated Criteria for Reporting Qualitative Studies guidelines for the design and analysis of this interview study were followed (27) (See: Supplementary material 1).

Participant sampling

Three groups of participants were interviewed: ICU physicians, ICU nurses and former ICU patients and their close family members. Physicians and nurses were approached within the professional network of the authors (MvdB and MZ), and were sampled purposively to ensure a variety in demographic and professional characteristics. Former ICU patients and their family members were reached through appealing to patient association volunteers, as well as an advertisement on the ICU patient association website (www.fcic.nl).

Patient and Public Involvement

Former patients and family members were involved in the preparatory phase of this study. Patient organization board members and the audience members of a patient organization symposium were asked for input into the topic of SDM in the ICU, which informed the development of the two semi-structured topic guides used in this study (See: Supplementary material 2). Interview participants responded to an advertisement on the ICU patient organization website.

Data collection

All interviews took place face-to-face in either of the two tertiary centres. Two researchers conducted the first interview (MZ and NW). All subsequent interviews were conducted by one researcher (NW). Both researchers are trained to conduct interviews and execute interview analysis. The main interviewer did not have established relationships with any of the interviewees before study commencement. Interviewees were asked to take part in an interview about ICU (shared) decision-making. The interviewers had not conducted qualitative work regarding this topic before.

The two topic guides were applied to ICU clinicians and former ICU patients and their family members, respectively. Topics in both guides included experiences with SDM in the ICU, wishes for its expansion in the ICU and changes necessary to achieve this. The translated topic guide can be read in Supplementary materials 3 and 4. Data was collected until data saturation was reached. Transcripts were not returned to participants for comment.

Data analysis

All audio recordings were transcribed verbatim by an external professional party, and subsequently coded using a grounded theory approach, where categories, themes and codes were derived through the analysis of the data. Coding is an interpretative process in which conceptual labels are assigned to data (28). Two researchers (NW and MZ) coded four interviews independently, before discussing and agreeing upon a coding framework. NW then applied open coding to the remainder of the transcriptions under supervision of MZ. Data analysis was performed using Atlas.ti software.

Ethical approval

The study was approved by the research ethics committee of the Radboud University Medical Center, CMO region Arnhem-Nijmegen (number 2020-6306). Participant information and an invitation for the interview were sent in reply to an informal consent to an interview via e-mail. Additional information about participation was given on request either in the e-mail correspondence or before the start of the interview. An informed consent form was signed before the start of the interview.

Results

A total of 19 interviews were conducted with 29 participants: five ICU nurses, seven ICU physicians, nine former ICU patients and eight family members (Table 1). None of the participants dropped out. The interviews took between 30 and 75 minutes. 50% of the ICU clinicians and 41.2% of the former patients and family members were male. Mean age was 47.7 (SD: 2.6) and 57.4 (SD: 3.5), respectively.

Table 1. Participant characteristics

The data analysis resulted in 16 categories from which 3 themes were derived: (I) Struggles of ICU physicians (Table 2), (II) Needs of former patients and family members (Table 3), and (III) the Role of the ICU nurse (Table 4).

Theme I: Struggles of ICU physicians

A total of eight categories (Table 2) were identified in this theme: uncertainty and unpredictability of long-term outcomes; responsibility; unwillingness of patients to participate in decision making; physicians prioritize medical facets; trust in patients and families; physicians fear a loss of control; time; and ‘acting in a treatment mode’ in the case of acute or long-term admissions.

ICU physicians described the uncertainty about long-term health outcomes as one of the main struggles they experienced. They cited literary or anecdotal evidence about unexpected outcomes as a reason for struggling with ICU decision making, such as a patient’s satisfaction with life after losing the ability to walk where they expressed only sorrow at first. They cited feeling the weight of this responsibility when dealing with conflicts with nursing staff about continuing or ending treatment. According to the ICU physicians, these conflicts mainly arise over complex, long-stay patients. While they sometimes were uncertain about continuing treatment themselves, earlier experiences with success stories kept them cautious. They expressed a need for more long-term data on survival and quality of life after ICU treatment.

Several barriers to explore the wishes and needs of patients were discussed. ICU physicians mentioned experiences with patients and families who did not want to involve themselves in the medical decision-making process. Also reported by clinicians and former patients and families was a prioritization of medical facets in discussions leading to less attention for ‘softer’ topics, such as quality of life. Physicians described that these factors often did not come into play unless the patient’s chances of recovery become low. Moreover, physicians applied their own ideas about what constitutes a good quality of life, while not spending enough time clarifying if a certain patient agreed with their interpretation of a good quality of life. ICU physicians also described doubting wishes expressed by patients and their families, again citing literary evidence and anecdotal experiences with patients changing their mind. They expressed doubts about whether patients and families could actually grasp what certain decision in the ICU could lead to in future. They feared that having families be too involved in ICU decision-making would lead to more medically pointless treatment.

Furthermore, the acute setting of the ICU was cited as a struggle in the decision-making process, with the general rush cited as a barrier. A ‘treatment mode’ was described as a rush-driven attitude where physicians do not take enough time to assess whether treatment is still in line with patients’ best interests or wishes.

184 *Table 2. Theme I: Categories pertaining to struggles of ICU physicians*

Category	Codes	Quote
Uncertainty, interpretability and unpredictability of long-term outcomes	Lack of long-term outcome information; More long-term outcome knowledge causes you to stop treatment sooner; Long-term uncertainty limits conversations about continuing treatment	Physician (P): "Overall I think there is an understandable tendency to postpone [decision making about] problems. […] Again, the problem is always that uncertainty. The other day we lost a patient after 6 weeks of treatment. […] On the one hand you can say that we all saw that coming. On the other hand – well, you only know for certain if you've tried it."
Responsibility	ICU physicians have final responsibility; Physician determines treatment plan; Stopping treatment is always an option down the line	P: "Look, eventually we are the ones that have to bring the message to the family when we stop treatment … and that is our responsibility. So for a nurse it is easier to question whether we should continue, whereas we really need to do so based on good and substantial arguments."
Unwillingness of patients to participate in decision making	Certain types of patients don't want to be involved in decision making; Older patients; Family members hold back	P: "[…]especially older people say: no, you've studied for this – I don't know, you tell me. They just put everything back in your hands. You want to have those people decide for themselves but they're not going to."
Physicians prioritize medical facets	Conversations about continuing treatment are difficult when patients are doing badly; Quality of life is a 'soft' topic; Medical point of view takes precedence; Quality of life not a standard part of multidisciplinary discussions; ICU patients' needs center around communication and (non-medical) treatment	P: "Look, in the end we all prefer talking about the fluid balance and CRP levels. That's the truth. So [talking about quality of life] is 'soft' drivel to many people." P: "Of course everyone will agree that [a patient's biography] is an important topic, but it will often end up last in discussions. I think that the medical side, prognosis, chance of improvement, what are possibilities or alternatives, etc. is always first. These things don't come up until you start wondering if [continuing treatment is still proportional]." Former patients and their families (PF): "[patient with very long admission] I've often called it prison. Everything was decided for me. The theme of my illness was losing all sense of control."
Trust in patients and families	Physicians use own interpretation of what constitutes good quality of life; Physicians do not always trust that patients and families know what they want; Physicians know patients can change their minds; Well-informed patients make different choices	P: "What I used to see, and still see a bit – is that we physicians have our own opinions about what constitutes a good quality of life – in other words, what a good outcome looks like. And we do not look at the patient well enough." P: "Things like what would they have wanted, right – […] we know that it's proven in literature that people who did not want a certain situation, that when it actually happened to them, they were happy with that outcome […]. So that information – 'he would never have wanted to end

		up in a wheelchair' or 'he would never have wanted to be dependent', when it happens to you, we are apparently flexible enough in our behaviors and emotions, that we eventually can be very happy, and very happy to be alive. So that information has limited value".
Physicians fear a loss of control	Family or patient wants to continue treatment disproportionally; ICU physicians have final responsibility	P: "[On reasons other physicians might not ask a patient or family's wishes] Not wanting to be surprised with things you might not be able to do. That you're scared of promising something you can't fulfill. It's weird to then not ask the question, but that is a way of doing things. Or fearing totally irrational wishes from people."
Time	Admission rush or other time constraints limit conversations about treatment wishes	P: "The limits are mostly put on by time and space. Sometimes you have a really busy day so you don't have time for it. Then you need to cut back a little on those conversations, because there isn't any time."
'Treatment mode' in acute settings	Treatment mode limits conversations about treatment wishes; Stopping treatment is always an option down the line; To admit at all or to discontinue treatment;	P: "At the same time it's easier for me to intubate, […] to start renal replacement therapy – far easier than not starting treatment. So I think that's an important point. […] Sometimes we use the multidisciplinary discussion to say to each other: are we really still on the right track? […] And then you sometimes get one-liners like: 'You can always stop [treatment], the patient can always say that they don't want it like this [at a later stage]." P: "I'm convinced that people have an interest in being told there is a chance of an unfortunate outcome. […] I think it's also to do with that many physicians, due to their nature, are in 'treatment mode', and principally still want to treat. Stopping treatment is not a standard reflex of the average physician."
Abbreviations: N = ICU Nurse, P = ICU physician, PF = Former ICU patients and their family members		

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Theme II: Needs of former patients and family members

Four categories (Table 3) were identified within this theme, including: a holistic approach; feeling included in the medical process and knowing what's coming; information about long-term outcomes; and communication between medical staff and patients and families.

