EMPIRICAL RESEARCH QUALITATIVE

Three patterns of symptom communication between patients and clinicians in the intensive care unit: A fieldwork study

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Abstract

Aim: To describe different patterns of communication aimed at preventing, identifying and managing symptoms between mechanically ventilated patients and clinicians in the intensive care unit.

Design: We conducted a fieldwork study with triangulation of participant observation and individual interviews.

Methods: Participant observation of nine patients and 50 clinicians: nurses, physiotherapists and physicians. Subsequent individual face-to-face interviews with nine of the clinicians, and six of the patients after they had regained their ability to speak and breathe spontaneously, were fully alert and felt well enough to sit through the interview.

Findings: Symptom communication was found to be an integral part of patient care. We identified three communication patterns: (1) proactive symptom communication, (2) reactive symptom communication and (3) lack of symptom communication. The three patterns co-existed in the cases and the first two complemented each other. The third pattern represents inadequate management of symptom distress.

Conclusion: Recognition of symptoms in non-speaking intensive care patients is an important skill for clinicians. Our study uncovered three patterns of symptom communication, two of which promoted symptom management. The third pattern suggested that clinicians did not always acknowledge the symptom distress.

Implications for Patient Care: Proactive and reactive symptom assessment of non-speaking patients require patient verification when possible. Improved symptom prevention, identification and management require a combination of sound clinical judgement and attentiveness towards symptoms, implementation and use of relevant assessment tools, and implementation and skill building in augmentative and alternative communication.

Impact: This study addressed the challenges of symptom communication between mechanically ventilated patients and clinicians in the intensive care unit. Our findings may have an impact on patients and clinicians concerned with symptom management in intensive care units.

Reporting Method: We used the consolidated criteria for reporting qualitative research.

Patient Contribution: A user representative was involved in the design of the study.

KEYWORDS

clinicians, communication, intensive care patients, interviews, nursing, participant observation, qualitative research, symptoms

1 | INTRODUCTION

Relief of symptom distress is a key component of care for patients in the intensive care unit (ICU), regardless of diagnosis and prognosis (Puntillo et al., 2014). Symptoms are defined as subjective experiences of discomfort associated with changes in sensation, cognition, and/or biopsychosocial functioning. In contrast, signs are defined as abnormalities indicative of disease that are observed by others (Harver & Mahler, 1990). Symptom distress is the burden or suffering in the individual caused by the symptoms (Kugler et al., 2009; Rhodes & Watson, 1987). The degree of distress is often related to the intensity of the symptom, but vary among individuals depending for instance on the meaning of the symptom for the individual (Lenz & Pugh, 2018). ICU-patients experience a high symptom burden (Puntillo et al., 2010; Saltnes-Lillegård et al., 2023). Common distressful symptoms are reported to be thirst, pain, dyspnoea, anxiety and sleep disturbances (Decavèle et al., 2019; Devlin et al., 2018; Kalfon et al., 2019). ICU patients also experience discomfort related to medical equipment, reduced mobility, and disturbances in the ICU environment (Kalfon et al., 2019).

Since symptoms are subjective and cannot be objectively measured or monitored, the gold standard for symptom assessment is self-report by the patient (Devlin et al., 2018). Self-report implies that the patients communicate their symptoms to clinicians, and it is the clinicians' responsibility to provide the patients with the opportunity to communicate in a manner adapted to their abilities. Adequate patient–clinician communication is considered a premise for effective symptom management (Bender et al., 2018; Choi & Tate, 2021).

The ICU is a highly technological environment with constant noise, light and busy staff. The patients' critical condition and the complexity of care encumber meaningful patient participation. Adequate communication, however, is essential for patients to express their needs. The patient's capacity to communicate is often obstructed by illness and treatment (e.g. fatigue, delirium or cognitive impairment, the presence of artificial airways or assisted ventilation, sedation). Symptom communication under these premises is a challenge for patients and clinicians alike, and impaired communication often contributes to poor symptom assessment and management and is in itself a cause of symptom distress in critically ill patients (Choi & Tate, 2021; Freeman et al., 2022).

