Prolonged mechanical ventilation in Swedish intensive care units

Prevalence, patient characteristics, weaning and challenges in care

Carl-Johan Cederwall

Institute of Health and Care Sciences
Sahlgrenska Academy, University of Gothenburg

UNIVERSITY OF GOTHENBURG

Gothenburg, Sweden 2021

Cover illustration by Anders Lundmark

Prolonged mechanical ventilation in Swedish intensive care units
– Prevalence, patient characteristics, weaning and challenges in care

carl-johan.cederwall@vgregion.se

ISBN 978-91-8009-266-1 (print)
ISBN 978-91-8009-267-8 (PDF)
http://hdl.handle.net/2077/67650

Printed in Borås, Sweden 2021
Stema Specialtryck AB, Borås

SVANENMÄRKET
Trycksak
3041 0234

To my family

‘There’s a new day at dawn and I’ve finally arrived
If I’m there in the morning baby, you’ll know I’ve survived
I can’t believe it, I can’t believe I’m alive.’

Bob Dylan

ABSTRACT

The overall aim of this thesis was to explore the care of adult patients on prolonged mechanical ventilation (PMV) in Swedish intensive care units (ICUs). Secondary aims were to identify the prevalence, characteristics and outcome in patients with PMV and the presence of person-centred care (PCC) during prolonged weaning in Swedish ICUs.

Study I. Registry study identifying adult admissions to Swedish ICUs requiring mechanical ventilation ≥ 7 days. Admissions on PMV > 21 days constituted a small proportion of all admissions but occupied a significant part of ICU capacity. Use of ICU bed days and ICU mortality was lower compared to international studies.

Study II. Survey of adult Swedish ICUs (n = 77) identifying care practices and protocols for adult patients undergoing mechanical ventilation > 7 days. Results showed low levels of weaning and mobilisation protocols, individualised approaches were preferred and interprofessional decisions were common. Few ICUs promoted primary nursing models or PCC approaches.

Study III. Qualitative interview study exploring critical care nurses' approach for management of patients during prolonged weaning from mechanical ventilation. Results showed that critical care nurses played a key role in prioritising, initiating and driving the weaning process.

Study IV. Secondary analysis of qualitative interviews identifying the presence of PCC during prolonged weaning from mechanical ventilation. Results showed evidence of PCC undertaken during prolonged weaning, but also barriers such as a lack of team collaboration and staff resources.

In conclusion, patients on PMV in Swedish ICUs comprised a relatively small proportion of ICU admissions but consumed a significant part of ICU capacity. Individualised approaches were preferred, and interprofessional collaboration was common. ICUs showed low level of care practices based on PCC, but PCC was present during prolonged weaning. Critical care nurses in the ICU played a key role in individualising care and increasing patient participation during prolonged weaning.

Keywords: Intensive care; mechanical ventilation; prolonged mechanical ventilation; ventilator weaning; nursing; person-centred care.

SAMMANFATTNING PÅ SVENSKA

Ventilatorvård på en intensivvårdsavdelning (IVA) kan vara nödvändigt för att upprätthålla liv, men samtidigt innebära ett stort psykiskt och fysiskt lidande för den enskilde patienten. Det är dessutom förenat med allvarliga komplikationer och ökad risk för död. Därför är det av högsta prioritet att avveckla ventilatorn så snart patienten är redo att andas själv. Ventilatorvård är inte en behandling i sig, men den ger patienten tid att återhämta sig från den underliggande orsaken till akut andningssvikt. Avvecklingen av ventilatorn är vanligtvis en okomplicerad process men vid vårdtider längre än en vecka kan den så kallade ventilatorurträningen bli komplicerad. Standardiserade rutiner kan vara svåra att tillämpa vid längre urträningsförlopp och individuella strategier som ställer högre krav på vårdteamets kompetens kan därför krävas.

Personer som vårdas lång tid i ventilator på IVA är ofta äldre och det är inte ovanligt att de dessutom har flera sjukdomar sedan tidigare. Intensivvården har dock utvecklats över tid och idag klarar man att rädda allt fler svårt sjuka människor. Samtidigt är en ökande äldre befolkning en utmaning för vården vilket troligen kommer att kräva större intensivvårdsresurser i framtiden. Det övergripande syftet med avhandlingen var att undersöka vården av patienter på svenska IVA som kräver lång vårdtid i ventilator och därmed ökad urträningstid. Det specifika syftet var att identifiera patientgruppen, vårdrutiner samt förekomst av person-centrerad vård under långvarig urträning ur ventilator.

Avhandlingen omfattar fyra delstudier. Studie I var en registerstudie som undersökte samtliga vårdtillfällen, under en period av 12 månader, av vuxna patienter som vårdades i ventilator i sju dygn eller mer på svenska IVA. Resultatet visade att dessa vårdtillfällen upptog en betydande del av intensivvårdskapaciteten trots att de utgjorde en liten del av det totala antalet vårdtillfällen på IVA. Den grupp som vårdades mer än 21 dygn i ventilator upptog däremot mindre intensivvårdskapacitet och visade en lägre dödlighet på IVA jämfört med internationella studiers resultat. Studie II var en enkätundersökning där vårdansvariga på 77 intensivvårdsavdelningar i Sverige tillfrågades om vårdrutiner och dokument som används för vuxna patienter som vårdas i ventilator mer än sju dygn. Resultatet visade att individualiserad vård var vanligt förekommande under ventilatorurträning och mobilisering, och att vårdbeslut vanligtvis togs av läkaren och intensivvårdssjuksköterskan tillsammans. Det var få intensivvårdsavdelningar som använde sig av en patientansvarig sjuksköterska. De flesta avdelningar saknade vårdrutiner baserade på person-centrerad vård och patienternas medverkan i vårdbeslut var dessutom låg. Studie III var en intervjustudie där 19 intensivvårdssjuksköterskor deltog. Syftet var att undersöka hur intensivvårdssjuksköterskan planerar och genomför vården av patienter som genomgår långvarig urträning ur ventilator. Resultatet visade att intensivvårdssjuksköterskorna tog ett stort ansvar när det gällde att prioritera, initiera och driva urträningsprocessen framåt samt att skapa ett fungerande teamarbete. Studie IV var en andra analys av intervjuerna från studie III. Syftet var att identifiera förekomst av och hinder för person-centrerad vård under långvarig ventilatorurträning. Analysen visade att person-centrerad vård existerade under urträningsprocessen trots att det inte hade skett någon implementering av person-centrerad vård på dessa enheter. Det framkom också att hinder för person-centrerad vård förekom i form av bristande teamsamarbete och bristande personalresurser.

Sammanfattningsvis visar avhandlingen att patienter med lång vårdtid i ventilator på IVA i Sverige utgjorde en liten del av alla vårdtillfällen men att dessa ändå krävde stora intensivvårdsresurser. Vården var vanligtvis individualiserad och baserades på gemensamma beslut i vårdteamet. Intensivvårdssjuksköterskorna hade en nyckelroll i urträningsprocessen när det gällde teamarbetets funktion och urträningens fortskridande. Trots att implementerade vårdrutiner för person-centrerad vård var ovanligt förekommande kunde person-centrerad vård påvisas under långvarig ventilatorurträning. På grund av att antalet äldre intensivvårdspatienter förväntas öka de kommande åren leder det förmodligen till att antalet patienter som kräver lång vårdtid i ventilator på IVA kommer att öka. Effektivare vård i syfte att reducera ventilatorvårdtid för denna begränsade patientgrupp som vårdas längre tid i ventilator skulle därför kunna ha betydande effekt på akuta intensivvårdsresurser. En långvarig urträningsprocess skulle troligen underlättas av en vårdmiljö som är separerad från akut vård och har resurser för långsiktig vård och planering. Ökad person-centrering under långvarig ventilatorvård och urträning skulle kunna öppna för ytterligare individualisering och patientmedverkan i syfte att minska ventilatorvårdtiden och risken för komplikationer och död.

LIST OF PAPERS

This thesis is based on the following studies, referred to in the text by their Roman numerals.

I. Cederwall, C. J., Naredi, S., Olausson, S., Rose, L., & Ringdal, M. (2021). Prevalence and Intensive Care Bed Use in Subjects on Prolonged Mechanical Ventilation in Swedish ICUs. *Respiratory Care*, *66*(2), 300–306. https://doi.org/10.4187/respcare.08117

II. Cederwall, C. J., Rose, L., Naredi, S. Olausson, S., & Ringdal, M. Care practices and protocols for patients requiring mechanical ventilation more than seven days in Swedish ICUs: a national survey. *In manuscript.*

III. Cederwall, C. J., Plos, K., Rose, L., Dubeck, A., & Ringdal, M. (2014). Critical care nurses management of prolonged weaning: an interview study. *Nursing in Critical Care*, *19*(5), 236–242. https://doi.org/10.1111/nicc.12092

IV. Cederwall, C. J., Olausson, S., Rose, L., Naredi, S., & Ringdal, M. (2018). Person-centred care during prolonged weaning from mechanical ventilation, nurses' views: an interview study. *Intensive and Critical Care Nursing*, *46*, 32–37. https://doi.org/10.1016/j.iccn.2017.11.004

CONTENTS

ABBREVIATIONS

CAM-ICU	Confusion assessment method for the ICU
CCI	Chronic critical illness
CCN	Critical care nurse
ECMO	Extracorporeal membrane oxygenation
ICU	Intensive care unit
I-CVI	Item-content validity index
LTACH	Long-term acute care hospital
MET	Medical emergency teams
MV	Mechanical ventilation
Nu-DESC	Nursing Delirium Screening Scale
PCC	Person-centred care
PEEP	Positive end expiratory pressure
PFCC	Patient and family-centred care
PMV	Prolonged mechanical ventilation
SAPS 3	Simplified Acute Physiology Score version 3
SBT	Spontaneous breathing trial
SIR	The Swedish Intensive Care Registry

INTRODUCTION

To breathe is a symbol of life, and ever since the introduction of artificial ventilation, breathing has been associated with preserving life for patients with a failure in the respiratory system. In the 1950s, when patients at the time of the polio epidemic were treated and systematically monitored, mechanical ventilation (MV) was introduced and became a lifesaving intervention associated with intensive care (Mendelson & Foley, 1956). MV is not defined as a treatment, but it gives patients time to recover from the acute cause of respiratory failure (Goligher et al., 2016). However, prolonged time on MV increases complications and the risk of death, so an important priority for care is to initiate processes to liberate patients from MV as soon as possible.

Patients cared for in an intensive care unit (ICU) are critically ill and often suffer from serious multiple organ failure. They are not capable of maintaining normal physiological bodily functions and are therefore in need of intervention and support. Care provision in an ICU is therefore dependent on advanced technologies and qualified professional staff. The ICU is also a complex environment for patients to interact with their families due to limited visiting times, problems in communication due to ongoing MV treatment and high-level technological devices. Patients on MV are therefore generally totally dependent on their caregivers during, usually, one of the most dangerous times in their lives. The focus of this thesis is on the care of patients on prolonged mechanical ventilation (PMV) in the ICU. The thesis aims to highlight the complex care situations of the target group, patients' resources, challenges and possibilities for health care professionals to make a difference for patients with the aim of improving outcomes.

BACKGROUND

Intensive care

Intensive care includes monitoring, treatment and care of critically ill patients with failure in vital functions. Advanced treatment is possible due to the high level of technologies and higher staffing levels. Intensive care has been defined as: *'... an organized system for the provision of care to critically ill patients that provides intensive and specialized medical and nursing care, an enhanced capacity for monitoring, and multiple modalities of physiologic organ support to sustain life during a period of acute organ system insufficiency'* (Marshall et al., 2017, p. 274). In addition, today ICU activity often extends beyond the walls of a specific space and includes several services of acute care in a hospital (Marshall et al., 2017).

Organisation

Intensive care is one of the most costly and resource-intensive care modalities in health care and is staffed by physicians, nurses, physiotherapists and other health care providers, all specialised in ICU care, working together in teams (Ervin et al., 2018). Care focuses on patients' most vital functions, such as circulation and ventilation, and on increasing patients' chances to survive during critical conditions (Marshall et al., 2017). This specialised care and treatment require highly skilled personnel resources. Critical care nursing education is different worldwide, and Swedish ICUs require critical care specialised nurses (CCN) training with a one-year diploma after university studies to become registered nurses. Scandinavian CCNs also have high autonomy in ventilator adjustments, in contrast to ICUs in the US, where respiratory therapists are mainly responsible for ventilator treatments, parallel to other care practices by bedside nurses (Rose, Blackwood, Burns, et al., 2011). As personnel profiles in the ICU vary worldwide, it is essential to recognise this distinction in the discussion about ICU nurses/CCNs' clinical care and ventilator treatment in an international ICU context.

For the most part, the Swedish health care system is publicly funded and accessible for all citizens. Sweden is divided into six regions with local hospitals at different levels referring patients to the seven university hospitals, and advanced specialist care is only performed in the university hospitals (SALAR, 2015). In 2012, Sweden had one of the lowest numbers of ICU beds per capita in Europe, with 5.8/100,000 population; only Portugal had fewer beds (Rhodes et al., 2012). In 2017, 516 ICU beds were available in 80 of 84 ICUs reporting to the Swedish Intensive Care Registry (SIR), including four paediatric ICUs (SIR, 2017). During the same year, there were 39,510 admissions in 74/80 Swedish adult ICUs reporting to the SIR, and the mean care time in an ICU was 2.7 days. Of all admissions, 15,564 (39%) required MV (SIR, 2020b). In general, patients on PMV > 21 days in Sweden are cared for in acute care ICUs, and there are no post-acute care units outside the hospitals, such as long-term acute care hospitals (LTACHs) or weaning centres, as in other European countries or the U.S. (Carpene et al., 2010; Davies et al., 2017; Munoz-Price, 2009). There is only one private clinic in Stockholm caring for patients with varying diagnoses and respiratory issues after a prolonged stay in an ICU.

Patients in intensive care

Patients in an ICU usually arrive from the emergency department, hospital wards, operation room or other ICUs due to a worsening health condition. The first hours in the ICU focus on resuscitating body functions with a prioritised diagnosis and treatment (SIR, 2020c). ICU patients are a heterogeneous group of patients with diagnoses such as trauma, sepsis and cardiac or respiratory failure. In 2015, the Swedish ICU population consisted of 57% male patients, and the median age was 64 years old (Samuelsson et al., 2015). Respiratory insufficiency often includes intubation, sedation and inability of the patient to communicate due to sedation and a critical health condition. In addition to a severe critical condition, they are totally dependent on their caregivers and in an unknown and highly technological environment, having tubes and lines in the body (Engstrom et al., 2013). Patients can feel unsafe due to loss of control, communication difficulties and experience hallucinations and nightmares. Family members can play an important role with their presence, but visiting the ICU is complicated and often limited due to care practices and treatment (Wassenaar et al., 2014).

Artificial ventilation of patients is needed to support gas exchange and acid-base homeostasis when patients are unable to maintain normal pulmonary functionality. This can be due to acute or chronic pulmonary dysfunction or other systemic diseases that affect the patient's normal alveolar ventilation (Goligher et al., 2016). MV has been described as 'a necessary evil', a technique that saves lives but also can cause serious complications for patients. Despite modern technological development, ventilators still require positive pressure, which has effects on hemodynamic and ventilatory functions in patients, and results in a high intrathoracic pressure, which decreases the heart afterload and can result in hemodynamic instability (Pham et al., 2017).

As a result of this positive pressure by ventilators, there are potential risks for harmful ventilator-induced lung injury during long periods of controlled ventilation modes (Hess, 2014). In addition, patients on MV initially need sedation and opioid levels to accept the endotracheal tube and the artificial ventilation situation. Sedative drugs also have side effects, such as hemodynamic instability, and high levels of sedation over time can contribute to prolonged MV, delirium and poor long-term outcomes (Pham et al., 2017). Therefore, caregivers strive to use ventilatory support modes that enable patients to breathe spontaneously in the ventilator, which can contribute to reduced use of sedative drugs and a successful removal of MV (Goligher et al., 2016).

Prolonged Mechanical Ventilation

Patients and definitions

Critically ill patients exposed to PMV in the ICU are in an extremely vulnerable situation. Although modern sedation routines, including light sedation levels, improved medications and more humane ICU environments, patients are still experiencing the burden of extreme symptoms for a prolonged time during their ICU stay (Egerod et al., 2015). Previous research emphasises that being cared for in an ICU on PMV can be a traumatic life experience. Patients on MV also experience loss of voice, feelings of anxiety, fear and loneliness, and in addition, they are dependent on health care professionals and technology for their survival (Baumgarten & Poulsen, 2015). Today an increasing number of patients on MV survive their ICU time, and among them, patients on PMV > 21 days are an increasing group. This growing patient group consists mostly of elderly patients with high comorbidity, resulting in an additional burden on intensive care staff (Cox, Carson, Govert, et al., 2007; Zilberberg et al., 2008). In international studies, patients on PMV > 21 days constitute about 4% of all ICU admissions, but occupy up to 11%–29% of all available ICU bed days (Lone & Walsh, 2011; Rose, Fowler, et al., 2015). This group of patients seems to be a negligible part, but research shows that this group results in significant pressure on acute ICU resources and increased hospital costs (Hung et al., 2013).

There is no consensus on the definition of PMV, and therefore, that in the literature varies from a few hours to > 21 days (Rose et al., 2017). The most common definition to date in the literature is MV > 21 days, and this is also recommended by the National Association for Medical Direction of Respiratory Care (NAMDRC) (MacIntyre et al., 2005). This definitions of PMV are based on time, but new reports suggest that approximately seven days on MV signifies a shift from acute care to a more chronic condition with increased risk for complications and mortality (Carson, 2012; Iwashyna et al., 2015). In addition, the common timing of tracheostomy for patients after seven days of MV could also act as a marker for PMV, and that the patient will survive the acute and initial phases of intensive care (Cheung & Napolitano, 2014).

To further understand the complexity of defining PMV, there is a need to explain two closely connected concepts: chronic critical illness (CCI) and persistent critical illness. These are two additional definitions close to PMV, describing patients who have survived acute critical illness but need prolonged intensive care. These definitions develop the definition of PMV further and describe the complexity of continuing a stay of long duration in the ICU but are more based on the patient's condition and not focused primarily on time. CCI was first described in 1985 by Girard and Raffin (1985), who present a managing strategy to improve patient care, including issues with withholding or withdrawing life support treatment in intensive care patients on MV. This increasing group of patients is in addition to PMV, characterised by suffering from deep bodily weakness, malnutrition, anasarca, prolonged brain dysfunction and extreme symptom burden (Maguire & Carson, 2013; Nelson et al., 2010). Although the transition from acute care to CCI is gradual, the decision to perform a tracheostomy plays an important role, and this is one of the most common definitions for CCI. The decision for a tracheostomy, often taken after approximately seven days on MV, indicates that the time on MV is expected to be prolonged and that the patient is sufficiently stable to survive in the near future (Carson, 2012). In a U.S. patient population, a total of 7.6% of all ICU admissions met the criteria for CCI, and the most common conditions were MV ≥ 96 hours and sepsis. These patients also showed a high level of comorbidity, and in-hospital mortality was 33% (Kahn et al., 2015).