Former ICU patients and their families described an overwhelming satisfaction with medical care. Their needs centred around how they remembered being treated in a broader sense. They reported sometimes struggling with lingering feelings and memories. Some recalled feeling seen as a condition rather than a human being, which caused them to feel helpless during their stay.

While some had no additional needs with regards to their part in the ICU decision-making process, others' needs focused on two areas: being made to feel included in everyday decisions, and being better prepared for their recovery post-ICU.

Former patients also reported a sense of lack of control about their ICU care. They expressed that this might have been different if they had felt more included in the decision-making process by being explained why things were being done to them. Especially during longer stays they cited a frustration with their sense of lack of control regarding their schedule in the ICU that they did not experience once leaving the ICU. Some felt that more integration between the medical and 'human' side was needed. For example, being explained exactly why inserting a catheter was necessary instead of feeling like the insertion was a foregone conclusion. They cited that *feeling* heard and included was the most important factor, rather than having an equal hand in every and all decisions.

Moreover, they described that the long road to recovery post-ICU was sometimes unexpected and they expressed a need for more information. This did not only pertain to physical recovery, but to mental health and emotional recovery and issues regarding returning to the workforce as well. They described different levels of received aftercare post-ICU, and the difference it had made to their recovery.

209 *Table 3. Theme II: Categories pertaining to the needs of former ICU patients and their close family members*

Categories	**Codes**	**Quotes**
A holistic approach	ICU patients' needs center around communication and (non-medical) treatment; Little attention for the human behind the condition; Physician coming to sit next to you to ask you how you are	PF: "Treating me as a human being instead of a patient with some mystery illness – yes, I would have appreciated that very much, especially now looking back." PF: "Being nicer to you. I've heard it from many patients. There are very little things someone does when maybe having a bad day at work, but for a patient in such a situation – that's not normal for you. So those are things that you remember months later, while the nurse probably doesn't think about it at all."
Feeling included in the process and knowing what's coming	Communication needs: knowing what's coming; Conversations about shared decision making are physician-driven; Patients and families lack a feeling of control	PF: "Well, it all happens to you. I think that happens a lot in the ICU, because most of the time things aren't planned, so things happen. […] But if you wanted to optimize it, in my experience, you can tell people: what are you doing, why are you doing it. Even if people are half-conscious, you don't know what they will remember. I think they are very much in a 'state of doing'."
Communication between medical staff and patients and families	ICU patients' needs center around communication and (non-medical) treatment; Patients and families lack a feeling of control; No attention for the family	PF: "I've noticed that the physicians mainly focus on getting better, while you're still in a completely different phase. Coordinating those views, I think that's very healthy. The medical part – they have to decide and give you choices and options, but the human part you have to coordinate together because otherwise I won't understand your decision at all. […] And at some point you think: well, whatever, do it, but if you don't agree mentally and you feel so weak – I don't think that's good for your physical recovery."
Information about long-term outcomes	Needs for long-term information; Information regarding recovery; Answers to standing questions; Well informed patients decide differently; Better information provision leads to better outcomes	PF: "My feeling about the ICU is – the onus is on quick action, and survival. But then there is a long road afterwards and I think there should be more attention to that. Like a conversation with the partner, or whoever, someone close to the patient to say: what is important for the patient down the line?" PF: "Now I've noticed that the better the aftercare, the better your recovery." PF: "Afterwards it's worse, it seems like. Then it really gets through to you how bad it could have been – and then immediately how good it has been that you've managed to prevent that."
Abbreviations: PF = Former ICU patients and their family members		

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Theme III: The Role of ICU nurses

Four categories were identified within this theme: the role of the ICU nurse being a liaison and translator between the physician and the patient and their family; questioning ICU physician's decisions to continue treatment; difficulties in communication between physicians and nurses; and offering non-medical information to complement ICU decision-making.

Within ICU decision-making, ICU nurses were generally focused on their communication with ICU physicians. They described functioning as a liaison between ICU physicians and patients and their families, mainly due to their continuous presence at the bedside. Both physicians and nurses described the role of the nurse as an advocate for the social context and needs of patients and their families to physicians, as well as a translator of the sometimes difficult medical 'speak' of physicians. Some nurses reported that they used this role to compensate for the variety in physician communication skills with patients and families.

Nurses reported being able to provide context for physicians to incorporate in medical decision-making by giving their insights in the patient and family situation. They generally felt listened to, even if their more holistic points of view were not always incorporated in the eventual medical decision. However, in non-complex, everyday cases, they were generally not troubled by this. They noted difficulties in communication between their two professions depending wholly on the various types of physician and nurse. Assertive nurses made sure their voices were heard, but acknowledged that not all of their colleagues have this capability.

Conflicts arose in situations of complex patient cases being in the ICU for a prolonged period of time. These struggles centred around continuing or ending treatment, with physicians oftentimes advocating for the former, while nurses want the latter. They felt this was mostly due to being more affected by complex, poignant cases, due to their continuous presence at the bedside. Within this context they reported feeling not being taken seriously and feeling blindsided by decisions being made in multidisciplinary meetings dominated by physicians. They felt frustrated with the returning nature of this type of conflict. They urged bridging the gap between physicians and nurses through team-building, moral deliberation and sharing vulnerabilities about treatment doubts.

Table 4. Theme III: Categories pertaining to the role of ICU nurses

Categories	Codes	Quotes
Liaison and translator between physician, and patient and family	Nurse is eyes and ears of the physician; Nurse translates medical world for patient; Nurse makes sure information is clear after a family conference; Sharing vulnerabilities can improve communication between clinicians	ICU Nurse (N): "Then after the family conference, you let it sink in, and you start repeating it and repeating it. And you try to use the same words as the physician – because I've noticed families say: I think it's so difficult, one says this and the others says this – but that's because [families] don't understand." P: "What kind of support we need, how the family is doing, how the patient is doing, sleeping, pain – there are a lot of things they have a lot of insight about, yes." P: "Where I see the nurse is […] as a translator of what the patient was like at home, who are they, what type of person were they, what is their social safety net like […]. That information is very valuable […]. So I think that their added value is in the clarification of the social context." N: "That is kind of the role we take on: [translating the family's wishes for the physicians."
Incorporating non-medical information in ICU decision-making	Nurse provides social and empathetic point of view; ICU nurse is at bedside for 24 hours a day; Talking about it when something doesn't feel right; Nurse participation in conversation depends on how assertive they are	N: "Yes – [nurses] think it's important to be of value in decision moments. Continuing or not, you know. Of course you need to do so based on medical information, but also based on the holistic view, and I think we should play a larger part in that, because we also know the family really well." N: "I think generally it is a very medically-focused decision-making process in which the nurse is heard and listened to […] but I don't think we have that big of a share in the eventual decision."
Difficulties in communication between physicians and nurses	Cooperation with nurses; Discrepancy of opinion between ICU physicians and nurses regarding end-of-life care for complicated cases; Nurse doesn't feel welcome in multidisciplinary meeting; ICU nurse feels like they are not being taken seriously	P: "There are nurses that are well spoken and they'll tell you their stuff. They are there, but they are a minority. Plus, they won't always say it to everyone, because they know some [physicians] won't listen." N: "Then the next day there was a new [intensivist] that didn't know the patient, but I had been at the bedside the entire day, so I told them [what the previous intensivist and I had decided]. [Then they said:] 'Well, that wasn't communicated with me, I don't agree with you, we won't do it'. So then you're not heard."

Questioning physician's decision to continue treatment	Conflict arises around complex patients who are at the ICU for a long time; Medical point-of-view takes precedence; Whether nurse's point-of-view is heard depends on which physician is on shift	N: "We often feel that when the patient is there for a very long time, and we see them deteriorating – the physicians often think: we can try this and we should approach them, maybe they know something – and then we think: should we do all of this?" N: "I think: there are limits. Sometimes it's enough. If you've done everything – you shouldn't stop based on emotions […] but other times I think: [recovery]'s just not going to happen.
Abbreviations: N = ICU Nurse, P = ICU physician		

Overall, clinicians were focused on the struggles with implementing SDM in critical care practice. The cited the practical difficulties surrounding end-of-life decision making, the formal necessities for SDM and their role in it. Patients and their family members offered a different perspective on incorporating SDM. Their unmet needs were mainly focused on wanting a more holistic approach characterized by an open style of communication wherein they continuously feel part of the decision-making process, albeit not at the helm. Nurses spoke of their current role in the SDM process, and where they felt they could contribute more but where inconsistently listened to (Figure 1).

Figure 1. ICU physicians mainly spoke of struggles with implementing SDM in the ICU, while patients and families elaborated on their needs, and ICU nurses talked about how their current role in the ICU decision-making process could be improved.

Discussion

This qualitative interview study explored the views, experiences, and needs for SDM in the ICU experienced by ICU physicians, nurses and former patients and their family members. Interviewees reported struggles, needs and an elucidation of their current and preferred role in the SDM process in the ICU.

ICU physicians mainly associated SDM with struggles, such as the uncertainty of the future disease course and feeling pressure because of having final responsibility. They also reported several barriers that prevented them from open communication about wishes of patients or proxies, such as a fear of losing control of the situation. ICU patients and their families reported unmet needs with regards to communication and general (non-medical) treatment, wanting to continuously feel included in the ICU decision-making process, not just during formal meetings. ICU nurses drew a clear picture of their role in the SDM process as a liaison between the physician and patient. They translate medical jargon for patients, and advocate for patients' needs and wishes in the decision-making process. They reported communication struggles with physicians that limited a more balanced decision-making process, in which nurses provide physicians with more information about the wishes and needs of patients.