2 | BACKGROUND

Adequate symptom assessment is the first step towards symptom management and relief of symptom distress (Chanques et al., 2015;

Puntillo et al., 2010). Chanques et al. (2015) and Saltnes-Lillegård et al. (2023) identify five of the most stressful symptoms experienced by ICU -patients and suggest that these symptoms should be assessed daily. The prototype of symptom assessment in patients able to self-report is pain assessment, and the most basic form of general symptom assessment in patients with communication difficulties is asking yes/no questions (Chanques et al., 2015). Existing assessment tools have limited usability for patients with communication impairments (Ull et al., 2022), but Choi et al. (2017) offer a description of how to facilitate symptom assessment in non-vocal ICU patients, emphasizing the need to adapt the assessment to the communication abilities of the patient, and minimizing the burden of the assessment for the patient. When patients are unable to self-report, symptoms are assessed by observing behaviour, observations by proxies, or by assuming the presence of symptoms under certain circumstances (Choi et al., 2017; Devlin et al., 2018; Puntillo et al., 2014). Studies looking at associations between symptoms and objective measures like pupillometry or vital signs conclude that vital signs are not valid means of identifying symptoms (Fratino et al., 2023; Shahiri & Gélinas, 2023). A recent Norwegian study describing the symptom burden of ICU-patients reported that out of 603 included patients, 250 were unable to self-report their symptoms during the first 7 days in the ICU (Saltnes-Lillegård et al., 2023). For this large proportion of patients, there is yet to be identified an optimal assessment method. Studies have shown that nurses tend to underestimate and undertreat patients' symptoms (Gentzler et al., 2019; Randen et al., 2013). Berntzen et al. (2019) found that nurses assessed pain systematically, but acted unsystematically in their approach to patients' other symptoms and discomforts. Failure to assess and treat symptoms may cause patients to suffer and have unfavourable outcomes and long-term consequences (Chanques et al., 2015; Jacques et al., 2019) such as pain and post-traumatic stress symptoms for up to 12 months and perhaps even longer after ICU discharge (Langerud et al., 2018; Valsø et al., 2022). The degree of such long-term consequences may be associated with symptoms and suffering experienced while in the ICU (Kyranou & Puntillo, 2012; Valsø et al., 2022).

While the symptom burden remains high in ICU-patients, there is a lack of tools and guidelines for the assessment and management of multiple symptoms suitable for patients with impaired communication abilities. Even when guidelines and tools exist, there is a lack of systematic use, and there is a gap in knowledge about how clinicians identify and manage patient symptoms. In patients unable to self-report, prevention becomes increasingly important and should be studied alongside assessment and management. Thus, there is a need to study symptom communication as it actually takes place between non-speaking patients

and clinicians, without emphasizing specific symptoms or the use of tools. For a holistic picture of the research topic, we chose to conduct a field study exploring the perspectives of both patients and clinicians when looking for patterns of symptom communication, with a wide approach to the term communication. In their communication theory, Watzlawick et al. (1967) define communication as all behaviours in an interactional situation, an approach we found useful when studying communication involving patients with impaired ability to communicate. When describing symptom communication in the following, we include patient behaviour indicative of symptoms as well as the actions of clinicians that might prevent, alleviate or cause symptoms occurring in actual, observed interactions.

3 | THE STUDY

The aim of the study was to describe different patterns of communication aimed at preventing, identifying and managing symptoms between mechanically ventilated patients and clinicians in the intensive care unit.

4 | METHODS

4.1 | Design

We conducted a fieldwork study triangulating participant observation and interviews (Hammersley & Atkinson, 2007). In fieldwork studies, actions and accounts are studied in everyday contexts, data are gathered from several sources, data collection is relatively unstructured, the focus is on a small number of cases, and analysis involves interpretation of meaning and consequences of human practice. A fieldwork study approach was useful in this study where our aim was to explore and describe patterns of symptom communication in the everyday context of the ICU. By entering the participants' environment and exploring the research topic from different perspectives, we ensured a holistic approach that harmonized with our chosen communication theory.

4.2 | Setting

The study was conducted between December 2017 and February 2019 in two general, level 3 ICUs at a Norwegian university hospital. Level 3 is the most advanced level where the ICUs provide complex and comprehensive support and management of organ dysfunction, including advanced pulmonary and hemodynamic support for the most critically ill patients (Marshall et al., 2017). The hospital is a regional and nationwide referral hospital. Level 3 ICUs in Norway are staffed with registered nurses, most of whom hold a formal specialization in intensive care on a master's degree level. Physicians are intensivists or anaesthesiologists with ICU training. Other professions

are available upon referral and besides nurses and physicians; physiotherapists treat the patients on a daily basis. The staffing at the study sites equals a patient: nurse ratio of 1:1.5, with the possibility of adapting to the patient's needs. One unit had six staffed beds and the other had ten.

4.3 | Participants

Mechanically ventilated, non-speaking patients with a Richmond Agitation and Sedation Scale (RASS) score of −1 to +2 (Sessler et al., 2002) were eligible for recruitment. This means that the patients had to be awake or lightly sedated to collaborate. ICU-patients are a heterogeneous group and in a small, qualitative study, the sample will not be representative. Nevertheless, to gather a rich data material, we sought to include a variety in participants and situations. In a fieldwork study, the sample is typically small, but with a varied sample of cases and different approaches to data collection, a rich data material can be ensured. We aimed for a sample with a variety of sedation level, age, gender, illness experiences and observed interactions. For individual face-to-face interviews, we included previously observed patients when they had regained their ability to speak and breathe spontaneously, were fully alert and felt well enough to sit through the interview.

