

Patient involvement in micro-decisions in intensive care

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ABSTRACT

Objective: The objective of this study was to explore how bedside micro-decisions were made between conscious patients on mechanical ventilation in intensive care and their healthcare providers.

Methods: Using video recordings to collect data, we explored micro-decisions between 10 mechanically ventilated patients and 60 providers in interactions at the bedside. We first identified the types of micro-decisions before using an interpretative approach to analyze the decision-making processes and create prominent themes.

Results: We identified six types of bedside micro-decisions; non-invited, substituted, guided, invited, shared and self-determined decisions. Three themes were identified in the decision-making processes: 1) being an observer versus a participant in treatment and care, 2) negotiating decisions about individualized care (such as tracheal suctioning or medication), and 3) balancing empowering activities with the need for energy restoration.

Conclusion: This study revealed that bedside decision-making processes in intensive care were characterized by a high degree of variability between and within patients. Communication barriers influenced patients' ability to express their preferences. An increased understanding of how micro-decisions occur with non-vocal patients is needed to strengthen patient participation.

Practice Implications: We advise providers to make an effort to solicit patients' preferences when caring for critically ill patients.

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1. Introduction

Patients on mechanical ventilation in intensive care units (ICUs) experience communication barriers due to the endotracheal tube or tracheostomy [1–3]. Patients have described the experience of trying to communicate without a voice as frustrating, terrifying, [4,5] and associated with negative emotions, such as anxiety, anger [6–9] and feeling powerless [4,10]. Current ICU clinical guidelines [11–13] recommend that ventilated patients should be conscious, spontaneously breathing, and mobilized as quickly as possible in a family-engaged environment [13,14]. This has led to an increasing number of conscious patients on mechanical ventilation.

Previously the norm was to use substantial amounts of sedatives, making patients unable to communicate. There was also less focus on early weaning from ventilation and increased physical activity, compared to current recommendations [15–17]. A one-way communication style dominated bedside interactions, with healthcare providers being the most active participants [2,18]. In a very critical phase of their lives, patients experience reduced ability to participate in decisions about their treatment and care in ICUs [19–21].

Intensive care treatment is complex and fraught with ambiguity and uncertainty, [22,23] and bedside decision-making is often based on limited information [22]. Ofstad et al. [24] define treatment decisions as an expression from either a provider or the patient to commit to a particular course of clinically relevant action, implying a shared understanding of agreement and patient consent. A decision can also be to withhold treatment or to wait for further assessment of the situation. The American College of Critical Care Medicine and American Thoracic Society describes shared decision-making as “a collaborative process that

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allows patients, or their surrogates, and clinicians to make healthcare decisions together, taking into account the best scientific evidence available, as well as the patient's values, goals and preferences" [23, p. 190]. Kukla [25] highlights the complexity of making autonomous decisions, and how decision-making relies on previous history, relationships with the providers, and normative expectations of the patient role; therefore, they must be seen as part of a larger context. A self-determined decision can even be to ask providers or relatives to make the decision.

Micro-decisions [26], small-scale decisions made numerous times a day at a patient's bedside, are often not perceived as treatment decisions. Micro-decisions in ICUs may relate to mechanical ventilation (weaning attempts from ventilatory support, use of tracheostomy speaking valve), symptom management, mobilization, or other procedures (i.e. wound care).

There is a paucity of knowledge regarding micro-decisions in ICUs, compared to other decision-making [3,27], such as life-sustaining treatment decisions. A more thorough understanding of the interaction between patients and providers could improve patient participation. In this study we explored how micro-decisions were made between conscious patients on mechanical ventilation and healthcare providers in intensive care with the following research questions:

- What types of micro-decisions are made between patients and healthcare providers in intensive care?
- In what ways does decision-making occur at the bedside in intensive care?
- How are patients on mechanical ventilation engaged in decision-making?

2. Methods

2.1. Study design, setting and data collection

A phenomenological-hermeneutical approach [28–30] was chosen to describe and interpret the participants' interactions and the phenomena of micro-decisions as we observed them. This entails moving between descriptions and interpretations towards the content of meaning in the data collected to achieve a new and deeper understanding of the observed interaction [28–30]. Hence, we used video recordings to collect data, enabling repeated access to the subtle details of natural interaction [29]. It was necessary to capture non-vocal communication since mechanically ventilated patients are unable to produce vocal speech. The study was conducted in two ICUs at a university hospital in Norway. The units had 10 and 11 beds, respectively. Patients had single rooms and a nurse was always present. We installed two surveillance cameras and two sound-recording devices in each patient's room in the morning and left them to run continuously for 3–4 h. The first author stayed outside the patients' rooms making field notes. We collected demographic data from each patient.

2.2. Participants

We purposively recruited patients receiving mechanical ventilation between 2016–2017. The inclusion criteria were patients over the age of 18, mechanically ventilated for at least 48 h, a Richmond Agitation and Sedation Scale [31] score of 0–2, without diagnosed delirium for the previous 24 h, and negatively screened for the Confusion Assessment Method for the ICU (CAM-ICU) [32] at study enrollment. Patients were excluded if they did not speak

Norwegian, had severe visual, hearing, or cognitive deficits; or were in end-of-life care.

2.3. Data analysis

The first author watched the videos numerous times to become familiar with the data. The segments of the video recordings related to micro-decisions (the series of scenes that form a distinct narrative unit, connected by the continuity of time, where a specific decision-making process occurs), were first identified and transcribed. We used Ofstad et al.'s [24] definition of decisions to identify the bedside micro-decisions. We then performed a two-step analysis, first grouping the types of micro-decisions that occurred and then analyzing the meaning of the decision processes.

2.3.1. Analysis of the types of micro-decisions

We observed that decisions evolved in several ways, leading to patients' involvement on different levels. Each identified micro-decision segment was therefore analyzed according to a stepwise model for shared-decision making (initiation of dialogue, presentation of options, exploration of patient preferences, and making the decision) [33]. We also described other characteristics such as how the communication unfolded, who was present and what occurred in the room [29]. The situations were compared for commonalities and differences and eventually grouped into types of decisions. Observed non-medical micro-decisions were excluded from the analyses (i.e. morning bath or bed-positioning). This analysis led to a typology of micro-decisions, presented in the results. We used Mangold Interact[®] 16.4 to organize the visual data [34].

