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Mechanical ventilation and weaning: Roles and competencies of intensive care nurses and patients' experiences of breathing

Breath of Life

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List of papers

This study is based on the following original publications, which are referred in the text by the Roman numerals I-IV:

I. Haugdahl, HS., Storli, SL., Rose, L., Romild, U. and Egerod, I. (2014). Perceived decisional responsibility for mechanical ventilation and weaning: a Norwegian survey. *Nursing in Critical Care*, 19(1), 18-25
II. Haugdahl, HS. and Storli, SL. (2012). “In a way, you have to pull the patient out of that state ...”: the competency of ventilator weaning. *Nursing Inquiry*, 19(3), 238-246.
III. Haugdahl, HS., Storli, SL., Meland, B., Dybwik, K., Romild, U. and Klepstad P. (2015). Underestimation of Patient Breathlessness by Nurses and Physicians During a Spontaneous Breathing Trial. *American Journal of Respiratory and Critical Care Medicine, 192*(12), 1440-1448.
IV. Haugdahl, HS., Dahlberg, H., Klepstad, P. and Storli, SL. The Breath of Life. Patients’ Experiences of Breathing During and After Mechanical Ventilation (submitted)

APRV	Airway pressure release ventilation
ARF	Acute respiratory failure
ASV	Adaptive support ventilation
Extubation	Discontinuation of an artificial airway
ICU	Intensive care unit
ICN	Intensive care nurse
MV	Mechanical ventilation
NAVA	Neurally adjusted ventilator assist
PAV	Proportional assist ventilation
pCO_2	Partial pressure of carbon dioxide in blood
pO_2	Partial pressure of oxygen in blood
PICS	Post-intensive care syndrome
SBT	Spontaneous breathing trial/test
Weaning	Process of gradual ventilator support withdrawal

Summary

Background: Breathlessness is an under-recognized problem in intensive care; it is related to anxiety, fatigue or pain and associated with neuropsychological problems in long-term survivors. The overall aims of this study were to enhance knowledge of the roles and competencies of nurses in mechanical ventilation and weaning, and to explore patients' experiences of breathing during and after mechanical ventilation.

Method: The study employed the following methods: survey data from 38 nursing and physician leaders in Norwegian ICUs, six in-depth interviews and three field observations of intensive care nurses in concrete weaning situations, a prospective observational study of 100 mechanically ventilated patients' self-report of breathlessness and, a qualitatively driven sequential mixed method design combining prospective observational breathlessness data during MV from 11 patients and data from follow-up in-depth interviews.

Results: In Study I, nursing leaders perceived nurses to have greater autonomy, influence and collaborative interaction regarding decisions on mechanical ventilation, compared to the perceptions of physician leaders. Nursing and physician leaders agreed that nurses collaborated in assessments of patient response to ventilator changes and titrating settings (92% vs 87%) and weaning failure (84% vs 84%) and agreed that knowledge of the patient was important for successful weaning. Study II showed that competencies that included detailed knowledge of pathophysiology and ventilator skills, coupled with attention and the ability to interpret the patient's body language, were fundamental for clinical judgements and actions. Facilitating the patient's well-being gave rise to confidence and trust, which was an important factor in the further weaning process. Study III demonstrated that 62% of patients were short of breath, and that more than half of physicians and nurses underestimated breathlessness, compared with the patient's own assessments. This underestimation showed no correlation with the expertise or experiences of physicians and nurses. Study IV demonstrated that breathlessness during the mechanical ventilation phase was not subsequently recalled by all patients. The experience of breathing was not necessarily a separate experience, but intertwined with the entire illness experience, described by four themes: “existential threat”, “the tough time”, “an amorphous and boundless body” and “getting through”. The essential meaning associated with MV was expressed as being in a space between life and death where the patient felt he had to choose a direction.

Conclusion: Breathing was intertwined with the entire illness experience, and breathlessness was common in ventilated patients and underestimated by physicians and nurses. The competencies of ICU nurses were expressed in interaction with patients through mindful presence and by facilitating a feeling of well-being that underpinned the patient’s will to get through the illness. A potential link between breathlessness and post-intensive care syndrome is an argument for patients’ own reports of breathing to form part of nursing interventions and follow-up to support patients’ quest for meaning. To enhance the quality of care in MV and weaning, intensive care nurses have an important role in the interprofessional team in order to discuss, reflect and learn how to assess and respond to patients’ experiences of breathing.

1. Introduction

1.1. Background

After years working in intensive care, first as an intensive care nurse and later as a teacher of intensive care, I realized that some of the experienced intensive care nurses seemed to be more successful in weaning patients from mechanical ventilation (MV) than their colleagues. These observations made me curious and made me ask myself questions like: What is this skill all about? What do nurses themselves say about competencies in MV and weaning? How do patients experience being on MV?

In 2009, my supervisor Sissel Storli and I were asked by Ingrid Egerod, the leader of NOFI (Nordic Association for Intensive Care Nursing Research), to contribute to a European survey on nurses' roles and responsibilities in mechanical ventilation. We accepted the invitation, but I was not comfortable doing a survey among nursing leaders only, mainly because of my clinical experiences of the close collaborative practice between nurses and physicians. Therefore, we also decided to conduct a survey of physicians. This decision led to new questions and laid the foundation for my PhD project.

A brief overview of the research on mechanical ventilation at the time I started this PhD demonstrated that MV was among the most common interventions in the intensive care unit (ICU) (Frutos-Vivar, Ferguson, & Esteban, 2009), and that over the last two decades, numerous studies had investigated methods to improve outcomes of patients receiving MV (Macintyre, 2012). Deficiencies in collaboration and communication between healthcare professionals showed a negative impact on the provision of healthcare and on patient outcomes (Martin, Ummenhofer, Manser, & Spirig, 2010), suggesting that effective teamwork among nurses and physicians is crucial for providing optimal patient care in the ICU (Reader, Flin, Mearns, & Cuthbertson, 2009).

The introduction of the weaning protocol led to reduced weaning time and improved results in patients (Caroleo, Agnello, Abdallah, Santangelo, & Amantea, 2007), but the evidence was not consistent across all populations (Blackwood et al., 2010; Krishnan, Moore, Robeson, Rand, & Fessler, 2004; Rose, Nelson, Johnston, & Presneill, 2007). Protocols aim to reduce practice variation by replacing subjectivity with objectivity (Blackwood et al. 2010). The concepts of "clinical worsening" (Caroleo et al., 2007) and "evidence of increasing effort", such as increased accessory muscle activity, facial signs of distress and dyspnoea (Boles et al., 2007), were highlighted as key assessments made through use of protocols. This reflected that the use of a protocol should not preclude individual considerations and clinical judgement.

Furthermore, research revealed a connection between weaning time and the qualifications and experience of intensive care nurses (MacIntyre et al., 2001; Thorens, Kaelin, Jolliet, & Chevrolet, 1995). However, the significant aspects of the context and the qualities important in the nurse-patient relationship in weaning were not sufficiently described (MacIntyre et al., 2001; Rose & Nelson, 2006), thus it was emphasized that more empirical research was needed to examine competencies in intensive care nursing (Aari, Tarja, & Helena, 2008).

In summary, weaning protocols and effective teamwork seemed to improve results in mechanical ventilation and weaning. However, a large multi-national cohort study found that clinical outcomes such as duration of mechanical ventilation and ICU stay had not improved significantly between 1998 and 2004 (Esteban et al., 2008). Therefore, more knowledge of the context-specific nurse-patient relationship was needed. Furthermore, there was a lack of knowledge from the patient perspective, considering the fact that breathlessness was one of the most prevalent and distressing physical symptoms experienced by intensive care patients

(Schmidt et al., 2011). In routine care, the patients‘ self-reported perception of breathing was usually not obtained (Puntillo et al., 2010).

In conclusion, the questions I raised on mechanical ventilation based on my own clinical experiences seemed relevant and the knowledge gap in clinical research provided grounds for developing my research topic as presented below.

1.2. Topic of the study and structure of the thesis

This thesis explores (1) the agreement in perceptions of nursing leaders and physician leaders regarding ICU nurses' roles, responsibilities and clinical decision-making related to mechanical ventilation and weaning in Norwegian intensive care units, (2) the competency important in the nurse-patient relationship in weaning by studying experienced ICU nurses in concrete weaning situations, (3) the agreement between nurses', physicians', and patients' scores of breathlessness at the end of a spontaneous breathing trial (SBT) and (4) patients' experiences of breathing and breathlessness during and after mechanical ventilation.

In Chapter 2, current and relevant empirical research on MV is described. Chapter 3 demonstrates the theoretical framework, including the three concepts of "body", "breath" and "competence", which are central to the analysis and discussion of the main findings later in this thesis. The aims of the thesis are presented in Chapter 4, followed by the methodology and research process in Chapter 5. The results from the four papers are individually summarized in Chapter 6, and further discussed in Chapter 7 in terms of theoretical concepts and empirical research, including methodological considerations. On this basis, clinical and research implications are suggested in Chapter 8.

2. Mechanical ventilation and discontinuation

This chapter reviews current research on mechanical ventilation, including the patient's perspective. The following MeSH terms were used in the PubMed database: clinical competence; critical care nursing; dyspnea; nurses; nurse's role; patients; professional competence; respiration, artificial; respiration; role; ventilator weaning; ventilators, mechanical (see Appendix 1 for the search strategy). In addition, key concepts/free-term search were performed in the CINAHL, PubMed and Cochrane Library databases.

2.1. Mechanical ventilation

Respiratory failure is the most common and important organ failure in intensive care medicine. The national intensive care registry of Norway (NIR) (Kvåle, 2015) reports that 58% of all ICU stays involve mechanical ventilation support (9561 of 16431) and that the average duration of ventilation support is 3.2 days (median 0.9). Patients are intubated and placed on mechanical ventilators when their own ventilatory and/or gas exchange capabilities are decreased due to serious illness and/or acute respiratory failure (ARF) (Figure 3).

Figure 3 Intubated patient connected to a mechanical ventilator

Mechanical ventilation also is required when the respiratory drive is incapable of initiating ventilator activity, either because of disease processes or drugs/medications (MacIntyre et al., 2001). Once the underlying disease has improved and respiratory failure stabilizes and begins to reverse, the ventilator should be removed as soon as possible. A schematic representation of the different stages in mechanical ventilation is presented in Figure 4.

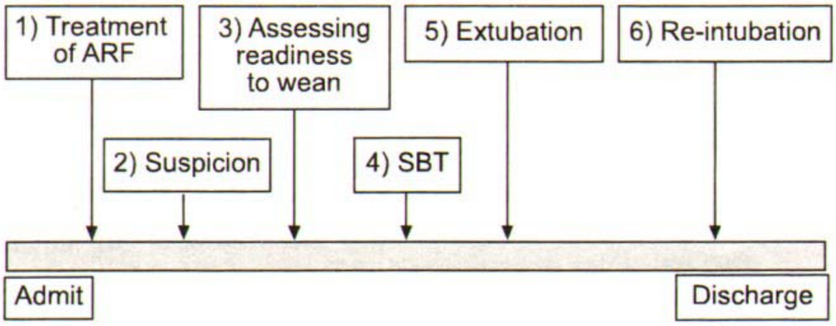


Figure 4 Schematic representation of the different stages occurring in a mechanically ventilated patient. ARF: acute respiratory failure; SBT: spontaneous breathing test (Boles et al. 2007, p1034)

Mechanical ventilation is associated with pain and anxiety. Therefore it is common practice to sedate the patients (Kress, Pohlman, O'Connor, & Hall, 2000), but too much sedation is associated with prolonged weaning (Kress et al., 2000; Sessler, Grap, & Ramsay, 2008). New advances in ventilator modes and techniques aim to provide lung protective ventilation (e.g. APRV, ASV), facilitate the ventilator discontinuation process by automatic adjustment of support according to changes in the patient’s respiratory demands and improve patient-ventilator synchrony (e.g. PAV, NAVA) (Haas & Bauser, 2012). Improvement in ventilator modes and techniques may shorten the duration of ventilation by making the patients more comfortable and potentially reduce the need for sedatives (Vincent & Singer, 2010). In order to improve patient care and clinical outcome, a recent review article introduced a new paradigm for intensive care, the eCASH concept - early Comfort using Analgesia, minimal Sedatives and maximal Humane care, which aims to provide optimal patient comfort with minimal sedation (Vincent et al., 2016).

2.2. Discontinuation of mechanical ventilation

Discontinuation of mechanical ventilation can be defined as the process of gradual (weaning) or sudden ventilator support withdrawal in critically ill patients and represents one of the most important challenges in intensive care units (Esteban et al., 2008; Frutos-Vivar & Esteban, 2014). It has been estimated that 40% of the time a patient is mechanically ventilated is dedicated to the process of weaning (Esteban et al., 2008).

Failure to recognize discontinuation potential will result in undue delay in ventilator withdrawal, leading to increased stay, higher costs, excessive sedation needs and an increased risk of pneumonia and infection (MacIntyre et al., 2001). On the other hand, premature ventilator withdrawal can lead to airway loss, compromised gas exchange, aspiration and inspiratory muscle fatigue (Jubran & Tobin, 1997; Tobin et al., 1987). A failed extubation is associated with an 8-fold higher odds ratio for nosocomial pneumonia and a 6-fold to 12-fold increased mortality risk (Frutos-Vivar et al., 2011; Macintyre, 2012).

Due to the clinical challenge in deciding the right time to remove the endotracheal tube, the American College of Chest Physicians (ACCP), the Society for Critical Care Medicine (SCCM) and the American Association for Respiratory Care (AARC) agreed on 12 evidence-based guidelines/recommendations for clinicians to follow in the ventilator discontinuation process (see Table 1) (Macintyre, 2012). The recommendations include a formal assessment of discontinuation potential, performing an SBT every 24 hours and implementation of weaning/discontinuation protocols designed for non-physician healthcare professionals. Recommendation 3 describes formal discontinuation assessments, where one important point is the criterion of “subjective comfort”.

Table 1 Recommendations regarding management of mechanically ventilated ICU patients from the ACCP/AARC Ventilator Discontinuation Evidence Based Guidelines Task Force* (MacIntyre 2001)

Recommentation 1

In patients requiring mechanical ventilation for > 24 hours, a search for all the causes that be contributing to ventilator dependence should be undertaken. This is particularly true in the patient who has failed attempts at withdrawing the medical ventilator. Reversing al possible ventilator and nonventilatory issues should be an integral part of the ventilator discontinuation process.

Recommendation 2

Patients receiving mechanical ventilation for respiratory failure should undergo a formal assessment of discontinuation potential if the following criteria are satisfied:

- Evidence for some reversal of the underlying cause for respiratory failure
- Adequate oxygenation ($PaO_2/FiO_2 > 150$-200cm Hg, requiring PEEP $\leq$ 5-8 H_2O, FiO $_2 \leq$ 0,4-0,5), and
  pH $\geq$ 7.25)

- Hemodynamic stability, as defined by the absence of active myocardial ischemia and the absence of clinically important hypotension (ie. A condition requiring no vasopressor therapy or therapy with only low-dose vasopressors such as dopamine or dobutamine, < 5 µg/kg/min)
- The capability to initiate an inspiratory effort

The decision to use these criteria must be individualized. Some patients not satisfying all of the above criteria (eg. Patients with chronic hypoxemia values below the thresholds cited) may be ready for attempts at the discontinuation of mechanical ventilation.

Recommendation 3

Formal discontinuation assessment for patients receiving mechanical ventilation for respiratory failure should be performed during spontaneous breathing rather than while the patient is still receiving substantial ventilatory support. An initial brief period of spontaneous can be used to assess the capability of continuing onto a formal spontaneous breathing trial (SBT). The criteria with which to assess patient tolerance during SBTs are the respiratory pattern, the adequacy of gas exchange, hemodynamic stability, and subjective comfort. The tolerance of a 30-120 min SBT should prompt consideration for permanent ventilator discontinuation.

Recommendation 4

The removal of the artificial airway from a patient who has successfully been discontinued from ventiilatory support should be based on assessments of airway patency and the ability of the patient to protect airway.

Recommendation 5

Patients receiving mechanical ventilation for respiratory failure who fail an SBT should have the cause for the failed SBT determined. Once reversible causes for failure are corrected, and if the patient still meets the criteria in Recommandation 2, SBTs should be performed every 24 hours.

Recommendation 6

Patients receiving mechanical ventilation for respiratory who fail an SBT should receive a stable, nonfatiguing, comfortable form of ventilator support.

Recommendation 8

Weaning/discontinuation protocols that are designed for nonphysician healthcare professionals should be developed and implemented by ICUs. Protocols aimed at optimizing sedation also should be developed and implemented.

*Only 7 of the 12 guidelines relating to the ventilator discontinuation process are listed here

As most critically ill patients requiring mechanical ventilation will tolerate extubation with minimal weaning, identification of strategies to improve management of those patients experiencing difficult and prolonged weaning should be a priority for clinical practice, quality improvement initiatives and weaning research (Rose, 2015).

2.2.1. Strategies for weaning

Strategies shown to be effective in promoting timely weaning include weaning protocols and the use of spontaneous breathing trials (Rose, 2015). Previous studies have shown that weaning protocols are much more accurate than individual assessments by clinicians (McConville & Kress, 2013). An algorithm for withdrawal from mechanical ventilation helps clinicians to decide when to start the process of weaning (see Appendix 2) (Penuelas, Thille, & Esteban, 2015).

Over time, we have become better at identifying those patients capable of breathing spontaneously, and more patients are extubated at the first attempt of withdrawal. However, in their article in Intensive Care Medicine, based on studies published in the last 20 years, Frutos-Vivar and Esteban demonstrated that in those patients who required more than one day for discontinuation from mechanical ventilation, weaning duration remained stable (Frutos-Vivar & Esteban, 2014). Additionally, the rate of reintubation has not changed. Consequently, the question of how we can improve the prognosis of difficult-to-wean patients remains to be answered (Frutos-Vivar & Esteban, 2014, p. 1454). “Difficult to wean” applies to between 25% (Blackwood et al., 2010) and 45% of patients (Boles et al., 2007), and the current clinical challenge is to improve weaning from mechanical ventilation in patients who fail the first test of spontaneous breathing (Penuelas et al., 2015).

2.2.2. Recognition of readiness to wean and readiness to extubate

The most important steps in the weaning process to prevent unnecessary prolongation of mechanical ventilation are timely recognition of both readiness to wean and readiness to extubate (Rose, 2015). To facilitate the process of weaning, researchers have focused on identifying objective criteria for determining the ideal time for withdrawal of MV (see Table 1, Recommendation 2). The recommendation from Frutos-Vivar and Esteban (Frutos-Vivar & Esteban, 2014), is to perform a daily test (SBT). The following three SBT methods are in clinical use to assess readiness for extubation: pressure-supported (PS) ventilation of 6-8 cm H_2O with positive end-expiratory pressure of 6-8 cm H_2O, a T-piece or external continuous positive airway pressure with positive end-expiratory pressure of 5 cm H_2O (Boles et al., 2007; Ladeira et al., 2014). If tolerated for 30 minutes, the possibility for extubation should be assessed. If there are signs of intolerance, the patient should be re-connected to assist-control ventilation. Twenty-four hours should then pass before a new trial is initiated, since the respiratory muscles may require 24 hours or longer to recover from the stress (Laghi, D'Alfonso, & Tobin, 1995). This practice simplifies the work of nurses and physicians and, in the case of failed patients, could help to relieve the stress on the respiratory muscles caused by the increased work of breathing.

Clinical use of SBT is commonplace and gradually increasing, especially in patients judged to be clinically ready for discontinuation. However, there still appears to be a persistent aversion to SBTs in the majority of patients about whom clinicians have concerns. In one study, SBTs were used 82% of the time in simple discontinuation patients but only 47% and 38% of the time in difficult and prolonged discontinuation patients, respectively (Macintyre, 2012).

2.2.3. Clinical assessments

Already during the Crimean war, Florence Nightingale (1860/1992) established a hospital unit for the care of seriously ill patients requiring continuous surveillance (Grenvik, 2012). Nightingale suggested that observation abilities included knowing how to observe, discriminate between symptoms, and decide which symptoms show an improvement and which show the contrary (Martinsen, 2006, p. 98). The statement from 1860 is still valid, including the observation of ICU patients during mechanical ventilation and weaning.

The criteria used to define SBT “tolerance” are often integrated indexes, since single parameters alone perform so poorly. These integrated indexes usually include several physiological parameters (e.g. respiratory rate, blood pressure, heart rate) (Penuelas et al., 2015) (see Appendix 2), as well as clinical judgement, which includes such difficult-to-quantify factors as “anxiety”, “discomfort”, and “clinical appearance” (Macintyre, 2012) or “increased work of breathing” and “other signs of distress” (Penuelas et al., 2015). Since the publication of the original ACCP/SCCM/AARC guidelines (2001) (see Table 1), “the criteria to assess SBT success/failure remained largely unchanged, essentially an integrated index of clinical assessments that do not rely on rigid numbers” (Macintyre, 2012).

Health professionals tend to underestimate patients’ symptoms (Laugsand et al., 2010). What complicates symptom assessment of ventilator patients is their reduced ability to communicate (Baumgarten & Poulsen, 2015). Although there are simple but validated instruments to measure breathlessness (Powers & Bennett, 1999), there is little knowledge about how ventilator patients’ experiences correlate with health professionals’ assessments (Schmidt et al., 2014).

2.2.4. The ABCDE bundle approach

In the last decade, awakening and breathing coordination (ABC) has been bundled with delirium management and early mobilization to form the ABCDE bundle (Pandharipande, Banerjee, McGrane, & Ely, 2010). The bundle approach combines a set of evidence-based practices shown to be effective for improving patient outcomes (Resar et al., 2005) such as reducing the duration of mechanical ventilation. Monitoring for delirium using a validated screening tool such as the CAM-ICU (Ely et al., 2001) was recommended in the 2013 Pain, Agitation and Delirium (PAD) guidelines endorsed by several professional societies (Barr et al., 2013). Early mobilization was shown to reduce duration of ventilation (Schweickert et al., 2009), reduce length of stay in the ICU (Winkelman et al., 2012) and may also reduce the duration of delirium and improve neuropsychiatric outcomes (Hopkins, Suchyta, Farrer, & Needham, 2012).

The combination of these activities in a bundle approach can be viewed as an effective strategy for weaning as it has been shown to decrease ventilation time, not only due to timely recognition of weaning and extubation readiness but also through reductions in the administration of sedation and delirium incidence (Balas et al., 2014).

2.2.5. Interprofessional collaboration

A multinational consensus within the European Society of Intensive Care Medicine provided guidelines and recommendations for ICUs and stated: "Intensive care medicine is the result of close cooperation among physicians, nurses, and allied health professionals" (Valentin & Ferdinande, 2011). The nursing staff is managed by a nursing leader, responsible for the functioning and quality of the nursing care, and works in collaboration with the medical director in order to provide policies and protocols, and directives and support to the team (Valentin & Ferdinande, 2011). The Guidelines for intensive care in Norway (*Retningslinjer for intensivvirksomhet i Norge* 2014), worked out by The Norwegian society for anesthesiology (Norsk anestesiologisk forening) and The Norwegian nurses organisation's professional interest group of intensive care nurses (Norsk sykepleierforbunds landsgruppe av intensivsykepleiere), propose that a physician held the medical management of the ICUs, and is in charge of the multi-professional team. The multi-professional team is in the Norwegian guidelines emphasized to ensure optimal process and patient outcomes. In clinical practice, this mean the intensive care nurse and physician comprise a team with independent responsibilities according to the Health Personnel Act (1999), and together are responsible to coordinate diagnose, treatment and care to the individual patient (*Retningslinjer for intensivvirksomhet i Norge* 2014).

As demonstrated so far in this chapter, the process of weaning from mechanical ventilation can be complex, and collaborative weaning plans can be useful to decrease duration of mechanical ventilation. A European survey among ICU nurses demonstrated that collaborative decision making for ventilaton and weaning was employed in most ICUs in all countries. About 63-88% of the decisions were made by nurses in collaboration with physicians. Moreover, nurses performed 40-68% of ventilator adjustments independently of physicians. Collaborative decisions were more likely in ICUs that had a nurse-patient ratio of 1:1 and a weaning protocol (Rose et al., 2011). However, a potential bias in studies based on nurse responses alone is the risk of overestimation of the role of nurses (Jubran, 2012; Rose, Nelson, Johnston, & Presneill, 2008).