All clinicians interacting with the included patients during observation were included for participant observations. These were nurses, physiotherapists and physicians. One patient and all the participants interacting with that patient constituted one case. Clinicians who had a significant role in the care of the patient and who participated substantially during the observations were selected for interviews. Of the three professions observed, the nurses and physiotherapists spent most time with the patients and took part in individual face-to-face interactions. The physicians mainly spoke briefly to the patients during rounds. Our intention was to interview all the observed patients as well as one clinician per patient, but we experienced dropouts due to death and patient transfer to other hospitals. We considered that the sample size was adequate due to that the triangulation of methods and analysis produced a data material sufficiently rich to meet the aim of the study. The characteristics of the participants, and the content of the material from both participant observations and individual interviews provided us with rich information suitable for this explorative study (Malterud et al., 2016). The characteristics of cases and participants are described in Table 1.

4.4 | Data collection

4.4.1 | Participant observation

The first author (RN) conducted participant observation at the bedside aiming for minimal interference in the interactions between patients and healthcare professionals. Each patient was

observed for 1–3 days, the observations lasted from 5 min to 2.5 h, yielding a total observation time of 2–4.5 h per patient. The duration of observation was determined by relevant activity for symptom communication, i.e., beginning of shifts, where the nurses routinely performed patient assessment, procedures, and physical therapy. Particular attention was paid to all non-verbal communication regarding patient comfort and discomfort. All sounds, including verbal exchange and technical equipment were audio recorded. Data consisted of field notes and transcribed recordings from approximately 28 h of observation. Table 2 illustrates how an observation guide was used to write field notes and to fill in the transcripts from the audio recordings.

4.4.2 | Individual interviews

As soon as possible after participant observation, RN conducted semi-structured individual interviews with patients and relevant clinicians. We developed interview guides with open-ended questions that were similar for patients and clinicians (see Table 3). Interviews varied from 20 to 90 min with a mean of 54 min for patients and 29 min for staff. According to scheduling, staff interviews were conducted immediately or up to 4 weeks after observation.

4.5 | Data analysis

Analysis was based on the principles of ethnographic research as described by Hammersley and Atkinson (2007). We analysed interviews and observation field notes separately, before combining the preliminary analysis for triangulation and further analysis. Interviews were coded and categorized using NVivo 11 software (QSR International, Burlington, MA, USA). All initial coding was performed by RN, assuring analytic consistency. Thereafter, we applied investigator triangulation by discussing codes and themes among all authors who

TABLE 1 Case characteristics.

Case no.	Patient age	Patient sex	Days in ICU at observation	RASS at observation	Participants observed with the patient	Participants interviewed
1	32	Male	18	0/ −2	Nurses = 3 Physiotherapist = 1 Physician = 1	Patient and nurse
2	32	Female	59	0	Nurses = 4	Patient and nurse
3	49	Female	12	0	Nurses = 6 Physicians = 2	Patient and nurse
4	54	Male	11	0	Nurses = 5 Physician = 1	Nurse. Patient already transferred
5	55	Male	2	0	Nurses = 2 Physiotherapists = 2 Physician = 1	Patient and nurse
6	58	Female	9	0	Nurses = 3 Physiotherapist = 1	Patient and physiotherapist
7	66	Male	26	0	Nurses = 4 Physiotherapist = 1 Physician = 1	Nurse. Patient died
8	66	Female	17	0	Nurses = 3 Physiotherapist = 1 Physician = 1	Physiotherapist. Patient died
9	75	Male	10	−1	Nurses = 6 Physiotherapist = 1 Physician = 1	Patient and nurse

TABLE 2 Excerpt from participant observation.

Patient action (field note)	Nurse action (field note)	Other action (field note)	Dialogue (recording)	Sounds (recording)
Lying on her back. Eyes open. Shows few facial expressions and little movement. Shakes her head to questions on pain. Nods when the nurse asks if she is comfortable.	Standing by the patient's bed. Informs, asks. To the patient's response, he asks a questioning 'yes'? When the patient nods, he confirms with a 'yes!'		Nurse: How are you now? Are you in any pain now? Are you comfortable? 'Yes!' 'I will be starting Metavision, the computer program, and then we can talk more a little later?' 'Yes!'	

TABLE 3 Interview guides.

