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Title

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

Abstract

Background: The medical and nursing care of the patient on mechanical ventilation has developed and proceed in terms of ventilator functions, sedation strategies and patient participation. New data is 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 ICU-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 ICU.

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.

Implications of Clinical practice

- * By including the patient during the weaning process, he/she gets 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 ICU context and during the weaning process needs to be further explored and including the family perspective to optimise the implementation.

Keywords

hermeneutic phenomenology, intensive care, mechanical ventilation, nursing, patients, weaning

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 (Ricoeur, 1994). PCC is established by the patient narrative, the partnership, and the documentation and also consider 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 at 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 were in accordance to 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,

sex, 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).

Data collection

Data were collected between October 2015 and January 2017, using semi-structured interviews (Polit and Beck, 2016, Van Manen, 1997) conducted by the first author (CT). The interviews took place two to four months after discharge from the ICU. All participants were asked to choose the time and place for the interview, which was mainly performed in conjunction with a routine ICU follow-up visit. Six participants chose a day other than their follow-up visit and one wanted to be interviewed in her/his own home. Four participants were accompanied by a next-of-kin. Prior the interview, trust was established by informal conversations. An interview guide (Kvale and Brinkmann, 2009) was employed, consisting of one main question and four subject areas to fully cover the experience and Van Manen (1997) lifeworld existentials; lived space, lived body, lived time and lived human relations (Table 1). An opening question was posed to create a positive atmosphere during the interview: “Can you please describe what happened and why you had to be cared for on MV in the ICU?”. The main question was: “Can you describe what it is like to be on MV in the ICU?” followed by probing questions to fully explore the subject area and capture the weaning perspective. Each interview lasted 20 to 45 minutes and was audio recorded.

Table 1. Interview-guide based on the four existentials.

Main question: Can you describe what it is like being on mechanical ventilation in the ICU?	
- Lived Body	- Lived Space
Follow up questions/areas: How did you experience your body? Were you able to move? Discomfort, pain? Facilitations? How did you experience the equipment that was attached to your body? Did you dare to move? How did you experience resting and relaxation? How did you experience training, rehabilitation and mobilisation? Did you experience that your privacy was preserved? How? How did you experience when other taking care of you and your basic needs (e.g. washing, turning)? What was it like breathing by mechanical ventilation? What was it like to be able to breath by your own again?	Follow up questions/areas: How did you experience the room, space? Where were you? Other rooms? Unreal experiences? Hallucinations? How did you experience the sound/noise? How did you experience the light? How did you experience the temperature? How did you experience other people in the room?
- Lived Human Relations	- Lived Time
Follow up questions/areas: How did you experience people around you? How did you experience the contact with others? How did you experience communication? How did you experience others taking care of you?	Follow up questions/areas: How did you experience the time? Night? Day? Circadian rhythm? Sleep? How did you experience the time that passed? What was a day like in the ICU? How did you experience the time spent on MV? How was it to get rid of MV?

Data analysis

Data were inductively analysed using hermeneutic phenomenology according to Van Manen (1997). Considering and reflecting on the parts and whole was essential throughout the analysing process, as well as to write and rewrite. Similarities, and differences, for example variations of similar aspects of the phenomenon, were put together and reflected written text began to emerge. Through discussion within the research group and rewriting, the related themes emerged, and by reflecting on similarities and differences, the themes emerged. Hermeneutic phenomenological research is a dynamic interaction using different strategies throughout the process. *The holistic reading* included transcription and repeated reading of each interview to grasp the overall meaning. Reflexive notes were written during the interview process, transcription, and reading. These notes were included in the analysis and interpretation. Interpretations were formulated for each interview to answer the question “What does this reveal about the meaning of being a patient during the MV weaning process in the ICU?”. The notes and the interpretations remained the basis of the related themes. *The selective reading* included identification of meaningful sections of the transcripts that

answered the question “What does this unit reveal about the phenomenon?” and the sections were highlighted. *The line-by-line reading* confirmed the emerging related themes and themes by identifying several quotations for each subtheme. Related themes and themes were formulated by focusing on the experience as a whole, identifying meaningful phrases and interpreting them. The first author (CT) mainly conducted the data analysis, while the whole research team discussed the emerging themes on several occasions in order to reach consensus. The research team also contributed to writing and rewriting the descriptions of the themes.