In a retrospective study of ventilator decision making, Norwegian ICU nurses often initiated weaning without physicians' orders and disregarded orders if they considered them detrimental to the patient (Hansen, Fjaelberg, Nilsen, Lossius, & Soreide, 2008). A related study on the same population found that the weaning process was dependent on the individual nurses and physicians on duty (Hansen & Severinsson, 2009). A similar observation was reported in a Danish study of nurse decisions and interventions related to mechanical ventilator weaning (Egerod, 2003). A Swedish explorative study of anaesthetists from four different ICUs underlined that weaning is managed by nurses and physicians, where nurses' competencies facilitated the weaning process, dependent on their experience. An important role for nurses was being at the bedside and ensuring progress in weaning according to the weaning plans (Pettersson, Melaniuk-Bose, & Edell-Gustafsson, 2012).

There seems to be variation between countries in ICU organization and philosophies of interprofessional collaboration. For example, differences exist in nurse and physician staffing models, specialized education for nurses, decision-making hierarchy, and assignment of roles and responsibilities for weaning (Rose, Dainty, Jordan, & Blackwood, 2014).

2.3. Patient perspectives

2.3.1. The experience of being on mechanical ventilation in intensive care

In a review article, patients' experiences of weaning from mechanical ventilation were characterized by frustration, uncertainty, hopelessness, fear, and lack of mastery (Cook, Meade, & Perry, 2001). Patients only felt safe when they considered the staff competent and trustworthy (Morse, 1997). A recent meta-synthesis (Baumgarten & Poulsen, 2015) among patients on mechanical ventilation showed similar results and the authors argued that being dependent on health professionals, without being able to communicate, causes experiences of anxiety, fear and loneliness. How intensively these feelings are experienced seems to depend on health professionals' ability to be present with these patients (Baumgarten & Poulsen, 2015).

In a Norwegian follow-up study of ICU patients, delusional memories or chaotic experiences of being somewhere else were described as experiences inherently real in the lived body. These experiences were grounded in the patients' life world, and were interpreted as expressions of basic aspects related to being human (Storli, Lindseth, & Asplund, 2007).

2.3.2. The experience of breathing during mechanical ventilation

As early as the late 1980s, the Swedish intensive care nurse Ingegerd Bergbom published several studies on patient experiences of MV. Data from telephone interviews with 304 patients showed that 52% recalled having been on MV. About half of all patients had anxiety and/or fear, where the inability to speak and communicate was the dominant explanation for anxiety and sleep problems for months and years afterwards. Problems with synchronization with the ventilator in connection with endotracheal suctioning were also later associated with anxiety and insecurity (Bergbom-Engberg & Haljamae, 1989).

The first Norwegian PhD on patient experiences with MV came five years later; here, a phenomenological study by Eva Gjengedal found that the patients' experiences had an existential charachter due to bodily changes and strange ICU environments, leading to disruption of meaning and existential crises (Gjengedal, 1994, p. 240). Memories of breathing were sparse, but some patients narrated they were scared of losing the tube, feeling that the tube kept them alive and/or afraid of not being able to breathe without the machine. According to changed bodily image, patients got used to the tracheal tube, and felt the tube had become part of their bodies (Gjengedal, 1994, pp. 113-152).

After these pioneers in clinical ICU research, there has been a shift to more awake patients as described in Chapter 2.1. A Swedish qualitative study among intensive care patients who were conscious during mechanical ventilation reported that the inability to breathe and voicelessness were considered the worst experience (Karlsson, Bergbom, & Forsberg, 2012). Patients' feelings of breathlessness were described as a subjective experience related to various physiological, psychological, social and environmental factors (Ambrosino & Serradori, 2006), which for ventilated patients were associated with anxiety and delayed extubation (Schmidt et al., 2011). The presence of dyspnea and pain seems to be predictive of post-traumatic stress disorder (PTSD) (Schelling, 2002; Schelling & Kapfhammer, 2013).

Based on this, it seems important to get more knowledge about patients' experiences of breathlessness (Mularski et al., 2010) and trust and caring relationship with health professionals during the ventilator weaning phase (Tsay, Mu, Lin, Wang, & Chen, 2013).

2.3.3. Post-intensive care syndrome

Recent years have seen a greater focus on long-term consequences for ICU patients after hospital discharge. Post-ICU patients may suffer from physical and mental health problems with a negative impact on quality of life and daily functioning (Mehlhorn et al., 2014). In 2012, the Society of Critical Care Medicine and invited experts agreed upon the term Post-

Intensive Care Syndrome (PICS) to describe new or worsening problems in physical, cognitive, or mental health status arising after a critical illness and persisting beyond acute care hospitalization (Needham et al., 2012). Possible mechanisms of PICS are e.g. hypoxia and treatment provided during critical illness, including endotracheal intubation, frequent use of benzodiazepines, immobilization, and interruption of the sleep-wake cycle (Needham et al., 2012). A systematic review concludes that the lack of overall effectiveness of post-ICU interventions on physical and mental health might be attributed to a delayed start of rehabilitation efforts. Of particular interest for my research is the potential relationship between traumatic experiences with breathing, including bodily experiences at a pre-reflective level and PTSD (Schelling, 2002; Schelling & Kapfhammer, 2013; Storli, Lindseth, & Asplund, 2008) and/or PICS (Needham et al., 2012).

In summary, despite progress in MV, weaning duration remains stable for patients who require more than one day for discontinuation from MV (Frutos-Vivar & Esteban, 2014). Clinical judgement of increased work of breathing (Penuelas et al., 2015) and discomfort (Macintyre, 2012) is challenging for both nurses and physicians. Breathlessness is prevalent among MV patients and routine care does not usually capture patients' self-reported perception of breathlessness (Puntillo et al., 2010). MV represents a traumatic event for patients regardless of how well weaning proceeds clinically (Rose et al., 2014). How intensively these feelings are experienced seems to depend on health professionals' ability to be present with these patients (Baumgarten & Poulsen, 2015). Caring for an increasing number of awake non-sedated patients (Strom, Martinussen, & Toft, 2010; Vincent et al., 2016) underlines the need to know more about patient perspectives on MV and the experience of breathing. By exploring the nurse-patient relationship in concrete weaning situations, this study aims to add context-specific information relevant to exploring competence in ICU nursing.

3. Theoretical framework of body, breath and competence

In order to understand and explore central phenomena in intensive care, like experiences of breathing, and competencies in mechanical ventilation, I take a pragmatic view and base the theoretical framework on phenomenology and medical scientific knowledge. The medical view is important to understand the physiological mechanisms during critical illness, and the phenomenological view is appropriate when exploring phenomena we take for granted in everyday clinical practice. Phenomenology is primarily a philosophical method for questioning, not a method for drawing definite conclusions. But the questioning allows for possibilities and potentialities for experiencing openings, understandings and insights which produce cognitive or non-cognitive perceptions of existentialities, giving us knowledge of the meaning of phenomena and events in their singularity (Van Manen, 2014, p. 29). Lived experience is a key concept in phenomenology and refers to the world as we immediately experience it pre-reflectively rather than as we conceptualize, categorize, or reflect on it (Van Manen, 1997, p. 9).

The relationship between phenomenology and other epistemologies, such as the biomedical epistemology, should be viewed as complementary and not contradictory to phenomenology (Nortvedt, 2008). The founder of phenomenology, Edmund Husserl, developed the philosophical justification for the life world as a starting point for any inquiry (Todres & Wheeler, 2001). Therefore, this chapter will include theory from phenomenology, existentialism, respiratory physiology and nursing.

My theoretical perspective is based on my view of nursing as a practical discipline and on the philosophy of caring formulated by the Norwegian nurse and philosopher Kari Martinsen. Care has a relational, practical and moral dimension (Martinsen, 1989, pp. 14-20). A central ontological feature of Martinsen’s theoretical work is the assumption that human beings are interconnected and dependent upon each other. The caring situation in nursing is by nature concrete and contextual. Care is to relate to the other and to be able to recognize and respond to the patient's needs. The concrete meeting with a patient has thus a moral dimension. As nurses, we can look, and overlook. Moreover, there are different dimensions of the clinician's gaze; a recording gaze, referred to as a powerful and objectifying gaze, and the perceiving eye, characterized by openness towards the world, where sensations and emotions are working together (Martinsen, 2006, pp. 82-112). The latter includes being touched and emotionally involved before we understand the needs of the patient. Care is to be concrete and present in a relationship by our senses and our bodies. It always involves a movement away from ourselves and towards the other (Martinsen, 1990). This illustrates two central philosophical/theoretical concepts in nursing: the intentional act and the interpretive process, arising within the practitioner's relationship with the patient.

Intentionality, a key concept within phenomenology, is about the relationship between consciousness and the world and implies that consciousness is always directed toward *something* (Merleau-Ponty, 1994). What appears as something (i.e. breathlessness) appears to someone (a bodily subject) and it appears in a context. Therefore, bodily experiences have a meaning dimension, involving the person's life story and past memories. This makes any experience unique, characterized by the person's situational awareness and previous life experiences. This means that the body no longer can be understood as a passive object of consciousness, but is itself interpretive and meaningful (Merleau-Ponty, 1994).

In the following sections, I will present theory relevant to patients' experiences of breathing, as well as theory to enhance understanding of the competencies needed to care for mechanically ventilated patients. The three main concepts involved are body, breath and competence.

3.1. Body

Merleau-Ponty (1994) made the body the centre of his philosophical thinking. The way we can relate to and access this world is through our bodies. It is through our bodies we experience, learn and express ourselves. The phenomenology of the body emphasizes the ambiguousness of the body. Merleau-Ponty uses the term "lived body" as the body is simultaneously both a perceiving subject and a perceived object, always directed to the world but also already inhabiting it (Merleau-Ponty, 1994). The medical doctor and philosopher Drew Leder (1990), who draws on Merleau-Ponty, argues that our body is not usually in the centre of our consciousness. However, if we suddenly experience a change in our everyday bodily routines or a strong emotional feeling, or if we become ill, the body breaks through into our consciousness (Leder, 1990). Concepts within phenomenology may therefore be useful when studying patients' experiences of breathing.

A clinical situation contains both an objective and a subjective component. The physician or nurse is often perceived as an objective observer, looking at, observing and examining the ICU patient's body and bodily expressions. The patient is a subject, experiencing breathlessness, discomfort or relief, but at the same time, during the examination, the patient may feel his or her body as a medical object. Hence, at the same time, the patient is both subject and object. This also applies to nurses and physicians; in observing the ventilated patient, the nurse takes an objective stance, tests blood gases, observes the patient's respiratory rate, etc. In the course of helping the breathless patient into a better position in bed, or during the daily bed bath, the nurse's hands become an instrument and the focus of her awareness. Her hands must be careful but firm in a way that is not exhausting for the patient, when finally helping the patient to a position in bed that seems comfortable. The nurse's hand receives a message if there is a problem, because it can sense shivering, body heat or body tension. Acknowledging the shifting from objective to subjective in both patients and nurses helps us to understand that we have the possibility to create a shared world of meaning (Havi Carel & Macnaughton, 2012).

3.2. Breath

“Where does the breath end and the wind begin?” (Levin, 1984, p. 129). Breathing comes naturally; it is essential to life, but invisible. With every exchange of air, breathing in and breathing out, we are woven into the atmosphere, an encompassing presence from which we are inseparable. Existence is inspiration and expiration (Merleau-Ponty 1964, p.167). This is illustrated by the word “psyche” in Greek, which bears two different meanings: “breath” and “soul”/”self”, indicating that the self and breathing are related (Levin, 1984, pp. 122-123). Breathing is related to our thoughts and feelings; when we become anxious or feel threatened, our breathing changes.

At the very moment of birth, the baby’s body is already a respiratory body. Not only the mouth but the whole respiratory apparatus gives the newborn a kind of experience of space (Merleau-Ponty, 1964, p. 122). In the phenomenological perspective, breathing involves us in the world; it enables both speech and silence and it marks our coming into being and our end (Carel, Macnaughton, & Dodd, 2015).

3.2.1. Regulation of breathing

Breathing is a basic physiological function. It is unique in being consciously controllable, but also automatic (Booth, Moosavi, & Higginson, 2008). The objective of respiration is to maintain normal levels of pO_2 and pCO_2 in arterial blood. The centre of respiratory control is the medulla oblongata and pons (brain stem), regulating contractions of diaphragm and intercostal muscles. Areas of the medulla regulating respiration are the ventral respiratory group (VRG), and the dorsal respiratory group (DRG) (Burki & Lee, 2010), see Figure 1. The VRG controls the inspiration by nerve cells that send rhythmic signals leading to contractions of diaphragm and intercostal muscles. The DRG receives signals from blood vessels, muscles and lung tissue. The DRG, via the VRG, regulates the frequency and depth of breathing (Burki & Lee, 2010). The chemical mechanisms regulating respiratory frequency and depth are pCO_2 and pH, and to a certain degree pO_2. Chemical receptors are located in the aortic arch and cerebral arteries. Stretch receptors in lung tissues and muscles stimulate respiratory frequency. There are also chemical receptors in the lung tissue sensitive to irritating particles and mucus influencing respiration. The cerebral cortex can overrule the respiratory centre and regulate inspiration and expiration (Hedenstierna, 2012).

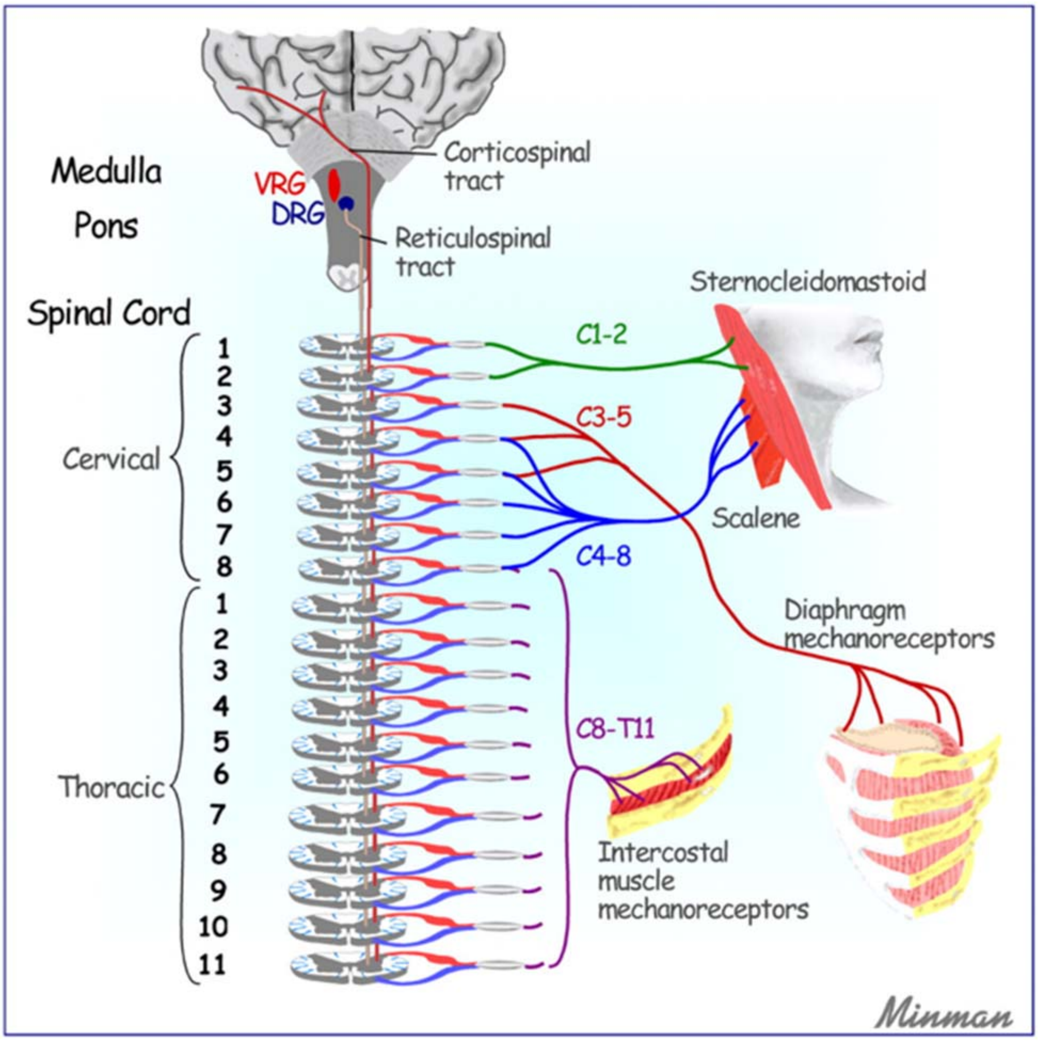


Figure 1 Schematic representation of afferent pathways from respiratory muscle mechanoreceptors to the central nervous system.(CNS). DRG = dorsal respiratory group; VRG = ventral respiratory group (Burki & Lee, Chest, 2010).

3.2.2. The complexity of breathlessness

Breathlessness is a symptom of serious disease, an internal sensation that warns of impending danger (Lansing, Gracely, & Banzett, 2009). On the other hand, for many people breathlessness is a pleasant experience, e.g. a sense of well-being during sporting activities.

There are at least three distinguishable kinds of dyspnoea: air hunger, physical breathing effort and tightness (Lansing et al., 2009). The sensations have distinct perceptions, with different afferent sources, see Figure 2 below.

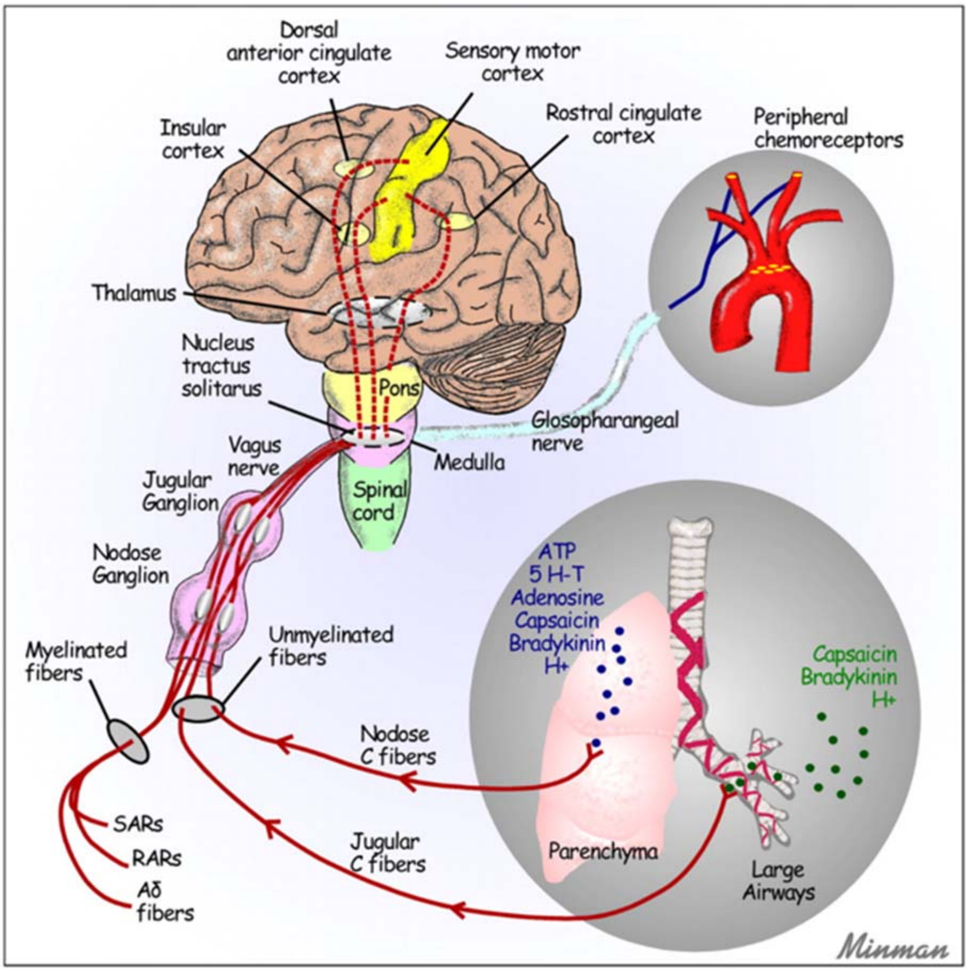


Figure 2 Schematic representation of afferent pathways of dyspnea from vagal receptors and peripheral chemoreceptors to the CNS. The precise pathways from the nucleus tractus solitarius to the limbic system and cortex are not clearly delineated and are therefore shown as broken lines. RAR = rapidly adapting receptor; SAR = slowly adapting receptor (Burki & Lee, Chest, 2010).

“Air hunger” is the perception of the urge to breathe. This fundamental biological drive arises when pulmonary ventilation is insufficient. The “physical breathing effort” is perceived as uncomfortable when the work of breathing is increased by high ventilation, increasing resistance to inspiration, weakness of respiratory muscles, or shortened inspiratory muscle length. “Tightness” appears to be associated with bronchoconstriction (Lansing et al., 2009).

In a recent article, Banzett et al. added two more sensations: hyperpnea (increased depth of breathing) and mental breathing effort (Banzett et al., 2015). The symptoms of dyspnea vary between patients and are not fully explained by differences in disease severity (Banzett, Dempsey, O'Donnell, & Wamboldt, 2000; Teeter & Bleecker, 1998). This suggests that the perception of dyspnea is not necessarily linearly related to the sensory input, but is modulated by cognitive and affective factors (De Peuter et al., 2004). There is a growing awareness that dyspnea, like pain, is a multidimensional experience (Lansing et al., 2009; Laviolette, Laveneziana, & Faculty, 2014). A recent instrument, the Multidimensional Dyspnea Profile (MDP), assesses discomfort, modality of sensation and emotional response (Banzett et al., 2015). The MDP is useful in clinical studies in which diagnoses are heterogeneous (Banzett et al., 2015), but the scale has not yet been translated into Norwegian.

A Respiratory Distress Observation Scale (RDOS) has been developed for patients unable to self-report dyspnea in palliative care (Campbell, Templin, & Walch, 2010). A recent article found that the RDOS, incorporating respiratory and behavioural clinical signs, correlated with self-reported breathlessness among ICU patients able to communicate. Whether this scale is useful for ICU patients with difficulties in communication remains to be determined (Persichini et al., 2015).

Although there is much knowledge about respiratory physiology and pathophysiology, the phenomenological (subjective, experiential) understanding of breathing and breathlessness and its cultural and metaphorical significance are poorly understood (Carel et al., 2015).

3.3. Competence in nursing

Nursing as a practical discipline underlines my understanding of knowledge as knowledge in action (Molander, 1996). This perspective is also highlighted in the research on nursing by Benner et al. (Benner, Hooper-Kyriakidis, & Stannard, 1999). The authors show how certain types of work require expertise that is created and applied to a specific situation, and refer to Merleau-Ponty's phenomenology of the body, where the body is described as the core of experience, perception and knowledge (Merleau-Ponty, 1994). Knowledge of diagnoses and treatment has to be used in complex, ambiguous and often unpredictable situations. Hence, experience and discretion are important factors in clinical performance (Martinsen, 1993) and professional competence. Professional competence was presented as follows in a review article in JAMA, 2002:

> *Professional competence is the habitual and judicious use of communication, knowledge, technical skills, clinical reasoning, emotions, values, and reflection in daily practice for the benefit of the individual and community being served. Competence builds on a foundation of basic clinical skills, scientific knowledge, and moral development. It includes a cognitive function – acquiring and using knowledge to solve real-life problems; an integrative function – using biomedical and psychosocial data in clinical reasoning; a relational function – communicating effectively with patients and colleagues; and an affective/moral function – the willingness, patience, and emotional awareness to use these skills judiciously and humanly. Competence depends on habits of mind, including attentiveness, and presence. Professional competence is developmental, impermanent, and context-dependent* (Epstein & Hundert, 2002)

This definition, originally developed for physicians, is based on, among others, the physician and philosopher Michael Polanyi, the nurse Patricia Benner, and the philosopher and psychologist John Dewey (Epstein & Hundert, 2002). Competence depends on attentiveness, also underlined and further described by Martinsen: a fundamental element in competence emerges from a bodily experience in the concrete situation, where attentiveness and a sense of bodily awareness are a necessary openness to the patients' needs (Martinsen, 2000, p. 29).