Previous research studies indicate that seven days after admission to ICU, some patients transform from an acute to a more persistent critical illness, when the primary admission diagnosis is no longer more predictive for mortality than the patients' prehospital condition (Iwashyna et al., 2016). In 2015, Iwashyna and colleagues introduced the term 'persistent critical illness', asserting that the current definition of CCI was unclear and not useful outside the context of U.S. intensive care (Iwashyna et al., 2015). The authors argued that these patients show a more complex multi-organ dysfunction, and they are not captured by a single use of organ support or intervention such as MV. This transition from acute care to persistent critical illness has been shown to occur on days 7–9 after ICU admission, but ranging between 5 and 21 days, and previous research demonstrates that this group of patients constitutes 5%–16% of all ICU patients and 32%–54% of all ICU bed days (Bagshaw et al., 2018; Iwashyna et al., 2016).

Complications and outcome

Being on MV is in general associated with potentially harmful physiological respiratory and cardiovascular consequences and increased risk of ventilator-associated pneumonia and respiratory muscle fatigue (Kallet, 2011; Stewart et al., 2011; Waters & Muscedere, 2015). Prolonged stay in ICU on MV also increases the risks for severe complications and mortality, and an age over 65 years old and high level of comorbidities increases the potential risk for mortality (Dettmer et al., 2017; Leroy et al., 2014). In addition, severe physical conditions during MV, including periods of higher sedation levels or the need for prolonged sedation in patients, often induce the risk of agitation, delirium, anxiety and delusional memories (Rose, Nonoyama, et al., 2014). Although new, light sedation strategies have been developed with the aim of decreasing time on MV to improve outcome and patients' ability to communicate, patients still need conventional sedation levels to tolerate MV in the acute phase (Egerod et al., 2013; Reade & Finfer, 2014).

Long stays in the ICU are associated with several complications and poor outcomes. Similar to the above description, PMV also includes an increased risk of pulmonary embolism, acute respiratory distress syndrome (ARDS), sepsis, gastrointestinal bleeding and pressure ulcers (Loss et al., 2015). The possible consequences are even more severe: in general, mortality for patients on PMV > 21 days is high; hospital mortality is reported as 40%–65%, and ICU morality 26%–52% (Lone & Walsh, 2011; Loss et al., 2015). Moreover, mortality in patients on PMV > 21 days six months after surviving discharge has been reported as 54%, and for patients surviving PMV >21 days in the ICU, mortality after one year in the U.S. and French populations is reported as between 48% and 60% (Carson et al., 2012; Cox, Carson, Lindquist, et al., 2007; Leroy et al., 2014). The one-year mortality of 60% in the French population was specifically associated with three variables: age > 65 years old, the need for vasopressors and haemodialysis during their ICU stay (Leroy et al., 2014). In studies of long-time survivors of PMV > 21 days, 10-year morality has been reported as 58% (Hill et al., 2017).

A long time on MV also includes comprehensive rehabilitation for patients with already high levels of comorbidities. However, patients in the ICU, both with and without MV, have shown improved health-related quality of life five years after discharge from the ICU. Two factors, pre-existing disease and delusional memories during their time in the ICU, were most closely associated with a lower health-related quality of life (Ringdal et al., 2010) Finally, patient support needs after the ICU are a multifaceted and complex process, both during the stabilisation process in the hospital ward and after discharge to home. Patients discharged to home need tools for recovery support to manage their daily home life after surviving ICU care (King et al., 2019).

Critical care nurses and teamwork

In Swedish ICUs, similar to other Scandinavian countries, specialised CCNs work in teams together with physicians, assistant nurses (non-registered nurses) and physiotherapists. Generally, physicians have the overall medical responsibility, but CCNs in these countries have high autonomy to make adjustments to the ventilators' setup and adjustments to the patients' response and clinical changes. They are also responsible for the administration and dosages of sedative drugs (Rose, Blackwood, Burns, et al., 2011). In addition, nurses in the ICU assess and manage pain, agitation and delirium (Rozycki et al., 2017), and there is evidence for lower mortality in ICUs with higher nurse staffing levels (Neuraz et al., 2015). Nurses in ICUs play a key role in family care, including decision-making about the goals of care (Davidson et al., 2017). Taking all these factors into account, the role of the CCN includes an overall responsibility for the patient on MV in the ICU.

Teamwork is essential to secure and ensure safe and high-quality care among patients in the ICU, especially for patients on MV and their families. The ICU environment includes multifaceted personnel of specialists, and daily care requires many competences (Dietz et al., 2014). Teamwork has been defined as *'a set of two or more individuals interacting adaptively, interdependently and dynamically towards a common and valued goal*' (Salas et al., 2000, p.341). Effective team processes can also have an impact on compliance with protocols, patients' outcomes, for example mortality, length of stay, and also on the team members, for example satisfaction with teamwork, job satisfaction, staff morale and burnout (Reader et al., 2009).

Patient experience and family presence

Exposure to MV in the ICU can be a traumatic experience for patients. This includes difficulties for patients to communicate, difficulties breathing, thirst, pain and sleeping problems, but also feelings of anxiety and fear of dying. Patients could also experience a fearful time, including the stress of being isolated and left alone from family or next of kin (Danielis et al., 2020). Patients also require sedatives and opioids to tolerate MV, interventions or daily care, and this could result in feelings of isolation, being invisible and lonely (Stayt et al., 2015). ICU environments with a high level of technological equipment can be a frightening but also a safe experience for patients. This can include feelings of being in the hands of others, not able to communicate, feelings of vulnerability and dependence on others in an unknown environment (Engstrom et al., 2013). Patients in the ICU are in an artificial environment for one of their worst times, when life is fragile, and they are likely to experience a tension between life and death. At the same time, the ICU environment can also be perceived as a space for trust and security with a specialised staff and lifesaving technology (Olausson et al., 2013).

Today, family members are seen as team members and an active part in daily ICU care. This can include both daily patient care but also participating in team rounds and information meetings, and they should also be offered to participate in acute resuscitation situations (Davidson et al., 2017). Unfortunately, the ICU is a complicated area for patients to meet and interact with their families. The environment, with a high level of staffing and technology, makes it difficult for families to visit their next of kin during their stay in the ICU. Even though normally scheduled visiting times, or flexible visiting times, are available, the visitors are dependent on patient activities and ongoing care and are often interrupted by acute interventions and care activities for hours (Ning & Cope, 2020).

Weaning from mechanical ventilation

Most patients that require MV will easily be disconnected from the ventilator and extubated after clinical decisions of their readiness for extubation. At the same time, some patients fail one or several extubation trials, end up in extensive time on MV and need extra support to be liberated from the machine. This process, which includes reduction of ventilator support, MV removal over a short or long term and extubation of patients to safe and secure spontaneous breathing, is known as weaning from MV.

Weaning from MV has been defined as '*the period of transition from total ventilatory support to spontaneous breathing'* (Mancebo, 1996, p.1923), or: *'... the gradual reduction of respiratory support until the point has been reached when either the patient no longer requires assistance or has reached their maximum potential and further reduction of respiratory support is neither feasible nor realistic'* (Crocker, 2009, p.185). The weaning process can be easy or complicated, depending on the patient's condition, complications and reason for MV, and can continue over hours and days. Weaning is an ongoing process and can be initiated early during MV treatment, but the specific process of reducing ventilator support has been estimated to represent up to 40% of the total duration of MV. For many patients, weaning consists of daily progress or failure, depending on the individual's condition, resulting in increased risk of complications, suffering and cost of care and resources (Penuelas et al., 2015).

The weaning process

In 2007, a more systematic management of the weaning and extubation process was initiated in a statement by the Sixth International Consensus Conference on Intensive Care Medicine (Boles et al., 2007). This process includes: (1) treatment of acute respiratory failure; (2) assessment of patients' readiness to wean; (3) spontaneous breathing trials (SBT); and (4) extubation. Assessing patients' readiness to wean is the most challenging part but is central to the clinical care of patients on MV (Blackwood, 2000). This assessment should include objective assessments, such as clinical stability, adequate oxygenation, adequate pulmonary function and adequate mentation, and also clinical assessments, such as adequate cough, absence of tracheal secretion and certainty that the acute reason for intubation or underlying diseases is under control (Boles et al., 2007). The SBT is an essential step before extubation and includes breathing through a T-tube or low levels of pressure support (5–8 cmH_2O) in combination with a positive end expiratory pressure (PEEP) of 5 cmH_2O or lower for at least 30 to 120 minutes. During the SBT, patients are observed for both objective parameters, such as adequate gas exchange, hemodynamic stability and respiratory pattern, but also subjective parameters, such as diaphoresis, consciousness alertness and increased work of breathing (Penuelas et al., 2015).

Weaning classifications

The systematic management of the weaning process and extubation of patients by Boles et al. (2007) included a weaning group classification: simple, difficult and prolonged weaning. In the simple weaning group, patients successfully pass a first SBT and are extubated on the first attempt. This group of patients comprises 30%–

58% of all weaning patients. The prognosis for this group of patients is good, with low levels of mortality. Patients in the difficult weaning group comprise 26%–40% and usually need up to three SBTs or up to seven days from their first SBT to complete extubation. The prolonged weaning group, comprising approximately 6%–30% of all weaning patients, is defined as more than three SBTs or more than seven days of weaning after the first SBT (Penuelas et al., 2015). However, this weaning classification does not directly address patients not exposed to SBTs and could therefore not be applied to almost half of mechanically ventilated patients. Beduneau and colleagues (2017) therefore developed this definition of the weaning process by suggesting that the classification should be based upon the concept of separation attempts, and not on SBTs. This new classification defines the start of weaning as any sort of separation attempt, including both intubated and tracheotomised patients. The definitions also include patients who do not wean for extubation or patients who receive tracheostomy to wean from MV without passing an SBT.

Reduction of time on MV can be facilitated by a structure early in the process. Various strategies have been developed and evaluated to shorten MV time; one such strategy is the use of respiratory therapist- or nurse-led weaning and extubation protocols. Weaning protocols can help health care professionals determine when to initiate the weaning process by focusing more on weaning and by making the process more systematic (Blackwood et al., 2014). A protocol also gives nurses permission to act in the physician's absence and helps them to feel secure and have a motivation for patient weaning (Kydonaki, 2010). A weaning protocol should contain three main components: (1) a list of objective criteria to decide if a patient is ready to start weaning; (2) a structured guideline for reducing ventilatory support; and (3) a list of criteria for deciding if the patient is ready for extubation (Blackwood et al., 2014).

The effectiveness of weaning protocols to reduce time on MV has been evaluated, and a Cochrane review found a 26% reduction in time on MV for patients in surgical, medical and mixed settings with standardised protocols compared to non-protocolised practice (Blackwood et al., 2014). However, the significant heterogeneity among studies recommends some caution in generalising the results, and the authors recommend further studies in order to distinguish between intervention and implementation effects. In recent decades, manufacturers of ventilator equipment have developed different types of automatic weaning or closed-loop systems. These systems can reduce avoidable delays because they do not rely on healthcare professionals to make ventilator changes, which may be influenced by knowledge, decision-making and workload (Platen et al., 2020). The research area of automatic weaning is growing, but evidence for its advantages is limited; however, compared to the usual care, automated closed-loop weaning systems can reduce time on the ventilator and reduce MV in ICU patients (Rose, Schultz, et al., 2015).

Care of patients on PMV

The care of patients on PMV is complex, and patients are influenced by their long stay in the ICU, malnutrition, muscle weakness, serious complications and a high age with a high level of comorbidity. The care process for patients on PMV includes several important domains when providing effective care but has been proposed to focus on ventilator care and weaning; mobilisation; nutrition; and symptom management. In addition, patients and their families play a key role in care and should be included as a part of the care team in daily care (Rak et al., 2020; Rose et al., 2019).

Ventilator care and prolonged weaning

Prolonged weaning is a complex process and requires more of an individual adaptation of the weaning processes and planning than weaning over the short term. PMV, which includes a protracted weaning process, can be defined as a process of liberation, to better emphasise the hard work for the patients, suffering from ventilator dependence due to malnutrition and respiratory muscle weakness after a long stay on MV in the ICU (Brandstetter & Tamarin, 1992; Penuelas et al., 2015). Such a prolonged weaning process must also rely on interprofessional collaboration that requires effective team communication. A lack of collaboration may result in delayed weaning periods and additional prolongation of MV (Rose, Blackwood, Egerod, et al., 2011).

Although weaning is an interprofessional collaborative process, in some contexts nurses in the ICU have an extensive responsibility for ventilator setting adjustment and determination of extubation readiness and actively work to shorten patient time on the ventilator (Rose, Blackwood, Egerod, et al., 2011). Nurses in the ICU observe the patient 24/7 and often develop a personal relationship and knowledge about the patient’s resources and needs (Kydonaki, 2010). This constant bedside presence and knowledge about the patient puts the nurse in the best position for assessment and decision-making for titration of ventilator settings in response to a patient’s physiologic and mental conditions.

Patients on prolonged weaning can be facilitated by a tracheostomy. This airway management can reduce sedative use, improve patient comfort, induce earlier weaning and easier mobilisation and reduce risks of ventilator-associated pneumonia (Cheung & Napolitano, 2014). Several studies have systematically investigated the impact of early versus late tracheostomy on ventilator time, but the results are uncertain due to the absence of high-quality randomised controlled studies. Early tracheostomy can reduce sedation, but there is no significant evidence that early tracheostomy reduces mortality, incidence of VAP, duration of MV or time in ICU (Andriolo et al., 2015; Meng et al., 2016). Regarding the discussion of timing, one international survey from 59 countries showed that about 20% of patients get their tracheostomy within seven days and a further 54% of patients within two weeks of admission to the ICU, mainly for the expectation of PMV (Vargas et al., 2015).

Intermediate intensive care units or weaning units located in or outside hospitals could be an alternative to more acute care for weaning 'post ICU-patients' on PMV. In Sweden, there is only one private clinic, which is in Stockholm, but these units are more common in Europe. The U.S. has had a well-established system since the 1980s, with almost 400 LTACHs, for the purpose of reducing cost (Munoz-Price, 2009). General acute ICUs are valuable but extremely expensive for the care of more stable patients on PMV. In some Italian studies, respiratory intermediate care units, including patients on PMV, have shown some cost-effectiveness. These units require less personnel, monitoring and technical equipment, and put a greater focus on rehabilitation, but their effect on patient outcome and cost-effectiveness has been debated (Bertolini et al., 2005; Heili-Frades et al., 2019; Polverino et al., 2010).

Mobilisation, nutrition and delirium

Muscle weakness is common in patients on PMV, and about 25% develop general or persistent muscle weakness. This muscle deterioration occurs early when patients lie down in bed, and studies show increased inspiratory muscle weakness in patients after seven days on MV (Ambrosino & Vitacca, 2018; Bissett et al., 2015). One systematic review has shown the positive effects of early mobilisation as increased muscle strength and reduced activity limitations, but no effect on patient mortality (Tipping et al., 2017). Another intervention of early mobilisation protocol within three days of MV start in patients in the ICU resulted in increased time on MV and shorter length of stay in the ICU, and was also associated with a lower risk for MV more than seven days (Lai et al., 2017). Bed cycling in ICU patients during MV as a part of early mobilisation has also shown a positive effect on patients' experience. A study found that patients' participation in their own recovery in the form of bed cycling motivated them, and they felt engaged in their own recovery by having the choice to be active or not (Ringdal et al., 2018). Although there is a low level of high-quality evidence for improved outcome, mobilisation protocols are recommended by the American Thoracic Society and the American College of Chest Physicians for adult patients on MV > 24 hours towards early mobilisation of patients in the ICU (Girard et al., 2017).

Patients on PMV require an optimal nutrition level to cope with the hard work of weaning. There are relations to malnutrition and poor outcomes in critically ill patients, such as nosocomial infections and increased mortality (Ambrosino & Vitacca, 2018). The importance of optimal nutrition during MV has been reviewed. One Cochrane review evaluated the efficacy of early nutrition within 48 hours of ICU admission versus delayed start in critically ill patients, but could not establish significant results due to low-quality evidence (Fuentes Padilla et al., 2019). Another Cochrane review compared the effects of enteral versus parenteral nutrition on mortality, stay in the ICU and adverse events, but found only a few effects on increased mortality, pneumonia and sepsis level (Lewis et al., 2018). Moreover, one RCT in 475 patients on PMV showed that an optimal calorie level in the first week in ICU resulted in increased 6-month survival and was associated with improved functional aspects on health-related quality of life after 3-month follow-up (Wei et al., 2015). Although there were still poor effects on patient outcome, optimal nutrition and nutrition protocols must be seen as a part of an overall care bundle for patients on MV. To fit the best care practice for each individual unit, such bundles must be implemented and evaluated in an organisation on the local level (Allen & Hoffman, 2019).

Delirium is a common complication in more than 50% of patients on PMV in the ICU and is associated with a longer duration of MV and hospital length of stay (Mehta et al., 2015). Delirium has been defined as '*A disturbance of consciousness characterised by a sudden onset and a fluctuating course of attention accompanied by a change in perception or cognition*' (Kotfis et al., 2018, p.129). In ICU patients, delirium often occurs as agitation or disillusions and can be caused by several factors, such as pain, anxiety, sleep disturbances, depression and infections (O'Connor et al., 2014). Several elements can reduce the risk for delirium, such as minimising the use of benzodiazepines and opioids, early mobilisation and orientation or surroundings together with extended visiting times for family members and avoiding noise-related sleep disturbances. These elements together in an extended visiting model have been associated with reduced risk for delirium and shorter ICU stay (Rosa et al., 2017). To reduce the risk of delirium, it is essential to identify signs of delirium early to reduce complications. There are several tools to identify delirium, and two of the most common and validated instruments are the Confusion Assessment Method for the ICU (CAM-ICU) and the Nursing Delirium Screening Scale (Nu-DESC) (Luetz et al., 2010). Treatment of ICU delirium is mostly non-pharmacological, and there are care bundles and protocols focusing on the implementation of preventive strategies to manage delirium in the ICU (Kotfis et al., 2018; Morandi et al., 2017; Rivosecchi et al., 2016).

Family engagement

During PMV and weaning periods in the ICU, patients usually receive lower levels of sedatives; this facilitates communication, not only with caregivers, but also for patients' interactions with their families. Intervention studies involving families in the ICU have shown increased family satisfaction and improved mental health status for family members, but there are no studies associated with the impact of family presence on mortality in patients (Goldfarb et al., 2017). Family members can play an important role in care because they have information about the patient, their needs and personality. The involvement of family members could influence the outcome of daily care and could also be a resource for the ICU care team, especially during periods of PMV (Urner et al., 2018).

Family engagement in the ICU has been growing in recent years, and nurses should promote and facilitate family members to be a part of patient care (Kean & Mitchell, 2014). Family engagement in care can include presence during rounds, assisting in patient care, but also support caregivers to give relevant information about diagnosis, treatment and prognosis and be sensitive to family members' comfort needs in the environment around the ICU (Au et al., 2017; Urner et al., 2018). Evidence-based clinical guidelines for family-centred care by international experts in the field include 23 recommendations focusing on topics such as family presence, family support, communication with family members and operational and environmental issues (Davidson et al., 2017).