Ethical considerations

The study was conducted in accordance with The International Council of Nurses’ code of ethics (ICN, 2012) and Northern Nurses’ Federation guidelines (2003). Ethical approval was obtained from the Regional Ethical Review Board in Linköping, Sweden, No.2015-268-31. All participants received written and oral information and provided their informed consent.

Findings

The analysis revealed five themes (underlined) and thirteen related themes (italic style) that explored the meaning of being a patient on MV during the weaning process (Figure 1). The themes and the related themes describes various aspects of the phenomenon where the pleasant experiences were prominent. Weaning was clearly intertwined with the lived experience of being a patient in the ICU and not a separate experience. The variations in the patients’ experiences of MV included the overall feeling of being a human being with a sense of stability and balance in life, to feelings of being in an unreal and strange environment. Although the descriptions of the lived experience differed, and sometimes contrasted each other, as well as varied over time, it was the same patient expressing the various experiences.

Figure 1. Overview of the themes and the related themes: the intertwined and varied lived experience of patients being on MV in the ICU during the weaning process.

Maintaining human dignity

Being a patient on MV in the ICU meant a sense of security, which comprised various dimensions and led to a feeling of being respected as a person and maintaining one's sense of dignity.

The patients experienced a sense of security by being treated with *humanity and respectfulness*. Healthcare professionals and next-of-kin mediated safety in various ways and another contributory factor was their awareness that the care was for their own good.

"...and I was really calm... people talk about having hallucinations and dreams... traumatic experiences and all sorts of weird things... but I think that everybody was quite simply fantastic...//... I just had the feeling that everybody was taking care of me in the best possible way..."
(H)

Next-of-kin mediated calm and support, repeated information and were there for the patient. The patients stated that being on MV in the ICU was fantastic, referring to the considerate and professional way in which they were cared for in a calm, pleasant and safe environment where they were encountered with humanity.

The patients were encouraged to *be involved in the care*, which was important for maintaining their self-esteem. Being allowed to do the things they were able to do was essential, even simple things like wiping their mouth or changing their body position. Patients with a tracheostomy were

gradually allowed to control their weaning and decide the periods when they were on or off the ventilator.

” ...at first the staff perhaps took charge a bit more because at that time I wasn’t able to tell them how long I could manage... well those who work in a hospital know that...//... but I was allowed to decide more or less all of this...//... so it was quite okay... sometimes I didn’t have enough strength for the length of time that they wanted and sometimes it was the opposite...” (G)

The patients negotiated with the nurses about the weaning, such as the length of the weaning period, as they had no knowledge about what was best for them, which thus enabled the nurses to urge them forward.

With the help of healthcare professionals and next-of-kin, the patients could retain a sense of stability and balance, which was described as having *both feet firmly on the ground*. This was facilitated by healthcare professionals and next-of-kin who could explain the situation and point to progress. Chatting with nurses and next-of-kin was essential and provided glimpses of what happened outside the hospital or in everyday life. When the patients were unconscious, they still sensed the presence of their next-of-kin. They perceived touch and smells that were familiar to them, which evoked calm, security and motivation to struggle.

”...I recall feeling our son’s hand...//... I also recognised his scent... but I couldn’t recall what he looked like... only his hands and scent...//... but I wasn’t scared... I really wasn’t...” (U)

Understanding the context or previous care experience gave significant benefit to endure the situation. The care environment evoked memories of previous care experiences, which created hope and trust. The patients learnt to know themselves and the context in another way and interpreted unfamiliar signs in an effort to gain control over their life. One way of gaining control over time was by noting the staff changing shifts. Their body functions had changed, as they had become used to breathing differently on a ventilator, which made them feel secure.