The best approach to determining a patient's readiness for ventilator discontinuation is a spontaneous breathing trial (SBT) (Hess & MacIntyre, 2011; MacIntyre et al., 2001). The criteria used to define SBT "tolerance" are based on both objective and subjective assessments, and are dependent on clinical judgement. Clinical judgement is an essential skill in nursing practice and requires an understanding of not only the pathophysiological and diagnostic aspects of a patient's clinical presentation and disease, but also the patient's illness experience, including their physical, social, and emotional strengths and coping resources (Tanner, 2006). Christine Tanner presents a model of clinical judgement (see Appendix 3), based on a review of nearly 200 studies (Tanner, 2006). The model describes the clinical judgement of experienced nurses, and provides language to describe how nurses think when working in complex clinical situations. The process includes four aspects which also seem relevant for nurses in MV and weaning: noticing, interpretation, responding and reflecting:

Noticing: getting a perceptual grasp of the situation, as a function of nurses' expectations of the situation. These expectations stem from nurses' knowledge of the particular patient and his or her patterns of responses, their clinical or practical knowledge of similar patients, drawn from experience, and their theoretical knowledge.

Interpretation: evolving a sufficient understanding of the situation to respond. For example, when a nurse is unable to immediate make sense of what she has observed, a hypotheticodeductive reasoning pattern might be triggered, through which interpretive or diagnostic hypotheses are generated.

Responding: deciding on a course of action deemed appropriate for the situation, which may include “no immediate action”.

Reflecting: reflection-in-action and reflection-on-action together comprise a significant component of the model. Reflection-in-action refers to the nurse’s ability to read the patient, how the patient is responding, and to adjust the intervention based on that assessment. Because much of this reflection is tacit (not verbalized/bodily knowledge), reflection-on-action is the ability to take a step back, including the habit and skill to review the outcomes of the action.

In summary, breathlessness is a complex sensation, and may be understood in terms of pathophysiological, cognitive and emotional factors. To further understand the experience of breathing in the clinical ventilation setting, it seems relevant to use a phenomenological approach both in terms of ontology and methodology, combined with a natural science approach with hermeneutics as a unifying structure.

4. Aims of the study

The overall aim of this thesis is to explore intensive care nurses' roles and competencies in mechanical ventilation and weaning, and patients' experiences of breathing during and after mechanical ventilation.

The thesis consists of four parts with the following specific aims:

I. To explore agreement in the perceptions of nursing leaders and physician leaders regarding roles, responsibilities and clinical decision-making related to mechanical ventilator weaning in Norwegian intensive care units
II. To explore, describe and contextualize aspects of competencies applied by intensive care nurses in ventilator weaning
III. To compare nurses', physicians', and patients' scores of breathlessness, perception of feeling secure, and improvement of respiratory function during mechanical ventilation (at the end of a spontaneous breathing trial)
IV. To explore the lived experience of breathing during and after mechanical ventilation, and to explore how a period of needing help to breathe was lived through and given meaning to by former ICU patients

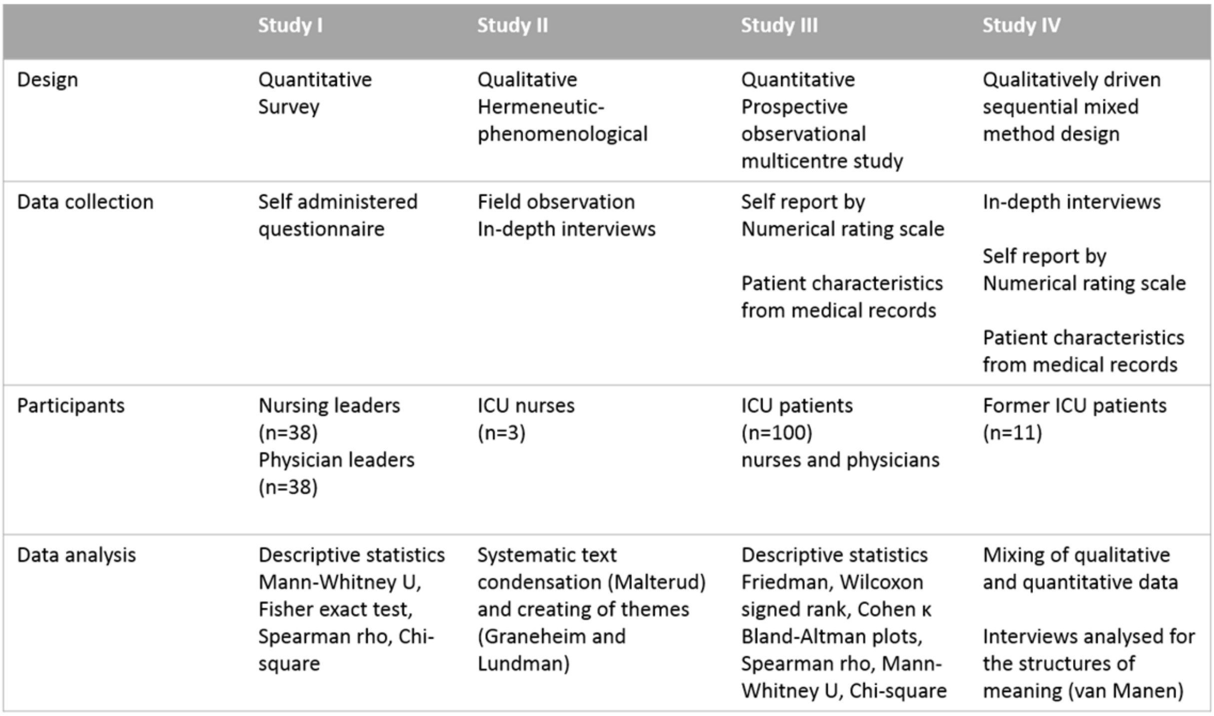
5. Methodology and research process

This section begins with a presentation of the multimethod approach (5.1), including the study design and study setting, followed by the hermeneutical phenomenological approach. The researcher's preconceptions are outlined in Chapter 5.2, and the four different studies are presented in Chapters 5.3-5.6. The studies will be presented as follows: criteria for inclusion and recruitment of participants, followed by enrollment procedure, data production, data analysis and finally research ethics considerations.

5.1. Multimethod approach

In accordance with multimethod and mixed methods research (MMMR) (Hesse-Biber & Johnson, 2015), I take a pragmatic approach in asking: "What is needed to explore different aspects of the overall research question?" Multimethod research refers to the use of either multiple quantitative methods, multiple qualitative methods, or mixtures of these two types of methods (Hunter & Brewer, 2015). Table 2 below demonstrates the study design. Study I represents Paper I, Study II represents Paper II and so on.

Table 2 Study design



	Study I	Study II	Study III	Study IV
Design	Quantitative Survey	Qualitative Hermeneutic-phenomenological	Quantitative Prospective observational multicentre study	Qualitatively driven sequential mixed method design
Data collection	Self administered questionnaire	Field observation In-depth interviews	Self report by Numerical rating scale Patient characteristics from medical records	In-depth interviews Self report by Numerical rating scale Patient characteristics from medical records
Participants	Nursing leaders (n=38) Physician leaders (n=38)	ICU nurses (n=3)	ICU patients (n=100) nurses and physicians	Former ICU patients (n=11)
Data analysis	Descriptive statistics Mann-Whitney U, Fisher exact test, Spearman rho, Chi-square	Systematic text condensation (Malterud) and creating of themes (Graneheim and Lundman)	Descriptive statistics Friedman, Wilcoxon signed rank, Cohen κ Bland-Altman plots, Spearman rho, Mann-Whitney U, Chi-square	Mixing of qualitative and quantitative data Interviews analysed for the structures of meaning (van Manen)

Traditional medical research is hypothetical-deductive and characterized by objectivity and generalizability, and is a useful perspective in Papers I and III. Qualitative method is used in Paper II, and mixed methods research is used in Paper IV, defined as research where the researcher mixes or combines quantitative and qualitative research techniques, methods, approaches, concepts or language in a single study (Johnson & Onwuegbuzie, 2004).

The survey study (Paper I) was performed in Norwegian ICUs. Data in Paper II were collected in one ICU, and three ICUs provided data for the prospective observational study (Paper III). In-depth interviews with former MV patients were performed after hospital discharge (Paper IV).

The hermeneutical phenomenological approach was regarded suitable for both Study II and Study IV. In the explorative, descriptive design, the research was directed towards people's experiences. The informants' knowledge, understandings, experiences and interaction represent a meaningful expression of the social reality that the research questions sought to answer. Knowledge was generated through interaction between the informant, context and researcher.

The principle of openness is central in the phenomenological and hermeneutical tradition. When investigating lived experiences, the researcher should be willing to see a phenomenon in new ways, without taking for granted common perceptions, perspectives and theory. Researchers must show sensitivity to the unexpected and unpredicted (Dahlberg, Dahlberg, & Nyström, 2008, pp. 97-99), so that the phenomenon will present itself on its own terms.

In order to understand human experiences, my basis has been the work of the philosopher Hans-Georg Gadamer, which includes concepts such as openness and interpretation (Gadamer, 1999). According to Gadamer, all knowledge consists of prejudice/

pre-understanding (Van Manen, 2014, p. 133) as we all have a history and an understanding of the world before we begin to think about it. In her book “Reflective Lifeworld Research” (Dahlberg et al., 2008), Karin Dahlberg suggests some methodological principles based on Gadamer’s philosophy. The first principle is openness followed by awareness of the power of tradition, including a healthy suspicion of oneself as a researcher. The second principle is a cautious use of theory to prevent pre-understanding from controlling the process of understanding. The final principle is to search for an understanding of a phenomenon that is not given by one’s pre-understanding (Dahlberg et al., 2008, pp. 277-278).

By reference to the hermeneutic circle (Gadamer, 1999), the movement of understanding is constantly from the whole to the parts and back to the whole. This circular movement is necessary because nothing that needs interpretation can be understood at once. This circular, hermeneutic process has no absolute starting point nor any obvious final end point to our understanding (Todres & Wheeler, 2001). It is like working in a spiralling movement. To gain a new understanding, we bridle (Dahlberg et al., 2008) our first understanding, by comparing it to another view or new experience. It is important to remain open to meaning, as meaning is never fixed or static, but always contextual and historical, which emphasize the interpretative act of understanding.

5.2. The researcher’s preconceptions

In all research, the researcher’s pre-understanding is of significance, such as in the choice of research topic or analytical methods or in how she chooses to present a table or interpret interview data. Ever since I started work as an ICU nurse over twenty years ago and saw how important it was for patients’ progress that they had skilled doctors and nurses who helped them, it has been important for me to describe and explore clinical competence. Specific patient meetings, professional dilemmas and discussions with colleagues have all influenced my choice of research topic. Furthermore, when I look back, I see that my professional and emotional commitment have opened up paths for me and helped me to choose the most suitable areas to be explored.

The idea that logical thinking should be free of emotions is well-known from the philosophers Plato, Kant and Descartes. However, professor of neuroscience Antonio Damasio argues that reasoning has a biological basis. When reasoning is defined as independent of biological factors, it is easier to overlook the role played by emotions. Our so-called rational decisions may be imperceptibly manipulated by our emotions that we want to keep at a distance (Damasio, 1994). On this basis, it seems reasonable also to recognize the significance of emotions in the research process.

Over time, my research moved more specifically towards the study of ICU patients' breathing experiences. Since these patients are very ill and have difficulty in expressing themselves verbally, I found it particularly important to develop new knowledge in this area. The philosopher Martin Heidegger formed a theoretical basis for hermeneutics where he refuted the Cartesian binary division between mind and body. Human existence is a "being-in-the-world". This is not a theoretical but a practical world - imbued with meaning (Fjelland, 1999, p. 213). The experiential world of MV patients is an important area to study, which can be accessed through the patients' own stories. On the other hand, data based on specific figures is in many ways easier to communicate, and it was therefore also important for me to quantify degrees of breathlessness.

Throughout the research process, various factors have influenced how I thought and what choices I made, such as theoretical knowledge, my clinical background as an ICU nurse and the traditions and culture I am part of. I have therefore aimed to be conscious of my pre-understanding, and to be open to viewing the field of research with a critical eye. The principle of openness is central to both the phenomenological and hermeneutical traditions. The study of perceived reality requires a willingness to see a phenomenon in a new light, without taking for granted general perceptions, perspectives and theory. I have therefore attempted to be sensitive to unexpected and unforeseen factors (Dahlberg, Dahlberg, & Nyström, 2008:97-99), to allow the phenomenon to emerge on its own terms. “The scientific adventure of questioning and restraining pre-understanding in research is an act that requires knowledge, patience, discipline, and not least self-awareness” (Dahlberg et al., 2008, p. 147).

The following section is divided into four parts corresponding to each of the studies that comprise the data material for this thesis.

5.3. Study 1

This was a cross sectional study, conducting self-administered questionnaires to compare perceptions of nurse leaders and physician leaders regarding roles, responsibilities and clinical decision making in MV. The study was performed with data from Norwegian ICUs, from November 2009 to January 2010.

Criteria for inclusion and recruitment of participants

We invited 60 nursing leaders and 52 physician leaders of adult ICUs to participate. More nurses than physicians were eligible to participate as some hospitals with several ICUs had only one physician leader. Paediatric and neonatal ICUs or units not routinely providing mechanical ventilation such as coronary care and high dependency units were excluded.

Enrollment procedure

Surveys were distributed via e-mail and returned to a secure collector maintained by Questback (http://www.questback.com/). Two reminders to complete the survey were sent via e-mail at two week intervals from initial distribution.

Data production

The questionnaire, originally used in Australia and New Zealand (Rose et al., 2008) and further refined in a European survey (Rose et al., 2011), was contextually adapted to the Norwegian setting (ICU demographics and staffing) based on input from senior nurses and physicians. The adapted questionnaire was forward and back translated into Norwegian by the authors and inconsistencies in the two English versions (initial version and back-translated) were resolved. The questionnaire included: (1) Professional responsibility for six key ventilator decisions; (i) selecting initial ventilator settings; (ii) evaluating patient response and titrate settings; (iii) recognizing weaning readiness; (iv) selection of weaning method; (v) recognizing weaning failure; and (vi) recognizing extubation readiness. All had four alternatives; “Physicians only”, “Physicians and nurses in collaboration”, “Nurses only” and “Others”. (2) Frequency of 10 ventilation decisions implemented independently by nurses; (i) change of mode; (ii) titration of respiratory rate; (iii) tidal volume; (iv) inspiration pressure; (v-xx) increase and decrease of; pressure support; Peep; and $FiO_{2,}$ had five alternatives: “Never; “Seldom”; “Frequently”; “Often”; and “Routinely”. (3) Nurses’ autonomy and influence in decisions on ventilation practices. Answers were recorded on a Numeric Rating Scale (NRS) ranged from 0 (no autonomy or influence) to 10 (complete autonomy and always influenced decisions). (4) Comment sections were offered to allow respondents to add additional information.

Based on expert feedback and current literature, we added five questions on clinical judgement in relation to knowing the patient (Crocker & Scholes, 2009), increased work of breathing (Frutos-Vivar et al., 2011), well-being (Beeby, 2000), and clinical deterioration (Caroleo et al., 2007). Answers were recorded on a NRS of 0-10, where 0 was unimportant and 10 was very important. Prior to distribution, face validity was assessed by a panel of six experienced ICU nurses and physicians. Respondents were encouraged to discuss the survey with bedside staff to obtain the most accurate information on mechanical ventilation and weaning management in their unit.

Data analysis

Organizational characteristics such as hospital type, staffing ratio, and use of a weaning protocol were analysed using descriptive statistics. Due to small numbers in the category of nurse input alone, we collapsed the classification of professional responsibility to create a binary distinction between interprofessional collaboration and medical input alone. Comparisons of nursing leader and physician leader responses were analysed using non-parametric Mann-Whitney U tests and Fisher's exact tests or chi-square tests as appropriate. Work of breathing, well-being and clinical worsening were correlated to the nurse's knowledge of the patient and analysed using Spearman's rho. We considered a p-value of <0.05 as statistically significant. Analysis was performed using PASW Statistics 18.0 (SPSS 18.0).

Research ethics consideration

Approval was obtained from the Regional Committee for Medical Research Ethics (REK - 2009/840-6). Return of a completed questionnaire was considered indicative of consent. Participants were advised that participation in the survey was voluntary. To maintain anonymity, no ICU or participant identifiers were collected.

5.4. Study II

In order to explore competencies in mechanical ventilation, we performed field observations of ICU nurses and narratives of experiences with concrete weaning situations. The study was performed on a medical/surgical intensive care unit with eight beds at a local hospital with about 500 ventilator days per year.

Criteria for inclusion and recruitment of participants

Nurses holding a specialized post-graduate qualification (18 months) in intensive care and a minimum of five years' experience of ventilator weaning. A purposive sample of three nurses was taken from among 27 intensive care nurses in an ICU at a local hospital.

Enrollment procedure

Respondents were first asked orally by the nursing leader to participate, and later received written information and a formal request to participate.

Data production

To gain insight into the phenomenon of competencies, we used in-depth interviews and field observation, which is a suitable research method to focus on embodied, implicit knowledge and interactions (Dahlberg et al., 2008, p. 211). The nurses were interviewed about their experiences with ventilator weaning. After the interviews, informants were observed in clinical weaning settings during an entire shift. Field observation provided a perspective difficult to capture in ordinary interviews, as I could study nurses' interactions and communications with MV patients in their natural setting (Dahlberg et al., 2008, pp. 112-115). Field notes were written to preserve the first impressions and were an important part of data production as they represented clinical situations the researcher and the interviewee experienced in common. The notes included sequences of the weaning process focusing on the interaction between nurse(s) and patient. These contextual situations were used later in the follow-up interview and in the data presentation. The follow-up interview was conducted immediately after each field observation, lasted from 30 minutes to 1 hour and was tape recorded and transcribed verbatim.

Data analysis

The analysis was performed with systematic text condensation (Malterud, 2001) through the following four stages: (i) reading all the material to obtain an overall impression, bracketing previous preconceptions, (ii) identifying units of meaning, representing different aspects of nurses' experiences with weaning, (iii) condensing and abstracting the meaning within each of the coded groups and (iv) summarizing the content of each code group to generalized descriptions and concepts reflecting the most important factors reported by the informants.

The condensed meaning units (sub-themes) were presented as headers, reflecting the informants' behaviour and expressions and were interpreted into three themes of intensive care nurse competence in ventilator weaning (Todres & Wheeler, 2001). Creating themes was a way to link underlying meanings in the text (Graneheim & Lundman, 2004). The themes were then discussed in light of previous research and theoretical perspectives.

Research ethics consideration

This study was approved by the hospital management and recommended by the Norwegian Social Science Data Service (NSD-10204). The participants gave informed consent. The patients did not participate themselves, but since they formed part of the interaction examined, the study was submitted for review and approval by the Regional Committee for Medical Research Ethics (REK).

5.5. Study III

Three Norwegian ICUs (one local hospital and two university hospitals) provided data for the prospective observational study in order to assess the agreement between physicians', nurses' and patients' scores of breathlessness at the end of a spontaneous breathing trial. Admitted patients in the study period were 1955.

Criteria for inclusion and recruitment of participants

Patients scheduled for SBT were eligible if MV >24 hours, they were aged ≥18 years, and had a motor activity assessment score (MAAS) of 3-4 (Devlin et al., 1999). The patients fulfilled the SBT criteria: (a) reversal of the cause of respiratory failure, (b) no uncontrolled infection or metabolic disturbance, c) heart rate <120, systolic BP 90-180 mmHg, d) oxygen saturation >90%, FiO_2 <0.5, PEEP ≤8 cmH_2O (Schmidt et al., 2014). Non-communicative patients due to sedation, cognitive failure, auditory or visual impairment, or inadequate knowledge of Norwegian were excluded. One hundred consecutive adult mechanically ventilated (MV) patients were prospectively recruited from three Norwegian ICUs. The units treat all patient categories except cardiac surgery and transplant patients.

Enrollment procedure

All ICU patients were screened every weekday by a study nurse.

Data production

The SBT was performed by pressure support (PS) ventilation of 6-8 cmH_2O with PEEP of 6-8 cmH_2O (SERVOi or Engström Carestation Ventilator), a T-piece, or external CPAP with PEEP of 5 cmH_2O. The three SBT methods are in clinical use to assess readiness for extubation (Boles et al., 2007; Ladeira et al., 2014).

Breathlessness was rated by a validated 11-point NRS (Gift & Narsavage, 1998; Powers & Bennett, 1999). The operational definitions of perception of security and improvement of respiratory function were developed into two questions both rated by an 11-point NRS ranging from 0 to 10. We asked patients: (1) "Do you have a sensation of breathlessness?" with extremes of "No, not at all" (least) and "Yes, worst imaginable" (most), (2) "Do you feel secure during the spontaneous breathing trial?" and (3) "Do you feel an improvement of respiratory function?", both with extremes of "Yes, absolutely" and "No, not at all". The nurses and physicians responded to similar questions and NRS scales. At the end of an SBT, a nurse and a physician individually rated the patient for breathlessness. Immediately afterwards, the nurse asked patients to provide their ratings. Patients unable to move their arms gave a response by showing the relevant number of fingers or alternatively the nurse pointed at the NRS scale following instructions from the patient.

Data analysis

Descriptive variables were reported as absolute numbers, percentages and medians (25th-75th percentiles). Agreement between patient and nurse/physician assessments of intensity of symptoms was examined using several approaches. First, agreement between patients, nurses and physicians was addressed by Friedman's test for repeated measurements, and post hoc analyses were made by pairwise tests between patient-nurse, patient-physician and nurse-physician using a Wilcoxon signed rank test where a significance level of 0.02 was used to correct for multiple testing. Second, difference scores for each symptom (difference score = nurse/physician score minus patient score) were calculated. A difference score within ±1 was good agreement, while a difference score of $\leq$-2 represented underestimation and one of $\geq$2 overestimation by the nurse/physician. Third, strength of agreement between the assessments was tested using Cohen's kappa. The differences between patients and health care providers regarding breathlessness were described by Bland-Altman plots (Bland & Altman, 1986), originally developed for continuous variables, but later extended to visualize categorical data (Smithline, Caglar, & Blank, 2010).

Correlation between symptoms was calculated by Spearman's rho. Associations between patients' assessments, demographic data and respiratory observations were tested by the chi-square test for nominal or dichotomized variables and the Mann-Whitney U test for ordinal and continuous, non-normal distributed variables. Applying a clinical difference of interest of 1 in the breathlessness numeric rating scale (NRS) (Currow, Higginson, & Johnson, 2013), a two-sided t-test, significance level 0.05, power 0.80, and the standard deviation (SD) of 2.40 observed in this study, a post hoc sample size calculation resulted in 51 observations, suggesting that 100 patients were sufficient (Machin, 1997). IBM SPSS Statistics for Windows, Version 21.0. Armonk, NY, United States was used for all analysis.

Research ethics consideration

An ICU nurse informed the patients and oral consent was obtained prior to the study. Extubated patients gave a deferred written consent. The Regional Committee for Medical

Research Ethics approved the study (REK - 2012/1230). The study was registered as NCT01928277 at ClinicalTrials.gov.

5.6. Study IV

In-depth interviews with former MV patients were performed after hospital discharge to explore the experiences of breathing during and after MV.

Criteria for inclusion and recruitment of participants

Patients already included in Study III. From the population of 100, 18 died in hospital and a purposive sample for the study was selected among the 82 surviving patients.To obtain examples of experientially rich descriptions (Van Manen, 2014, p. 353) and variation in experiences, we purposely recruited participants using the following criteria: low (<4) and high (≥4) breathlessness Numerical Rating Scale score (NRS) (range from 0-10) during SBT, and differences in age, gender and time on ventilator.