Person-centred care

For this thesis, a theoretical model of person-centred care (PCC) was chosen to develop and discuss new visions in care for patients on PMV. PCC requires opportunities for patients to communicate, and this can be a challenge in the ICU due to patients' severe conditions and unconsciousness. However, today, patients on PMV and during weaning are given lighter sedation levels. This means that PCC care with the patient as an active part in care and decision-making could be a resource to improve the outcome. PCC has gained ground as an imperative within health care settings outside of the ICU, as it recognises a patient's right to be involved in her/his own care. A PCC approach puts the patient at the forefront as she/he assumes an active role in decisions about the care process (Brummel-Smith, 2016; Ekman et al., 2011; McCormack & McCance, 2006).

From a historical perspective, there was a shift during the second half of the twentieth century from regarding patients as passive individuals to giving patients a more active role in the decision-making process. Today, caregivers inform the patient, discuss and seek agreement and informant's consent to a greater extent than in the past. These changes have resulted in a new understanding of patients' autonomy, patient education and the involvement of patients in their own treatment as experts (Leplege et al., 2007). The basic assumption of PCC is the need to bring forth the person behind the patient or illness, acknowledging each individual's identity, history and life narrative so that this unique individual is more than just an illness or disease (Ekman, 2014). There are several theories of frames describing the delivery of PCC. Central to many of these frameworks is the idea that the patient is an individual and active person in daily care. The care environment is often in focus and including the patient with the care team is important. Several theories result in a framework valid to general or specific care situations (Brummel-Smith, 2016; Leplege et al., 2007; McCormack & McCance, 2006). PCC today is mainly employed in long-term diseases, such as chronic heart failure (Ekman et al., 2012), Alzheimer's disease (Edvardsson et al., 2008) and geriatrics (Brummel-Smith, 2016) and puts the emphasis on the person behind the disease instead of viewing the person in the role of a patient.

There are several concepts close to PCC, such as 'patient-centred care,' 'family-centred care' or 'patient and family-centred care' (PFCC). While PCC as a theory is almost absent in the intensive care research literature, the use of 'patient-centred care' is more commonly used (Cao et al., 2017; Jakimowicz & Perry, 2015; Slatore et al., 2012). Central to PCC, in contrast to patient-centred care, is that PCC does not reduce and objectify the person to a disease. PCC lets the patient take responsibilities and control over their own care, and results in a person who is responsible for his/her own acts (Ekman et al., 2011). Recently, a synthesis review of the literature revealed that the goal of patient-centred care is a functional life, while the goal of PCC is a meaningful life (Håkansson et al., 2019). PFCC has grown in the ICU context and has been described as a natural extension of patient-centred care, including care to improve patient outcomes, including guidelines for clinicians to optimise support to patients and families in the ICU (Davidson et al., 2017; Goldfarb et al., 2017). PFCC has evolved from the paediatric area to adult

ICUs and insists that the patient is embedded in a family system; therefore, it is essential to include both patients and their families in care (Mitchell et al., 2016). Interventions with PFCC in the ICU have been associated with increased satisfaction among patients and families, improved mental status and decreased length of stay (Goldfarb et al., 2017).

The elements of person-centred care

In this thesis, the theoretical framework of PCC suggested by Ekman et al. (2011) was employed. This framework is based upon the philosophy of Paul Ricœur (1994) and his view of human beings. According to Ricœur, every human being is a capable creature, and responsibilities can be attributed to his or her actions. This could increase the patients' feeling of the importance of playing an active part and having a direct impact upon the results of daily care. A patient's narrative is central to a provider-patient partnership, and the theory according to Ekman et al. (2011) consists of the following three steps: (1) initiating the partnership – patient narratives; (2) working the partnership – shared decision making; and (3) safeguarding the partnership – documenting the narrative. PCC based on these elements has the potential to improve patient-reported outcomes, and several intervention studies conducted outside the ICU also indicate a reduced hospital length of stay and reduced care costs with a PCC approach (Ekman et al., 2012; Hansson et al., 2016). In one randomised controlled trial, patients with acute coronary syndrome were given PCC and customary care, and PCC in patients under 65 years old was both more effective and less costly than customary care (Pirhonen et al., 2019). There are no observations from the ICU context, but two studies have reported the presence of PCC from observations and interviews in various emergency departments and Integrated Critical Care Units (Bolster & Manias, 2010; Walker & Deacon, 2016).

RATIONALE

Patients with PMV in the ICU are in an extremely vulnerable situation with an increased risk for physical and mental complications and increased mortality. Patients in need of PMV do not risk just physiological complications in different organ systems; they are also often affected by cognitive imbalance, caused by sedatives, analgesics and other drugs. Also, as a result of ventilator care, they are unable to communicate with caregivers and family. International studies have shown that this patient group, dominated by elderly patients > 65 years old, with high comorbidity, probably will grow significantly in the coming decades. This will cause an increased need for intensive care resources, leading to increased costs for health care. It is therefore important to find alternatives to shorten the time on ventilator and to be able to find ways to safely shorten the weaning process.

There is a lack of knowledge of the situation in Sweden regarding the prevalence of patients on PMV, CCNs' management of patients on PMV and how prolonged weaning from MV is performed. Furthermore, there is a lack of knowledge about existing care practices and policies for patients on MV to minimise the risks associated with PMV. Finally, there is limited experience of PCC in the ICU setting in order to individualise care and to get the patient more actively involved in decision-making during PMV in the ICU. Increased understanding about the care given to patients on PMV would generate important knowledge that could help to improve the organisation of care and how to best use the available intensive care resources. The importance of setting up an individual plan with the goal of creating the best possible prerequisites for reducing time on ventilator, based on the patient's possibilities and resources, would probably reduce complications due to PMV.

AIMS

The overall aim of this PhD thesis was to explore the care of adult patients on PMV in Swedish ICUs. Secondary aims were to identify the prevalence, characteristics and outcome for patients with PMV and the presence of PCC care during prolonged weaning in Swedish ICUs.

The specific aims of this thesis are as follows:

Study I: The primary aim of this study was to identify the prevalence of ICU admissions requiring MV ≥ 7–21 days and PMV > 21 days in Swedish ICUs, as well as the use of ICU bed days by these admissions. Secondary aims were to describe patient characteristics and patient outcomes, and to explore differences between baseline characteristics in admissions mechanically ventilated ≥ 7–21 days and with PMV > 21 days.

Study II: To identify existing unit characteristics, unit policies, care practices, organisation of care and protocols for ventilator weaning, mobilisation, communication, nutrition, symptom assessment and psychological support for adult patients undergoing MV > 7 days in Swedish ICUs.

Study III: To explore CCNs' approach for management of patients experiencing prolonged weaning in the ICU.

Study IV: To determine: 1) if the three elements of PCC (initiating, working and safeguarding the partnership) were present, and 2) to identify evidence of barriers to PCC during prolonged weaning from MV.

METHODS

Study design

Traditionally, two paradigms have been used to develop evidence in clinical research. These are quantitative research, which is related to a positivistic tradition, and qualitative research, which is allied with a naturalistic tradition (Polit, 2016). Quantitative research includes numeric information in a systematic and controlled process; results are usually based on empirical evidence, and researchers strive for generalisability. The qualitative methods approach is holistic and strives for an understanding of the whole, with research focusing on the human experience through the collection and analysis of narrative and subjective data (Polit, 2016). To grasp the whole in understanding and description based on the overall aims of this thesis, both qualitative and quantitative methods were used in the four included studies.

Study I was a registry study on patients in need of PMV in a Swedish population during 2017. Study II was a national survey exploring the existing care practices, protocols and guidelines used for patients undergoing PMV in all adult Swedish ICUs. Finally, Studies III and IV were interview studies exploring CCNs' work during the prolonged weaning process. The third study emphasised CCNs' strategies and management of the weaning situation. The fourth study was a secondary analysis, exploring the elements of PCC during the prolonged weaning process. An overview of the studies is presented in Table 1.

Table 1. Overview of the studies.

	Study I	**Study II**	**Study III**	**Study IV**
Design	Retrospective registry study	Explorative quantitative study	Qualitative interview study	Qualitative interview study
Data collection	Register data	Questionnaire	Semi-structured interviews	Semi-structured interviews
Participants	Admissions to Swedish ICUs on MV $\geq$ 7 days, n = 1950	Adult ICUs in Sweden, n = 77	CCNs in ICU n = 19	CCNs in ICU n = 19
Data analysis	Descriptive and comparative statistics	Descriptive and comparative statistics	Content analysis, inductive method	Thematic analysis, deductive method

Study I

Settings and participants

For Study I, data from SIR were used. The SIR started in 2001 and is approved as a national quality registry by the Swedish National Board of Health and Welfare (SIR, 2020b). Members of the SIR are Swedish ICUs, and this non-profit association is funded by membership fees and national grants. The registry contains prospectively collected data on ICU admissions, and in 2017, 80 of 84 ICUs in Sweden were members and continuously reported data. Data from the SIR were included for adult patients on MV ≥ 7 days for a 12-month period, from January to December 2017. As this thesis focuses on adult patients, data from paediatric ICUs and patients younger than 18 years old were excluded.

Data collection

After ethical approval, a request was sent to the SIR to obtain data from the registry. Data were requested on all adult (≥ 18 years old) admissions on MV ≥ 7 days from January to December 2017. Paediatric ICUs and admissions < 18 years old to all ICUs were excluded. To obtain denominators for calculating the prevalence, the percentage of ICU beds and mortality, open source data from the SIR for 2017 were used. The following variables for admissions were requested: age; sex; admission source; severity of illness assessed using the Simplified Acute Physiology Score version 3 (SAPS 3) (Moreno et al., 2005); primary ICU diagnosis (ICD-10 SE); day for tracheostomy; duration of MV; length of ICU stay; ICU-, 30- and 90-day mortality; and university or non-university hospital admission.

Data analysis

Descriptive statistics were used, including number and percentage for categorical data and median (range) for continuous data. To compare the two groups, MV ≥ 7–21 days and PMV > 21 days, a logistic regression model was used to predict categorical and continuous outcomes in the two categories (Wiest et al., 2015). Logistic regression was performed for the variables of sex, age, university/non-university ICU, SAPS 3 and diagnosis to analyse which variable was the strongest predictor for the need for PMV > 21 days, compared to admissions requiring MV ≥ 7–21 days. For statistical calculation, SPSS version 25.0 (IBM, Armonk, NY, USA) and STATA version 15.1 (Stata Corp, College Station, TX, USA) were used.

Study II

Setting and participants

Study II was an explorative quantitative study using a questionnaire that included 79 ICUs in Sweden; children and extracorporeal membrane oxygenation (ECMO) units were excluded. A cut-off of MV > 7 days was used in this study according to the definitions of CCI and persistent critical illness (Carson, 2012; Iwashyna et al., 2016).

Data collection

In study II, a questionnaire was used based on a study on Canadian care practice and patients on PMV (Rose, Fowler, et al., 2015). For this study, the original questionnaire was translated, revised and finally modified for the Swedish ICU context. This final version included 46 questions in seven groups: (1) unit details and organisation of care (unit speciality, staffing, visiting policies, general care); (2) ventilator weaning (weaning methods used, available protocols and use of individual planning); (3) mobilisation (available protocols and use of individual planning, use of bed cycling); (4) communication (use of communication tools, sedation scales); (5) nutrition (available protocols, assessment of nutrition); (6) delirium/anxiety/dyspnoea (assessment and scales); and (7) psychosocial support (psychiatric and psychological counselling for patients and families). Questions were answered as yes/no or category response options, and there were options for open answers.

The questionnaire was modified and revised as follows:

1) Revision of the original questionnaire. Items not related to the Swedish context were deleted and questions regarding weaning and family and patient participation were added.
2) Translation to Swedish to enable the Swedish expert group to validate the questions.
3) Revision again to fit the new version with new headings for the seven groups of questions.
4) Validation by a Swedish expert group of five CCNs according to a 1 to 4 graded scale (1 = not relevant, 2 = somewhat relevant, 3 = quite relevant and 4 = highly relevant). This resulted in an item-content validity index at an item level (I-CVI) of 0.91 for the new Swedish version (Polit, 2016; Polit et al., 2007).
5) Under guidance of the expert group, meanings of the text were revised.

6) Back translation to English by an independent translator so the English-speaking author of the original questionnaire to guarantee structure and content.
7) Finally, the questionnaire was piloted to three ICUs to check delivery and collection.

Nurse managers in all units were contacted in March 2018 by email with a request to participate in the study. The email included information about the study and the questionnaire for participants to prepare information if needed for the interview. Nurse managers or CCNs in the ICUs completed the questionnaire by telephone interviews during 11–26 April 2018. The questionnaires were completed by the first author and two experienced CCNs onto a paper version, and thereafter data were manually transferred to SPSS. Despite repeated requests, two ICUs declined to participate.

Data analysis

For Study II, descriptive results were given in numbers and percentages. For the statistical calculation, SPSS version 25.0 (IBM, Armonk, NY, USA) was used.

Studies III and IV

Settings and participants

In Studies III and IV, a qualitative design was employed in order to understand CCNs' strategies and whether elements of PCC were present in the daily clinical work. After obtaining ethical approval and consent from the heads of the actual ICU clinics, information about the study was provided to nurse managers in three different ICUs in western Sweden. This information included a request for the nurse managers to recruit CCNs to participate in the study. All units were general ICUs admitting both medical and surgical patients. Two of the ICUs were located in university hospitals, and the third was in a regional hospital. None of these units had formally adopted PCC at the time of the interviews. The inclusion criteria to participate in the study were ICU specialist CCNs with a minimum of two years of experience in ICU, and there were no exclusion criteria. After contact with the three nurse managers, 19 CCNs chose to participate.

Data collection

Semi-structured interviews were conducted by the first author of the paper. Interviews took place in a quiet room close to the ICU, were 10–50 minutes in length and digitally audio recorded and transcribed verbatim. In accordance with the interview guide, interviews commenced by requesting the participant to describe his or her strategies when managing patients experiencing prolonged weaning and were followed by several follow-up questions about their specific assignments during the process. There were no specific questions regarding PCC in the interview guide.

Qualitative content analysis

For analysis of Study III, a qualitative content analysis according to Graneheim and Lundman (2004) was chosen. Content analysis was early developed to quantify text in a positivistic paradigm, but later this method was moved to a more interpretative paradigm of qualitative research (Krippendorff, 2004). The epistemological and ontological aspects are unclear and depend on the researcher's perspective. Consequently, researchers with a quantitative approach maintain distance and separation from the objects of the study, while those aiming for a more qualitative approach strive to be close to the participants and the text during the different degrees of interpretation (Graneheim et al., 2017). Qualitative content analysis is a flexible and structured way of processing and clarifying textual material from interviews. This method can be either inductive when the phenomenon is fragmented or deductive to test a specific theory according to the data (Elo & Kyngäs, 2008). For this study, an inductive approach was chosen, which gave an unbiased analysis of the text. This was appropriate to the interviews and the aims, which consisted of exploring the CCNs' experiences of their strategies while weaning patients. The method focuses on the interpretation of the text and can be expressed either manifestly or latently, and for Study III, a manifest focus was chosen (Graneheim et al., 2017).

The analysis starts with the coding of meaning units and then condensation of the text, a process that shortens the text while still preserving the core. Then abstraction emphasises the descriptions and interpretations on a higher level, and the creation of subcategories and categories is the core feature of the qualitative content analysis. Finally, a theme can be created as a way to link the underlying interpretation through the categories (Graneheim & Lundman, 2004). The first author therefore started the analysis process by reading the text transcripts from the interviews. During the reading, meaning units were identified and noted. The content of meaning units was critically reflected upon, and then the text was condensed and abstracted into 14 subcategories; the subcategories were related to each other and resulted finally in four categories. These categories were finally discussed by the research team to reach a consensus. The categories were then verbalised into an overall theme defining the underlying meaning of the text source.

Thematic analysis

In Study IV, a thematic theoretical method according to Braun and Clarke (2006) was used. Thematic analysis is described as a flexible method and is not tied to a theoretical or epistemological tradition. This method could therefore be applied across different theoretical and epistemological approaches. Thematic analysis is a foundational method for qualitative analysis and provides the basic skills for the researcher to conduct other qualitative research (Braun & Clarke, 2006). For analysis, this deductive approach can be summarised as comprising five steps: (1) familiarisation with data; (2) coding; (3) searching for themes; (4) reviewing themes; and finally (5) defining and naming themes (Braun & Clarke, 2006).

For this study, a theoretical frame for PCC according to Ekman et al. (2011) was chosen. This frame is based on the routines to establish PCC, and this opened a way to use a more deductive approach for the analysis in the study. To familiarise the researchers with the data, interviews were read repeatedly to understand the meaning as a whole. Then, the first author coded the dataset looking for evidence of PCC, and coded data extracts were then compared to each other and reflected upon. This resulted finally in themes and related subthemes. To further define the themes, a detailed description was provided that identified the theme's meaning to avoid overlapping the themes. The first two authors then reviewed the themes across the coded data to ensure that the coded data were consistent. Themes and subthemes were then discussed among the whole research team until no more overlaps appeared and consensus was reached.

Ethical considerations

In accordance with the World Medical Association Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects, ethical aspects of research on human beings were taken into consideration for all four studies (WMA, 2013). Nordic nursing research is further guided by these principles and has adapted four ethical principles to Nordic conditions: autonomy, beneficence, non-maleficence and justice (NNF, 2003). These principles are intended to ensure that participation in all research is voluntary and that research will contribute to knowledge to promote and restore health and prevent disease and suffering. Furthermore, that the research will not be identifiable as relating to any individual, and finally to safeguard individuals belonging to weak or vulnerable groups. These principles were all taken into consideration in the four studies.

Studies I and II were approved by the Regional Ethical Review Board in Gothenburg (2017-12-14, no: 996-17). In Study I, register data included no personal data and only serial number, age, sex and diagnosis. All patients in Swedish ICUs are given a written standard document on discharge from the ICU to the ward. This includes information that data will be transferred to the SIR and can be used for research after ethical approval. Patients or next of kin can delete their data at this time. Data files will be saved for 10 years and password secured for the research group only. Register data included only admission numbers, so there were low risks of identifying the patients included in the study. Study II was implemented as a telephone interview, and the questionnaire was answered by nurse managers or CCNs in the unit with knowledge about the units' routines and care practises. The questions were not personal, and it is impossible to connect the questionnaire data to the answering persons. The participants were all informed in both written form and orally about the study and its purpose. Studies III and IV were approved by the Regional Ethical Review Board in Gothenburg (2012-03-08 no: 121–12). Participants provided verbal and written consent; they were informed their participation was voluntary and that they had the right to withdraw from the study without any explanation.

RESULTS

Study I

Data from 74/80 (93%) ICUs reporting to the SIR were included, and of the 74 ICUs, 22 (29%) were in university hospitals. According to SIR open source data, there were 39,510 admissions ≥ 18 years old to the 74 ICUs included in the study 2017. Of these admissions, 1,950 required MV ≥ 7 days, and 307 PMV > 21 days (Table 2).

