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A sense of agency: An ethnographic exploration of being awake during mechanical ventilation in the intensive care unit

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ABSTRACT

Background: There is a current trend towards lighter or no sedation of mechanically ventilated patients in the intensive care unit. The advantages of less sedation have been demonstrated as shorter duration of mechanical ventilation and reduced length of stay in the intensive care unit and hospital. Non-sedated patients are more awake during mechanical ventilation, but little is known about how this affects the intensive care patient.
Aim: To explore patients' experiences of being awake during critical illness and mechanical ventilation in the intensive care unit.
Design & methods: The study was based on Interpretive Description, an applied inductive, qualitative approach with an ethnographic exploration of the patient experience. A longitudinal perspective was obtained through 13 months of fieldwork followed by two patient interviews after intensive care and after hospital discharge. Data were analyzed using thematic analysis.
Setting & participants: The fieldwork was conducted in two intensive care units at a university hospital in Denmark, where the no sedation strategy for mechanically ventilated patients was implemented. Twenty-eight patients were observed in the intensive care unit. Twenty patients, who had been awake for most of the time on mechanical ventilation, were interviewed during the first week after discharge from intensive care. Thirteen of these patients were interviewed again two to four months after discharge.
Findings: Three themes were identified: "A sense of agency", "The familiar in the unfamiliar situation" and "Awareness of surrounding activities". Patients had the ability to interact from the first days of critical illness and a sense of agency was expressed through initiating, directing and participating in communication and other activities. Patients appreciated competent and compassionate nurses who were attentive and involved them as individual persons. Initiatives to enhance familiar aspects such as relatives, personal items and care, continuity and closeness of nurses contributed to the patients' experience of feeling safe and secure in the unfamiliar setting. Patients were aware of the surrounding activities and felt powerless when ignored by the staff and were affected when witnessing fellow patients' suffering.
Conclusion: Being awake during mechanical ventilation entailed new opportunities and challenges for critically ill patients. Patients found themselves at the interface between agency and powerlessness as they were able to interact, yet were bound by contextual factors such as bodily weakness, technology, spatial position and relational aspects. This knowledge is important to develop patient-centered nursing practice in the context of lighter sedation.

What is already known about the topic?

- There is an international trend towards lighter sedation in mechanically ventilated patients in the ICU.
- Research has shown that patients are perceived as passive objects during the critical stage of illness.
- Research into patients' experiences of being awake during mechanical ventilation is sparse and often derived from only one post intensive care interview.

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What this paper adds

- Being awake during mechanical ventilation enabled the patient to interact and express a sense of agency even during the first, critical phase of the ICU stay.
- Patients preferred competent and compassionate nurses who involved them and were attentive to make them feel safe and secure in the unfamiliar ICU.
- Awake patients were particularly disturbed by witnessing other patients suffering in the ICU.
- Awake, mechanically ventilated patients sense of agency was bound by contextual factors such as critical illness, bodily weakness, spatial position and relational aspects.

1. Introduction

In recent years there has been a trend towards lighter sedation for mechanically ventilated patients in the intensive care unit (ICU) (Kress and Hall, 2012; Roberts et al., 2012; Wunsch and Kress, 2009). A randomized controlled trial showed that the duration of mechanical ventilation as well as ICU and hospital length of stay were decreased in patients receiving no sedation versus patients receiving sedation with daily sedation interruption (Strom et al., 2010). A study found that patients receiving no sedation were significantly more awake and alert during the first week of mechanical ventilation, than sedated patients with daily sedation interruption (Laerkner et al., 2016). The present study exploring patient experience of being awake during mechanical ventilation is part of a larger study investigating experiences, actions and interactions of patients and nurses in the context of no sedation during mechanical ventilation in the ICU. It is our assumption that the new paradigm of light or no sedation, early mobilization and delirium management has implications for the patient experience and for nursing practice.

2. Background

Continuous and heavy sedation is associated with prolonged mechanical ventilation, increased complications, and a longer ICU and hospital length of stay (Barr et al., 2013; Burns, 2012). Currently, national and international guidelines recommend light or no sedation during mechanical ventilation, where patients are pain free and able to communicate (Fonsmark et al., 2015; Barr et al., 2013).