Earlier literature into the subject shows a focus on decisions pertaining to end-of-life (15, 29-31). This decision is sometimes viewed as one of the main and most difficult decisions to be made in the ICU, so much so that clinician interviewees oftentimes presumed it to be the natural focus point of the interview. Consistently, there was a variety of interpretations regarding what SDM in the ICU looked like. This signals a possible need for training and role models (15, 32, 33) to improve both clinician-patient and interprofessional understanding and execution of SDM.

In earlier literature it is reported that a significant part of patients and family members might not be willing to participate in the decision-making process (34). This was reflected in our sample too: not all interviewees had additional needs with regards to decision-making. The needs that were reported here bear some similarities to literature into patient palliative care preferences: mainly, value-focused care aimed at preserving the patient's sense of personhood (35). An ICU-based study aimed at improving communication between families and physicians has noted the importance of family members feeling involved in informal physician interactions as well as larger formal ones to establish their role in the decision-making process and improve family empowerment (36). Patient and family empowerment through information provision and awareness of the presence of choices are necessary ingredients to improve patient involvement in ICU decision-making (37).

The findings in this study pertaining to the struggles of physicians confirm findings in earlier studies, especially the difficulties surrounding end-of-life decision-making and the resulting communication struggles between physicians and nurses (14, 29, 38). Clinicians appeared hesitant to surrender control of the decision-making process due to their past experiences, as well a lack of trust in the understanding of the situation exhibited by the patient and family members. The unavailability of long-term outcome information around survival and quality of life was important to their hesitance in starting conversations around decision-making. Though long-term outcome data collection in the ICU has its challenges (39), there is an increase in big data initiatives to tackle the current gaps in knowledge (40).

Communication struggles reported mainly by the ICU nurses pertaining to decisions to limit treatment have been documented before and appear widespread (41, 42). Nurses have been described to detect any type of ICU conflict quicker than physicians (43), and these conflicts can lead to augmented levels of stress in nurses (44). This again signals an urgent need for training to improve interprofessional collaboration and communication, perhaps through more frequent moral deliberation meetings (45). As was reported in previous literature, the levels of their involvement in ICU decision-making processes were variable and depended on assertiveness and the type of physician on call (46). It therefore follows that the information about patient context and background cannot always be sufficiently imparted, though research has shown that nurse involvement in ICU decision-making improves both patients' and nurses' satisfaction-of-care (47). To equalize the instances of nurse involvement and provide nurses with a more consistent opportunity to provide their knowledge, it may be beneficial to increase and better define their role during decision-making moments, such as during patient handovers, bedside rounds and multidisciplinary meetings.

To ensure a more complete understanding of the complexities of an ICU stay, general practitioners could play a part in information provision to patients and family members in an environment not yet defined by quick action (48), while also being able to provide ICU clinicians with context information about the patient. With the large variety in staff attitude to SDM in the ICU, and the interventions surrounding education, prioritization and resource (re)allocation needed to further implement SDM, the organization at large should play a role in guideline development and setting a work standard involving SDM (49, 50).

This study offers further elucidation of reasons for the variable levels of uptake of SDM in the ICU. It is a further step towards implementation, paving the way towards a more satisfactory exchange of values between all three stakeholder groups to make preference-based decisions. A strength of this study is the inclusion of all three major stakeholder groups.

Our study has several limitations. Though our sample size may be regarded as small, the number of interviews in this study is more than the number suggested by Guest et al (51). The findings of qualitative research need to be verified for frequency of occurrence in larger samples through questionnaire research. Moreover, our focus on two tertiary centres as the main source of interviewed clinicians, may have skewed the results. However, our findings are in accordance with literature as well as with the preparatory data collected from ICU clinicians and former patients and family members at the national patient organization symposium (Supplementary material 2). Lastly, views and articulations of experiences are influenced by culture. More studies concerning all three main stakeholder groups from different cultures can be a way of elucidating whether the concepts described here are universal or if there are more or different themes.

Though ascertainment of the frequency of these findings might be necessary, the similarities of these results to the literature and preliminary data collection embolden us to say that to further improve SDM implementation there is a need for:

- A more continuous role of patients and family members in ICU decision-making, as individually desired and ascertained
- Long-term, specific outcome information about survival and quality of life to support SDM discussions
- A more substantial role for the ICU nurse to ensure their imparting of knowledge about patient context and background during handover meetings, bedside rounds and the multidisciplinary meetings
- Interventions to improve communication between the three stakeholder groups, such as moral deliberation, interprofessional collaboration, and the involvement of the general practitioner

Conclusions

In the ICU, necessary steps should be taken to implement SDM in a way that satisfies physicians, nurses and patients and their family members. This study gives several recommendations to ensure that all three stakeholder groups can fulfill their role in the SDM process. All in all, there is an essential need for more long-term health outcomes, a more informal inclusion of patients and their family members role in decision-making processes, and a more substantial role for the ICU nurse to systematically integrate patients' values and needs in the decision-making process. There is a need for interventions that tackle the communication struggles between the three stakeholder groups.

Declarations

Competing interests

The authors declare that they have no competing interests.

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Authors' contributions

NW, MvDB, HvdH and MZ contributed substantially to the conception of the work. Each author contributed substantially to the design of the work. NW, MvdB and MZ contributed substantially to the acquisition and analysis of the data. Each author contributed substantially to the interpretation of the data. NW drafted the manuscript. Each author contributed substantially to the revision of the work.

Each author approved the submitted version. Each author agrees to be personally accountable for the author's own contributions and to ensure that questions related to the accuracy or integrity of any part of the work, even ones in which the author was not personally involved, are appropriately investigated, resolved, and the resolution documented in the literature.

Availability of data and materials

The data used and/or analysed during the current study are available from the corresponding author on reasonable request.

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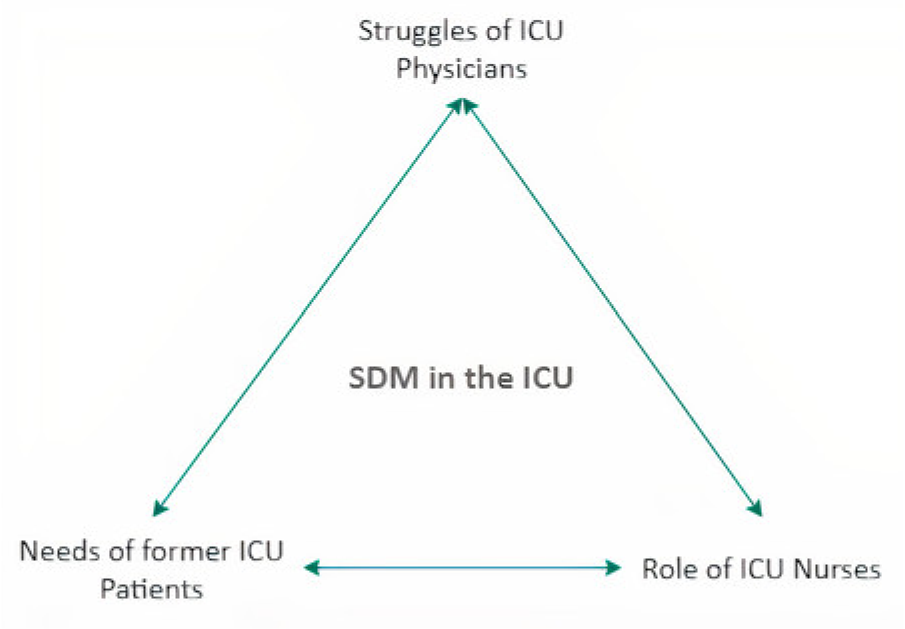

Figure 1. ICU physicians mainly spoke of struggles with implementing SDM in the ICU, while patients and families elaborated on their needs, and ICU nurses talked about how their current role in the ICU decision-making process could be improved.

38x26mm (300 x 300 DPI)

Supplementary Materials

Supplementary material 1: COREQ Checklist

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	4
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	1
Occupation	3	What was their occupation at the time of the study?	1
Gender	4	Was the researcher male or female?	1
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Relationship established	6	Was a relationship established prior to study commencement?	4
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Domain 2: Study design			
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Non-participation	13	How many people refused to participate or dropped out? Reasons?	6
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Transcripts returned	23	Were transcripts returned to participants for comment and/or correction?	4
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	5
Description of the coding tree	25	Did authors provide a description of the coding tree?	-
Derivation of themes	26	Were themes identified in advance or derived from the data?	4
Software	27	What software, if applicable, was used to manage the data?	5
Participant checking	28	Did participants provide feedback on the findings?	4
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	7-14
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Supplementary material 2: Preliminary data collection used to develop Topic guide.

Table 1. Preliminary data inventory used to develop Topic guide. Data was collected at the ICU patient organization symposium, following the authors' presentation about SDM in the ICU. The audience, consisting of ICU physicians, ICU nurses, and former patients and their family members, were asked to write down their views on what was needed and what they saw as barriers to implementing SDM in the ICU. Notes were received from 54 individuals. The information was categorized in six topics. Some factors were mentioned multiple times.