Table 2. Admissions and use of ICU bed days in 74 Swedish ICUs during 2017.

	All	MV ≥ 7 days	MV ≥ 7–21 days	PMV > 21 days
Admissions, n (%)	39,510 (100)	1,950 (5)	1,643 (4)	307 (0.8)
ICU bed days, n (%)	109,457 (100)	35,235 (32)	24,250 (22)	10,985 (10)

ICU: Intensive care unit; MV: Mechanical ventilation; PMV: Prolonged mechanical ventilation

In the group of 1,950 admissions requiring MV ≥ 7 days, the median age was 65 (18–89) years old, 57% were 61–80 years old, 6% were > 80 years old, and 64% were male (Figure 1).

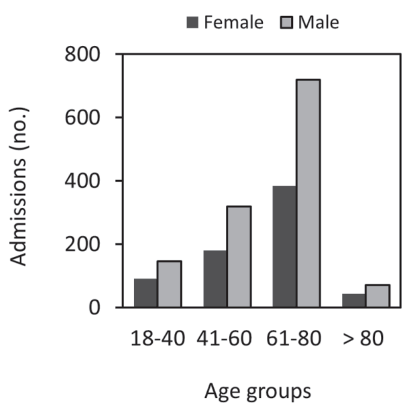

Figure 1. Age groups and female and male admissions with MV ≥ 7 days to Swedish ICUs during 2017, n = 1,950.

Most admissions, 593/1,950 (30%), arrived from the hospital ward, and 500/1,950 (26%) from ICUs. The most common primary ICU diagnoses were septic shock/sepsis and respiratory insufficiency (Figure 2).

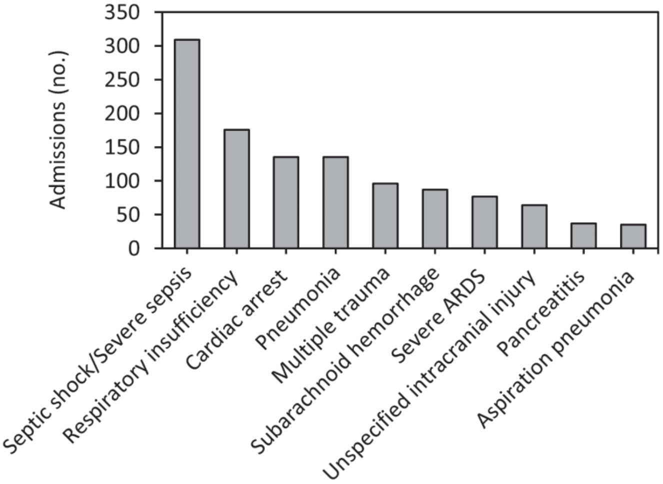

Figure 2. Ten most common primary ICU diagnosis in 1,151/1,950 (59%) of admissions to Swedish ICUs during 2017.

Of the 39,510 admissions, the ICU mortality was 9%, 30-day mortality was 18% and 90-day mortality was 22%. For the 1,643 admissions with MV ≥ 7–21 days, 30-day mortality was 32% and 90-day mortality was 40%, documented for 1,606 admissions. Admissions with PMV > 21 days had lower 30-day mortality (12%) than admissions with MV ≥ 7–21 days (32%). Admissions with a diagnosis of pancreatitis or respiratory insufficiency were the only variables that distinguished admissions requiring PMV > 21 days to MV ≥ 7–21 days.

Study II

In this survey, 77 of 79 (97%) of all invited ICUs answered the questionnaire regarding unit policies, care practices and protocols care for patients on MV > 7 days. Fifty of the ICUs (65%) were non-university hospitals and 20 (26%) were specialist ICUs. There were regular structured care conferences in 39 (51%) ICUs, and in 15/39 (38%) ICUs, families participated, while patients participated when able in 5/39 (13%). Only 11 (14%) of the units indicated any care based on the concepts of PCC and 19 (25%) used models for primary nursing. Counselling from psychiatrists or psychologists for patients was available in 64 (83%) of the ICUs, and 72 (94%) provided access to a psychologist or social worker for families. There were free visiting times in 64 (83%) ICUs. Weaning protocols were available in 42 (55%) ICUs but were mostly individually planned (Table 3). Progressive reduction of pressure support was the most common weaning method, used by 95%. The choice of weaning method was decided in collaboration between CCNs and physicians in 65% of the units and in 27% of the units by a physician alone.

Table 3. Weaning and mobilisation routines for patients on PMV in 77 intensive care units in Sweden.

Routines	n (%)		
	All units n = 77	Non-university n = 50	University n = 27
Weaning			
Weaning protocol available	42 (55)	31 (62)	11 (41)
Protocol includes PMV strategies	14/42 (33)	12/31 (39)	2/11 (18)
Individual weaning plan	52 (68)	36 (72)	16 (59)
Patient participates in establishment	32/52 (62)	21/36 (58)	11/16 (69)
Family participates in establishment	8/52 (15)	5/36 (14)	3/16 (19)
Mobilisation			
Protocol for mobilisation	26 (34)	17 (34)	9 (33)
Individual plan for mobilisation	58 (75)	37 (74)	21 (77)
Bed-cycling	48 (62)	27 (54)	21 (78)

PMV: Prolonged mechanical ventilation; MV: Mechanical ventilation

Mobilisation protocols were available in 34% of the ICUs, but 75% used individual plans for mobilisation (Table 3). Physiotherapists were available five days/week in 97% of the ICUs, and 86% of the ICUs reported that early mobilisation was important and prioritised in their unit. A nutrition protocol was common in 96%, and nutrition status was assessed and decided in 57% of the ICUs by a physician alone. A dietician was involved in nutrition assessment and decisions alone or together with the team in six (8%) ICUs. The most common communication tools were paper and pen (99%) and alphabet/picture boards (97%). There were fewer digital devices, and laptops or tablets were only used by 23% of the ICUs. Almost all units (92%) had sedation scales, and 64% of the ICUs used scales to assess delirium. Only in 4% of the ICUs was a scale for assessing anxiety used, and no ICU used scales to assess dyspnoea.

Study III

The overall findings of this study showed that CCNs in the ICU took great responsibility for the weaning process, both in the initial phase but also to drive the process. This was completed through a patient-centred approach, including assessments of the patients' physical and mental resources. CCNs in the ICU also felt a great responsibility to practice teamwork and collaboration during the process. The results from this study reveal the key role played by CCNs in weaning patients from MV. The interviews in Study III resulted in four categories and one theme (Table 4). In the first category, 'Individual planning', CCNs expressed the need for individualisation of the weaning process and the problems with standardised care. 'Assessing patient capacity' was the second category and included an assessment of patients' capacity and conditions for each shift. In the third category, 'Managing the process', CCNs expressed that they were active in initiating, prioritising and driving the weaning process forward. 'Managing the team interaction' was the last category and described the CCNs' responsibility for collaboration with the interprofessional team.

Table 4. Theme, categories and subcategories in Study III.

Theme	Categories	Subcategories
CCNs drive the weaning process using both a patient-centred and targeted approach	Individual planning	Creating an individual plan Creating continuity Evaluating the process
	Assessing patient capacity	Conditions Respiratory function Well-being Resources Reactions
	Managing the process	Initiating the process Prioritising time for weaning Driving the process forward
	Managing the team interaction	Collaborative planning Collaboration with the enrolled nurse Dialogue with the physician

CCN: Critical care nurse

Study IV

The second analysis of data in Study IV using a deductive approach resulted in three themes and nine subthemes related to the central themes of PCC and one theme and two subthemes related to barriers to the delivery of PCC (Table 5).

Table 5. Themes and subthemes in Study IV related to the three elements of person-centred care.

Themes and subthemes	**Elements of person-centred care***
Finding a person behind the patient	1) Initiating the partnership: patient narratives
Giving back the voice *Empathic listening* *Forming a true picture*	
Striving to restore the patient's sense of control	2) Working the partnership: shared decision-making
Caring encounter *Promoting participation* *Family participation*	
The impact of patients' involvement	3) Safeguarding the partnership: documenting the narrative
Design the plan *Communicate the plan* *Secure the plan*	
Barriers to person-centred care	
Lack of team collaboration *Lack of resources*	

* = Three elements of person-centred care according to Ekman et al. (2011).

In the first theme, 'Finding a person behind the patient', CCNs tried to facilitate communication with the patients by reducing sedation. They created opportunities for communication, to sit down and listen and form a true picture about who the patient was. In the second theme, 'Striving to restore patients' sense of control', CCNs emphasised the importance of staying close to the patient during weaning sessions. They had opportunities to explain the situation and evaluate the response during periods of weaning. Sometimes they had the role of a pilot to inspire the patient to fight during the weaning process. 'The impact of patient involvement' was the third theme, and here the weaning plan was central. The plan was usually designed in the morning and revised several times. CCNs expressed the importance of communicating the plan with the patient and adjusting to the patient's status and situation in the ICU room. Finally, barriers to the delivery of PCC were described as 'Barriers to person-centred care'. This theme described a lack of team collaboration with no time for reflection on the situation and a lack of personal resources or high workload as barriers to listening to the patient and individualising the weaning plan.

DISCUSSION

This thesis explores the patient group on PMV, care practices during PMV and the existence of PCC during prolonged weaning. The discussion addresses the definition of the patient group and the Swedish population in relation to the international situation. Organisation of care, patient involvement and PCC will be discussed, and finally the methodological considerations will be given.

Reflections on the results

To define prolonged mechanical ventilation

Study I in this thesis identified patients on ≥ 7–21 days on MV and > 21 days of PMV. The only significant differences that were found in a logistic regression model between these two groups were that patients on PMV > 21 days were more likely to have pancreatitis and respiratory insufficiencies. There were no differences in sex, age, illness severity or hospital type between groups. Traditionally, patients on PMV have been defined based on time on MV, from a few hours to three weeks. As definitions vary, there is no consensus, even though the most common definition since 2005 has been MV > 21 days (MacIntyre et al., 2005; Rose et al., 2017). CCI has been used to define patients in the ICU with tracheostomy and suffering from deep bodily weakness (Carson, 2012). Recently, persistent critical illness has been used to further indicate patients transforming from an acute level to a more persistent form where the prehospital conditions are more predictive for outcome than the reason for ICU admission (Bagshaw et al., 2018). In contrast to the traditional definitions of PMV, these classifications are based on the patient's clinical conditions and not on time. Interestingly, they already have an earlier time focus and appearance about a week after ICU admission. These, taken together, show that the traditional definition of PMV needs to be discussed to include MV > 7 days rather than the former MV > 21 days.

This thesis shows that in 1950, admissions on MV ≥ 7 days to Swedish ICUs, admissions on PMV > 21 days constituted only 307 admissions/year. Most Swedish ICUs have only a few patients during a year, and more than half of admissions on PMV > 21 days are treated in seven university hospitals. A wider definition of PMV means that more ICUs would prioritise the development of evidence-based care practices, thereby improving care for a more common patient group to minimise time on MV prolonged stay in the ICU. A change of definition of PMV to approximately MV > 7 days could contribute to an earlier focus on care to minimise the risks for protracted time on MV in ICU patients. This is in contrast to the previous definition of > 21 days, which normally is too late to change care, while patients on MV longer than three weeks have already achieved a more rehabilitative phase (Ambrosino & Vitacca, 2018).

The Swedish population

The Swedish population of subjects on PMV > 21 days constituted only 0.8% of all adult ICU admissions, while international studies from the UK and Brazil both have reported up to 4% of all ICU admissions on PMV (Lone & Walsh, 2011; Loss et al., 2015). In comparison with international populations, on PMVs that use 11%–29% of all bed days, the Swedish population used 10% of all available ICU bed days. Study I also showed that ICU mortality (22%) among patients on PMV > 21 days was lower in Sweden, whereas studies from France, the UK and Brazil show ICU mortality rates between 26% and 52% (Leroy et al., 2014; Lone & Walsh, 2011; Loss et al., 2015).

In 2012, Sweden had one of the lowest number of ICU beds in Europe (Rhodes et al., 2012). From this perspective, it can be concluded that Sweden had fewer patients on PMV > 21 days, even though the country has at its disposal one of the lowest levels of acute ICU beds available in Europe. One previous Swiss study reported that ICU admissions are determined mostly by short-time survival and not by expected long-term mortality (Escher et al., 2020). Data exist indicating that the number of available ICU beds can influence physicians' decisions to admit patients to the ICU. One French study reported bed availability affected triage decisions, and more patients were admitted to ICUs with high bed availability than ICUs with low bed availability (Robert et al., 2015). However, one effect of the lower availability of ICU beds in Sweden may be that decisions regarding meaningful care in the ICU are made early, maybe already in the ward. This may have the result that patients with high comorbidities and poor prognoses are not admitted to the ICU.

Organisation of care

Can low rates of admissions and low mortality be influenced by care practices or by organisational structures in Swedish ICUs? There are differences in personnel resources in Swedish and Scandinavian personnel resources in comparison to other countries. Traditionally, in Swedish ICUs, teams including CCNs, physicians, physiotherapists and assistant nurses, all specialists in ICU care, are working closely with the patient. Swedish ICUs also require CCNs specialised in critical care with a one-year diploma after university studies to work as a registered nurse, working bedside and shouldering extensive responsibility for sedative drug levels and ventilator adjustments (Rose, Blackwood, Burns, et al., 2011). Educational levels for nurses have been proven to decrease hospital mortality levels in patients after surgery, but the data included only education at the bachelor's level (Aiken et al., 2014). Systems with critical care outreach teams, liaison nurses and similar nurse-led services are established in several countries to optimise care for patients at risk in the ward and/or to reduce ICU readmissions (So et al., 2019; Tabanejad et al., 2014). Sweden has no established organisation with liaison nurses, but medical emergency teams (METs), including CCNs and physicians, are established in most Swedish hospitals. These METs provide support 24/7 to wards with patients failing in body functions and at risk for ICU care. As observed in Study I, this service could have an impact on the low numbers of Swedish admissions, but so far, no MET data has been published from the Swedish context (SIR, 2020a).

Sweden lacks a general system for care provision regarding patients on MV in need of long-term acute care. Patients who are qualified to be discharged from ICU but in need of MV remain within the ICUs. However, this thesis shows that admissions on MV ≥ 7–21 days occupied 22% and admissions on PMV > 21 days 10% of all ICU bed days. Today, only one private weaning unit is located in Stockholm for patients on PMV and prolonged ICU care. At first glance, it would be expected to move patients on PMV from the ICU to another facility, which has also been recommended in the literature, in order to free acute ICU resources, reduce costs and optimise care and outcome for patients on PMV (Lone & Walsh, 2011). Internationally, essentially two types of alternative units for patients on MV are represented: respiratory intermediate care units, within acute care hospitals, and long-term weaning units, usually located outside acute care hospitals (Ambrosino & Vitacca, 2018). Since the 1990s, the U.S. has had a well-established system with LTACHs for patients with CCI and extended time on MV (Munoz-Price, 2009). However, these units have shown problems with increasing costs and one-year mortality up to 69% (Cox, Carson, Govert, et al., 2007; Kahn et al., 2010).

Study II demonstrated that the existence of weaning protocols in Swedish ICUs was low in comparison to European countries, but higher than in Canadian ICUs

(Rose, Blackwood, Egerod, et al., 2011; Rose, Fowler, et al., 2015). The protocols also showed a low level of strategies for PMV. However, the availability of weaning protocols in Swedish ICUs has increased since 2002, when the authors identified weaning protocols in only 7 of 61 (11%) ICUs (Mårtensson & Fridlund, 2002). Protocols could be useful for patients in short-term weaning to avoid PMV, and evidence exists supporting that the use of weaning protocols reduces weaning time and ICU stay (Blackwood et al., 2014). However, protocols are not usually applicable when the weaning process is prolonged or patients require a more individualised approach to weaning (Kydonaki et al., 2014). Interviews with CCNs in Study III featured their attempts to individualise and ensure continuity over time during the weaning process. CCNs mostly strived to create individual weaning plans because they found a standardised protocol difficult to use on patients on prolonged weaning, and they had to create individual plans for each patient in the weaning process. Study II also showed that ICUs preferred individual approaches in weaning patients, even if protocols were available. The use of protocols in PMV is problematic, as patients need a more individual approach the longer they need MV. However, protocols must be of importance in the ICU, as they reduce time on MV in the short term and consequently reduce the risk for PMV.

The Swedish ICUs in Study II showed a high level of collaborative care. The choice of weaning method and development of individualised weaning plans were mostly in collaboration between CCNs and physicians. Care for patients on prolonged weaning is a complex process that requires not only individual adaptation in patient care but also effective teamwork (Rose, Blackwood, Egerod, et al., 2011). The ICU environment includes multifaceted personnel, and daily care routines necessitate many competences, while teamwork is essential to secure and ensure safe and high-quality care among ICU patients (Dietz et al., 2014). In Study III, collaborative planning was essential for CCNs, and they took the responsibility of involving all team members early in the weaning process and ensuring that all team members were updated about the plan for the day. CCNs stressed the importance of having a dialogue with the physician while planning and working with the weaning process. According to Kydonaki et al. (2014), collaboration during weaning requires a relationship with the team and must be based on trust, appreciation, respect and confidence. A working collaboration between nurses and physicians is therefore a prerequisite for an effective weaning process and progress in patient outcome.

Person-centred care and patient participation

The ICUs in Study II showed a low level of care practices or policies based on PCC. Care based on PCC involves individualisation and includes the patient as an important team member in care (Ekman et al., 2011). There is a lack of published intervention studies on PCC in the ICU context, but interventions in non-ICU environments have reported reduced length of stay and costs (Ekman et al., 2012; Hansson et al., 2016). Interestingly, interviews with CCNs in Study IV confirmed the existence of the three elements of PCC, according to Ekman et al. (2011) during prolonged weaning. However, the included ICUs in this thesis were not exposed to any implementation of PCC, and the interviewed participants were not aware of the research question. Obviously, even if this confirms the existence of PCC in the ICU, there is a need to define and improve the structure for the ICU settings to achieve a successful strategy for PCC and patient participation during prolonged weaning. However, this thesis shows the potential for PCC as a tool to implement a structured individualisation in prolonged weaning and inviting patients to participate in decision-making in care.

The individual weaning plan was created and revised by CCNs day by day depending on the patient's condition. To achieve partnership and involve the patients, CCNs emphasised the importance of communicating the plan with the patient. Today, patients in ICUs are considered team members in ICU care (Rak et al., 2020), and a person-centred approach considers the patient as a member of the care team (Ekman et al., 2011). Participants in Study IV stated that patients were more motivated and cooperative if they understood the plan. To secure the weaning plan, CCNs adjusted and tailored the plan to the patient's condition and to the best time during the day for weaning sessions. Research shows that if the patients are able to communicate, it is important for them to take part in decision-making and cooperate during the weaning process (Tingsvik et al., 2015). However, patient participating in care is not only dependent on patients condition but also nurses ability to include the patient (Schandl et al., 2017). Therefore, it is important for CCNs to strive to involve patients in care to be more active and participate in decision-making.