Interview with patients	Interview with clinicians
Please tell me about your experience of being in the intensive care unit and on a ventilator.	Please tell me what happened while I observed you and the patient, what you experienced, and your reflections on the patient's situation.
Could you tell me about what symptoms you experienced while in the ICU?	Was it your impression that the patient was experiencing any symptoms?
You mentioned [symptom] (follow up with questions about the symptoms the patient mentions). How often did you experience [symptom]? How intense was the [symptom]? How distressful was [symptom]? How did it affect you? Did anything make it worse? What helped?	How did you proceed to assess the patient's well-being and symptoms?
Did you experience several symptoms at once? How did they affect each other?	How did you communicate with the patient to enable her/him to convey potential symptoms?
How did you convey your symptoms to the people around you?	I noticed a situation where … Can you tell me about that?
Follow up if needed:	
How did you convey your symptoms to the staff who looked after you?	
What did the staff do to find out what was bothering you?	
When I observed you in the ICU, I noticed… Do you remember that? Could you tell me about that situation?	

confirmed or contested the emerging categories. Through inductive coding, we identified six main categories: *Symptoms, symptom actions, communication, the role of family members, the role of clinicians,* and *patient-centred care.*

The field notes, including transcribed audio recordings from participant observations in each case were condensed and organized for *context, content, characteristics of communication* and *communicants.* Within *content,* we looked specifically at symptoms, and for cross case comparison, we used the most frequently coded symptoms in the interviews to investigate the context, communicants, and communication characteristics for each case.

To meet the aim of our study, the three themes: symptoms, symptom actions and communication were investigated further and compared to participant observation data within each case and across cases. We investigated how patients expressed their symptoms and how clinicians assessed, interpreted, and helped the patients to manage the symptoms. We compared coded observation data with interview text within each case to identify potential inconsistencies regarding symptom communication. Thereafter, we investigated how the different groups of participants, across cases, communicated about and acted on symptoms. Triangulation of data from the interviews and participant observations, within and across cases and participant groups, generated a picture of patterns of communication to prevent, identify and manage symptoms.

4.6 | Ethical considerations

This study was approved by the Regional Committee for Medical and Health Research Ethics (approval number 2017/991) and the data protection officer at the hospital. It was conducted according to the Declaration of Helsinki. Further, verbal and written information about the study was provided, and informed consent was obtained from all participants. First we included patients for participant observation, then we obtained consent from everyone interacting with the patients during the observations. ICU nurses assisted with identification and invitation of eligible candidates. Patients with permanent cognitive/psychological impairment or

those who did not understand Norwegian were excluded. RN (the researcher) approached potential participants to inform them about the study and to obtain consent. Nurses who were familiar with the patients assessed their competence by using the confusion assessment method for the intensive care unit (CAM-ICU) (Ely et al., 2001). If a patient was competent, yet physically unable to sign the consent form, the researcher asked the patient to indicate a response and then a family member or the researcher with an independent witness signed on the patient's behalf. Those who participated in interviews provided separate consent. The researcher is an experienced critical care nurse, currently working at one of the study sites. This has enabled close collaboration with the ICU-staff and decisions on the best timing for observation and interviews.

4.7 | Validity and rigour

Application of multiple triangulations in this study was an asset to obtain trustworthiness (Polit & Beck, 2020). Participant triangulation contributed to credibility by investigating symptom communication from the perspective of patients, nurses and other clinicians. Triangulation of methods enriched the data further. Dependability was obtained by conducting participant observation for several days and in different situations, and then combining the data with the participants' stories from the interviews. Transferability is enhanced by detailed descriptions of sample, setting and observed patterns of communication. The study group consists of nurses with different expertise in research and the clinic. RN had extensive and current experience as an ICU nurse, whereas the last author (MK) is an experienced researcher without particular ICU experience. The remaining authors have extensive experience from intensive care research and symptom research in different patient populations, ensuring different perspectives within the research group. All phases of the process of analysis were discussed within the research group for reflexivity, confirmability and transferability (Polit & Beck, 2020). Moreover, a user representative was involved in the creation of the study and the analysis process. By providing diverse perspectives, differences in interpretation and understanding surfaced and were discussed

until consensus was reached. Confirmability was ensured through a detailed methodological description, using the consolidated criteria for reporting qualitative research to help report important aspects of the study methods, context of the study, findings, analysis and interpretations (Tong et al., 2007).

5 | FINDINGS

Our analysis uncovered a variety of ways in which patients and clinicians communicated about symptoms. Communication of physical symptoms such as pain or dyspnoea was observed more often than psychological symptoms such as fear or anxiety. Participant observation revealed symptom communication as an integral part of patient care. Although not always the main focus of dialogue, symptoms were addressed as part of the patient–staff interaction, and a culture of symptom prevention and comfort promotion were reflected in the actions of the clinicians. Rather than asking about specific symptoms, clinicians asked general questions regarding patients' well-being or needs. Typical examples from different cases are shown in Table 4.