Category	**Quotes**
Time	'Often there is a lack of time in acute settings' to properly talk, listen and explain. This is necessary to really talk though the consequences of certain choices.' 'No time to sit with patients or surrogates before treatment starts' 'As a clinician I expect there to be space for conversation regardless of the point in time'
Factors pertaining to Patients and surrogates	'More human, less patient' 'How did the patient function before admission?' 'What do the patient and family want? How far do they want to go?' 'But what if the patient is sedated?! Permission needed to share decision-making in their place.' 'Jump from ICU to home is large. Care is taken care of by GP, but they aren't specialists..' 'Don't just monitor the patients' QoL, but the entire family's!' 'In order to share decision-making you need access to the medical dossier and visit patient whenever.' 'Being involved in assessment emotions and mental health symptoms of patients' 'Being allowed to share care to a degree.' 'Direction: it happens to you, but you can't steer. You're dependent on everything.' 'Trust, equality, being taken seriously.' 'Surrogates' knowledge about what the patient truly wants.' 'Talk through resuscitation preference.'
Factors pertaining to clinicians	'A multidisciplinary meeting with different medical specialists about recovery possibilities.' 'Explain where possible before admission. When admission is planned, in the outpatient clinic.' 'Talk about a possible ICU admission with the GP before it happens.' 'Talk about treatment limitations before ICU admission' 'Physician who dares to discuss difficult topics' 'Nurses can talk through things with patients and families beforehand, as a bridge toward the physician. Physicians have to be open to this information' 'More information about who the patient is as a human being before they were admitted' 'When a patient is transferred, this is about more than just medical facets. Also: rehabilitation, GP, etc.' 'Trust that we act in the patient's best interests.' 'Ethical or moral deliberation in the ICU.' 'Passionate clinicians who value SDM.' 'As a topic to nurses' education.'

	'Keep remembering that as a physician you should not put the responsibility at the family members' feet' 'Clinician expects: don't force it.'
Organizational factors	'More attention for Post-ICU Syndrome in all facets of the organization.' 'One person as the main communicator, or communication and information coach' 'A truly multidisciplinary conference: social, psychological and medical. Maybe even with family members.' 'Clear, shared vision about SDM in entire team.' 'Acknowledge the importance of SDM.' 'Knowledge within treatment team about communication to and between patients and family members.' 'Practical tips, courses and education'.
Information	'Patients and family members need good information about prognosis and treatment possibilities to decide. Also: how can you provide personalized information, while keeping cultural background, health skills, etc. in mind' 'Clarity about the consequences of some choices, what are the consequences of not treating, what will and won't you choose' 'Clear explanations about the current situation' 'Long-term data.' 'Use social workers.' 'Information in the outpatient clinic.' 'Information about wishes, expectations, pre-existent functioning – this only comes up later in the treatment trajectory instead of at the start' 'Patients and family members need a prognosis to examine whether treatment is in line with wishes and expectations for QoL' 'Explanation: what does an ICU-admission entail?'
Miscellaneous	'Not going to the ICU does not always equal stopping treatment. Palliative sedation is treatment too.' 'Not resuscitating does not mean there is no treatment happening.'

Supplementary material 3: Clinician Topic Guide

- Can you describe the current process of ICU-admission and treatment? What is your role in this process? Can you name an example of your experiences with these processes?

- How do you experience the degree of involvement of ICU nurses in the ICU decision-making process? Can you name an example of your possible experiences with involving the ICU nurse in the ICU decision-making process? Should the ICU nurse have a bigger role in the ICU decision process? Why?

- How does the multidisciplinary meeting contribute to the ICU decision-making process? Can its current role be improved upon?

- How do you experience the degree of involvement of patients and family members in the ICU decision-making process? Should they be involved more? What would the advantages and disadvantages of involving them more be? What is needed in order to involve them more? What information is important and needed to allow patients and their family members to share in the decision-making process?

Supplementary material 4: Former patient and family member Topic Guide

- Why were you admitted to the ICU? Can you describe the period of admission for me?

- How were decisions regarding ICU admission made? Who was consulted? Were you involved in these decisions? Can you give me an example of your experiences regarding admission decision making?

- How were decisions regarding ICU treatment made? Who was consulted? Were you involved in these decisions? Can you give me an example of your experiences regarding admission decision making?

- What information do you think is of importance when talking about ICU admission and treatment decision making?

- Would you or your family member have liked to be more involved in the ICU decision process? If yes, how? What would you have needed to achieve this? If no, why not?

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

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Shared Decision Making in the ICU from the perspective of physicians, nurses and patients: A Qualitative Interview study

Nina Wubben, MSc[1], Mark van den Boogaard, RN, PhD[1], Johannes G van der Hoeven, MD, PhD[1], Marieke Zegers, PhD[1]

1. Radboud university medical center, Radboud Institute for Health Sciences, Department Intensive Care, Nijmegen, The Netherlands

Corresponding author: Dr Marieke Zegers

Institution where work was performed: the Department of Intensive Care Medicine of the Radboud University Medical Center in Nijmegen, the Netherlands.

Author email addresses

Nina Wubben nina.wubben@radboudumc.nl

Mark van den Boogaard mark.vandenboogaard@radboudumc.nl

Johannes van der Hoeven hans.vanderhoeven@radboudumc.nl

Marieke Zegers marieke.zegers@radboudumc.nl

Abstract

OBJECTIVE To identify views, experiences, and needs for Shared Decision Making (SDM) in the ICU according to ICU physicians, ICU nurses, and former ICU patients and their close family members.

DESIGN Qualitative study.

SETTING Two Dutch tertiary centers.

PARTICIPANTS 19 interviews were held with 29 participants: seven with ICU physicians from two tertiary centers, five with ICU nurses from one tertiary center, and nine with former ICU patients, of whom seven brought one or two of their close family members who had been involved in the ICU stay.

RESULTS Three themes, encompassing a total of 16 categories, were identified pertaining to struggles of ICU physicians, needs of former ICU patients and their family members, and the preferred role of ICU nurses. The main struggles ICU physicians encountered with SDM include uncertainty about long-term health outcomes, time constraints, feeling pressure because of having final responsibility, and a fear of losing control. Former patients and family members mainly expressed aspects they missed, such as not feeling included in ICU treatment decisions and a lack of information about long-term outcomes and recovery. ICU nurses reported mainly opportunities to strengthen their role in incorporating non-medical information in the ICU decision-making process and as liaison between physicians, and patients and family.

CONCLUSIONS Interviewed stakeholders reported struggles, needs and an elucidation of their current and preferred role in the SDM process in the ICU. This study signals an essential need for more long-term outcome information, a more informal inclusion of patients and their family members in decision-making processes, and a more substantial role for ICU nurses to integrate patients' values and needs in the decision-making process.

Keywords: Shared decision-making, Qualitative study, Interview study, Family, Patient experiences, Critical Care

Strengths and limitations of this study

- Strengths of our study contain the inclusion of diverse samplings of the three major stakeholder groups for SDM in the ICU, and interviews were held until data saturation was reached
- Thorough analysis lead to the identification of three overarching themes and corresponding categories
- A limitation is that clinician participants were recruited from two tertiary centers
- Views and articulations of experiences are influenced by culture and should be verified in more international qualitative studies

Background

Shared decision-making (SDM) has been endorsed as the most ethical and appropriate decision making approach (1, 2). SDM is defined as a cooperative process between clinicians and patients and, often in the Intensive Care Unit (ICU), their surrogates that enables a way of healthcare decision making that combines both the clinician's expertise as well as the patient's values and healthcare goals (3, 4).

SDM in the ICU is recommended when defining the overall goals of care and when making major treatment decisions that are preference-sensitive (2). The SDM process should contain as its three main ingredients: information exchange, a deliberation period and making an eventual treatment decision. SDM processes occurring between ICU physicians, ICU nurses and other members of the ICU team are defined as interprofessional SDM. It is recommended to occur before discussions with patients and family members take place, to enable the ICU team to speak as one (5). It *is associated* with more accurate prognoses, reduction of moral distress and a more resilient team (5-9). Overall, ICU physicians, ICU nurses and patients and surrogates can be viewed as the three pillars of ICU decision-making.

Though SDM has received a lot of attention by healthcare policy makers as a proponent of a patient's right to self-determination, there is a lack of evidence for associations between SDM interventions and patient outcomes (10, 11). Moreover, its implementation in healthcare settings is oftentimes not without difficulty. There is enormous diversity in care practices influenced by workplace culture and practice style (12, 13). Clinicians also interpret guidelines differently, and subsequently do not always follow the recommendations when it comes to information provision (14, 15). In practice, families might not be seen as decision-makers but rather as informants who should be protected from feeling responsible for choices made for a loved one (3).

While patients and families and clinicians do not always agree when it comes to treatment decision making (16), making family members feel involved in ICU care and treatment decision-making has been shown to reduce fear and anxiety and prepares them in aiding patients during their recovery process (17-21). SDM also increases the likelihood of patients forgoing aggressive care if this is not in line with their care goals (22), though caution is warranted when decisions can be influenced by the manner in which complex information about disease and treatment is provided by health care professionals, as well as cultural context (23). SDM interventions are able to improve families' ratings of quality of communication and shorten the ICU length of stay (24).

By elucidating the views of the three main SDM stakeholder groups in current ICU care, it is possible to elaborate on current ideas about when to incorporate patient and family preferences, when these preferences should be overridden by clinicians and how clinicians can improve their own interprofessional SDM (5, 25-27). Therefore, the aim of this study was to explore the views, experiences, and needs for SDM in the ICU according to ICU physicians, ICU nurses and former ICU patients and their close family members.