Study IV also identified barriers to PCC during prolonged weaning. The first barrier constituted a lack of team collaboration, resulting in a process of trial and error with no structure. Interprofessional teamwork is key to delivering the best critical care to patients in the ICU (Donovan et al., 2018), especially in clinical situations as the weaning process (Kydonaki et al., 2014). The other barrier to delivering PCC during weaning was a lack of resources associated with the unit's organisation of care, several patients in the room or acute care situations. This is basically a question of resources, and the ICU's priorities are to save lives. Patient participation can therefore be affected by a high workload or when CCNs are responsible for more than one patient (Falk et al., 2019). However, barriers to PCC in all settings can be overcome through multidisciplinary teamwork, including collaboration with the patient, professionals and specialists. Implementation of PCC in the ICU has been discussed, and authors highlight the importance of an adequate skill mix, optimal education level and experience, and organisation of care (Rattray & McKenna, 2012). Seeing patients and professionals as equals can also promote PCC and reduce more traditional structures of care (Moore et al., 2016). To solve problems with barriers, patients on prolonged weaning could be facilitated by separate environments. A non-acute care setting with a skilled care team and resources to plan and evaluate care could increase the opportunities to deliver patient participation and implementation of PCC.

In Study III, CCNs' knowledge of patients' preferences and personal information about each patient was seen as valuable. If they knew the patient, they also knew the patient's resources and how much work the patient was capable of during a weaning period. 'Knowing the patient' as a concept has been analysed previously in patients on ventilator weaning by Jenny and Logan (1992) and mentioned as essential in weaning situations (Crocker & Scholes, 2009). Knowing the patient is also stated as important in the assessment of work of breathing, wellbeing and clinical deterioration during weaning (Haugdahl et al., 2014). CCNs in Study IV stated that 'knowing the patient' started with finding the person behind the patient by giving back their voice. This can be a challenge in the ICU environment due to the use of sedative medication for facilitating MV and tolerating a high level of technologies and life-saving interventions. This dilemma starts when the patient arrives at the ICU intubated or sedated and is unable to communicate due to severe medical conditions and is often reduced to a diagnosis, injury or bed number (Jakimowicz & Perry, 2015). Knowing the patient has been described as important to individualising care during a patient's long stay in the ICU. This is therefore of importance when individualising and increasing patient participation in care during PMV and prolonged weaning.

Methodological considerations

This thesis originates in Study III, exploring CCNs strategies and management of patients during prolonged weaning. The results opened questions regarding the Swedish patient population on PMV and organisation of patient care. Several aspects were therefore considered in the choice of methods. In order to get a relevant estimate of the extent of patients in need of PMV in Swedish ICUs for Study I, data were extracted from the SIR. The SIR offers patient data from all Swedish ICUs and, therefore, this data can help to deliver a good picture of what the situation is like in Sweden for patients on PMV. To explore the organisation of care, the use of protocols and care practices in Swedish ICUs, Study II was carried out using a questionnaire. This study identified the ICU's structure in care practice and policies. To better understand how CCNs work during prolonged weaning, a second analysis in Study IV identified the appearance and barriers of PCC. This contributed to a deeper understanding of CCNs' care of patients during prolonged weaning.

Definitions

Even though PMV was defined as MV > 21 days in Study I, according to the prevailing international definition, patients with MV ≥ 7 days were included. In Study II, the questions put forward were related to MV > 7 days. This was due to recently published data suggesting that prolonged stay in the ICU and PMV is dependent on the patients' condition rather than only on the number of days on MV (Iwashyna et al., 2016; Maguire & Carson, 2013). For the interviews in Studies III and IV, the term 'prolonged weaning' was used to focus on a situation rather than a patient's time on MV. Using only time on MV could be difficult for participants to describe patient care for PMV and express general care for patients a 'long time' on MV. Focus on prolonged weaning was assessed to give more specific information and data relevant for the whole thesis. Weaning is also a care situation that includes specific skills and increased workload and needs strategies where CCNs' competence will be central (Kydonaki et al., 2016).

Quantitative data collection and analysis

Data for patients on MV ≥ 7 days were requested from the SIR. In addition to the requested data, open data from the SIR for all patients during the same period and the same ICUs were used for comparison. All register results are dependent on correctly reported data to provide information feedback to health care (van der Veer et al., 2010). For Study I, admissions were described only as admissions and not specific patients. The registry data counted only admissions, and individual patients re-admitted to ICU could be counted for several admissions. This could result in interruption of time on MV when moving patients between different ICUs and hospitals.

For Studies I and II, descriptive statistics were used to describe the cohort and results, but a more in-depth comparison, such as between hospitals or regions, was not relevant to the aims. A logistic regression model was used to explore the differences in admissions on MV $\geq$ 7–21 days and PMV > 21 days. Variables such as sex, age, university/non-university ICU, SAPS 3 and diagnosis were used in the model. These variables were assessed as most relevant to the aim and contributed to further distinguishing admissions on PMV > 21 days compared to admissions on MV $\geq$ 7–21 days. Mortality, such as ICU-, 30-, and 90-days mortality, was evaluated in Study I. Usually, in international studies, only ICU- and in-hospital mortality are reported, making it difficult to compare (Leroy et al., 2014; Lone & Walsh, 2011; Loss et al., 2015). Comparison in mortality to data in several previous studies on PMV was therefore not feasible. In-hospital morality can be influenced by several parameters, such as differences in discharge strategies, transports of patients outside the hospital or to another ICU, or discharge to home. A fixed time point is therefore preferable to use for mortality and outcome indicator (Brinkman et al., 2013).

In Study II, a questionnaire previously used in Canada was revised and modified for Swedish conditions (Rose, Fowler, et al., 2015). The original questionnaire included several domains of importance to PMV and weaning, which were previously identified in earlier surveys (Mårtensson & Fridlund, 2002; Rak et al., 2020). To focus on these care practices, domains of discharge options and end-of-life care were excluded, and items regarding weaning and individualisation were included. The telephone interview secured a level of respondents as high as 97% of all Swedish adult ICUs who participated in the study. A mail-distributed questionnaire would probably have given a lower response level.

Qualitative data collection and analysis

Study IV was a secondary analysis of interview data collected for Study III. The primary interview data included rich descriptions of CCNs' strategies during prolonged weaning, but the data also included CCNs' descriptions of their bedside work close to the patients during prolonged weaning. The data described how CCNs recognise the patient during prolonged weaning as a unique person and the CCNs' efforts to individualise the process. Therefore, a second analysis was conducted with a theoretical framework for PCC, but the data used in Study III were not included in Study IV. Participants were not asked questions about PCC, as PCC was not introduced in care in the ICUs. The study aim was not to explore an intervention of PCC or an established care policy. The study only sought to identify if the elements of PCC were present during prolonged weaning. The interviews in this thesis were performed during 2011–2012. There is a risk that the settings for the interviews had changed and therefore were not representative of the study. Care changes over time, and one alteration of importance during the last decade is the evolution in light sedation practice (Laerkner et al., 2016). However, for these two studies, the assessment was that the interviews were representative. The care situation in interviews considered lightly sedated patients during prolonged weaning, but not depending on the specific drug used or sedation strategies.

For Study III, a content analysis with an inductive approach was chosen, and for Study IV, a thematic analysis with a deductive approach was chosen. The differences between these two methods have been discussed, but there are still many similarities. Both methods are suitable for analysis of a low level of interpretation in contrast to hermeneutics phenomenology or grounded theory. The main difference between these two methods is that the content analysis opens the opportunity to quantify data by measuring the frequency of subcategories and categories (Vaismoradi et al., 2013). Another difference is the use of categories and themes in the analysis. A category answers the question of 'what' and can include things, opinions or experiences and is often sorted by hierarchy for categories and subcategories. These are decided early in the process to compare and contrast coded data for the categories or subcategories. Themes and subthemes, in contrast, describe a 'read thread' through the text and are usually more abstract and reflect 'what is this all about?', while describing a meaningful essence for the data (Graneheim et al., 2017). The use of two different methods, including both an inductive and a deductive approach, was assessed as giving a relevant result to the aims.

This thesis only explores CCNs' experience of prolonged weaning and not patients'. Patients' experiences of weaning could contribute to a deeper understanding of the research problem from a patient's perspective. However, patients' experience of ICU, MV and weaning has been previously explored and reviewed in qualitative data in the literature, specifically in the Nordic countries, and therefore is not relevant for this thesis (Baumgarten & Poulsen, 2015; Carruthers et al., 2018; Egerod et al., 2015; Rose, Dainty, et al., 2014). However, nurses' experiences have earlier been explored in MV and weaning situations but not in a prolonged weaning context and not from a PCC perspective.

Trustworthiness in qualitative studies

The qualitative judgment of qualitative research has been under discussion. There are several positions, such as the use of the same criteria as quantitative research or the need for a different set of criteria (Rolfe, 2006). Traditionally, in quantitative research, concepts such as validity, reliability and generalisability have been used. To develop trustworthiness in qualitative research, terms such as credibility, dependability, confirmability and transferability to describe characteristics of trustworthiness have been described by Lincoln and Guba (1985).

Credibility is dependent on significant variations in participants' characteristics, number of interviews, the selection of participants and a rich description of the study context. To achieve dependability, it is necessary to carefully describe the analysis process. This can include a description of the researcher's pre-understandings, as these can influence the asked questions, used follow-up questions and finally the analysis of the text. Confirmability refers to objectivity and means that the text and interpretations represent the information that the participants delivered and not the researchers' perspectives. Transferability is important for obtaining trustworthiness and for determining how the results can be applied to other situations or contexts. It is the reader who decides if the results can be transferred to other contexts, and therefore it is important to describe the entire process in detail, including the selection of participants, the study context and finally the analysis process (Graneheim et al., 2017; Polit, 2016).

Credibility, dependability, confirmability and transferability were achieved by including 19 participants for Studies III and IV from three different units of varying ages and varying years of experience. Nurse managers recruited the participants, and this could have introduced sampling bias, as there is a risk that only specific nurses were asked or nurses interested and positive about weaning were chosen. A structured interview guide was used for all interviews, and the same researcher completed all interviews. The same researcher coded the data in Study III, but all members of the research team discussed the analysis until a consensus was reached. In Study IV, the first author coded the data, and the themes were reviewed by the two first authors and finally discussed by the whole research team. The first author has many years' experience as an ICU nurse and a specific interest in weaning and MV. This pre-understanding could have influenced the results during the interviews and the analysis process. The selection and characteristics of interviewed persons, together with data collection, study culture and context, were described. Finally, the analysis process of the study, together with applicable quotations, was presented.

CONCLUSION

In 2017, patients with MV ≥ 7 days constituted only 5% of all ICU admissions in Sweden but accounted for 32% of all ICU bed days. Even though Sweden, in comparison with other European countries, has a low number of ICU beds, the occupancy of ICU bed days for patients on PMV > 21 days and ICU mortality were lower compared to the internationally reported data. The traditional definition of PMV, based on time and not on patients' condition, needs to be discussed and should preferably include MV > 7 days rather than the current definition of PMV, which is MV > 21 days. Weaning and mobilisation plans in Swedish ICUs were mostly individually tailored and interprofessionally decided, although protocols were available. Early mobilisation was prioritised, and decisions regarding weaning were usually made in collaboration with the CCN and the physician.

Although individual care was preferred, few ICUs applied PCC approaches for care, but PCC existed in Swedish ICUs during prolonged weaning, although there were barriers, such as a lack of personnel resources and team collaboration. CCNs took a great responsibility in the weaning process to achieve the best patient outcome and performed weaning using an individual assessment of patients' resources and responses during the weaning process. They also managed the individual weaning approach by initiating, prioritising time and driving the process forward in collaboration with the ICU team. This study shows that CCNs are in a unique position and play a key role in managing and individualising the prolonged weaning of patients in the ICU.

IMPLICATIONS FOR CARE

- Improved organisation and effective care practices of care for patients on MV > 7 to reduce time on MV can have substantial effects on limited ICU resources.

- A wider definition of PMV based on patients' condition after approximately one week of MV can contribute to an earlier focus and management of patients during the weaning process.

- Care for patients with PMV requires team collaboration and staff resources for an improved individualised care approach.

- PCC could facilitate the further improvement of individualised care and increase patient participation during PMV and weaning.

- The prolonged weaning process could be improved by a care environment separated from acute care including resources for long-term planning of care.

FUTURE PERSPECTIVES

Due to an increasing number of older ICU patients with several co-morbidities, there is a significant risk that the need for PMV will increase. It is therefore important to implement strategies to shorten MV time. Such strategies could be a more individualised weaning process and a movement towards PCC in the ICU. Even though these studies have shown that the problem in Sweden with patients in need of more PMV is not imminent and that a high degree of individual planning already exists, a more structured approach by introducing PCC also in the ICU could avoid future problems of a lack of ICU resources.

PCC can be a valuable tool to increase patient participation, but this tool needs to be defined and customised to be effective and suitable for the ICU environment. Therefore, further research is needed to develop, implement and evaluate PCC strategies to increase individualised care and patient participation during PMV. Finally, delivery of PCC in the ICU will be influenced by how care is organised. More individualised care regarding PCC needs active leadership by policy makers and ward managers to generate resources and organisational structure. Such care needs a culture that values continuity of care, prioritises resources and puts patients in the first place.

ACKNOWLEDGEMENTS

There are so many people who have contributed to this work and supported me through these years.

Thank you to the *Sahlgrenska Academy, Institute of Health and Care Science* for giving me the opportunity to become a PhD student. Thanks to *all critical care nurses* at CIVA Sahlgrenska Hospital and IVA Östra Hospital, at Sahlgrenska University Hospital, and IVA Kungälvs Hospital who participated with your experiences in the interviews. Also thank you all *managers at Swedish ICUs* that contributed with information and thank you to *the board of the Swedish Intensive Care Registry* for register data.

Thank you to all supervisors. You have all contributed to so many parts, in your own way and with your specific competence.
Mona Ringdal, my main supervisor and promotor, thank you for always believing in me and this project from the very beginning. So many times you have pushed me through periods of low self-esteem and supported me to believe that there is a life after this project. Thank you for your engagement and inspiration during these years.
Sepideh Olausson, assistant supervisor, thank you for your patience in writing and reading and for always being there to support and listen. Your ability to see the meaning of the text and find the right words has been so important for the final results.
Silvana Naredi, assistant supervisor, your clinical experience has been so valuable, and you have contributed with an eye for details in this project. Thank you for always answering my stupid questions during the analysis of data and for teaching me the difference between assumptions and results.
Louise Rose, assistant supervisor, you have taught me that real science authorship is hard work, and thanks for your patience with my English. I am deeply impressed by your research and thank you for taking the time to support me and this project through these years.

Ingela Henoch, Stefan Lundin and *Karin Samuelsson* on the review board for my half-time seminar, and *Isabell Fridh, Axel Wolff,* and *Jenny Milton* on the review

board for my pre-defence. Thank you all for your valuable comments and help to go forward with this work.

Thank you, Sahlgrenska University Hospital and CIVA, my place of work through more than 20 years and the place where I really learnt what intensive care is all about. All colleagues at CIVA, but specially thanks to my managers, *Lilian Martinson*, who supported my master's project from the beginning, and *Håkan Joelsson*, who gave me the opportunity to start this project and combine my clinical work with PhD studies. And of course, old and new colleagues in 'Team 2', you are the best!

Thank you, *Kaety Plos* and *Amanda Dübeck*, for your support of and contribution to the manuscript during my first interview study, *Emelie Atterskog och Maria Bågenholm*, for data collection and many phone calls, *Max Petzold,* for your work and valuable comments on statistics and *Louise Freytag* for translation work.

Thank you to all PhD students (and PhDs) at the institution. As an external PhD student, I am so grateful that you let me be a part of the life inside the institution. A special thank you to: *Hilda Svensson, Sara Wallström*, and *Karolina Linden,* you taught me how to celebrate a PhD public defence. *Malin Hansson, Elin Siira* and *Elin Blanck*, thank you for letting me sit in your room in the upper floor. *Jonna Norman* and *Hannan Hamdan Alshehri*, thank you for interesting discussions in the room on the third floor. Finally, the basement league: *Lina Bergman, Markus Saarijärvi, Mariela Acuna Mora, Ulrika Langegård* and *Jenny Milton*, only you understand how to perform and celebrate a PhD during a pandemic situation.

Finally*, Sofia, Ludvig and Oliver,* my beloved family. Thank you for your patience and support throughout these years. Your dad and husband has finally arrived and I'm alive.