2.3.2. Analysis of the micro-decision processes

The interactions between patients and the healthcare providers were initially interpreted through naïve descriptions of what we observed, focusing on both verbal and non-vocal actions [28–30]. We then analyzed the meaning in the interaction before creating subthemes and themes. An example of this is displayed in Table 1. The first author attained a deeper understanding of the written and visual material, moving between parts of the data and the data as a whole [30], and by watching the selected video segments repeatedly and revising the written analysis accordingly.

The final analytic step involved a review of all the types of micro-decisions and the themes to ensure coherence between presentation and understanding of the data as these were two separate analytic phases. The first and last authors watched an entire three-hour video recording of one patient separately, and discussed differences in their interpretations to ensure rigor and reflection. The other authors watched numerous segments of the micro-decisions and participated in the analysis and discussion of findings via regular meetings. Malterud's concept of information power was applied to evaluate the data from our sample [35]. The information power was considered high as the aim of the study was specific and a considerable amount of interaction relevant to the research questions was collected from key informants. Saturation was reached during the analytic phase by the amount and meaning of micro-decisions that occurred during the 30 h of recordings [29].

2.4. Ethical considerations

The South-Eastern Regional Committees for Medical and Health Research Ethics in Norway approved this study (2015/2012). We performed it in accordance with the Code of Ethics of the Helsinki Declaration [36]. Videos were stored on a digital server following the university hospital's regulations. Participation was voluntary,

Table 1

This is an example of a micro-decision and how the process unfolded between the provider and the patient. Each type of micro-decision we observed is identified and transcribed in the left column. Then, we captured the essence of the observation in the next column before creating preliminary subthemes. The subthemes were then grouped into the three themes as described in the analysis. We also documented the time the segment occurred to be able to refer to it.

Micro-decision	Interaction as observed	Essence of the interaction	Subthemes
The need for tracheal tube suctioning 01:31:00	Patient Rebecca increases her respiratory rate and it sounds like there is mucus in the tube. Nurse Elizabeth tells her. "I believe we need to suction because you seem bothered by mucus in your lungs." Nurse Elizabeth turns on the suctioning. "Should we go down and remove it?" She asks this as she inserts the catheter down into the tracheostomy. Rebecca looks down and forms words with her mouth and starts to cough several times. "breath calmly," Elizabeth says. After some seconds while Rebecca breathes heavily, Elizabeth says "Is it better, still some left? There is still some left. Should we try once more? Regain your breath first." After some seconds of rest, again Elizabeth says, "Should we try to make you cough properly and I will go down?" She performs the suctioning. After this suctioning Rebecca coughs several times and also spit up some mucus from her mouth which Elizabeth removes with some paper. "There is some left, but I think it must come gradually," she says.	Suctioning to relieve symptoms (deciding together), but it is still ultimately the healthcare provider's decision Decision to withdraw from performing suction Guiding the patient towards tracheal suctioning by explicit statements of the need for it Decision to delay suctioning because of previous actions and the professional's assessment	Information Invitation to participate in decisions Guiding the patient towards agreeing to the decision Balancing decisions up against one other

and the video recordings could be turned off at any time. The patients consented non-vocally (e.g., by nodding) during their ICU-stay. Each participating patient's ability to understand the information provided was systematically ensured (through the use of CAM-ICU, assessment of communication skills and dialogue with the nurses). Each patient was also informed orally several times about the study. After ICU discharge, they signed a written consent form. The nurses were asked to be sensitive to indications from the patients to stop the recordings. The providers involved in the care and the relatives who visited during the video recordings received oral and written information and signed a written consent form.

3. Results

Fourteen patients were invited, and ten agreed to participate in the study (seven and three from respective ICUs). No provider declined participation. A visiting relative was present in two of the videos. In total, we collected 30 h and 23 min of video recordings ranging from 1 h and 7 min to 3 h and 30 min per patient.

The patients were five females and five males of European ethnicity representing a variety of diagnoses. The mean age was 53.6 years (range: 36–72). The median length of days on mechanical ventilation before inclusion was 20 days (range: 4–68). The mean severity of illness score (SAPSII) was 42.0 (Standard deviation [SD]: 13.1). More detailed patient demographics are published elsewhere [37]. Sixty providers (29 nurses, 18 physicians, 9 physiotherapists, and 4 radiographers) cared for the patients during the video recordings. The interactions varied from a few minutes to being present throughout the entire video recording. Most often, physicians visited the patient once (5–25 min), physiotherapists visited for mobilization routines (10–40 min), radiographers visited for X-rays (5–10 min), and nurses spent most of the time at the patients' bedside.

3.1. Types of micro-decisions

We extracted 142 segments from the video recordings that involved micro-decisions (5–28 segments per patient). Patients' involvement in the decision-making was grouped into six communicative patterns. Table 2 presents the types of decisions and the criteria for each group as well as examples of the micro-decisions that were made within each group.

Decisions about the same treatment or procedure unfolded in different ways and varied from patient to patient. More than half of the decisions we observed were non-invited decisions, meaning the decisions were both initiated and decided by the provider, without explicitly asking for the patient's preference. Approximately one quarter were invited decisions meaning that the patients were asked to express their opinion about the decision at stake.

3.2. Bedside micro-decision-making processes

Three themes were identified after observation and further analysis of the patients' and healthcare providers' interactions: 1) being an observer versus a participant in treatment and care, 2) negotiating decisions about individualized care, and 3) balancing empowering activities with the need for energy restoration. The first theme illuminates the patients' involvement in the micro-decisions, the second theme describes how the providers and patients interacted to achieve some type of agreement, and the third theme illustrates how the procedures and intense activity were balanced with rest. The three themes are presented below and illustrated with narrative examples, and references to types of decision-making. Examples of types of decisions across themes are given in appendix 1.