Methods

Study design and setting

This is a qualitative interview study carried out between June 2019 and January 2020 in two tertiary centres. The Consolidated Criteria for Reporting Qualitative Studies guidelines for the design and analysis of this interview study were followed (28) (See: Supplementary material 1). Decision-making in the ICU between the three stakeholder groups roughly occurs in daily multidisciplinary meetings mainly attended by ICU physicians, in regular family conferences where the presence of the ICU nurse is preferred but not required (29), and, more informally, at the bedside.

Participant sampling

Three groups of participants were interviewed: ICU physicians, ICU nurses and former ICU patients and their close family members. Physicians and nurses were approached within the professional network of the authors (MvdB and MZ), and were sampled purposively to ensure a variety in demographic and professional characteristics. Former ICU patients and their family members were reached through appealing to patient association volunteers, as well as an advertisement on the ICU patient association website (www.fcic.nl). As the vast majority of ICU patients survive their stay (30), and many studies are focused on the end-of-life patient category, our patient and family member sampling focused on ICU survivors (31-34).

Patient and Public Involvement

Former patients and family members were involved in the preparatory phase of this study. Patient organization board members and the audience members of a patient organization symposium were asked for input into the topic of SDM in the ICU, which informed the development of the two semi-structured topic guides used in this study (See: Supplementary material 2). Interview participants responded to an advertisement on the ICU patient organization website.

Data collection

All interviews took place face-to-face in either of the two tertiary centres. Two researchers conducted the first interview (MZ and NW). All subsequent interviews were conducted by one researcher (NW). Both researchers are trained to conduct interviews and execute interview analysis. Neither of the researchers has clinical training.

The main interviewer did not have established relationships with any of the interviewees before study commencement. Interviewees were asked to take part in an interview about their experiences with ICU shared decision-making and ICU decision-making in general. The interviewers had not conducted qualitative work regarding this topic before.

The two topic guides were applied to ICU clinicians and former ICU patients and their family members, respectively. Topics in both guides included experiences with SDM in the ICU, wishes for its expansion in the ICU and changes necessary to achieve this. The translated topic guide can be read in Supplementary materials 3 and 4. Data was collected until data saturation was reached, in other words, when no new information was identified in the interviews (35). Transcripts were not returned to participants for comment.

Data analysis

All audio recordings were transcribed verbatim by an external professional party, and subsequently coded using a grounded theory approach, where categories, themes and codes were derived through the analysis of the data. Coding is an interpretative process in which conceptual labels are assigned to data (36). Two researchers (NW and MZ) coded four interviews independently, before discussing and agreeing upon a coding framework. NW then applied open coding to the remainder of the transcriptions under the general supervision of MZ. Data analysis was performed using Atlas.ti software.

Ethical approval

The study was approved by the research ethics committee of the Radboud University Medical Center, CMO region Arnhem-Nijmegen (number 2020-6306). Participant information and an invitation for the interview were sent in reply to an informal consent to an interview via e-mail. Additional information about participation was given on request either in the e-mail correspondence or before the start of the interview. An informed consent form was signed before the start of the interview.

Results

In total, 29 participants were interviewed: five ICU nurses, seven ICU physicians, nine former ICU patients and eight family members (Table 1). Former patients and their family members were interviewed together, making for a total of 19 separate interviews. None of the participants dropped out. The interviews took between 30 and 75 minutes. 50% of the ICU clinicians and 41.2% of the former patients and family members were male. Mean age was 47.7 (SD: 2.6) and 57.4 (SD: 3.5), respectively. Of the nine former patients, five had had a medical admission (55.6%), three a planned surgery (33.3%) and one an emergency surgery (11.1%). The seven ICU physicians had a median of 12.0 years of work experience [Interquartile range (IQR): 5.0 – 20.0], whereas the median number of work experience years was 18.0 [IQR: 11.0-29.5] for the five ICU nurses.

Table 1. Participant characteristics

Interview order	*ICU physicians and nurses*	*Age category*	*Sex*
1	Intensive Care Nurse	<40	Male
2	Intensive Care Nurse	40-60	Female
3	Intensivist	40-60	Male
4	Intensivist	40-60	Male
5	Intensive Care Nurse	40-60	Female
6	Intensivist	40-60	Female
7	Intensive Care Nurse	>60	Male
8	Intensive Care Nurse	40-60	Female
9	Intensivist	40-60	Male
12	Intensivist	<40	Female
28	Intensivist	40-60	Female
29	Intensivist	40-60	Male
Interview order	*Former ICU patients and their family members*	*Age category*	*Sex*
10	Former patient #1	>60	Male
11	Spouse of former patient #1	>60	Female
13	Former patient #2	40-60	Female
14	Former patient #3	>60	Male
15	Spouse of former patient #3	>60	Female
16	Former patient #4	<40	Female
17	Former patient #5	<40	Female
18	Spouse of former patient #5	40-60	Male
19	Former patient #6	40-60	Male
20	Spouse of former patient #6	40-60	Female
21	Child of former patient #6	<40	Female
22	Former patient #7	>60	Female
23	Spouse of former patient #7	>60	Male
24	Former patient #8	>60	Male
25	Spouse of former patient #8	>60	Female
26	Former patient #9	40-60	Male
27	Spouse of former patient #9	40-60	Female

The data analysis resulted in 16 categories from which 3 themes were derived: (I) Struggles of ICU physicians (Table 2), (II) Needs of former patients and family members (Table 3), and (III) the Role of the ICU nurse (Table 4).

Theme I: Struggles of ICU physicians

A total of eight categories (Table 2) were identified in this theme: uncertainty and unpredictability of long-term outcomes; responsibility; unwillingness of patients to participate in decision making; physicians prioritize medical facets; trust in patients and families; physicians fear a loss of control; time; and 'acting in a treatment mode' in the case of acute or long-term admissions.

When asked about ICU decision-making and SDM, ICU physicians gravitated towards discussing examples of decisions about end-of-life and stopping treatment. ICU physicians described the uncertainty about long-term health outcomes as one of the main struggles they experienced. They cited literary or anecdotal evidence about unexpected outcomes as a reason for struggling with ICU decision making, such as a patient's satisfaction with life after losing the ability to walk where they expressed only sorrow at first. They cited feeling the weight of this responsibility when dealing with conflicts with nursing staff about continuing or ending treatment. According to the ICU physicians, these conflicts mainly arise over complex, long-stay patients. While they sometimes were uncertain about continuing treatment themselves, earlier experiences with success stories kept them cautious. They expressed a need for more long-term data on survival and quality of life after ICU treatment.

Physicians described variety among their colleagues about starting discussions around treatment wishes and patient needs, with some expressing doing so in the majority of patients, while others thought that doing this more sparingly was sufficient. Several barriers to explore the wishes and needs of patients were discussed. ICU physicians mentioned experiences with patients and families who did not want to involve themselves in the medical decision-making process. Also reported by clinicians and former patients and families was a varying degree of prioritization of medical facets in discussions by physicians leading to less attention for 'softer' topics, such as quality of life. Some physicians described that these factors often did not come into play unless the patient's chances of recovery become low. Moreover, physicians applied their own ideas about what constitutes a good quality of life, while not spending enough time clarifying if a certain patient agreed with their interpretation of a good quality of life. ICU physicians also described doubting wishes expressed by patients and their families, again citing literary evidence and anecdotal experiences with patients changing their mind. They expressed doubts about whether patients and families could actually grasp what certain decision in the ICU could lead to in future. They feared that having families be too involved in ICU decision-making would lead to more medically pointless treatment.

Furthermore, the acute setting of the ICU was cited as a struggle in the decision-making process, with the general rush cited as a barrier. A ‘treatment mode’ was described as a rush-driven attitude where physicians do not take enough time to assess whether treatment is still in line with patients’ best interests or wishes.

224 *Table 2. Theme I: Categories pertaining to struggles of ICU physicians*

Category	Codes	Quote
Uncertainty, interpretability and unpredictability of long-term outcomes	Lack of long-term outcome information; More long-term outcome knowledge causes you to stop treatment sooner; Long-term uncertainty limits conversations about continuing treatment	Physician (P): "Overall I think there is an understandable tendency to postpone [decision making about] problems. […] Again, the problem is always that uncertainty. The other day we lost a patient after 6 weeks of treatment. […] On the one hand you can say that we all saw that coming. On the other hand – well, you only know for certain if you've tried it."
Responsibility	ICU physicians have final responsibility; Physician determines treatment plan; Stopping treatment is always an option down the line	P: "Look, eventually we are the ones that have to bring the message to the family when we stop treatment … and that is our responsibility. So for a nurse it is easier to question whether we should continue, whereas we really need to do so based on good and substantial arguments."
Unwillingness of patients to participate in decision making	Certain types of patients don't want to be involved in decision making; Older patients; Family members hold back	P: "[…]especially older people say: no, you've studied for this – I don't know, you tell me. They just put everything back in your hands. You want to have those people decide for themselves but they're not going to."
Physicians prioritize medical facets	Conversations about continuing treatment are difficult when patients are doing badly; Quality of life is a 'soft' topic; Medical point of view takes precedence; Quality of life not a standard part of multidisciplinary discussions; ICU patients' needs center around communication and (non-medical) treatment	P: "Look, in the end we all prefer talking about the fluid balance and CRP levels. That's the truth. So [talking about quality of life] is 'soft' drivel to many people." P: "Of course everyone will agree that [a patient's biography] is an important topic, but it will often end up last in discussions. I think that the medical side, prognosis, chance of improvement, what are possibilities or alternatives, etc. is always first. These things don't come up until you start wondering if [continuing treatment is still proportional]." Former patients and their families (PF): "[patient with very long admission] I've often called it prison. Everything was decided for me. The theme of my illness was losing all sense of control."
Trust in patients and families	Physicians use own interpretation of what constitutes good quality of life; Physicians do not always trust that patients and families know what they want; Physicians know patients can change their minds; Well-informed patients make different choices	P: "What I used to see, and still see a bit – is that we physicians have our own opinions about what constitutes a good quality of life – in other words, what a good outcome looks like. And we do not look at the patient well enough." P: "Things like what would they have wanted, right – […] we know that it's proven in literature that people who did not want a certain situation, that when it actually happened to them, they were happy with that outcome […]. So that information – 'he would never have wanted to end