“... I realized that I had to (being on MV) ... that I could not manage ... that was a strange feeling ... somehow I got used to it ... it did not feel scary at that time ...”

The period in the ICU was important and feelings of being born again or having gained a new perspective on life was described.

Accepting the situation

The patients wanted to make the best of their situation. They accepted it, trusted that things would turn out well and signs of progress encouraged them to believe that it was possible.

The patients' acceptance involved *facing reality* and making the most of difficult circumstances. They accepted the fact that they required help to breathe by means of a ventilator, as they realised that it was necessary. Being monitored and needing assistance with personal things was difficult, but they told themselves that they had to cope.

"...the first time they washed me and I had soiled myself... what can you do...//... it felt embarrassing... but how can you deal with it... you really have no choice..." (G)

As they lacked the strength to protest or question, they had no choice but to accept the situation.

Signs of progress provided confidence and hope. When the patients were admitted to the ICU and had difficulty breathing, they would have done anything to get help. A feeling of relief and alleviation occurred when ventilator treatment was initiated. When the weaning began, it was likewise experienced as a relief and, although strenuous, as a step in the right direction.

"...I took very deep breaths... felt that now it's me [who is breathing] ... it was such a great feeling... even when you learnt [breathing] the other way as well... it was difficult in the beginning... but it worked fairly well when I accepted it...." (F)

The patients trusted to being able to breathe on their own when it was time to start the weaning process. When the number of tubes and wires employed for monitoring and treatment was reduced, they regarded it as a sign of progress that motivated them to struggle. Other signs were being able to help when changing position in bed or with hygiene. These steps in the right direction reinforced the feeling that everything would turn out well.

Enduring the difficulties

This theme highlights the physical and mental difficulties that the patients had to endure as well as the total sense of exhaustion.

Being on MV meant *a strain on the body*. Several aspects such as pain, thirst, loss of appetite, difficulty sleeping and inability to move were considered difficult.

"...I was thirsty the whole time... your mouth becomes very dry... I had no sense of taste... they tried to force it down... but failed...it had no taste...//... I was given rosehip soup but it tasted horrible... and water was disgusting..." (M)

Being intubated was distressing and the patients could feel as if they had a lump of rubber in their mouth to chew on. It was both unpleasant and a relief to get help to remove mucus from the respiratory tract. The patients were only to a limited extent aware of the weaning, which was perceived as a distressing process characterised by worry and doubts about whether they would be able to breathe naturally again. The patients experienced that the phasing out of the endotracheal tube was unpleasant and painful but progressed quickly.

The *experience of exhaustion* and weakness was present and the patients felt that their body was finished but lacked the ability to communicate it. The exhaustion was both physical and mental and the feeling of lacking the necessary strength was evident, and occasionally a feeling of giving up and wanting to die emerged.

"... I told them (family) to go home... I can't cope... at that time I wished that I could just pass away... that they would give me an injection to speed it up..." (T)

The exhaustion implied feelings of being unable to continue or that what they had to undergo was not worth the effort.

Inadequate interaction

Being on MV meant being unable to interact with the people around them. The patients described their struggle to achieve well-functioning communication but also a feeling of being neglected.

The communication with others was problematic and the patients *struggled to make themselves understood* despite obstacles such as the tracheostomy tube and exhaustion. They were encouraged to write but were sometimes too weak to do so legibly, while on other occasions they had no problem. Communication was facilitated if they had established a relationship with or knew the person who tried to understand them.

"... when I first tried to write... I only made strokes... then I managed to write some letters which later became more linked... but our daughter deciphered what I wanted fairly quickly even when I didn't write whole words... she knows me very well so she understood..." (H)

The difficulty communicating led to worry and frustration, as both simple and more complex matters were difficult to convey. Thus, it was very important to achieve well-functioning communication in order to endure the situation. The patients were inventive and tried various ways of communicating. They experienced relief and joy when others understood them. In most cases they succeeded in conveying simple things but their ability to pursue deep conversation, for example about how they experienced their situation or how they really felt, was restricted.

