Communication and interaction between conscious and alert critically ill patients on mechanical ventilation and healthcare providers in intensive care units:

An in-depth study

Marte-Marie Wallander Karlsen, RN, CCN, MNSc

Institute of Basic Medical Sciences
Faculty of Medicine
University of Oslo
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Summary

Background

In order to optimize patient outcomes, intensive care treatment has shifted in recent decades toward less sedation, early weaning from mechanical ventilation, and increased physical activity. Mechanically ventilated patients in intensive care unfortunately experience communication barriers, such as lack of voice. This affects their ability to express their needs, to participate in treatment decision-making, and to interact with healthcare providers and relatives.

Aims

This thesis aimed to obtain in-depth knowledge of the communication and interaction between patients and healthcare providers when patients are conscious and alert and assisted by mechanical ventilation in intensive care units.

Methods

The research design was qualitative and based on a phenomenological-hermeneutical approach. The thesis includes four papers: Paper one is a literature review of the existing literature on communication with intensive care patients. Papers two and three reports findings from video recorded observations of ten conscious and alert patients on mechanical ventilation in intensive care in interaction with 60 healthcare providers. The fourth paper presents findings from interviews with nine healthcare providers about their experiences when communicating with conscious and alert patients on mechanical ventilation (critical care nurses, anesthesiologists, and physiotherapists).

Findings

The literature review demonstrates the need for more interprofessional research on this topic, as most of the published studies were conducted from a nursing perspective. It was observed though the video recordings that the patients used various non-vocal methods to obtain healthcare providers' attention and tried to communicate their needs (immediately responded to, with delayed response or understanding, intensified or given up). The thesis also reveals that a number of bedside micro-decisions were made regarding matters such as tracheal suctioning, medication, or the processes of weaning the patient off the mechanical ventilation. The ways in which the patients were involved in the micro-decisions were categorized into six types of decision-making: non-invited, substituted, guided, invited, shared, and self-determined. The patients varied from being an observer to a participant. Negotiations between the patients and the healthcare providers were observed to individualize the care given. Through dialogue with the patients, the providers were able to balance activities that empowered the patients with the need for energy-restoration. The interviews illuminated the complexity of communication between healthcare providers and patients and the perceived dissonance between ideals and the real-world encounters for both patients and providers.

Conclusion

Previous studies suggest that good communication may reduce negative emotions such as anxiety and frustration. The thesis confirms that patients and healthcare providers struggle to

communicate with each other when patients are awake and alert on mechanical ventilation. The communication barriers were shown to have consequences for the patients' care and treatment, affecting both for their attempts to communicate and the bedside micro-decisions. It is necessary to increase providers' competence in communicating with mechanically ventilated patients in the future to meet both patients' expectations of involvement and the healthcare providers' legal obligation to facilitate patient participation.

Sammendrag

Bakgrunn

De siste tiårene har intensivbehandling endret form for å forbedre behandlingsresultater. Intensivpasienter får derfor nå mindre sedering enn tidligere, blir raskere avvent fra respirator og er økt fysisk aktive selv ved kritisk sykdom. Pasienter på respirator har imidlertid store kommunikasjons barrierer, som mangel av stemme. Dette påvirker deres muligheter til å utrykke behov, delta i behandlingsavgjørelser og samhandle med helsepersonell og familie.

Hensikt

Studiens hensikt var å få dybdekunnskap om kommunikasjon og samhandling mellom pasienter og helsepersonell når de er våkne på respirator i intensivavdelinger.

Metode

Studien har et kvalitativt design basert på en fenomenologisk-hermeneutisk tilnærming. og består av fire studier. Studie en er en litteraturstudie om tidligere litteratur om kommunikasjon med intensivpasienter. Studie to og tre rapporterer funn fra videofilmede observasjoner av samhandling mellom ti våkne pasienter på respirator og 60 helsepersonell i to intensivavdelinger. Studie fire presenterer funn fra dybdeintervjuer av ni helsepersonell om deres erfaringer med kommunikasjon med våkne intensivpasienter (intensivsykepleiere, leger og fysioterapeuter).

Funn

Litteraturstudiet viste et behov for mer tverrfaglig forskning på området, mesteparten av studiene var gjort ut fra et sykepleieperspektiv. Det ble observert at pasientene tok i bruk en rekke metoder for å få helsepersonellets oppmerksomhet og forsøke å kommunisere sine behov (umiddelbart respondert på, med forsinket respons eller forståelse, intensifiert eller forsøk som gis opp). Det ble også observert at en rekke behandlingsbeslutninger tatt ved pasientens seng; slik som trakealsuging, medikamentell behandling eller avvenning av respirator. Måtene pasientene ble involvert i disse beslutningene var kategorisert i seks ulike type beslutningsformer: ikke-inviterte, erstattede, guidede, inviterte, delte og selvbestemte beslutninger. Pasientene varierte dermed mellom å være observatører og deltagere i ulike behandlingsbeslutninger. Forhandling mellom pasienter og helsepersonell var med å individualisere behandlingen. Helsepersonellet balanserte også fysisk aktivitet med behovet for hvile, gjennom dialog med pasientene. Intervjuene ga en økt forståelse for hvor kompleks samhandlingen er mellom pasientene og helsepersonellet, og at helsepersonellet strever med å forene sine idealer med virkelighetens pasientmøter og tverrprofesjonell samhandling.

Konklusjon

Tidligere studier viser at god kvalitet på kommunikasjon kan redusere negative emosjoner som angst og frustrasjon. Avhandlingen bekrefter at våkne respiratorpasienter og helsepersonell strever med å kommunisere med hverandre. Barrierene for kommunikasjon fikk konsekvenser for pasientens pleie og behandling, og for deres forsøk på å kommunisere og deltagelse i behandlingsbeslutninger. Det er nødvendig å øke helsepersonells kompetanse

kommunikasjon med respiratorpasienter i fremtiden for å møte pasienters forventninger og helsepersonells lovfestede plikt til å tilrettelegge for pasientdeltagelse.

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Kind regards, Marte-Marie Wallander Karlsen

Abbreviations

AAC: Augmentative and alternative communication
ABCDEF-Bundle: Assess, prevent and manage pain; Both spontaneous awakening trials and spontaneous breathing trials; Choice of analgesia and sedation; Delirium: assess, prevent and manage; Early mobility and exercise; and Family engagement and empowerment
CAM-ICU: The Confusion Assessment Method for the Intensive Care Unit
DICTUM: Decision Making and Classification Taxonomy in Medicine
eCASH: Early comfort and patient-centered care without excessive sedation
ECMO: Extracorporal Membrane Oxygenation
HP: Healthcare providers
ICU: Intensive Care Unit
NCCR11: Nursing Recording System 11
PICS: Post Intensive Care Syndrome
PICS-F: Post Intensive Care Syndrome-Family
RIAS: Roter Interaction Analysis System
SAPSII: Simplified Acute Physiology Score II
SD: Standard Deviation
TSD: Services for sensitive data, USIT, University of Oslo
VR-CoDES: Verona coding definitions of emotional sequences
UN: United Nations

List of Papers

The following articles are included in the thesis:

Paper 1

Karlsen, M.M.W., Ølnes, M., Heyn, L.G. (2018). Communication with patients in intensive care units: a scoping review. *Nursing in Critical Care,* 24(3), 115-131. doi:10.1111/nicc.12377

Paper 2

Karlsen, M.M.W., Heggdal, K., Finset, A., Heyn, L.G (2019). Attention-seeking actions by patients on mechanical ventilation in intensive care units: A phenomenological-hermeneutical study. *Journal of Clinical Nursing,* 28(1-2), 66-79. doi:10.1111/jocn.14633

Paper 3

Karlsen, M.M.W., Happ, M.B., Heggdal, K., Finset, A., Heyn, L.G. (2020). Patient involvement in bedside micro-decisions in intensive care. *Patient Education & Counseling,* IN PRESS. doi: 10.1016/j.pec.2020.04.020

Paper 4

Karlsen, M.M.W., Finset, A., Heggdal, K., Heyn, L.G. Caught between ideals and reality: A qualitative study of health-care provider's experiences of interaction with conscious patients in Intensive Care Units**. (***Submitted in Journal of Interprofessional Care, November 2019)*

Content

1.0 Introduction

This thesis aims to obtain in-depth knowledge of the communication and interaction between adult patients and healthcare providers (HP) when patients are conscious and alert while assisted by mechanical ventilation in intensive care units (ICUs). I want to start this thesis by describing how I first became interested in the topic, almost 15 years ago.

As a recently graduated critical care nurse, I cared for a 21-year old female patient, admitted to the ICU for six months. She had severe complications after a surgical procedure, respiratory failure, and numerous infections. She was only able to communicate non-vocally while being ventilated and minimally sedated. The interaction was extremely difficult and demanding. Especially during the last month of her stay, the focus shifted continuously from hope and treatment to end-of-life care. Elisa, as I will call her, was a very empathetic young woman and she enjoyed it when we cared for her, or spent time with her, letting her be a normal girl, talking about her dog, about music or other things that reminded her of the life outside of the ICU. One afternoon, we watched Idol together. The music was compelling; she fell asleep. Watching her, it hit me like a heavy wall that she did not have long left to live. The tears started to flow. Then, she suddenly looked up, and with a surprised look on her face she formed words with her lips to ask me "why do you cry?" I told her how sad it was to be unable to help her more. That evening, we talked about her death, Elisa grimacing and forming words with her lips, and me trying to interpret what she was saying. She died a couple of days later. Looking back, I realize that I had no education in the use of appropriate communication aids and I felt unprepared as a nurse to discuss such heavy topics with a patient who had to fight to express even the simplest thought. Although all the HP did their best, I keep wondering if more could have been done to make it easier for her to be understood.

The thesis consists of background, outlining the current knowledge status in the field of communication and interaction with patients on mechanical ventilation. It then explains the theoretical background and describes the methodology of the four papers included. The main findings from the papers will then be presented, discussed, and summarized in a conclusion. The most important implications of the findings for clinical practice, education, and future research will be highlighted at the end of the thesis.

2.0 Background

2.1 A historical look at mechanically ventilated patients in intensive care

During the polio epidemics in Copenhagen in 1952, medical students assisted patients with severe respiratory problems continuously ventilating tracheostomized patients with manual rubber bags, since the Blegdam hospital had an insufficient number of the iron lungs that would normally be used to ventilate patients in need of respiratory support. The efforts of the medical staff saved the lives of many patients (West, 2005). The polio epidemic triggered the start of modern mechanical ventilatory support as we know it today, with advanced treatment departments such as ICUs (Berthelsen & Cronqvist, 2003). One of the medical students in Denmark later described his experiences:

> The difference between ordinary patients requiring ventilation and polio patients was characteristic: they were conscious! The students invented ways to communicate with their patients. Some patients holding a small stick in their mouth communicated by pointing at letters on a poster, laboriously spelling what they wanted to say. … If the student was no way near the correct answer, the patient could point at the word "Idiot" written on the poster.
>
> (West, 2005, p. 10)

This occurred almost 70 years ago, but it provides a good illustration of how patients and HP struggle to communicate and find creative ways to understand each other. The move from negative pressure to positive pressure ventilation, combined with improved ventilator synchrony, has improved the possibility of patients breathing on their own while being mechanically ventilated (Slutsky, 2015). Initially there was only one volume-controlled ventilator mode, but there are now a variety to choose from. Spontaneous breathing modes, which provides lung protective ventilation and the best patient comfort, are most often selected (Kacmarek, 2011). This development affects the way patients are treated and interacted with in ICUs today.

In the 1990s, studies started to report lower mortality with a corresponding decrease in the number of days spent on mechanical ventilation and the length of stay in ICUs and in hospitals, all of which were associated with reduced sedation (J. Barr et al., 2013; Girard et

al., 2008; Kress, 2013; Kress, Pohlman, O'Connor, & Hall, 2000). This led to a shift in treatment, which is still developing, where analgo-sedation has become the explicit goal. Analgo-sedative approaches aim to sedate the patients as little as possible while relieving pain sufficiently. Studies are even reporting non-sedative practices in some ICUs, with positive outcomes for the patients (Laerkner, Egerod, & Hansen, 2015; Laerkner, Stroem, & Toft, 2016; Strøm, Martinussen, & Toft, 2010). Increasing awareness of the benefits of less sedation, of the negative cognitive effects of intensive care treatment, and positive benefits of early physical activity have inspired a more holistic approach to intensive care treatment, known as the ABCDEF-bundle (Balas et al., 2012; Marra, Ely, Pandharipande, & Patel, 2017; Morandi, Brummel, & Ely, 2011). The ABCDEF-bundle is an abbreviation for: Assess, prevent and manage pain; both spontaneous awakening trials and spontaneous breathing trials; choice of analgesia and sedation; delirium: assess, prevent and manage; early mobility and exercise, and family engagement and empowerment. The approach includes the active reduction of ventilatory support as quickly as possible, a reduction in sedatives with frequent pain assessment, with analgo-sedation the preferred goal. The treatment and prevention of delirium is also included in the bundle, as is increased physical activity and accommodation of support from relatives. This treatment philosophy is implemented in many ICUs worldwide, and a growing body of evidence supports the ABCDEF-bundle as safe and positive for patient outcomes (Balas, Buckingham, Braley, Saldi, & Vasilevskis, 2013; Balas et al., 2012; Balas et al., 2014; Trogrlic et al., 2015). Some years later, the early comfort and patient-centered care without excessive sedation concept (eCASH-concept) was also launched (Vincent et al., 2016). This concept was developed as a guide for HP in coping with some of the challenges of providing patient-centered care in ICUs due to the increasing number of conscious and alert, non-vocal mechanically ventilated patients.

Although the non-sedative practice has been controversial in the scientific community, a study from Denmark indicates that this approach does not have any more long-term psychological sequela for the patients relative to the daily awakening sedation regimes (Strøm, Stylsvig, & Toft, 2011). Many intensive care patients develop symptoms of post-traumatic stress and struggle with their experiences during the period of critical illness both mentally and physically. Today, this is recognized as a specific condition among previous ICU patients, and called post intensive care syndrome (PICS) (Harvey & Davidson, 2016). It is hypothesized that more than half of all intensive care survivors suffer from some aspects of PICS (Up to date, 2019). Myhren et al.'s study (2010) in which they followed 194 former

intensive care patients over a year, revealed the relevance of this in the Norwegian context. Of the patients included, 27% were over the cut-off level for predicting post-traumatic stress symptoms (22.5) according to the Impact of Event Scale ratings. ICUs have started to incorporate patient diaries into their care or in follow-up clinics to help patients who struggle after leaving intensive care (Gjengedal, Storli, Holme, & Eskerud, 2010; Modrykamien, 2012; Ullman et al., 2015). However, these are not standardized services implemented in all ICUs. The majority of ICU-patients are left to manage their experiences on their own after hospital discharge.

The United Nations (2006) declaration on disability states it is a universal right to have access to communication despite existing barriers and that everyone should have the possibility of using compensatory communication aids when they have a functional speaking disorder. Norway also has one of Europe's most formalized rights to participate in clinical decision-making though its Patients' Rights Act (1999). In §3-1, this explicitly states:

> The patient or user has the right to participate in the implementation of health and care services. Among other things, the patient or user has the right to participate in choosing between available and justifiable forms of services, examinations and treatment methods. The form of participation must be adapted to the individual's ability to give and receive information. (Patients' Rights Act, § 3-1; translated freely from Norwegian by the PhD student)

In the western world, there is an increasing ethical and legal obligation to promote patient-centered care, which will also affect the treatment of critically ill patients. As a result, patients expect to participate in their care and treatment decision-making, and they expect to encounter a flexible and adaptable healthcare system (McCormack, 2003; Stiggelbout, Pieterse, & De Haes, 2015). This can mean that patients participate in deciding treatment goals. During this decision-making process, it is expected that the HP will discuss the patients' treatment options, ask for the patient's personal preferences, and incorporate scientific evidence for the various options into the dialogue (Kon, Davidson, Morrison, Danis, & White, 2016). The decisions can be of different types, such as overarching goals (chemotherapy or radiation), or choices between different medications for the same disease. They may also include bedside micro-decisions about treatment and care, the small-scale decisions that are made numerous times a day at a patient's bedside (Hardyman, Daunt, & Kitchener, 2015). In ICUs, typical

micro-decisions may be deciding when and how to perform physical activity, tracheal suctioning, attempts at weaning from the ventilator or adjusting the dosage of medication such as sedation or analgesia.

Kuhn (2012, p. 22) defines a paradigm as "actual scientific practice-examples which include law, theory, application, and instrumentation together-provide models from which spring particular coherent traditions of scientific research." As defined, a paradigm is therefore a description of what we hold to be the truth at a specific moment. An anomaly in an accepted truth will eventually lead to the creation of a new truth and possibly, a new paradigm. This can change the fundamental basic concepts and experimental practice of a scientific discipline and our perception of normality. Through a process of recognition, new terminology and new areas for scientific activity are created. This means that a scientific field will evolve, on the basis of the new concepts developed over time. Several researchers claim that we are in the midst of a paradigm shift in intensive care through the application of analgo-sedative strategies (Egerod, 2009; Kress, 2013; Strøm & Toft, 2016). Through this thesis, I argue for the need for a more comprehensive understanding of the phenomenon of communication with conscious and alert patients on mechanical ventilation in ICUs. Descriptions and interpretations of how this occurs between patients and HP will be presented by using previous studies, combined with video recordings and interviews, as data material.

2.2 The conscious and alert patient on mechanical ventilation

2.2.1 Critical care illness

Intensive care patients are critically ill with potential, manifest or acute failure in one or more several vital functions, and the failure is fully or partly reversible. Their condition implies the need for increased surveillance and treatment (Norwegian Association of Critical Care Nurses, 2015). There are multiple medical reasons for being admitted to critical care units, but the common factor is that patients are critically ill. Intensive care patients require constant attention and advanced support by specialized HP, who typically include anesthesiologists, critical care nurses, ward-responsible physicians, and physiotherapists. ICU treatment often implies the support of vital functions through the use of advanced technological equipment

such as ventilators or dialysis (Norwegian Society of Anesthesiology and the Norwegian Associaton of Critical Care Nurses, 2014).

Sedation and analgesia are commonly used in the treatment of critical illness, both as a means of enabling the patient to handle the treatment and also to reduce the impact of sensory impressions, to treat agitation, and to lower the cerebral metabolism. (Devlin et al., 2018; Reade & Finfer, 2014). Validated instruments is recommended for assessing a patient's condition, including mental scores and sedation scores[1] (J. Barr et al., 2013; Devlin et al., 2018; Trogrlic et al., 2015). The scoring systems can be used to determine adherence to treatment goals and the patient's capacity to interact with the staff or relatives. These scoring systems provide an understanding of how patients are functioning cognitively and how alert they are. However, they do not assess patients' capability to communicate non-vocally.

2.2.2 Assessment of communication skills and commonly used terminology

No scale exists in widespread use that assesses communication skills of the mechanically ventilated patient. However, a communication screening protocol has been suggested and implemented in some ICUs, as seen in Figure 1 (Happ et al., 2015).

ICU Communication Screening Protocol*

Is patient alert?	Y or N	Partial
Can patient follow commands? -Raise your arm and make a fist._____ -Blink your eyes twice._____	Y or N	Partial
Does patient have a reliable yes and no signal? -How does patient signal yes? _____ -How does patient signal no? _____	Y or N	Partial
Can the patient point? -Point to your feet. -Point to your (name of family member) in person or in a photo.	Y or N	Partial
Can the patient write?(assess literacy & motor ability) -Write your name. -Write your favorite color.	Y or N	Partial
Are patient's mouth movements clear when mouthing speech? -Count from 1 to 10. -Tell me what your first job was (in a sentence).	Y or N	Partial

[1] A number of scores exist for sedation, delirium, and management of pain in intensive care without going further in detail in this thesis. There has also been a development in guidelines the recent decades. Barr et al. (2013) published a consensus guideline for agitation, sedation and pain on behalf of the American College of Critical Care Medicine (a revision of 2002 guidelines in the USA about sustained used of sedatives and analgesics). The newest guidelines from Devlin et al. (2018) for the prevention and management of pain, agitation/sedation, delirium, immobility and sleep disruption in adult ICU patients are developed based on Barr et al. (2013). The panel responsible for the last revision was a global expert group and established through the Society of Critical Care Medicine.

Figure 1. ICU Communication Screening Protocol, SPEACS-2 Communication Program, https://nucleus.con.ohio-state.edu/media/speacs2/speacs.htm.

Each patient's unique motor and cognitive skills impact on the various challenges HPs encounter in their interactions with patients. Some patients can be paralyzed due to ICU weakness and communicate only by blinking their eyes. Other patients are able to write on their own, or even use a tablet or cell phone. Table 1 presents the terminology found during a search of previous literature. It illustrates the variety of professional language that exists to describe the conscious and alert patient on mechanical ventilation. The terminology used is also sometimes value-laden: for example, "cognitively intact ventilator-dependent patient," or "non-sedated and more awake," imply something very distinct from "dysarthric patient." Some of the terminology is also difficult to interpret without having experience caring for these patients in the ICU, such as the subtle difference between a "fully conscious-patient" or a "non-sedated more awake patient."