3.2.1. Being an observer versus a participant in treatment and care

Patients' preferences and desires were manifested via non-vocal techniques, such as eye gazes, forming words with their lips, writing, grimacing, or pointing. The patients' capability to express desires non-vocally on one hand, and the degree to which the provider facilitated this communication on the other, influenced the degree of patients' involvement in the micro-decisions. Table 3 illustrates how patient Dina¹ became an observer rather than a participant in the decision-making about the ventilator strategy. Because the provider both initiated and made the decision, and Dina was informed but not asked about her preferences, we categorized this as a non-invited decision.

In other situations, the patients asked treatment-related questions, expressed their preferences, or signaled by pointing (e.g., back to the bed). They expressed reluctance by shaking their heads or moving restlessly around in the bed, which we

¹ The names of all the patients and providers mentioned here have been modified to ensure confidentiality

Table 2

The definitions illuminate the differences and similarities between the different types of micro-decisions observed. The last column explains the decisions being made within each type of micro-decision more in-depth.

Types of decision-making	Criteria	Identified micro-decisions within each type of decision-making
Non-invited decisions	The healthcare provider initiates and makes the decision. Patients may receive information or ask about a specific decision, but the provider does not solicit patient preferences or include the patient in the (final) decision.	The use of a tracheostomy speaking valve Treatment options (various procedures, increase/decrease medication, changes in ventilator-settings, wound care) The timing and type of activity during physiotherapy and mobilization Plans to discharge from the ICU Hygienic procedures (such as disinfection of central venous lines) The need for tracheal suctioning
Substituted decisions	The healthcare provider initiates and makes the decision, indicating knowledge about the patient's preferences and involving the patient in the process via assumed consent.	Ways of performing procedures Treatment options (i.e. increase/decrease of medication) The use of a tracheostomy speaking valve
Guided decisions	The healthcare provider initiates and proposes the decision to the patient, as a decision that the patient would benefit from. Preferences are not actively solicited unless the patient actively expresses something related to the decision. The provider assumes the patient's consent.	Treatment options (i.e. increase/decrease medication) The need for sleep/rest
Invited decisions	The healthcare provider initiates the decision. The provider solicits the patient's preferences by indirectly asking for permission or directly providing options about the decision.	Physicians treatment plan The need for tracheal suctioning The amount and timing of weaning attempts The timing and type of activity during physiotherapy and mobilization
Shared decisions	Either the patient or the healthcare provider may initiate the decision. Both the patient's preferences and the provider's assessment are considered, and the patient takes an active role in the dialogue. Both agree on the final decision.	Long term plans for treatment The amount and timing of weaning attempts and changes in ventilator-settings The need for tracheal suctioning The timing and type of activity during physiotherapy and mobilization
Self-determined decisions	The patient initiates the decision either by communicating non-verbally using communication aids or by physically expressing preferences/needs. The decision is carried out with the assistance of the healthcare provider.	The need for tracheal suctioning The amount and timing of weaning attempts The timing and type of activity during physiotherapy and mobilization

Table 3

BEING AN OBSERVER VERSUS A PARTICIPANT IN TREATMENT AND CARE.

Patient Dina expresses that it feels heavy to breathe when the physicians assess her condition. Physician Victor asks nurse Cristian whether there have been any changes on the ventilator, and he responds looking at the ventilator, "The pressure support and the PEEP have been the same. I raised the oxygen since she had some feeling of dyspnea."
Physician Victor goes over to the ventilator before he looks down at Dina and says, "I will try to make it easier for you to breathe." After making the adjustments, he asks her "Does it feel better?"
Dina forms "a little" with her lips and nods, still breathing heavily.
"I think the setting can be like this; it seems more important that she is comfortable than to reduce the support of the ventilator. Let's wait until the lungs recover," Victor says looking at nurse Cristian. Then he turns around and repeats the same thing to Dina. She looks at him and nods slightly, Victor does not ask her any more questions and leaves the room.

interpreted as a desire to become a participant rather than an observer. Each patient's level of involvement in decisions as well as their overall level of involvement varied across decisions.

3.2.2. Negotiating decisions about individualized care

Patients and providers sometimes negotiated aspects of a micro-decision, such as the timing of procedures, who would be present, the level of assistance, the order of steps to complete the procedure, or whether the procedure was necessary. This was most typically seen in invited, shared, and self-determined decisions (appendix 1). Either the patient or the healthcare provider could initiate a negotiating dialogue. However, the patients tended to indicate opposition either by forming words, making gestures showing reluctance, or shaking their heads ("no") if they disagreed. Patients also used subtle non-vocal signs such as facial expressions (grimacing) or shoulder shrugs to express themselves. An example of how negotiations unfold in this context is provided in Table 4, where patient Raphael negotiated the duration of a nasal cannula

procedure. We categorized the situation as a self-determined decision, as Raphael initiated the dialogue and negotiated the timing based on his preferences.

The negotiations led to multiple pathways to manage treatment decisions, exemplified in the various approaches to the use of tracheostomy speaking valves. One of the patients used the tracheostomy speaking valve extensively; however, the physician wanted to ensure that the patient's lungs were sufficiently humidified. After negotiating several alternatives, they agreed upon using another treatment option (Optiflow™) when the patient was resting, to provide humidity. This decision integrated both the patient's desire to communicate and the physician's professional judgment. Another patient expressed feeling anxious using the tracheostomy speaking valve, therefore, she only used it for brief periods. These tailored and shared decisions showed that treatment decisions were adjusted to each patient's needs and preferences.

Raphael made self-determined decisions, as well as being invited into the decision-making by the providers. Fig. 1 illustrates

Table 4
NEGOTIATING DECISIONS ABOUT INDIVIDUALIZED CARE.