REFERENCES

Aiken, L. H., Sloane, D. M., Bruyneel, L., Van den Heede, K., Griffiths, P., Busse, R., Diomidous, M., Kinnunen, J., Kozka, M., Lesaffre, E., McHugh, M. D., Moreno-Casbas, M. T., Rafferty, A. M., Schwendimann, R., Scott, P. A., Tishelman, C., van Achterberg, T., Sermeus, W., & consortium, R. C. (2014). Nurse staffing and education and hospital mortality in nine European countries: a retrospective observational study. *Lancet*, *383*(9931), 1824-1830. https://doi.org/10.1016/S0140-6736(13)62631-8

Allen, K., & Hoffman, L. (2019). Enteral Nutrition in the Mechanically Ventilated Patient. *Nutrition in Clinical Practice*, *34*(4), 540-557. https://doi.org/10.1002/ncp.10242

Ambrosino, N., & Vitacca, M. (2018). The patient needing prolonged mechanical ventilation: a narrative review. *Multidisciplinary Respiratory Medicine*, *13*, 6. https://doi.org/10.1186/s40248-018-0118-7

Andriolo, B. N., Andriolo, R. B., Saconato, H., Atallah, A. N., & Valente, O. (2015). Early versus late tracheostomy for critically ill patients. *Cochrane Database of Systematic Reviews*, *1*, Cd007271. https://doi.org/10.1002/14651858.CD007271.pub3

Au, S. S., Roze des Ordons, A., Soo, A., Guienguere, S., & Stelfox, H. T. (2017). Family participation in intensive care unit rounds: Comparing family and provider perspectives. *Journal of Critical Care*, *38*, 132-136. https://doi.org/10.1016/j.jcrc.2016.10.020

Bagshaw, S. M., Stelfox, H. T., Iwashyna, T. J., Bellomo, R., Zuege, D., & Wang, X. (2018). Timing of onset of persistent critical illness: a multi-centre retrospective cohort study. *Intensive Care Medicine*, *44*(12), 2134-2144. https://doi.org/10.1007/s00134-018-5440-1

Baumgarten, M., & Poulsen, I. (2015). Patients' experiences of being mechanically ventilated in an ICU: a qualitative metasynthesis. *Scandinavian Journal of Caring Sciences*, *29*(2), 205-214. https://doi.org/10.1111/scs.12177

Beduneau, G., Pham, T., Schortgen, F., Piquilloud, L., Zogheib, E., Jonas, M., Grelon, F., Runge, I., Nicolas, T., Grange, S., Barberet, G., Guitard, P. G., Frat, J. P., Constan, A., Chretien, J. M., Mancebo, J., Mercat, A., Richard, J. M., & Brochard, L. (2017). Epidemiology of Weaning Outcome according to a New Definition. The WIND Study. *American Journal of Respiratory and Critical Care Medicine*, *195*(6), 772-783. https://doi.org/10.1164/rccm.201602-0320OC

Bertolini, G., Confalonieri, M., Rossi, C., Rossi, G., Simini, B., Gorini, M., & Corrado, A. (2005). Costs of the COPD. Differences between intensive care unit and respiratory intermediate care unit. *Respiratory Medicine*, *99*(7), 894-900. https://doi.org/10.1016/j.rmed.2004.11.014

Bissett, B., Leditschke, I. A., Neeman, T., Boots, R., & Paratz, J. (2015). Weaned but weary: One third of adult intensive care patients mechanically ventilated for 7 days or more have impaired inspiratory muscle endurance after successful weaning [Article]. *Heart and Lung*, *44*(1), 15-20. https://doi.org/10.1016/j.hrtlng.2014.10.001

Blackwood, B. (2000). The art and science of predicting patient readiness for weaning from mechanical ventilation. *International Journal of Nursing Studies*, *37*(2), 145-151. https://doi.org/10.1016/S0020-7489(99)00062-0

Blackwood, B., Burns, K. E., Cardwell, C. R., & O'Halloran, P. (2014). Protocolized versus non-protocolized weaning for reducing the duration of mechanical ventilation in critically ill adult patients. *Cochrane Database of Systematic Reviews*, *11*, CD006904. https://doi.org/10.1002/14651858.CD006904.pub3 [doi]

Boles, J. M., Bion, J., Connors, A., Herridge, M., Marsh, B., Melot, C., Pearl, R., Silverman, H., Stanchina, M., Vieillard-Baron, A., & Welte, T. (2007). Weaning from mechanical ventilation. *European Respiratory Journal*, *29*(5), 1033-1056. https://doi.org/10.1183/09031936.00010206

Bolster, D., & Manias, E. (2010). Person-centred interactions between nurses and patients during medication activities in an acute hospital setting: qualitative observation and interview study. *International Journal of Nursing Studies*, *47*(2), 154-165. https://doi.org/10.1016/j.ijnurstu.2009.05.021

Brandstetter, R. D., & Tamarin, F. (1992). Weaning is demeaning. It's time for liberation! *Chest*, *101*(6), 1488. https://doi.org/10.1378/chest.101.6.1488

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77-101. https://doi.org/10.1191/1478088706qp063oa

Brinkman, S., Abu-Hanna, A., de Jonge, E., & de Keizer, N. F. (2013). Prediction of long-term mortality in ICU patients: model validation and assessing the effect of using in-hospital versus long-term mortality on benchmarking. *Intensive Care Medicine*, *39*(11), 1925-1931. https://doi.org/10.1007/s00134-013-3042-5 (Intensive Care Med)

Brummel-Smith, K. e. a. (2016). Person-Centered Care: A definition and essential elements. *Journal of the American Geriatrics Society*, *64*(1), 15-18. https://doi.org/10.1111/jgs.13866

Cao, V., Tan, L. D., Horn, F., Bland, D., Giri, P., Maken, K., Cho, N., Scott, L., Dinh, V. A., Hidalgo, D., & Nguyen, H. B. (2017). Patient-Centered Structured Interdisciplinary Bedside Rounds in the Medical ICU. *Critical Care Medicine*. https://doi.org/10.1097/ccm.0000000000002807

Carpene, N., Vagheggini, G., Panait, E., Gabbrielli, L., & Ambrosino, N. (2010). A proposal of a new model for long-term weaning: respiratory intensive care unit and weaning center. *Respiratory Medicine*, *104*(10), 1505-1511. https://doi.org/10.1016/j.rmed.2010.05.012

Carruthers, H., Gomersall, T., & Astin, F. (2018). The work undertaken by mechanically ventilated patients in Intensive Care: A qualitative meta-ethnography of survivors' experiences. *International Journal of Nursing Studies*, *86*, 60-73. https://doi.org/10.1016/j.ijnurstu.2018.05.013

Carson, S. S. (2012). Definitions and epidemiology of the chronically critically ill.(Conference Proceedings). *Respiratory Care*, *57*(6), 848. https://doi.org/10.4187/respcare.01736

Carson, S. S., Kahn, J. M., Hough, C. L., Seeley, E. J., White, D. B., Douglas, I. S., Cox, C. E., Caldwell, E., Bangdiwala, S. I., Garrett, J. M., & Rubenfeld, G. D. (2012). A multicenter mortality prediction model for patients receiving prolonged mechanical ventilation. *Critical Care Medicine*, *40*(4), 1171-1176. https://doi.org/10.1097/CCM.0b013e3182387d43

Cheung, N. H., & Napolitano, L. M. (2014). Tracheostomy: epidemiology, indications, timing, technique, and outcomes. *Respiratory Care*, *59*(6), 895-915; discussion 916-899. https://doi.org/10.4187/respcare.02971

Cox, C. E., Carson, S. S., Govert, J. A., Chelluri, L., & Sanders, G. D. (2007). An economic evaluation of prolonged mechanical ventilation. *Critical Care Medicine*, *35*(8), 1918-1927. https://doi.org/10.1097/01.ccm.0000275391.35834.10

Cox, C. E., Carson, S. S., Lindquist, J. H., Olsen, M. K., Govert, J. A., & Chelluri, L. (2007). Differences in one-year health outcomes and resource utilization by definition of prolonged mechanical ventilation: a prospective cohort study. *Critical Care*, *11*(1), R9. https://doi.org/10.1186/cc5667

Crocker, C. (2009). Weaning from ventilation -- current state of the science and art. *Nursing in Critical Care*, *14*(4), 185-190. https://doi.org/10.1111/j.1478-5153.2009.00334.x

Crocker, C., & Scholes, J. (2009). The importance of knowing the patient in weaning from mechanical ventilation. *Nursing in Critical Care*, *14*(6), 289-296. https://doi.org/10.1111/j.1478-5153.2009.00355.x

Danielis, M., Povoli, A., Mattiussi, E., & Palese, A. (2020). Understanding patients' experiences of being mechanically ventilated in the Intensive Care Unit: Findings from a meta-synthesis and meta-summary. *Journal of Clinical Nursing*. https://doi.org/10.1111/jocn.15259

Davidson, J. E., Aslakson, R. A., Long, A. C., Puntillo, K. A., Kross, E. K., Hart, J., Cox, C. E., Wunsch, H., Wickline, M. A., Nunnally, M. E., Netzer, G., Kentish-Barnes, N., Sprung, C. L., Hartog, C. S., Coombs, M., Gerritsen, R. T., Hopkins, R. O., Franck, L. S., Skrobik, Y., Kon, A. A., Scruth, E. A., Harvey, M. A., Lewis-Newby, M., White, D. B., Swoboda,

S. M., Cooke, C. R., Levy, M. M., Azoulay, E., & Curtis, J. R. (2017). Guidelines for Family-Centered Care in the Neonatal, Pediatric, and Adult ICU. *Critical Care Medicine*, *45*(1), 103-128. https://doi.org/10.1097/ccm.0000000000002169

Davies, M. G., Quinnell, T. G., Oscroft, N. S., Clutterbuck, S. P., Shneerson, J. M., & Smith, I. E. (2017). Hospital outcomes and long-term survival after referral to a specialized weaning unit. *British Journal of Anaesthesia*, *118*(4), 563-569. https://doi.org/10.1093/bja/aex031

Dettmer, M. R., Damuth, E., Zarbiv, S., Mitchell, J. A., Bartock, J. L., & Trzeciak, S. (2017). Prognostic Factors for Long-Term Mortality in Critically Ill Patients Treated With Prolonged Mechanical Ventilation: A Systematic Review. *Critical Care Medicine*, *45*(1), 69-74. https://doi.org/10.1097/ccm.0000000000002022

Dietz, A. S., Pronovost, P. J., Mendez-Tellez, P. A., Wyskiel, R., Marsteller, J. A., Thompson, D. A., & Rosen, M. A. (2014). A systematic review of teamwork in the intensive care unit: what do we know about teamwork, team tasks, and improvement strategies? *Journal of Critical Care*, *29*(6), 908-914. https://doi.org/10.1016/j.jcrc.2014.05.025

Donovan, A. L., Aldrich, J. M., Gross, A. K., Barchas, D. M., Thornton, K. C., Schell-Chaple, H. M., Gropper, M. A., & Lipshutz, A. K. M. (2018). Interprofessional Care and Teamwork in the ICU. *Critical Care Medicine*, *46*(6), 980-990. https://doi.org/10.1097/ccm.0000000000003067

Edvardsson, D., Winblad, B., & Sandman, P. O. (2008). Person-centred care of people with severe Alzheimer's disease: current status and ways forward. *Lancet Neurology*, *7*(4), 362-367. https://doi.org/10.1016/s1474-4422(08)70063-2

Egerod, I., Albarran, J. W., Ring, M., & Blackwood, B. (2013). Sedation practice in Nordic and non-Nordic ICUs: a European survey. *Nursing in Critical Care*, *18*(4), 166-175. https://doi.org/10.1111/nicc.12003

Egerod, I., Bergbom, I., Lindahl, B., Henricson, M., Granberg-Axell, A., & Storli, S. L. (2015). The patient experience of intensive care: a meta-synthesis of Nordic studies. *International Journal of Nursing Studies*, *52*(8), 1354-1361. https://doi.org/10.1016/j.ijnurstu.2015.04.017

Ekman, I. (2014). *Personcentrering inom hälso- och sjukvård : från filosofi till praktik*. Liber.

Ekman, I., Swedberg, K., Taft, C., Lindseth, A., Norberg, A., Brink, E., Carlsson, J., Dahlin-Ivanoff, S., Johansson, I. L., Kjellgren, K., Liden, E., Ohlen, J., Olsson, L. E., Rosen, H., Rydmark, M., & Sunnerhagen, K. S. (2011). Person-centered care--ready for prime time. *European Journal of Cardiovascular Nursing*, *10*(4), 248-251. https://doi.org/10.1016/j.ejcnurse.2011.06.008

Ekman, I., Wolf, A., Olsson, L. E., Taft, C., Dudas, K., Schaufelberger, M., & Swedberg, K. (2012). Effects of person-centred care in patients with chronic heart failure: the PCC-HF study. *European Heart Journal*, *33*(9), 1112-1119. https://doi.org/10.1093/eurheartj/ehr306

Elo, S., & Kyngäs, H. (2008). The qualitative content analysis process. *Journal of Advanced Nursing*, *62*(1), 107-115. https://doi.org/10.1111/j.1365-2648.2007.04569.x

Engstrom, A., Nystrom, N., Sundelin, G., & Rattray, J. (2013). People's experiences of being mechanically ventilated in an ICU: a qualitative study. *Intensive and Critical Care Nursing*, *29*(2), 88-95. https://doi.org/10.1016/j.iccn.2012.07.003

Ervin, J. N., Kahn, J. M., Cohen, T. R., & Weingart, L. R. (2018). Teamwork in the intensive care unit. *American Psychologist*, *73*(4), 468-477. https://doi.org/10.1037/amp0000247

Escher, M., Nendaz, M., Scherer, F., Cullati, S., & Perneger, T. (2020). Physicians' predictions of long-term survival and functional outcomes do not influence the decision to admit patients with advanced disease to intensive care: A prospective study. *Palliative Medicine*, 269216320963931. https://doi.org/10.1177/0269216320963931

Falk, A. C., Schandl, A., & Frank, C. (2019). Barriers in achieving patient participation in the critical care unit. *Intensive and Critical Care Nursing*, *51*, 15-19. https://doi.org/10.1016/j.iccn.2018.11.008

Fuentes Padilla, P., Martínez, G., Vernooij, R. W., Urrútia, G., Roqué, I. F. M., & Bonfill Cosp, X. (2019). Early enteral nutrition (within 48 hours) versus delayed enteral nutrition (after 48 hours) with or without supplemental parenteral nutrition in critically ill adults. *Cochrane Database of Systematic Reviews*, *2019*(10). https://doi.org/10.1002/14651858.CD012340.pub2

Girard, K., & Raffin, T. A. (1985). The chronically critically ill: to save or let die? *Respiratory Care*, *30*(5), 339-347. https://pubmed.ncbi.nlm.nih.gov/10315661/

Girard, T. D., Alhazzani, W., Kress, J. P., Ouellette, D. R., Schmidt, G. A., Truwit, J. D., Burns, S. M., Epstein, S. K., Esteban, A., Fan, E., Ferrer, M., Fraser, G. L., Gong, M. N., Hough, C. L., Mehta, S., Nanchal, R., Patel, S., Pawlik, A. J., Schweickert, W. D., Sessler, C. N., Strøm, T., Wilson, K. C., Morris, P. E., & Adults, A. C. A. H. C. o. L. f. M. V. i. (2017). An Official American Thoracic Society/American College of Chest Physicians Clinical Practice Guideline: Liberation from Mechanical Ventilation in Critically Ill Adults. Rehabilitation Protocols, Ventilator Liberation Protocols, and Cuff Leak Tests. *American Journal of Respiratory and Critical Care Medicine*, *195*(1), 120-133. https://doi.org/10.1164/rccm.201610-2075ST

Goldfarb, M. J., Bibas, L., Bartlett, V., Jones, H., & Khan, N. (2017). Outcomes of Patient- and Family-Centered Care Interventions in the ICU: A Systematic Review and Meta-Analysis. *Critical Care Medicine*, *45*(10), 1751-1761. https://doi.org/10.1097/ccm.0000000000002624

Goligher, E. C., Ferguson, N. D., & Brochard, L. J. (2016). Clinical challenges in mechanical ventilation. *Lancet*, *387*(10030), 1856-1866. https://doi.org/10.1016/S0140-6736(16)30176-3

Graneheim, U. H., Lindgren, B. M., & Lundman, B. (2017). Methodological challenges in qualitative content analysis: A discussion paper. *Nurse Education Today*, *56*, 29-34. https://doi.org/10.1016/j.nedt.2017.06.002

Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, *24*(2), 105-112. https://doi.org/10.1016/j.nedt.2003.10.001

Hansson, E., Ekman, I., Swedberg, K., Wolf, A., Dudas, K., Ehlers, L., & Olsson, L. E. (2016). Person-centred care for patients with chronic heart failure - a cost-utility analysis. *European Journal of Cardiovascular Nursing*, *15*(4), 276-284. https://doi.org/10.1177/1474515114567035

Haugdahl, H. S., Storli, S., Rose, L., Romild, U., & Egerod, I. (2014). Perceived decisional responsibility for mechanical ventilation and weaning: a Norwegian survey. *Nursing in Critical Care*, *19*(1), 18-25. https://doi.org/10.1111/nicc.12051

Heili-Frades, S., Carballosa de Miguel, M. D. P., Naya Prieto, A., Galdeano Lozano, M., Mate García, X., Mahillo Fernández, I., Fernández Ormaechea, I., Álvarez Suárez, L., Ezzine de Blas, F., Checa Venegas, M. J., González Mangado, N., & Peces Barba, G. (2019). Cost and Mortality Analysis of an Intermediate Respiratory Care Unit. Is It Really Efficient and Safe? *Archivos de Bronconeumologia*, *55*(12), 634-641. https://doi.org/10.1016/j.arbres.2019.06.008

Hess, D. R. (2014). Respiratory mechanics in mechanically ventilated patients. *Respiratory Care*, *59*(11), 1773-1794. https://doi.org/10.4187/respcare.03410

Hill, A. D., Fowler, R. A., Burns, K. E., Rose, L., Pinto, R. L., & Scales, D. C. (2017). Long-Term Outcomes and Health Care Utilization after Prolonged Mechanical Ventilation. *Annals of the American Thoracic Society*, *14*(3), 355-362. https://doi.org/10.1513/AnnalsATS.201610-792OC

Hung, T. C., Lai, Y. F., Tseng, C. W., Hong, Y. H., & Shi, H. Y. (2013). Trend analysis of hospital resource utilization for prolonged mechanical ventilation patients in Taiwan: a population-based study. *Respiratory Care*, *58*(4), 669-675. https://doi.org/10.4187/respcare.01519

Håkansson, J., Holmström, I. K., Kumlin, T., Kaminsky, E., Skoglund, K., Höglander, J., Sundler, A. J., Condén, E., & Summer Meranius, M. (2019). "Same same or different?" A review of reviews of person-centered and patient-centered care. *Patient Education and Counseling*, *102*(1), 3-11. https://doi.org/10.1016/j.pec.2018.08.029

Iwashyna, T. J., Hodgson, C. L., Pilcher, D., Bailey, M., van Lint, A., Chavan, S., & Bellomo, R. (2016). Timing of onset and burden of persistent critical illness in Australia and New Zealand: a retrospective, population-based, observational study. *Lancet Respiratory Medicine*, *4*(7), 566-573. https://doi.org/10.1016/s2213-2600(16)30098-4

Iwashyna, T. J., Hodgson, C. L., Pilcher, D., Orford, N., Santamaria, J. D., Bailey, M., & Bellomo, R. (2015). Towards defining persistent critical illness and other varieties of chronic critical illness. *Critical Care and Resuscitation*, *17*(3), 215-218. https://ccr.cicm.org.au/file/download-article?id=440e4e95-b196-47ea-ace0-8a282f7cb2bb&settings=litnzgC1RAsiHS43rCo4xl0o6fJ2vkUs7E1idqsazv0%3D

Jakimowicz, S., & Perry, L. (2015). A concept analysis of patient-centred nursing in the intensive care unit. *Journal of Advanced Nursing*, *71*(7), 1499-1517. https://doi.org/10.1111/jan.12644

Jenny, J., & Logan, J. (1992). Knowing the patient: one aspect of clinical knowledge. *Journal of Nursing Scholarship*, *24*(4), 254-258. https://doi.org/10.1111/j.1547-5069.1992.tb00730.x

Kahn, J. M., Benson, N. M., Appleby, D., Carson, S. S., & Iwashyna, T. J. (2010). Long-term acute care hospital utilization after critical illness. *JAMA*, *303*(22), 2253-2259. https://doi.org/10.1001/jama.2010.761

Kahn, J. M., Le, T., Angus, D. C., Cox, C. E., Hough, C. L., White, D. B., Yende, S., Carson, S. S., & ProVent Study Group, I. (2015). The epidemiology of chronic critical illness in the United States*. *Critical Care Medicine*, *43*(2), 282-287. https://doi.org/10.1097/CCM.0000000000000710

Kallet, R. H. (2011). Patient-ventilator interaction during acute lung injury, and the role of spontaneous breathing: part 1: respiratory muscle function during critical illness. *Respiratory Care*, *56*(2), 181. https://doi.org/10.4187/respcare.00964

Kean, S., & Mitchell, M. (2014). How do intensive care nurses perceive families in intensive care? Insights from the United Kingdom and Australia. *Journal of Clinical Nursing*, *23*(5-6), 663-672. https://doi.org/10.1111/jocn.12195

King, J., O'Neill, B., Ramsay, P., Linden, M. A., Darweish Medniuk, A., Outtrim, J., & Blackwood, B. (2019). Identifying patients' support needs following critical illness: a scoping review of the qualitative literature. *Critical Care*, *23*(1), 187. https://doi.org/10.1186/s13054-019-2441-6

Kotfis, K., Marra, A., & Ely, E. W. (2018). ICU delirium - a diagnostic and therapeutic challenge in the intensive care unit. *Anaesthesiology Intensive Therrapy*, *50*(2), 160-167. https://doi.org/10.5603/AIT.a2018.0011

Krippendorff, K. (2004). *Content analysis : an introduction to its methodology*. Sage.