Terminology	**References using the terminology**
Clients on mechanical ventilator	Rathi, R. & Baskaran, M. (2014)
Cognitively intact ventilator-dependent patient	Leder, S. B., Pauloski, B. R., Rademaker, A. W. Grammer, T., Dikeman, K., Kazandjian, M. Mendes, J. & Logemann, J. A. (2013)
Conscious while receiving/during mechanical ventilator treatment/respirator treatment	Karlsson, V. & Forsberg, A. (2008) Karlsson, V., Bergbom, I. & Forsberg, A. (2012) Karlsson, V., Forsberg, A. & Bergbom, I. (2012) Karlsson, V., Lindahl, B. & Bergbom, I. (2012)
Communication challenges/problems/difficulties/experiences with patients on mechanical ventilation	Dithole, K. S., Sibanda, S., Moleki, M. M. & Thupayagale-Tshweneagae, G. (2016) Wojincki-Johansson, G. (2001) Tembo, A. C., Higgins, I. & Parker, V. (2015) Flinterud, S. I. & Andershed, B. (2015) Patak, L., Gawlinski, A., Fung, N. I., Doering, L., Berg, J. & Henneman, E. A. (2006)
Critically ill non-sedated mechanically ventilated patients	Laerkner, E., Egerod, I. & Hansen, H.P. (2015)
Dysarthric ICU-patients	Maringelli, F., Brienza, N., Scorrano, F., Grasso, F. & Gregoretti, C. (2013)
Fully conscious patients	Maringelli, F., Brienza, N., Scorrano, F., Grasso, F. & Gregoretti, C. (2013)
Intubated (intensive care unit) patients (being unable to speak)	El-Soussi, A. H. Elshafey, M. M., Othman, S. Y. & Abd-Elkader, F. A. (2015)

	Happ, M. B., Garrett, K. L., Tate, J. A., DiVirgilio, D., Houze, M. P., Demirci, J. R., George, E. & Sereika, S. M. (2014)
Lighter (or no) sedation (regimens)	Baumgarten, M., & Poulsen, I. (2015) Egerod, I., Bergbom, I., Lindahl, B., Henricson, M., Granberg-Axell, A. & Storli, S. L. (2015) Karlsson, V., Bergbom, I. & Forsberg, A. 2012)
Loss of voice	Donnelly, F. & Wiechula, R. (2006)
Nonspeaking (critically ill/hospitalized) patients treated with mechanical ventilation (in the intensive care unit)	Happ, M. B., Tuite, P., Dobbin, K., DiVirgilio-Thomas, D., & Kitutu, J. (2004) Happ, M.B., Garrett, K., Thomas, D. D., Tate, J., George, E., Houze, M., Radtke, J. & Sereika, S. (2011) Rodriguez, C. S. & Blischak, D. M. (2010)
Nonvocal (ventilated) patients	Carroll, S. M. (2004, 2007)
Non vocal patient communication	Happ, M. B., Sereika, S. M., Houze, M. P., Seaman, J. B., Tate, J. A., Nilsen, M. L., Van Panhuis, J., Sculli, A., Paull, B., George, E., Angus, D. C. & Barnato, A. E. (2015)
Non-sedated and more awake	Laerkner; E., Egerod, I. & Hansen, H. P. (2015)
Temporarily non-speaking	Happ, M. B., Tuite, P., Dobbin, K., DiVirgilio-Thomas, D., & Kitutu, J. (2004) Happ., M. B., Roesch, T.K. & Garrett, K. (2004)
Nonverbal	Happ, M. B., Tuite, P., Dobbin, K., DiVirgilio-Thomas, D., & Kitutu, J. (2004) Happ., M. B., Roesch, T. K. & Garrett, K. (2004)
Patients being (connected to/undergoing) mechanically ventilated (during) critical illness in intensive care units	Baumgarten, M. & Poulsen, I. (2015) Cutler, L. R., Hayter, M. & Ryan, T. (2013) Egerod, I., Bergbom, I., Lindahl, B., Henricson, M., Granberg-Axell, A. & Storli, S.L. (2015) Happ, M. B., Garrett, K. L., Tate, J. A., DiVirgilio, D., Houze, M. P., Demirci, J. R., George, E. & Sereika, S. M. (2014) Engström, P., Nyström, N., Sundelin, G. & Rattray, J. (2013) Jordan, P. J., Van Rooyen, D. & Strümpher, J (2002) Patak, L., Gawlinski, A., Fung, N. I., Doering, L. & Berg, J. (2004)
Patients requiring artificial ventilation	Wojincki-Johansson, G. (2001)
Patients treated with mechanical ventilation	Khalaila, R., Zbidat, W., Anwar, K., Bayya, A., Linton, D. M. & Svriri, S. (2011)
Patient who are voiceless due to mechanical ventilation	Kozalinski, R. S., Tappen, R. & Viggiano, D. (2015)
(hospitalized) Suddenly speechless critical care patients	Rodriguez, C. S., Rowe, M., Thomas, L., Schuster, J., Koeppel, B. & Cairns, P. (2016) Rodriguez, C. S., Spring, H. J. & Rowe, M. (2015)
Temporary or permanent speech impairments	Rodriguez, C. S. & Bilschak, D. M. (2010)

Tracheostomised patients in intensive care	Flinterud, S. I. & Andershed, B. (2015)
Unable to speak out loud	Carroll, S. M. (2004, 2007)
Unable/able to speak/talk/communicate (as result of ventilation)	Magnus, V. S. & Turkington, L. (2006) Guttormson, J. L., Bremer, K. L. & Jones, R. M. (2015) Fitch, M. I., Remus, S. & Stade, B. (1998) Carroll, S. M. (2004)
Voicelessness	Carroll, S. M. (2004, 2007)

Table 1. Terminology used to describe conscious patients on mechanical ventilation in intensive care units.

2.2.3 Communication with relatives during critical care illness

When a patient is admitted to an ICU, relatives play an important part as the patient's advocate and decision-making surrogates, and they often know more about the patient's desires and preferences than the HP. The patient usually appreciates visits from their loved ones and needs their presence. However, former patients report how the encounters were affected by the communication barriers they experienced (Engström et al., 2013; Karlsson, Lindahl, et al., 2012).

The relatives, on the other hand, describe feeling helpless, not knowing how to make contact, or failing to understand what their loved ones are trying to communicate. Frivold et al. (2015) interviewed the relatives of patients and described their experience of finding themselves in two roles: in the role of family member they needed the support of the HP, but as a caregiver they must be supporting the patient. Post Intensive Care Syndrome also encompasses the family of patients (PICS-F). The participation of relatives in decision-making and patient care are described as essential to reducing psychological stress (Davidson, Jones, & Bienvenu, 2012; Davidson et al., 2007). HP have a special obligation to ensure continuity and quality in their communication with relatives in a crisis, and to educate them about how to communicate with their loved ones. However, in this thesis, the focus is on communication and interaction with the patient. Hence, the impact of communication with relatives is beyond the scope of the thesis.

2.3 Current knowledge about communication and interaction with patients on mechanical ventilation

Figure 2 displays a PubMed result on communication and intensive care units as MESH-terms, drawn from all published papers from 1963 up until 2016. Especially over the last twenty years, there has been a considerable increase in published articles, in line with the paradigmatic shift in the treatment philosophy. In 2016, there were over 400 publications.

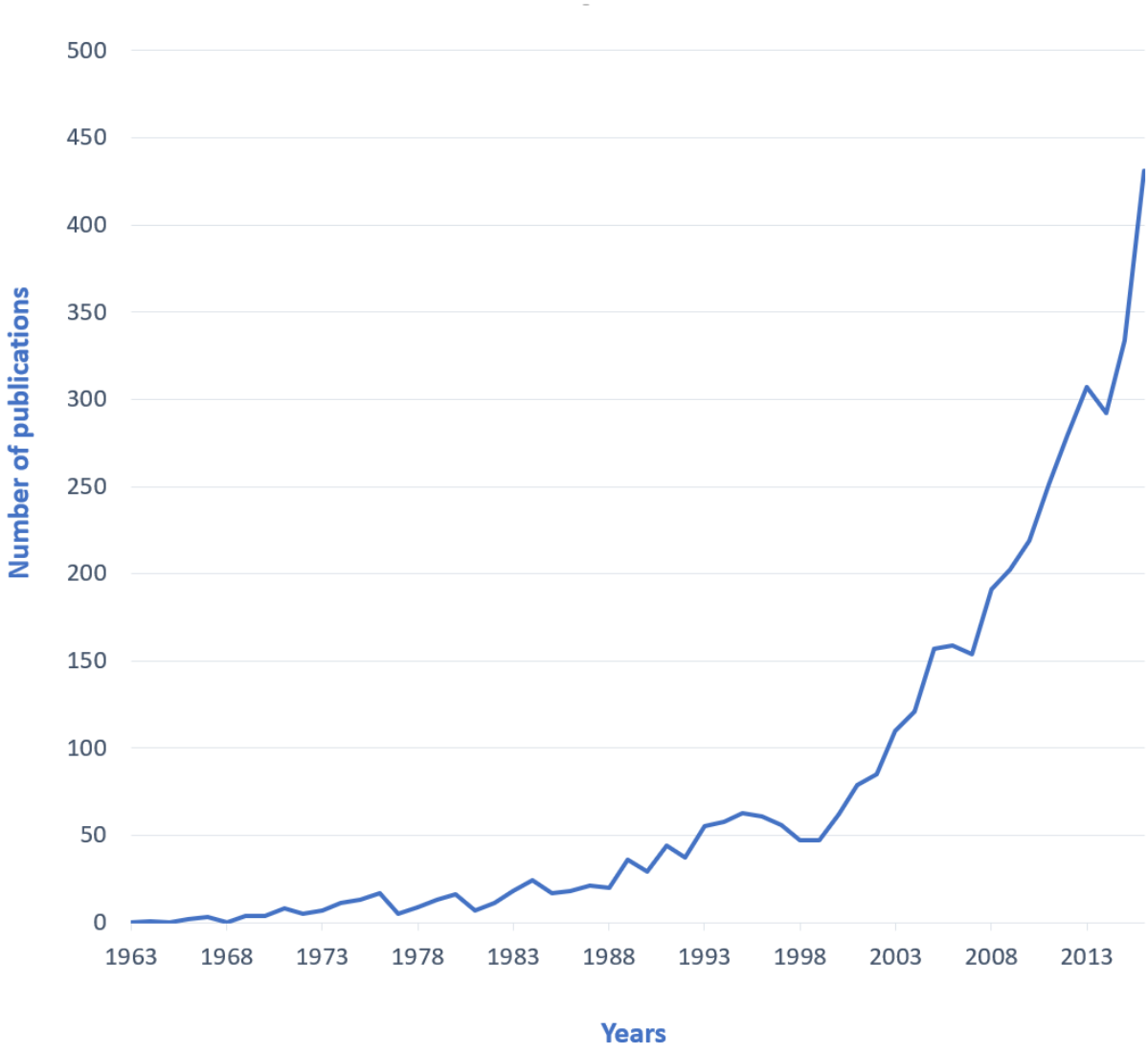

Figure 2. Increase in publications with search terms 'communication' and 'intensive care unit', PubMed.

2.3.1 Literature reviews summarizing the current knowledge

In the preparation for this thesis, the literature search was limited to recent studies, defined as 1998 or later. This was when the first publications about the benefits of less sedation was identified. Nine essential literature reviews were identified, displayed in table 2. Here, patient experiences of intensive care, communication, and patient participation are presented chronologically.

Review	Aims and methodology	Sample	Findings	Conclusion
Llenore, E. & Ogle, K. R. (1999)	*Aim:* To review the literature on nurse-patient communication in the ICU *Methods:* Literature review (not defined methodology)	24 studies (1980-1997) Unidentified number of participants	The literature reveals a challenge in nursing practice when communicating with patients on mechanical ventilation due to many factors, such as patient's communication abilities, nursing attitudes, and workload.	Patients are able to remember significant parts of their ICU-stay. Communication strategies fail to be implemented in clinical practice.
Carroll, S. M. (2004)	*Aim:* To explore what characterizes the non-vocal ventilated patients' perceptions of being understood *Method*: Qualitative metasynthesis	12 qualitative studies (1982-2000) 111 participants included in all the studies, ranging from 1-30	Five overarching themes with subcategories categorized in two groups: the characteristics of non-vocal patients' communication *(not being understood, loss of control, negative emotions)* and nursing care desired *(individualized care and caring presence)*.	There are basic similarities in findings across the studies where patients describe negative experiences related to the lack of voice. The nurses have a critical role in facilitating communication with this patient population.
Finke; E. H., Light, J. & Kitko, L. (2008)	*Aim:* To systematically review the research regarding communication between nurses and patients with complex communication needs *Method:* Systematic review	12 studies (1993-2007) with both qualitative and quantitative designs Participants: 204 77 patients 13 Family members 114 Professionals Ranging from 1-39 Did not only include intensive care patients, also patients with cerebral palsy	Importance of nurse-patient communication (9 of the 12 studies) Barriers to effective nurse-patient communication (11 of the 12 studies) Supports for effective nurse-patient communication (11 of the 12 studies) Recommendations for communication (4 of the 12 studies)	Nurses have limited formal education or experience with augmentative and assisted communication systems. This makes it difficult for nurses to take greater responsibility and to promote successful communication.

Cutler, L. R., Hayter, M. & Ryan, T. (2013)	*Aim:* To critically review the literature to describe the themes associated with the experience of critical illness and to consider how these inform the patient's understanding *Method:* Inspired by systematic review approach but has broad inclusion criteria	26 qualitative studies (1965-2011) 677 participants included in all the studies, ranging from 5-250	Eight main themes. Transformation of perceptions: unreal experiences and dreams, proximity to death, transformation and perception of body in illness, transformation and perception of time, the critical care environment: technology and dependence, care communication and relationships with healthcare professionals, the support of family and friends and desire for contact, transfer from critical care and recovery from critical illness.	The experience of an ICU stay is individual but there are common threads of personal meaning. A more comprehensive long-term perspective is needed in future research.
Baumgarten, M. & Poulsen, I. (2015)	*Aim:* To gather and synthesize interpreted knowledge from qualitative studies about patients' experiences of being mechanically ventilated *Method:* Qualitative metasynthesis	9 qualitative studies (1994-2012) 335 participants in all the studies included, ranging from 8-250.	Not being able to communicate, experiences of staff being present, experience of changed bodily functions, experience of the ICU, experience of the time, experience of sleep, experience of anxiety, fear and loneliness, experience of being dependent, experience of suction, experience of involvement, experience of hope and longing, importance of relatives/significance of relative.	Patients being mechanically ventilated experience vulnerability. This should be taken into consideration in the daily care of the mechanically ventilated patient.
Egerod, I., Bergbom; I., Lindahl, B., Henricson, M., Granberg-Axell, A. & Storli, S. L. (2015)	*Aim:* To systematically review and reinterpret newer Nordic studies of the patient experience of intensive care to obtain a contemporary description of human suffering during life-threatening illness	22 qualitative studies (2000-2013) 188 participants included in the studies, ranging from 1-19	The patient experience when life itself is at stake was the main description of the patients' experiences. Four themes further elaborating on this further were: existing in liminality, existing in unboundness, existing in mystery, and existing on the threshold.	Suffering is a natural consequence of intensive care. The patients may enter a liminal, vulnerable state. To assist the patients back to life, caring values in nursing are essential.

	Method: Qualitative meta-synthesis			
Dithole, K., Sibanda, S., Moleki, M. M. & Thupayagale-Tshweneagae, G. (2016)	*Aim:* To identify communication challenges that exist between nurses and mechanically ventilated patients in intensive care *Method:* Systematic review	6 studies (2005-2014) 244 participants included in the studies, ranging from 4-99	Factors influencing communication that that have been studied: Patient attributes, nature of nurse-patient interactions, communication methods, staff skills and perceptions, and the impact of the ICU physical environment.	There is a need for communication assessment, since patients vary in communication challenges. Nurses have a particular responsibility to implement communication strategies and reduce the challenges.
Olding, M., McMillian, S. E., Reeves, S., Schmitt, M. H., Puntillo, K. & Kitto, S. (2016)	*Aim:* To investigate the extent and range of literature on patient and family involvement in critical care and intensive care settings *Method:* Scoping review	124 articles were included (2003-2014) Interprofessional staff, family and patients included in 61 quantitative, 61 qualitative and 2 mixed method studies	The findings revealed various research gaps, and the most prominent areas of research Five components of patient/family involvement were identified: presence (n = 40), having needs met/being supported (n = 33), communication (n = 17), decision making (n = 17) and contribution to care (n = 12)	A variety of research gaps were identified, such as the scope and extent of patient involvement, the broader socio-cultural processes, and the co-dependent links between patient/family involvement and interprofessional teamwork.
ten Hoorn, S., Elbers, P. W., Girbers, A. R. & Tuinman, P. R. (2016)	*Aim:* To summarize current published evidence on communication methods used with adult nonverbal mechanically	31 articles representing 29 different randomized controlled trials, quasi-experimental and	Four communication intervention types identified: communication boards, specialized tracheostomy tubes, electrolarynx and high tech augmentative and	The implementation of augmentative and alternative communication resulted in an improvement in

	ventilated patients in the ICU *Method:* Systematic review.	observational studies about communication interventions in ICUs were identified (1973-2015) 635 participants included in the studies, ranging from 1-90.	alternative communication devices	communication with mechanically ventilated patients. A combination of various augmentative and alternative communication devices may be the most effective approach.

Table 2. Literature reviews patients and HP experiences of communication and patient participation in ICUs.

The first study conducted in Norway on patients' experiences of communication while being mechanically ventilated was published in 1994. Gjengedal (1994) interviewed eighteen patients following intensive care during her PhD study. The patients reported that the loss of voice was probably one of their worst experiences while being mechanically ventilated during their intensive care stay. The experience of trying to communicate was exhausting, and they had vivid, confusing, and sometimes frightening, recollections of their stay. Storli and colleagues (2008) explored patients' memories ten years after their intensive care stays. The interviews revealed that former patients still had profound, and sometimes frightening, memories about this period in their lives. Since 2008, numerous studies have been performed, especially within Scandinavia (Egerod et al., 2015) that focus on the existential and unique experience of being critically ill. Communication barriers are reported in most of these studies (see Table 2 for details) as important aspects of the intensive care stay that are in need of further exploration.

2.3.2 Current knowledge about communication during an ICU stay

This section will describe the findings from identified studies performed during the ICU-stay. Menzel (1998) explored 48 patients' self-esteem, difficulties with communication, and emotional responses to a lack of voice. Patients experienced moderate feelings of worry and anger. An average of 3.6 ways of communication (such as gestures, writing, and lip-forming) were found. The study also showed a positive association between severity of illness, greater difficulty in communication, lower self-esteem and the feeling of anger of being unable to speak.

Carroll (2007) interviewed 19 patients in Canada while they were being ventilated to explore their experiences of being admitted to the ICU. The patients described the experience as "living in a silent, slow lifeworld." The results emphasized how important the possibility of communicating was to the patients so they could participate in what was going on.

Karlsson and colleagues have observed, video recorded, and interviewed (both during and after an intensive care stay) patients on mechanical ventilation in Sweden (Karlsson, Bergbom, et al., 2012; Karlsson & Forsberg, 2008; Karlsson, Forsberg, et al., 2012; Karlsson, Lindahl, et al., 2012). The interviews with 15 patients who were on mechanical ventilation at the time lasted for only 3-16 minutes, due to the patients' exhaustion when communicating their experiences non-vocally. The study revealed the extent of the discomfort patients experience at being able to communicate. They also hoped for improvement in their illness and longed for the presence of their relatives as that made them feel secure (Karlsson, Lindahl, et al., 2012).

Happ and colleagues have reviewed patient documentation and studied patients' experiences of communication and involvement in intensive care units in the USA by using observational methods (Happ et al., 2011; Happ, Swigart, Tate, Hoffman, & Arnold, 2007; Happ, Tuite, Dobbin, DiVirgilio-Thomas, & Kitutu, 2004). These studies revealed that nurses are the main professionals mainly responsible for communication with the patient. In one of the studies almost half of the treatment decisions documented in one of the studies occurred without the patients being invited to participate in the decision-making process. Most of the decisions identified were typical bedside micro-decisions, such as weaning from mechanical ventilation, from feeding tubes, or withdrawal of dialysis (Happ et al., 2007).

In the following sections, I will continue to describe the main barriers to communication and interaction with the mechanically ventilated patient. The current knowledge status regarding experiences of patients and HP with communication during mechanical ventilation will then be presented.

2.3.3 Physical barriers for communication during mechanical ventilation

The endotracheal tube or the tracheostomy impedes the flow of air passing through the vocal cords to produce voice and is the most significant barrier to communication for the patient on

mechanical ventilation. ICU-acquired weakness is commonly manifested in critically ill patients in three ways : neuropathy, myopathy, or muscle atrophy (Jolley, Bunnell, & Hough, 2016; Kress & Hall, 2014). The incidence of ICU-acquired weakness is both underreported (somewhere between 25-100 % in total) and hard to diagnose. Exact numbers of patients suffering from this condition are also hard to obtain due to the difficulties in testing (Jolley et al., 2016; Kress & Hall, 2014). The patient's reduced strength eventually impedes their ability to communicate. Not being able to move their limbs or lips, can further reduce their ability to communicate by non-vocal signals.

Environmental and physiological barriers to communication also reduce intensive care patients' ability to communicate. Different types of restraints are widely used in ICUs, although very variable in prevalence (Benbenbishty, Adam, & Endacott, 2010). Some professionals claim that physical restraints are necessary to ensure patient safety and to prevent the risk of self-extubating. However, conflicting evidence exist about this (Devlin et al., 2018). In Scandinavian ICUs, physical restraints are not part of the cultural norm or clinical practice (Benbenbishty et al., 2010). Many Scandinavian ICUs have reported the implementation of analgo-sedative or non-sedative approaches (Egerod, Albarran, Ring, & Blackwood, 2013; Strøm et al., 2010; Wøien, Værøy, Aamodt, & Bjørk, 2014). Another factor impacting the interaction between patients and HP's is the physical environment of the ICUs, often described as confusing and harsh, with a lot of noise, light, activity, and constant interruption, making it hard to sleep or concentrate (Meriläinen, Kyngäs, & Ala-Kokko, 2010, 2013; Reade & Finfer, 2014). It may, for example, be harder to get the attention of the HP if the room contains many patients and much noisy technology.

Whether patients are orally intubated or tracheostomized, it affects their ability to form words and makes it difficult for HP to read their lips. Many ICUs now practice early percutaneous dilatational tracheostomy. The tracheostomy makes it easier for the patients to be conscious and communicable during mechanical ventilation, and it is considered more comfortable for the patients than an endotracheal tube (Norwegian Intensive Care Registry, 2016; Rørbæk Madsen, Guldager, Rewers, Weber, & Køpke-Jacobsen, 2015).

In summary, the physical barriers mentioned can contribute to patients' feelings of being almost paralyzed and unable to control their own bodies, while also being important communication barriers in the ICU (Egerod et al., 2015; Gjengedal, 1994).

2.3.4 Psychological and cognitive barriers to communication during mechanical ventilation

Delirium reduces the patient's cognitive ability to communicate their needs. Although estimates are inconsistent, up to 80 % of the patients on mechanical ventilation experience delirium during their ICU stay (Critical Illness Brain Dysfunction and Survivorship Center, 2019). Delirium is defined as "a disturbance of consciousness with inattention accompanied by a change in cognition or perceptual disturbance that develops over a short period (hours to days) and fluctuates over time" (Critical Illness Brain Dysfunction and Survivorship Center, 2019). Many patients report these symptoms both during and after their ICU stay (Guttormson et al., 2015; Myhren et al., 2010; Tembo et al., 2015). A range of explanations exist for the development of delirium: it is linked to medication, the illness itself, to the environment, or to individual patient characteristics such as feelings of frustration and anxiety (Reade & Finfer, 2014). The long-term cognitive impairment in ICU survivors is reported to be significant. Memory loss and attention problems have also been reported in patients after an ICU stay. In a multi-center study with a mixed intensive care patient population, 40% of patients had global cognition scores 1.5 standard deviation (SD) below the population means three months after their ICU stay. One out of four patients had cognitive impairment even one year after their ICU stay (Pandharipande et al., 2013).

No clear link exists between communication barriers and the development of delirium. However, being able to communicate does have a positive impact on the psychological state of intensive care patients (Flinterud & Andershed, 2015; Karlsson & Forsberg, 2008; Menzel, 1998). Communication and patient involvement are also reported to inspire hope for the future and a will to keep on fighting through the critical illness experience (Alpers, Helseth, & Bergbom, 2012; Karlsson & Forsberg, 2008).

2.3.5 Organizational barriers to communication during mechanical ventilation

Currently, approximately 13 700 patients are admitted to the Norwegian ICUs each year (Norwegian Intensive Care Registry, 2016). There is no nationwide register documenting their consciousness levels, or for how much of their intensive care stay they have been able to communicate. Approximately 60% of these patients require mechanical ventilation during their stay. In the United States, the estimated number is 5.7 million ICU admissions annually

(Society of Critical Care Medicine, 2018). If 60% of these patients are on mechanical ventilation, annually, 3 420 000 patients, in the United States alone, may be struggling to communicate during their hospital stay. Unfortunately, there is no European register of how many patients are admitted, and whether or not they are conscious.

ICUs are extremely demanding on resources, and staffing costs are a substantial part of the hospital's budget. Staffing and the time available for direct patient care will vary across countries. The current recommendations in Norway is a minimum of 1:1, or more, depending on the severity of the illness and nursing workload (Norwegian Society of Anesthesiology and the Norwegian Associaton of Critical Care Nurses, 2014).