Experiences of *being excluded*, of not being involved or someone who need not be taken into account constituted a threat to their sense of security and dignity. In some cases, patients were not involved or informed about their care. Experiencing that healthcare professional talked about rather than with them contributed to a feeling of being excluded.

"... I suppose they were tired of me... because I continually nagged about it... asking for more pain relief... I didn't think it helped... it went directly into a line so I didn't know whether I received pain relief or not... I had such terrible pain and I didn't think it alleviated the pain... now you have received more they told me... but I didn't notice any difference, well... I suppose they have their own criteria..." (T)

Experiences of *inadequate integrity* were reported. Situations involving hygiene were perceived as embarrassing and led to thoughts of declining tube feeding. Inadequate integrity was also described when other patients were exposed in vulnerable situations, underwent various interventions or died and they had to overhear, watch and witness discussions about and interventions for other individuals who were cared for in proximity to them.

"... I could see the other person they were busy with on the other side... I didn't see everything... but the curtain was not drawn so I saw that they were doing something to an old lady... I perceived that they made an incision and did something..."

The patients felt powerless when they were unable to help others who were seriously ill and suffering.

A sense of unreality

Being a patient in the ICU meant finding oneself in a strange and unreal situation. This involved not only the unfamiliar physical environment but also the feeling of not knowing where one is, what has happened, the absence of stability and balance in one's life as well as a sense of unreality.

The patients experienced *an unfamiliar environment* that differed in terms of sounds, lighting and people around them. They heard alarms and signals from medical equipment but had difficulty

understanding what they meant. Their body and existence felt different due to being restricted by the attachment of monitoring wires, catheters and intravascular lines. Although the patients perceived the monitoring wires and medical lines as restricting, they were not always aware of being connected to a ventilator. However, having people around them alleviated their fear and panic and facilitated being in the unfamiliar environment.

" ... there are people there all the time... you are never alone... // ... but at the same time it's good to see ... it would probably be worse being all alone... not seeing anyone ..."

(F)

Receiving MV implied a feeling of *lacking stability and balance in life*. The patients found it difficult to grasp the context, as they shifted between sleep, drowsiness and wakefulness, interspersed by fragmentary recollections. At times they felt abandoned, which gave rise to feelings of insecurity and panic. They did not always understand how ill they were or the help they required and had difficulty distinguishing between real, harmless experiences and unreal, threatening ones, which made it difficult for them to comprehend the aim of the nursing interventions.

" ... they were going to suction [phlegm] and I didn't know if it was for real or not... I felt that someone was trying to kill me...//... I started to panic [becomes tearful] ... she stood there and tried to kill me... it was that very situation that made me panic so I tore it off... I was terrified... "

(N)

The patients had difficulty making rational decisions and failed to realise the gravity of their situation, which gave rise to behaviour such as wanting to disconnect monitoring wires and intravascular lines. While they were unable to control the situation, they nevertheless had feelings of not daring to let go. This led to an inner conflict, in turn giving rise to worry and thoughts about fleeing and escaping in addition to feelings of irritation and agitation.

The patients *experienced delusions*, dreams and hallucinations, which constituted an undefined existence where reality, dreams, time and space were indistinguishable. The delusions were perceived as real and could be frightening but also agreeable.

"... I dreamed about a pal... he worked as a nurse in my dream... he was to take care of me and he didn't have time to stay in the hospital so... I was allowed to accompany him to his home... he is a farmer and I followed him when he was doing various jobs and he took care of me in his home..."

(S)

Frightening dreams and hallucinations about, for example, war, conspiracies and death, could be strong, real and give rise to terrifying feelings and fear. There was a feeling of being in the realm

of death, where the deceased were treated in an undignified manner, which created discomfort and fear.