Kydonaki, K. (2010). Observing the approaches to weaning of the long-term ventilated patients. *Nursing in Critical Care*, *15*(2), 49-56. https://doi.org/10.1111/j.1478-5153.2010.00389.x

Kydonaki, K., Huby, G., & Tocher, J. (2014). Difficult to wean patients: cultural factors and their impact on weaning decision-making. *Journal of Clinical Nursing*, *23*(5-6), 683-693. https://doi.org/10.1111/jocn.12104

Kydonaki, K., Huby, G., Tocher, J., & Aitken, L. M. (2016). Understanding nurses' decision-making when managing weaning from mechanical ventilation: a study of novice and experienced critical care nurses in Scotland and Greece. *Journal of Clinical Nursing*, *25*(3-4), 434-444. https://doi.org/10.1111/jocn.13070

Laerkner, E., Stroem, T., & Toft, P. (2016). No-sedation during mechanical ventilation: impact on patient's consciousness, nursing workload and costs. *Nursing in Critical Care*, *21*(1), 28-35. https://doi.org/10.1111/nicc.12161

Lai, C. C., Chou, W., Chan, K. S., Cheng, K. C., Yuan, K. S., Chao, C. M., & Chen, C. M. (2017). Early Mobilization Reduces Duration of Mechanical Ventilation and Intensive Care Unit Stay in Patients With Acute Respiratory Failure. *Archives of Physical Medicine and Rehabilitation*, *98*(5), 931-939. https://doi.org/10.1016/j.apmr.2016.11.007

Leplege, A., Gzil, F., Cammelli, M., Lefeve, C., Pachoud, B., & Ville, I. (2007). Person-centredness: conceptual and historical perspectives. *Disability and Rehabilitation*, *29*(20-21), 1555-1565. https://doi.org/10.1080/09638280701618661

Leroy, G., Devos, P., Lambiotte, F., Thevenin, D., & Leroy, O. (2014). One-year mortality in patients requiring prolonged mechanical ventilation: multicenter evaluation of the ProVent score. *Critical Care*, *18*(4), R155. https://doi.org/10.1186/cc13994 (Crit Care)

Lewis, S. R., Schofield-Robinson, O. J., Alderson, P., & Smith, A. F. (2018). Enteral versus parenteral nutrition and enteral versus a combination of enteral and parenteral nutrition for adults in the intensive care unit. *Cochrane Database of Systematic Reviews*, *6*, CD012276. https://doi.org/10.1002/14651858.CD012276.pub2

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Sage.

Lone, N. I., & Walsh, T. S. (2011). Prolonged mechanical ventilation in critically ill patients: epidemiology, outcomes and modelling the potential cost consequences of establishing a regional weaning unit. *Critical Care*, *15*(2), R102. https://doi.org/10.1186/cc10117

Loss, S. H., de Oliveira, R. P., Maccari, J. G., Savi, A., Boniatti, M. M., Hetzel, M. P., Dallegrave, D. M., Balzano Pde, C., Oliveira, E. S., Hoher, J. A., Torelly, A. P., & Teixeira, C. (2015). The reality of patients requiring prolonged mechanical ventilation: a multicenter study. *Revista Brasileira de Terapia Intensiva*, *27*(1), 26-35. https://doi.org/10.5935/0103-507x.20150006

Luetz, A., Heymann, A., Radtke, F. M., Chenitir, C., Neuhaus, U., Nachtigall, I., von Dossow, V., Marz, S., Eggers, V., Heinz, A., Wernecke, K. D., & Spies, C. D. (2010). Different assessment tools for intensive care unit delirium: which score to use? *Critical Care Medicine*, *38*(2), 409-418. https://doi.org/10.1097/CCM.0b013e3181cabb42

MacIntyre, N. R., Epstein, S. K., Carson, S., Scheinhorn, D., Christopher, K., Muldoon, S., & National Association for Medical Direction of Respiratory, C. (2005). Management of patients requiring prolonged mechanical ventilation: report of a NAMDRC consensus conference. *Chest*, *128*(6), 3937-3954. https://doi.org/10.1378/chest.128.6.3937

Maguire, J. M., & Carson, S. S. (2013). Strategies to combat chronic critical illness. *Current Opinion in Critical Care*, *19*(5), 480-487. https://doi.org/10.1097/MCC.0b013e328364d65e

Mancebo, J. (1996). Weaning from mechanical ventilation. *European Respiratory Journal*, *9*(9), 1923-1931. https://doi.org/10.1183/09031936.96.09091923

Marshall, J. C., Bosco, L., Adhikari, N. K., Connolly, B., Diaz, J. V., Dorman, T., Fowler, R. A., Meyfroidt, G., Nakagawa, S., Pelosi, P., Vincent, J. L., Vollman, K., & Zimmerman, J. (2017). What is an intensive care unit? A report of the task force of the World Federation of Societies of Intensive and Critical Care Medicine. *Journal of Critical Care*, *37*, 270-276. https://doi.org/10.1016/j.jcrc.2016.07.015

McCormack, B., & McCance, T. V. (2006). Development of a framework for person-centred nursing. *Journal of Advanced Nursing*, *56*(5), 472-479. https://doi.org/10.1111/j.1365-2648.2006.04042.x

Mehta, S., Cook, D., Devlin, J. W., Skrobik, Y., Meade, M., Fergusson, D., Herridge, M., Steinberg, M., Granton, J., Ferguson, N., Tanios, M., Dodek, P., Fowler, R., Burns, K., Jacka, M., Olafson, K., Mallick, R., Reynolds, S., Keenan, S., & Burry, L. (2015). Prevalence, risk factors, and outcomes of delirium in mechanically ventilated adults. *Critical Care Medicine*, *43*(3), 557-566. https://doi.org/10.1097/ccm.0000000000000727

Mendelson, J. H., & Foley, J. M. (1956). An abnormality of mental function affecting patients with poliomyelitis in a tank-type respirator. *Transactions of the American Neurological Association*, 134-138. https://pubmed.ncbi.nlm.nih.gov/13409490/

Meng, L., Wang, C., Li, J., & Zhang, J. (2016). Early vs late tracheostomy in critically ill patients: a systematic review and meta-analysis. *Clinical Respiratory Journal*, *10*(6), 684-692. https://doi.org/10.1111/crj.12286

Mitchell, M. L., Coyer, F., Kean, S., Stone, R., Murfield, J., & Dwan, T. (2016). Patient, family-centred care interventions within the adult ICU setting: An integrative review. *Australian Critical Care*, *29*(4), 179-193. https://doi.org/10.1016/j.aucc.2016.08.002

Moore, L., Britten, N., Lydahl, D., Naldemirci, O., Elam, M., & Wolf, A. (2016). Barriers and facilitators to the implementation of person-centred care in different healthcare contexts. *Scandinavian Journal of Caring Sciences*. https://doi.org/10.1111/scs.12376

Morandi, A., Piva, S., Ely, E. W., Myatra, S. N., Salluh, J. I. F., Amare, D., Azoulay, E., Bellelli, G., Csomos, A., Fan, E., Fagoni, N., Girard, T. D., Heras La Calle, G., Inoue, S., Lim, C. M., Kaps, R., Kotfis, K., Koh, Y., Misango, D., Pandharipande, P. P., Permpikul, C., Cheng Tan, C., Wang, D. X., Sharshar, T., Shehabi, Y., Skrobik, Y., Singh, J. M., Slooter, A., Smith, M., Tsuruta, R., & Latronico, N. (2017). Worldwide Survey of the "Assessing Pain, Both Spontaneous Awakening and Breathing Trials, Choice of Drugs, Delirium Monitoring/Management, Early Exercise/Mobility, and Family Empowerment" (ABCDEF) Bundle. *Critical Care Medicine*, *45*(11), e1111-e1122. https://doi.org/10.1097/ccm.0000000000002640

Moreno, R. P., Metnitz, P. G., Almeida, E., Jordan, B., Bauer, P., Campos, R. A., Iapichino, G., Edbrooke, D., Capuzzo, M., & Le Gall, J. R. (2005). SAPS 3--From evaluation of the patient to evaluation of the intensive care unit. Part 2: Development of a prognostic model for hospital mortality at ICU admission. *Intensive Care Medicine*, *31*(10), 1345-1355. https://doi.org/10.1007/s00134-005-2763-5

Munoz-Price, L. S. (2009). Long-term acute care hospitals. *Clinical Infectious Diseases*, *49*(3), 438-443. https://doi.org/10.1086/600391

Mårtensson, I. E., & Fridlund, B. (2002). Factors influencing the patient during weaning from mechanical ventilation: a national survey. *Intensive and Critical Care Nursing*, *18*(4), 219-229. https://doi.org/10.1016/S0964339702000630

Nelson, J. E., Cox, C. E., Hope, A. A., & Carson, S. S. (2010). Chronic critical illness. *American Journal of Respiratory and Critical Care Medicine*, *182*(4), 446-454. https://doi.org/10.1164/rccm.201002-0210CI

Neuraz, A., Guérin, C., Payet, C., Polazzi, S., Aubrun, F., Dailler, F., Lehot, J. J., Piriou, V., Neidecker, J., Rimmelé, T., Schott, A. M., & Duclos, A. (2015). Patient Mortality Is Associated With Staff Resources and Workload in the ICU: A Multicenter Observational Study. *Critical Care Medicine*, *43*(8), 1587-1594. https://doi.org/10.1097/ccm.0000000000001015

Ning, J., & Cope, V. (2020). Open visiting in adult intensive care units - A structured literature review. *Intensive and Critical Care Nursing*, *56*, 102763. https://doi.org/10.1016/j.iccn.2019.102763

NNF. (2003). *Ethical guidelines for nursing research in the Nordic countries*. Retrieved from https://ssn-norden.dk/wp-content/uploads/2020/05/ssns_etiske_retningslinjer_0-003.pdf

O'Connor, H., Al-Qadheeb, N. S., White, A. C., Thaker, V., & Devlin, J. W. (2014). Agitation during prolonged mechanical ventilation at a long-term acute care hospital: risk factors, treatments, and outcomes. *Journal of Intensive Care Medicine*, *29*(4), 218-224. https://doi.org/10.1177/0885066613486738

Olausson, S., Lindahl, B., & Ekebergh, M. (2013). A phenomenological study of experiences of being cared for in a critical care setting: the meanings of the patient room as a place of care. *Intensive and Critical Care Nursing*, *29*(4), 234-243. https://doi.org/10.1016/j.iccn.2013.02.002

Penuelas, O., Thille, A. W., & Esteban, A. (2015). Discontinuation of ventilatory support: new solutions to old dilemmas. *Current Opinion in Critical Care*, *21*(1), 74-81. https://doi.org/10.1097/mcc.0000000000000169

Pham, T., Brochard, L. J., & Slutsky, A. S. (2017). Mechanical Ventilation: State of the Art. *Mayo Clinic Proceedings*, *92*(9), 1382-1400. https://doi.org/10.1016/j.mayocp.2017.05.004

Pirhonen, L., Bolin, K., Olofsson, E. H., Fors, A., Ekman, I., Swedberg, K., & Gyllensten, H. (2019). Person-Centred Care in Patients with Acute Coronary Syndrome: Cost-Effectiveness Analysis Alongside a Randomised Controlled Trial. *PharmacoEconomics - open*, *3*(4), 495-504. https://doi.org/10.1007/s41669-019-0126-3

Platen, P. v., Pomprapa, A., Lachmann, B., & Leonhardt, S. (2020). The dawn of physiological closed-loop ventilation—a review. *Critical Care*, *24*(1). https://doi.org/10.1186/s13054-020-2810-1

Polit, D. F. (2016). *Nursing research : generating and assessing evidence for nursing practice*. Wolters Kluwer.

Polit, D. F., Beck, C. T., & Owen, S. V. (2007). Is the CVI an acceptable indicator of content validity? Appraisal and recommendations. *Research in Nursing and Health*, *30*(4), 459-467. https://doi.org/10.1002/nur.20199

Polverino, E., Nava, S., Ferrer, M., Ceriana, P., Clini, E., Spada, E., Zanotti, E., Trianni, L., Barbano, L., Fracchia, C., Balbi, B., & Vitacca, M. (2010). Patients' characterization, hospital course and clinical outcomes in five Italian respiratory intensive care units. *Intensive Care Medicine*, *36*(1), 137-142. https://doi.org/10.1007/s00134-009-1658-2

Rak, K. J., Ashcraft, L. E., Kuza, C. C., Fleck, J. C., DePaoli, L. C., Angus, D. C., Barnato, A. E., Castle, N. G., Hershey, T. B., & Kahn, J. M. (2020). Effective care practices in patients receiving prolonged mechanical ventilation: an ethnographic study. *American Journal of Respiratory and Critical Care Medicine*, *201*(7), 823-831. https://doi.org/10.1164/rccm.201910-2006OC

Rattray, J., & McKenna, E. (2012). Person-centred care in intensive care: a myth or reality? *Nursing in Critical Care*, *17*(5), 225-226. https://doi.org/10.1111/j.1478-5153.2012.00529.x

Reade, M. C., & Finfer, S. (2014). Sedation and delirium in the intensive care unit. *New England Journal of Medicine*, *370*(5), 444-454. https://doi.org/10.1056/NEJMra1208705

Reader, T. W., Flin, R., Mearns, K., & Cuthbertson, B. H. (2009). Developing a team performance framework for the intensive care unit. *Critical Care Medicine*, *37*(5), 1787-1793. https://doi.org/10.1097/CCM.0b013e31819f0451

Rhodes, A., Ferdinande, P., Flaatten, H., Guidet, B., Metnitz, P. G., & Moreno, R. P. (2012). The variability of critical care bed numbers in Europe. *Intensive Care Medicine*, *38*(10), 1647-1653. https://doi.org/10.1007/s00134-012-2627-8

Ricœur, P. (1994). *Oneself as another*. University of Chicago Press.

Ringdal, M., Plos, K., Ortenwall, P., & Bergbom, I. (2010). Memories and health-related quality of life after intensive care: a follow-up study. *Critical Care Medicine*, *38*(1), 38-44. https://doi.org/10.1097/CCM.0b013e3181b42909

Ringdal, M., Warren Stomberg, M., Egnell, K., Wennberg, E., Zätterman, R., & Rylander, C. (2018). In-bed cycling in the ICU; patient safety and recollections with motivational effects. *Acta Anaesthesiologica Scandinavica*, *62*(5), 658-665. https://doi.org/10.1111/aas.13070

Rivosecchi, R. M., Kane-Gill, S. L., Svec, S., Campbell, S., & Smithburger, P. L. (2016). The implementation of a nonpharmacologic protocol to prevent intensive care delirium. *Journal of Critical Care*, *31*(1), 206-211. https://doi.org/10.1016/j.jcrc.2015.09.031

Robert, R., Coudroy, R., Ragot, S., Lesieur, O., Runge, I., Souday, V., Desachy, A., Gouello, J. P., Hira, M., Hamrouni, M., & Reignier, J. (2015). Influence of ICU-bed availability on ICU admission decisions. *Annals of Intensive Care*, *5*(1), 55. https://doi.org/10.1186/s13613-015-0099-z

Rolfe, G. (2006). Validity, trustworthiness and rigour: quality and the idea of qualitative research. *Journal of Advanced Nursing*, *53*(3), 304-310. https://doi.org/10.1111/j.1365-2648.2006.03727.x

Rosa, R. G., Tonietto, T. F., da Silva, D. B., Gutierres, F. A., Ascoli, A. M., Madeira, L. C., Rutzen, W., Falavigna, M., Robinson, C. C., Salluh, J. I., Cavalcanti, A. B., Azevedo, L. C., Cremonese, R. V., Haack, T. R., Eugênio, C. S., Dornelles, A., Bessel, M., Teles, J. M. M., Skrobik, Y., & Teixeira, C. (2017). Effectiveness and Safety of an Extended ICU Visitation Model for Delirium Prevention: A Before and After Study. *Critical Care Medicine*, *45*(10), 1660-1667. https://doi.org/10.1097/ccm.0000000000002588

Rose, L., Blackwood, B., Burns, S. M., Frazier, S. K., & Egerod, I. (2011). International perspectives on the influence of structure and process of weaning from mechanical ventilation. *American Journal of Critical Care*, *20*(1), e10-18. https://doi.org/10.4037/ajcc2011430

Rose, L., Blackwood, B., Egerod, I., Haugdahl, H. S., Hofhuis, J., Isfort, M., Kydonaki, K., Schubert, M., Sperlinga, R., Spronk, P., Storli, S., McAuley, D. F., & Schultz, M. J. (2011). Decisional responsibility for mechanical ventilation and weaning: an international survey. *Critical Care*, *15*(6), R295. https://doi.org/10.1186/cc10588

Rose, L., Dainty, K. N., Jordan, J., & Blackwood, B. (2014). Weaning from mechanical ventilation: a scoping review of qualitative studies. *American*

Journal of Critical Care, *23*(5), e54-70. https://doi.org/10.4037/ajcc2014539

Rose, L., Fowler, R. A., Fan, E., Fraser, I., Leasa, D., Mawdsley, C., Pedersen, C., Rubenfeld, G., & group, C. A. (2015). Prolonged mechanical ventilation in Canadian intensive care units: a national survey. *Journal of Critical Care*, *30*(1), 25-31. https://doi.org/10.1016/j.jcrc.2014.07.023

Rose, L., Istanboulian, L., Allum, L., Burry, L., Dale, C., Hart, N., Kydonaki, K., Ramsay, P., Pattison, N., & Connolly, B. (2019). Patient and Family Centered Actionable Processes of Care and Performance Measures for Persistent and Chronic Critical Illness. *Critical Care Explorations*, *1*(4), e0005. https://doi.org/10.1097/cce.0000000000000005

Rose, L., McGinlay, M., Amin, R., Burns, K. E., Connolly, B., Hart, N., Jouvet, P., Katz, S., Leasa, D., Mawdsley, C., McAuley, D. F., Schultz, M. J., & Blackwood, B. (2017). Variation in definition of prolonged mechanical ventilation. *Respiratory Care*, *62*(10), 1324–1332. https://doi.org/10.4187/respcare.05485

Rose, L., Nonoyama, M., Rezaie, S., & Fraser, I. (2014). Psychological wellbeing, health related quality of life and memories of intensive care and a specialised weaning centre reported by survivors of prolonged mechanical ventilation. *Intensive and Critical Care Nursing*, *30*(3), 145-151. https://doi.org/10.1016/j.iccn.2013.11.002

Rose, L., Schultz, M. J., Cardwell, C. R., Jouvet, P., McAuley, D. F., & Blackwood, B. (2015). Automated versus non-automated weaning for reducing the duration of mechanical ventilation for critically ill adults and children: a cochrane systematic review and meta-analysis. *Critical Care*, *19*(1), 48. https://doi.org/10.1186/s13054-015-0755-6