2.3.6 Communication aids available for intensive care patients on mechanical ventilation

Augmentative and alternative communication (AAC) refers to the aids and alternative methods of communication provided for patients with various kinds of speech disorder (Hurtig & Downey, 2008). Although communication aids are not the main focus of this thesis, it is an important area for improvement in clinical practice. In addition, it is strongly linked to the communication and interaction in the ICU. However, critically ill patients are described as an under-prioritized group in the field of speech-language pathology (Hurtig & Downey, 2008; Mobasheri et al., 2016). Little use of communication aids as standard clinical practice has been reported in ICUs (Happ et al., 2011; Mobasheri et al., 2016). Several low- and high-tech communication aids have been both developed, tested, and implemented, with positive outcomes. Many of the studies have been done with small samples, and some are only pilot studies or small quality-improvement projects by ICUs. Few of the studies reported have implemented more than one communication aid at a time (Happ et al., 2014; Happ et al., 2015; Ten Hoorn et al., 2016). Appendix 1 of the thesis presents identified studies, from 1998 until this study started in 2016, that have tested communication aids, together with their findings. Two algorithms for assessing communication skills and choosing between communication aids have been developed, of which one has been reported in use (Happ et al., 2015; Ten Hoorn et al., 2016). The communication barriers encountered in intensive care imply the need for a variety of tools to enhance the quality of care and, this way, to relieve patient suffering.

2.3.7 Healthcare providers' experiences and the use of aids in the care of mechanically ventilated patients

A team of HPs caring for intensive care patients will include a range of professionals with specialized skills and varied areas of responsibility. The composition of an ICU team will differ between countries. In Norway, the professionals most commonly participating in ICU treatment on a regular basis are nurses, physicians and physiotherapists. The majority of former studies have explored nurses' experiences of communication and interaction with the patients on mechanical ventilation. These studies, using observations, interviews and questionnaires, reveal that nurses see it as a challenge, both to both ensure understanding and also to involve the patients in their daily care (Laerkner et al., 2015; Tingsvik, Bexell, Andersson, & Henricson, 2013). Magnus & Turkington (2006) included physiotherapists and physicians in their study about communication and interaction with ICU patients. Their findings reveal that there was a disparity between the patients and the HP in their perceptions of the communication difficulties, with the patients rating their experience of communicating as being more difficult than the HP.

Happ and colleagues designed a four-hour educational course (SPEACS) for nurses to increase HP competence with the use of communication aids. They evaluated the course-effect based on 356 video recorded observations of the nurses' interactions with patients (89 nurse-patient dyads, video recorded several times). They measured the frequency of communication acts and the number of positive nurse behaviors (such as physical assistance of patients in communication, repeating patient responses for clarification, augmenting comprehension, or greeting patients by name). They then assessed the success and quality of the communication based on observation. The course was found to have had an impact on nurses' communication patterns in only one of the two ICUs included in the study ($p = 0.02$) (Happ et al., 2014). The educational program was therefore redesigned as a one hour online-course. Standardized communication materials were implemented in the ICUs and a weekly speech-language pathologist round was initiated in the participating ICUs (SPEACS-2). A total of 1440 patients were included (626 pre-intervention group, 814 intervention group) in the study. The nurses improved their overall knowledge about communication after the online course (from 3.21–3.42, $p < 0.001$). However, no significant difference was found in the selected outcomes: nursing care, ICU days with physical restraint, heavy sedation, pain score documentation, or length of stay (Happ et al., 2015).

Some studies have described interprofessional interaction in relation to specific topics, such as communication and end-of-life care. Conflicts have been reported at many levels in ICUs relating to interprofessional care, both between different groups of professionals and more often, relatives or patients (Fassier & Azoulay, 2010). Breen et al. (2001) had similar results, finding that that the HP or the relatives reported an experienced conflict in almost 80% of the encounters. Rose et al. (2014) found it was essential for a team to have good communication with patients to facilitate treatment and the process of weaning from mechanical ventilation.

In summary, it would seem that the application of AAC devices and training off the HP in the use of these is an important, and especially challenging area of care (Vento-Wilson, McGuire, & Ostergren, 2015). The results of previous studies indicate that the impact of communication on both patients and providers in ICUs requires further attention.

2.4 Knowledge gaps

Despite the apparent development and interest in the topic of communication and patient involvement in intensive care, recent studies report that the patients in intensive care still struggle to express themselves (Egerod et al., 2015; Happ et al., 2011; Karlsson, Bergbom, et al., 2012). No studies have been conducted in Norway on the use of communication aids in this context. Previous studies' recommendations have not been fully implemented in clinical practice (Hurtig & Downey, 2008; Mobasheri et al., 2016). Even if the lack of voice is temporary, the literature shows that it impacts the patient negatively and affects the quality of care and treatment. Important core components have been identified that affect the patient-provider interaction, such as the patient's ability to communicate, the severity of the patient's illness, and situational and environmental factors. It is apparent that more empirical studies are needed to illuminate this topic. This is especially pressing considering the complexity of the communication with patients on mechanical ventilation.

So far, the majority of the studies have been based on retrospective accounts of patients' experiences. This has contributed to the development of the field, but there is still a knowledge gap about the actual interaction between patients on mechanical ventilation and HP. Detailed knowledge about how patients attempt to communicate is needed in order to

understand how professionals can facilitate patients' attempts to express themselves. Several important communication topics, such as patient participation, also appear to be gravely under-investigated (Happ et al., 2007; Olding et al., 2016). There are few examples of ICU interventions that have tried to improve HP communication skills at an advanced level (Carruthers, Astin, & Munro, 2017; Ten Hoorn et al., 2016). HP therefore have little evidence-based guidance about how to deliver their care in the ICU. Lastly, much of the literature has been conducted from the nursing perspective and does not include the perspectives of other professionals. To gain a more comprehensive understanding, it is necessary to study all professions who have responsibilities related to patients on mechanical ventilation in ICUs. This is in line with the knowledge gaps identified in the literature (Olding et al., 2016). This thesis will, therefore, explore aspects of communication and interaction between mechanically ventilated patients and HP, using video recordings and interviews to obtain rich descriptions of clinical practice in the ICU.

3.0 Objectives and research questions

The overarching objective of this thesis was to obtain in-depth knowledge of the communication and interaction between patients and healthcare providers when patients are conscious and alert during mechanical ventilation in ICUs. The thesis has four aims:

- To assess previous knowledge about interaction and communication between healthcare personnel and conscious and alert patients under mechanical ventilation in intensive care units.
- To explore the interaction between mechanically ventilated patients and healthcare personnel in intensive care units, with a special emphasis on patients' initiation of communication.
- To explore how beside micro-decisions were made between conscious patients on mechanical ventilation in intensive care and their healthcare providers.
- To explore healthcare providers experiences of their collaboration and communication with conscious patients on mechanical ventilation in intensive care.

4.0 Theoretical perspectives

4.1 A phenomenological-hermeneutical approach

A phenomenological-hermeneutical approach investigates the meanings of a phenomenon, with the particular purpose of understanding the human experience. The phenomenon in this study is communication and interaction between patients on mechanical ventilation and healthcare providers. Phenomenological hermeneutics can be understood both as an ontological way of understanding the world and also as an epistemological approach to interpretations of data (Creswell & Poth, 2013; Zahavi, 2010). Practical acts of living can reveal the underlying meanings of a phenomenon, usually through observations or interviews. Heidegger, one of the founders of this approach, argued that our existence is inseparable from the world in which we live (1996). According to Heidegger, as human beings, we are constituted by our interpretations of the world. Meaning is created by the individual, through their own language, cultural tradition, and context, and also through the individual's existence in their own lived body (1996).

The context for this study is the ICU-environment. Here, patients and HP create their own meaning for the situations that arise in their interactions, and they act accordingly. Heidegger (1996) argues that we exist in a "here and now-state" while interacting, and our expressions constitutes our "being in the world" *(dasein)* and define what we engage in and care about. According to Zahavi (2019) our understanding of the world is so embedded in our existence that we normally don't observe everything around us in each moment. Patients in intensive care and the HP who care for them, spend a huge amount of time together in a small room in a high-tech environment. This will inevitably, impact their individual interpretations of the situations they experience simultaneously. Time and space are therefore also essential factors in the interpretation of a phenomenon (Draucker, 1999).

Van Manen (2014) says that, in interaction with others, although everything is not implicitly communicated through a verbal phrase, the content of the communication still reveals something about how the world is experienced. The cognitive dimensions of human beings may therefore be externalized and reflected upon by observing others. An example of this is, if I see a person cry, I will relate this to my own emotions, and through my own personal experience, I will get an impression about how that person may be feeling. The experience of this situation will be unique for each person, and it is through our bodily and spatial sensations that experience is gained. When observing, we can also interpret how humans

create situations and meaning by being together. Situations in intensive care unfold through both the verbal and non-verbal utterances and expressions of the participants' experiences are shared in this dialogue (Van Manen, 2014). As soon as the moment is gone, it is in the past, and it becomes possible to reflect on it. This is what Heidegger means by our being "here and now," and the significance we later realized it had (Heidegger, 1996; Zahavi, 2010).

Written texts are valuable as a means of achieving understanding, but the primary source of data for phenomenological-hermeneutical research is everyday activities. When making observations, activities can sometimes be taken for granted, to the extent that we are incapable of noticing what it is that we observe, since we are so accustomed to "being in it" (Benner, 1994; Zahavi, 2019). This challenges the researcher to reflect on what the data reveals, and to "play" with the texts phenomenologically in a search for the essence of the phenomenon (Lindberg, Sivberg, Willman, & Fagerström, 2015; Sharkey, 2001). Van Manen (2014) explains the phenomenological approach in the following way:

> Doing phenomenology means developing a pathos for the great texts, and, simultaneously reflecting in a phenomenological manner on the living meanings of everyday experiences, phenomena and events. (Van Manen, 2014, p. 23)

In poetic texts, meaning is often embedded, and this evokes another aspect of the meaning rather than just simply describing it. This requires a sensitive approach, to stories need to be told with accuracy so the meaning reveals itself. In this thesis, both phenomenology and hermeneutic philosophy are used to interpret the participants' observed and expressed experiences. When it is opened to the expressions and interpretations of communication and interaction, the research will be inspired to look for both the essence of everyday practices and also beyond the obvious actions of everyday life (Creswell & Poth, 2013; Van Manen, 2014; Zahavi, 2019). This epistemological approach has been employed in understanding and entering the worlds of both the intensive care patients and the HP, with a constant and careful movement between descriptions, interpretations and understanding of the data through the hermeneutical cycle (Creswell & Poth, 2013).

There are moments when I have been closely involved with the video recordings and texts, whereas in other moments, I have been more distant while reflecting on and abstracting the data. The analytic process involves a constant change of understanding, and Graneheim,

Lindgren and Lundeman (2017) describe it as fluctuating in its degree of interpretation degree and degree of abstraction.

To understand another person's experiences, or a phenomenon, requires an open attitude toward the other person's expressions and understanding, so that he or she can be met with understanding. Our own lived experiences form our preunderstanding when entering a field or having a dialogue. These encounters create a movement in our own understanding and create what Gadamer has metaphorically labeled as a "fusion of two horizons." This is an ongoing process in which a researcher will reinterpret the other person and situation and never return to the same understanding, and thereby, engage in a continually evolving understanding of both parties (Creswell & Poth, 2013).

4.2 Patient-centered healthcare in intensive care settings

The National Academy of Medicine in The United States defines patient-centered care as care that responds to individual patient preferences, needs, and values, and that ensures that patient values guide all clinical decisions (Committee on Quality of Health Care in America: Institute of Medicine, 2001). They also state it is necessary to coordinate the care, provide information, communication, and education, together with the physical and emotional support of both patients and relatives to reach this goal. A key consideration of patient-centered health care is to optimize individual autonomy so the person (the patient) can determine and participate in their own care as much as they wish to (McCormack & McCance, 2010). For this to take place, it is necessary to create meaningful patient encounters and to establish mutual understanding between patients and HP (Kleinpell, Buchman, Harmon, & Nielsen, 2017).

Cornerstones of patient-centered care are partnership, solidarity, empathy and collaboration (Epstein & Street, 2011). Patient-centered care is not only a legal and ethical obligation, but it is a moral imperative for HP to meet in their care for other persons (McCormack, 2003; McCormack & McCance, 2010). The newest treatment philosophy for providing a more patient-centered and humane care in ICUs is the eCASH-concept, proposed by Vincent et al. (2016). They strongly emphasize that the premises for patient-centered care, rely mostly on good interprofessional collaboration and the responsiveness, capacity, and ability of the HP to communicate and connect with their patients.

4.2.1 The meaning of patient participation

Several terminologies describing patient participation have emerged during the last decades, such as shared decision-making, patient empowerment, patient participation, patient autonomy, or user participation (Longtin et al., 2010). This thesis will not explain the similarities and differences between these terms in any depth. While recognizing that patient participation does not undermine the professional's knowledge or capacity to make decisions on behalf of patients, one also has to take into account that each patient is unique and has their own values, wishes, needs, and knowledge. This applies equally to the conscious patients on mechanical ventilation. Much of the treatment is highly specialized and it is too complicated to provide sufficient information to patients; however, possibilities for including the patients in the decision-making processes normally exist. Some studies suggest that patient involvement is affected by the severity of their illness, meaning that critically ill patients may want a lesser degree of involvement than patients in a more stable condition (Thompson, 2007). These considerations make the concept of patient participation challenging for HP, since they have to take into account the legal regulations and the best available evidence for treatment and care while also incorporating the wishes of patients and relatives.

Kukla (2005) argues that autonomy involve more than one specific decision, and that autonomy also evolves over time. There is a need to understand each patient's decisions as more than punctuated decision points. Autonomy may function as an ideal for practice but be challenging to realize. Autonomy may even be overvalued relative to the other ethical principles in medicine, such as beneficence, justice or nonmaleficence. Decisions are also made on the basis of other values. They may be based on previous experiences, on what is at stake in the moment for the patient involved, and also on what the patient believes others (such as family or HP) find important. Informal and formal rules therefore influence and affect our behavior and choices. As humans, we may not always even be conscious of our choices or the consequences of our decisions in the moment that we make them, or we may even choose to let others make decisions on our behalf (Kukla, 2005).

4.3 Interprofessional perspectives on intensive care treatment

Interprofessional collaboration involves different health professions who regularly come together to solve problems or provide services (H. Barr, Koppel, I., Reeves, S., Hammick, M.,

Freeth, D., 2005). Especially in acute care settings, such as in intensive care units, the patient's condition changes rapidly, and there is a need for advanced and specialized competence. A growing body of evidence highlights interprofessional communication and collaboration as a positive strategy for improving of the quality of care, patient safety, and patient outcomes in ICUs (Manojlovich, Antonakos, Ronis, & Manojlovich, 2009; Rose et al., 2014). The different professional groups among HPs have their distinct priorities and agendas that impact on the interactions between the professional groups as well as on their interactions with patients. The professionals' roles are specific, intertwined, and interdependent, at the same time. In some areas, they are linked, whereas in other areas they deviate. This also affects responsibilities for work tasks and can make the workflow "unpredictable."

The professional roles in ICUs are dynamic, shaped by culture, knowledge, hierarchy, and organizational structure (H. Barr, Koppel, I., Reeves, S., Hammick, M., Freeth, D., 2005). Tensions have been reported amongst the different professionals working in intensive care, especially between nurses and physicians, as related to end-of-life decisions. In a cross-country survey involving 7458 HP from 24 countries, 72% of the HP reported at least one conflict in the last week, and the majority of the reasons were the result of interprofessional team disputes prompted by "personal chemistry", mistrust, a communication gap, or a lack of formal meetings (Azoulay et al., 2009). Manias and Street (2001) describe in their findings from an observational study how a lack of opportunities for nurses to speak out and to participate in the treatment decisions was a significant barrier to good collaboration between nurses and physicians in patient care in ICUs. The nurses expressed their willingness to be involved in treatment decisions, and not just to inform the physicians about the patient's condition. In summary, it would seem that the fluctuating roles of the professionals, the unpredictable workflow, and the lack of collaboration all impact treatment, care, and communication with ICU patients.

4.4 Theoretical perspectives on communication

4.4.1 Social interaction

The ability to interact with others and engage in meaningful communication is defined as a central characteristic of being human (Goodwin, 2000; Heidegger, 1996). As newborns, we do understand and engage in interaction long before we learn to speak and verbalize our

thoughts and emotions. Even before grasping the meaning of words, babies pay attention to the tone of voice and to details in the sounds of the language, and their first words express their own experiences. What starts with small sounds, or babbling, evolves to become small words and eventually, meaningful sentences. The premises for communication are that the person has the intention to communicate something, and the capacity to understand intersubjectivity (Nugent, Keefer, Minear, Johnson, & Blanchard, 2007). Older patients may experience reduced ability to communicate, due to sensory difficulties, aphasia after stroke, dementia, or other reasons and they may struggle to deliver their message in a verbal language. Despite this, they will still try to communicate and engage in interaction with others by using, for example emotional expressions or gestures (Kontos, 2011)

Social interaction is defined as any relationship between two or more individuals. It is a relational phenomenon, the meaning of which can only be created situationally and with the specific context in mind (Järvinen & Mik-Meyer, 2005). Interaction is collaborative, and through engaging in a joint action, the participants mutually influence each other. The spoken language is only one part of the interaction, it is accompanied by bodily expressions such as hand or facial gestures and eye-gaze. Dialogue is therefore coordinated and evolves in collaboration between two or more individuals (Gerwing, 2016; VanLear & Canary, 2017). It is impossible to not communicate, even silence contains meaning (Van Manen, 2014; Watzlawick, Bavelas, Jackson, & O'Hanlon, 2011). Many gestures that display aspects of meaning are not present in our talk, and the complex dynamics and flow of interaction can be very difficult to describe without the visible embodied actions of the participants in the setting. Talk and gesture mutually elaborate and depend on each other, and together they create the actual situation and the meaning of it (Cowley, 2011; Goodwin, 2000).

4.4.2 Communication theory and premises for human interaction

Traditional theory about communication often assumes that the communication partners have equal ability in expressing themselves verbally. In Schramm's model (1971), the core dimensions defined in the communication are the message, the sender, the receiver, and the channel. Human interaction is both syntactic, pragmatic, and semantic. However, these presuppositions are disrupted in the communication with patients on mechanical ventilation where the same set of meaningful symbols may be lacking between the patients and the HP.

Watzlawick, Bavelas, Jackson and O'Hanlon (2011) explain the premises for human communication with five axioms as displayed in table 4. The axioms recognize both the verbal and non-vocal communication to be of importance, and also highlight the difference between the digital and the analog language (verbal and non-vocal).

Watzlawick et al.'s axioms of communication	
One cannot not communicate	All behavior is communication
Content and relationship	Metacommunication, the person responds to both the content of what is said and to the context in which it is said.
Punctuation	Dependent on pauses, verbal communication has no clear punctuation in comparison to written language
Digital and analogic	There is spoken and unspoken language, the digital language is what the person says, the analog is what the person does.
Symmetric or complementary	Relationships can be defined by whether the persons are engaging on an equal level (for example, friendship) or an unequal level (mother-child).

Table 4. Watzlawick et al.'s (2011) axioms of communication with a condensed explanation**.**

When the models of Schramm (1971) and Watzlawick et al. (2011) are combined, the theories offer an understanding of the importance of non-vocal behavior in communication as a premise for understanding between humans. There is a need for a shared ground between communication partners in order to communicate effectively and to understand the complexity of the daily interactions between human beings.

4.4.3 Attention-seeking actions and initiation of dialogue

In order to be able to communicate, the person needs to get the other person's attention. These attempts can be called attention-seeking actions, and can either be both verbal or non-vocal gestures (Caruana, McArthur, Woolgar, & Brock, 2016; Frischen, Bayliss, & Tipper, 2007; Moore, 2014). Normally, the actions will in one way or another be directed toward the communication partner. Every bodily expression is not necessarily an intent to communicate, so wheter actions are attention-seeking depends on the context. The signs may be very clear (screaming "Hey" across the street when you see someone familiar) or more subtle (eye-

gazing at an interesting person in a bar). As human beings, the the eyes are reckognized to be important "mirrors" that interpret the person's gaze and how they are approaching their communication partner. It may be that looking into a person's eyes, can reveal "*suffering", "joy", "lack of tranquility"* or another emotional expressions. The eye gazes offers an important possibility for interpreting the meaning content in the dialogue, and can also can be used to see if someone wants to initiate communication, especially when accompanied by other behaviors such as waiving a hand. To clarify, an attention-seeking action is an attempt to communicate, which can be recognized or not by the communication partner, and will then hopefully, evolve into a dialogue (Caruana et al., 2016; Langton, Watt, & Bruce, 2000).

Patients on mechanical ventilation are suddenly unable to speak, since the tube or tracheostomy blocks their airways, making it impossible to verbalize their needs. Therefore, they lack a fundamental part of the normal communication repertoire, and this abruptly, and often without preparation, creates the need to communicate in ways that are different from before. In summary, many of the conditions for communication and interaction between HP and patients are also asymmetrical. This theoretical understanding (and the underlying bias) has been a premise for the studies presented in this thesis. However, it is possible to capture the intensive care patient's non-vocal communication and interaction, and the way in which this was done will be described further in the methods section.

5.0 Methods

The thesis uses a qualitative explorative design, to gain understanding of the phenomenon under investigation (Creswell & Poth, 2013). It consists of four papers: one literature review, two observational studies, and an interview study. The papers illuminate the topic of "communication and interaction with patients on mechanical ventilation," using several methods of data collection to achieve a deeper understanding in line with the phenomenological-hermeneutical approach (see chapter 4.0). Table 5 presents each paper briefly, followed by a detailed description of the research setting, data collection, analysis, sample and findings.

	Paper 1	Paper 2	Paper 3	Paper 4
Design	Literature Review	Qualitative	Qualitative	Qualitative
Method	Scoping methodology	Phenomenological-hermeneutical approach	Phenomenological-hermeneutical approach	Phenomenological-hermeneutical approach
Data Collection	Literature search in prominent databases	Observations by the use of video recordings and field notes	Observations by the use of video recordings and field notes	Observations Interviews
Aims	To assess previous knowledge about interaction and communication between healthcare personnel and conscious and alert patients under mechanical ventilation in intensive care units.	To explore the interaction between mechanically ventilated patients and healthcare personnel in intensive care units, with a special emphasis on patients' initiation of communication.	To explore how beside micro-decisions were made between conscious patients on mechanical ventilation in intensive care and their healthcare providers.	To explore healthcare providers experiences of their collaboration and communication with conscious patients on mechanical ventilation in intensive care.
Sample	46 studies	10 patients 60 HP	10 patients 60 HP	5 Nurses 2 Physicians 2 Physiotherapists

Table 5. Overview of the papers included in the thesis.

5.1 Data collection and research setting

5.1.1 Literature review

The first paper in this thesis is a scoping review, which aimed to assess previous knowledge about interaction and communication between HP and conscious and alert patients under mechanical ventilation. Scoping reviews aim to map a specific field with the purpose of understanding potential knowledge gaps (Arksey & O'Malley, 2005; Booth, Papaioannou, & Sutton, 2012; Colquhoun et al., 2014). We developed a detailed strategy to identify relevant literature, and then used it to search in the databases Cinahl, Embase, Medline, PsycINFO, and Scopus between May 2016 and August 2017. The search strategy consisted of both truncated keywords and medical subject headings, adapted to the databases. Main search

terms used were: “ventilator patient,” artificial respiration,” “tracheostomy,” “communication,” “nonverbal communication,” “communication aids for diabled,” “nurse-patient relations,” and “professional-patient relations.” The search was performed by a librarian in close cooperation with the PhD student (MMWK) and last author (LGH).