Nurse Benjamin says, "I will now disconnect the tube, and you get this plastic device instead and some extra oxygen supply, and you get the same amount of oxygen as what you get on the ventilator."
Benjamin is holding up the nasal cannula, pointing towards his neck in front of Raphael, who is grimacing.
Nurse Benjamin says, "It is going to feel different to breathe compared to the ventilator, but you are supposed to breathe normally . . . only through the tube in your neck. If it is uncomfortable, I will put you back on the ventilator immediately. I'll be here all the time and won't run away."
Raphael makes first one signal with his right palm out in the air, and then another signal with both hands crossing them as a stop signal as nurse Benjamin is about to connect him to the nasal cannula.
"A time out? No time out now, let's just do this," Benjamin responds and finishes the procedure and disconnects the ventilator.
Raphael makes signals to write, and he writes on the communication board that he is scared.
Benjamin responds, "Yeah, you get scared . . . but you were also scared yesterday, and then I did not hook you up to the device to get you used to the idea."
The dialogue is interrupted by Raphael's coughing, Benjamin removes some mucus from the tracheostomy. Afterward, Raphael writes once more and shows it to Benjamin who reads it out loud standing next to him, "when it stops . . . I get more afraid because it gets so quiet."
Benjamin remains at the bedside and nothing is said for a while. Then Raphael writes again and shows it to Benjamin who responds, "You want to get back on the ventilator? You have been six minutes on the nasal cannula now. Do you want to get connected back to the ventilator?"
Raphael looks at him and nods slightly. Benjamin reconnects him to the ventilator.

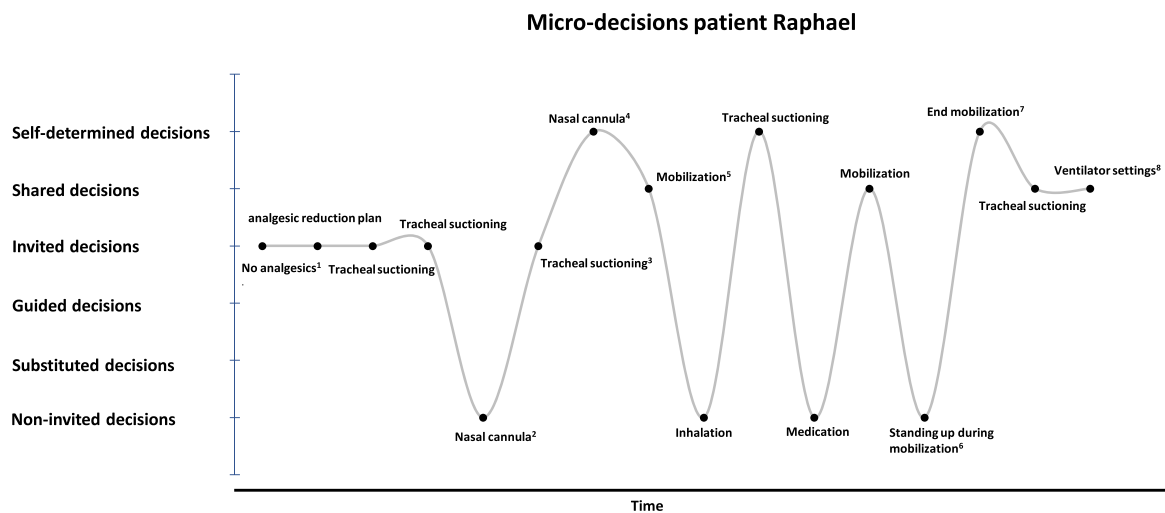


Fig. 1. The figure demonstrates each micro-decisions made in the recording of patient Raphael. The punctate decision points are illustrated in the types of micro-decision it was grouped within. Further elaboration and exemplification of the decisions that occurred: 1. No analgesics: Patient is asked if he is in pain and needs more analgesics, responds no with lips shaking head. 2. Nasal cannula: Patient is being put on nasal cannula, says no both by shaking head and holding out a hand. Nurse says "I let you off yesterday, today we'll just do it. I will be with you the whole time." 3. Tracheal suctioning: Patients coughs, nurse asks If it is okay if he removes mucus and patient nods. 4. End nasal cannula: Patient writes to stop attempt and shows it to the nurse. He puts him back on the ventilator. 5. Mobilization: Patient writes that he would like to sit on bedside if physician allows. Nurse confirms decision. 6. Standing up during mobilization: Patient tries to stand up on his own initiative, gets told by nurse and physiotherapist he cannot do that so quickly and should just sit down on the bedside. 7. End mobilization: Patient tries to lay back in bed on his own initiative signaling by moving in the bed, assisted by the nurses and physiotherapist. 8. Ventilator settings: Patients express dyspnoea and nurse adjusts ventilator. Asks afterwards about patient comfort.

how his level of involvement in the micro-decisions varied over time within the types of decision-making identified. We also saw this pattern in other patients.

3.2.3. Balancing empowering activity and energy restoration

The amount and appropriate timing of activities were frequent topics in the videos. Balancing procedures with patients' preferences and need for rest was not easy. Often, plans of care and providers' workflow conflicted with patients' wishes. For example, some patients expressed reluctance towards procedures to wean from mechanical ventilation and to do physiotherapy due to the amount of energy it required. We interpreted these dialogues as the providers trying carefully not to overly pressure the patient, constantly assessing the patients' tolerance for the potentially painful or energy-consuming procedures. Sometimes they pushed patients a step forward in the process of weaning from the ventilator or tried to increase the amount of physical activity, whereas other times they held back, preserving the patients' energy. This contradiction appeared most typically in non-invited and guided decisions, illustrated in the dialogue between patient

David and his providers (Table 5). We interpreted the situation as a guided decision, since the providers encouraged David to rest after the activity to benefit his recovery.

The balancing act required the providers to invest time in dialogue and interpret the patients' signs of energy/exhaustion while considering what other activities and procedures would need to be prioritized. Sometimes, limiting the activities was beneficial; whereas other times they expected increased effort and progress. The level of activity seemed to be guided by professional judgment, as decisions about balancing activity and rest were often made without inviting the patient to participate in the decision-making.

4. Discussion and conclusion

4.1. Discussion

The present study provides a novel understanding of ICU patients' involvement in their treatment and care. We found the interaction between patients and the healthcare providers to be

Table 5
BALANCING EMPOWERING ACTIVITY AND ENERGY RESTORATION.