Discussion

One main finding was that patient's experiences varied during their time in the ICU and that favourable experiences were more clearly described compared to previous research (Baumgarten and Poulsen, 2015, Egerod et al., 2013, Egerod et al., 2015). Another main finding was that the patients normally did not distinguish between various care processes, such as MV or weaning, but integrated them into the whole experience of being cared for in the ICU.

The variations in the patients' experiences of MV included the feeling of being a human being with a sense of stability and balance in life in addition to unpleasant experiences, both real and unreal. Difficulties as well as the whole situation were managed in a constructive way by accepting the situation. Thus, this study shows a confident event where the good experiences is evident even though patients still have unpleasant ones. The fact that the patients in our study expressed favourable experiences more clearly than in previous research (Baumgarten and Poulsen, 2015, Engstrom et al., 2013, Holm and Dreyer 2017a, Karlsson et al., 2012a, Karlsson et al., 2012b, Rose et al., 2014, Schou and Egerod, 2008) may be related to factors such as the context or the medical and nursing care. However, our results indicate that aspects of being a patient on MV, such as communication, inclusion, participation and proximity to healthcare professionals and next-of-kin, contributed to the experience being characterised by a sense of involvement as well as stability and balance in life. Taken together, this contributed to an experience where the patient was regarded as a human being, albeit in need of care but with her/his own capabilities and resources. A study investigating the patient perspective in terms of autonomy and partnership in an ICU context revealed that patients want to be involved (Lindberg et al., 2015) which enables a safe handing over of decisions to others when they themselves lack the ability. Similar findings shows an ethnographic study (Laerkner et al., 2017) where the non-sedated patient on MV expresses a sense of agency, which is not always met. The influences of person centred care and the fact that healthcare professionals during the last years have developed understanding, knowledge and experience to care for less sedated patient on MV during weaning may have contributed to the favourable experiences clearly described in this study. Person centred care needs to be developed in intensive care with the overall aim of minimising variations between pleasant and unpleasant experiences to make the patient's experience as favourable as possible. This presupposes deeper inter-professional collaboration (Reeves et al., 2015), where the knowledge of each profession is utilised and patients and their next-of-kin are made partners in the care.

As previously shown, (Samuelson, 2011, Svenningsen et al., 2016) the range of experiences also included negative ones. These consisted of a sense of unreality, which to some extent can be explained by disease and medication but also by other circumstances, such as inadequate inclusion,

integrity and communication. A factor contributing to discomfort and fear was the difficulty communicating, which has been reported in earlier studies (Karlsson et al., 2012c, Rose et al., 2014, Schou and Egerod, 2008). However, the present study reveals that the patients wanted to communicate and were able to find out, partly by their own ability, a way in which this might function. Allowing patients to express their needs and experiences contributes to a sense of control and security, which is supported by previous research (Holm and Dreyer, 2017b, Karlsson et al., 2012c). One of the preconditions for person centred care is well-functioning communication between patient, next-of-kin and healthcare professionals. A study of nurses' perceptions of patient participation in the ICU (Schandl et al., 2017) indicated that communicating with and involving the patient requires more than verbal communication and that enlisting the help of next-of-kin, interpreting body language and reading previous medical records are examples of how to fulfil the patient's wishes. Healthcare professionals must demonstrate commitment to and co-operate with the patient as a means of helping each patient to communicate. Communication with patients on MV requires time and patience, is hugely important and more knowledge of how to develop this is essential.