5.1.2 Observations

Observations were performed with the help of video recordings. The video recordings were made of conscious and alert patients in two intensive care units at a university hospital in Southern Norway in 2016-2017. The equipment was borrowed from the Teaching Learning Video Lab at the Faculty of Educational Sciences at the University of Oslo. The illustration in figure 3 below demonstrates how the cameras were placed to capture an overview of the interaction.

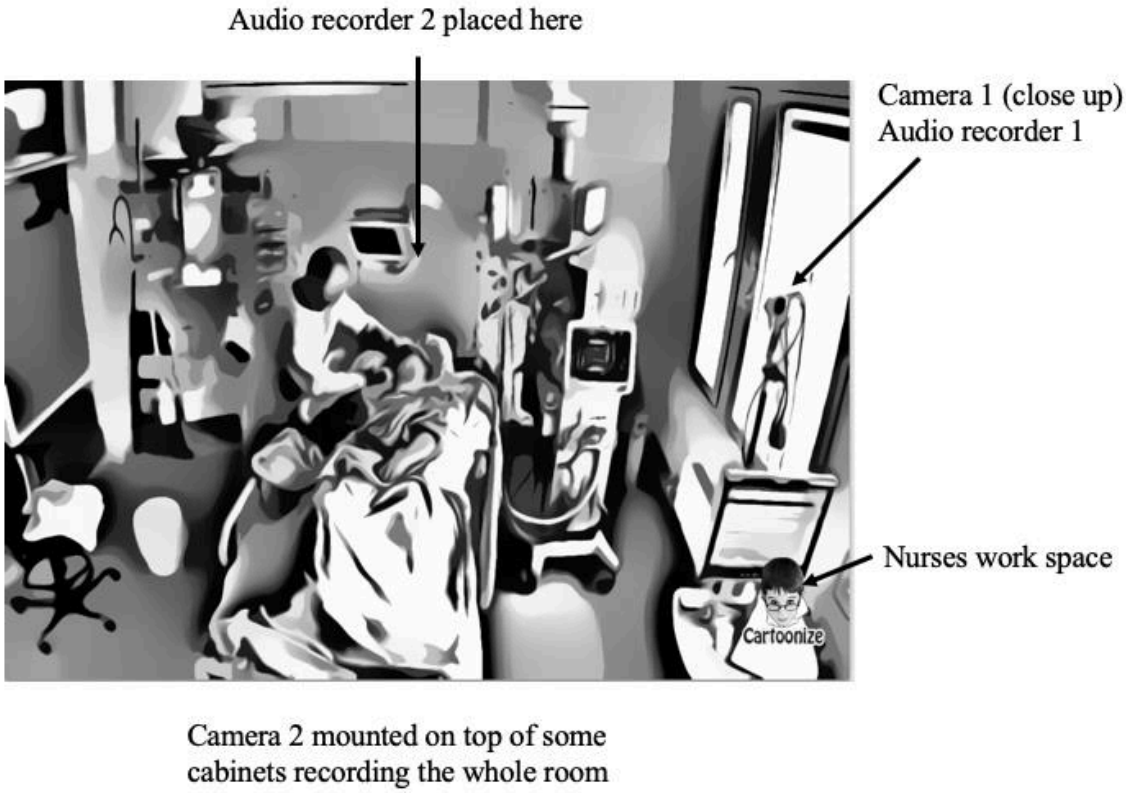

Figure 3. One of the patient’s rooms from the “overview camera” angle. All the rooms in the ICU had surveillance equipment, infusion pumps, a ventilator, equipment for acute emergency, and a computer to document the care. Effects on the picture (to anonymize) were created by the use of filters from www.cartoonize.net.

In addition to the cameras and audio recorders, there was a suitcase with the complete audio recording system (frequency modulation (FM)), and a laptop with cables connected to the cameras to synchronize the recordings and audio in real time. This was placed on a bench behind the nurse's workspace to disturb as little as possible. The equipment was mounted directly before the video recordings were taken in the morning, and this could take about 30-45 minutes. The cables between the cameras and the laptop were securely fixed to ensure safety. Two pilots were conducted with other types of camera equipment, but the recordings were difficult to synchronize. The pilot recordings are therefore not included in the data analysis but served to decide where to place the technical equipment to obtain the best possible data. Through the pilots, I also had a first impression of how the study would be received by the HP and patients.

During the video recordings, I was positioned outside the room, in case the recordings needed to be stopped immediately or a technical problem occurred. This allowed me to inform the HP and to obtain consent easily. Field notes were written during these hours, containing reflections and what was expressed about the treatment plan for the patient that particular day to increase understanding of the interaction.

5.1.3 Interviews

In addition to the video recordings, HP were purposively recruited for interviews afterwards. These interviews were also collected at the hospital, in undisturbed rooms, apart from one interview that was conducted at another location in response to the participant's desire. During the interviews, I tried to ask open questions about the participants' general experiences of communication and interaction, and then narrowed down to the specific setting observed and offered the participants the possibility of seeing selected segments of the video recordings. The time frame for the video recordings and the interviews was not set initially, but the HP was interviewed anywhere from a couple of weeks until nine months after the recording was made.

Patients were also asked if they were prepared to be interviewed after their ICU-stay, again with the possibility of viewing segments of the video recordings. Those who consented to be interviewed chose, themselves, the location. Unfortunately, it is beyond the scope of this

thesis to present the results from the patient interviews, but they will be analyzed at a later stage.

5.1.4 Clinical study context

The two intensive care units admit between 750–900 patients, in total, annually. The two ICUs had approximately 4500 intensive care days during 2016. Both ICUs had complex patients with medical and surgical conditions on mechanical ventilation (except for the thoracic-surgical patients and children under the age of 18) and are on the highest level for ICUs (Norwegian Society of Anesthesiology and the Norwegian Associaton of Critical Care Nurses, 2014). This is demonstrated by the use of the Simplified Acute Physiology Score (SAPSII), which indicates the severity of the patients' conditions. The patients admitted had a mean SAPSII of 47.0 in ICU 1 and 46.0 in ICU 2 in 2016, compared to the national average of 36.0. They had a higher mean length of stay than the national average (4.1 in ICU 1 and 2.5 in ICU 2, compared to a 2.1 days national average). They also had a larger proportion of intensive care days on mechanical ventilation (77% compared to the Norwegian average of 62.8%). The patients in the selected ICUs are also younger than the national average (median of 59 years compared to 67) (Norwegian Intensive Care Registry, 2016). Because the university hospital has designated national treatment responsibility (Extracorporal Membrane Oxygenation (ECMO) and organ transplantations), it makes the patient population slightly different from the population of a regional hospital ICU.

The ICUs both have an analgo-sedative approach, meaning that in delivering care they focus on light sedation, delirium monitoring and management, adequate pain relief, and early mobilization. The ICUs were organized as service departments run by anesthesiologists' (the same group ran both ICUs) in close collaboration with the physicians in each specialized department through which a patient was admitted. The physiotherapists treat their patients in collaboration with the ICU staff. The ICUs have a minimum of a 1:1 patient-nurse ratio and about 80% were critical care nurses with either a master's degree or a specialization according to the postgraduate framework for the education of critical care nursing (Norwegian ministry of Education, 2005).

5.2 Sample

5.2.1 Review of the literature

The first search returned 7386 unique references. The PhD student (MMWK) and the main supervisor (LGH) independently searched through all the references, using separate EndNoteX8-files to identify relevant, published research studies between 1998 and 2017. A broad sample was desirable according to the scoping methodology chosen, and studies of different types of design were included. The results were then compared, and it was agreed which of the identified studies would be read and further investigated. The reference lists of the included articles included were also investigated to identify potentially relevant articles and also to conduct a search of ten key authors who appeared frequently. Nine key journals with numerous studies published on the topic were also manually searched. Inclusion and exclusion criteria are displayed in table 6. Eventually 89 studies were considered potentially relevant for further investigation.

Inclusion criteria	**Exclusion criteria**
• Studies about communication between ICU-patients over the age of 18 and HP • Empirical studies or literature reviews • Studies published later than 1998, due to the change in treatment philosophy • Studies published in English, Norwegian, Danish or Swedish	• Case studies • Studies with a sole focus on end-of-life care • Studies with only HP included • Grey literature

Table 6. Inclusion and exclusion criteria for the literature review (paper 1).

5.2.2 Patients

Conscious and alert patients receiving mechanical ventilation were purposively recruited between April 2016 and May 2017. Table 7 shows the inclusion and exclusion criteria for the patients on mechanical ventilation. Study nurses and staff managers in the ICUs assisted in the recruitment to help identify the potential patients. However, the PhD student also called several times a week to ensure recruitment.

Inclusion criteria	**Exclusion criteria**

• Patients over the age of 18 • Mechanically ventilated for at least 48 hours • Richmond Agitation and Sedation Scale score of 0–2 • Without diagnosed delirium for the previous 24 hours • Negatively screened for the Confusion Assessment Method for the ICU at study enrollment	• Patients who did not speak Norwegian • Patients with severe visual, hearing, or cognitive deficits • Patients in end-of-life care

Table 7. Inclusion and exclusion criteria for patient enrollment (papers 2 and 3).

Doubts regarding the patient's ability to understand the information, or if it would be an unnecessary burden for them to participate, were evaluated in consultation with the nurses who recruited the particular patient. All of these assessments of the patients' decision-making capacities were also discussed with the main supervisor (LGH).

5.2.3 Healthcare providers

HP (nurses, physiotherapists, physicians and radiographers) involved in the care and treatment of the patients who had agreed to be video-recorded were also asked to participate (papers 2 and 3). The interaction varied from a few minutes to being present throughout the entire length of the video recording. The study nurse or staff manager organized the recruitment of the nurses with the main patient responsibility. I had an additional conversation with the providers to prepare them with further information about the study once they had agreed to participate. When the video-recorder was on, I placed myself outside the patient room to inform and asked everyone who entered. No data was collected on age, years of experience, or other demographic data for the HP, except for the nurses who were present in the room the whole time. Information meetings were held with the staff on several occasions (separate meetings for nurses, physicians, radiologists and physiotherapists), and an email was sent to all staff from their managers with written information about the study before the data collection started. The HP who participated in the videos were also recruited for interviews after the video recordings (paper 4). This included nurses, physicians, and physiotherapists.

5.3 Ethical considerations

Paper 1 did not need any further approval as it was based on a literature review. The permission request to perform the rest of the studies (papers 2, 3, and 4) was approved by the South-Eastern Regional Committees for Medical and Health Research Ethics in Norway (2015/2012) and was carried out in accordance with the Code of Ethics of the Helsinki Declaration (World Medical Association, 2013). Participation was voluntary, and the video recordings could be turned off at any time. The patients consented non-vocally during the ICU stay (for example, by nodding) and they also signed a written consent form after their ICU-discharge. The consent process also involved dialogue with the relatives, to ensure their understanding of what the study entailed and so that they could express their opinions. The HP involved in the patients' care and treatment during the video recordings received oral and written information and also signed written consent forms. The videos were recorded only in single rooms to protect the privacy of other patients. On the door outside of the patient room, there was a note alerting HPs and relatives that video recordings were being made. The video recordings and the interviews were stored on a secure platform, according to the hospital's and university's regulations on research data, on the services for sensitive data (TSD). In 2016, TSD was (and most likely is still today) the most secure platform for storage of research data in Norway and provided an easy way to access the data. Obviously, some aspects of the thesis have been required thorough ethical considerations and reflexivity. This was related to both the dialogue with the participants and the use of video-recordings. But this was also related to the dilemmas around performing a study in a familiar context, since the PhD student is employed in one of the ICUs where the data was collected as a critical-care nurse. She, therefore, already had pre-established relationships with many of the participants in the study. These topics will be elaborated on later in the discussion.

5.4 Analyses

5.4.1 Analyses of studies in the literature review

The 89 potential studies were investigated and described in a standardized data-charting model with reference (journal, title, year of publication), country of origin, aim of study, profession of authors, participants, inclusion/exclusion criteria, methodology and analysis, main findings, and conclusion. An example of this table is displayed in paper 1. After this process, the final sample was reduced to 46 empirical studies. Next, the topics of the 46

studies were investigated. This was done by re-reading and systematically searching for similarities or differences between the studies. It was also decided to compare all studies that used the same methodology; such as intervention studies, the qualitative studies and the mixed-method studies. The literature reviews identified were excluded since they did not yield any further references.

5.4.2 Analyses of video recordings

The videos were analyzed in several steps, resulting in two publications (papers 2 and 3). The findings presented in paper 2 focus on patients' attempts to communicate. Paper 3 presents its findings with an emphasis on bedside micro-decisions. This chapter outlines how the process evolved, and how the data were interpreted. First, transcriptions were made of both verbal and non-verbal actions, with initial coding and reflections on all the videos. A Microsoft Excel document was used for each video recording with columns for each HP containing descriptions of their verbal and non-verbal actions. Since the patients were non-vocal (except for some who periodically tested tracheostomy speaking valve) only their non-verbal actions were described. Initial codes and reflections were also written down. An example of this is demonstrated in table 8.

Time	**Patient**	**Nurse 1**	**Physiotherapist**	**Actions**	**Codes**	**Reflections**
01:09:25	Patient turns away from nurse 1. Closes the eyes.	You are tired today? Really tired. But unfortunately, we have to do some stuff today too. So now the physiotherapist is here to do a little round with you. I think it will be good for you. I understand you are tired; I understand		Nurse1 removes a cloth from the patient's bed, looking at the patient while he talks. Physiotherapist is getting ready (putting on a gown) and looking into the room.	Opening up the patient's life world. Withdrawal-patient behavior	A statement made more as a question than a statement. Nurse 1 soft in voice, leans towards the patient occasionally. Pauses in the communication, perhaps to wait for patient response.

		that very well. Especially if you are tired... it is an enormous challenge for you.				
	Patient turns toward Nurse1 and forms words with the lips. Nods the head.			Nurse 1 leans toward the patient. Physiotherapist comes into the room and walk towards the patient.	Vigilance. Engaging or not in the patient situation.	The patients forms words with the lips nurse 1 does not ask what. Does nurse 1 understand the patient's expression or choose to focus on other tasks?
	Patient closes eyes		Hey… I talked with the physician about your tracheostomy because it has been somewhat clogged and uncomfortable for you when you sit up, right?		Information	

Table 8. Example of initial transcription, coding and reflections. If several actions occurred simultaneously, they were all written down. Each row in the excel-sheet was used to describe what happening at one time. Each HP had their own column and their statements were described there.

For paper 2 of the thesis, all the attention-seeking actions were identified. Mangold Interact® was used as a tool for coding non-vocal communication acts from the patients to describe accurately what was going on and to observe the actions chronologically. The coding scheme

that was used to code the non-vocal interactions is presented in table 9. The content of every attention-seeking action was also classified, to observe what the patients was wanting to communicate.

Patient (P) **Healthcare providers (HP)**	**Codes**	**Code definition**
Patient	**Arm/hand movements**	Any movement with the upper extremities, i.e. a wave, thumbs up, moving a little, or forming other symbolic signs with the hands or arms.
Patient	**Eye gaze/eye contact**	Patient looks directly at an HP.
Patient	**Facial expressions**	A movement in the face, the meaning will be interpreted as the context arises. Maybe both eyebrows crunching, wrinkles of the eyes, smiles, etcetera.
Patient	**Head movements**	Any movement the head makes either forwards, backwards, to the side, shaking or nodding. As with facial expressions, the meaning of the movement must be interpreted with the context in mind.
Patient	**Leg movements**	Movement of one or both legs.
Patient	**Lip movements**	Attempt to form words using the lips.
Patient	**Shaking shoulders**	A shrug of the shoulders by lifting them upwards.
Patient	**Sounds**	Any noise the patient intentionally makes, using different sources, to make contact. Examples are banging on equipment and tongue clicking.
Patient	**Swallowing**	A deep swallow after or before speaking.
Patient	**Upper body movements**	Movements of the whole upper body.
Patient	**Writing**	Patient writes/tries to write on a paper or a writing board. Using this code excludes the code for arm/handmovements.
HP	**Talk**	HP talks out loud addressing the patient.

HP	**Eye gaze/eye contact**	HP looks at patient
HP	**Head movements**	Turns the head, nods, shakes it.
HP	**Touch**	Touches patient.
HP	**No visual response**	No identifiable from the HP, or it is not visible in the camera angle.

Table 9. Coding scheme for attention-seeking actions by patients and HP responses.

Two coded segments are illustrated in figures 4 and 5. The interactions timeline is visualized by the coding and also the amount of non-vocal interaction occurring.

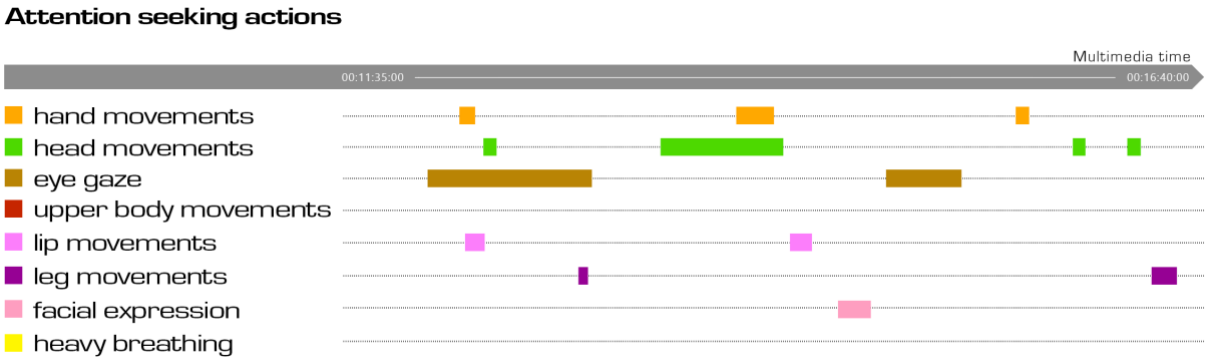

Figure 4. Segment of attention seeking actions from a patient exemplified visually on a chronological timeline**.** As shown, the patient is using multiple non-vocal communication techniques. Illustration created by Tore Bø, Lovisenberg Diaconal University College, based on the visual presentation of the timeline in Mangold Interact®.

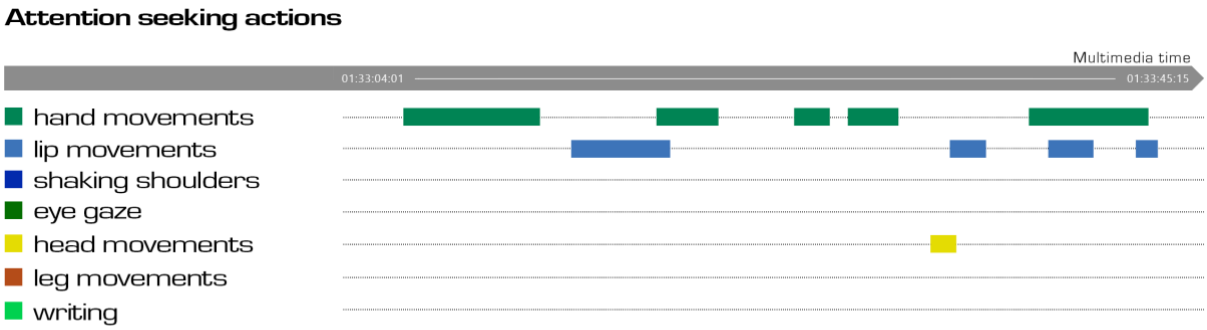

Figure 5. Segment of attention seeking actions from a patient exemplified visually on a chronological timeline**.** As shown, there is less use of different non-vocal techniques than the previous example in figure 4. Illustration created by Tore Bø, Lovisenberg Diaconal University College, based on the visual presentation of the timeline in Mangold Interact®.

From this coding, the situations were re-transcribed as narrative, situational descriptions. This was done quite descriptively, as the actions coded occurred. They were then compared to

identify differences and similarities, and grouped into themes to illustrate the various aspects of the phenomenon of attention-seeking (Van Manen, 2014). Examples of the narratives are presented in paper 2.

In paper 3 of the thesis, the topic was decision-making. Many of the initial codes identified from the videos revealed bedside micro-decisions being made that seemed to have certain patterns. The initial codes "information," "autonomy," and "shared decision" occurred consistently across the data. Every segment of bedside micro-decisions was isolated from the 30 hours of video recordings. The segments were then re-transcribed and coded all over again with a focus on what was observed to occur in decision-making situations. This process is illustrated in Table 10.

Procedure (time)	**What occurs**	**Initial interpretations**	**Subthemes**
Mobilization 00:37:00 00:51:00 01:02:00 01:21:00- 01:57:00	When nurse Elma talks about the plans, she says that the physiotherapist Evelyn will come after the morning bath, if that is okay. Jasper nods. Jasper looks down in the bed. During the morning routine, Elma and nurse Brigitte both comment that Jasper has gained much more mobility and that he is gradually becoming better. They also say that the physiotherapist will be pleased, if they have not made him too tired before that. Nurse Elma says that he should get analgesics, because he experienced pain during the mobilization previously. Jasper nods and smiles. When the physiotherapist Evelyn comes in, she asks *"Hey... is it okay with physiotherapy session now?"* Jasper looks towards Evelyn and nods with his head. Elma says *"Yes that is good. He has much better mobility than before. He has moved arms and legs and even tried to help a little during the morning bath, so he is much better than even yesterday."* Evelyn walks over to the ventilator and comments, on the settings and that he is without the dialysis and she is pleased to see that. *"Maybe we only need to be two in the mobilization now?"* she suggests. Elma responds, *"might be, he moves a lot better and helps more and has a clearly improved strength even from yesterday."* Jasper has his eyes closed but as Evelyn approaches, she says *"I think we prioritize to get up on the bed side at once, using the energy for that."* Jasper nods. *"Look- he is much better than yesterday"* Elma says, and Brigitte responds, *"yeah that is amazing."* Evelyn then starts to move his legs over to the	Decision competency/choices Information Decisions based on previous knowledge /prevention Patient safety discussions Surrogate decision maker, HP with knowledge about his previous experiences. Performance based discussions Motivating communication Talking about- not with- patient. Responding on behalf of patient	Invited decisions Balancing decisions of activity and rest Substituted decisions Non-invited decision-making Motivating and planning for the care and pain management according to the patient's condition

	bedside, and he stops moving *"Are you dizzy? Nauseas?"* she asks, Jasper responds forming *"no"* with his lips. *"Are you in pain?"* she then asks, and Elma responds saying *"he got analgesics since it was a bit painful last time he was sitting up and I don't think he has pain now."* They praise Jasper's efforts during the mobilization and say that Jasper is much better, this is the way to get out of the ICU and that it is beneficial for the lungs. Jasper manages to stay up at the bedside seven minutes and that is a new record. After that he moves a little back and forth in the bed holding himself up steadily. Elma asks, *"getting tired? yeah this is a real effort."* Evelyn says, "*Should we consider the return?"* looking at him and Jasper nods. When he gets back the Evelyn says, *"I can see how exhausted you are right now, great effort."* Elma adds *"I promised he would get an hour of sleep now, so we can continue with other stuff later."* They make his position in bed comfortable then dims the lights so Jasper can get some rest.		