David has been 21 days in the ICU, struggling with prolonged weaning from mechanical ventilation, ICU-acquired weakness, and postoperative complications. During the physiotherapy, David has worked hard, and physiotherapist Bridget comments as she is about to close the session “Well done, now I think you are tired.”

David responds forming “no” with his lips, looking at her shaking his head.

“You never get tired?” Bridget responds laughing, and David smiles at her shrugging his shoulders. Bridget then continues “A physiotherapist will be back to get you up on the bedside later, but you’ll get some rest first.”

Nurse Oscar comes up to the bedside and says “I thought you would lay on the side and rest a bit. Do you think you will be able to relax some? You have worked out now. It is good to sleep in the morning and not in the evening, to not interrupt the night sleep.”

David looks towards Oscar and forms words with his lips and grimaces.

“No? You think it will be painful?” Oscar responds and David nods. “why don’t we try, if it is uncomfortable for you, we will change position again?” Oscar asks and David again nods a, a bit slower this time and he looks around.

Bridget and Oscar position David on his right side and make sure he is comfortable. Before Bridget leaves the room, she says “goodbye, rest now it’s been a tough session. Great job!” to David. David forms words with his lips looking at her while he nods.

more varied across and within patients than previously reported both in terms of the types and processes of micro-decisions [18,19,27]. We identified six types of decision patterns: non-invited, substituted, guided, invited, shared and self-determined decisions. The analysis revealed variations in how micro-decisions evolved and were influenced by providers, patients, and other factors such as the disease characteristics. We identified three main features in the decision-making processes: how the patients continuously shifted between being in observer or participant positions when interacting, how the patient and the provider negotiated micro-decisions, and how decision-making was limited by the need for energy restoration. These features have not been addressed in previous studies, which have tended to highlight that patients often feel vulnerable, struggle to communicate, and are isolated from the treatment [18,27].

This study contributes to a more situation-specific understanding of decision-making, in ICUs. Even when patients made self-determined decisions, their physical limitations meant a provider needed to carry them out (e.g., tracheal suctioning). We interpreted patient-initiated communication about treatment or care as self-determined decisions (perhaps an over-statement considering the patient’s communication barriers). However, we did observe treatment decisions based on the patients’ explicit bodily signals, such as pointing to the tracheostomy.

Our findings illustrate how autonomy is not a fixed state, and that patient involvement must be understood in the cultural, social, physical and embodied practice where it occurs [38]. Kukla argues that autonomy is not necessarily measurable by punctuated decision points but should include several health decisions made over time and considering the degree to which the patients can make a conscientious decision [25]. Thompson [39] interviewed both patients and members of voluntary health care organizations about their involvement in treatment decisions, finding that many prefer providers to make decisions during critical illness. Micro-decisions do not pose the same dilemmas or significance as decisions about life-sustaining treatment; therefore, the severity of the decision may affect the patients’ desire to participate in the decision-making. Our study indicates that ICU patients’ autonomy depends upon the context, the severity of the illness, the communication barriers, information needs, and the time available to communicate. However, even though the patients were critically ill they also expressed a desire to participate. Patient participation in treatment decisions does not necessarily imply that they should be making only self-determined decisions; however, we recommend that providers invite patients into decision making whenever possible and to explore the patients’ preferences.

The study is one of the first to investigate how micro-decisions are made at the patients’ bedsides in ICUs. In a focused ethnography of weaning from prolonged mechanical ventilation, Happ et al. [18] found that 12 out of 30 (40%) patients they observed were involved in making decisions about their care.

These decisions included bedside decisions such as weaning procedures and initiation/withdrawal of mechanical ventilation, surgery, feeding tubes, tracheostomy insertions, or withdrawal of dialysis, which is similar to our study. Happ reported that only 19% of the decision-making processes were patient-initiated, and in 55% of the processes, patients were not invited. This concurs with our findings, as many of the observed micro-decision processes were non-invited decisions, and the patients’ opinions were not solicited. We do not know whether the patients agreed to the decisions being made or not if they did not express their opinions in the observations.

Negotiations in micro-decisions, such as mobilization, have been reported in other studies [19,40]. Negotiating ways of performing painful and exhausting procedures may be interpreted as patients’ ways of gaining control of their somewhat chaotic and uncertain existence [41–43]. These negotiations may challenge providers’ professional judgement, which must be incorporated in decision-making in ICUs, but with consideration of the patients’ experiences, resources, and cognitive capacity, as well as the best available evidence for the different choices [24,26,44]. Mechanically ventilated patients are completely dependent on the providers’ assistance and attention [37], and they lack negotiation power. Encouragement from providers, to become gradually more involved, can lead to patient empowerment [26,27]. Invitation to participate in decisions, by providers, is described by patients in a previous study as a positive act [19] and is empowering over time [19,42,24]. Patient involvement in micro-decisions is therefore an important part of the recovery process [19,42,45]. However, this requires that enough time be spent soliciting patient preferences to ensure correct understanding, due to the communication barriers [44,46].

The negotiations we observed revealed how patients who underwent bedside procedures numerous times (such as tracheal suctioning) gained personal experiences that they subsequently applied in the decision-making. For example, patient Rebecca’s (Table 1) previous bad experience with the tracheostomy speaking valve and Raphael’s (Table 4) reluctance towards the nasal cannula. Providers can ensure they consider patients’ wishes in the micro-decisions over time by both documenting and sharing their preferences with other healthcare team members. Shared decision-making processes often involve soliciting preferences and reaching an agreement from both the patient’s and the provider’s perspectives [33]. In the “negotiating space” there is potential to involve the patients and to ensure individualized care. The current study shows that micro-decisions can impact important treatment decisions, such as weaning off ventilation, eventually affecting patient outcomes.

For patients on mechanical ventilation, it is difficult to explore options in depth. Exploration of options is an important step in shared decision-making [33]. Facilitative strategies could be to use communication aids, or to involve relatives in the decision-making

as communication partners. Our study demonstrates the variety of micro decisions in intensive care and that different decision-making processes occur within this healthcare setting. Decision-making must be understood in the context in which it occurs [46].