Rozycki, A., Jarrell, A. S., Kruer, R. M., Young, S., & Mendez-Tellez, P. A. (2017). Feasibility of a Nurse-Managed Pain, Agitation, and Delirium Protocol in the Surgical Intensive Care Unit. *Critical Care Nurse*, *37*(6), 24-34. https://doi.org/10.4037/ccn2017528

SALAR. (2015). *Swedish health care from an international perspective, International comparison 2015*. Retrieved from https://webbutik.skr.se/sv/artiklar/swedish-health-care-from-an-international-perspective.html

Salas, E., Burke, C. S., & Cannon ‐ Bowers, J. A. (2000). Teamwork: emerging principles. *International Journal of Management Reviews*, *2*(4), 339-356. https://doi.org/10.1111/1468-2370.00046

Samuelsson, C., Sjoberg, F., Karlstrom, G., Nolin, T., & Walther, S. M. (2015). Gender differences in outcome and use of resources do exist in Swedish intensive care, but to no advantage for women of premenopausal age. *Critical Care*, *19*, 129. https://doi.org/10.1186/s13054-015-0873-1

Schandl, A., Falk, A. C., & Frank, C. (2017). Patient participation in the intensive care unit. *Intensive and Critical Care Nursing*. https://doi.org/10.1016/j.iccn.2017.04.006

SIR. (2017). *Analyserande årsrapport 2017*. Retrieved from https://www.icuregswe.org/globalassets/arsrapporter/analyserande_arsrapport_2017.pdf

SIR. (2020a). *Medical Emergency Team - MET*. Retrieved from https://www.icuregswe.org/en/patients--relatives/medical-emergency-team---met/

SIR. (2020b). *The Swedish Intensive Care Registry*. Retrieved from https://www.icuregswe.org/en/

SIR. (2020c). *What is intensive care?* Retrieved from https://www.icuregswe.org/en/patients--relatives/what-is-intensive-care/

Slatore, C. G., Hansen, L., Ganzini, L., Press, N., Osborne, M. L., Chesnutt, M. S., & Mularski, R. A. (2012). Communication by nurses in the intensive care unit: qualitative analysis of domains of patient-centered care. *American Journal of Critical Care*, *21*(6), 410-418. https://doi.org/10.4037/ajcc2012124

So, H. M., Yan, W. W., & Chair, S. Y. (2019). A nurse-led critical care outreach program to reduce readmission to the intensive care unit: A quasi-experimental study with a historical control group. *Australian Critical Care*, *32*(6), 494-501. https://doi.org/10.1016/j.aucc.2018.11.005

Stayt, L. C., Seers, K., & Tutton, E. (2015). Patients' experiences of technology and care in adult intensive care. *Journal of Advanced Nursing*, *71*(9), 2051-2061. https://doi.org/10.1111/jan.12664

Stewart, N. I., Jagelman, T. A. J., & Webster, N. R. (2011). Emerging modes of ventilation in the intensive care unit. *British Journal of Anaesthesia*, *107*(1), 74-82. https://doi.org/10.1093/bja/aer114

Tabanejad, Z., Pazokian, M., & Ebadi, A. (2014). A Systematic Review of the Liaison Nurse Role on Patient's Outcomes after Intensive Care Unit Discharge. *International Journal of Community Based Nursing and Midwifery*, *2*(4), 202-210. http://www.ncbi.nlm.nih.gov/pmc/articles/pmc4201211/

Tingsvik, C., Johansson, K., & Martensson, J. (2015). Weaning from mechanical ventilation: factors that influence intensive care nurses' decision-making. *Nursing in Critical Care*, *20*(1), 16-24. https://doi.org/10.1111/nicc.12116

Tipping, C. J., Harrold, M., Holland, A., Romero, L., Nisbet, T., & Hodgson, C. L. (2017). The effects of active mobilisation and rehabilitation in ICU on mortality and function: a systematic review. *Intensive Care Medicine*, *43*(2), 171-183. https://doi.org/10.1007/s00134-016-4612-0

Urner, M., Ferreyro, B. L., Doufle, G., & Mehta, S. (2018). Supportive Care of Patients on Mechanical Ventilation. *Respiratory Care*, *63*(12), 1567-1574. https://doi.org/10.4187/respcare.06651

Vaismoradi, M., Turunen, H., & Bondas, T. (2013). Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study.

Nursing and Health Sciences, *15*(3), 398-405. https://doi.org/10.1111/nhs.12048

Walker, W., & Deacon, K. (2016). Nurses' experiences of caring for the suddenly bereaved in adult acute and critical care settings, and the provision of person-centred care: A qualitative study. *Intensive and Critical Care Nursing*, *33*, 39-47. https://doi.org/10.1016/j.iccn.2015.12.005

van der Veer, S. N., de Keizer, N. F., Ravelli, A. C., Tenkink, S., & Jager, K. J. (2010). Improving quality of care. A systematic review on how medical registries provide information feedback to health care providers. *International Journal of Medical Informatics*, *79*(5), 305-323. https://doi.org/10.1016/j.ijmedinf.2010.01.011

Vargas, M., Sutherasan, Y., Antonelli, M., Brunetti, I., Corcione, A., Laffey, J. G., Putensen, C., Servillo, G., & Pelosi, P. (2015). Tracheostomy procedures in the intensive care unit: an international survey. *Critical Care*, *19*, 291. https://doi.org/10.1186/s13054-015-1013-7

Wassenaar, A., Schouten, J., & Schoonhoven, L. (2014). Factors promoting intensive care patients' perception of feeling safe: a systematic review. *International Journal of Nursing Studies*, *51*(2), 261-273. https://doi.org/10.1016/j.ijnurstu.2013.07.003

Waters, B., & Muscedere, J. (2015). A 2015 Update on Ventilator-Associated Pneumonia: New Insights on Its Prevention, Diagnosis, and Treatment. *Current Infectious Disease Reports*, *17*(8), 1-9. https://doi.org/10.1007/s11908-015-0496-3

Wei, X., Day, A. G., Ouellette-Kuntz, H., & Heyland, D. K. (2015). The Association Between Nutritional Adequacy and Long-Term Outcomes in Critically Ill Patients Requiring Prolonged Mechanical Ventilation: A Multicenter Cohort Study. *Critical Care Medicine*, *43*(8), 1569-1579. https://doi.org/10.1097/ccm.0000000000001000

Wiest, M. M., Lee, K. J., & Carlin, J. B. (2015). Statistics for clinicians: An introduction to logistic regression. *Journal of Paediatrics and Child Health*, *51*(7), 670-673. https://doi.org/10.1111/jpc.12895

WMA. (2013). World Medical Association. World Medical Association declaration of Helsinki: ethical principles for medical research involving human subjects. *JAMA*, *310*(20), 2191-2194. https://doi.org/10.1001/jama.2013.281053

Zilberberg, M. D., de Wit, M., Pirone, J. R., & Shorr, A. F. (2008). Growth in adult prolonged acute mechanical ventilation: implications for healthcare delivery. *Critical Care Medicine*, *36*(5), 1451-1455. https://doi.org/10.1097/CCM.0b013e3181691a49

APPENDIX

SAHLGRENSKA AKADEMIN
INSTITUTIONEN FÖR VÅRDVETENSKAP OCH HÄLSA

ENKÄT Göteborg 2018-02-12

Långvarig ventilatorvård och ventilatorurträning på IVA

Modifierad enkät av ”Canadian Prolonged Mechanical Ventilation Survey” utarbetad och publicerad av Rose L. et al. Prolonged mechanical ventilation in Canadian intensive care units: A national survey. *J Crit Care.* 2015;30:25-31. Den svenska versionen är modifierad och validerad vid Institutionen för vårdvetenskap och hälsa, Göteborgs universitet november 2017 av:

Carl-Johan Cederwall, MSc, Specialistsjuksköterska intensivvård, Sahlgrenska universitetssjukhuset, Doktorand Institutionen för vårdvetenskap och Hälsa, Sahlgrenska akademin, Göteborgs universitet

Mona Ringdal, Lektor, PhD, Institutionen för vårdvetenskap och Hälsa, Sahlgrenska Akademin, Göteborgs universitet

Silvana Naredi, Professor, PhD, Institutionen för kliniska vetenskaper, Sahlgrenska Akademin, Göteborgs universitet

Louise Rose, Docent, PhD, Lawrence S. Bloomberg Faculty of Nursing, Toronto University

Sepideh Olausson, Lektor, PhD, Institutionen för vårdvetenskap och Hälsa, Sahlgrenska Akademin Göteborgs universitet

Carl-Johan Cederwall
Specialistsjuksköterska intensivvård, doktorand
GÖTEBORGS UNIVERSITET
Sahlgrenska akademin, Institutionen för vårdvetenskap och hälsa
CIVA/POSTOP AVDELNING 96
Sahlgrenska Universitetssjukhuset, Göteborg
031- 342 10 96
+46 705-80 96 92
carl-johan.cederwall@vgregion.se

Faktauppgifter

Dagens datum:

Avdelning:

Sjukhus:

Län:

Region:

Sjukhusets upptagningsområde
(region, län eller länsdelssjukhus):

Frågor besvarade av (befattning):

1. Uppgifter om avdelningen

1.1 a) Ange antal intensivvårdsplatser på er avdelning: __________ *(maxkapacitet vid full bemanning)*

b) Ange totalt antal öppna intensivvårdsplatser på er avdelning idag:________*(bemannade vårdrum)*

c) Ange hur många av dessa öppna intensivvårdsplatser har tillgång till ventilator:____________

1.2 Ange antal tillgängliga patientrum på er avdelning idag.

1 bäddsrum:_______
2 bäddsrum:_______
3 bäddsrum:_______
4 bäddsrum:_______
5 bäddsrum:_______
6 bäddsrum:_______

1.3 Hur många av de patienter ni har inskriva idag har hittills vårdats mer än 7 dygn i ventilator?

Antal:___________

1.4 Vilken är avdelningens specialitet?

- ☐ Allmän IVA
- ☐ Allmän IVA + Trauma
- ☐ Thorax IVA
- ☐ Neuro IVA
- ☐ Brännskade IVA
- ☐ Infektions IVA
- ☐ Annan

1.5. Ange det normala sjuksköterska per patient-förhållandet för patienter som vårdas i ventilator.

- ☐ 1:1
- ☐ 1:2
- ☐ Annat:

1.6 Ange det normala undersköterska per patient-förhållandet för patienter som vårdas i ventilator.

- ☐ 1:1
- ☐ 1:2
- ☐ Undersköterskor på vår avdelning vårdar inte patienter i ventilator
- ☐ Annat:

1.7 Finns det en eller flera fysioterapeuter som arbetar på er avdelning?

- ☐ Ja
- ☐ Nej

1.8 Om ja på föregående fråga, hur ofta finns tillgång till fysioterapeut?

- ☐ Alla dagar i veckan
- ☐ Fem dagar i veckan
- ☐ Mindre än fem dagar i veckan

1.9 Finns det som rutin hos er att utse patient- eller omvårdnadsansvarig sjuksköterska (PAS/OAS) under patientens vårdtid på IVA?

- ☐ Ja
- ☐ Nej

1.10 Finns det som rutin hos er att utse patientansvarig intensivvårdsläkare (PAL) under patientens vårdtid på IVA?

- ☐ Ja
- ☐ Nej

1.11 Vilka regler finns angående besökstider på avdelningen?

- ☐ Fria besökstider
- ☐ Fasta besökstider
- ☐ Annat

1.12 Finns det vårdrutiner på er avdelning som är framtagna utifrån begreppet ”personcentrerad vård”?

- ☐ Ja
- ☐ Nej

Om ja, beskriv vilka:____

1.13 Hålls regelbunden vårdplanering för patienter som vårdas lång tid i ventilator?

- ☐ Ja
- ☐ Nej

Om ja, hur ofta:____

1.14 Om ja på föregående fråga, vem deltar i en sådan vårdplanering? (flera alternativ om möjligt)

- ☐ Patient
- ☐ Patientansvarig sjuksköterska
- ☐ Patientansvarig läkare
- ☐ Undersköterska
- ☐ Fysioterapeut
- ☐ Närstående
- ☐ Annan:____

2. Ventilatorurträning

2.1 Ange de tre *vanligaste* urträningsmetoderna för patienter som vårdas lång tid i ventilator på er avdelning (både patienter med tub/tracheostomi).

- ☐ Gradvis sänkning av SIMV frekvens
- ☐ Gradvis sänkning av tryckunderstöd (TU)
- ☐ Volymunderstöd (VU)
- ☐ Gradvis ökad tid med CPAP
- ☐ Gradvis ökad tid med fuktnäsa och syrgas över tracheostomi
- ☐ Gradvis ökad tid med aktiv befuktning och högflödessystem över tracheostomi

- ☐ Annan metod:____

2.2 Ange de vanligaste automatiska mode som används vid urträning på er avdelning.

- ☐ Proportional Assist Ventilation Plus (PAV)
- ☐ INTELLiVENT- Adaptive Support Ventilation (ASV)
- ☐ Neurally Adjusted Ventilatory Assist (NAVA)
- ☐ SmartCare
- ☐ Annan metod:
- ☐ Ingen av dessa metoder används

2.3 Val av urträningsmetod påverkas av:

Vem som är patientansvarig sjuksköterska	☐ Ja	☐ Nej
Vem som är patientansvarig läkare	☐ Ja	☐ Nej

- ☐ Annan person:____

2.4 Finns det ett protokoll för urträning ur ventilator på er avdelning?

- ☐ Ja
- ☐ Nej

2.5 Om ja på föregående fråga, innehåller det specifika åtgärder för patienter som vårdas lång tid i ventilator?

- ☐ Ja
- ☐ Nej

2.6 Upprättas och dokumenteras en individuell urträningsplan för patienter som vårdas lång tid i ventilator på er avdelning?

- ☐ Ja
- ☐ Nej

Om ja, hur dokumenteras den?____

2.7 Om ja på föregående fråga, vem upprättar en sådan plan?

- ☐ Patientansvarig läkare
- ☐ Patientansvarig sjuksköterska
- ☐ Läkare och sjuksköterska tillsammans
- ☐ Annan person:____

2.8 Om det finns en dokumenterad urträningsplan, hur ofta utvärderas och revideras den?

- ☐ Varje dag
- ☐ Flera gånger varje vecka
- ☐ Mindre än en gång/vecka
- ☐ Någon enstaka gång

2.9 Är patienten på något sätt delaktig när en individuell urträningsplan upprättas eller utvärderas?

- ☐ Ja
- ☐ Nej
- ☐ Ibland
- ☐ Om ja, på vilket sätt?____

2.10 Är närstående delaktiga på något sätt när en individuell urträningsplan upprättas eller utvärderas?

- ☐ Ja
- ☐ Nej
- ☐ Om ja, på vilket sätt?____

2.11 Används rutinmässigt lungrekrytering med hjälp av ventilator på er avdelning?

- ☐ Ja
- ☐ Nej

2.12 Används rutinmässigt manuellt assisterad slemmobilisering på er avdelning?

- ☐ Ja
- ☐ Nej

2.13 Används hostmaskin rutinmässigt på er avdelning?

- ☐ Ja
- ☐ Nej

3. Mobilisering

3.1 Hur tidigt bedöms om den ventilatorvårdade patienten är aktuell för mobilisering?

☐ På ankomstdagen till IVA
☐ Dag 2-4 efter ankomst
☐ Dag 5-7 efter ankomst
☐ Dag 8-14 efter ankomst
☐ Dag 15-21 efter ankomst
☐ Vi bedömer inte om patienten är aktuell för mobilisering

3.2 Finns det ett mobiliseringsprotokoll på er avdelning?

☐ Ja
☐ Nej

3.3 Upprättas och dokumenteras en individuell mobiliseringsplan för patienter som vårdas lång tid i ventilator på er avdelning?

☐ Ja
☐ Nej
☐ Om ja, hur dokumenteras den?

3.4 Mobiliseras patienter till gående med ventilator på er avdelning?

☐ Ja
☐ Nej
☐ Ibland

3.5 Används sängcykel för att mobilisera patienter i ventilator på er avdelning?

☐ Ja
☐ Nej

3.6 Anser du att tidig mobilisering av ventilatorvårdade patienter prioriteras på er avdelning?

☐ Ja
☐ Nej

4. Kommunikation

4.1 Vilka kommunikationshjälpmedel används på er avdelning för patienter som vårdas lång tid i ventilator? (ange gärna flera alternativ)

☐ Alfabet-/ ord- eller bildplatta
☐ Papper och penna
☐ Skrivplatta/ whiteboard
☐ Dator/ surfplatta
☐ Kufflösa tracheostomikanyler
☐ Fenestrerade tracheostomikanyler
☐ Talventil över trachealkanyl
☐ Annat:____

4.2 Har ni tillgång till en logoped för bedömning och behandling av patientens kommunikationsförmåga?
- ☐ Ja
- ☐ Nej

4.3 Används en sederingsskala för att bedöma sederingsnivå patienter som vårdas i ventilator på er avdelning?
- ☐ Ja
- ☐ Nej
- ☐ Om ja, vilken skala?

5. Nutrition

5.1 Finns det ett nutritionsprotokoll på er avdelning?
- ☐ Ja
- ☐ Nej

5.2 Vem bedömer nutritionsstatus och val av nutrition på patienter som vårdas lång tid i ventilator?

- ☐ Läkare
- ☐ Sjuksköterska
- ☐ Dietist

5.3 Bedömer ni rutinmässigt svalgfunktion på patienter som vårdas lång tid i ventilator på er avdelning?
- ☐ Ja
- ☐ Nej

5.4 Om ja på föregående fråga, hur bedöms svalgfunktion på er avdelning?
- ☐ Klinisk undersökning av oral reflex
- ☐ Klinisk undersökning av laryngal reflex
- ☐ Svälgtest med färgad vätska
- ☐ Svälgtest med passerad kost
- ☐ Fiberoptisk undersökning av sväljfunktion
- ☐ Annat:____

6. Delirium, ångest och dyspné

6.1 Används någon skala för att bedöma ångest på patienter som vårdas lång tid i ventilator på er avdelning?
- ☐ Ja
- ☐ Nej

Om ja, vilken skala?____

6.2 Används någon skala för att mäta andnöd/lufthunger på patienter som vårdas lång tid i ventilator på er avdelning?

- ☐ Ja
- ☐ Nej

Om ja, vilken skala?____

6.3 Används någon skala för att bedöma delirium på patienter som vårdas lång tid ventilator på er avdelning?

- ☐ Ja
- ☐ Nej

Om ja vilken skala?____

7. Psykosocialt stöd

7.1 Har ni tillgång till psykiatri-eller psykologkonsultation för patienter som vårdas lång tid i ventilator?

- ☐ Ja
- ☐ Nej

7.2 Erbjuder ni psykolog- eller kuratorkontakt för närstående till patienter som vårdas lång tid i ventilator?

- ☐ Ja
- ☐ Nej

7.3 Håller ni regelbundna möten/ vårdkonferenser för närstående till patienter som vårdas lång tid i ventilator?

- ☐ Ja
- ☐ Nej