Table 10. Transcripts of re-interpretation of segments of the video recordings. Transcription was made of all bedside micro-decisions for all patients. These included weaning attempts, tracheal suctioning, physical activity, wound care or physicians' visits. The time noted is when it occurred during the video recordings.

After this process, similarities and differences were observed between the various micro decisions. This led to a two-step analysis where it was 1) developed a typology of the micro-decisions was developed, and 2) the identified micro-decision processes manifested and the latent content was explored while trying to elucidate the meaning of the bedside decision-making. This resulted in a thematic interpretation of all the micro-decisions. Examples of the types of decisions made across themes were also explored, as illustrated in paper 3.

5.4.3 Analyses of interviews

The interviews with the HP in paper 4 were analyzed using a phenomenological-hermeneutical approach, using content analytic techniques to explore the participants' perceptions (Creswell & Poth, 2013; Graneheim & Lundman, 2004; Van Manen, 2014). To organize the data, NVivo 11 was used. An illustration of the coding process is presented in table 11, extracted from one of the themes identified: "interdependence on other providers in treatment and care."

Subthemes	Quotes from participants
Recognition of physiotherapists' relation to patient	"In that interaction with the physiotherapists it is fun to see how they also can have… a really good relationship with the patient, right." (Physician)
Recognition of nurses' unique competence in communication with mechanically ventilated patients	"My experience is that the nurses are much better at reading lips than we are because they are more used to it." (Physiotherapist)
To take on responsibility for patients' needs for communication	"We nurses can be.. at least I try to be, if not a diplomat then a middleman between… physicians who are not here, bedside 24 hours a day.. and they have other challenges communicating with patients since they don't know them that way.. they come and go." (Nurse)
Cooperation between HP affects communication with patients	"It`s much more comfortable to work with nurses I have a good tone with, if the communication is tense, it also affects the communication with the patient." (Physician)
To simplify communication for critically ill patients	"it is perhaps important to take what is most important and not much more than that…one day at a time take a piece at a time… not all over." (Physician)
To not get other HP aboard on the plans	"I try to be conscious that we all hear what is about to happen in a team... I think it is a bigger challenge than communicating with the patient… having a common goal all of us." (Nurse)
To position yourself within the team	"In one way it is our role, and first you got to try it in a good manner but when that did not work we tried to push her.. it was difficult and I think most who were there experienced it as a challenge to get her aboard on the team…" (Nurse)
To be professional in meetings with critically ill patients	"Even though she has a bad day, you try to meet her at the same professional level… give her an understanding of the situation she is in…it is hard." (Nurse)

Table 11. Subthemes from the themes, in analysis of interviews with HP (paper 4).

5.5 Rigor

Rigor has been ensured throughout the whole process of the thesis, trying to achieve credibility, transparency, and trustworthiness (Lincoln & Guba, 1985). This has been done both by being open about my reflections with the supervisors, by challenging preconceptions, and by staying critical toward both the methodology and the interpretation of the data. Several reviews of the analysis and interpretations were performed in accordance with the supervisors. They have watched parts of the videos and participated in the analysis. The quality and information power of the data was also evaluated through the principles made by

Malterud, Siersma and Guassora (2016). As a PhD student I have been primarily responsible for the data collection, the analysis and the drafting of the articles. Relationships with the participants were also reflected upon in the field notes so as to critically assess how these might affect both the processes and the findings. My role as researcher will be elaborated on in the discussion section of the thesis.

6.0 Summary of Findings

6.1 Paper 1

The aim of paper 1 was to assess previous knowledge about interaction and communication between healthcare personnel and conscious and alert patients under mechanical ventilation in intensive care units. Out of the 46 studies included in the literature review, 36 were from the perspectives of nurses, four from that of physicians, four from that of speech language pathologists and one from that of psychologists. Of the studies, 17 used a quantitative design, 16 used a qualitative design, six used a mixed-method design, and seven were pilot and feasibility studies. Of the studies, 21 came from North America, 14 from Europe, five from Asia, three from Africa and two from Australia. The whole sample is described in more detail in paper 1.

After analyses of the content of the studies included, the most prominent topics were identified as "experiences with communication while on mechanical ventilation" and "communication exchanges." These are displayed underneath in figure 6 with their subtopics.

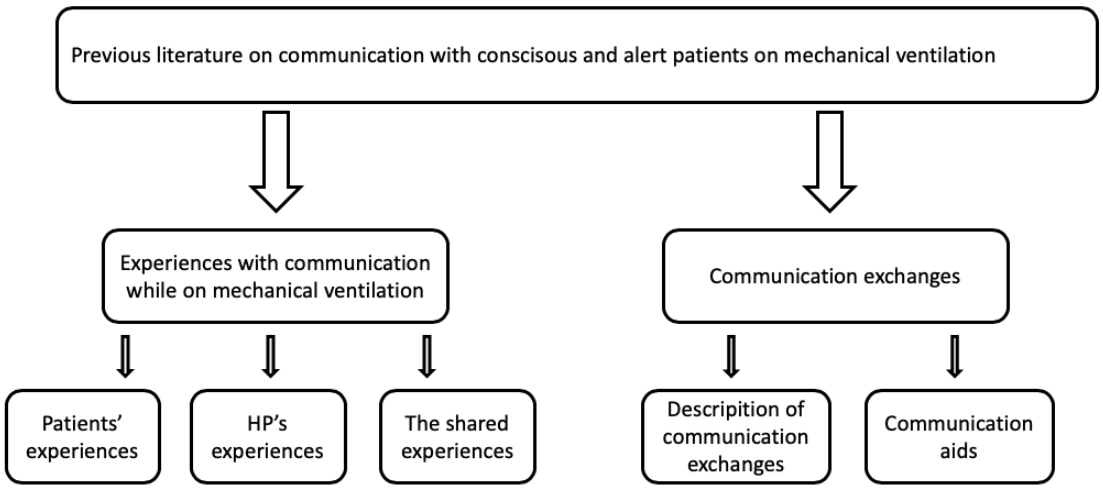

Figure 6. Findings of content from the studies included in paper 1.

The analysis revealed that patients had both positive and negative experiences when communicating with HP. Intervention studies that have tested the use of communication aids, indicate that they positively influences the interaction between patients and HP. Few of the intervention studies included had implemented a variety of communication aids, and they had also used different outcome measures, so it was not possible to compare the effect of the various communication aids.

Frustration was a core component of the shared experiences of patients and HP, with the lack of understanding making frustration inevitable. The literature review in paper 1 served to give a comprehensive understanding of the previous studies and also identified certain knowledge gaps. For example, the lack of interprofessional perspectives in the previous research makes this a useful background for the analyses in papers 2, 3, and 4, all of which were empirical studies.

6.2 Paper 2

The aim of paper 2 was to explore the interaction between mechanically ventilated patients and healthcare personnel in intensive care units, with a special emphasis on patients' initiation of communication. In total, 30 hours and 23 minutes of video recordings were collected from ten patients, ranging from 1 hour and 7 minutes to 3 hours and 30 minutes. Fourteen patients were invited and ten agreed to participate in the study (seven and three from the respective ICUs). Three of the patients invited declined the request to participate in the study. One patient was too exhausted to be video recorded on the scheduled day, and the recording was therefore cancelled. There were also discussions about several other patients during the data collection period. A couple of patients were excluded due to behavior indicating delirium although they had not scored as positive on the CAM-ICU.

Five of the ten patients included were females and five males, with a mean age of 53.6 years (range 36–72), and all were of European ethnicity. The median length of stay on mechanical ventilation before the video recordings was 20 days (range 4–68). The mean SAPSII was 42.0 (SD 13.1). One patient was orally intubated, the other nine were tracheostomized. They all had invasive equipment like central venous lines, arterial blood pressure monitors and urinary catheters. One of the patients had an intra-aortic balloon pump, another was receiving

continuous renal replacement therapy. A total of 60 HP (29 nurses, 18 physicians, 9 physiotherapists, and 4 radiographers) participated in the video-recordings. They all, apart from two nurses and one physiotherapist, had more than two years of experience with intensive care patients. No HP declined to participate in the video recordings, but one physician indicated that he would return after the video recordings. Table 11 presents more detail about the patients and the HP.

Patient number	**Age**	**Reason for admission ICU**	**Days on mechanical ventilation**	**Analgesics or sedatives during the video recordings** **Bolus: B** **Continuous Infusion: CI**	**Total time of video recordings**	**Total number of HP attending to the patients during the recording session**
Patient 1	43	Liver failure	21	Fentanyl (CI) Deksmedetomidin	03:05:19	3 nurses 1 physiotherapist 1 anesthesiologist 1 physician responsible ward
Patient 2	36	Respiratory failure	47	Deksmedetomidin (CI)	03:47:41	3 nurses 1 physiotherapist 1 anesthesiologist
Patient 3	71	Postoperative complications	15	Deksmedetomidin (CI) Propfol (B) Ketobemidon (B)	03:20:24	3 nurses 1 physiotherapist 2 anesthesiologists 1 physician responsible ward
Patient 4	65	Postoperative complications	8	Deksmedetomidin (CI)	03:16:10	3 nurses 1 physiotherapist 1 anesthesiologist 1 physician responsible ward 2 radiographers
Patient 5	43	Necrotizing fasciitis	19	Deskmedetomidin (CI) Fentanyl (CI)	02:55:56	3 nurses 1 physiotherapist
Patient 6	48	Postoperative complications	4	Deskmedetomidin (CI) Fentanyl (CI)	02:46:39	3 nurses 1 physiotherapist 1 physician responsible ward 2 radiographers
Patient 7	53	Leukemia	68	Morphine (B)	03:32:27	3 nurses 1 physiotherapist 1 physician responsible ward 1 anesthesiologist

Patient 8	72	Sarcoma	30		03:00:34	3 nurses 1 physiotherapist 1 anesthesiologist
Patient 9	60	Postoperative infection	25	Ketobemidon (B)	03:31:03	3 nurses 1 physiotherapist 1 anesthesiologist 1 physician responsible ward
Patient 10	45	Liver failure and infection	16		01:07:00	2 nurses 1 anesthesiologist 1 physician responsible ward

Table 11. Sample of patients and HP (papers 2 and 3).

A total of 66 situations were identified in which patients attempted to attract the attention of others and to express themselves on their own initiative. Attention-seeking actions, defined as the act of seeking attention and understanding without a voice, became the essential theme. Four patterns of interaction were identified occurring and organized according to theme: immediately responded to, delayed response or understanding, intensified attempts, or giving up. To communicate with the HP, the patients first had to obtain the HP's attention, and was being non-vocal this was not always easy. It was observed that patients used both sounds, eye-gazes, and also limb-movements to catch attention. After getting the attention, they then had to communicate their message, which also could be difficult and lead to further delays in understanding. How this could look like, is visualized below in figure 7.

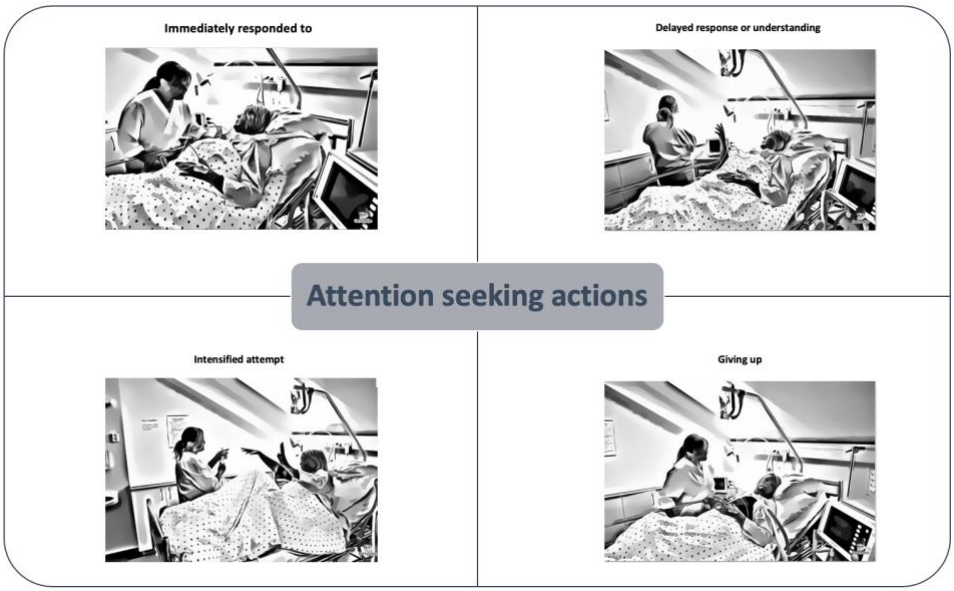

Figure 7. Photos taken by Cathrine T. Pettersen, Lovisenberg Diaconal University College, formatted by the use of cartoonize.net by the PhD student.

The patients had a variety of reasons for seeking attention, classified into four domains: psychological expressions, physical expressions, social expressions, and medical treatment. It was observed that many of the patient' expressions related to wishes or questions about treatment or bedside decisions. It was therefore decided to go into further depth about this in paper 3.

6.3 Paper 3

The aim of paper 3 was to explore how beside micro-decisions were made between conscious patients on mechanical ventilation in intensive care and their healthcare providers.
Paper 3 has the same sample as that described in paper 2. The videos contained 142 situations that could be identified as micro-decisions. There were six types of micro-decisions: non-invited, substituted, guided, invited, shared, and self-determined decisions. These therefore varied from the patient not being involved in the decision-making at all, to their making self-determined decisions. The analysis of the micro-decision process also demonstrated this variety in the level of patient involvement and resulted in three themes: "being an observer of treatment versus participant in treatment and care," "negotiating decisions about individualized care," and "balancing empowering activity and energy restoration." The last theme illuminates how the professional judgement of the HP still need to be exercised when involving the patients in their own treatment decisions. The balancing act where the professionals used their professional judgement, played an essential part role in influencing the decision-making and in the interaction with the patients. In paper 4, an understanding of how the HP experiences communication with intensive care patients was explored further.

6.4 Paper 4

The aim of paper 4 was to explore healthcare providers' experiences of their collaboration and communication with conscious patients on mechanical ventilation in intensive care. Out of the 60 HP included in the video-recordings, nine HP were interviewed: five nurses, two physicians and two physiotherapists (seven women and two men). These HP had between 1.5 and 31 years of work experience with intensive care patients. To protect the anonymity of the HP, more detailed demographics are not revealed.

The total interview time was 7 hours and 12 minutes, with a mean time of 48 minutes (ranging from 26–91 minutes). The communication barriers encountered in the patient communications were a challenge that HP needed to overcome, and this requires engagement, time, and willingness to understand the patients, and at the same time, being dependent on other providers. This challenge can be interpreted as experiencing a cognitive dissonance and being caught between their ideals and the realities of the daily communication with patients in clinical practice. This experience was described in three themes: "willingness to engage and understand the mechanically ventilated patient," "the potential risk of neglecting the patient in the encounters," and "interdependence on other providers in treatment and care." Many of the HP expressed frustration at not being able to understand the patients, and at the same they expressed a desire to collaborate more closely with the other professionals in the care team. Nurses, physiotherapists and physicians all carried their own areas of responsibility in the treatment, but at the same time they had to communicate if they were to perform certain areas of patient care that required cooperation between professions.

6.5 Main findings from the thesis' empirical studies

Figure 8 shows the main findings, and how paper 2, 3 and 4 contribute to each other illuminating the complexity of bedside interaction with mechanically ventilated patients.

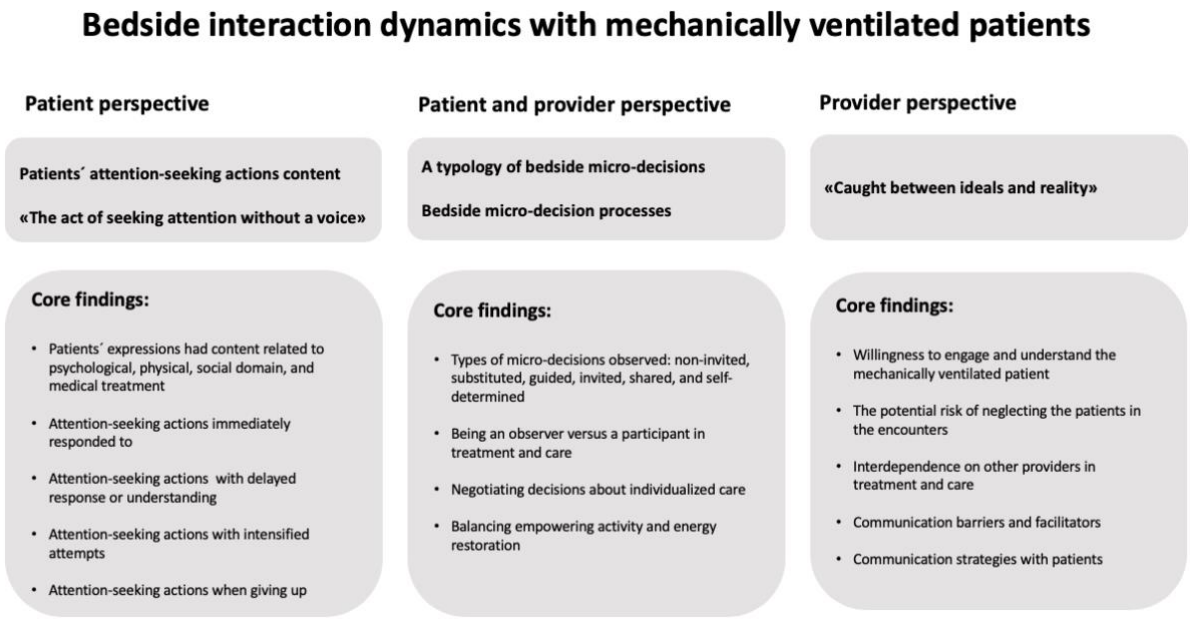

Figure 8. Presentation of main findings from papers 2, 3 and 4.

Patients' attention-seeking initiatives affects the HP and must be responded to. From the HP perspective, these initiatives are experienced as challenging because responding to them takes time, and sometimes, communication attempts fail. HP can either facilitate or be an obstacle to involving a patient in micro-decisions, depending on their efforts to understand the patients. The HP also struggled to combine their ideals of providing patient-centered care with the realities. This became apparent in their efforts to communicate and to understand even the simplest phrases that the patients tried to express both during the video recordings and from the interviews.

7.0 Discussion

Summarizing the results from the four papers included in this thesis, it would appear that the patient's frustration experienced by patients when attempting to communicate, and the lack of understanding, is also experienced by the HP. This shared experience of a lack of success in communication warrants more attention. The discussion will start with methodological considerations regarding sample selection, trustworthiness and the PhD student's position as a researcher during the data collection. The connection between the findings and their novelty value will be presented in relation to the phenomenological-hermeneutical approach chosen, communication theory and previous studies in the field. Potential methodological disconnects between observations and interviews as methods of data collection will be highlighted, as will communication as a quality indicator in intensive care. The final section will present a general discussion on the value of introducing shared decision-making into intensive care units in the future. The findings will be summarized in the conclusion and will highlight the thesis' contributions to the understanding of communication and interaction in healthcare. Some studies published after the initiation of this thesis in 2016, will also be mentioned in the discussion.

7.1 Methodological considerations

7.1.1 Sample selection

The methodology of each study has been described in the papers attached, and the possible limitations of each have been mentioned. Together, papers 2, 3, and 4 make a strong contribution to the topic of interest and suggest potential directions for further research. However, the thesis must be understood within its context. The most important overall

limitation of the thesis is the sample of patients and providers in papers 2, 3 and 4. The ICUs where the studies were performed are high-level departments. The patients observed were in prolonged intensive care treatment, with a median of 20 days of ICU-care before recruitment. As described earlier, they were also more seriously ill than the average intensive care patient in Norway, but they were representative of the normal population in the ICUs where the data were collected. More of the 60 HP who were video recorded could have been included in the interviews. Patient in prolonged stay in ICUs can have other needs for communication and interaction than patients with shorter stays, such as a stable group of HP who provide continuity, safety, and understand their communication patterns (Minton, Batten, & Huntington, 2018; Wassenaar, Schouten, & Schoonhoven, 2014). A broader sample might have led to additional findings and analyses. However, the interviews were considered to contain thick descriptions of interaction with a high information power, and sufficient data for analysis and for offering relevant and valid answers to the research questions of this thesis (Malterud et al., 2016).

In qualitative studies, "representativeness" has a slightly different meaning from that in quantitative research. The generalizations in qualitative studies are not aimed at causal explanations, but at the degree to which the experiences of patients and HP in intensive care are recognized as typical. The descriptions and interpretations from both the videos and interviews were detailed and rich, and an understanding of the data material evolved over time (Lincoln & Guba, 1985; Malterud et al., 2016).

7.1.2 Trustworthiness

Visual data provide the possibility of returning to the original recordings, provided the recordings are of good quality, both audibly and visually (Camic, Rhodes, Yardley, & Ratcliff, 2003; National Centre for Research Methods, 2012). There were situations where the whole picture of a segment was not captured, either because a participant was out of the camera's range, faces were turned away, or parts of the dialogue were inaudible. Details of interactions may provide completely new understandings and analytical thoughts, and overlooked details constitute a risk for the trustworthiness of video analysis (Knoblauch & Schnettler, 2012). This was also an issue in the analytic phase of this thesis, and repeated watching of the videos was essential to minimize this risk. Especially in paper 2, the detailed sequence coding of the interactions made the order in which actions occurred obvious.

Writing it down chronologically, ensured that relevant features in the data were not overlooked. Analyzing the video-recordings required considerable time as both open and more focused observation techniques were used, and observer fatigue is an acknowledged risk (Heath, Hindmarsh, & Luff, 2010). A considerable amount of time was also spent on developing definitions and clear criteria for the segments that were chosen for in-depth investigation, in accordance with the methodological suggestions (Haidet, Tate, Divirgilio-Thomas, Kolanowski, & Happ, 2009; Heath et al., 2010). However, there were many alternative methodological choices that could have been made. For example, following patients over several days, or even through their whole ICU stay, could have led to a greater understanding of how communication, patient participation, and relationships between HP and patients evolves over time. This was even commented upon by one of the patients when he was visited later. He said it would be interesting to have observations done during the night shifts. If the interviews had been conducted sooner after the situations video recorded, it could have provided greater insights into their reactions and memories from the situations. However, showing portions of the video recordings in the interviews did enhance the participants' recall of the situations. This can be an advantage to elicit the persons cognitive reasoning during an interview (Lyle, 2003).

Some video studies potentially give too much credit either to what was observed or to what was said (Heath et al., 2010; Spiers, 2004). This can happen if the analytic focus is on the written transcripts of the rather than on the non-verbal communication and other things going on in the room that might affect the interaction. This can occur in observations both with and without video recordings. In this thesis, the video recordings used in papers 2 and 3 were analyzed with a focus on both the verbal and non-verbal communication, as the analytic approach described in the methods section reveals. To avoid making premature interpretations of the interactions, the transcriptions were kept at a descriptive level so that the initial focus was on the interaction details. However, there was a separate section in which to write down reflections about what was going on so that they were not forgotten. Building up an inductive analytic strategy was time consuming, but it was also very useful. Already well-established coding systems, such as the Verona Coding Definitions of emotional sequences (VR-CoDES) (Verona Network on Sequence Analysis, 2016) or the Roter interaction analysis system (RIAS) (Roter & Larson, 2002) could have been used for the analysis in paper 2. These, and other types of coding system, were explored and served as inspiration in the process. However, no one coding system was identified that sufficiently captured the patients' non-

vocal communication. For paper 3, we again created a coding system based on inspiration from other coding systems, such as the Decision Making and Classification Taxonomy in Medicine (DICTUM) (Ofstad, Frisch, Schei, & Gulbrandsen, 2015). The DICTUM- coding system is originally made for medical encounters. The definition of a decision was therefore adapted to a context with several professionals, where the focus was bedside micro-decisions. There are various ways in which coding systems can function as productive methods for eliciting the meaning of events and situations. When used in qualitative studies, coding systems should fit the aim of the study and useful for the interpretative analysis (Morse, 2018; Morse, Barrett, Mayan, Olson, & Spiers, 2002).