Our definition of shared decisions (Table 2) is as follows: “Either the patient or the healthcare provider may initiate the decision. Both the patient’s preferences and the provider’s assessment are considered, and the patient takes an active role in the dialogue. Both agree on the final decision.” Our understanding is not focused specifically on eliciting treatment options, such as Stiggelbout et al.’s or others’ suggestions [33,47–49], but it is more on the immediate “here and now” agreement with the patient. Nor is it a stepwise model to reach an informed decision where one first focuses on choices, then options, before the final decision stage, as Elwyn et al. recommend [47]. It is a situation-specific understanding of decision-making, not explicitly integrating the best evidence available in the decision [23–25]. Further attention on decision-making is therefore required, especially due to the changes of treatment philosophy in ICUs, with more conscious ventilated patients than before. To reduce the patients’ difficulties, communication and decision tools suitable for intensive care are vital [1–3], to foster a systematic approach to patient involvement [49]. The findings from our and former studies [18,19,27,50], reveal that providers seem to lack frameworks to understand and enhance patient participation within a clinical context with non-vocal patients.

This study’s main limitations include the risk of participants being affected by the cameras and loss of privacy. We implemented numerous measures to help the participants feel comfortable while being video recorded. A few of the videos contained segments with poor lighting, but most of the data had good audio and visual quality [29,51]. Collection of additional data on the participants’ experiences by, for example, interviews, could have contributed to a deeper understanding and strengthened the credibility of the interpretations [52]. Other types of decision-making processes may have occurred over a longer period than we observed.

4.2. Conclusion

The study revealed a variety of ways in which conscious mechanically ventilated patients participate in bedside decision-making, from being an observer of treatment decisions to making self-determined decisions. Decision processes varied considerably between and within patients, and communication barriers influenced patients’ ability to express their preferences. Understanding how micro-decisions evolve between patients and providers delivers an opportunity to discuss how shared decisions can be applied bedside in ICUs. Situation-specific decision-making processes, such as guided decisions, should be recognized as important in intensive care.

4.3. Practice implications

Today’s standard of care requires a comprehensive understanding and multi-disciplinary approach toward decision-making in intensive care. Our findings reveal the potential for improvement. We would like to emphasize the importance of providers’ responsibility to invite patients to participate in decision-making while being mechanically ventilated. Despite the complex communication barriers, providers should create a secure environment for patients to communicate. Continuing education is needed to understand and embrace the negotiating dialogues with the patients to potentially involve them in their treatment and care to promote their recovery and health.

CRediT authorship contribution statement

Marte Marie Wallander Karlsen: Conceptualization, Methodology, Software, Validation, Formal analysis, Investigation, Writing - original draft, Visualization, Funding acquisition. **Mary Beth Happ:** Conceptualization, Methodology, Formal analysis, Validation, Writing - review & editing, Supervision. **Arnstein Finset:** Conceptualization, Methodology, Formal analysis, Validation, Writing - review & editing, Supervision. **Kristin Heggdal:** Conceptualization, Methodology, Formal analysis, Validation, Writing - review & editing, Supervision. **Lena Günterberg Heyn:** Conceptualization, Methodology, Formal analysis, Validation, Writing - review & editing, Project administration, Supervision.

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References

- [1] H. Carruthers, F. Astin, W. Munro, Which alternative communication methods are effective for voiceless patients in intensive care units? A systematic review, *Intensive Crit. Care Nurs.* 42 (2017) 88–96, doi:<http://dx.doi.org/10.1016/j.iccn.2017.03.003>.
- [2] M.B. Happ, K. Garrett, D.D. Thomas, J.A. Tate, E. George, M. Houze, J. Radtke, S. Sereika, Nurse-patient communication interactions in the intensive care unit, *Am. J. Crit. Care* 20 (2011) 28–40, doi:<http://dx.doi.org/10.4037/ajcc2011433>.
- [3] M.M.W. Karlsen, M.A. Olnes, L.G. Heyn, Communication with patients in intensive care units: a scoping review, *Nurs. Crit. Care* 24 (2019) 115–131, doi:<http://dx.doi.org/10.1111/nicc.12377>.
- [4] J.L. Guttormson, K.L. Bremer, R.M. Jones, “Not being able to talk was horrid”: a descriptive, correlational study of communication during mechanical ventilation, *Intensive Crit. Care Nurs.* 31 (2015) 179–186, doi:<http://dx.doi.org/10.1016/j.iccn.2014.10.007>.
- [5] E. Laerkner, I. Egerod, F. Olesen, H.P. Hansen, A sense of agency: an ethnographic exploration of being awake during mechanical ventilation in the intensive care unit, *Int. J. Nurs. Stud.* 75 (2017) 1–9, doi:<http://dx.doi.org/10.1016/j.ijnurstu.2017.06.016>.
- [6] M.B. Happ, P. Tuite, K. Dobbins, D. DiVirgilio-Thomas, J. Kitutu, Communication ability, method, and content among nonspeaking nonsurviving patients treated with mechanical ventilation in the ICU, *Am. J. Crit. Care* 13 (2004) 210–220.
- [7] A. Wassenaar, J. Schouten, L. Schoonhoven, Factors promoting intensive care patients’ perception of feeling safe: a systematic review, *Int. J. Nurs. Stud.* 51 (2014) 261–273, doi:<http://dx.doi.org/10.1016/j.ijnurstu.2013.07.003>.
- [8] R. Khalaila, W. Zbidat, K. Anwar, A. Bayya, D.M. Linton, S. Sviri, Communication difficulties and psychoemotional distress in patients receiving mechanical ventilation, *Am. J. Crit. Care* 20 (2011) 470–479, doi:<http://dx.doi.org/10.4037/ajcc2011989>.
- [9] L.K. Menzel, Factors related to the emotional responses of intubated patients to being unable to speak, *Heart Lung* 27 (1998) 245–252, doi:[http://dx.doi.org/10.1016/S0147-9563\(98\)90036-X](http://dx.doi.org/10.1016/S0147-9563(98)90036-X).
- [10] V. Karlsson, I. Bergbom, A. Forsberg, The lived experiences of adult intensive care patients who were conscious during mechanical ventilation: a phenomenological-hermeneutic study, *Intensive Crit. Care Nurs.* 28 (2012) 6–15, doi:<http://dx.doi.org/10.1016/j.iccn.2011.11.002>.
- [11] M.C. Balas, E.E. Vasilevskis, K.M. Olsen, K.K. Schmid, V. Shostrom, M.Z. Cohen, G. Peitz, D.E. Gannon, J. Sisson, J. Sullivan, Effectiveness and safety of the awakening and breathing coordination, delirium monitoring/management, and early exercise/mobility (ABCDE) bundle, *Crit. Care Med.* 42 (2014) 1024–1036, doi:<http://dx.doi.org/10.1097/ccm.0000000000000129>.
- [12] E.W. Ely, The ABCDEF bundle: science and philosophy of how ICU liberation serves patients and families, *Crit. Care Med.* 45 (2017) 321–330, doi:<http://dx.doi.org/10.1097/ccm.00000000000002175>.
- [13] J.L. Vincent, Y. Shebani, T.S. Walsh, P.P. Pandharipande, J.A. Ball, P. Spronk, D. Longrois, T. Strøm, G. Conti, G.H. Funk, R. Badenes, J. Mantz, C. Spies, J. Takala, Comfort and patient-centred care without excessive sedation: the eCASH concept, *Intensive Care Med.* Exp. 42 (2016) 962–971, doi:<http://dx.doi.org/10.1007/s00134-016-4297-4>.