We identified three different patterns of communication to prevent, identify and manage symptoms: (1) proactive symptom communication; (2) reactive symptom communication and (3) lack of symptom communication. (Table 5).

5.1 | Pattern 1: Proactive symptom communication

Proactive symptom communication was seen when clinicians took charge and asked about patients' symptoms or well-being. The

clinicians systematically aimed to prevent and identify symptoms. Apart from assessment tools for pain, we neither observed nor received report of systematic use of instruments for symptom mapping. While performing procedures, clinicians studied the patients' facial expressions for signs of pain, fear, or discomfort and looked for communication attempts. They continually explained their actions, aiming to prevent anxiety by ensuring the patient was informed: 'We'll start with changing this dressing, so it'll be nice and clean' and 'we are going to turn you towards me, and then remove the sheet and place a clean one under you'. Gentle handling and careful positioning in bed were performed to prevent pain. Patients reported that the behaviour of clinicians during procedures could cause or prevent symptoms. One patient described how each nurse performed tracheal suctioning differently, a procedure she found painful and traumatic: 'Some went down quickly, fixed it… probably effectively and fine. But it wasn't fine for me. It was better when they didn't go as deep down that felt more okay to me'.

At the beginning of shifts and before and during procedures, clinicians asked about pain or other symptoms relevant to the situation. Except for rating the patients' pain on numeric rating scale, no tool was used for other symptoms. Patients commonly responded with nodding or shaking head, mouthing or gesturing. Symptoms relevant to mobilization and physical therapy were e.g., pain, shortness of breath, tiredness, nausea, and dizziness. If necessary, activities were adjusted and medications administered. A physiotherapist said: 'I always start with assessing pain at rest. Then I repeat the question when bending knees and hips before further mobilisation'. In the following excerpt from observation of case 7, a physiotherapist and nurses are preparing to reposition the patient from supine position to sitting on the bedside (Table 6).

5.2 | Pattern 2: Reactive symptom communication

Reactive symptom communication was seen when clinicians got their clues from the patient and asked the patient to verify the observation. Clinicians observed and interpreted facial expressions, body language, and vital signs in context to identify symptoms. Typically,

TABLE 4 Examples of inquiry by clinicians.

- 'How are you today? Better?'
- 'Are you comfortable? Or do you want us to change your position in bed?'
- 'Are you doing okay?'
- 'Is there something you were wondering about?'
- 'Is there something else you would like to tell me, or try to write or…?'

TABLE 5 Three patterns of symptom communication.

	Proactive symptom communication	Reactive symptom communication	Lack of symptom communication
Prevent	Systematic inquiry aimed at preventing symptoms.		
Identify	Assessment at the beginning of the shift and before and during procedures.	Ongoing observation of patient expressions indicating distress. Interpretation of signs and verification with patient.	Making assumptions regarding symptoms without patient verification. Observing signs or patient expressions.
Manage	Non-pharmacological treatment before medication.	Treatment of the underlying cause, e.g. optimizing breathing, adjusting nutrition and promoting sleep.	Treatment of unconfirmed symptoms or not following up on observations or patient expressions.

a nurse made an observation, asked the patient about a symptom that could be related to that observation, and waited for verification:

> 'When she was off the ventilator... I'm not quite sure what I saw in her face. But I felt in a way that she changed somehow in the way she was, that she wasn't quite as present, her heart rate increased, and she seemed more insecure. So, we asked if she was anxious, and she confirmed it'.

The nurse observed the patient's body language and based on her professional experience, interpreted it as anxiety related to ventilator weaning and asked for verification. When verified, the nurse took measures to alleviate the symptom and then reassessed.

In the following example, the nurse responded to low oxygen saturation alarm by increasing oxygen level and simultaneously asking the patient about symptoms (Table 7).

If a patient expressed dyspnoea, the clinician optimized oxygenation and ventilation and then informed and reassured the patient that everything was okay:

> 'He gets very anxious, and then he feels shortness of breath, according to himself, so I ask if it is hard to breathe in? Is it hard to breathe out? I need to be aware because of his chest tube, so things could happen, although I should be able to see it on the monitor. But it's okay to ask, and when everything else is ruled out, I think it is most probably anxiety'.

With the underlying causes of potential dyspnoea checked, treated, or eliminated, the nurse interpreted the patient's response as anxiety.

5.3 | Pattern 3: Lack of symptom communication

Lack of symptom communication was seen when clinicians failed to address symptoms, although they were present or anticipated. In one case, both nurse and patient discussed the patient's anxiety during the interviews, but never addressed anxiety during participant observation (Table 8).