Morse (2018) argues that there is no "golden-standard" for ensuring rigor and trustworthiness in qualitative analysis, but it also depends on the aim of the study. Increasing the "hardness of the data" can increase the rigor, enabling others to reproduce the analytic path. However, it is, according to Morse, it is important to acknowledge that only the analysist can have a full understanding of the entire data set. One of the challenges encountered in this process was to not stop the analytic process too early. Already when selecting segments in the videos of interest, choices were made that eventually altered the focus (Heath et al., 2010; Knoblauch & Schnettler, 2012). Rigor was exercised in the analytic phases, by presenting the analysis to the supervisors so that other potential interpretations of the data could be explored. An entire video recording was also watched by the main supervisor, to identify potential micro-decisions. Through this process we arrived at a common identification of the micro-decisions in the videos, and we were able to discuss various interpretations of the decision-making that occurred.

Travers (2009) is skeptical about the use of videos, arguing that there are few advances in the analytical approaches in video studies, and they often lack depth compared to other types of study. The complexity of the video recordings can easily become "overwhelming". The researcher may experience fatigue and become unable to analyze productively. However, descriptions and interpretations can be made from different angles, and an extensive number of analytic programs exist. Videos may be used to count, identify patterns, thoroughly transcribe the patterns, or to code deductively in both quantitative and qualitative designs (Heath et al., 2010). My own experience is that the coding systems functioned both as a means for becoming familiar with the data and also to identify what was observed and to break it down into functional units. The codes developed for paper 2 were very descriptive.

Several codes were used in one situation, and the end product needed further narrative analysis as presented to elicit the full understanding of the phenomena. The other coding system (Paper 3) was process-oriented, and only one code was used to identify each segment, based on the criteria developed in the analysis. In this analysis, the segments were located, but again further analysis was needed to understand the processes of the interaction.

In comparison with other video recordings studies in ICUs, the video recordings in this thesis (papers 2 and 3) had a longer time-period, and a more interprofessional approach as all HP interaction were included in the analyses. The video recordings in the study by Karlsson et al. (2012) were mostly between 6–12 minutes and focused on the patients' expressions while being ventilated. The interviews were performed by a semi-structured interview guide, interaction with HP was not an explicit focus. Meriläinen et al. (2010) video-recorded intensive care patients for at least 24 hours, but they mostly focused on the impact of the environments on the patients and not on the interprofessional collaboration. However, some of their findings point toward the intensity of the interaction patients may experience. The longer segments in papers 2 and 3 gave a deeper understanding of the nuances in the interaction, and especially the amount of interaction that occurs with various HPs. The patients had between three to eight professionals in the room during the time of the video-recordings that they were communicating with. Sometimes the same decision was discussed with all HP involved, which also resulted in decision-making processes which would not have been identified with other methods (paper 3). Another example of a nuance in the interaction, was the amount of attention-seeking actions (paper 2). Some of the patients had none and others had many. This would not have been easy to identify if the recordings would have been shorter.

When interpreting observations of HP communicating, one should be aware that they are making very complex clinical judgments while interacting with the patients. The observer's understanding of the participants reflections and reasons for behavior lacks without further exploration. Interviews were therefore performed so that there would be various data sources, making the complexities of the interaction more apparent. This strengthen the thesis design and the power of the information (Creswell & Poth, 2013; Malterud et al., 2016). The interviews complement the videos and richly enhance the reflections about what was observed. For example, attention seeking behaviors of patients and a lack of attention from HP was observed, but the verbal descriptions given in the interviews revealed the awareness

and reflections of the HP around this. The process of guiding the patients through micro-decisions was thus not only observed, but the HP gave detailed accounts of how they were doing this, as presented in paper 4. The physiotherapists' descriptions of "fighting to find time" to treat the patients was also identified during some of the videos when the nurses said the patient had to wait before starting physiotherapy. This could either be because they had to perform other procedures (such as morning bath) or to prioritize rest. These dynamics between the data sources was helpful in achieving a systematic and transparent analytical process.

The human attention span is limited and there is always something new and surprising to observe in the videos (Spiers, 2004). I would recommend others to use video recordings for their data collection in ICUs. However, for more specific purposes such as observing differences in communication patterns between HPs, a quantitative design might be appropriate. Validation of the communication coding systems developed would also be useful for using in continuing studies on the topics. It would also be interesting to explore video-recordings as a systematic intervention, which would allow the patients to see their own ICU-stay and comment it. This could for be included in a therapeutic session or in a conversation with HP at a follow-up clinic after discharge. In preparation for the interviews with the patients (not yet published), an ethical concern was that the patients might find it traumatic to view videos from their ICU-stay. It was therefore decided to offer the patients this possibility but to be careful and follow up on how they experienced it. I will not go into depth about this, but several ethical considerations and privacy concerns need to be addressed before video recordings from ICU stays can be integrated in follow-up clinics.

As an observer you always affect the situations you observe (Heath et al., 2010). The observer's role extends beyond what is said and done and involves the interpretation of the emotional climate, the roles of the participants, and the meaning of the utterances and actions in the specific context. Shrum, Duque and Brown (2005) positions the camera as an independent actor in their video observations, and as a researcher, it is important to pay attention to the action both in front of and behind the camera. Videos are also a two-dimensional representation of the world (National Centre for Research Methods, 2012). The effect of being observed can, to some extent, be evaluated by paying attention to whether the participants look into the camera or gazes at the equipment. From this, it is possible to evaluate the interference of the cameras with the natural interaction happening (Heath et al.,

2010). One patient was observed consciously using the camera to communicate with me independently of the interaction going on. He had attempted to get the nurse's attention for quite some time. When he did not achieve any response, he probably got irritated, and deliberately turned over, gazing directly into the camera and shaking his head with a frustrated expression, and then looking back at her. I also observed dialogues between HP and patient relating to the video recordings, for example whether they should be stopped during sensitive procedures. These examples indicate that both HPs and patients were remembering that they were being observed. The effect of being observed can make the participants so conscious of the video recordings that they do not act naturally, known as the Hawthorne-effect (Haidet et al., 2009; Mulhall, 2003). Some of the patients might have been nervous and acted abnormally. The opposite was also experienced by participants who expressed forgetting about the cameras and becoming engaged in the patient-HP interaction. The video recording lasted over a fairly long time-period, and this may have contributed to reducing the feeling of being observed since it is debatable how long a person can "keep up an appearance" and act differently compared to their normal behavior (Mulhall, 2003).

As we enter an encounter, we bring with us our predesigned ideas, history, and understanding of the world before we even begin to think about the actual encounters. This will include our prejudices, pre-meanings and pre-conceptions. In interaction with other persons, we introduce this horizon of our own understanding of the world (Zahavi, 2019). I had no previous experience with the use of video recordings and limited experience with qualitative analysis, but I did have an extensive experience in the field of critical care. My own prejudices and preconceptions have been challenged in the process, both through dialogue with other researchers in regular meetings and also by reflecting on the meaning of the data (Pink, 2001). Through repeated viewings of the video recordings, I was able to see how others interacted with their patients, and so did not draw on my personal experiences. This has made it possible to obtain a more nuanced "meta-perspective" rather than the purely patient-nurse perspective that I have normally had in my clinical practice. The relationship with the data has also been addressed in the phenomenological literature. According to Heidegger phenomenology requires a constant struggle against this typical self-understanding, which is our normal tendency in our everyday existence (Heidegger, 1996; Zahavi, 2010).

Even though I was responsible as a PhD student for the data collection and analysis, the understanding has evolved in dialogue with my supervisors while watching the video

recordings or reading interview segments. This analytic approach has provided a strength to the thesis, and also ensured trustworthiness, since the supervisors asked different questions of the data. When the videos were first shown, the supervisors had many questions regarding how the communication they observed. To them, the patients seemed very apathetic, while I was observing and focusing on the small non-vocal signs such as head movements in the interaction. This dynamic forced me to explain what I saw as normal, and perhaps not would not otherwise have paid attention to. This is linked with the recognition that everyday activities, in becoming mundane, may become unrecognizable as phenomena for investigation (Van Manen, 2014).

Validity in qualitative research does not merely involve measures taken to achieve trustworthiness, it also implies that there is little or no reason to doubt the truth. This is often complicated to demonstrate, but can be achieved through transparency and openness (Lincoln & Guba, 1985). Writing systematic reflections during the data collection and analytic phase created a rigorous audit trail from the start to the end of the project (Rolfe, 2006). In a single study, rigor can be evaluated on the basis of the level of information power the data have (Malterud et al., 2016). "Incremental" evidence is created by accumulating evidence, study by study. One study does not stand alone in solitude; studies are clustered together, and in this way, the evidence on a specific phenomenon accumulates (Morse et al., 2002). In this thesis, several qualitative studies were conducted on the basis of one data collection period. A broad overarching aim was combined with more specific and targeted analyses aimed at particular aspects of the phenomenon. Interpreted together in this thesis, the in-depth approach of the video recording analyses aids the understanding of how communication functions at a micro-level in the ICU. The papers have also applied a number of theoretical concepts as the means by which to understand and reflect on the data through comparing various patient cases and HP stories across the sample.

In the background section of the thesis, the numerous terms describing patients who are conscious and alert on mechanical ventilation were mentioned as problematic, resulting in ambiguous and value-laden language being used to describe the patient's communication barriers. However, this thesis has also been inconsistent in its terminology, since my understanding has evolved constantly throughout the PhD period. It is through language that we understand a phenomenon, and it is through language that we communicate our own understanding to others (Goodwin, 2000; Van Manen, 2014).

The PhD student (MMWK) and the last author (LGH) independently studied the results of the literature searches in the review (paper 1). After publication, one relevant article was identified as missing from the results presented in the article, although present in the literature searches. It is an article that presents cases of the use off above cuff ventilation. This is a novel method for vocalization which has drawn increasing interest in recent years (McGrath, Lynch, Wilson, Nicholson, & Wallace, 2016). An explanation for why this was missed, is most likely the methodology and inclusion/exclusion criteria applied.

Looking back, the study could have been strengthened by having a patient-representative and a HP during the whole process with whom to consult. This would perhaps have contributed to other reflections and methodological approaches. However, preliminary findings were presented to clinicians and other researchers before being finalized. Also, the interviews with the patients and HP were performed after the initial analysis was commenced. This was done to prepare specific questions related to the video recordings.

7.1.3 Ethical considerations

This chapter will highlight and discuss some of the ethical dilemmas encountered in relation to the relationships with the participants, the use of video recordings, and being a researcher in a familiar context. During the recruitment period, several guiding ethical principles were applied: the participants should be properly informed, not exposed to any excessive harm, not feel pressured to participate, and be able to understand what they were consenting to (World Medical Association, 2013). Unfortunately, two patients died during their hospital stay without yet signing the consent form. I was initially unsure whether it would be correct to approach the relatives after a sudden death, thinking that it could be a burden for them. However, the husband of the first patient who died contacted me a couple of weeks after his wife's death. This was to let me know that the participation in the study had been important to her, and he urged me to use the video recordings to tell her story. He even wanted to supplement the story with papers where she had tried to communicate during the stay, which he had collected. Consent to use the data from these two patients was therefore obtained through the relatives after consulting with the Regional Ethical Committee to get permission for this approach. When I reached out to the relatives of the second patient, they also agreed and signed a consent form after conducting a family meeting. This illustrates that the

participation in the study was experienced valuable, and that even in grief relatives find meaning in sharing their loved one's stories.

In my visits afterward, all patients remembered agreeing to the study despite being so sick, and some of them even expressed gratitude for being included and being able to contribute through their stories. I also became more aware of the frustration that patients felt at being non-vocal during the data collection. One of the patients managed to write a note when the aim of the study was explained to her: "they forgot to tell me the most important thing, that I would be without a voice when I woke up." Another patient still preferred to write even after extubation, since using his voice was painful. He wrote: "I was terrified, but I feel secure now." Two patients told me, on their own initiative, about hallucinations and frightening memories when being admitted to the ICU. Through meetings with participants, a deeper understanding and sensitivity towards their situation was developed (Bonner & Tolhurst, 2002; Gair, 2012).

Some HP expressed that they had felt somewhat vulnerable. It was not possible to hide their participation from other staff members because of the cameras. The biggest concern during the data collection was that unexpected things would happen, and that the recordings would interrupt the normal treatment or disturb the HP. Measures was taken to ensure that the video equipment would not interfere or be potentially harmful in the environment (such as taping and securing cables, and positioning equipment so it did not disturb workflow). To avoid unnecessary stress, I was always outside, able to turn the cameras off at any time.

Being an insider can be difficult as the everyday activities are so familiar that they are often taken for granted, and it is easy to have problems identifying patterns of practice. This can affect both the trustworthiness and the findings (Bonner & Tolhurst, 2002; Mulhall, 2003). The essence of a phenomenological approach involves a focus on the mundane experiences of everyday life (Van Manen, 2014; Zahavi, 2019). To reflect upon this, field notes were written. An illustration of one of the field notes follows.

> Exactly when does a researcher act as an insider or as an outsider? After turning off the video recordings a situation arouse that challenged my role. The nurse suddenly said, "I need help, something is happening." I observed the patient having problems getting air into the lungs, and the ventilator indicated

> that the endotracheal tube was blocked. I asked the nurse about the emergency equipment and suggested the physician should come quickly. We managed to ventilate the patient before the physician came. I chose to intervene although not more than direct the nurse in her interactions. I am not sure if this was a reflex in this moment or if I managed to think before assisting. Becoming passive could have made my presence problematic since the nurse directly asked for assistance. The situation could potentially have had a negative impact, making the nurse feel less competent in the situation and regretting that she accepted the video recording or making the patient unsure about the nurse. (Interviewing the patient, a couple of months later, she gratefully mentioned the nurse, praising her kindness and all her effort during the ICU stay.)

As an insider, the culture and the institution's routines were familiar. This was an advantage in the field. I already had pre-established relationships with some of the HP and used to communicate with the patients, especially in one of the ICUs. Some researchers argue for the "unknown, unbiased and objective researcher" in field work (Bonner & Tolhurst, 2002). As an outsider, you might enable the participants to disclose their thoughts with less reserve. Outsiders also have fewer prejudices, and this may result in an increased ability to meet the field with openness (Mulhall, 2003). I have reflected on the role I played in the field throughout the process. Even though I think of myself as an insider, I have only worked part-time in the ICU the last seven years. Perhaps having a part-time position made me less of an insider than I expected, and I experienced facilitating trust from both patients and HP. My researcher-role also had to be "earned;" therefore I had extensive dialogues with the patients and their relatives to ensure not to be experienced as putting pressure on vulnerable patients to consent. This was important in gaining legitimacy in the recruitment process. I was aware that some of the relatives were nervous that it was too much for the patient to handle. It was not the relatives who needed to consent, but for the research purpose it was still desirable they found the video recording process appropriate. If I had done something against the relatives' will, this might also have a negative effect on the recruitment process with the HP. These reflections on the insider-outsider positions were, as explained above, also linked to the ethical considerations in the recruitment phase preceding the data collection. Reflecting about the ethical dilemmas and trustworthiness, is an important part of the qualitative research process (Watt, 2007).

7.1.3 Theoretical considerations

The phenomenological-hermeneutic approach, patient-centered care, and an understanding of modern intensive care treatment provided the overarching approach for the thesis. Figure 9 illustrates this explicitly, linking the theoretical background to the findings. Each study has a specific focus, and its findings are reflected on in relation to different theoretical frameworks.

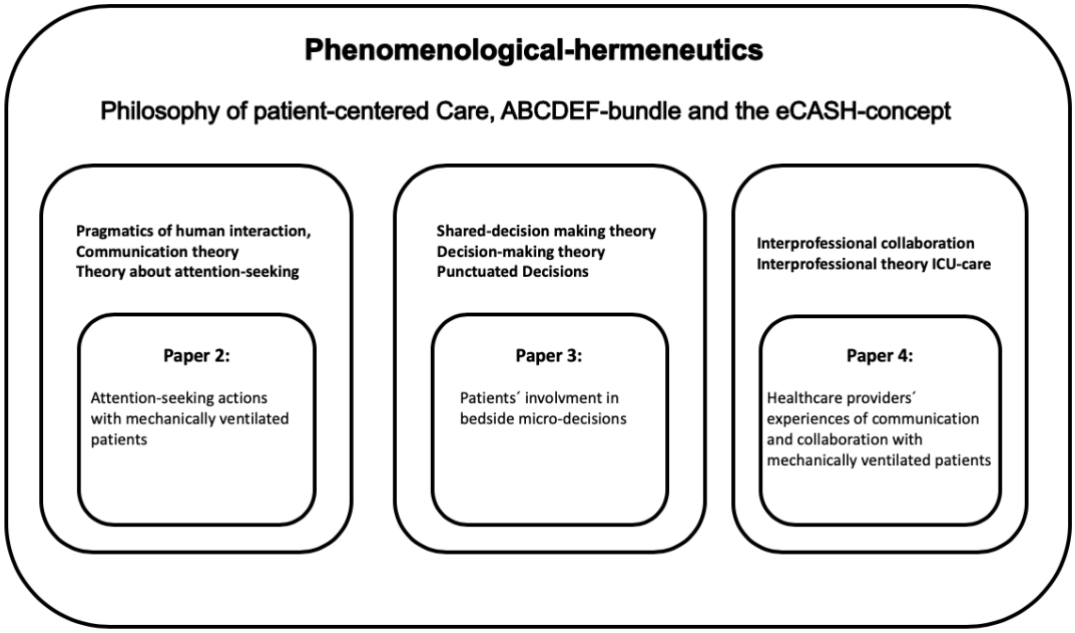

Figure 9. Theoretical background to the thesis.

Methodologically, there is a distinction between interviews that aim to capture and describe the participants' experiences, and the observations used to interpret human behavior (Creswell & Poth, 2013; Zahavi, 2019). The phenomenological approach was chosen since the whole study has a patient-centered framework, and a phenomenon was to be investigated from different angles. The patients' initiatives to communicate while being mechanically ventilated provided the unit of analysis for paper 2. Many of the verbal and non-vocal expressions previously described in paper 2 relate to the patients' feelings of both loneliness, loss of control, anxiety, and other important emotions. These are explicit expressions revealing the patients' lived experiences in the moment (Van Manen, 2014; Zahavi, 2019). A disadvantage was, of course, not having the possibility of asking the patients to elaborate on these expressions due to being an observer and positioned outside of the patient's room. However, sometimes further elaboration occurred if the HP acknowledged the attention-seeking action and tried to understand by asking the patient follow-up questions. In addition, it was also possible to get detailed information of the bodily expressions of the patients and HP by using

the video recordings, which contained both the non-verbal actions of the patients and the HP's responses. Statements and expressions were interpreted phenomenologically-hermeneutically, in both papers 2 and 3. Reflecting upon the analytical process retrospectively, I strongly argue that the patients' perspective would have been less present, if the interaction from the providers had been the initial focus. The HP's experiences became a major focus in paper 3, where I studied both the HP's initiation of communication about micro-decisions and also how the patients expressed themselves on this matter. I paid attention to patients' expressions of preferences and their responses toward decisions suggested by the HP. Van Manen says that phenomenological research begins with wondering at "what gives itself, and how something gives itself" before moving on to understanding specific aspects of a phenomena or events (Van Manen, 2014, p. 27).

Paper 4 had an explicit focus on the HP experiences; however during the interviews, they also, to a certain degree, explained their communication on the basis of how they had interpreted the patients' needs. To summarize, across this thesis, three empirical studies with different levels of descriptive (phenomenological) and interpretative (hermeneutical) methodology were employed in the analytic phase. Heidegger rejects the notion that it is possible to obtain complete neutrality, humans are always are a part of the world in which they exist and cannot be separated from it (Heidegger, 1996; Zahavi, 2010).

The detailed theoretical background of this thesis is displayed in tables 13, 14, and 15. This is done to explain the intertwined relationships between the phenomenological-hermeneutic theory, communication theory, previous research, and findings from the thesis.

Relationship between methodological theory, previous knowledge, and the findings in paper 2				
Phenomenological-hermeneutic approach	**Communication theory**	**Previous research**	**Findings**	**Novelty value**
Describes the unique/essential meaning of the phenomenon attention-seeking actions for mechanically ventilated patients(Creswell & Poth, 2013; Van Manen, 2014) Both verbal and non-verbal utterances create	Joint attention is basis for human interaction and understanding(Frischen et al., 2007; Langton et al., 2000; Mundy & Newell, 2007) One cannot not communicate(Watzlawick et al., 2011)	Only 15 % of the communication comes from the patient's initiative(Happ et al., 2011) Patients experience trouble getting attention(Engström et al., 2013; Happ et al., 2011; Laerkner, Egerod, Olesen, &	Attention-seeking actions: The act of seeking attention without a voice	*The descriptions of dominant patterns observed illustrate how patients struggle, and give another understanding rather than recollections of their ICU-experiences*

meaning in a situation (Heidegger, 1996; Van Manen, 2014)	Focus on typical non-vocal behavior such as eye-gaze and limb-movements or facial grimaces may reveal what patients want to express (Bavelas & Chovil, 2017) Two steps in understanding: first to get attention, and then to understand the content of the communication(Caruana et al., 2016; Moore, 2014)	Hansen, 2017; Mobasheri et al., 2016) Reports of unsuccessful communication in ICUs exist and have existed as long as patients have been awake on mechanical ventilation(Carroll, 2007; Holm & Dreyer, 2017; Wojnicki-Johansson, 2001)		*related afterwards.*
Describes what is observed in the communication between patient and HP once the patients has got their attention (Creswell & Poth, 2013; Van Manen, 2014) Without communication and interaction, we do not exist as a human beings(Heidegger, 1996)	Relationships are both social, interactive and shifting depending on the context(Järvinen & Mik-Meyer, 2005; VanLear & Canary, 2017)	The experience of being socially isolated is common for ICU-patients (Egerod et al., 2015; Engström et al., 2013) The experience of wondering about the future while being critically ill is an existential phenomenon (Baumgarten & Poulsen, 2015; Egerod et al., 2015) Patient-centered approaches in ICUs requires communication about various domains(Slatore et al., 2012)	Four domains in the content of the communication (Psychological, physiological, social expressions, medical treatment)	*Even during critical illness, we strive to communicate and interact with other humans, as sharing experiences constitutes our being in the world.*
Describes narratively the observations of how patients achieve attention(Creswell & Poth, 2013; Van Manen, 2014) Merging horizons of understanding once the communicative partners achieve sustainable communication (Creswell & Poth, 2013)	Joint attention requires the ability to attract the communication partner's attention(Caruana et al., 2016) Both partners have to realize they are communicating to interact(Caruana et al., 2016) Both non-verbal and verbal communication channels are used to obtain attention(Gerwing, 2016; Watzlawick et al., 2011)	It feels good to be understood as a patient even while being mechanically ventilated. It can potentially promote healing and empowerment(Alpers et al., 2012; Wassenaar et al., 2014)	Attention-seeking actions: immediately responded too	*Attention and understanding between two communication partners normally happen almost simultaneously but is two-phased and this is revealed in the narratives from the patients' situations in the ICU.*

Describes observations where communication is challenging(Van Manen, 2014) Time is essential in understanding a phenomenon, also communicative episodes (Heidegger, 1996; Van Manen, 2014)	Disruptions in communication channels(Schramm & Roberts, 1971; Watzlawick et al., 2011) Using different techniques both to try to convey a message, and also to understand that the communication partner wants to say something(Cowley, 2011; Frischen et al., 2007; Goodwin, 2000) Noise in communication channels (Langton et al., 2000; Schramm & Roberts, 1971)	The experience of failed attempts to understand is described in the literature from both the nurses' and the patients' perspectives (Flinterud & Andershed, 2015; Holm & Dreyer, 2017; Karlsson & Forsberg, 2008; Karlsson, Forsberg, et al., 2012; Laerkner et al., 2015; Magnus & Turkington, 2006)	Attention-seeking actions: with delayed response or understanding	*Other providers, in addition to the nurses, who have normally been the focus, had the opportunity to speak out and express themselves about these issues.*
Interprets/describes how interaction is observed to become more intense when it is troublesome to achieve attention (Creswell & Poth, 2013; Van Manen, 2014)	When you have something important to communicate, all methods are used to convey the message(Langton et al., 2000)	Examples of intensification in communication have previously been described(Engström et al., 2013; Guttormson et al., 2015)	Attention-seeking actions: with intensified attempts	*The way non-vocal language plays a role in the intensification of the interaction.*
Describes what is observed when communication breaks down and the patients or providers fail to achieve understanding (Creswell & Poth, 2013; Van Manen, 2014)	Communication breakdown occurs when sender and receiver do not understand each other (Schramm & Roberts, 1971)	The experience of breakdown in communication affects both HP and patients(Laerkner et al., 2015; Tingsvik et al., 2013)	Attention-seeking actions: when giving up	*Consequences of failed attempts at communication include lack of understanding, reduced symptom reporting, and patient non-involvement.*

Table 13. Findings and their relations to theory in paper 2. The previous research column presents studies relevant to the thematic findings.