Enrollment procedure

Patients were invited consecutively after ICU discharge. Eleven participants were included and interviewed between 5 and 14 months after MV, at home (8), at work (1) or at a local hospital (2).

Data production

The interviews were introduced with a short briefing of the purpose. The emphasis was on narratives of concrete situations. An open dialogue was aimed at, including sequences of questions (Dahlberg et al., 2008), such as: “Can you tell me about your breathing during your hospital stay?” “Can you tell me about a time when you felt breathless?”, and “Can you give an example/tell me more about…” At the beginning of the narrative, I made an effort to show openness towards experiences that came spontaneously, and I was aware that experiences could be awakened through dwelling on episodes and evoking feelings (Van Manen, 1990, pp. 64-68). The pre-reflective was an important dimension of the experiences. Being open also involved willingness to reformulate questions and derive new ones from the responses (Dahlberg et al., 2008). This approach relegated the interview guide to the background. Furthermore, demographic data, patients' self-reported NRS scores of breathlessness, feeling secure and breathing progress (quan-data) were included by data from Study III.

Data analysis

Descriptive variables and demographic data were reported as absolute numbers, percentages and medians (25th-75th percentiles) (quan-data). The interviews (QUAL-data) were individually read and analysed through the following questions: 1. Does the patient experience breathing problems several months after mechanical ventilation? 2. Does the patient remember severe breathlessness during the ICU stay? Both were dichotomized as yes/no.

Second, the findings from interview data were mixed (the points of interface) (Morse & Cheek, 2015) with the following quan data from Study III for each of the 11 patients during SBT: gender, breathlessness (rated by 0-10 on the NRS scale), feeling secure and breathing progress (both dichotomized as < and ≥4 on the NRS scale). A joint display was created describing the mixing of quan-QUAL data.

Third, interviews were analysed in terms of meaning structures, and the three analytic steps described by van Manen (Van Manen, 1990, pp. 92-93) guided the analysis and the process of writing up essential themes. All interviews were read and listened to several times to get an overall impression, followed by a selective approach to search for essential clusters of meaning within and across interviews. The analysis was guided by the question: How do the participants describe their experiences of breathing during MV and in the recovery process? In the final step, we looked at every single sentence or sentence cluster and asked: What does this reveal about the experience of breathing during and after MV?

Fourth, a figure was created to illustrate the overall interpretation of the findings. The results of the analysis were presented to two artists (one of them is also an intensive care nurse) who were inspired to create prints based on the material. I use two of these in my discussion in Chapter 7 to elaborate on the findings and encourage further interpretation (Van Manen, 2014, p. 46).

Research ethics consideration

The participants received written information and a request to participate at least one month after hospital discharge. When written consent was given, the first author telephoned them to ask where they preferred the interview to be held. The study was approved by the Regional Committee for Medical Research Ethics (REK - 2013/2078).

6. Summary of results

6.1. Paper I

Perceived decisional responsibility for mechanical ventilation and weaning: a Norwegian survey

Weaning a patient from the ventilator is one of the main challenges in intensive care nursing, and effective teamwork among nurses and physicians is crucial for providing optimal patient care in the ICU and may improve patient outcome. Perceptions of nurse-physician collaboration are variable, and more knowledge of nurses' and physicians' perceptions of responsibility in clinical decision-making for mechanical ventilation was needed. Therefore, we explored the agreement in perceptions of nursing leaders and physician leaders regarding roles, responsibilities and clinical decision making related to mechanical ventilator weaning in Norwegian ICUs.

Our main findings were that nursing leaders perceived nurses to have greater autonomy, influence and collaborative interaction regarding decisions on mechanical ventilation, compared to the perception of physician leaders. On an NRS scale of 0-10, nurse autonomy was rated as a median of 7 (IQR 5-8) and 5 (3-6) by nurses and physicians respectively ($p<.01$). Physician leaders reported less collaboration than nursing leaders in the decisions made on readiness to wean: 23 (61%) versus 31 (82%), ($p=.04$), choosing the weaning method: 16 (42%) versus 26 (70%), ($p=.01$), and recognizing readiness to extubate: 11 (29%) versus 25 (68%), ($p<.01$). The varying perceptions of nurses and physicians on the role of intensive care nurses might impact practice; however professional boundaries in ICU are blurred by interdependence rather than autonomy of professional groups. Both nursing leaders and physician leaders were in agreement that nurses were key to determining whether ventilation settings should be changed in response to the patients' weaning tolerance; they also agreed that 'knowing the patient' was critical to individualize care and manage the weaning process.

6.2. Paper II

In a way, you have to pull the patient out of that state ...: the competency of ventilator weaning

There is a connection between weaning time and the qualifications and experience of intensive care nurses. However, the significant aspects of the context and the qualities important in the nurse-patient relationship in weaning have not yet been sufficiently described. In order to explore and contextualize aspects of competency in ventilator weaning, we analysed qualitative data from six in-depth interviews and field observations of three experienced intensive care nurses in weaning situations.

Competence was based on thorough knowledge of physiology and ventilator skills. Awareness and the ability to interpret the patient’s body expressions were fundamental for the clinical judgement and actions that followed in the weaning process. The concept of comfort-discomfort was important; here, technical knowledge, intuition and emotional involvement aroused the attention of the nurse. In situations where patients continued to be uncomfortable, the nurses themselves felt physically disturbed and their alertness and unease worked as forces to find explanations.

Knowing the patient and facilitating well-being was a crucial part of competence in weaning and allowed for the establishment of the necessary trust and confidence to reach into the patient’s world and “pull” the patient back to life, to “here and now”. This “pulling” was connected to “pushing” the patient further in the weaning process.

Behaving competently involved a continuous dialogue with the situation, observation of the patient’s body language and symptoms over a period of time and the ability to see the interrelationships between all these elements. Competence in ventilator weaning was linked to personal qualifications, while also being dependent on a professional community that both confirmed and acknowledged this competence.

6.3. Paper III

Underestimation of patient breathlessness by nurses and physicians during a spontaneous breathing trial

There is a lack of knowledge of breathlessness from the patient perspective, even though it is one of the most prevalent and distressing physical symptoms experienced by intensive care patients. Therefore, we assessed the agreement between nurses', physicians', and patients' 11-point Numerical Rating Scale scores of breathlessness, perception of feeling secure, and improvement of respiratory function at the end of an SBT. We also determined the association between breathlessness and demographic factors or respiratory observations.

Sixty-two patients (62%) reported moderate or severe breathlessness (Numerical Rating Scales ≥4). The median intensity of breathlessness reported by patients was five, compared with two by nurses and physicians (p<.001). Patients felt less secure (p=.005) and reported less improvement of respiratory function (<.001) compared with nurses' and physicians' ratings. About half of the nurses and physicians underestimated breathlessness compared with the patients' self-reports. Underestimation of breathlessness was not associated with professional competencies. There were no major differences in objective assessments of respiratory function in patients with moderate or severe breathlessness, and no apparent relationship between breathlessness during the SBT and extubation outcome. In summary, patients reported higher breathlessness at the end of an SBT than nurses and physicians.

6.4. Paper IV

The Breath of Life. Patients' Experiences of Breathing During and After Mechanical Ventilation – a Qualitatively-Driven Mixed Method Study

Breathlessness is a prevalent and distressing symptom in intensive care, underestimated by nurses and physicians. Therefore, we explored patients' experiences of breathing during and after mechanical ventilation. By combining prospective observational breathlessness data from 11 patients during MV (Paper III), and data from the same patients in post-discharge interviews, we found that four out of six patients who reported breathlessness during MV did not remember being breathless in retrospect.

The experience of breathing was not necessarily a separate experience, but was intertwined with the whole illness experience and described in four themes: "existential threat", "the tough time", "an amorphous and boundless body" and "getting through". The essential meaning of needing help to breathe was expressed as being in a sort of in-between space at the threshold between life and death. The MV patients' experiences of being in a space in between life and death elicited feelings of having to choose a direction. The results in this study suggest that bonds to family and attuned caring are essential to help and promote ICU patients' *getting through* and to support their existential choice to keep on living. Insight into the phenomenon of breathing could enhance communication between health professionals and patients in MV treatment and follow-up care.

7. Discussion

The main findings of this study are briefly outlined below, and will subsequently be discussed in relation to current research. As mentioned in Chapter 5.6, I chose to use two artistic prints to bring a new perspective into the discussion, and to invite the reader into further interpretation of the text (Van Manen, 2014, p.46). After this, methodological considerations, ethics and strengths and limitations of this thesis will be discussed before concluding.

7.1. Main findings

There was a certain disagreement on perceived decisional responsibility for MV and weaning between nursing leaders and physician leaders. However, both groups agreed that nurses were key to assessing when ventilation settings should be changed in response to patients' weaning tolerance and that 'knowing the patient' was critical to individualize care and manage the weaning process. Knowing the patient and facilitating well-being was a crucial part of competence in weaning and opened up for establishing trust and confidence, which were necessary to reach into the patients' world and "pull" the patient back to life, to the "here and now". This "pulling" was connected to "pushing" the patient further in the weaning process. The prevalence of breathlessness among MV patients was high, and underestimated by nurses and physicians, regardless of professional competencies or knowing the patient. Mechanically ventilated patients' experiences of breathing were not necessarily a separate experience, but intertwined with the whole illness experience and existential dimensions of life.

I choose to start the following section by discussing patients' experiences of breathing, because this knowledge is an important prerequisite for further discussions of intensive care nurses' roles and competencies in mechanical ventilation and weaning.

7.2. Patients' experiences of breathing and breathlessness

The prevalence of breathlessness among MV patients in our study (Paper III) was high. Other studies (Powers & Bennett, 1999; Schmidt et al., 2014) have also shown that breathlessness is prevalent among MV patients. However, routine care does not usually capture patients' self-reported perception of breathlessness (Puntillo et al., 2010). A meta-analysis suggests that treatment guidelines do not focus on symptoms, but rather on more easily measurable outcomes such as paO_2 and respiratory rate (Neto et al., 2012). The American Thoracic Society (ATS) Official Statement on Dyspnea strongly emphasizes that "dyspnea per se can only be perceived *by the person experiencing it*", and dyspnoea can and should be measured (Parshall et al., 2012, pp. 436-437). Hence, instead of the usual practice of solely relying on the clinician's perspective, our study shifts the focus of outcome measurement to the patient's perspective. To our knowledge, this is the first prospective multicentre study specifically designed to examine subjective assessments of breathlessness at the end of an SBT.

Breathlessness (Schmidt et al., 2011) and voicelessness are considered the worst experiences among intensive care patients who are conscious during mechanical ventilation (Karlsson et al., 2012). Breathlessness was also prevalent in Paper III, demonstrating that 62% had an NRS symptom score of ≥4. Unlike other studies, by following up MV patients' self-report of breathlessness during MV, we further investigated the same patients after ICU discharge. Interestingly, our mixed data (Paper IV) gave contradictory findings concerning breathlessness, as four out of six patients who actually reported breathlessness during MV did not later remember being breathless in the ICU.

However, our patient-reported breathing data from SBTs (Paper III) give only a snapshot and cannot provide information about breathlessness experienced during MV as a whole. Patients who did not report breathlessness during the SBT may therefore have had experiences related to breathlessness in other stages of the ventilation process, which may explain why these patients described difficulty in breathing in the post-discharge interview (Paper IV). On the other hand, Paper IV reveals the complexity of the phenomenon of breathing, and lends support to the idea that breathing is a multidimensional phenomenon involving emotions, bodily sensations and thoughts (Lansing et al., 2009). This may explain why MV represents a traumatic event for patients regardless of how well weaning proceeds clinically (Rose et al., 2014). Hence, it is essential for health personnel to realize that bodily experiences of breathlessness have an existential dimension that must be interpreted and understood in order to alleviate the patient’s suffering.

The mixed data (Paper IV) demonstrated that the perception of “feeling secure” during SBT was less prevalent among the breathlessness group. This is not surprising, as anxiety and dyspnea are related (Mularski et al., 2010). Interestingly, all patients in the no-breathlessness group who felt secure during SBT reported breathing progress as well. This underlines the fact that more research is needed to understand the central mechanisms that modulate the lived experience of breathlessness (Currow & Johnson, 2015).

The phenomenon of breathing is complex, and not fully understood (Banzett et al., 2015). Therefore, the phenomenological approach in Paper IV was helpful to provide a deeper understanding of the phenomenon of breathing, as pathological breathlessness is a pervasive experience, with multilayered meanings for patients (Lansing et al., 2009). The essential meaning of needing help to breathe is expressed as being in a sort of in-between space. The patient is still breathing, but not on his/her own; he/she is still alive, but not yet living. This experience of being at a threshold or a kind of tipping point connects all the themes of meaning in our study (Paper IV): “existential threat” “the tough time” “an amorphous and boundless body” and “getting through”.

The existential threat is not only expressed as a fear of death, but more precisely as being on the threshold of life and death (see Figure 5 below). To be “stuck” in this space in between life and death, or between a life supported by machines and a normal life, elicits feelings of having to choose a direction. The importance of *getting through* is thus not only associated with the struggle to get well from serious illness, but also with the existential will to keep on living.

Figure 5 Being on the threshold of life and death

The experiences of having a body without bounds, of losing one's identity as a person or merging with someone else, further shows us how this in-between space is a floating experience where the regular world loses its boundaries. The inability to breathe on one's own leads to hazy borders between one’s self and others, one’s self and machines and between the person and the world.

Patients in our study describe how being in this in-between space, not really sure how to get through to the other side, was experienced as a tough or burdensome time. The experience of heavy breathing is here connected to, and cannot be separated from, a general feeling of weight and tiredness. This demonstrates how breathing is not only a function but also a *dimension* of being. Merleau-Ponty (Merleau-Ponty, 1994) emphasizes the rhythms of existence that belong to and characterize our existence because we are bodily. Thus we go in and out of sleep, and in and out of relationships with other people and with the world. Breathing is one of our most fundamental rhythms, a basic to and fro movement that characterizes our being in and with the world. Far from being only a biological fact, breathing is what connects us to the world, to life.

But breathing is a borderline phenomenon also in another way. It is one of the few physiological functions that both work automatically and can also be consciously controlled (Hedenstierna, 2012, p. 282). In this way, breathing as a dimension of being demonstrates how our involvement in the world is both active and passive at the same time. For example, going to sleep is a sort of surrendering to the situation – instead of breathing on my own, the situation breathes me (Merleau-Ponty, 1994). It is of course no coincidence that Merleau-Ponty uses the function of breathing to illustrate how being in and perceiving the world is not only an activity but also a sort of surrendering. The function of breathing is not only our connection to life; it is also a door opened to that part of life which we do not (fully) control. This might illustrate what the patients in this study communicate when they try to express the experience of “being breathed for”. It is as though they are not fully in life, not fully *living*, but all the same still alive. They are in the space in between actively involving themselves in life and passively receiving it, in between life and death.

The complexity of breathlessness is also described in other studies, suggesting that dyspnea is a multifactorial symptom, involving interaction between various physiological, psychological and environmental factors (Laviolette et al., 2014). It is not clear how many different types of dyspnea exist and whether their differences are mechanistic (i.e. subjective manifestations of different neurophysiological mechanisms) or semantic (i.e. the same neurophysiological mechanisms may be expressed differently in relation to age, social and cultural context, etc.) (Laviolette et al., 2014). Based on the results from Paper IV, our study adds to this by showing that breathing, besides being a *function* of being (i.e. a fundamental premise of living), is also at the same time a *dimension* of being. In this way, breathing is an essential subjective bodily experience (Edwards, 2006, p. 3). This may help to explain the the poor correspondence between patients' and clinicians' assessments of breathlessness in Paper III.

Another explanation for the disagreement between patients' self-reports of breathlessness and the dyspnoea quoted by observers may be a crosstalk between dyspnoea and other discomfort as suggested by Banzett (Banzett & Schwartzstein, 2015) in an editorial to our Paper III. Our empirical data (Paper IV) support and further illuminate this, as mechanically ventilated patients' experiences of breathing were intertwined with the whole illness experience, which is in line with the philosophical thinking of how the self and breathing are related (Levin, 1984, pp. 122-123). This may possibly explain empirical findings demonstrating that patients' feelings of breathlessness are associated with anxiety and delayed extubation (Schmidt et al., 2011), as the presence of dyspnoea and pain seem to be predictive of post-traumatic stress disorder (Schelling, 2002; Schelling & Kapfhammer, 2013).

7.3. Competence

Paper II demonstrates that competence was based on thorough knowledge of physiology and ventilator skills. This is further underlined in Paper I by nursing leaders and physician leaders who agreed that nurses have an important role in assessing when to change ventilation settings in response to patients' weaning tolerance. Behaving competently involved a continuous dialogue with the situation, observation of the patient's body language and symptoms over a period of time and the ability to see the interrelationships between all these elements.

7.3.1. Experience and discretion in assessing breathlessness

In the decade since the publication of the original ACCP/SCCM/AARC guidelines (2001) (see Table 1), the criteria to assess SBT success/failure have remained largely unchanged, essentially as integrated indexes of clinical assessments do not rely on rigid numbers (Macintyre, 2012). In Paper III, 62% of patients had an NRS symptom score of ≥ 4. For many symptoms, there is no clear evidence as to what the optimal cut-off points are, but a systematic review article on cancer patients suggests that in daily clinical practice, a symptom score of ≥ 4 should elicit a more comprehensive symptom assessment to properly identify the symptom burden (Oldenmenger, de Raaf, de Klerk, & van der Rijt, 2013).

The NRS scores of breathlessness is not included in weaning guidelines, and there is little evidence of the ability of health care workers to assess the patients' experiences of breathing (Banzett & Schwartzstein, 2015; Schmidt et al., 2014). As our Paper III demonstrates, it is challenging both to measure and to draw conclusions on the basis of different scores. Experience and discretion are considered to be important factors of clinical performance (Martinsen, 1993). Paper III adds to this, demonstrating that training and experience are not necessarily related to success in assessing dyspnoea. Our findings are supported by a systematic review which found that length of professional experience is often unrelated and even negatively related to performance measures and outcomes (Choudhry, Fletcher, & Soumerai, 2005). Thus, it seems that dyspnoea is inherently difficult to assess on the basis of observations of patient behaviour and physical findings. Another explanation may be due to that self-report of breathlessness and health care workers assessments are measurements not of the same phenomenon or that the 2 measurements have very different scaling (Tulaimat, Patel, Wisniewski, & Gueret, 2016).

However, to ask the patient about his/her breathing comfort is the clinicians' responsibility (Banzett & Schwartzstein, 2015). One reason for this is that the presence of dyspnoea (Schelling, 2002), and the recall of frightening ICU experiences (Parker et al., 2015) are predictive of PTSD. Secondly, the findings in Paper IV underscore that to acknowledge the presence and impact of breathlessness is in itself a therapeutic intervention, as it validates the experience of the person's sensation (Currow & Johnson, 2015). Thirdly, effective symptom management is associated with improved patient outcomes such as more ventilator-free days and shorter length of stay (Campbell & Happ, 2010), and patients' perception of breathing during a spontaneous breathing trial (SBT) might be related to extubation success (Perren et al., 2010).

Observations of respiratory signs are probably not random, as the data in Paper III suggest a much higher correlation between nurses and doctors than between either clinician group and patients (Banzett & Schwartzstein, 2015). The patients' in this study were ventilated in accordance to good medical practice. Except for a clinically insignificant but statistically significant difference in respiratory rate and SaO_2 before the SBT between patients with versus without breathlessness, objective variables, such as changes in FiO_2, PaO_2, $PaCO_2$, pH, tidal volume, hearth rate and systolic blood pressure before and after the SBT, were not associated with the patients' self-report of breathlessness. I therefore question whether the definition of competence (Epstein & Hundert, 2002) is too narrow. I suggest that it should also include bodily knowledge, where attentiveness and a sense of bodily awareness are a necessary openness to interpret the patient's needs (Martinsen, 2000, p. 29).

7.3.2. The ability to interpret the patient's bodily expressions

The lack of significant aspects of the context and the qualities important in the nurse-patient relationship in weaning is questioned in previous research (Aari et al., 2008; MacIntyre et al., 2001; Rose & Nelson, 2006). In Paper II we found that awareness and the ability to interpret the patient's bodily expressions were fundamental for the clinical judgement and actions that followed in the weaning process. These findings are in line with the key nursing concepts (Martinsen, 2006), of the intentional act and the interpretive process (see Chapter 3). The study gives details which demonstrate the complexity of correct timing in MV and weaning. Timing is unique to each patient. The research approach in Paper II, observing concrete weaning situations, offers insight into how nurses interpret patients' responses to many contextual factors, and in doing so make sound clinical judgements about weaning. Competence in ventilator weaning might thus be linked to personal qualities, while also being dependent on a professional community that both confirms and acknowledges this competence.

Being dependent on health professionals, without being able to communicate, causes experiences of anxiety, fear and loneliness. How intensively these feelings are experienced seems to depend on health professionals' ability to be present with these patients (Baumgarten & Poulsen, 2015). This is in line with, and further illuminated in, our study, as the MV patients' experiences of being in a space in between life and death elicited feelings of having to choose a direction (Paper IV). But do they really make a choice? To help and promote the ICU patients' *getting through* (See Figure 6 below), it seems important to support the existential will to keep on living, through attuned care.

Figure 6 Getting through

Below, I have chosen to discuss in more detail the starting point for my PhD, namely the question of why some nurses are more competent than others in the weaning process. Is this competence an individual ability to be receptive to sensory input, and to the moral appeal for help that emanates from the sight of a sick person? And if so, what can allow such sensing to emerge? Is it a question of personal qualities, and willingness to try to understand and help the others? Or is it dependent on the nurse's expertise and experience from similar situations with MV patients?

7.3.3. How attuned caring allows for sensing

Løgstrup describes how sensing comes to us, as an impression without interpretation or conscious thinking (Løgstrup, 1995). A field study of Norwegian intensive care nurses showed how the nurse becomes emotionally affected by the patient's expressions in such a way that her attention is directed towards early signs of changes in the patient's condition (Kvande, Delmar, Lykkeslet, & Storli, 2015). The nurse's sensing is necessary to understand the situation. The nursing theorist Christine Tanner (Tanner, 2006) uses the term "perceptual grasp of the situation" as the first stage of her competency model (Chapter 3.3). The nurse's attention is grounded in an expectation of what she should look for on the basis of her knowledge and clinical experience with similar patients. As mentioned above, there was no correlation in Study III between experience and expertise and underestimation of patient breathlessness. Could it be that experience and expertise may sometimes stand in the way of the nurse's attention?

Unlike Tanner's model (2006) (Appendix 3), Paper II shows that feelings and sensitivity to the situation are important. Study II shows how the patient's expressions of stress/pain/discomfort arouse the nurse's attention in the form of an emotional unease that leads her to seek out the problem. This emotional unease interacts with knowledge and experience in order to try to understand the situation and find an explanation to help the patient. When the nurse does not immediately understand what she observes, she forms a preliminary understanding, a hypothesis for a possible explanation that is then tested. This fits in with Tanner's competency model (2006) where interpretation is necessary to develop an adequate understanding of the situation as a basis for responding and intervening.

Attunement and sensing can help the nurse to understand the situation - when the patient is "on the threshold" - and here the human relationship can mean turning in the right direction. Furthermore, the benefits of genuine empathy should not be underestimated (Currow & Johnson, 2015). It is suggested that dyspnoea relief is more than a reduction of negative sensations; an important component of dyspnea relief is the rewarding and positive sensation of "pleasantness" that accompanies it (Laviolette et al., 2014).

The nurse has a duty to identify, interpret and respond to the patient's bodily cues which indicate stress, physical agitation and discomfort. Facilitating relief and comfort is a key aspect of nursing. The nursing theorist Janice Morse (Morse, 1997) defines comfort as " a state of well-being that may occur during any stage of the illness-health continuum. […] two comfort states have been identified: a temporal state that eases, relieves, and assists the patient to endure; and the achievement of a more constant, long-term state, such as the attainment of optimal health" (Morse, 1997).