Intensive care is primarily aimed at saving lives. The application of life-sustaining technology, advanced treatment and close observations, however, might lead to objectifying and depersonalizing the patient during the most critical phase of illness (Almerud et al., 2007; Koksvik, 2016; Mclean et al., 2016). The vulnerability caused by organ failure, existential threat coupled with dependence on medical equipment, leaves the critically ill patient in a state of passivity, being speechless, powerless and dependent on health professionals (Lykkegaard and Delmar, 2013). The patient experience of mechanical ventilation in the ICU has been explored for years, and several papers have synthesized the qualitative data. A *meta*-synthesis of 26 papers (1967–2011) identified eight common themes related to altered perceptions of reality, body and time, the proximity of death, the ICU environment, technology and dependence, communication, relationship with staff, family support and transfer from ICU (Cutler et al., 2013). A *meta*-synthesis of 16 publications (1994–2012) identified five themes: fear due to loss of control, disconnection with reality, impaired embodiment, construction of coping patterns, and trust/caring relationships (Tsay et al., 2013). A *meta*-synthesis of nine Nordic papers (1996–2013) identified 15 common themes related to the experience of communication, proximity of staff, altered body functions, ICU environment, time, reality, information, sleep, anxiety/fear/loneliness, dependence, suffocation, suction, involvement, hope/longing and relatives (Baumgarten and Poulsen, 2015). Finally, a second Nordic *meta*-synthesis of 22 papers (2000–2013) identified the core theme of existential fear, 'the patient experience when existence itself is at stake', and four common themes of existing in liminality, unboundedness, mystery and on the threshold (Egerod et al., 2015). None of the above *meta*-syntheses reflected changes in the patient experience related to altered sedation strategies in the ICU within the past 10–15 years.

Only a few small-sample studies have investigated the experience of being conscious and awake during mechanical ventilation. In a study of eight patients, Karlsson and Forsberg (2008) found that patients sought to master their situation and were comforted by the presence of somebody close by and by being treated with dignity. The patients suffered when they experienced negligent care and objectification. These patients were sedated during the acute phase and it is unclear how long after ICU discharge the interviews took place. In another study, Karlsson et al. (2012a) interviewed 12 patients one week after ICU discharge. The patients were conscious for at least 18 h on mechanical ventilation and described the sensation of being held captive in a passive state of helplessness yearning for independence. In a recent study, Holm and Dreyer (2017) interviewed four patients 1–2 days after extubation, who had been conscious most of the time during mechanical ventilation. The patients were bothered by the endotracheal tube and felt drugged although they were assessed as conscious. However, the majority of the patients received opioids as infusion. Prime et al. (2016) conducted post ICU interviews based on a survey of 16 patients who had been lightly sedated during mechanical ventilation. They found that some patients accepted lighter sedation and willingly endured pain and discomfort in exchange for the ability to communicate. A different approach was used in a study by Karlsson et al. (2012c), who videorecorded interviews with 14 conscious patients during intubation and mechanical ventilation in the ICU. The patients experienced discomfort related to pain, endotracheal suctioning, breathing difficulties and frequent disturbances. Most of these studies were based on single interviews and some fell short regarding detailed contextual information on the ICU environment, staffing ratio, patient illness severity and level of consciousness during the entire time on mechanical ventilation. We assume the change from deep to lighter or no sedation in many ICUs might have affected the patient experience. Longitudinal studies of awake mechanically ventilated patients in the particular context of the ICU are needed to get a nuanced and contextualized understanding of patients' experiences. This important aspect of intensive care could expand the health professionals' awareness and improve their focus on patient concerns.

2.1. Aim

The study aimed to explore patients' experiences of being awake during critical illness and mechanical ventilation in the ICU.

3. Methods

The study was based on Interpretive Description, an applied inductive, qualitative approach inspired by ethnography, grounded theory and phenomenology (Thorne, 2016; Thorne et al., 2016). This direction was relevant to obtain knowledge about patientś experiences of being awake during mechanical ventilation, as it takes into account the dynamic complexities of clinical practice and seeks to gain insight and knowledge in line with nurses' disciplinary understanding. Based on the ethnographic approach (Emerson et al., 2011; Spradley, 1980), we chose participant observation in ICU and post-ICU interviews to get close to everyday patient experiences. Data were generated during 13 months of fieldwork in two ICUs (August 2011–February 2012, and September 2012–February 2013). Patients were interviewed once during the first week after ICU discharge followed by a second interview after two to four month. The first author had experience with the methodology and conducted all participant observations and interviews.