Relationship between methodological theory, previous knowledge, and the findings in paper 3				
Phenomenological-hermeneutic approach	**Communication theory**	**Previous research**	**Findings**	**Novelty value**
People want to take part in their own life, and we understand ourselves in interplay with others through recognition (Gallagher, 2017) Describe and interpret the unique/essential meaning of the phenomena decision-making bedside with mechanically ventilated	Micro decisions are punctuated, and part of patients' autonomy (Kukla, 2005; Watzlawick et al., 2011) Concepts of shared decision-making from various theoretical angles(Elwyn et al., 2017; Légaré & Thompson-Leduc, 2014; Longtin et al., 2010; Stiggelbout et al., 2015; Thompson, 2007)	Reduced patient involvement reported(Happ et al., 2007; Olding et al., 2016) Patients feel left out of their own treatment while being non-vocal(Carroll, 2007) The goal is to involve patients, as	Patients' involvement in bedside micro-decisions	*The focus on micro-decisions as participation, and how this is observed in the intensive care context over a continuum of time.*

patients (Creswell & Poth, 2013; Van Manen, 2014)	Decisions are expressions from either the provider or the patient to commit to a particular course of clinically relevant action, implying a shared understanding of the agreement, with patient consent(Ofstad et al., 2015)	this may be beneficial for their recovery and well-being(Karlsson & Forsberg, 2008) Discrepancy in what patients and providers feel they need to be involved in(Fitch et al., 1998)		
Describes patterns and behavior of communication(Heidegger, 1996; Van Manen, 2014; Zahavi, 2010) Intentionality: trying to break down the phenomenon to describe its parts (Creswell & Poth, 2013)	Shared decision making, offering choices as options(Elwyn et al., 2017; Kon et al., 2016; Stiggelbout et al., 2015) Patient participation promotes empowerment(Longtin et al., 2010) Shared decision-making should be used to define over all goals of care in intensive care(Kon et al., 2016) Symmetric or complementary relationships between patients and HP(Watzlawick et al., 2011)	Invitations to participate from HP described as positive from the patient's perspective (Lindberg et al., 2015) Non-invited attempts also described, where HP is seen as hierarchical and non-including(Karlsson & Forsberg, 2008; Karlsson, Forsberg, et al., 2012)	Six types of decision-making (non-invited, substituted, guided, invited, shared and self-determined)	*Patients get involved not only through shared decisions, but also by being invited into decisions where the HP facilitates the communication.* *Guided decisions and non-invited decisions given more context, explaining how they occur.* *Autonomous bedside decisions occur, that are also related to patient's treatment.*
Which place a participant has/takes in an interaction can define their perception of the situation. Categories such as insider/outsider does not explain the relationship between *dasein* (defined as a sense of presence or being their) and the world. Constant shifts occur, but by definition dasein is always inside(Heidegger, 1996; Zahavi, 2019) Nearness and distance in the way things are positioned by meanings and actions(Van Manen, 2014)	To be acknowledged or not as a human being(Goodwin, 2000) Autonomy principle: self-determination is a desirable goal (Elwyn et al., 2017)	The patient's experience of being left out of decisions, and how it is experienced when you participate again(Laerkner et al., 2015; Magarey & McCutcheon, 2005)	Being an observer versus a participant in treatment and care	*Illuminating the complexity in the constant shifting of roles between patients and providers. The possibility of interacting both as participant and observer sometimes gives the patient the choice to step up and contribute their opinions. Other times, they let the providers make the decisions.*
Expressions of what creates meaning in the	Negotiating choices, providing alternatives to	Negotiations described in	Negotiating decisions	*Negotiations are described in*

patient's life, or *dasein*(Van Manen, 2014)	create person-centered care (Epstein & Street, 2011) Dialogue evolves in collaboration between individuals(Gerwing, 2016)	previous literature relating to micro-decisions, both regarding hygiene/weaning (Happ et al., 2007) and mobilization(Laerkner et al., 2015)	about individualized care	*previous literature, but not as a way of individualizing care for mechanically ventilated patients.*
Expressions of the unique responsibilities of the healthcare providers as observed (Creswell & Poth, 2013; Van Manen, 2014)	Professional judgement may be a barrier to shared decisions(Légaré & Thompson-Leduc, 2014) Balance between participation, patient's wishes and professional judgement(Kukla, 2005) Shared decisions should also incorporate the best evidence available for the treatment(Kon et al., 2016)	A paternalistic, technological environment dominates the patient's life world in ICUs (Almerud, 2008; Almerud, Alapack, Fridlund, & Ekebergh, 2007)	Balancing empowering activity with energy restoration	*To function as a healthcare provider is also to use professional judgement, but the way this is managed affects how patients may be involved in their own care.*

Table 14. Findings and their relations to theory in paper 3. The previous research column presents studies relevant to the thematic findings.

Relationship between methodological theory, previous knowledge, and the findings in paper 4				
Phenomenological-hermeneutic approach	**Communication theory**	**Previous research**	**Findings**	**Novelty value**
Describes and interprets the unique experience of being a provider for patients on mechanical ventilation (Heidegger, 1996; Van Manen, 2014; Zahavi, 2019) Understanding the social relations and cultural meaning of interactions in the context of intensive care(Creswell & Poth, 2013; Van Manen, 2014; Zahavi, 2019) Describe experiences of providers wanting to deliver care they sometimes feel is not the proper care (Creswell & Poth, 2013; Van Manen, 2014; Zahavi, 2019)	Ethical and moral principles require providers to strive to involve patients rather than abandoning the attempts Légaré et al. (2014), McCormack et al. (2010) Communication channels between patient and provider become disrupted and this is an important barrier(Schramm & Roberts, 1971) Lack of time is a barrier providers experience in communication/participation with patients(Longtin et al., 2010) Cognitive dissonance: conflict between ideals and reality(Festinger, 1962)	Having a responsibility as a provider to promote communication and patient participation is a rather new concept in intensive care Vincent et al. (2016) Nurses have a unique role in the care of patients in the ICU (Rodriguez et al., 2016; Slatore et al., 2012) Experience of frustration when not understanding the patients is normal for HP in ICUs (Laerkner et al., 2015) Advanced communication requires presence, knowledge, creativity, respect, and involvement (Kleinpell et al., 2017; Tingsvik et al., 2013)	Caught between ideals and reality: healthcare providers' experiences	*Advancements in research and medical innovation shapes the role of the provider, which is not without consequences for their relationships with the patients.* *Physicians' and physiotherapists' experiences of communication with patients during mechanical ventilation.* *Dissonance experienced between own values and actions challenges health provider's moral compass.*
Our human existence is an embodied cultural experience of being in the world. Phenomenology focuses on the "first-person-perspective". However, it is possible to present a phenomenon from different angles(Van Manen, 2014; Zahavi, 2019)	Person-centered care and shared decision-making as a health care core concept and why the patient's opinions matter (Barry & Edgman-Levitan, 2012)	The development of the ABCDEF-Bundle (Balas et al., 2014; Pandharipande, Banerjee, McGrane, & Ely, 2010) Comfort, non-sedation, and a humanitarian environment is described as important and beneficial in ICUs(Kleinpell et al., 2017; Vincent et al., 2016) Aids facilitate understanding, but little use is reported(Garry et al., 2016; Happ et al., 2011; Happ et al., 2015; Mobasheri et al., 2016)	Willingness to engage and understand the mechanically ventilated patients	*Trying to implement the ideal of patient-centered care is a challenging task when communication barriers exist to the degree that they do in ICUs.*

Active or passive involvement in dasein(Heidegger, 1996; Van Manen, 2014)	Dehumanizing behavior is non-desirable and morally problematic, but it is a potential consequence if there is a communication break-down(Zoffmann, Harder, & Kirkevold, 2008) To experience a conflict between desired and delivered to patients(Festinger, 1962)	Challenging situations arise in complicated communication encounters (Karlsson, Forsberg, et al., 2012; Laerkner et al., 2015) HP's moral compass is challenged(Laerkner et al., 2015; Tingsvik et al., 2013)	The potential risk of neglecting the patient in the encounters	*The constant awareness and efforts of the providers to try to avoid this potential neglect through various communication strategies.*
Describes the feelings of relating to other professionals and working as a team (Creswell & Poth, 2013; Van Manen, 2014; Zahavi, 2019) Without others we cannot interact and exist(Heidegger, 1996)	Hierarchical structures and non-egalitarian relationships are inevitable in communicative practice(Watzlawick et al., 2011)	Tensions are described as damaging to the relationships with patients and other providers but also to treatment decisions (Manias & Street, 2001; Rose et al., 2014) Positive effects of having a good communication are to be able to deliver good care and having a good "work-flow" (Hofhuis et al., 2008; Karlsson & Forsberg, 2008)	Interdependence on other providers in treatment and care	*The importance of organizing the teamwork so it is adapted to the patient's condition but also balances professionals' responsibilities to create a shared ground.*

Table 15. Findings and their relations to theory in paper 4. The previous research column presents studies relevant to the thematic findings.

7.2 Discussion related to the results

7.2.1 Efforts to achieve understanding

This thesis has contributed to in-depth insight and knowledge about the interactions between HP and awake patients on mechanical ventilation, both by mapping the field of previous knowledge and through the video recordings and interviews conducted. It was a surprise to discover that a systematic approach toward communication barriers in intensive care had not yet been developed despite many years of awareness of how these patients struggle to communicate. Based on the results of paper 1, intensive care units in Norway should be advised to incorporate the use of speech-language pathologists into their units, providing necessary knowledge, communication aids, and adequate communication skills (and aids) training (for both HP, patients and relatives). The observations (papers 2 and 3) and the interviews (paper 4) elicited how HP experience helplessness and frustration when unable to

understand their patients. The HP attempted to do their best but still felt inadequate at times. At the same time, the patients expressed frustration when seeking attention and sometimes gave up their attempts to communicate. One of the premises for human interaction is that one cannot not communicate (Watzlawick et al., 2011). This was evident in the videos and it was therefore seen to be important to describe more thoroughly in this thesis the non-vocal actions occurring between the patients and HP. An example would be the patient (Fiona) reported in paper 2 who was nauseous and trying to communicate this. Watching the video, it was very evident that she was struggling, both swallowing deeply, and looking at the vomit bag. However, she failed to communicate this to the HP, and it was some time before she managed to get attention. The details of the patient's expressions and communication acts during these processes are therefore new knowledge arising from the thesis. It was apparent that there was a disruption in the communication flow between providers and patients, and that this required an extra effort. According to Schramm et al. (1971), what is delivered as a message from the sender can be interpreted differently by the receiver than what was the intended meaning. So, when patients try to communicate, their attempts can be perceived differently from what was intended. Correcting misunderstandings requires the additional capacity to communicate coherently, and over time. The communication barriers are therefore also energy-consuming for both patients and providers, as illustrated by the findings in papers 2 and 3.

Different patterns of communication, such as simplification and HP guessing what the patients tried to express, were observed during the video recordings (papers 2 and 3). Holm and Dreyer (2017) also found similar communication techniques to be typical when they performed interviews and field observations with patients and providers in ICUs. In their study, the communication was described as a movement between comprehension and frustration from the perspectives of both the patients and nurses. Another important factor that Holm and Dreyer (2017) observed affecting the communication was the change in power dynamics when the patients became non-vocal. These patterns were identified through the observations (papers 2 and 3) and the interviews with the HP (paper 4). There is reason to believe that the energy used to communicate, such as when attention-seeking actions are not acknowledged by the HP, invokes feelings of powerlessness and frustration. This is possibly a factor contributing to the physical and emotional fatigue experienced during an ICU stay (Egerod et al., 2015; Jolley et al., 2016). Environmental factors and not being in control and being excluded from participation may contribute to the development of this weakness.

The frustration in communication encounters with mechanically ventilated patients leads the HP to experience what is interpreted as a cognitive dissonance where they struggle to deliver the care and treatment they want to (paper 4). This thesis does not have sufficient data on whether or not this cognitive dissonance change with the providers years of experience in ICUs. In the interviews, one of the nurses highlighted this difference, trying to put herself in the unexperienced nurses' position and compare what type of patients she used to care for when she was newly graduated. Mortensen et al. (2019) explored the perceptions of expert and competent nurses with less sedated patients in the ICUs, and they also found that the HP experienced frustration. Attempts at dialogue and to try to understand were important but also time-consuming for the HP. They also found that the frustration was more apparent in the expert nurses, since the newly graduated nurses lacked experience of other patient groups which whom to compare. This thesis has demonstrated that the struggle to understand is not the unique experience of nurses but is also experienced by physiotherapists and physicians. This make the struggle to understand the patients on mechanical ventilation a shared concern across the disciplines.

Not being able to express oneself can impact on the development of anxiety, confusion, and delirium which are all severe symptoms of discomfort (Garry et al., 2016). It should therefore be a matter of concern for all HP in intensive care, especially since the risk of developing delirium is linked to an increased mortality and reduced cognitive abilities after an ICU stay (Critical Illness Brain Dysfunction and Survivorship Center, 2019; Pandharipande et al., 2013). Reducing the risk of confusion can therefore be seen as a holistic, interprofessional, and preventive task and not simply as a symptom that needs treatment. Recommended measures to manage confusion in ICUs are improving patients' cognition and optimizing sleep, physical activity, hearing, and vision (Devlin et al., 2018; Vincent et al., 2016). These measures resolve around improving the patient's ability to understand what is occurring and to communicate. The next logical step in improving the care in ICUs should therefore incorporate the use of facilitative techniques for communication.

A broad range of communication aids should be present in ICUs (Carruthers et al., 2017; Happ et al., 2014). The patients have different communication barriers and skills that can change in the course of their stay. In the observations in papers 2 and 3, it was revealed that few communications aids were available, and these aids sometimes failed, for a variety of reasons. It was also observed that patients refused to use them (paper 2). Continuing

education in the use of communication aids needs to be conducted with special regard for the needs of each professional group that participates in the patients' care. In order to make sustainable changes in the way HP interact with non-vocal patients, the ICU needs to identify potential barriers to the implementation of aids. Introducing champions who can promote and be expert users of communications aids is one way to ensure effective implementation of the aids (Miech et al., 2018). The communication aids should facilitate discussions of the elements of communication themes that are important for patients, such as the topics addressed on the patient's own initiative (paper 2: physical, psychological, social needs and medical treatment), or bedside micro-decisions (paper 3: micro-decisions such as physical activity, weaning, tracheostomy speaking valve, or tracheal suctioning). The attention-seeking was also as demonstrated as a two-phased process where the patient first obtained the attention of the HP and then communicated what it was that they were seeking attention for. By introducing an easy-to-use technical device, such as an audible attention-button, the first part of the attention-seeking process would be facilitated. This also exists already, according to the AAC-literature (Hurtig & Downey, 2008).

7.2.2 The thesis' consequences for clinical practice and interprofessional collaboration in ICUs

Physicians, nurses, and occupational therapists are stable groups of professionals in the ICU environment, although some countries also have assistant nurses, speech-language pathologists, pharmacologists, and respiratory therapists. Through this thesis, it was discovered inefficient patterns of communication, such as attention-seeking actions that are not acknowledged or properly understood (papers 2 and 4), or due to HP constantly who constantly have to maneuver between competing agendas, or who do not involve the patients in their own care (papers 3 and 4). Some of the consequences for patient care have been problematized in the thesis, such as reduced participation and reduced symptom management. Some of the solutions has also been suggested along the way. Interprofessional collaboration in the patient care is one of the key factors in improve patient participation as demonstrated by the findings in papers 3 and 4. Finding good solutions and work toward shared goals with the patients therefore seems of importance.

The healthcare system is part of a larger public service. The roles of professionals in advanced practice contexts, such as ICUs, fluctuate in assigned responsibility, technical performance, and professional roles (Balas et al., 2012; Manojlovich et al., 2009; Paradis et al., 2014). The

findings indicate that in various situations where communication is challenging, the HP seem to revert to actions or communication techniques that reduce the patient's perception of involvement in their own treatment. This is done as a temporary measure while trying to find a better solution. This was observed (paper 3) when the physiotherapist and nurse were trying to communicate with the patient at the same time but with different priorities. The HP was also observed trying to balance the treatment against physical activity by encouraging rest. The opposite was also observed, making a patient sit up on the side of the bed although the patient had expressed a clear wish to not do this. This was also revealed in the interviews with HP (paper 4) when they described "fooling" or using other deviation techniques to get the patient to do what they wanted. Schandl, Falck and Frank (2017) also found that negotiation techniques was the nurses way of "give-and-take" in the dialogue about decision-making with patients. Instead of adjusting the medication to relieve pain, the nurse could for example propose to stand by the patients' hand to provide comfort and safety.

In many of the previous studies performed it has been mentioned that time is of the essence, and that effective communication with patients cannot happen without sufficient HP present (Fitch et al., 1998; Laerkner et al., 2015; Tingsvik et al., 2013). Making sure that patients receive sufficient time and constructive guidance in communication requires personnel resources and knowledge. The communication can therefore be affected by the ICU management by staffing resources provided. This was not specifically investigated in this thesis, but it was apparent that this is an important issue in the ICU in need of more knowledge. It is also hypothesized that a shortage of staff is an argument for a greater use of sedatives since the nurses are then able to prioritize other tasks they need to attend to rather than using their time to understand the patients' communication attempts (Ogundele & Yende, 2010; Strøm & Toft, 2016). The shortage of personnel might, therefore, also be a barrier to implementation of the ABCDEF-bundle and the eCASH-principles in ICUs (Balas, Burke, et al., 2013; Balas et al., 2012; Vincent et al., 2016). Laerkner et al. (2016) conducted a randomized controlled trial comparing non-sedated patients with patients following a daily wake up trial, measuring patients' consciousness, nursing workload, and costs. The self-reported nurse workload was similar in both groups ($p = 0.085$). However, the workload measured by the Nursing Care Recording System (NCR11) was surprisingly higher for the group with daily wake up trials compared to the non-sedated patients (19.95 compared to 17.05, $p = 0.00001$). These finding make it hard to argue whether or not it is a higher workload or not, based on the instruments used in their study. To our knowledge, no studies

have looked closely into the workload impact of the interprofessional collaboration with conscious and alert patients on mechanical ventilation. Balas et al. (2012) has however highlighted the nurse's role in the ABCDEF-bundle as crucial for its successful implementation, and that the approach should be based on interprofessional teamwork.

7.2.3 Communication as an indicator of quality in intensive care.

The impact of good communication may be difficult to measure, and it can be challenging to establish a direct link between the different patient-centered interventions and the actual patient outcomes (Epstein & Street, 2011; Street, Makoul, Arora, & Epstein, 2009). While both legal regulations and patients' expectations are high regarding patient involvement, it is still uncertain whether we manage to succeed. The Norwegian guidelines for critical care medicine (2014) recommends anesthesiologists as the responsible physicians and treatment coordinators, in close collaboration with nurses, physiotherapists, and the physicians from the specialized hospital departments. One recommendation in the Norwegian standard is for a daily meeting, a "visitation routine," in order to discuss the patient's treatment plan. The patient's role in this meeting is however unclear. These meetings could be an opportunity to discuss the communication challenges for each patient and make individualized plans for the communication. Based on the paradigmatic change of treatment of treatment in the last decades and the findings from this thesis, I would like to suggest that visitation routines should incorporate the patient's participation, and guidelines should provide recommendations for ensuring their participation in the dialogue.

The findings from this thesis elicit the importance of a redefinition of the concept of quality in the interactions that occurs in clinical practice. Observations showed that patients' attempts to communicate were frequently not acknowledged, and furthermore, that patients were not sufficiently involved in decisions. According to the legal regulations, the patients should be involved, based on their capacity, and HPs should facilitate patient participation (Patients' Rights Act, 1999). ICU staff working with conscious patients on mechanical ventilation cannot assume that the patient is incompetent to participate in decision-making despite their temporary lack of a voice. The Patients' Rights act (Patients' Rights Act, 1999) states that involuntary treatment may be considered if the patient is incompetent to consent. Treatment against the patient's desire should be done with respect for the patient's right to self-

determination, limited to situations in which a treatment decision is absolutely necessary, and when involuntary help is the only way to reach the treatment goals.

Some of the situations observed could even be interpreted as though the HP was acting against the patient's expressed desires. Examples are given in paper 3, with non-invited decisions where the patients expressed reluctance when a decision was being made but were not asked about their preferences. To promote autonomous decision-making in a situation where you are critically ill is challenging, and it is the HP's responsibility to do their utmost to ensure that the patient's competency to consent is evaluated sufficiently. Self-determined decisions, such as patients wanting to be mobilized up or communicating special requests regarding procedures (e.g., tracheal suctioning), may be an indicator of a willingness to participate. However, attention-seeking actions to pose questions about the treatment (examples in paper 2) may be another indicator of interest and willingness by the patient to engage in decision-making. Requirements that ensure evidence-based implementation of shared decision-making processes in ICUs would seem to be an important area for future research. No European or Norwegian consensus on this area has been found searching the literature. The definition of shared decision-making from the American College of Critical Care Medicine and American Thoracic Society (Kon et al., 2016) does not specifically include bedside micro-decisions as important options. However, whether or not professionals manage to invite their patients into bedside micro-decisions, could be a measure of quality in the communication in ICUs.