In the interview example (Table 8) the nurse assumed that the patient was anxious but failed to seek patient verification. As such, care was on non-communicated assumptions.

One patient described nightmares as a major concern, causing both fear and sleep disturbances:

> 'It puts a fear in you of closing your eyes. I tried it, and there it was, immediately, and then the eyes stay open. It's like choosing between the devil and the deep blue sea. So, you choose to be tired, with eyes open, rather than that awful...it becomes a no-rest, because it is exhausting, really. Scary'.

The researcher observed that the patient expressed this to a nurse (Table 9).

The nurse understood the patient's experience of the nightmares that were troubling her, but she did not follow up on it. The nurse minimized the experience by asking about 'a little bit of a nightmare'. These nightmares and subsequent fear were later among the patient's strongest memories from her ICU stay.

The first two patterns of symptom communication were seen in all cases as integrated, essential parts of patient care. The third pattern was not always obvious until different sources were triangulated to provide a more complete view of the interaction.

TABLE 6 Excerpt from participant observation, case 7.

Patient action (field note)	Nurse action (field note)	Other action (field note)	Dialogue (recording)	Sounds (recording)
Following the nurses and physiotherapist with his eyes. Responding with nods and mouthing 'a little'.	Standing by the patient's bed. Observing the patient.	The physiotherapist (PT) is standing by the patient's bed, elevating the head of the bed to move the patient to a sitting position. PT pauses the bed elevation.	Nurse: Are you getting dizzy when you come up like this? ... A little. Then we will take a break before we continue.	

TABLE 7 Excerpt from participant observations, case 2.

Stimuli/environment	Nurse	Patient
Monitor alarm 'Low SpO2'	*How are you feeling? Are things okay now?* Increases FiO_2 on ventilator *Is your breathing okay? Yes!* (repeats patient's confirmation) *No pain? No! Okay!* (repeats patient's invalidation)	Nods (indicates breathing is okay) Shakes head (indicates that she has no pain)

TABLE 8 Excerpts from interviews, case 1.

Patient interview	Nurse interview
Patient: *I have not told them that I'm anxious and afraid, but other things I needed help with, they fixed.*	Nurse: *Anxiety. I do not think he realizes it himself. So, it's difficult.*
Interviewer: *Did they ask you?*	Interviewer: *Did you ask him about it?*
Patient: *No. They asked, 'are you okay?' sort of. 'Is there anything you want?'*	Nurse: *No. So it's just my perception.*

TABLE 9 Field note from participant observation, case 6.

Patient writes on a writing board.
Nurse reads out loud: *Difficult to rest with my eyes closed. Seeing so many dramatic pictures.*
Nurse: "Are you having a little bit of a nightmare when you fall asleep?"
Patient nods and writes: *Pictures*
Nurse: "Pictures yes. Pictures from your stay in the ICU?" [Patient shakes head] "No? Shall I take the board away?"

6 | DISCUSSION

We will discuss the three previously described patterns of symptom communication in the ICU in the following section.

6.1 | Pattern 1: Proactive symptom communication

Our findings show how clinicians proactively prevented and assessed for symptoms through systematic actions. This pattern of symptom communication covered targeted assessment of expected symptoms as well as ensuring patient comfort. Certain symptoms were explicitly stated, while considerations such as gentle handling, continuous information, and reassurances were integrated in care, i.e., observed as action, but not addressed or thematized verbally by the staff during patient interaction. We interpret these actions as attempts to prevent pain or anxiety and consider this approach to suggest that the clinicians acknowledged that patients might experience symptoms and discomfort that they were unable to express (Nyhagen et al., 2022). While use of assessment tools is considered essential for targeted and systematic symptom management in intensive care (Chanques et al., 2015; Choi et al., 2017; Devlin et al., 2018), non-speaking patients may have difficulties responding to such tools, and few tools exist that are custom made for patients unable to self-report. Preventive measures based on experience on when to expect symptoms to occur reduce the need for patients to report symptoms and may be particularly valuable in the care of patients unable to self-report. An important finding was that physical symptoms were easier subjects of communication than psychological experiences, such as fear, anxiety, hallucinations, and nightmares. This means that the clinicians need to find ways to discuss less visible symptoms.