Even though the favourable experiences were clearly described, it is desirable that the variation in patients' experiences is further reduced in favour of pleasant ones. Distressing experiences such as loneliness, fear and panic (Baumgarten and Poulsen, 2015) seem to be offset by favourable experiences, described by the patients in our study as stability and balance in life as well as proximity to healthcare professionals and next-of-kin. The latter contributed to the patients' perception of stability and balance in life, inspired hope and motivation as well as providing a wider perspective, which is supported by previous research (Engström and Söderberg, 2007). The positive effects of person centred care identified in other contexts should be further explored in the ICU context and include the family perspective (Olding et al., 2016). Patient participation is not easy to attain, irrespective of context, and adaptation to existing circumstances is necessary (Ekman et al, 2011, Kvangarsnes et al., 2013, Tobiano et al., 2016). Intensive care and weaning presents challenges that do not arise in other healthcare areas to the same extent. The situation is complex and consists of several aggravating and adding factors, like acute and critical illness, MV, and sedation. From the patient perspective, participation includes more than just being informed about or taking part in decisions; they wish for knowledge and to collaborate with healthcare professionals (Eldh et al., 2010). Intensive care needs to address these challenges and it is therefore essential to obtain more knowledge about the way in which patients during weaning want to and can be included as well as how healthcare professionals can meet patients' need for participation and communication.

The patients' narratives describe a wider experience, where various aspects of being cared for in the ICU are intertwined. Thus, weaning was not a separate experience but integrated into that of being a patient on MV. A previous study (Haugdahl et al., 2017) reported similar findings, namely that patient's experiences of breathing during and after MV cannot be separated from the

experience of being seriously ill and cared for in the ICU. Consequently, patients experience the meaning of being a patient on MV as an integrated whole, something ICU healthcare professionals need to be aware of. Health care today strives to be person-centred and patients' right to participation has been strengthened (WHO, 2013). However, traditionally and for practical reasons, care is often process oriented, making knowledge and understanding of how patients experience it even more important for creating a safe and effective care environment based on the patient perspective.

Study limitations and strengths

To ensure trustworthiness the Lincoln and Guba (1985) framework was used throughout the research process. The broad experience of the research team in terms of critical care, nursing and qualitative and/or clinical research contributed to credibility and dependability. The first author (*CT*) has an extensive experience as a critical care nurse and this could be an advantage (familiar with the research field) as well as a disadvantage (risk for affecting the data collection and analysis). According to Van Manen (1997), the preunderstanding can never be disregarded, but should be made explicit, this was achieved by reflecting and discussing it within the research team. One of the researchers (*JM*) does not have any experience of critical care, which further contributed to strengthen credibility and dependability.

Van Manen (1997) means that qualitative data never can be generalised but the study can bring new insights, and the reader needs to value transferability. The purposive sample has been described and variation was reached to enhance transferability. The data collection generated a rich material that illuminated the aim of the study and nothing new emerged at the last interviews. There could be a limitation of the sample since the patients who chose not to visit the follow-up clinic nor were invited to participate in the study. This could have affected credibility and transferability by missing important experiences for the understanding of the phenomena. The interview guide, based on the existentials Van Manen (1997), ensured dependability by encouraging the narratives. All of the participants have contributed to the findings and quotations from different participants are used in the text. The quotations confirm the interpretations and strengthen confirmability. The data analysis was conducted alternately individually and in the research team, a critical attitude and balancing of the pre-understanding was fundamentally to ensure credibility and dependability. The study generated a big amount of data, thus there was a risk not to reach sufficient analysis. By discussing the analysis for several times in the research team, considering and reflecting on the parts and whole, and by confirming interpretations by quotes this was handled.

Conclusions

This study shows that the patient's experiences differ and vary over time, with the same patient expressing both pleasant and unpleasant experiences. Surprisingly, the patients had difficulties to

outline the weaning process, thus weaning was not a separate experience but clearly intertwined with that of being on MV in the ICU. The favourable experiences were considerably more clearly described, compared to previous research, and we think this might depend on factors related to communication, inclusion, participation and proximity to healthcare professionals and next-of-kin. The patient is a person who is more than a passive recipient of health care, thus a person with resources and capabilities to be promoted. This approach seems to have a positive impact on patient's well-being during mechanical ventilation and weaning. According to the results of this study, increased knowledge and understanding of the importance of person centred care in terms of patient and family participation should be a major goal in intensive care, further explored and implemented on all levels. In particular, the real and unpleasant experiences, like failing interaction and inclusion, are circumstances that healthcare professionals have the opportunity and responsibility to influence and contribute to becoming more favourable.

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