		up in a wheelchair' or 'he would never have wanted to be dependent', when it happens to you, we are apparently flexible enough in our behaviors and emotions, that we eventually can be very happy, and very happy to be alive. So that information has limited value".
Physicians fear a loss of control	Family or patient wants to continue treatment disproportionally; ICU physicians have final responsibility	P: "[On reasons other physicians might not ask a patient or family's wishes] Not wanting to be surprised with things you might not be able to do. That you're scared of promising something you can't fulfill. It's weird to then not ask the question, but that is a way of doing things. Or fearing totally irrational wishes from people."
Time	Admission rush or other time constraints limit conversations about treatment wishes	P: "The limits are mostly put on by time and space. Sometimes you have a really busy day so you don't have time for it. Then you need to cut back a little on those conversations, because there isn't any time."
'Treatment mode' in acute settings	Treatment mode limits conversations about treatment wishes; Stopping treatment is always an option down the line; To admit at all or to discontinue treatment;	P: "At the same time it's easier for me to intubate, […] to start renal replacement therapy – far easier than not starting treatment. So I think that's an important point. […] Sometimes we use the multidisciplinary discussion to say to each other: are we really still on the right track? […] And then you sometimes get one-liners like: 'You can always stop [treatment], the patient can always say that they don't want it like this [at a later stage]." P: "I'm convinced that people have an interest in being told there is a chance of an unfortunate outcome. […] I think it's also to do with that many physicians, due to their nature, are in 'treatment mode', and principally still want to treat. Stopping treatment is not a standard reflex of the average physician."
Abbreviations: N = ICU Nurse, P = ICU physician, PF = Former ICU patients and their family members		

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Theme II: Needs of former patients and family members

Four categories (Table 3) were identified within this theme, including: a holistic approach; feeling included in the medical process and knowing what's coming; information about long-term outcomes; and communication between medical staff and patients and families.

Former ICU patients and their families described an overwhelming satisfaction with medical care. Their needs centred around how they remembered being treated in a broader sense. They reported sometimes struggling with lingering feelings and memories. Some recalled feeling seen as a condition rather than a human being, which caused them to feel helpless during their stay.

While some had no additional needs with regards to their part in the ICU decision-making process, others' needs focused on two areas: being made to feel included in everyday decisions, and being better prepared for their recovery post-ICU.

Former patients also reported a sense of lack of control about their ICU care. They expressed that this might have been different if they had felt more included in the decision-making process by being explained why things were being done to them. Especially during longer stays they cited a frustration with their sense of lack of control regarding their schedule in the ICU that they did not experience once leaving the ICU. Some felt that more integration between the medical and 'human' side was needed. For example, being explained exactly why inserting a catheter was necessary instead of feeling like the insertion was a foregone conclusion. They cited that *feeling* heard and included was the most important factor, rather than having an equal hand in every and all decisions.

Moreover, they described that the long road to recovery post-ICU was sometimes unexpected and they expressed a need for more information. This did not only pertain to physical recovery, but to mental health and emotional recovery and issues regarding returning to the workforce as well. They described different levels of received aftercare post-ICU, and the difference it had made to their recovery.

Table 3. Theme II: Categories pertaining to the needs of former ICU patients and their close family members

Categories	**Codes**	**Quotes**
A holistic approach	ICU patients' needs center around communication and (non-medical) treatment; Little attention for the human behind the condition; Physician coming to sit next to you to ask you how you are	PF: "Treating me as a human being instead of a patient with some mystery illness – yes, I would have appreciated that very much, especially now looking back." PF: "Being nicer to you. I've heard it from many patients. There are very little things someone does when maybe having a bad day at work, but for a patient in such a situation – that's not normal for you. So those are things that you remember months later, while the nurse probably doesn't think about it at all."
Feeling included in the process and knowing what's coming	Communication needs: knowing what's coming; Conversations about shared decision making are physician-driven; Patients and families lack a feeling of control	PF: "Well, it all happens to you. I think that happens a lot in the ICU, because most of the time things aren't planned, so things happen. […] But if you wanted to optimize it, in my experience, you can tell people: what are you doing, why are you doing it. Even if people are half-conscious, you don't know what they will remember. I think they are very much in a 'state of doing'."
Communication between medical staff and patients and families	ICU patients' needs center around communication and (non-medical) treatment; Patients and families lack a feeling of control; No attention for the family	PF: "I've noticed that the physicians mainly focus on getting better, while you're still in a completely different phase. Coordinating those views, I think that's very healthy. The medical part – they have to decide and give you choices and options, but the human part you have to coordinate together because otherwise I won't understand your decision at all. […] And at some point you think: well, whatever, do it, but if you don't agree mentally and you feel so weak – I don't think that's good for your physical recovery."
Information about long-term outcomes	Needs for long-term information; Information regarding recovery; Answers to standing questions; Well informed patients decide differently; Better information provision leads to better outcomes	PF: "My feeling about the ICU is – the onus is on quick action, and survival. But then there is a long road afterwards and I think there should be more attention to that. Like a conversation with the partner, or whoever, someone close to the patient to say: what is important for the patient down the line?" PF: "Now I've noticed that the better the aftercare, the better your recovery." PF: "Afterwards it's worse, it seems like. Then it really gets through to you how bad it could have been – and then immediately how good it has been that you've managed to prevent that."
Abbreviations: PF = Former ICU patients and their family members		

Theme III: The Role of ICU nurses

Four categories were identified within this theme: the role of the ICU nurse being a liaison and translator between the physician and the patient and their family; questioning ICU physician's decisions to continue treatment; difficulties in communication between physicians and nurses; and offering non-medical information to complement ICU decision-making.

Within ICU decision-making, ICU nurses were generally focused on their communication with ICU physicians. They described functioning as a liaison between ICU physicians and patients and their families, mainly due to their continuous presence at the bedside. Both physicians and nurses described the role of the nurse as an advocate for the social context and needs of patients and their families to physicians, as well as a translator of the sometimes difficult medical 'speak' of physicians. Some nurses reported that they used this role to compensate for the variety in physician communication skills with patients and families.

Nurses reported being able to provide context for physicians to incorporate in medical decision-making by giving their insights in the patient and family situation. They generally felt listened to, even if their more holistic points of view were not always incorporated in the eventual medical decision, depending on the ICU physician on call. However, in non-complex, everyday cases, they were generally not troubled by this. They noted difficulties in communication between their two professions depending wholly on the various types of physician and nurse. Assertive nurses made sure their voices were heard, but acknowledged that not all of their colleagues have this capability.

Conflicts arose in situations of complex patient cases being in the ICU for a prolonged period of time. The ICU nurse study participants, when asked about ICU decision-making and SDM, gravitated towards discussing these struggles, which predominantly centred around continuing or ending treatment, with physicians oftentimes advocating for the former, while nurses want the latter. They felt this was mostly due to being more affected by complex, poignant cases, due to their continuous presence at the bedside. Within this context they reported feeling not being taken seriously and feeling blindsided by decisions being made in multidisciplinary meetings dominated by physicians. They felt frustrated with the returning nature of this type of conflict. They urged bridging the gap between physicians and nurses through team-building, moral deliberation and sharing vulnerabilities about treatment doubts.

282 *Table 4. Theme III: Categories pertaining to the role of ICU nurses*

Categories	**Codes**	**Quotes**
Liaison and translator between physician, and patient and family	Nurse is eyes and ears of the physician; Nurse translates medical world for patient; Nurse makes sure information is clear after a family conference; Sharing vulnerabilities can improve communication between clinicians	ICU Nurse (N): "Then after the family conference, you let it sink in, and you start repeating it and repeating it. And you try to use the same words as the physician – because I've noticed families say: I think it's so difficult, one says this and the others says this – but that's because [families] don't understand." P: "What kind of support we need, how the family is doing, how the patient is doing, sleeping, pain – there are a lot of things they have a lot of insight about, yes." P: "Where I see the nurse is […] as a translator of what the patient was like at home, who are they, what type of person were they, what is their social safety net like […]. That information is very valuable […]. So I think that their added value is in the clarification of the social context." N: "That is kind of the role we take on: [translating the family's wishes for the physicians."
Incorporating non-medical information in ICU decision-making	Nurse provides social and empathetic point of view; ICU nurse is at bedside for 24 hours a day; Talking about it when something doesn't feel right; Nurse participation in conversation depends on how assertive they are	N: "Yes – [nurses] think it's important to be of value in decision moments. Continuing or not, you know. Of course you need to do so based on medical information, but also based on the holistic view, and I think we should play a larger part in that, because we also know the family really well." N: "I think generally it is a very medically-focused decision-making process in which the nurse is heard and listened to […] but I don't think we have that big of a share in the eventual decision."
Difficulties in communication between physicians and nurses	Cooperation with nurses; Discrepancy of opinion between ICU physicians and nurses regarding end-of-life care for complicated cases; Nurse doesn't feel welcome in multidisciplinary meeting; ICU nurse feels like they are not being taken seriously	P: "There are nurses that are well spoken and they'll tell you their stuff. They are there, but they are a minority. Plus, they won't always say it to everyone, because they know some [physicians] won't listen." N: "Then the next day there was a new [intensivist] that didn't know the patient, but I had been at the bedside the entire day, so I told them [what the previous intensivist and I had decided]. [Then they said:] 'Well, that wasn't communicated with me, I don't agree with you, we won't do it'. So then you're not heard."