- [14] I. Egerod, J.W. Albarra, M. Ring, B. Blackwood, Sedation practice in Nordic and non-Nordic ICUs: a European survey, *Nurs. Crit. Care* 18 (2013) 166–175, doi:<http://dx.doi.org/10.1111/nicc.12003>.
- [15] A. Marra, E.W. Ely, P.P. Pandharipande, M.B. Patel, The ABCDEF bundle in critical care, *Crit. Care Clin.* 33 (2017) 225–243, doi:<http://dx.doi.org/10.1016/j.ccc.2016.12.005>.
- [16] P.P. Pandharipande, A. Banerjee, S. McGrane, E.W. Ely, Liberation and animation for ventilated ICU patients: the ABCDE bundle for the back-end of critical care, *Crit Care* 14 (2010) 1–3, doi:<http://dx.doi.org/10.1186/cc8999>.
- [17] A. Schandl, A.C. Falk, C. Frank, Patient participation in the intensive care unit, *Intensive Crit. Care Nurs.* 42 (2017) 105–109, doi:<http://dx.doi.org/10.1016/j.iccn.2017.04.006>.
- [18] M.B. Happ, V.A. Swigart, J.A. Tate, L.A. Hoffman, R.M. Arnold, Patient involvement in health-related decisions during prolonged critical illness, *Res. Nurs. Health* 30 (2007) 361–372, doi:<http://dx.doi.org/10.1002/nur.20197>.
- [19] C. Lindberg, B. Sivberg, A. Willman, C. Fagerström, A trajectory towards partnership in care—patient experiences of autonomy in intensive care: a qualitative study, *Intensive Crit. Care Nurs.* 31 (2015) 294–302, doi:<http://dx.doi.org/10.1016/j.iccn.2015.04.003>.
- [20] A. Morandi, N.E. Brummel, E.W. Ely, Sedation, delirium and mechanical ventilation: the “ABCDE” approach, *Curr. Opin. Crit. Care* 17 (2011) 43–49, doi:<http://dx.doi.org/10.1097/MCC.0b013e3283427243>.
- [21] A.W. Kushniruk, Analysis of complex decision-making processes in health care: cognitive approaches to health informatics, *J. Biomed. Inform.* 34 (2001) 365–376, doi:<http://dx.doi.org/10.1006/jbin.2001.1021>.
- [22] M. Maharmeh, J. Alasad, I. Salami, Z. Saleh, M. Darawad, Clinical decision-making among critical care nurses: a qualitative study, *Health* 8 (2016) 1807–1819, doi:<http://dx.doi.org/10.4236/health.2016.815173>.
- [23] E. Ofstad, DICTUM – The Decision Identification and Classification Taxonomy for Use in Medicine, (2015). (Accessed 28.08.2019) <http://oher.no/resources/2018>.
- [24] A.A. Kon, J.E. Davidson, W. Morrison, M. Danis, D.B. White, Shared decision making in intensive care units: an American college of critical care medicine and american thoracic society policy statement, *Crit. Care Med.* 44 (2016) 188–201, doi:<http://dx.doi.org/10.1097/CCM.0000000000001396>.
- [25] R. Kukla, Conscientious autonomy: displacing decisions in health care, *Hastings Cent. Rep.* 35 (2005) 34–44, doi:<http://dx.doi.org/10.1353/hcr.2005.0025>.
- [26] W. Hardyman, K.L. Daunt, M. Kitchener, Value co-creation through patient engagement in health care: a micro-level approach and research agenda, *Public Manag. Rev.* 17 (2015) 90–107, doi:<http://dx.doi.org/10.1080/14719037.2014.881539>.
- [27] M. Olding, S.E. McMillan, S. Reeves, M.H. Schmitt, K. Puntillo, S. Kitto, Patient and family involvement in adult critical and intensive care settings: a scoping review, *Health Expect.* 19 (2016) 1183–1202, doi:<http://dx.doi.org/10.1111/hex.12402>.
- [28] M. Van Manen, *Phenomenology of Practice: Meaning-Giving Methods In Phenomenological Research and Writing*, Left Coast Press, 2014.
- [29] C. Heath, J. Hindmarsh, P. Luff, *Video in Qualitative Research*, Sage Publications, 2010.
- [30] J.W. Creswell, C.N. Poth, *Qualitative Inquiry and Research Design: Choosing Among Five Approaches*, Sage Publications, 2017.
- [31] C.N. Sessler, M.S. Gosnell, M.J. Grap, G.M. Brophy, P.V. O’Neal, K.A. Keane, E.P. Tesoro, R. Elswick, The Richmond Agitation–sedation Scale: validity and reliability in adult intensive care unit patients, *Am. J. Respir. Crit. Care Med.* 166 (2002) 1338–1344, doi:<http://dx.doi.org/10.1164/rccm.2107138>.
- [32] E.W. Ely, S.K. Inouye, G.R. Bernard, S. Gordon, J. Francis, L. May, B. Truman, T. Speroff, S. Gautam, R. Margolin, Delirium in mechanically ventilated patients: validity and reliability of the confusion assessment method for the intensive care unit (CAM-ICU), *JAMA* 286 (2001) 2703–2710, doi:<http://dx.doi.org/10.1001/jama.286.21.2703>.