From the patient's perspective, the concept of comfort implies the ability to trust the nurse so that he can surrender to her and recover (Morse, 1997). Could there be something in the nurse-patient relationship that carries patients through this experience of making a choice to continue living? The associations of hope, meaning, and perceived nurse-patient interaction was in a recently cross-sectional study among cognitively intact nursing-home patients found as powerful health-promoting factors that significantly influence patients' quality of life (Haugan, Moksnes, & Lohre, 2016). Morse argues that facilitation of comforting (well-being and relief) is an important factor in the disease course (Morse, 1997, p. 4). This is further described by Martinsen as recognition by the nurse of the importance of presence and attention, allowing patients to express their troubles and their determination and potentially strengthening their will to live (Martinsen, 2006, p. 59). The feeling of security and well-being, considered by both doctors and nurses as significant in MV (Papers I and II), and confirmed by patients in Paper IV, seems particularly important for patients who experience their body as amorphous, and feel that their existence is threatened.

7.3.4. Knowing the patient – a prerequisite for "pull and push"

In Study III, we found that breathlessness was underestimated by nurses and physicians regardless of whether they knew the patient. These findings do not concur with those in Papers I and II, where nurses and physicians value the significance of "knowing the patient". The reason for these contradictory findings may be explained by the fact that NRS assessments take a short time (30 minutes) compared to caring for patients during the whole weaning process, as was the focus in Paper II. In the same paper, knowing the patient and facilitating well-being seem to be critical to individualizing care and managing the treatment process and are apparently a crucial aspect of competence in weaning.

Morse stressed that comforting also includes challenging the patient and that there has been little empirical research on this. This study responds to her suggestion. The "push and pull" dichotomy developed in Paper II shows how attunement and comfort (understood as both well-being and challenge) are important to succeed in the weaning process. In Paper II, experienced ICU nurses considered the "push and pull" concept and knowing the patient to be important in the weaning process. Familiarity with the patient and attuned care allow for the establishment of trust and confidence, which are necessary to reach into the patient's world and pull the patient back to life, to the "here and now". "Pulling" was connected to, and a prerequisite for, "pushing" the patient further in the weaning process. This is further described in Paper IV, where MV patients' experiences of being in a space in between life and death elicited feelings of having to choose a direction.

Attuned care and knowing the patient seems essential to help and promote ICU patients' *getting through* and to support their will to keep on living. Our findings are in accordance with a recent meta-synthesis of Nordic studies (Egerod et al., 2015) which demonstrates that patients with a life-threatening illness descend into a liminal state, where they face the choice of life or death. Caring nurses and family members play an important role in assisting the patient in the transition back to life (Egerod et al., 2015).

7.4. Roles and responsibilities in MV and weaning

In Paper I, organizational factors as hospital type and weaning protocol do not explain how ICN autonomy and influence are perceived by leaders. We found that many decisions were collaborative in the absence of protocols and that nurse input played an important role in management of ventilated patients.

Simple measures in individual patients can be useful in tracking disease progress or treatment efficacy, and are essential in targeting individual symptom management (Banzett & O'Donnell, 2014). In the three ICUs (Paper III), clinicians usually did not use a systematic rating scheme for signs of breathlessness, reflecting practice in most institutions (Campbell & Templin, 2015). However, clinical assessment of increased work of breathing (Penuelas et al., 2015) and discomfort (Macintyre, 2012) is challenging for both nurses and physicians, suggesting that symptom assessments should be more systematic (Egerod, Christensen, & Johansen, 2006; Woien, Stubhaug, & Bjork, 2012) and more often discussed between professionals.

As we have seen, a new paradigm in intensive care treatment is evolving toward a greater number of awake patients (Karlsson & Bergbom, 2015; Laerkner, Egerod, & Hansen, 2015; Vincent et al., 2016), with minimal or no sedation (Strom, 2012). This will further challenge interaction and communication with patients experiencing breathlessness, as well as roles and responsibilities for nurses and physicians. Caring for more awake non-sedated patients in Danish ICUs required the nurses to act at the interface between ambiguous possibilities and needs, which was perceived as both demanding and rewarding (Laerkner et al., 2015). Despite the complexity of care, nurses preferred to care for more awake patients and appreciated caring for just one patient at a time. The importance of close collaboration between nurses and doctors to ensure patient comfort during mechanical ventilation was also valued (Laerkner et al., 2015).

In a recent Swedish study of ICU professionals' experiences with more awake patients, physicians suggest it is more humane for patients to be conscious as they then play a more active part (Karlsson & Bergbom, 2015). On the other hand, staff found it distressing to witness suffering without being able to alleviate it. Nurses wished for closer teamwork when they realized they could not alleviate the patients' suffering (Karlsson & Bergbom, 2015).

To enhance the quality of care in weaning, a multistage focus group discussion between ICU nurses and physicians underlined the need for interprofessional teams as an arena for discussion, reflection and learning (Hansen & Severinsson, 2009), including ethical issues and how to assess and respond to patients' experience of breathlessness.

7.5. Methodological discussion

7.5.1. Multimethod: critical reflections

While qualitative approaches explore subjective and intersubjective meaning in human life, quantitative approaches are most common in natural science, where the aim is to produce measurable results. The different epistemological and ontological assumptions and paradigms associated with qualitative and quantitative research have raised discussions on whether integration of the two is feasible (Östlund, Kidd, Wengstrom, & Rowa-Dewar, 2011; Riis, 2000). The purist view suggests that quantitative and qualitative approaches cannot be merged, due to a threat to the advancement of science (Östlund et al., 2011). However, multimethod research can be viewed as an approach which draws upon the strengths and perspectives of each method, recognising the existence and importance of the physical, natural world as well as the importance of reality and influence of human experience (Johnson & Onwuegbuzie, 2004). "The research design builds in moments when the two methods speak to one another, traversing but not breaking down epistemological perspectives that hold qualitative and quantitative methodologies apart from one another" (Hesse-Biber, 2015, p. xxxvi). Hermeneutics as a fundamental view represents a possibility to unify the quantitative and qualitative approach (Riis, 2000). Below I will address how hermeneutic considerations and interpretation can be applied in order to discuss the possibility to measure breathlessness.

Nurse and philosopher Ingunn Elstad claims that the distinction between qualitative and quantitative methods is used as a primary distinction between the main approaches in the sciences (Elstad, 2014, p. 240). Elstad demonstrates that it is not a straightforward matter to use a scale for measuring qualitative experiences (Elstad, 2014, p. 242).

"Do you have a sensation of breathlessness?"

No, not at all *Yes, worst imaginable*

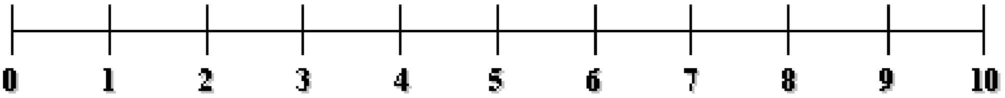


Figure 7 NRS scale

Although an ordinal scale from 0-10 (NRS) (See Figure 7 above) was used, as in this study, the phenomenon of breathlessness does not have a separate unit of measurement. The spaces between the numbers are difficult to measure; it is not obvious that a patient who gives a score of 10 is twice as short of breath as a patient giving 5. In other words, the rating provides a systematic indication of how the person ranks the personal experience, but the personal experience itself cannot be measured (Elstad, 2014). Objectivity in natural science thus has a hermeneutic element where the patient's self-reported values are influenced by his/her preconceptions, just as the interpretations of the NRS scores may be influenced by the nurse's preconceptions. What further complicates the interpretations of NRS scores is that experiences such as critical illness may cause a response shift (Hofhuis et al., 2009; Sprangers & Schwartz, 1999). It is therefore important to be aware that an ordinal scale is a human construction, but it can still help us to systematize knowledge and make communication more efficient (Johansson & Lynøe, 2008, p. 447).

7.5.2. Mixed method study

The strength of Study IV was that it examined breathing as a phenomenon from the patient perspective, both through self-reporting by hospitalized patients of the degree of breathlessness and later in-depth interviews after hospital discharge where they communicated their breathing experiences. Using narratives to add meaning to numbers produced more complete knowledge (Johnson & Onwuegbuzie, 2004), in order to expand one's understanding of the phenomenon of breathing, and to inform practice. By sampling directly from the quantitative study (Study III), both studies (III & IV) are directly linked. The qualitative sample is therefore reflective of the wider population in order to more readily generalize from in-depth research findings (Hesse-Biber, Rodriguez, & Frost, 2015).

A potential limitation is the variation in the length of time between hospitalization and interview, where a long interval might affect the patient's memory of the ICU experiences. However, the patient narratives were rich and detailed, seemingly independent of the time passed since the ICU stay, possibly because such existential experiences are bodily grounded, and can therefore be recalled and narrated in spite of a long timespan (Storli et al., 2008).

7.5.3. Single-centre studies versus multicentre studies

Study I was conducted at the majority of Norwegian ICUs, and there were few missing data. A potential weakness in Study I involved the difficulty of obtaining a general overview of the number of ICUs. The Directorate of Health had no precise list (2009). I rang all Norwegian hospitals, and concluded that there were 60 ICUs. But because of internal changes and mergers, some ICUs had been closed down. The number was therefore validated against the Norwegian Intensive Care Register, which covers the vast majority of hospitals/ICUs that meet its criteria. In the Register's annual report (Kvåle, 2015), 47 ICUs are mentioned, of which 41 provided data for 2014. In Study I, there was no evidence of systematic dropouts, and respondents represented both local hospitals, 16/27 (59%), and university hospitals, 5/11 (46%). The response rate of 63% and 73% for nursing and physician leaders respectively was therefore considered acceptable.

Study II was conducted in one ICU. This is considered sufficient because a qualitative study using both in-depth interviews and field observations gave context-specific rich descriptions in order to gain access to the phenomena and reflect on the meaning (Van Manen, 2014, p. 318) of competence in concrete weaning situations.

Study III was conducted at three Norwegian ICUs, from which the patients in Study IV were also recruited. To conduct studies at several hospitals is usually an advantage as more patients are included; this was crucial in Study III in order to perform relevant analysis. The three ICUs in Study III also represented different patient populations and three different cultures, which enhanced the generalization of the findings. We found it beneficial to take a convenience sample of the local hospital and the two university hospitals in Study III. Two of the hospitals were at a reachable distance, allowing me to follow up the nurses and physicians in the data collection for two years. The third hospital was suitable because the study nurse was an ICN clinician and researcher, dedicated to obtaining reliable and valid data.

Practice could vary somewhat between the units in Study III, due to different SBT methods (T-piece, CPAP, pressure support ventilation). However, all units followed a similar set of criteria as described by Boles et al. (2007), and a variation in practice was not expected to jeopardize the actual primary end-point of the study, namely inter-rater agreement.

7.5.4. Observational studies

Observational studies (quantitative method) describe relationships between variables and outcome in a defined population at a single point of time. Cross-sectional studies are simple to implement and provide data from many respondents at a relatively low cost. Despite the obvious advantage of resource efficiency and the ability to study many variables in a cross-sectional study, the lack of causation represents a limitation (Veierød, Lydersen, & Laake, 2012). Study I is as far as I know the first Norwegian survey including both nurses and physicians to describe the roles and responsibilities of ICU nurses in MV treatment. A potential weakness of the study is that the respondents were leaders, not clinicians who worked with the problems of weaning on a daily basis. Another potential weakness was that the questionnaire did not discriminate between differences in levels of competencies and experiences across nurses. This may have made it difficult to give valid answers. However, the questionnaire also allowed for open comments. The narrative data offered a deeper understanding of important conditions for professional collaboration.

7.5.5. Combining in-depth interviews and field observations

Study II was based on data from only three ICU nurses (six in-depth interviews) and three field observations. In qualitative research, this can still provide rich data (Van Manen, 2014, pp. 352-353). The sample consisted of experienced ICU nurses, considered by the head nurse and colleagues to be highly competent. The strength of the study was that the informants’ own descriptions of what characterizes expertise were supplemented with field observations of their actions and interactions with the patient (Dahlberg et al., 2008). Since I myself am an intensive care nurse, I was able to notice situations during weaning that I considered could represent competent action. By pursuing these observations in the subsequent interview, the informants were given the opportunity to articulate and deepen knowledge that they usually take for granted. I therefore believe that the study provides rich contextual data on which there has been little research, and which is of great importance to enhance our understanding of what is required in nurse-patient interaction during weaning. The validity was strengthened through the use of both field observations and interviews.

7.5.6. Additional strengths and limitations

A potential strength in this study was overcoming the power imbalance between health care provider's and patients' perceptions of health care by taking into account the patients' perspectives (Foss & Ellefsen, 2002). Using patients' self-reported scores of breathlessness (Paper III) and qualitative in-depth interviews (Paper IV) without fixed answers, the patients' voice had priority. A potential limitation of Study III was that we did not ask patients to differentiate between experiences of "air hunger" and "perceived increased work of breathing".

Another limitation could be that the overall research question is complex. On the other hand, ICU care is interdisciplinary and complex, and will benefit from complementing one method with another (Johnson & Onwuegbuzie, 2004). Secondly, it can be difficult to carry out both qualitative and quantitative research for one researcher (Johnson & Onwuegbuzie, 2004). However, I was part of a research team and supervised by ICU nurses and a physician with competence in qualitative and quantitative research, respectively.

7.6. Ethical discussion

Intensive care is a field of research that concerns critically ill patients and it is important to conduct acute medical research. Critically ill patients with a high risk of deterioration and death have the same need as other patients for new and better forms of treatment (Jones & Lyons, 2003) (Guidelines, Research Ethics Committees, 2005). An important principle in all research is that people’s integrity should not be violated. Kvale (1997) emphasizes three important ethical rules for research involving human beings, namely informed consent, confidentiality and consequences.

In Study II, I performed field studies of ICU nurses’ actions and dialogues with patients in specific weaning situations. In this way, the patients were included in the observations. I was therefore careful to treat all information confidentially, and no patient data was recorded. A potential drawback for the patient was the presence of an observer. But since I am an intensive care nurse and familiar with the routines and culture, I felt that I became part of the setting by assisting with simple minor tasks. I did not notice any change in patient care as a result of the activities related to the study. The nurses who participated gave written consent for the field observation and interviews before and after the observation.

Recording patient experiences of breathlessness (Study III) was not associated with risk, but the patients’ own recording of data could be perceived as a burden. A valid registration of data needed to be performed while the patient was connected to a ventilator, and patients were scored if they gave verbal consent. Although detailed guidelines had been drawn up in advance to assess whether a patient was ready to be scored and how the scoring should take place, there was uncertainty among some of the staff as to whether the patient had actually understood the questions and whether the answers they gave were valid. I therefore regularly came to the ICUs to enable us to discuss any problems that arose.

A minority of the patients had difficulty providing scores because they were severely weakened physically. We solved this by spending more time with those patients, and in some cases the patient could indicate a score by holding up the appropriate number of fingers or by the nurse pointing at the NRS form as instructed by the patient. Some of the nurses found it difficult to see patients getting tired because of the scoring. Feedback was continuously discussed with supervisors, and with regard to this problem, we argued that not allowing certain patients to express their degree of breathlessness was potentially a greater ethical dilemma.

Since MV patients may have reduced capacity to consent, patients were not finally included in the study until they gave retrospective consent. To ensure that patients had understood the information, they were therefore approached in the ward, where they were given verbal and written information and the opportunity to withdraw from the study or sign the consent form. Oral consent was considered by the Regional Ethics Committee as sufficient in cases where patients died in connection with the intensive care without having given written consent. ICUs have a high mortality rate, and to reduce bias I considered it important that these patients were also included in the study.

Patients in Study III were informed about the follow-up interview and consented that they could be contacted for this. Recruitment to Study IV was on the basis of the preliminary analysis in Study III. I myself sent out letters requesting participation because I already knew the identity of the patients and had no treatment-related role. The patients who consented sent back the consent form, after which I contacted them by telephone to arrange a time and place for the interview. Research shows that patients may have physical and emotional problems for months after an ICU stay (Vincent et al., 2016). I was therefore aware that the interviews could arouse stressful memories (Jones & Lyons, 2003), and therefore made an effort to demonstrate an open and supportive attitude. In prior consultation with my supervisors, I had outlined procedures for how to react if there were participants who had a particular need for follow-up care after the interview.

In one of the interviews, the informant had had a very negative experience of not being taken seriously by the nurse in connection with MV treatment. Following the interview, I discussed this issue with my supervisor. In consultation with the supervisor and the leaders of the ICU in question, it was decided that I should ring the informant to ask if he needed to talk to the leaders of the ICU, but he declined because he felt no need for it.

8. Conclusions and future perspectives

8.1. Conclusions

The findings in this thesis demonstrate that breathlessness is prevalent among mechanically ventilated patients, and underestimated by nurses and physicians. MV patients' experiences of breathing were not necessarily a separate experience, but intertwined with the whole illness experience and existential dimensions of life. The nurses' roles in MV and weaning are their continuous presence and vigilance detection of early changes in the patients' condition. To acknowledge the presence and impact of breathlessness seems important. Knowing the patient and facilitating well-being was a crucial part of competence in weaning and opened up for establishing trust and confidence, which were necessary to reach into the patients' world and "pull" the patient back to life, to the "here and now". This "pulling" was connected to "pushing" the patient further in the weaning process. To enhance the quality of care in MV and weaning, intensive care nurses have an important role in the interprofessional team in order to discuss, reflect and learn how to assess and respond to patients' experiences of breathing.

8.2. Clinical implications

Paper III demonstrates that nurses' and physicians' assessments do not appropriately reflect the patients' experience. We also know that intensive care is evolving toward more awake patients, and will further challenge interaction and communication with patients experiencing breathlessness. Therefore, I suggest that nurses should routinely assess and document dyspnea on each nursing shift.

Secondly, organizational factors as continuity of care and the nurse-patient ratio must be facilitated to make it possible for the intensive care nurse to be present by the patient and be able to recognize and respond to his/her needs.

Thirdly, Tanners' clinical judgement model could be used by intensive care nurses in order to reflect on and promote clinical skills in MV and weaning.

Fourthly, a potential link between breathlessness, PTSD and post-intensive care syndrome is an argument for patients' own reports of breathing to form part of nursing interventions and follow-up to support patients' quest for meaning.

Fifthly, the bundle approach in MV combines a set of evidence-based practices shown to be effective for improving patient outcomes. Based on the relationship between self-report of breathlessness and predicting weaning success and the results from Paper III demonstrating the high prevalence and underestimation of breathlessness, I suggest that the bundle approach also should include breathlessness NRS scores.

Sixthly, the intensive care nurse has an important role in the interprofessional team in identification and adoption of strategies to promote timely and successful weaning, as well as involvement in research and professional development.

8.3. Research implications

Breathlessness is one of the most prevalent and distressing symptoms experienced by intensive care patients. However, there is a lack of prospective studies of breathing discomfort and the significance of competencies in nursing to minimize suffering and subsequent stress disorder. Therefore, I will underline the importance of further prospective studies of mechanically ventilated patients:

Firstly, to promote the ICU patient's *getting through* the illness experience and to support the will to keep on living, future research should explore which factors promote or inhibit the MV patient's existential will to keep on living.

Secondly, research should explore the significance of routinely assessing and documenting breathlessness on each nursing shift.

Thirdly, it should be explored whether self-report of breathlessness can predict weaning outcome.

Fourthly, it seems important to validate dyspnea measures as patient-reported outcomes for use as endpoints in e.g. clinical trials.

Fifthly, associations between patient-ventilator asynchrony and patients' experiences of breathlessness should be explored.

Sixthly, loss of control is a strong predictor to PTSD. Therefore, I suggest exploring whether self-efficacy, including patients' self-report of breathlessness, is associated with PTSD.

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Appendices

Appendix 1
Search strategy

Appendix 2
Algorithm for the withdrawal from mechanical ventilation

Appendix 3
Clinical Judgement Model

Appendix 4
Questionnaire (Paper I)

Appendix 5
Information to participants, interview- and observational guide (Paper II)

Appendix 6
Information to participants, ICNs and physicians (Paper III)

Appendix 7
Information to patients (Paper III-IV)

Appendix 8
Interview guide (Paper IV)

Appendix 9
REK/NSD (Paper I, III, IV/Paper II)

Appendix 10
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Appendix 1 Search strategy

Table 1 Search strategy in PubMed to identify articles relevant to the thesis: Mechanical ventilation and weaning: roles and competencies of intensive care nurses and patients' experiences of breathing. A final search was performed on 23.05.2016

Concepts	MeSH terms	Other terms	Hits
Mechanical ventilation and weaning			
1	Ventilators, Mechanical		8439
2	Respiration, Artificial		64458
3	Ventilator weaning		3184
4		Mechanical ventilation	84209
5 (1 OR 2 OR 3 OR 4)			88680
intensive care nurses			
6	Nurses		75918
7	Critical care nursing		627
8		Intensive care nursing	34448
9		Intensive care nurse	27206
10		Intensive care nurses	16291
11 (6 OR 7 OR 8 OR 9 OR 10)			112723
roles and competencies			
12	Professional competence		93564
13	Clinical competence		72615
14		Competence	137389
15		competencies	10194
16	Nurse's role		35609
17	Role		95604
18 (12 OR 13 OR 14 OR 15 OR 16 OR 17)			227703
patients' experiences of			
19	Patients		50633
20		"intensive care patients"	2758
21		"critical care patients"	782
22		"patient experience"	2649
23		"patients experiences"	2192
24		experiences	141756
25 (19 OR 20 OR 21 OR22 OR 23 OR 24)			196256
breathing			
26	Dyspnea		17203

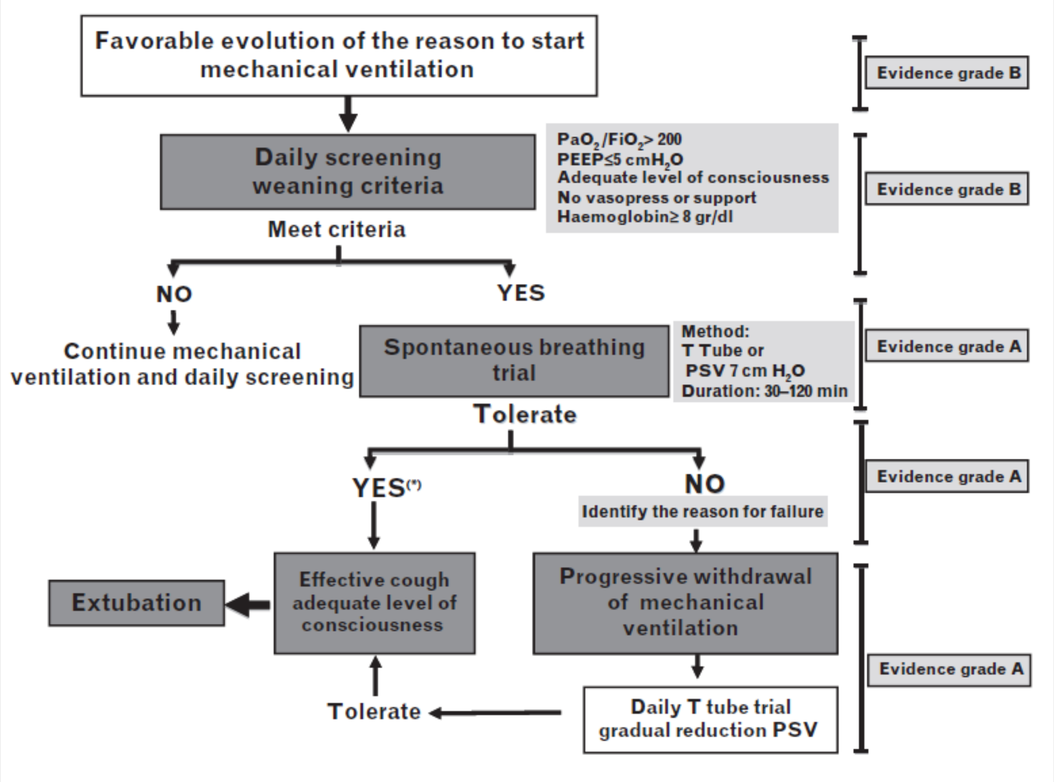
27	Respiration		106214
28		breathing	244714
29		breathlessness	41115
30 (26 OR 27 OR 28 OR 29)			281223

Table 2 Overview of articles identified in PubMed concerning Mechanical ventilation and weaning: roles and competencies of intensive care nurses and patients' experiences of breathing. A final search was performed on 23.05.2016

		All years			Last 5 years		
Two main groups	Concept and (hits)	Total articles	Systematic reviews	Qualitative studies	Total articles	Systematic reviews	Qualitative studies
The roles and competencies of intensive care nurses	# 5 Mechanical ventilation and weaning (88680) AND # 11 Intensive care nurses (112723) AND # 18 Role and competencies (227703)	214	41	19	35	6	7
Patients' experiences of breathing	# 5 Mechanical ventilation and weaning (88680) # 25 Patients' experiences of (196256) # 30 Breathing (281223)	824	37	47	123	11	21

*"Qualitative" was added by "AND" to the two main groups to identify qualitative studies
refers to search history in Table I

Appendix 2 Algorithm for the withdrawal from mechanical ventilation



(*)Criteria for tolerance of spontaneous breathing trial.