Questioning physician's decision to continue treatment	Conflict arises around complex patients who are at the ICU for a long time; Medical point-of-view takes precedence; Whether nurse's point-of-view is heard depends on which physician is on shift	N: "We often feel that when the patient is there for a very long time, and we see them deteriorating – the physicians often think: we can try this and we should approach them, maybe they know something – and then we think: should we do all of this?" N: "I think: there are limits. Sometimes it's enough. If you've done everything – you shouldn't stop based on emotions […] but other times I think: [recovery]'s just not going to happen.
Abbreviations: N = ICU Nurse, P = ICU physician		

Similarities and differences between stakeholder groups

Overall, barriers to and struggles with implementing SDM in critical care practice were highlighted by both ICU physicians and ICU nurses. They shared a focus on end-of-life decision making as the main decision in which SDM should be executed. They cited the practical difficulties surrounding end-of-life decision making, the formal necessities for SDM and their role in it. Clinicians differed when speaking about each other. ICU nurses were very focused on the mediating role and influence of the ICU physician and the level in which ICU nurses are invited and able to participate in the SDM process. ICU physicians spoke mostly about the responsibility they felt in imparting the correct information to patients and family members, and appeared to not view patients and family members as equal partners in the SDM process.

Patients and their family members offered a different perspective on incorporating SDM. If they had unmet needs, these were mainly focused on wanting a more holistic approach characterized by an open style of communication wherein they continuously feel part of the decision-making process, albeit not at the helm (Figure 1).

There were several similarities shared across the three stakeholder groups. The results indicated a shared need for more long-term outcome information that could guide both ICU decision-making and help manage future expectations. There was a desire for a more holistic integration of both medical information, as well as contextual information about the patient, such as their quality of life. This is interesting when considering ICU nurses' role as, translators, liaisons and advocates for patients' needs. Lastly, many of the needs surrounding SDM had a communicative nature.

Figure 1. ICU physicians mainly spoke of struggles with implementing SDM in the ICU, while patients and families elaborated on their needs, and ICU nurses talked about how their current role in the ICU decision-making process could be improved.

Discussion

This qualitative interview study explored the views, experiences, and needs for SDM in the ICU experienced by ICU physicians, nurses and former patients and their family members. Interviewees reported struggles, needs and an elucidation of their current and preferred role in the SDM process in the ICU. The three stakeholder groups shared a need for more long-term outcome information, and a desire for an integration of medical information with contextual information, paired with a more holistic approach. Many of the needs around SDM in the ICU had a communicative nature.

ICU physicians mainly associated SDM with struggles, such as the uncertainty of the future disease course and feeling pressure because of having final responsibility. They also reported several barriers that prevented them from open communication about wishes of patients or proxies, such as a fear of losing control of the situation. ICU patients and their families reported unmet needs with regards to communication and general (non-medical) treatment, wanting to continuously feel included in the ICU decision-making process, not just during formal meetings. ICU nurses drew a clear picture of their role in the SDM process as a liaison between the physician and patient. They translate medical jargon for patients, and advocate for patients' needs and wishes in the decision-making process. They reported communication struggles with physicians that limited a more balanced decision-making process, in which nurses provide physicians with more information about the wishes and needs of patients.

Earlier literature into the subject shows a focus on decisions pertaining to end-of-life (15, 31, 37, 38). This decision is sometimes viewed as one of the main and most difficult decisions to be made in the ICU, so much so that clinician interviewees oftentimes presumed it to be the natural focus point of the interview. Consistently, there was a variety of interpretations regarding what SDM in the ICU looked like. This signals a possible need for training and role models (15, 39, 40) to improve both clinician-patient and interprofessional understanding and execution of SDM.

In earlier literature it is reported that a significant part of patients and family members might not be willing to participate in the decision-making process (41). This was reflected in our sample too: not all interviewees had additional needs with regards to decision-making. The needs that were reported here bear some similarities to literature into patient palliative care preferences: mainly, value-focused care aimed at preserving the patient's sense of personhood (42). An ICU-based study aimed at improving communication between families and physicians has noted the importance of family members feeling involved in informal physician interactions as well as larger formal ones to establish their role in the decision-making process and improve family empowerment (43). Patient and family empowerment through information provision and awareness of the presence of choices are necessary ingredients to improve patient involvement in ICU decision-making (44).

The findings in this study pertaining to the struggles of physicians confirm findings in earlier studies, especially the difficulties surrounding end-of-life decision-making and the resulting communication struggles between physicians and nurses (14, 31, 45). Clinicians appeared hesitant to surrender control of the decision-making process due to their past experiences, as well a lack of trust in the understanding of the situation exhibited by the patient and family members. The unavailability of long-term outcome information around survival and quality of life was important to their hesitance in starting conversations around decision-making. Though long-term outcome data collection in the ICU has its challenges (46), there is an increase in big data initiatives to tackle the current gaps in knowledge (47). For instance, the collection of daily physiologic variable information has been shown to provide an increased understanding and knowledge about the likelihood of ICU survival (48, 49).

Communication struggles reported mainly by the ICU nurses pertaining to decisions to limit treatment have been documented before and appear widespread (50, 51). Nurses have been described to detect any type of ICU conflict quicker than physicians (52), and these conflicts can lead to augmented levels of stress in nurses (53), which may increase the incidence of burn-out among nurses (54). To keep nurses healthy and involved, there is an urgent need for training to improve interprofessional collaboration and communication, perhaps through more frequent moral deliberation meetings (55). As was reported in previous literature, the levels of their involvement in ICU decision-making processes were variable and depended on assertiveness and the type of physician on call (56). It therefore follows that the information about patient context and background cannot always be sufficiently imparted, though research has shown that nurse involvement in ICU decision-making improves both patients' and nurses' satisfaction-of-care (57). To equalize the instances of nurse involvement and provide nurses with a more consistent opportunity to provide their knowledge, it may be beneficial to increase and better define their role during decision-making moments, such as during patient handovers, bedside rounds and multidisciplinary meetings. Earlier literature has indicated that collaborative practice is possible, by, for instance, giving nurses responsibility for providing the physician with day-to-day specific information regarding the patient and signaling when physiological variables are cumulatively out of the normal range, and that it can improve both the clinical outcome as well as the satisfaction levels of ICU clinicians (48, 49, 54, 58-61).

To ensure a more complete understanding of the complexities of an ICU stay, general practitioners could play a part in information provision to patients and family members in an environment not yet defined by quick action

(62), while also being able to provide ICU clinicians with context information about the patient. With the large variety in staff attitude to SDM in the ICU, and the interventions surrounding education, prioritization and resource (re)allocation needed to further implement SDM, the organization at large should play a role in guideline development and setting a work standard involving SDM (63, 64).

This study offers further elucidation of reasons for the variable levels of uptake of SDM in the ICU. It is a further step towards implementation, paving the way towards a more satisfactory exchange of values between all three stakeholder groups to make preference-based decisions. A strength of this study is the inclusion of all three major stakeholder groups.

Our study has several limitations. Firstly, despite our decision to focus on ICU survivors, the many struggles surrounding end-of life decisions indicate that this is an important ICU decision-making theme. It may therefore have been better to include family members of deceased ICU patients as well. Furthermore, though our sample size may be regarded as small, the number of interviews in this study is more than the number suggested by Guest et al (65). Also, most of the interviews with ICU physicians and nurses were completed before the interviews with former patients and family members had taken place. Though patient interaction and involvement were discussed in the ICU nurse interviews, this order prevented discussions on more specific findings. However, as the ICU nurses predominantly focused heavily on ICU physicians in their interviews, the impact might be limited. The findings of qualitative research need to be verified for frequency of occurrence in larger samples through questionnaire research. Moreover, our focus on two tertiary centres as the main source of interviewed clinicians, may have skewed the results as decision-making culture may differ between ICUs (12). However, our findings are in accordance with literature as well as with the preparatory data collected from ICU clinicians and former patients and family members at the national patient organization symposium (Supplementary material 2). Lastly, views and articulations of experiences are influenced by culture. More studies concerning all three main stakeholder groups from different cultures can be a way of elucidating whether the concepts described here are universal or if there are more or different themes.

Though ascertainment of the frequency of these findings might be necessary, the similarities of these results to the literature and preliminary data collection embolden us to say that to further improve SDM implementation there is a need for:

- A more continuous role of patients and family members in ICU decision-making, as individually desired and ascertained
- Long-term, specific outcome information about survival and quality of life to support SDM discussions
- A more substantial role for the ICU nurse to ensure their imparting of knowledge about patient context and background during handover meetings, bedside rounds and the multidisciplinary meetings
- Interventions to improve communication between the three stakeholder groups, such as moral deliberation, interprofessional collaboration, and the involvement of the general practitioner

Conclusions

In the ICU, necessary steps should be taken to implement SDM in a way that satisfies physicians, nurses and patients and their family members. This study gives several recommendations to ensure that all three stakeholder groups can fulfill their role in the SDM process. All in all, there is an essential need for more long-term health outcomes, a more informal inclusion of patients and their family members role in decision-making processes, and a more substantial role for the ICU nurse to systematically integrate patients' values and needs in the decision-making process. There is a need for interventions that tackle the communication struggles between the three stakeholder groups.