Patients may also experience distress caused by other symptoms and discomfort than those assessed (Baumstarck et al., 2019). Assessment tools may enhance the assessment of a specific symptom, but the patients' symptom burden includes numerous symptoms and varies among individual patients. Pain assessment tools were in use at our study sites, but even after pain relief, patients might struggle with other symptoms (Berntzen et al., 2018). Although the clinicians in our study were aware of potential symptoms, they did not apply validated assessment tools. "Inconforts des Patients de REAnimation" (IPREA) is an 18-item questionnaire that enables ICU patients to self-report discomfort including, but not limited to, symptoms (Baumstarck et al., 2019). This comprehensive tool may meet the need for a holistic approach to symptom assessment, but the patients' experience may not always align with the symptoms described in the literature (Campbell & Happ, 2010). The Patient Symptom Survey (PSS) is another questionnaire, assessing prevalence, intensity and distress of common symptoms (Puntillo et al., 2010; Saltnes-Lillegård et al., 2023). Both IPREA and PSS are developed for patients able to self-report, and thus leaves out a large proportion of ICU-patients. Nurses have stressed the importance of using clinical judgement together with assessment tools, for example when distinguishing between pain and need for sedation (Wøien & Bjørk, 2013). With the gentle care and vigilance towards patients' expressions, clinicians in our study were alert towards unexpected symptoms. Moreover, enabling communication through continuous information provision, focused observations and non-verbal communication, such as touch, nodding and eye contact, in itself might help prevent symptoms like anxiety, depression and frustration (Freeman et al., 2022). Furthermore, augmentative and alternative communication (AAC) tools may be useful to encourage communication and detect hidden symptoms (Hosseini et al., 2018; Koszalinski et al., 2020). Although the participants in our study rarely used assessment tools, the pattern of proactive symptom communication revealed patient care with an aim to maximize comfort and minimize discomfort, including symptom distress. While studies show the limitations of assessment tools, the pattern of proactive symptom communication in our study demonstrates how clinicians rely on experience and clinical judgement to prevent, identify and manage patients' symptoms, as a supplement to assessment tools or when assessment tools are unavailable or futile.

6.2 | Pattern 2: Reactive symptom communication

In addition to proactive symptom communication, clinicians used a reactive approach to symptom assessment by observing patient expressions as indicators of symptoms. In addition to patients' self-reports, clinicians rely on physiological and behavioural signs to interpret symptoms (Devlin et al., 2018). These signs are not accurate indicators of symptoms, but must be interpreted according to context, applying professional experience and competence in symptom assessment (Puntillo et al., 2008; Puntillo et al., 2014).

It is essential that clinicians seek verification from patients, whenever possible. In our study, dyspnoea was often addressed following observation of poor breathing. When breathing improved, the clinician ruled out dyspnoea and re-labelled the symptom as anxiety. Campbell and Happ (2010) describe how it may be difficult to ensure that patient and staff are referring to the same aspects of the symptom when patients are experiencing breathing difficulties. We observed this cascade of symptom interpretation when dyspnoea was identified by clinicians as anxiety. Dyspnoea and anxiety often occur concurrently and intensify each other, so both symptoms are likely to be present (Decavèle et al., 2019). Clinicians acknowledged symptoms more aptly if they could be verified by objective signs. This is supported by Dodd et al. (2001) who point out how observable problems may be given more attention than non-observable problems. This agrees with our finding that physical symptoms are easier to communicate about than psychological symptoms. Furthermore, Choi et al. (2017) suggest that nurses assess symptoms from their own perspective and that their line of questioning may be influenced by their experience and ability to treat. During the interviews, clinicians in our study explained how they responded to clinical observations and monitor readings as observed by the researcher during participant observations. This provided insight into the rationale for their line of questioning and which problems were given attention. The interviews suggested that the clinicians prioritized the potentially most serious problem in terms of threats to the patient's organ functions. This may or may not align with what was most distressing to the patient. Due to potentially long-term consequences for patients (Jacques et al., 2019), it is essential that clinicians also systematically pay attention to distressing symptoms that may not be a threat to the patient's physiological functioning.

6.3 | Pattern 3: Lack of symptom communication

The third communication pattern revealed that clinicians could make assumptions about symptoms without patient verification or make observations that they failed to follow up. This prevented effective symptom communication. Communication issues in critically ill, sedated and intubated patients are well known. Our previous study suggested that unidentified communication challenges caused inadequate symptom management (Nyhagen et al., 2022). Campbell and Happ (2010) suggest that nurses may be reluctant to ask non-speaking patients about psychological symptoms, which supports our findings. Our field study showed that anxiety and nightmares were experienced by patients and anticipated by nurses but were not managed adequately in all instances. Failure to address psychological symptoms may be attributed to the assumption that issues of this nature are too complex to manage. Moreover, nurses might fear that raising existential questions to a patient with severely impaired communication abilities could result in difficult and inadequate dialogues, leading to increasing frustration rather than distress relief.