Objective parameters	Subjective parameters
• Adequate gas exchange ($SpO_2 \geq 85–90$ %) • Hemodynamic stability (HR<120–140 lpm; SBP<180–200 mmHg) • Dynamic respiratory (RR ≤ 35 rpm)	• Presence of diaphoresis • Consciousness altered (somnolence, coma, agitation, delirium) • Signs of increased work of breathing

Figure 1 Algorithm for the withdrawal from mechanical ventilation. HR, heart rate; PSV, pressure support ventilation; RR, respiratory rate; SBP, systolic blood pressure (Penuelas et al., 2015).

Appendix 3 Clinical Judgement Model

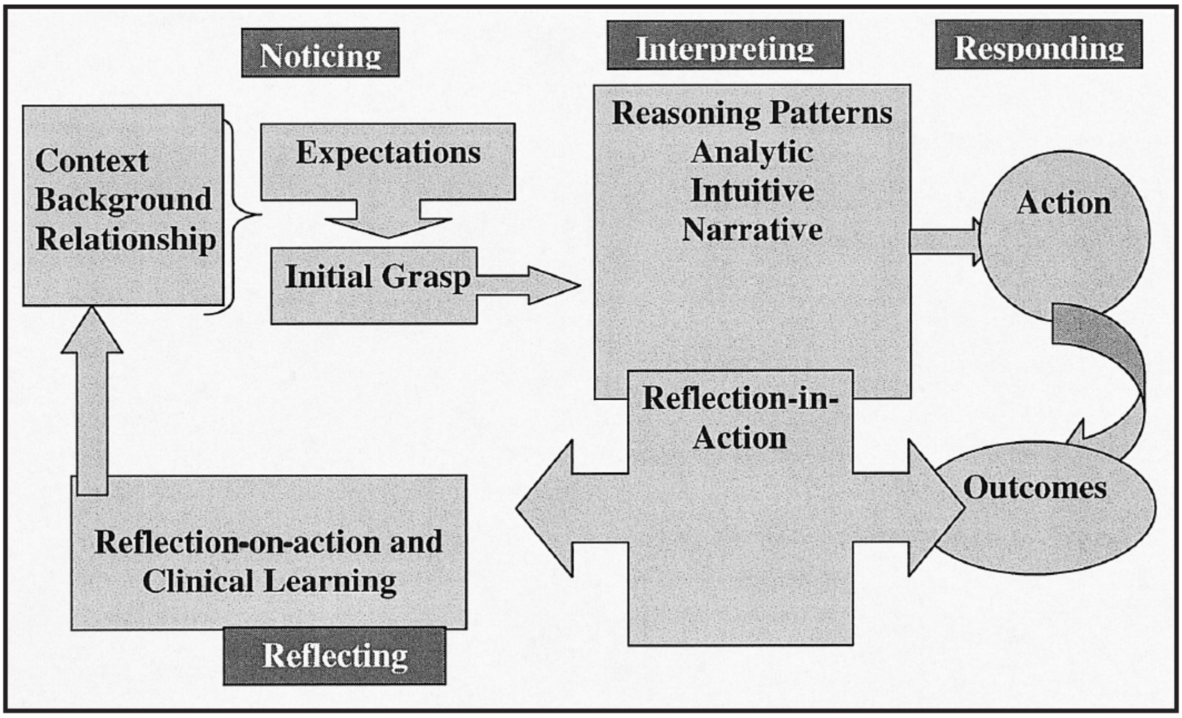
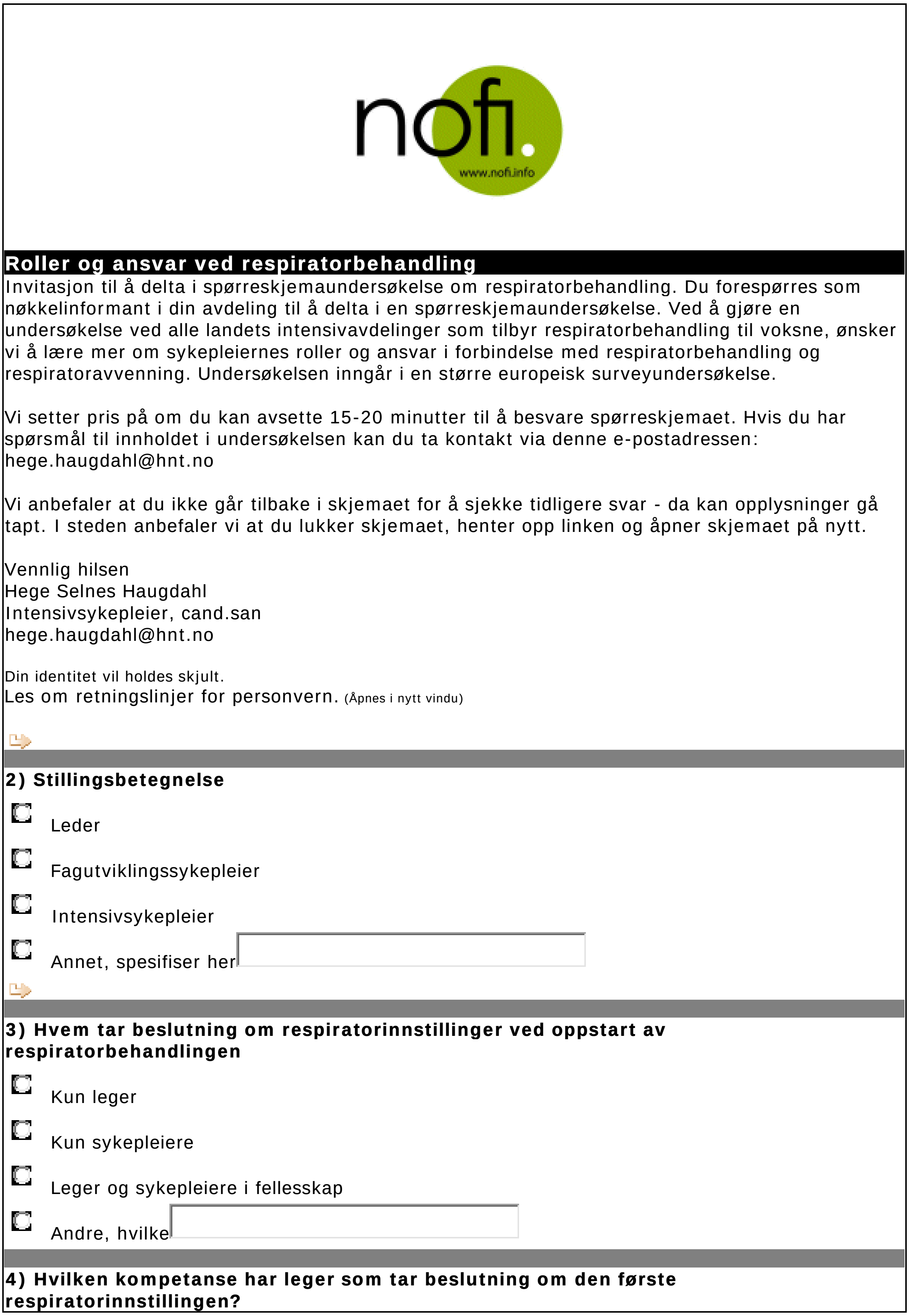


Figure 2 Clinical Judgement Model (Tanner 2006).

Appendix 4 Questionnaire (Paper I)



Roller og ansvar ved respiratorbehandling

Invitasjon til å delta i spørreskjemaundersøkelse om respiratorbehandling. Du forespørres som nøkkelinformant i din avdeling til å delta i en spørreskjemaundersøkelse. Ved å gjøre en undersøkelse ved alle landets intensivavdelinger som tilbyr respiratorbehandling til voksne, ønsker vi å lære mer om sykepleiernes roller og ansvar i forbindelse med respiratorbehandling og respiratoravvenning. Undersøkelsen inngår i en større europeisk surveyundersøkelse.

Vi setter pris på om du kan avsette 15-20 minutter til å besvare spørreskjemaet. Hvis du har spørsmål til innholdet i undersøkelsen kan du ta kontakt via denne e-postadressen: hege.haugdahl@hnt.no

Vi anbefaler at du ikke går tilbake i skjemaet for å sjekke tidligere svar - da kan opplysninger gå tapt. I steden anbefaler vi at du lukker skjemaet, henter opp linken og åpner skjemaet på nytt.

Vennlig hilsen
Hege Selnes Haugdahl
Intensivsykepleier, cand.san
hege.haugdahl@hnt.no

Din identitet vil holdes skjult.
Les om retningslinjer for personvern. (Åpnes i nytt vindu)

➪

2) Stillingsbetegnelse

☐ Leder

☐ Fagutviklingssykepleier

☐ Intensivsykepleier

☐ Annet, spesifiser her ____

➪

3) Hvem tar beslutning om respiratorinnstillinger ved oppstart av respiratorbehandlingen

☐ Kun leger

☐ Kun sykepleiere

☐ Leger og sykepleiere i fellesskap

☐ Andre, hvilke ____

4) Hvilken kompetanse har leger som tar beslutning om den første respiratorinnstillingen?

○ Kun overleger

○ Overleger og spesialister i anestesiologi

○ Overleger, spesialister i anestesiologi og assistentleger/leger i spesialutdanning

○ Andre, hvilke ☐

5) Hvis relevant, hvilken kompetanse har sykepleiere som tar beslutninger om den første respiratorinnstillingen?

○ Kun intensivsykepleiere/master i intensivsykepleie

○ Alle sykepleiere(etter opplæring på intensivavdeling)

○ Andre, hvilke ☐

6) Hvem evaluerer pasientens reaksjon på respiratorbehandlingen og justerer innstillingene etter behov?

○ Kun leger

○ Kun sykepleiere

○ Leger og sykepleiere i fellesskap

○ Andre, hvilke ☐

7) Hvilken kompetanse har leger som tar beslutning om justering av respiratorinnstillinger?

○ Kun overleger

○ Overleger og spesialister i anestesiologi

○ Overleger, spesialister i anestesiologi og assistentleger/leger i spesialutdanning

○ Andre, hvilke ☐

8) Hvis relevant, hvilken kompetanse har sykepleiere som tar beslutninger om justering av respiratorinnstillinger?

○ Kun intensivsykepleiere/master i intensivsykepleie

○ Alle sykepleiere(etter opplæring på intensivavdeling)

○ Andre, hvilke ☐

9) Hvem beslutter når pasienten er klar for å starte avvenning fra respiratorbehandlingen?

○ Kun leger

○ Kun sykepleiere

○ Leger og sykepleiere i fellesskap

○ Andre, hvilke ☐

10) Hvilken kompetanse har leger som har ansvar for å avgjøre om pasienten er klar for å starte respiratoravvenning?

○ Kun overleger

○ Overleger og spesialister i anestesiologi

○ Overleger, spesialister i anestesiologi og assistentleger/leger i spesialutdanning

○ Andre, hvilke ☐

11) Hvis relevant, hvilken kompetanse har sykepleiere som har ansvar for å avgjøre om pasienten er klar for å starte respiratoravvenning?

○ Kun intensivsykepleiere/master i intensivsykepleie

○ Alle sykepleiere(etter opplæring på intensivavdeling)

○ Andre, hvilke ☐

12) Hvem avgjør hvilken metode som brukes ved respiratoravvenning?

○ Kun leger

○ Kun sykepleiere

○ Leger og sykepleiere i fellesskap

○ Andre, hvilke ☐

13) Hvilken kompetanse har leger som avgjør hvilken metode som brukes ved respiratoravvenningen?

○ Kun overleger

○ Overleger og spesialister i anestesiologi

○ Overleger, spesialister i anestesiologi og assistentleger/leger i spesialutdanning

○ Andre, hvilke ☐

14) Hvis relevant, hvilken kompetanse har sykepleiere som har ansvar for å avgjøre avvenningsmetoden?

○ Kun intensivsykepleiere/master i intensivsykepleie

○ Alle sykepleiere(etter opplæring på intensivavdeling)

○ Andre, hvilke ☐

15) Hvem beslutter når pasienten er klar for å bli ekstubert?

○ Kun leger

○ Kun sykepleiere

○ Leger og sykepleiere i fellesskap

○ Andre, hvilke ☐

16) Hvilken kompetanse har leger som har ansvar for å avgjøre når pasienten er klar for å bli ekstubert?

○ Kun overleger

○ Overleger og spesialister i anestesiologi

○ Overleger, spesialister i anestesiologi og assistentleger/leger i spesialutdanning

○ Andre, hvilke ☐

17) Hvis relevant, hvilken kompetanse har sykepleiere som har ansvar for å avgjøre når pasienten er klar for å bli ekstubert?

○ Kun intensivsykepleiere/master i intensivsykepleie

○ Alle sykepleiere(etter opplæring på intensivavdeling)

○ Andre, hvilke ☐

18) Hvem avgjør at et avvenningsforsøk (endring av modus/spontane pusteforsøk) må avbrytes?

○ Kun leger

○ Kun sykepleiere

○ Leger og sykepleiere i fellesskap

○ Andre, hvilke ☐

19) Hvilken kompetanse har leger som avgjør at pasienten ikke kan gjennomføre et avvenningsforsøk?

○ Kun overleger

○ Overleger og spesialister i anestesiologi

○ Overleger, spesialister i anestesiologi og assistentleger/leger i spesialutdanning

○ Andre, hvilke ☐

20) Hvis relevant, hvilken kompetanse har sykepleiere som avgjør at pasienten ikke kan gjennomføre et avvenningsforsøk?

○ Kun intensivsykepleiere/master i intensivsykepleie

○ Alle sykepleiere(etter opplæring på intensivavdeling)

○ Andre, hvilke ☐

21) Hva er sykepleier-pasientratio (-forhold) for respiratorpasienter på din avdeling?

○ 1:1 ratio

○ 1:2 ratio

○ 1:3 ratio

○ Annet, hvilke ______

22) Hva er sykepleier-pasientratio (-forhold) for non-invasive respiratorpasienter på din avdeling?

○ 1:1 ratio

○ 1:2 ratio

○ 1:3 ratio

○ Annet, hvilke ______

23) Hvordan vil du betegne sykepleieres selvstendighet i forhold til respiratorbehandling?

○ 0 Ingen selvstendighet

○ 1

○ 2

○ 3

○ 4

○ 5

○ 6

○ 7

○ 8

○ 9

○ 10 Fullstendig selvstendighet

24) Kommentar (frivillig)

25) Hvor ofte har sykepleiernes bidrag innflytelse på beslutninger om respiratorbehandling?

○ 0 Aldri

○ 1

○ 2

○ 3

○ 4

○ 5

○ 6

○ 7

○ 8

○ 9

○ 10 Alltid

26) Kommentar (frivillig)

27) Hvor ofte tar og gjennomfører sykepleiere selvstendige beslutninger (uten å rådføre seg med en lege):

	Aldri(0%)	Sjelden<>(1-25%)	Ofte (26-50%)	Regelmessig(51-75%)	Rutinemessig(>75%)	Vet ikke
Endring av modus	○	○	○	○	○	○
Justering av respirasjonsfrekvens	○	○	○	○	○	○
Justering av tidal volum	○	○	○	○	○	○
Justering av inspirasjonstrykk	○	○	○	○	○	○
Økning av trykkstøtte	○	○	○	○	○	○
Reduksjon av trykkstøtte	○	○	○	○	○	○
Økning av PEEP	○	○	○	○	○	○
Reduksjon av PEEP	○	○	○	○	○	○
Økning av FiO2	○	○	○	○	○	○

Reduksjon av FiO2	○	○	○	○	○	○

28) Kommentarer (frivillig)

29) I hvor stor grad gjøres vurdering av pasientens evne til å tolerere respiratoravvenningen i fellesskap av leger og sykepleiere?

○ 0 I svært liten grad

○ 1

○ 2

○ 3

○ 4

○ 5

○ 6

○ 7

○ 8

○ 9

○ 10 I svært stor grad

30) Hvor stor betydning mener du det har for en vellykket avvenning at pasientansvarlig sykepleier kjenner pasienten godt?

○ 0 Ingen betydning

○ 1

○ 2

○ 3

○ 4

○ 5

○ 6

○ 7

○ 8

○ 9

○ 10 Svært stor betydning

31) Hvor stor betydning mener du det har for en vellykket avvenning at pasientansvarlig intensivlege kjenner pasienten godt?

○ 0 Ingen betydning
○ 1
○ 2
○ 3
○ 4
○ 5
○ 6
○ 7
○ 8
○ 9
○ 10 Svært stor betydning

32) I hvor stor grad mener du følgende kliniske vurderinger er viktig når man skal vurdere pasientens evne til å tolerere respiratoravvenningen?

	0 I svært liten grad	1	2	3	4	5	6	7	8	9	10 I svært stor grad
Økt ventilasjonsarbeid	○	○	○	○	○	○	○	○	○	○	○
Velvære	○	○	○	○	○	○	○	○	○	○	○
Klinisk forverring	○	○	○	○	○	○	○	○	○	○	○

33) På din intensivavdeling, har dere veileder/instruks/protokoll for respiratorbehandling?

○ Ja
○ Nei
○ Vet ikke

34) På din intensivavdeling, har dere veileder/instruks/protokoll for respiratoravvenning?

○ Ja
○ Nei
○ Vet ikke

Denne informasjonen vises kun i forhåndsvisningen

Følgende kriterier må være oppfylt for at spørsmålet skal vises for respondenten:

- (
    - Hvis På din intensivavdeling, har dere veileder/instruks/protokoll for respiratoravvenning? *er lik* Ja
-)

35) Hvis ja, inneholder den informasjon om hvordan man skal håndtere pasienter som ikke kan gjennomføre et avvenningsforsøk (endring av modus/spontane pusteforsøk)?

○ Ja

○ Nei

○ Vet ikke

36) På din intensivavdeling, har dere veileder/instruks/protokoll for non-invasiv respiratorbehandling?

○ Ja

○ Nei

○ Vet ikke

37) Anvendes noen av de følgende automatiske avvenningsmodi på din intensivavdeling?

	Aldri(0%)	Sjelden<>(1-25%)	Ofte(26-50%)	Regelmessig(51-75%)	Rutinemessig(>75%)	Vet ikke
SmartCare/PS	○	○	○	○	○	○
Adaptive support ventilation (ASV)	○	○	○	○	○	○
Mandatory minute ventilation (MMV)	○	○	○	○	○	○
Proportional assist ventilation (PAV)	○	○	○	○	○	○

38) Blir sykepleiere opplært i respiratorbehandling ved ansettelse i intensivavdelingen

○ Ja

○ Nei

○ Vet ikke

39) Eventuelt kommentar (frivillig)

40) Blir leger opplært i respiratorbehandling ved ansettelse i intensivavdelingen

○ Ja

○ Nei

○ Vet ikke

41) Eventuelt kommentar (frivillig)

42) Er det mulighet for løpende/jevnlig faglig utvikling i forbindelse med respiratorbehandling ved din avdeling?

○ Ja

○ Nei

○ Vet ikke

43) Hvis ja, beskriv (frivillig)

44) Sykehustype

○ Universitetssykehus

○ Lokalsykehus/sentralsykehus

○ Annet

45) Primær spesialitet ved din intensivavdeling

○ Kirurgisk(kun)

○ Medisinsk(kun)

○ Thoraxkirurgisk(kun)

○ Nevrointensiv(kun)

○ Traume/nevro

○ Brannsår(kun)

○ Blandet medisinsk/kirurgisk

○ Blandet medisinsk/kirurgisk/traume

46) Type intensivavdeling

○ Intensivavdelingen er definert som teknisk seng (Leger fra pasientens hovedavdeling har hovedansvar for pasientbehandlingen)

○ Intensivavdelingen er definert som moderavdeling (Anestesi-/intensivlege har hovedansvar for pasientbehandlingen)

47) Antall intensivavdelinger på sykehuset

Velg alternativ

48) Antall intensivsenger på sykehuset

Velg alternativ

49) Antall senger på hele sykehuset (ikke hele foretaket)

○ <100

○ 100-400

○ 401-750

○ >750

50) Antall respiratordøgn/år (ved din enhet):

51) Antall NIV-døgn/år (ved din enhet):

Nedenfor ønsker vi opplysninger om stillinger ved intensivenheten.

52) Antall sykepleiere totalt (inkludert spesialsykepleiere)

Velg alternativ

53) Antall sykepleiere (totalt, inkludert spesialsykepleiere)-omregnet til helstillinger

Velg alternativ

54) Antall hjelpepleiere

Velg alternativ

55) Antall hjelpepleiere-omregnet til helstillinger

Velg alternativ

56) Antall intensivsykepleiere

Velg alternativ

57) Antall intensivsykepleiere-omregnet til helstillinger

Velg alternativ

58) Antall kliniske spesialister i intensivsykepleie

Velg alternativ

59) Antall kliniske spesialister i intensivsykepleie-omregnet til helstillinger

Velg alternativ

60) Antall sykepleiere med master i intensivsykepleie

Velg alternativ

61) Antall sykepleiere med master i intensivsykepleie -omregnet til helstillinger

Velg alternativ

62) Antall fagutviklings- / forskningssykepleiere

Velg alternativ

63) Antall fagutviklings- / forskningssykepleiere-omregnet til helstillinger

Velg alternativ

Nedenfor ønsker vi opplysninger om stillinger tilknyttet intensivenheten.

64) Antall overleger

Velg alternativ

65) Antall overleger-omregnet til helstillinger

Velg alternativ

66) Antall spesialister i anestesiologi

Velg alternativ

67) Antall spesialister i anestesiologi-omregnet til helstillinger

Velg alternativ

68) Antall leger i utdanning / assistentleger

Velg alternativ

69) Antall leger i utdanning / assistentleger-omregnet til helstillinger

Velg alternativ

Appendix 5 Information to participants, interviewguide and observational guide (Paper II)

Til
Klinikkleder
Sykehuset ………………….

Søknad om tillatelse til å samle inn data

Jeg ber om tillatelse til å gjøre en kvalitativ studie på intensivavdelinga for å beskrive og analysere intensivsykepleiernes kompetanse ved respiratoravvenning. Det er gjort mye forskning omkring respiratoravvenning. Det kan synes som om kvaliteten på intensivsykepleiernes arbeid er en kritisk og målbar faktor. Imidlertid er det lite arbeid som er gjort for å beskrive hva som ligger i en slik type kompetanse.

Valg av metode for datainnsamling er feltobservasjon og intervju, hvor jeg skal følge tre sykepleiere i deres arbeid en dag hver. I forkant og etterkant av dette, vil jeg gjøre intervju med de respektive informanter. I henhold til forskningsetiske regler, vil sykepleierne forsikres om at de ikke skal kunne kjennes igjen framstillinga. Intervjuene tas opp med lydopptaker, men kobles ikke opp til navn, og slettes umiddelbart etter transkribering. Sykepleierne vil få forespørsel og informasjon om prosjektet i et eget brev. De velger sjøl om de vil delta og gjøres oppmerksom på at de kan trekke seg fra undersøkelsen underveis om de ønsker det. I forespørselen vedlegges en samtykkeerklæring som de undertegner dersom de ønsker å delta.

