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Research article

Patients' lived experience of intensive care when being on mechanical ventilation during the weaning process: A hermeneutic phenomenological study

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ABSTRACT

Background: The medical and nursing care of the patient on mechanical ventilation has developed and proceeds in terms of ventilator functions, sedation strategies and patient participation. New data are needed to explore the weaning process from the patients' perspective. Therefore, the aim of this study was to explore the meaning of being a patient on mechanical ventilation during the weaning process in the intensive care unit.

Methods: This study used van Manen's hermeneutic phenomenological approach. Interviews were conducted, including twenty former intensive care patients from three different hospitals in Sweden.

Findings: Five themes emerged including thirteen related themes; Maintaining human dignity, Accepting the situation, Enduring the difficulties, Inadequate interaction and A sense of unreality. The experiences differed from each other and varied over time, and the same patient expressed both pleasant and unpleasant experiences. Weaning was not a separate experience but intertwined with that of being on mechanical ventilation in the intensive care unit.

Conclusions: The patient's experiences differ and vary over time, with the same patient expressing various experiences. The favourable experiences were more clearly described, compared to previous research, this might depend on factors related to communication, participation and proximity to healthcare professionals and next-of-kin.

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Implications of Clinical Practice

- By including the patient during the weaning process, they get an experience of being a human being well taken care of, thus the unpleasant experiences might be reduced.
- The development of communication strategies for patients on mechanical ventilation needs to continue in daily clinical work, as well as in the clinical research and quality improvement field.
- Person centred care in the intensive care unit and during the weaning process needs to be further explored and including the family perspective to optimise the implementation.

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Introduction

Weaning from mechanical ventilation (MV) is challenging for patients in the intensive care unit (ICU). Furthermore, it is a complex process influenced by several factors, e.g., underlying and current medical and psychological conditions, sedation and the care culture. These factors place several demands on the critical care treatment and nursing (Brochard and Thille, 2009; Macintyre, 2012; Tingsvik et al., 2015). There are various definitions and descriptions of weaning in the literature, including guidelines recommending spontaneous breathing trials (SBT) (Boles et al., 2007; McConville and Kress, 2012) and the use of weaning protocols (Blackwood et al., 2010; Macintyre, 2012). Despite these recommendations, a substantial variety of clinical practice exists (Pham et al., 2017) often covering the entire process of liberating the patient from mechanical support and artificial airway. In this study we employed the definition of weaning by Mancebo (1996, p.1923): "Weaning from mechanical ventilation represents the period of transition from total respiratory support to spontaneous breathing". Regardless the clinical approach of weaning, the goal is to timely recognise the patient ready to wean and extubate (Boles et al., 2007; McConville and Kress, 2012; Rose, 2015).

In recent decades, there has been substantial development in the care of patients on MV. Ventilators have been developed to optimise the treatment and make it more comfortable (Boles et al., 2007; Karcz et al., 2012). Strategies for sedation and pain treatment have also improved (Barr et al., 2013; Egerod et al., 2013; Shah et al., 2017). Today, the benefits of less sedation during MV are well accepted. Lightly sedated patients have less complications (Barr et al., 2013; Schweickert et al., 2004), thus spend a shorter time on MV and in the ICU (Strøm et al., 2010). Furthermore, the importance of early mobilisation of patients in the ICU has been demonstrated and nowadays some level of mobilisation is a daily routine (Denehy et al., 2017; Needham, 2008). Less sedated patients have an increased need as well as better prerequisites to be involved in their own care. Currently, the concept of person centred care (PCC) is widespread in healthcare, in terms of the patient as a capable and vulnerable person with resources (Ricœur, 1994). PCC is established by the patient narrative, the partnership, and the documentation and also considers and synthesises the person's perspective and medical facts (Ekman et al., 2011). Studies outside the ICU have shown that PCC is of great benefit in terms of patient outcome, experience and satisfaction (Ekman et al., 2012; Hansson et al., 2017; Pirhonen et al., 2017). To the best of our knowledge, there is only limited research of PCC in the ICU (Goldfarb et al., 2017).

Studies focusing on patients' experiences of the weaning process are rare, but available research indicates that weaning constitutes both a physical and a psychological effort, which is often frightening and distressing, irrespective of progress (Engstrom et al., 2013; Rose et al., 2014; Schou and Egerod, 2008). Patients' experiences of MV in the ICU have been described in recent qualitative studies with few participants and evaluated in a metasynthesis of nine studies published between 1994 and 2012 (Baumgarten and Poulsen, 2015). In the synthesised findings, patients' experiences were characterised by dependence on healthcare professionals without being able to communicate. Although the included studies focused on different aspects such as sedation, communication and respiratory care, they indicated that being a patient on MV means placing one's life in the hands of others and being strongly dependent on staff and next-of-kin. Furthermore, the experience is expressed as an emic vulnerability consisting of anxiety, fear and loneliness. On the other hand, patients had both pleasant and unpleasant memories of the ICU

(Baumgarten and Poulsen, 2015). Therefore, it is essential to optimise the time spent on MV and improve the weaning process (MacIntyre, 2007; Schmidt et al., 2017), both from medical aspects as well as nursing care. The weaning process is complex and there has been a change in the medical and nursing care of patients on MV. This means other demands on the care of the patient on MV and weaning in terms of patient participation, communication and interaction. Moreover, the literature contains conflicting, and maybe confusing, information about when and in what way the weaning process should start and proceed (Boles et al., 2007; Pham et al., 2017; Rose, 2015) as well as the experiences of the patients.

Aim

The aim of the study was to explore the meaning of being a patient on mechanical ventilation during the weaning process in the ICU.

Method

Design

An explorative and inductive design with a hermeneutic phenomenological approach according to Van Manen (1997) was chosen. This approach enables a deep understanding of lived experiences by exploring a phenomenon from an individual's own perspective.

Settings and participants

The study was carried out on three ICUs in Sweden. The ICUs were at university, county and district level, had eight, seven and five beds respectively and the nurse-patient ratio was approximately 1.4:1. Clinical practice of the weaning process was in accordance with the definition stated in this paper, weaning protocols or spontaneous breathing trials were not common clinical practice. No physical restraints were used. Former patients who met the following inclusion criteria were identified: age > 18 years with experience of being on MV and weaning in the ICU for at least two days, a sedation level of -2 to +1 on the Richmond Agitation-Sedation Scale (Sessler et al., 2002), ability to remember some parts of their ICU stay, understand and speak Swedish and communicate their experience. A purposive sampling (Polit and Beck, 2016) was used, primarily based on age, gender, reason for MV, time on MV, type of artificial airway and hospital level. Comorbidity, self-estimated function level and occupation at enrolment were also considered.

Potential patients at the three ICUs were identified and discussed with first author (CT). Eligible patients (n = 26) were briefly informed about the study by the dedicated specialist nurse at their follow up clinic during a routine visit six to twelve weeks after discharge. They were then introduced to the first author, with whom they had no professional connection, who informed about the study, invited them to participate and requested their informed consent. Five declined participation and one was excluded due to dementia. Twenty participants, eleven men and nine women aged between 43 and 82 years (median 66 years), were included in the study. All had previously been hospitalised for a variety of medical and surgical diagnoses (e.g., sepsis, pneumonia, heart failure, cardiac arrest, aortic aneurysm, chronic obstructive pulmonary disease, cerebral haemorrhage and postoperative complications). The time on MV ranged from 2 to 42 days (median 8).

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