Declarations

Competing interests

The authors declare that they have no competing interests.

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Authors' contributions

NW, MvDB, HvdH and MZ contributed substantially to the conception of the work. Each author contributed substantially to the design of the work. NW, MvdB and MZ contributed substantially to the acquisition and analysis of the data. Each author contributed substantially to the interpretation of the data. NW drafted the manuscript. Each author contributed substantially to the revision of the work.

Each author approved the submitted version. Each author agrees to be personally accountable for the author's own contributions and to ensure that questions related to the accuracy or integrity of any part of the work, even ones in which the author was not personally involved, are appropriately investigated, resolved, and the resolution documented in the literature.

Availability of data and materials

The data used and/or analysed during the current study are available from the corresponding author on reasonable request.

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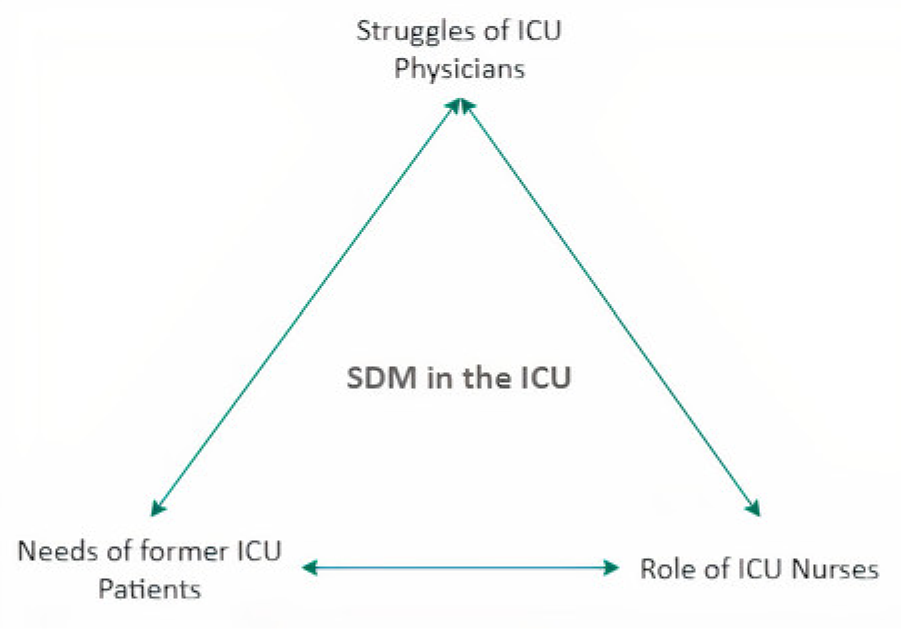

Figure 1. ICU physicians mainly spoke of struggles with implementing SDM in the ICU, while patients and families elaborated on their needs, and ICU nurses talked about how their current role in the ICU decision-making process could be improved.

38x26mm (300 x 300 DPI)

1 **Supplementary Materials**

2 *Supplementary material 1: COREQ Checklist*

Topic	**Item No.**	**Guide Questions/Description**	**Reported on Page No.**
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	5
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	1
Occupation	3	What was their occupation at the time of the study?	1
Gender	4	Was the researcher male or female?	1
Experience and training	5	What experience or training did the researcher have?	5
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	6
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	6
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	6
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	6
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	5
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	5
Sample size	12	How many participants were in the study?	7
Non-participation	13	How many people refused to participate or dropped out? Reasons?	7
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	5
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	5
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	7
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	6
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	NA
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	6
Field notes	20	Were field notes made during and/or after the inter view or focus group?	6

Duration	21	What was the duration of the inter views or focus group?	7
Data saturation	22	Was data saturation discussed?	6
Transcripts returned	23	Were transcripts returned to participants for comment and/or correction?	6
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	6
Description of the coding tree	25	Did authors provide a description of the coding tree?	-
Derivation of themes	26	Were themes identified in advance or derived from the data?	6
Software	27	What software, if applicable, was used to manage the data?	6
Participant checking	28	Did participants provide feedback on the findings?	6
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	8-17
Data and findings consistent	30	Was there consistency between the data presented and the findings?	8-17
Clarity of major themes	31	Were major themes clearly presented in the findings?	8-17
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	8-17

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Supplementary material 2: Preliminary data collection used to develop Topic guide.

Table 1. Preliminary data inventory used to develop Topic guide. Data was collected at the ICU patient organization symposium, following the authors' presentation about SDM in the ICU. The audience, consisting of ICU physicians, ICU nurses, and former patients and their family members, were asked to write down their views on what was needed and what they saw as barriers to implementing SDM in the ICU. Notes were received from 54 individuals. The information was categorized in six topics. Some factors were mentioned multiple times.

Category	**Quotes**
Time	'Often there is a lack of time in acute settings' to properly talk, listen and explain. This is necessary to really talk though the consequences of certain choices.' 'No time to sit with patients or surrogates before treatment starts' 'As a clinician I expect there to be space for conversation regardless of the point in time'
Factors pertaining to Patients and surrogates	'More human, less patient' 'How did the patient function before admission?' 'What do the patient and family want? How far do they want to go?' 'But what if the patient is sedated?! Permission needed to share decision-making in their place.' 'Jump from ICU to home is large. Care is taken care of by GP, but they aren't specialists..' 'Don't just monitor the patients' QoL, but the entire family's!' 'In order to share decision-making you need access to the medical dossier and visit patient whenever.' 'Being involved in assessment emotions and mental health symptoms of patients' 'Being allowed to share care to a degree.' 'Direction: it happens to you, but you can't steer. You're dependent on everything.' 'Trust, equality, being taken seriously.' 'Surrogates' knowledge about what the patient truly wants.' 'Talk through resuscitation preference.'
Factors pertaining to clinicians	'A multidisciplinary meeting with different medical specialists about recovery possibilities.' 'Explain where possible before admission. When admission is planned, in the outpatient clinic.' 'Talk about a possible ICU admission with the GP before it happens.' 'Talk about treatment limitations before ICU admission' 'Physician who dares to discuss difficult topics' 'Nurses can talk through things with patients and families beforehand, as a bridge toward the physician. Physicians have to be open to this information' 'More information about who the patient is as a human being before they were admitted' 'When a patient is transferred, this is about more than just medical facets. Also: rehabilitation, GP, etc.' 'Trust that we act in the patient's best interests.' 'Ethical or moral deliberation in the ICU.' 'Passionate clinicians who value SDM.' 'As a topic to nurses' education.'

	'Keep remembering that as a physician you should not put the responsibility at the family members' feet' 'Clinician expects: don't force it.'
Organizational factors	'More attention for Post-ICU Syndrome in all facets of the organization.' 'One person as the main communicator, or communication and information coach' 'A truly multidisciplinary conference: social, psychological and medical. Maybe even with family members.' 'Clear, shared vision about SDM in entire team.' 'Acknowledge the importance of SDM.' 'Knowledge within treatment team about communication to and between patients and family members.' 'Practical tips, courses and education'.
Information	'Patients and family members need good information about prognosis and treatment possibilities to decide. Also: how can you provide personalized information, while keeping cultural background, health skills, etc. in mind' 'Clarity about the consequences of some choices, what are the consequences of not treating, what will and won't you choose' 'Clear explanations about the current situation' 'Long-term data.' 'Use social workers.' 'Information in the outpatient clinic.' 'Information about wishes, expectations, pre-existent functioning – this only comes up later in the treatment trajectory instead of at the start' 'Patients and family members need a prognosis to examine whether treatment is in line with wishes and expectations for QoL' 'Explanation: what does an ICU-admission entail?'
Miscellaneous	'Not going to the ICU does not always equal stopping treatment. Palliative sedation is treatment too.' 'Not resuscitating does not mean there is no treatment happening.'

Supplementary material 3: Clinician Topic Guide

- Can you describe the current process of ICU-admission and treatment? What is your role in this process? Can you name an example of your experiences with these processes?
- How do you experience the degree of involvement of ICU nurses in the ICU decision-making process? Can you name an example of your possible experiences with involving the ICU nurse in the ICU decision-making process? Should the ICU nurse have a bigger role in the ICU decision process? Why?
- How does the multidisciplinary meeting contribute to the ICU decision-making process? Can its current role be improved upon?
- How do you experience the degree of involvement of patients and family members in the ICU decision-making process? Should they be involved more? What would the advantages and disadvantages of involving them more be? What is needed in order to involve them more? What information is important and needed to allow patients and their family members to share in the decision-making process?

Supplementary material 4: Former patient and family member Topic Guide

- Why were you admitted to the ICU? Can you describe the period of admission for me?

- How were decisions regarding ICU admission made? Who was consulted? Were you involved in these decisions? Can you give me an example of your experiences regarding admission decision making?

- How were decisions regarding ICU treatment made? Who was consulted? Were you involved in these decisions? Can you give me an example of your experiences regarding admission decision making?

- What information do you think is of importance when talking about ICU admission and treatment decision making?

- Would you or your family member have liked to be more involved in the ICU decision process? If yes, how? What would you have needed to achieve this? If no, why not?

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
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Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the inter view or focus group?	
Duration	21	What was the duration of the inter views or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.