Prosjektet er anbefalt av Norsk samfunnsvitenskapelig datatjeneste. Under forutsetning av at jeg får anbefaling fra Regional Etisk Komité, som har saken inne til behandling nå, ser jeg for meg at intervjuene kan starte i månedskiftet september/oktober.

Med hilsen
Hege S. Haugdahl
Kopi sendes til;
avdelingssykepleier ved Intensiv avdeling
leder ved FoU

Til

Forespørsel om deltakelse i forskningsprosjekt

Målet mitt er å komme nærmere en forståelse av intensivsykepleieres kompetanse ved respiratoravvenning. Det er gjort mye forskning omkring respiratoravvenning. Det kan synes som om kvaliteten på intensivsykepleiernes arbeid er en kritisk og målbar faktor. Imidlertid er det lite arbeid som er gjort for å beskrive hva som ligger i en slik type kompetanse.

For å komme nærmere en slik forståelse, skal jeg gjøre følgende:

- Innledende runde i form av intervju av tre intensivsykepleiere (ca 1/2 time). Intervjuene tas opp på lydopptaker og skrives ut.
- Deltagende observasjon hvor tre intensivsykepleiere observeres en dag hver. Observasjonsnotatene nedtegnes i eget notat.
- Oppfølgingssamtale (ca 1 time) ved bruk av intervju. Samtalene tas opp på lydopptaker og skrives ut.

Innledningsvis ønsker jeg en samtale for å få din erfaring med respiratoravvenning. Det vil være av en halvtimes varighet, hvor jeg er interessert i at du forteller om situasjoner med respiratorpasienter i avvenningsfasen, som har gjort inntrykk på deg. Dernest ønsker jeg å være i praksis sammen med deg en dag når du arbeider med en pasient i avvenningsfasen. Jeg vil gå inn som deltagende observatør, og framstå mer som en assistent enn som forsker den aktuelle vakta hvor observasjonen vil pågå, dersom det er greit for deg. Underveis vil jeg skrive ned momenter i form av stikkord som jeg anser som viktig å få belyst i et senere intervju.

Observasjonen i praksis vil etterfølges av et intervju. I praktisk sykepleiearbeid, vet jeg av erfaring at vi ofte vet mer enn vi setter ord på. Hensikten er å forsøke å få fram beskrivelser av hva som ble gjort, og hva du tenkte. Alle data vil bli behandla konfidensielt og de vil bli anonymisert ved prosjektslut. Prosjektet er godkjent av Personvernombudet for forskning, Norsk samfunnsvitenskapelig datatjeneste AS. Regional komité for medisinsk forskningsetikk har ingen innvendinger til at prosjektet gjennomføres.
Det er frivillig å delta, og du kan trekke deg underveis uten at du behøver å begrunne det. I så fall vil alle innsamlede data bli anonymisert eller sletta.
Med hilsen

Samtykkeerklæring

Jeg samtykker i at de opplysningene jeg gir kan brukes i forskning.

Jeg er kjent med at opplysningene ikke kobles til mitt navn, og at intervjuet blir sletta etter bruk. Jeg er forsikra om at jeg ikke skal kunne kjennes igjen i framstillinga.

Jeg er videre kjent med at jeg deltar på frivillig basis, og kan trekke meg underveis, om jeg ønsker det.

På bakgrunn av dette, erklærer jeg meg villig til å delta i undersøkelsen.

INTERVJUGUIDE 1

Etter å ha jobba med respiratorpasienter i mange år, har du sikkert gjort deg noen erfaringer med respiratoravvenning som har gjort inntrykk på deg. Kan du fortelle fra en situasjon du husker godt?

Jeg vil presisere at det skal være en konkret hendelse hvor hun sjøl har vært aktør.

Avhengig av hva som kommer til uttrykk, vil jeg følge opp med kommentarer eller spørsmål som har som hensikt å få fram gode beskrivelser. Det kan være:

- Hva så, kjente, følte du?
- Hva tenkte du?
- Hva gjorde du?
- Var det noe som endra seg forut for, underveis, etterpå?
- Hva tenker du om dette i etterkant?
- Samarbeid med pasienten – på hvilken måte har dette betydning?
- Hvordan ser du at pasienten tolererer avvenninga/ikke tolererer avvenninga?
- Hva er viktig i forhold til samarbeidet med legene?

MOMENTER VED FELTOBSERVASJON

- Status via rapport: søvn, innstillinger på respiratoren, blodgasser, sedering, våkenhet, spesielle problemstillinger
- Visuell (også lyd) observasjon av pasienten: leie i senga, våkenhet, kommunikasjon, respirasjonsfrekvens, pustemønster, respiratorinnstillinger/-justeringer
- Samhandling mellom sykepleier og pasient: stell, prosedyrer som for eksempel suging, tracheostomistell, kroppslige uttrykk, pasientens respons på og sykepleierens evaluering av endringer av respiratorinnstillinger
- Visitt: problemstillinger vedrørende nedtrappingsplan, respiratorinnstillinger, ekstubasjon, innspill og vurderinger fra sykepleier, kommunikasjon

INTERVJUGUIDE 2

Utgangspunktet for det vi skal snakke om, er den konkrete samhandlinga. Det er situasjonene som må få ”tale”. Men for å få vite noe mer, kan det være aktuelt å komme inn på noen av de følgende spørsmål:

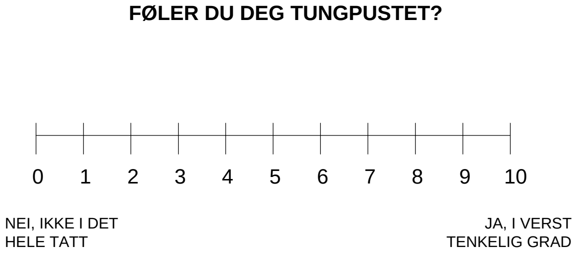
- Kan du si noe om hva du la vekt på i dag
- Kan du si noe om hvilken plan du hadde
- Hvordan vil du beskrive pasientens tilpasning til respiratoren/pasientens opplevelse?
- Hvordan går du fram for å forstå det som pasienten gir uttrykk for (se, føle, vurdere)?
- Hvilke forhold mener du er utfordrende eller vanskelig i samhandling med pasienten?
- Hvordan vil du beskrive pasientens mulighet til å ta over mer av pustearbeidet sjøl, hvordan vet du det?
- Når vi sier at det er ”tungt”, hvordan ser/vet du det, og hva er best å gjøre i slike situasjoner
- Skjedde det noe som overraska deg på noen måte, eller som gjorde at du endra opplegget/var det noe i selve situasjonen som krevde at du måtte handle/tenke annerledes?
- Hvordan vurderer du det å finne en balanse mellom aktivitet og hvile?

Appendix 6 Information to intensive care nurses and physicians (Paper III)

INFORMASJON OM FORSKNINGSSTUDIEN

Intensivpasienter som avvennes fra respirator -opplevelse og vurdering av tungpustethet

Respiratoravvenning er en av hovedutfordringene i intensivbehandling og vanskelig avvenning omfatter ca 25 % av pasientene. Nyere forskning viser at symptomvurderinger bør bli mer systematisk og differensiert. Det som imidlertid kompliserer symptomvurdering av respiratorpasienter, er pasientens reduserte evne til å kommunisere på grunn av at han/hun er intubert. Selv om det finnes enkle, men validerte instrumenter for å måle tungpustethet, er det lite kunnskap om hvordan respiratorpasientens opplevelse korrelerer med helsepersonells vurderinger.
Målet med denne studien er å undersøke grad av samsvar i vurdering av tungpustethet, trygghet og framgang ut fra egenvurdering fra pasient i avvenningsforsøk, og sykepleiers og leges vurderinger i samme tidsrom. Studien vil også undersøke samsvar mellom pasientens opplevelse av tungpustethet og demografiske forhold, kliniske observasjoner og målte parameter relatert til respirasjon.

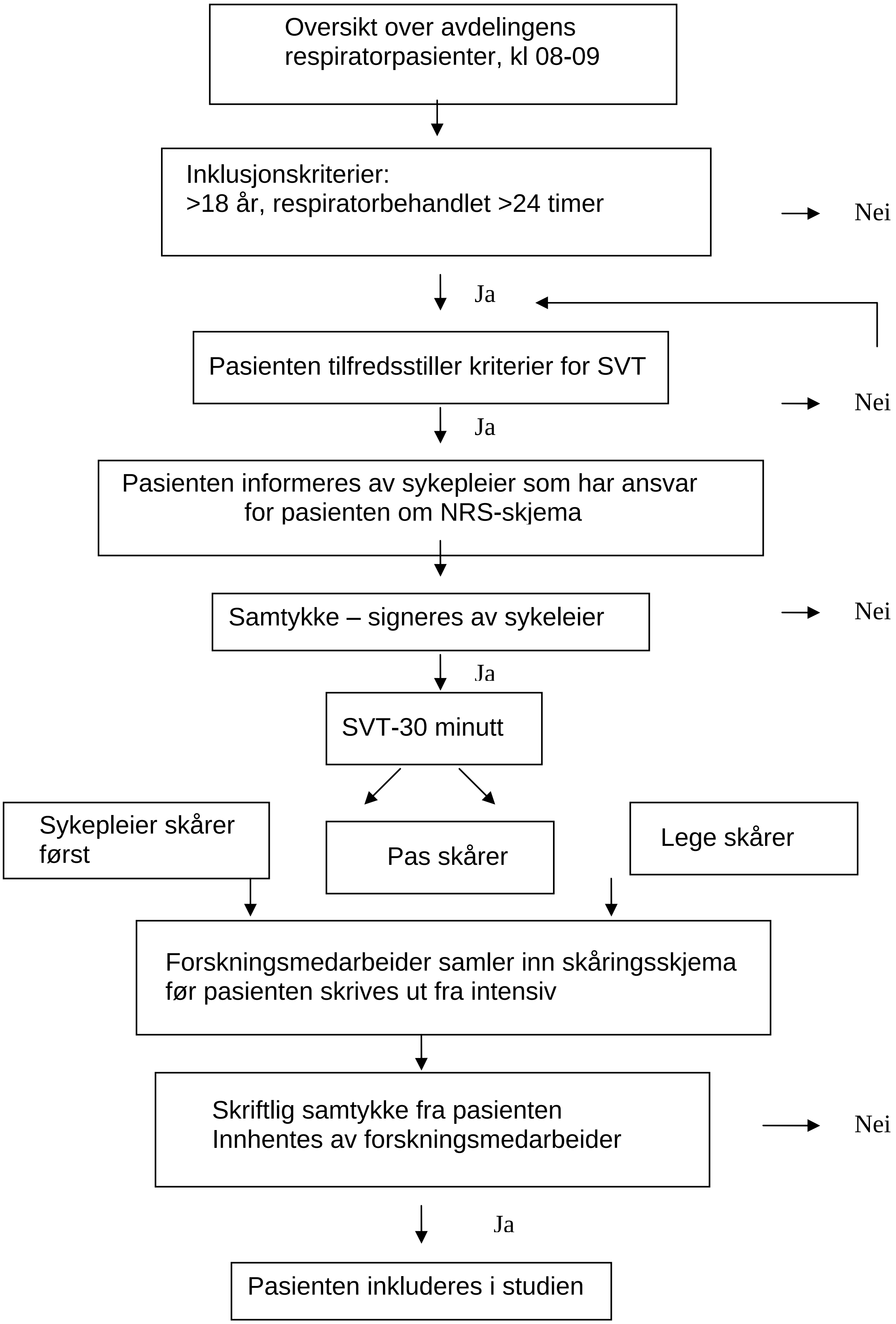


Instrument: The Numeric Rating Scale (NRS) er en validert 11-punkts VAS-skala som angir grad av tungpustethet (0 = ingen åndenød/tungpustethet og 10 = verst tenkelig åndenød/tungpustethet).

Metoder og registreringsskjemaer

Hver observasjon består av tre vurderinger: av pasientens grad av tungpustethet, trygghet og framgangsfølelse, utført av pasienten selv (se skjema nr 1 a-c, plastlaminert skala fra 0-10), lege og sykepleier (se skjema nr 2).

Flytskjema--respiratoravvenningsstudie



Forsøkspopulasjon og inklusjonskriterier

Utvalg: Pasienter rekrutteres fra intensivavdelingen ved St. Olavs hospital, sykehuset Levanger og nordlandssykehuset Bodø. Hver pasient skal observeres inntil seks ganger. Inklusjonskriterier: intensivpasienter som respiratorbehandles via endotrakealtube/trakeostomi, som er definert som klar for avvenning, forstår norsk, våken (MAAS-nivå 3-4) og i stand til å forstå og respondere på det som blir sagt. Eksklusjonskriterier: < 18 år, kjent eller mistenkt alvorlig myopati/nevropati (f.eks Guillain Barrè), alvorlig hodeskade

Framgangsmåte

1. Pasienten skal være definert som klar for avvenning (se skjema nr 3), og det er besluttet at det skal gjennomføres spontan ventilasjonstest (SVT).
2. Pasientansvarlig sykepleier vurderer om pasienten er aktuell for studien ut fra inklusjonskriteriene. De dagene pasienten registreres skal det tas trombocytter, bilirubin og kreatinin (prøver tas en gang per dag).
3. Før evt skåring skal pasientansvarlig sykepleier vurdere om pasienten er våken og i stand til å forstå informasjonen (se skjema nr 4).
4. Pasienten blir forevist skåringsskjema (om tungpustethet, trygghet og framgangsfølelse) (skjema nr 1, plastlaminert skala fra 0-10) og informeres om studien **før** SVT. Dersom pasienten samtykker – signerer sykepleier på skjema nr 4.
5. **Skåringen gjennomføres 30 minutter etter oppstart av SVT**. SVT forordnes av lege ut fra definerte kriterier (se skjema nr 3), og gjennomføres vanligvis mellom 30-120 min, avhengig av pasientens tilstand med respirator med innstilt trykk i trykkstøttet modus med PEEP 6-8 og PS 6-8 cm H_2O, eller med ekstern CPAP/kunstig nese/t-stykke i henhold til avdelingens rutiner.
6. For å unngå å påvirkes av pasientens skåringer, gjennomfører lege og sykepleier sine uavhengige skåringer, på egne skjema, umiddelbart før pasienten (se skjema nr 2). Helsepersonell skårer ved å sette ring rundt valgte tall. Pasientene skårer ved enten å peke på skalaen, holde opp antall fingre, eller nikke når sykepleieren peker på tallene (se skjema nr 1.
7. Pasientansvarlig sykepleier registrerer kliniske pasientdata i forbindelse med SVT på eget skjema (se skjema nr 5).

Monitoreringsprosedyre, logistikk-kontroll

Forskningsmedarbeider kvalitetssikrer at pasienter som blir inkludert i studien blir skåret i henhold til kriteriene og samler inn skåringsskjema før pasienten skrives ut fra intensivavdelingen (se skjema nr 6). Forskningsmedarbeider forespør pasienten om skriftlig samtykke om bruk av data fra skåringssekvensen og registreringsdata så snart pasienten vurderes som fullt samtykkekompetent (se skjema nr 7).

Datahåndtering

Når pasienten skrives ut, beholdes skåringsskjema på intensiv, og oppbevares på intensivavdelingen i låsbart skap fram til pasienten har gitt sitt samtykke. Deretter legges avidentifiserte data inn i SPSS på passordbeskyttet domene i Helseforetakets nettverk. Koblingsnøkkel oppbevares separat. Hvis pasienten ikke gir samtykke, makuleres skjema.

Spørsmål kan rettes til stipendiat Hege Selnes Haugdahl, e-post:
hege.s.haugdahl@hint.no eller tlf 90956250 eller
forskningsmedarbeider Knut Dybwik

Hovedveileder: Sissel Lisa Storli, førsteamanuensis, Institutt for helse- og omsorgsfag, Universitetet i Tromsø
Biveileder: Pål Klepstad, avdelingssjef, intensiv, St.Olavs hospital/prof II, NTNU

Skjema nr 4

Veiledning til pasientansvarlig sykepleier som skal spørre respiratorpasienten om samtykke til å delta i respiratorstudien:

- vurder om pasienten er våken og i stand til å forstå informasjonen
- informer om at det i avdelingen foregår en forskningsstudie på pasienter som får hjelp med pusten og at det innebærer å svare på tre spørsmål om hvordan hun/han erfarer å få pustehjelp
- informer om at svarene pasientene gir, skal sammenlignes med observasjoner som registreres i pasientjournalen, og som rutinemessig blir tatt av alle respiratorpasienter
- informere om at studien ikke innebærer noen risiko eller ekstra undersøkelser
- forsikre pasienten om at svarene anonymiseres, og at det er helt frivillig å delta

Muntlig samtykke til deltakelse i studien

Jeg bekrefter å ha gitt informasjon om studien og at pasient ………………………….har gitt muntlig samtykke til å delta

----
(Signert pasientansvarlig sykepleier, dato)

Skjema nr 5

Pasient: ☐

Pasientinformasjon ved spontan ventilasjonstest (SVT)

1. Kjønn ☐ Mann 1 ☐ Kvinne 2	**2. Dato innlagt intensivavdelingen:**	**3.Dato innlagt sykehus:**	**4. Innleggelsesdiagnose:**

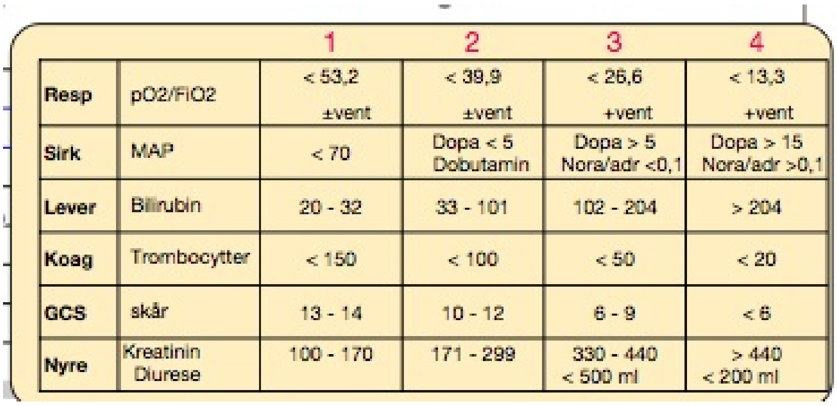
5. Årsak til respirasjonssvikt:	**6.Vekt (innkomst):**	**7.KOLS** ☐ Ja 1 ☐ Nei 2	**8. Når intubert:**

9. Når tracheostomert:	**10. Når ekstubert:**	**11. Utskrevet intensiv:**	**12: Utskrevet sykehus:**

		SVT 1	SVT 2	SVT 3	SVT 4	SVT 5	SVT 6
Dato for SVT:							
Pasientskåring Skriv ned verdien som **pasienten** anga da han pekte på plastlaminert skåringsskjema: **11**. Føler du deg tungpustet?							
12. Føler du deg trygg i forbindelse med pustetreninga							
13. Føler du at det går bedre med pusten							
14. Varighet SVT	minutter						
15. Evt avbrutt SVT	årsak						
16. Kontinuerlig sedering		☐ Ja ☐ Nei	☐ Ja ☐ Nei	☐ Ja ☐ Nei	☐ Ja ☐ Nei	☐ Ja ☐ Nei	☐ Ja ☐ Nei
17. Type sedering							

Fylles ut av pasientansvarlig sykepleier eller forskningsmedarbeider

		SVT 1	**SVT 2**	**SVT 3**	**SVT 4**	**SVT 5**	**SVT 6**
	Dato:						
FiO$_2$	før SVT						
	etter SVT						
SaO$_2$	før SVT						
	etter SVT						
evt pO$_2$	før SVT						
	etter SVT						
pCO$_2$	før SVT						
	etter SVT						
Respirasjons-frekvens	før SVT						
	etter SVT						
	hvert 30.min under SVT						
Tidalvolum	før SVT						
	etter SVT						
	hvert 30.min under SVT						
Puls	før SVT						
	etter SVT						
BT systolisk	før SVT						
	etter SVT						
MAAS	før SVT						
	etter SVT						
SAPS							
SOFA-score Utføres av lege de dagene pasienten gjør SVT-skåringer	**-respirasjon**						
	-sirkulasjon						
	-lever						
	-koagulasjon						
	-GCS						
	-nyre						



		1	2	3	4
Resp	pO2/FiO2	< 53,2 ±vent	< 39,9 ±vent	< 26,6 +vent	< 13,3 +vent
Sirk	MAP	< 70	Dopa < 5 Dobutamin	Dopa > 5 Nora/adr <0,1	Dopa > 15 Nora/adr >0,1
Lever	Bilirubin	20 - 32	33 - 101	102 - 204	> 204
Koag	Trombocytter	< 150	< 100	< 50	< 20
GCS	skår	13 - 14	10 - 12	6 - 9	< 6
Nyre	Kreatinin Diurese	100 - 170	171 - 299	330 - 440 < 500 ml	> 440 < 200 ml

Kriterier for å starte avvenning

- Noe reversering av årsaken til respirasjonssvikt
- Ikke ukontrollert alvorlig infeksjon
- Ikke alvorlig metabolsk avvik
- Stabil sirkulasjon (puls <120 og systolisk BT mellom 90-180)
- Sat O_2>90 eller pO_2>8,5 med pO_2/FiO_2>26,6(FiO_2<0,5 og PEEP ≤8)
- Hvis svekket pasient vurderes Respirasjonsfrekvens <30-35 og tidalvolum>5ml/kg og Resp frekv/tidalvolum <100

Kriterier for vellykket SVT:
Respirasjonsfrekvens <30-35, tidalvolum >5 ml/kg
pO>8,5, eller Sat O_2>90 med FiO_2 ≤0,5
pCO_2 -stigning <20%
Stabil sirkulasjon: (puls<120, BT_{syst} <180 og >90

Ikke:
Forverret mental status
Økt ubehag
Sliten
Tegn på økt ventilasjonsarbeid (bruk av respiratorisk tilleggsmuskulatur)

Referanse:
Avvenning fra korttids invasiv respiratorbehandling (< 3 uker), St.Olavs Hospital/Kl.anes./akutt./Hovedintensiv, 15.02.2012

Appendix 7 Information to patients (Paper III-IV)

Forespørsel om deltakelse i forskningsprosjektet

"Intensivpasienter som avvennes fra respirator -opplevelse og vurdering av tungpustethet"

Bakgrunn og hensikt

Dette er et spørsmål til deg om å delta i et forskningsprosjekt om respiratorbehandling og tungpustethet. Når intensivpasienter har hatt behov for pustehjelp, er det vanligvis en overgangsfase hvor pasienten må ta over mer og mer av pustinga sjøl. Noen pasienter synes denne pustetreninga er en slitsom periode, og det er vanlig at legen justerer pustestøtten litt opp eller ned, avhengig av hvor tungt pasienten synes det er å puste. Under respiratorbehandlingen får ikke pasienten til å bruke stemmen. Noen ganger kan det derfor være vanskelig for helsepersonell å vite helt sikkert hvordan pasienten har det. Hensikten med dette forskningsprosjektet er derfor å undersøke om pasientens egen følelse av å være tungpustet stemmer over ens med de vurderinger som leger og sykepleiere gjør, og om følelsen av å være tungpustet kan ha sammenheng med vanlige observasjoner knyttet til respiratorbehandling. Ettersom du nylig har hatt erfaring med å ligge på respirator, er din erfaring svært viktig. Ansvarlig for studien er førsteamanuensis Sissel Storli, Universitetet i Tromsø, og avdelingssjef Pål Klepstad, intensivavdelingen ved St.Olavs hospital.

Hva innebærer studien?