- [33] A.M. Stiggelbout, A.H. Pieterse, J.De Haes, Shared decision making: concepts, evidence, and practice, *Patient Educ. Couns.* 98 (2015) 1172–1179, doi:<http://dx.doi.org/10.1016/j.pec.2015.06.022>.
- [34] Mangold International GmbH, *Interact User Guide*, (2019). (Accessed 28.04.2019) <https://www.mangold-international.com>.
- [35] K. Malterud, V.D. Siersma, A.D. Guassora, Sample size in qualitative interview studies: guided by information power, *Qual. Health Res.* 26 (2016) 1753–1760, doi:<http://dx.doi.org/10.1177/1049732315617444>.
- [36] World Medical Association, *WMA Declaration of Helsinki- Ethical Principles for Medical Research Involving Human Subjects*, (2013). (Accessed 26.03.2019) <https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/>.
- [37] M.M.W. Karlsen, K. Heggdal, A. Finset, L.G. Heyn, Attention-seeking actions by patients on mechanical ventilation in intensive care units: a phenomenological-hermeneutical study, *J. Clin. Nurs.* 28 (2019) 66–79, doi:<http://dx.doi.org/10.1111/jocn.14633>.
- [38] S. Gallagher, Social interaction, autonomy and recognition, in: L. Dolezal, D. Petherbridge (Eds.), *Body/Self/Other: The phenomenology of social encounters*, SUNY Press, Albany, 2017.
- [39] A.G. Thompson, The meaning of patient involvement and participation in health care consultations: a taxonomy, *Soc. Sci. Med.* 64 (2007) 1297–1310, doi:<http://dx.doi.org/10.1016/j.socscimed.2006.11.002>.
- [40] E. Laerkner, I. Egerod, F. Olsesen, P. Toft, H.P. Hansen, Negotiated mobilisation: an ethnographic exploration of nurse-patient interactions in an intensive care unit, *J. Clin. Nurs.* 28 (2019) 2329–2339, doi:<http://dx.doi.org/10.1111/jocn.14828>.
- [41] M. Baumgarten, I. Poulsen, Patients’ experiences of being mechanically ventilated in an ICU: a qualitative metasynthesis, *Scand. J. Caring Sci.* 29 (2015) 205–214, doi:<http://dx.doi.org/10.1111/scs.12177>.
- [42] I. Egerod, I. Bergbom, B. Lindahl, M. Henricson, A. Granberg-Axell, S.L. Storli, The patient experience of intensive care: a meta-synthesis of Nordic studies, *Int. J. Nurs. Stud.* 52 (2015) 1354–1361, doi:<http://dx.doi.org/10.1016/j.ijnurstu.2015.04.017>.
- [43] A. Holm, P. Dreyer, Nurse-patient communication within the context of non-sedated mechanical ventilation: a hermeneutic-phenomenological study, *Nurs. Crit. Care* 23 (2017) 88–94, doi:<http://dx.doi.org/10.1111/nicc.12297>.
- [44] N. Joseph-Williams, G. Elwyn, A. Edwards, Knowledge is not power for patients: a systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making, *Patient Educ. Couns.* 94 (2014) 291–309, doi:<http://dx.doi.org/10.1016/j.pec.2013.10.031>.
- [45] S.G. Resnick, A. Fontana, A.F. Lehman, R.A. Rosenheck, An empirical conceptualization of the recovery orientation, *Schizophr. Res.* 75 (2005) 119–128, doi:<http://dx.doi.org/10.1016/j.schres.2004.05.009>.
- [46] J. Gerwing, P. Gulbrandsen, Contextualizing decisions: stepping out of the SDM track, *Patient Educ. Couns.* 102 (2019) 815–816, doi:<http://dx.doi.org/10.1016/j.pec.2019.03.024>.
- [47] G. Elwyn, M.A. Durand, J. Song, J. Aarts, P.J. Barr, Z. Berger, N. Cochran, D. Frosch, D. Galasiński, P. Gulbrandsen, A three-talk model for shared decision making: multistage consultation process, *BMJ* 359 (2017) 1–6, doi:<http://dx.doi.org/10.1136/bmj.j4891>.
- [48] G. Makoul, M.L. Clayman, An integrative model of shared decision making in medical encounters, *Patient Educ. Couns.* 60 (2006) 301–312, doi:<http://dx.doi.org/10.1016/j.pec.2005.06.010>.
- [49] F. Légaré, P. Thompson-Leduc, Twelve myths about shared decision making, *Patient Educ. Couns.* 96 (2014) 281–286, doi:<http://dx.doi.org/10.1016/j.pec.2014.06.014>.
- [50] M.B. Happ, J.A. Tate, V.A. Swigart, D. DiVirgilio-Thomas, L.A. Hoffman, Wash and wean: bathing patients undergoing weaning trials during prolonged mechanical ventilation, *Heart Lung* 39 (2010) 47–56, doi:<http://dx.doi.org/10.1016/j.hrtlng.2010.03.002>.
- [51] K.K. Haidet, J. Tate, D. Divirgilio-Thomas, A. Kolanowski, M.B. Happ, Methods to improve reliability of video-recorded behavioral data, *Res. Nurs. Health* 32 (2009) 465–474, doi:<http://dx.doi.org/10.1002/nur.20334>.
- [52] J. Saldaña, *The Coding Manual for Qualitative Researchers*, Sage, 2015.