Targeted interventions aiming to improve communication skills among clinicians and extend the use of AAC are shown to improve symptom communication and increase the length of communication exchange (Happ et al., 2014). These measures might enable communication about symptoms that are perceived as difficult to address. Extended use of high-tech AAC is perceived by patients to improve symptom management (Ju et al., 2021), however there are still uncertainties and disagreements on the effectiveness of AAC, and the choice of and timing of communication aids (Rose et al., 2021). In our study, we did not observe the use of high-tech AAC and we did not ask the clinicians specifically about their use of AAC in the interviews.

It has been shown that communication is often led by nurses and thus, the content is decided by nurses rather than patients (Happ et al., 2011). This often leads to brief and task-oriented communication, which is insufficient to meet patients' needs (Leung et al., 2018). Our patient interviews showed that some of the patients' main concerns were not addressed satisfactory, although this was not apparent in observation and interviews with staff. This illustrates yet again the complexity of symptom communication and the value of taking different approaches and perspectives in research. Lacking tools to help patients cope with symptoms may cause clinicians to hesitate to bring them up (Choi et al., 2017). Most patients in our study agreed that it was easy to get attention to acute pain, whereas patients with chronic pain experienced suboptimal pain relief. This may be because procedural and acute pain is often anticipated, straightforward to assess and manage, while chronic pain requires a more holistic and long-term approach with an uncertain outcome.

In 2008 Puntillo et al. found that nurses were accustomed to observing signs without consistently asking the patients about their experiences (Puntillo et al., 2008). Although contemporary ICU clinicians are familiar with conscious mechanically ventilated patients, some of our participants admitted to sometimes neglecting to ask patients about symptoms. Our findings suggest that it is still a challenge for clinicians to explore patients' symptom experiences rather than relying on their own observations and assessments.

The three patterns of symptom communication reflect the complexity of symptom assessment and management in the ICU. The first and second patterns complement each other, whereas the third illustrates failed symptom communication.

6.4 | Strengths and limitations

The timing of the interviews was variable. Thus, the findings from interviews could not be used to reconstruct specific episodes, but provided insights into issues that were of importance to the participants. In addition, the first author worked at one of the study sites. This may have influenced participants being observed and interviewed, but it also ensured that she could easily adapt to the activities and blend in. The data were collected pre-pandemic, in a setting unfamiliar with the consequences of COVID 19 and the strict infection control measures

had on i.e., communication and visitation policies. Although these issues were certainly relevant at the study sites during the pandemic, these changes have not been permanent. Furthermore, our patient participants' sedation level did not differ from today's norm.

6.5 | Recommendations for further research

Symptoms and symptom communication should be studied beyond the use of assessment tools and presence of single symptoms. More studies should also look into symptom communication as an integrated part of patient care and consider whether our findings are valid in other settings. The application of fieldwork methods are valuable in understanding complex and dynamic communication situations as they unfold. Use of video-based observations could add to more detailed explorations of communication in these complex situations, but raise important ethical issues. The three patterns of symptom communication could be the starting point for developing a situation specific theory of symptom communication in mechanically ventilated ICU patients (Im & Meleis, 1999). This would facilitate training of ICU clinicians in this complex skill. Further research should study how symptom communication can be improved by the use of assessment tools and augmentative and alternative communication. Particular attention should be directed towards assessment of psychological concerns and address symptom distress in order to reduce long-term consequences among ICU patients.

6.6 | Implications for practice

Our study may raise awareness among clinicians about the complexity of symptom communication and possible techniques and fall-pits in the prevention, identification and management of symptoms. It may serve as a starting point for the implementation of new routines and training of clinicians in symptom communication. Implementation and clinical testing of available AAC methods to facilitate symptom communication should be considered. Patient and family involvement in developing and testing useful tools might improve patient-centred approaches to symptom communication.

7 | CONCLUSION

Recognition of symptoms in non-speaking ICU-patients is an important skill for clinicians. ICU-patients' ability to express their symptoms enables effective communication. Our study uncovered three patterns of symptom communication, two of which promoted symptom management. The third pattern suggested that clinicians did not always acknowledge symptom distress. Improved symptom prevention, identification and management require a combination of sound clinical judgement and attentiveness towards symptoms, implementation and the use of relevant assessment tools, and implementation and skill building in augmentative and alternative communication.

AUTHOR CONTRIBUTIONS

All authors have agreed on the final version and met at least one of the following criteria (recommended by the ICMJE*): (1) substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data; (2) drafting the article or revising it critically for important intellectual content. *http://www.icmje.org/recommendations/.

CONFLICT OF INTEREST STATEMENT

We declare no conflicts of interest.

PEER REVIEW

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DATA AVAILABILITY STATEMENT

The data that support the findings of this study are not publicly available due to privacy or ethical restrictions. Parts of the data may be made available on request from the corresponding author.

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