I forbindelse med pustetreninga ble du bedt om å svare på tre spørsmål: 1) Føler du deg tungpustet 2) Føler du at det går framover med pusten 3) Føler du deg trygg i forbindelse med pustetreninga. Dette er spørsmål som er vanlig å stille til alle pasienter, det som er spesielt med dette prosjektet, var at svaret du ga ble nedtegnet på en skala fra 0-10. Det er ikke sikkert du husker denne perioden så godt fordi det er vanlig å få beroligende og/eller smertestillende medisiner som gjør at man er litt trøtt. Studien innebærer at dine svar sammenlignes med svarene til den legen og sykepleieren som hadde ansvar for deg. I tillegg skal dine svar sammenlignes med prøver som tas rutinemessig av alle respiratorpasienter, blant annet oksygeninnhold i blodet og hvor mange ganger i minuttet du pustet. Dette betyr at vi ber om samtykke til å bruke skåringsdata og de aktuelle registreringsdata fra journal.

Mulige fordeler og ulemper

Studien innebærer ingen risiko eller ekstra undersøkelse.

Denne studien skal etterfølges av en intervju-undersøkelse blant noen av pasientene. Det kan derfor hende at du etter utskrivelse blir kontaktet med spørsmål om du er villig til delta i en intervju-undersøkelse om dine erfaringer som respiratorpasient.

Hva skjer med informasjonen om deg?

Informasjonen som registreres om deg skal kun brukes slik som beskrevet i hensikten med studien. Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. En kode knytter deg til dine opplysninger og prøver gjennom en navneliste. Det er kun autorisert personell knyttet til prosjektet som har adgang til navnelisten og som kan finne tilbake til deg. Det vil ikke være mulig å identifisere deg i resultatene av studien når disse publiseres. Etter prosjektslutt i 2016 skal datamaterialet anonymiseres. Navneliste (koblingsnøkkel) vil slettes.

Frivillig deltakelse

Det er frivillig å delta i studien. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke til å delta i studien. Dette vil ikke få konsekvenser for din videre behandling. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Om du nå sier ja til å delta, kan du senere trekke tilbake ditt samtykke uten at det påvirker din øvrige behandling. Dersom du senere ønsker å trekke deg eller har spørsmål til studien, kan du kontakte intensivsykepleier og doktorgradsstipendiat Hege Selnes Haugdahl, tlf 90956250.

Samtykke til deltakelse i studien

Jeg er villig til å delta i studien

(Signert av prosjektdeltaker, dato)

Jeg bekrefter å ha gitt informasjon om studien

(Signert, rolle i studien, dato)

Information to patients (Paper IV)

Til

Forespørsel om deltakelse i forskningsprosjektet

”Livets pust”-tidligere intensivpasienters erfaringer med å puste i forbindelse med respiratorbehandling

Bakgrunn og hensikt

Du blir kontaktet fordi du allerede har deltatt i en studie hvor du ble spurt om hvor tungpustet du følte deg mens du lå på intensivavdelingen og var tilkoblet respirator. Dette er et spørsmål til deg om å delta i en oppfølgende forskningsstudie for å undersøke hvilke erfaringer tidligere intensivpasienter har med å puste under og etter respiratorbehandlingen, og hva som hemmet/fremmet følelsen av å få puste. Din erfaring er derfor svært viktig. Resultater fra denne studien vil gi økt kunnskap om hvordan respiratorpasienter best mulig kan støttes gjennom respiratorbehandling og i tiden etterpå med tanke på pusten. Ansvarlig for studien er førsteamanuensis Sissel Storli, Universitetet i Tromsø, og avdelingssjef Pål Klepstad, intensivavdelingen ved St.Olavs hospital.

Hva innebærer studien?

Studien innebærer å delta i en intervju-undersøkelse hvor du blir bedt om å fortelle om dine erfaringer med å være tilkoblet respirator, og hvordan det var å puste i tiden etter respiratorbehandlingen. Ikke alle pasienter husker oppholdet på intensivavdelingen så godt, men dine erfaringer er verdifulle uansett.

Mulige fordeler og ulemper

For mange kjennes det meningsfullt å bidra med kunnskap som kan gjøre helsetjenesten bedre. Pasienter som har vært innlagt ved en intensivavdeling kan ha oppstykkede minner og sterke følelser fra oppholdet. For mange kan det derfor være godt å dele sine erfaringer med andre etter å ha vært syk. For andre, som kanskje har opplevd denne tiden som vanskelig, kan samtalen vekke minner som man helst vil glemme. Hvis du skulle ha behov for å snakke med noen etter intervjuet, vil det kunne formidles kontakt med sykepleier på intensivavdelingen du var på.

Hva skjer med informasjonen om deg?

Samtalen med deg blir tatt opp på digital lydopptaker, og skrevet ut som tekst. Denne teksten blir analysert på en vitenskapelig måte og skal kun brukes slik som beskrevet i hensikten med studien. Lydopptaket og øvrige forskningsdata oppbevares på helseforetakets datanettverk og er kun tilgjengelig for autorisert personell knyttet til prosjektet. Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. Det vil ikke være mulig å identifisere deg i resultatene av studien når disse publiseres. Prosjektet er godkjent av Regional komité for medisinsk og helsefaglig forskningsetikk Midt-Norge.

Frivillig deltakelse

Det er frivillig å delta i studien. Dersom du ikke ønsker å delta, trenger du ikke å begrunne din avgjørelse. Samtykker du i å delta, kan du likevel når som helst og uten å oppgi noen grunn trekke ditt samtykke til å delta i studien. Om du ikke velger å delta, vil det ikke få noen konsekvenser for ditt forhold til sykehuset i fremtiden.

Dersom du kan tenke deg å dele dine erfaringer, kan du returnere samtykkeerklæringen i underskrevet form i vedlagte konvolutt. Jeg vil så kontakte deg for å avtale tid og sted. Intervjuet vil ta ca 1 time. Har du spørsmål til studien, kan du kontakte meg på telefon 90 95 62 50, eller via e-post: hege.haugdahl@hnt.no

Vennlig hilsen
Hege Selnes Haugdahl
Intensivsykepleier og doktorgradsstipendiat

Appendix 8 Interview guide (Paper IV)

Intervjuguide

Samtalen vil styres av pasientens fortellinger. Ettersom ikke alle pasienter husker at de har vært respiratorbehandlet innledes samtalen med et åpent spørsmål hvor pasienten bes om å fortelle om hvilke erfaringer han/hun hadde med pusten mens pasienten var innlagt på sykehuset. Aktuelle oppfølgingsspørsmål:

a) ”hvilke minner/kroppslige erfaringer har du med pusten da du var innlagt på sykehuset? ”

b) ”dersom du husker; kan du fortelle om hvordan det var å få hjelp med pusten da du lå på intensivavdelingen? ” Aktuelle oppfølgingsspørsmål:
  ”hva var det som hadde betydning da?” (hos deg selv, i omgivelsene, andre personer)
  ”hva tenker du om dette nå?”

c) ”kan du fortelle om en gang du strevde med pusten”,
  ”hva var det som hadde betydning da?” (hos deg selv, i omgivelsene, andre personer)
  ”hva tenker du om dette nå?”

d) ”kan du fortelle om en situasjon hvor du følte at pusten hadde blitt bedre og at du kjente at det var framgang”
  ”hva var det som hadde betydning da?” (hos deg selv, i omgivelsene, andre personer)
  ”hva tenker du om dette nå?”

e) ”hvordan opplevde du at det var å puste rett etter at du ble utskrevet fra sykehuset»?

f) ”hvordan opplever du at pusten er nå?» (hvile, aktivitet)

g) ”er det noe som har endret seg med pusten sammenlignet med hvordan det var før du ble innlagt? ” (situasjoner, noe i omgivelsene, minner)

h) ”og hva tenker du om dette? ”

Fra: Regional komite for medisinsk og helsefaglig forskningsetikk REK midt

Til:
Hege Selnes Haugdahl
Hege.Haugdahl@helse-nordtrondelag.no

Dokumentreferanse: 2009/840-6
Dokumentdato: 12.02.2010

ROLLER OG ANSVAR VED RESPIRATORBEHANDLING GODKJENNING

Med hjemmel i lov om behandling av etikk og redelighet i forskning § 4 og helseforskningsloven § 10 har Regional komité for medisinsk og helsefaglig forskningsetikk, Midt-Norge vurdert prosjektet i sitt møte 4. desember 2009 med følgende vilkår og vurdering:

Vi viser til tilbakemelding på komiteens merknader. Spørreskjemaet som benyttes er validert og benyttet internasjonalt. Spørreskjemaet er kvalitetssikret i samarbeid med anestesileger fra flere sykehus i Norge. Den akademiske kompetansen er ivaretatt i prosjektgruppen.

Vedtak:
"Regional komité for medisinsk og helsefaglig forskningsetikk, Midt-Norge godkjenner prosjektet."

Med hilsen
Sven Erik Gisvold
Leder i komiteen

Arild Hals
Kontorsjef, REK Midt-Norge

Norsk samfunnsvitenskapelig datatjeneste AS
NORWEGIAN SOCIAL SCIENCE DATA SERVICES

Hans Holmboes gate 22
N-5007 Bergen
Norway
Tel: +47/ 55 58 21 17
Fax: +47/ 55 58 96 50
nsd@nsd.uib.no
www.nsd.uib.no
Org.nr. 985 321 884

Hege Selnes Haugdahl
Dalhaugen, Halsan
7600 LEVANGER

Vår dato: 21.08.2003 Vår ref: 200300699 GHA /RH Deres dato: Deres ref:

KVITTERING FRA PERSONVERNOMBUDET

Vi viser til melding om behandling av personopplysninger, mottatt 31.07.2003. All nødvendig informasjon om prosjektet forelå i sin helhet 18.08.2003. Meldingen gjelder prosjektet:

10204 Intensivsykepleieres kompetanse ved respiratorbehandling

Norsk samfunnsvitenskapelig datatjeneste AS er utpekt som personvernombud av Universitetet i Tromsø, jf personopplysningsforskriften § 7-12. Ordningen innebærer at meldeplikten til Datatilsynet er erstattet av meldeplikt til personvernombudet.

Personvernombudets vurdering

Personvernombudet finner at behandlingen av personopplysningene er meldepliktig i henhold til personopplysningsloven § 31 og at behandlingen tilfredsstiller kravene i personopplysningsloven.

Personvernombudets vurdering forutsetter at prosjektet gjennomføres slik det er beskrevet i vedlegget. vurdering.

Behandlingen av personopplysninger kan settes i gang.

Ny melding

Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de punktene som ligger til grunn for personvernombudets vurdering.

Selv om det ikke skjer endringer i behandlingsopplegget, skal det gis ny melding tre år etter at forrige melding ble gitt dersom prosjektet fortsatt pågår.

Ny melding skal skje skriftlig til personvernombudet.

Offentlig register

Personvernombudet har lagt ut meldingen i et offentlig register, www.nsd.uib.no/personvern/register/

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	**Saksbehandler:**	**Telefon:**	**Vår dato:**	**Vår referanse:**
REK midt	Hilde Eikemo	73597508	24.09.2013	2012/1230/REK midt
			Deres dato:	**Deres referanse:**
			17.09.2013	

Vår referanse må oppgis ved alle henvendelser

Sissel Lisa Storli
Institutt for helse og omsorgsfag

2012/1230 Intensivpasienter som avvennes fra respirator - opplevelse og vurdering av tungpustethet

Forskningsansvarlig: Universitetet i Tromsø
Prosjektleder: Sissel Lisa Storli

Vi viser til søknad om prosjektendring datert 17.09.2013 for ovennevnte forskningsprosjekt. Søknaden er behandlet av leder for REK midt på fullmakt, med hjemmel i helseforskningsloven § 11.

Det søkes om følgende endringer
1. Ny prosjektmedarbeider (intensivsykepleier Knut Dybwik ved Nordlandssykehuset)
2. Datainnsamlingen skal utvides til også å foregå ved intensivavdelingen på Nordlandssykehuset, Sykehuset Bodø.
3. Endring i informasjonsskrivet til deltakerne hvor de nå får beskjed om at de kan bli kontaktet på nytt ifm. en oppfølgingsstudie som innebærer et intervju. De aktuelle deltakerne vil motta nytt informasjonsskriv vedrørende denne oppfølgingsstudien.

Vurdering
Endringene fremstår som konkrete og avgrensede, og komiteen har ingen forskningsetiske innvendinger.

Vilkår for godkjenning
Komiteen ber om at alle deltakende sykehus oppføres som forskningsansvarlig institusjon i tillegg til UiT. Dette begrunnes med at sykehusene er ansvarlig for inneliggende pasienter. Komiteen ber om en liste over institusjonene, og kontaktpersoner (oftest klinikksjef) med kontaktinformasjon (e-postadresse). Vennligst benytt e-postadresse post@helseforskning.etikkom.no og "REK midt 2012/1230" i emnefeltet.

Vedtak
Regional komité for medisinsk og helsefaglig forskningsetikk Midt-Norge godkjenner søknad om prosjektendring.

Klageadgang
Du kan klage på komiteens vedtak, jf. forvaltningslovens § 28 flg. Klagen sendes til REK midt. Klagefristen er tre uker fra du mottar dette brevet. Dersom vedtaket opprettholdes av REK midt, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag for endelig vurdering.

Med vennlig hilsen

Sven Erik Gisvold
Dr.med.
Leder, REK midt

Hilde Eikemo
Sekretariatsleder

Kopi til: *gyrd.thrane@uit.no*

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	**Saksbehandler:**	**Telefon:**	**Vår dato:**	**Vår referanse:**
REK midt	Hilde Eikemo	73597508	11.09.2012	2012/1230/REK midt
			Deres dato:	**Deres referanse:**
			19.06.2012	

Vår referanse må oppgis ved alle henvendelser

Sissel Lisa Storli
UiT

2012/1230 Intensivpasienter som avvennes fra respirator - opplevelse og vurdering av tungpustethet

Forskningsansvarlig: Gyrd Thrane
Prosjektleder: Sissel Lisa Storli

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK midt) i møtet 24.08.2012. Vurderingen er gjort med hjemmel i helseforskningsloven § 10, jf. forskningsetikklovens § 4.

Prosjektomtale

Respiratoravvenning er vanskelig for ca. 25 % av pasientene. Det er lite kunnskap om hvordan respiratorpasientens opplevelse korrelerer med helsepersonellets vurderinger mht. tungpustethet. Studiens formål er å undersøke grad av samsvar i vurdering av tungpustethet, trygghet og fremgang ut fra egenvurdering fra pasient i avvenningsforsøk, og sykepleiers/legers vurdering i samme tidsrom. Studien skal også undersøke samsvar mellom pasienten opplevelse av tungpustethet og demografiske forhold, kliniske observasjoner og målte parameter relatert til respirasjon. Data samles inn vha. klinisk undersøkelse, observasjon og spørreskjema. Studien skal omfatte minimum 119 pasienter under intensivbehandling som skal avvennes fra respirator. Det skal innhentes samtykke fra samtlige deltakere.

Vurdering

Forsvarlighet

Komiteen har vurdert søknad, forskningsprotokoll, målsetting og plan for gjennomføring. Prosjektet framstår som forsvarlig, og hensynet til deltakernes velferd og integritet er ivaretatt.

Samtykke

Komiteen viser til søknadsskjemaets punkt 3 om rekruttering og samtykke. Det skal gis muntlig samtykke mens pasienten er intubert, etterfulgt av skriftlig samtykke når pasienten er ekstubert og i stabil tilstand. Dersom pasienten dør før skriftlig samtykke, skal pasienten inkluderes. Det søkes om fritak fra skriftlig samtykke i disse tilfellene. Komiteen vurderer det muntlige samtykket som tilstrekkelig for inklusjon i prosjektet i tilfellene hvor pasienten dør før skriftlig samtykke har blitt innhentet.

Vilkår for godkjenning

1. Pasientansvarlig sykepleier skal vurdere pasientenes samtykkekompetanse før de forespørres om deltakelse i prosjektet.

2. I de tilfelller pasientansvarlig sykepleier er i tvil om samtykkekompetansen, kan pårørende spørres muntlig for å avgjøre spørsmålet om pasienten er samtykkekompetent. Kun samtykkekompetente pasienter kan inkluderes.
3. Komiteen viser til informasjonsskrivet, og ber om at det opplyses om at studien er godkjent av Regional komité for medisinsk og helsefaglig forskningsetikk Midt-Norge. Vennligst send inn revidert informasjonsskriv til post@helseforskning.etikkom.no med "REK midt 2012/1230" i emnefeltet.
4. Godkjenningen er gitt under forutsetning av at prosjektet gjennomføres slik det er beskrevet i søknaden og protokollen, og de bestemmelser som følger av helseforskningsloven med forskrifter.
5. Forskningsprosjektets data skal oppbevares forsvarlig, se personopplysningsforskriften kapittel 2, og Helsedirektoratets veileder for «Personvern og informasjonssikkerhet i forskningsprosjekter innenfor helse- og omsorgssektoren». Prosjektdata skal oppbevares i minimum 5 år etter prosjektslutt.

Øvrige kommentarer fra komiteen

Komiteen minner om at de aller fleste kliniske studier skal registreres i det offentlig tilgjengelige registeret www.clinicaltrials.gov. Prosjektleder er ansvarlig for å avklare om forskningsstudien omfattes av kravet til registrering.

Vedtak

Regional komité for medisinsk og helsefaglig forskningsetikk Midt-Norge godkjenner prosjektet med de vilkår som er gitt.

Klageadgang

Du kan klage på komiteens vedtak, jf. forvaltningslovens § 28 flg. Klagen sendes til REK midt. Klagefristen er tre uker fra du mottar dette brevet. Dersom vedtaket opprettholdes av REK midt, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag for endelig vurdering.

Sluttmelding og søknad om prosjektendring

Prosjektleder skal sende sluttmelding til REK midt på eget skjema senest 30.06.2017. Prosjektleder skal sende søknad om prosjektendring til REK midt dersom det skal gjøres vesentlige endringer i forhold til de opplysninger soim er gitt i søknaden, jf. helseforskningsloven § 11.

Med vennlig hilsen

Sven Erik Gisvold
Professor dr.med.
Leder REK Midt

Hilde Eikemo
Rådgiver

Kopi til: gyrd.thrane@uit.no

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK midt	Hilde Eikemo	73597508	19.12.2013	2013/2078/REK midt
			Deres dato:	**Deres referanse:**
			05.11.2013	

Vår referanse må oppgis ved alle henvendelser

Sissel Lisa Storli
UiT

2013/2078 Livets pust

Forskningsansvarlig: Universitetet i Tromsø
Prosjektleder: Sissel Lisa Storli

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK midt) i møtet 29.11.2013. Vurderingen er gjort med hjemmel i helseforskningsloven (hfl.) § 10, jf. forskningsetikklovens § 4.

Prosjektomtale

Formålet med studien er å undersøke hvilke erfaringer tidligere intensivpasienter hadde med å puste under og etter respiratorbehandlingen, og hva som hemmet og fremmet følelsen av få puste. Det skal utføres kvalitative intervju med 15 tidligere pasienter, som rekrutteres fra studiepopulasjonen i et relatert forskningsprosjekt (2012/1230). Det skal innhentes skriftlig, spesifikt samtykke fra deltakerne.

Vurdering

Forsvarlighet

Komiteen har vurdert søknad, forskningsprotokoll, målsetting og plan for gjennomføring. Prosjektet framstår som forsvarlig, og hensynet til deltakernes velferd og integritet er ivaretatt.

Informasjonsskriv

Komiteen viser til informasjonsskrivet til deltakerne, og ber om følgende endringer:

- a) Skrivet må dateres.
- b) Det må komme klart frem at reiseutgifter i forbindelse med studiedeltakelse refunderes.
- c) Det må stå at man skal bruke journalopplysninger innsamlet i relatert prosjekt.

Vilkår for godkjenning

1. Revidert informasjonsskriv sendes komiteen til orientering. Vennligst benytt e-postadressen post@helseforskning.etikkom.no og "REK midt 2013/2078" i emnefeltet.
2. Godkjenningen er gitt under forutsetning av at prosjektet gjennomføres slik det er beskrevet i søknaden og protokollen, og etter de bestemmelser som følger av helseforskningsloven med forskrifter.
3. Forskningsprosjektets data skal oppbevares forsvarlig, se personopplysningsforskriften kapittel 2,

og Helsedirektoratets veileder for «Personvern og informasjonssikkerhet i forskningsprosjekter innenfor helse- og omsorgssektoren». Av kontrollhensyn skal prosjektdata oppbevares i 5 år etter prosjektslutt, for deretter å slettes eller anonymiseres, jf. helseforskningsloven § 38.

Vedtak

Regional komité for medisinsk og helsefaglig forskningsetikk Midt-Norge godkjenner prosjektet med de vilkår som er gitt.

Sluttmelding og søknad om prosjektendring
Prosjektleder skal sende sluttmelding til REK midt på eget skjema senest 30.06.2017, jf. hfl. § 12. Prosjektleder skal sende søknad om prosjektendring til REK midt dersom det skal gjøres vesentlige endringer i forhold til de opplysninger som er gitt i søknaden, jf. hfl. § 11.

Klageadgang
Du kan klage på komiteens vedtak, jf. forvaltningslovens § 28 flg. Klagen sendes til REK midt. Klagefristen er tre uker fra du mottar dette brevet. Dersom vedtaket opprettholdes av REK midt, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag for endelig vurdering.

Med vennlig hilsen

Sven Erik Gisvold
Dr.med.
Leder, REK midt

Hilde Eikemo
Sekretariatsleder

Kopi til: gyrd.thrane@uit.no; rek-midt@medisin.ntnu.no

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Jun 21, 2016

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Fra: Hege Selnes Haugdahl
Sendt: 1. juni 2016 21:29
Til: Burki,Nausherwan
Emne: Re: question about Mechanisms of Dyspnea

Thank you very much, and also thanks for your advice.
hege

Sendt fra min iPad

Den 1. jun. 2016 kl. 20.25 skrev Burki,Nausherwan <nburki@uchc.edu>:

> Dear Mr Haugdahl,
> You have my permission to use the figures; you may have to also get approval from the Chest journal. Good luck.
>
> N. Burki
>
> ---
>
> **From:** Hege Selnes Haugdahl [mailto:hege.s.haugdahl@nord.no]
> **Sent:** Sunday, May 29, 2016 10:38 AM
> **To:** Burki,Nausherwan
> **Subject:** question about Mechanisms of Dyspnea
>
> Dear Nausherwan K. Burki
>
> I have with interest read your article Mechanisms of Dyspnea, published in Chest 2010.
> I am PhD-student, and my question is if you permit that I use two of your figures from the article in my theses?
> *Figure 1. Schematic representation of afferent pathways from respiratory muscle mechanoreceptors to the CNS. DRG 5 dorsal respiratory group; VRG 5 ventral respiratory group. AND Figure 2. Schematic representation of afferent pathways of dyspnea from vagal receptors and peripheral chemoreceptors to the CNS*
>
> My research topic is Mechanical ventilation and weaning: The role and competencies of intensive care nurses.
>
> Best regards
> Hege Selnes Haugdahl
> PhD-student
> The Arctic University of Norway

Fra:	Eva Olsen <eva.eva.o@gmail.com>
Sendt:	21. juni 2016 16:32
Til:	Hege Selnes Haugdahl
Kopi:	Laila Wiklund Andersen
Emne:	Bekreftelse

Jeg bekrefter tillatelse for Hege S. Haugdahl til ubegrenset å benytte/publisere bilder/grafikk fra min hånd.

Eva Olsen
7660 Vuku

Sendt fra min iPhone

Hege Selnes Haugdahl

Fra:	Laila Wiklund Andersen <la-wiklu@online.no>
Sendt:	20. juni 2016 13:23
Til:	Hege Selnes Haugdahl
Emne:	Re: SV:

Takk.

Sendt fra min iPad

Den 20. juni 2016 kl. 13:07 skrev Hege Selnes Haugdahl <hege.s.haugdahl@nord.no>:

> Takk for at du lar meg bruke bildene i min doktorgradsavhandling!
> De er virkelig fine.
> hege
>
> -----Opprinnelig melding-----
> Fra: Laila Wiklund Andersen [mailto:la-wiklu@online.no]
> Sendt: 20. juni 2016 12:47
> Til: Hege Selnes Haugdahl <hege.s.haugdahl@nord.no>
> Emne:
>
> Bruk bildene. Artig.
> Laila
>
> Sendt fra min iPhone
>
>