The introduction of a classification of communication skills used to document a patient's communication abilities in the ICUs (in addition to sedation, pain, or delirium scores), could potentially improve their care. A standardized classification and approach to the communication barriers would provide a more accurate descriptions of each patient's communication challenges. It would also assist the HP in choosing the appropriate communication methods while illuminating the variety of communication challenges intensive care patients experience. Further development of the guidelines with more specific advices would aid the HP in individualizing their care and adapting to a patient's specific needs and capacity for communication. Both patients and HP might benefit from this in many ways. Studies implementing communication aids in ICUs report increased patient satisfaction (El-Soussi et al., 2015; Happ, Roesch, et al., 2004; Rodriguez et al., 2016), reduced difficulty in communicating (Happ, Roesch, et al., 2004; Maringelli et al., 2013), an increase of

communication between HP and patients (Happ et al., 2014; Nilsen, Sereika, & Happ, 2013), and well-being, happiness, and quality of life (Garry et al., 2016). By adapting the care and communication, understanding would be easier to achieve. This would reduce the frustration in the encounters between patients and providers, and potentially reduce the patients' anxiety. Achieving a better communication may, therefore, reduce the HP's experiences of gap between desired ideals and the reality (paper 4).

7.2.4 Shared decision-making in intensive care: an unrealistic ideal or the future

Based on the research findings on the patient's perspective in this thesis and in previous studies presented, it becomes clear why patients should be involved as far as possible in their own treatment. A patient-centered approach also has a philosophical background, grounded in the way we see ourselves as human beings (Ely, 2017; Epstein & Street, 2011). From the HP's perspective, good practice and professional judgement were highlighted, as illustrated in paper 4. The HP's descriptions revealed various ways in which they managed the dissonance experienced in their patient care, and how they negotiated and maneuvered by using communication techniques.

Ensuring patients voices in intensive care is important for improvements in healthcare, as illuminated through the research grounding this thesis. It seems apparent that there is a need to focus on the processes by which the patients may be enabled to express their desires and on their capacity to participate in decision-making. The eCASH-concept (Vincent et al., 2016), the ABCDEF-approach (Balas, Burke, et al., 2013; Marra et al., 2017; Pandharipande et al., 2010), and the guidelines for relatives HP's participation in ICUs (Davidson et al., 2007; Kon et al., 2016) all point to the future directions of treatment in modern ICUs. There is, however, concern that there is a lack of shared ground as to what might be interpreted as patient-centered (or even person-centered) care. In paper 3, bedside micro-decisions were investigated, and the findings revealed that while patients did participate, there was greater room for further involvement in many of the decisions. Shared decision-making is normally investigated within other types of decisions (Elwyn et al., 2017; Stiggelbout et al., 2015), but the theoretical frameworks were still useful in the analysis of the bedside decisions. Consciousness of micro-decisions may improve HP communication with patients and increase potential patient participation. Even small decisions may have a great significance for the individual patient.

The focus on micro-decisions in this thesis makes it evident that the principle of autonomy in health care is constantly challenged by our own professional judgement. Allowing the patients to make their own choices, also means observing that they choose differently than us. Kukla argues that in order to make conscientious choices, the HP must "instill commitments and demand conscientiousness in order to enable patients sense of responsibility and critical engagement in their own health care practices" (Kukla, 2005, p. 40). She, thereby, makes a clear distinction between our moral and legal obligation as HP to protect patients right to autonomy, and HPs way of empowering the patients. An ICU patient is especially vulnerable due to the communication barriers and the critical illness. However, if HP never expect them to be capable to participate in decision-making, that also reduce their possibilities for involvement.

In papers 3 and 4, important limitations to patient participation for mechanically ventilated patients were described, such as communication barriers. However, we also observed various ways in which the patients could be included despite these barriers. These situations should be highlighted as good, contextualized examples of clinical practice, and we should focus on what promotes the positive involvement of patients. Although it is not possible to provide a standard approach for patient participation based solely on the findings from papers 2 and 3, at least these insights can give an increased understanding for HP practice.

To achieve shared decision-making, HP need to recognize the existence of an asymmetrical relationship with patients (Vincent et al., 2016) and that this affects their human interaction (Watzlawick et al., 2011). This implies a great responsibility on the HP to ensure quality in care and treatment, especially in encounters with non-vocal patients. Paper 3, on bedside micro-decisions, indicates that shared-decision making would be problematic as the gold-standard for measuring the quality of communication and patient involvement in ICUs. However, a variety of ways of making bedside micro-decisions should be embraced, such as inviting decisions, guiding decisions, and including non-invited decisions when necessary. Based on this thesis findings, no recommendations have been made about when or how it would be appropriate to use the different types of decision-making patterns identified. That would be an interesting research direction, and a logical step toward increased patient participation for mechanically ventilated patients.

8.0 Conclusion

This thesis aimed to obtain in-depth knowledge of the communication and interaction between patients and healthcare providers while patients are conscious and alert on mechanical ventilation in ICUs. Paper 1 revealed fundamental knowledge gaps in this topic that might affect patient care, such as the lack of an interprofessional approach towards communication with non-vocal patients and the inadequate use of appropriate communication aids. Paper 2 showed that the patients do take the initiative to communicate by seeking attention and that these attempts are responded to in various ways (immediately responded to, with delayed response or understanding, intensified or given up). The attention-seeking attempts were done by patients to communicate about physical, psychological, social or medical needs. In paper 3, bedside micro-decisions involving patients and HP were identified as occurring within six types of communicative pattern: non-invited, substituted, guided, invited, shared, and self-determined decisions. How the micro-decision process developed influenced the patient's further involvement in their treatment and care. It was observed that the patients varied between being an observer and a participant in the decisions made, and negotiations around individualized care were balanced against empowering activity and rest. Paper 4 focused on the HP's experience of difficulties when communicating with the patients, and their feelings of cognitive dissonance between their ideals and their real-world encounters with both patients and other professionals. The findings offer a deep insight into the complexity of communication with awake patients on mechanical ventilation, and how the communication barriers affect both patients and HP.

9.0 Implications

9.1 Implications for clinical practice and healthcare in intensive care units

The findings illuminate areas for improvement in our daily practice with patients. Based on the findings from this thesis, it appears that we fall short, in our interactions with patients on mechanical ventilation. Implementation of facilitative strategies for communication should be prioritized in clinical practice. To improve patient outcomes (avoiding confusion and reducing delirium) and to incorporate patient-centered care into intensive care, an understanding of the

patients' communication barriers and the development of HP competence in communication are both vital. Observing and being aware of attention-seeking actions and also of the various forms of decision-making can improve the HP's awareness of communicative patterns. Specially, a reduction of the number of non-invited decisions and non-observed attention-seeking efforts would result in improved understanding and greater patient participation. Collaborative efforts between the professionals should be encouraged in clinical practice, ensuring that all HP work toward the same goals. To improve care, follow up programs with ICU patients should address the impact of the temporary lack of voice and invite the patients to evaluate the professionals' approaches in their communication and interactions. These findings could be used to reflect upon patient encounters in clinical practice.

The data collection for this thesis was not done during the covid-19 pandemic, but the increased number of intensive care patients in recent months has further actualized the need for knowledge in this field. I would especially highlight that HP using infection control equipment also experience communications barriers. Their voices get quieter since they have covered themselves with masks, and many of their non-verbal signs are physically concealed. Communication is hard even with speaking colleagues, but it is particularly hard for patients to understand the HP. It is also uncertain how many communication aids could be implemented in isolation regimes.

9.2 Implications for future education

The findings confirm that students, from all health professions who enter the field of intensive care would benefit from educational programs focusing on the communication with mechanically ventilated patients. There is potential to improve professionals' communication and this should be acknowledged as an important part of treatment and care. Based on the findings of this thesis, specific training in communication with patients on mechanical ventilation should be incorporated into the specialist education for physiotherapists, anaesthesiologists and critical care nurses. Online educational programs such as that implemented in the SPEACS 2 trial (Happ et al., 2015), might not be adequate. Still, they could be a great supplement to more hands-on training, such as simulations. On the basis of this thesis, an educational course should be implemented as mandatory in which HP would increase their competence by progressing from basic communication training to more advanced communication skills. The course should also have a clear focus on patient

involvement and how to use different communication aids. Role-play or simulation could be incorporated into the course to give the professionals the possibility of enhancing their clinical skills and improving interprofessional collaboration. An advice would also be to incorporate discussions about the professionals' roles and their functions in relation to the patients in order to increase collaboration and interprofessional strategies for improved communication.

10.0 Recommendations for future research

Based on the findings, I would recommend the improvement of communication skills for clinicians in the intensive care field by developing educational interventions for the HP and by studying the effects of communication on patients. Interprofessional communication and collaboration seems to be among the core factors that have the potential to enhance interactions with patients and should, therefore, be investigated further. It would also be of interest to explore attention-seeking actions and bedside micro-decisions further to observe and identify potential new patterns not already described. The attention-seeking actions and the types of micro decisions may be used for coding systems and outcome measures for future intervention studies. Other useful outcome measures could be the patient's and HP's frustration and satisfaction levels with communication and communication aids, the prevalence of anxiety and delirium, and also the competence level of the HP. The effect of the potential improvement in communication on patients' memories and symptoms post-ICU would be useful information. Based on the struggles reported by HPs, here may be a connection between improvement in communication and reduced providers burn-out. Systematic implementation of communication aids and strategies for communication may facilitate understanding between the patients and their relatives, contributing to increased satisfaction and positive emotions (such as security, hope, and feeling involved in the care). Positive emotions could hopefully reduce anxiety, stress, and other uncomfortable symptoms patients experience during an ICU stay. Supporting relatives' communication and interaction with patients on mechanical ventilation has not been a focus in this study but it is a relevant topic for research as an increasing number of patients are more conscious and alert on mechanical ventilation. An understanding of patients' communication patterns, as described in this thesis, is also a baseline for communication between patients and their loved ones.

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PAPER 2

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ORIGINAL ARTICLE

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Attention-seeking actions by patients on mechanical ventilation in intensive care units: A phenomenological-hermeneutical study

Marte-Marie Wallander Karlsen[1] | Kristin Heggdal[1] | Arnstein Finset[2] | Lena Güntenberg Heyn[1]

[1]Lovisenberg Diaconal University College, Oslo, Norway

[2]Faculty of Medicine, Institute of Basic Medical Sciences, University of Oslo, Oslo, Norway

Correspondence
Marte-Marie Wallander Karlsen, Lovisenberg Diaconal University College, Lovisenberggata 15b, Oslo 0456, Norway.
Email: marte-marie.karlsen@ldh.no

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Abstract

Aims and objectives: The aim of this study was to explore the interaction between mechanically ventilated patients and healthcare personnel in intensive care units (ICUs), with a special emphasis on patients' initiative to communicate.

Background: Patients on mechanical ventilation in ICUs tend to be less sedated today compared to standard care in the past. Their experiences of being voiceless may cause emotional distress, and for many patients, communication is difficult. Healthcare personnel are reported to be the main initiators of the communication exchanges that occur.

Design: An observational study with a phenomenological–hermeneutical approach.

Methods: Video recording was used to collect data on the naturally occurring communication and interaction. Ten conscious and alert patients from two Norwegian ICUs were recruited. Two relatives and a total of sixty healthcare personnel participated. Content analysis was conducted, with focus on both the manifest and latent content meaning.

Results: We found a total of 66 situations in which patients attempted to attract the attention of others on their own initiative in order to express themselves. Attention-seeking actions, defined as the act of seeking attention and understanding without a voice, became an essential theme. Four patterns of interaction were identified: immediately responded to, delayed response or understanding, intensified attempts or giving up. Patients had a variety of reasons for seeking attention, which were classified into four domains: psychological expressions, physical expressions, social expressions and medical treatment.

Conclusions: Patients' attention-seeking actions varied in content, form and the types of responses they elicited. The patients had to fight to first gain joint attention and then joint understanding. This was both energy-draining and time-consuming.

Relevance to clinical practice: Healthcare personnel need to spend more time for communication purposes, giving attention and being more alert to bodily or symbolic gestures to understand the patient's needs.

KEYWORDS

artificial respiration, communication, hermeneutics, intensive care, mechanical ventilation, patient experience, phenomenological–hermeneutic, video recording

1 | INTRODUCTION

In recent decades, there has been a paradigmatic shift in the treatment of patients in intensive care units (ICUs) in the sense that patients are less sedated and more conscious even when they are on mechanical ventilation. The reason for this is that reduced amounts of sedation have been proven beneficial both for survival, to reduce the days on mechanical ventilation and the length of stay in the ICU (Egerod, 2009). To have more conscious patients also improves the possibilities for early mobilisation (Balas et al., 2013), interaction with relatives (Davidson, Jones, & Bienvenu, 2012) and patient participation (Happ, Swigart, Tate, Hoffman, & Arnold, 2007) despite critical illness.

The communication barrier caused by the tracheal tube, however, leads to numerous negative emotions on the part of the patient, such as frustration, anxiety and anger (Happ et al., 2011; Holm & Dreyer, 2017; Khalaila et al., 2011). Both patients and healthcare personnel report severe problems with communication, and patients rate the impact of the communication barriers as more troublesome than healthcare personnel rate it (Magnus & Turkington, 2006; Wojnicki-Johansson, 2001).

What does this paper contribute to the wider global clinical community?

- Patients' own initiative to communicate during mechanical ventilation may be characterised as attention-seeking actions, which include a variety of nonverbal techniques. The patterns identified as immediately responded to, delayed response or understanding, intensified and giving up describe the way the interaction may unfold.
- The act of seeking attention and understanding without a voice can be described as a constant fight: first, to obtain joint attention and then to achieve joint understanding with the healthcare personnel.
- Attention-seeking actions are related to the patient's physical, psychological and social needs as well as to questions regarding medical treatment.

2 | BACKGROUND

The communication barriers such as the tracheal tube and possible temporary loss of motoric and cognitive capacity during critical illness may affect the patient both during and after a stay in an ICU (Egerod et al., 2015), thereby reducing patient participation (Happ et al., 2007), satisfaction with care (Guttormson, Bremer, & Jones, 2015) and the ability to maintain normal contact with relatives (Davidson et al., 2012). Previous studies report that intensive care patients (ICU patients) use a variety of communication forms (Happ et al., 2011; Karlsson, Forsberg, & Bergbom, 2012; Nilsen, Sereika, & Happ, 2013).

Joint attention can be described as the basis for all communication, as a message can only be conveyed if the person attempting to express it is able to attract the attention of the communication partner (Caruana, McArthur, Woolgar, & Brock, 2017; Moore, 2014). A variety of factors, such as the illness, delirium, medication or other environmental factors in the ICU, may affect the ability of ICU patients to obtain attention, understand situations and respond coherently. Few studies have specifically focused on describing the content, initiation and patterns of interaction among this group of patients (Happ, Tuite, Dobbin, DiVirgilio-Thomas, & Kitutu, 2004; Happ et al., 2011). The main initiator of the communication is reported to be healthcare personnel, and only about 15% is based on the patients' initiative (Happ et al., 2011; Nilsen et al., 2013). Previous studies also reveal that patients have trouble initially gaining the attention of the healthcare personnel to convey their needs (Engström, Nyström, Sundelin, & Rattray, 2013; Laerkner, Egerod, Olesen, & Hansen, 2017; Mobasheri et al., 2016). The patients' efforts to achieve attention as well as what they communicate about will inform us regarding what meaning they make of their intensive care stay as it occurs. Describing these situations can provide useful knowledge both for clinical practice and for educational purposes. The aim of this study was thus to explore the interaction between mechanically ventilated patients and healthcare personnel in ICUs, with a special emphasis on patients' initiation of communication.

3 | DESIGN AND METHODS

The main research question that guided the study was as follows: What characterises the communication and interaction between conscious and alert mechanically ventilated patients and healthcare personnel? The underpinning questions were as follows:

- How do mechanically ventilated patients try to express themselves in the interaction with healthcare personnel?
- What is the content of the communication?

The study was an observational study conducted with a phenomenological–hermeneutic approach, as the aim was to capture the unique human experience to gain a deeper understanding of the participants' communication and interaction in this setting (Heidegger, 1996; Van Manen, 2014). We wanted to describe and interpret how the phenomenon of attention seeking occurred in the intensive care context. Video recordings were used to collect observational data while field notes were used to complement the data set. The observations are part of a larger study where interviews were also conducted with both patients and healthcare personnel.

3.1 | Setting and participants

The study was conducted in two ICUs at a university hospital in Norway in which a total of 850–900 ICU patients are admitted annually. The units had 10 and 11 beds, respectively, and all the

patients had single rooms. One or two nurses were always present in the patients' rooms because a 1:1 nurse–patient ratio is regarded as standard intensive care in Norway. Over 80% of the nursing staff had postgraduate intensive care nursing education. The anaesthesiologists ran the department, in close cooperation with the physicians in the specialised departments, who held treatment responsibility.

Conscious and alert patients on mechanical ventilation were purposively recruited between April 2016 and May 2017. The inclusion criteria were patients over the age of 18, mechanically ventilated for at least 48 hr, and with a Richmond Agitation and Sedation Scale (Sessler et al., 2002) score of 0–2. They had to be without diagnosed delirium for the last 24 hr, and they were screened with The Confusion Assessment Method for the ICU (CAM-ICU) (Ely et al., 2001). Patients who did not speak Norwegian or had severely impacted visual, hearing or cognitive capabilities or were in end-of-life care were excluded.

A trained nurse first explained the aim of the study to eligible patients and then asked whether they were interested in receiving information from the researcher. If they consented to participate after receiving additional information, video recordings were planned for the following day and relatives were informed. The researcher responsible for collecting the data disclosed her professional background as an intensive care nurse to the patients. Patients were informed numerous times that participation was voluntary and that the video recordings could be stopped at any moment without any consequences. They provided their written consent and received additional written information after they were weaned off mechanical ventilation and in a more stable phase of their illness.

Healthcare personnel were recruited and informed based on the same principle of voluntary participation, and both nurses, physicians, physiotherapists and radiographers were included. It was uncertain how many personnel would care for the patients on the day of the video recordings. They were therefore either approached by a trained nurse the day prior, or the researcher informed and asked them to participate directly on the same day the video recordings occurred. Healthcare personnel received written information and signed a written consent form. Relatives visited during two of the video recordings. They were informed the day before the video recording, with both verbal and written information, and signed a written consent form.

Fourteen patients were invited, and 10 volunteered and were included in the study (seven and three from the respective ICUs). Three of the invited patients declined before meeting the researcher, and one patient was too exhausted to be video-recorded on the scheduled day. No healthcare personnel declined during the video recordings. It is unknown how many healthcare personnel declined participation before the onset of video recording but one physician indicated that he would return after the video recordings had stopped and was not included. The researcher responsible for collecting the data was a ICU nurse with insider knowledge of the study site. It was important that participating colleagues had the opportunity to refuse without worrying about the relationship with the researcher afterwards. The study nurse or charge nurse therefore managed the recruitment of the nurses, based on how they planned the nursing care for the day. The researcher then gave additional information and obtained written consent once they had accepted to participate.

Table 1 offers an overview of the participating patients and healthcare personnel. The patients were five females and five males, with a mean age of 53.6 years (range 36–72). A variety of diagnoses were represented in the sample, including liver failure, respiratory failure, infections, cancer and complications after organ transplantation. The median length of stay on mechanical ventilation before video recordings was 20 days (range 4–68). The mean severity of illness score (SAPSII) was 42.0 (*SD* 13.1), the mean nine equivalents of nursing manpower (NEMS) score was 37.0 (*SD* 6.0), and the median nursing activities score (NAS) was 144 (IQR 123.0–150.7). None of the patients were restrained physically. A total of 60 healthcare personnel were involved in the care of the patients. The interactions varied from a few minutes to being present all the time, as the main responsible nurse usually was. All nurses except two had a postgraduate education in intensive care nursing and had worked more than two years in the ICU.

3.2 | Data collection

Video was chosen as the method for data collection because it allows for repeated access to the subtle details of natural interaction and communication, which are unavailable with other methods (Heath, Hindmarsh, & Luff, 2010). Two surveillance cameras and two sound recording devices were installed in the room of the patient in the morning and left to run continuously for three to four hours. The plan was to gather data from interaction when nurses, physicians, physiotherapists or radiographers visited, which normally occurs during this time of the day. One camera was an overview camera trying to capture the whole room; the other camera was focused on the bed and the patients' facial expressions. The researcher responsible for collecting data was placed outside the patient's room, dressed in a hospital gown to ease into the environment, but did not directly participate in patient care. It was intended to intervene as little as possible during the actual video recordings, but to be present in case the video recordings were to be paused or stopped at any moment. Context-specific information was written down in field notes before, during and after the video recordings. Demographic data were collected from each patient. Pilot recordings were conducted with two patients. These patients were not included in the study, as the pilot revealed a need to use new equipment to obtain better sound quality and to improve data management.

3.3 | Data analysis

Analysis was data-driven and inductive. Although the main topics of interest were communication and interaction, the researcher was open and curious to what happened in the field. The hermeneutic circle serves to attain a deeper understanding of the written and visual material, moving back and forth between parts of the data

TABLE 1 Overview of the sample

Patient number	Age	Days on mechanical ventilation	Analgesics or sedatives administered during the video recordings Bolus: B Continuous Infusion: CI	Total time of video recordings (hours: minutes: seconds)	Healthcare personnel present during the video recordings
Patient 1	43	21	Fentanyl (CI) Dexmedetomidine (CI[a])	03:05:19	3 nurses 1 physiotherapist 1 anaesthesiologist 2 physicians responsible ward[c]
Patient 2	36	47	Dexmedetomidine (CI)	03:47:41	3 nurses 1 physiotherapist 1 anaesthesiologist
Patient 3	71	15	Dexmedetomidine (CI) Propofol (B) Ketobemidone hydrochloride (B)	03:20:24	3 nurses 1 physiotherapist 2 anaesthesiologists 1 physician responsible ward
Patient 4	65	8	Dexmedetomidine (CI)	03:16:10	3 nurses 1 physiotherapist 1 anaesthesiologist 1 physician responsible ward 2 radiographers
Patient 5	43	19	Dexmedetomidine (CI) Fentanyl (CI)	02:55:56	3 nurses 1 physiotherapist
Patient 6	48	4	Dexmedetomidine (CI) Fentanyl (CI)	02:46:39	3 nurses 1 physiotherapist 1 physician responsible ward 2 radiographers
Patient 7	53	68	Morphine sulphate (B)	03:32:27	3 nurses 1 physiotherapist 1 physician responsible ward 1 anaesthesiologist
Patient 8	72	30		03:00:34	3 nurses 1 physiotherapist 1 anaesthesiologist
Patient 9	60	25	Ketobemidone hydrochloride (B)	03:31:03	3 nurses 1 physiotherapist 1 physician responsible ward 2 anaesthesiologists
Patient 10	45	16		01:07:00 [b]	2 nurses 1 anaesthesiologist 1 physician responsible ward
Total				30:23:13	29 nurses 9 physiotherapists 9 physicians responsible ward 9 anaesthesiologists 4 radiographers

[a]Continuous infusion of dexmedetomidine for the first 20 min of the recording. [b]Patient left room because of a radiographic intervention a little over one hour after the recordings started. [c]The anaesthesiologists ran the department, in close cooperation with the physicians in the specialised departments, who held treatment responsibility.

and the data as a whole (Creswell & Poth, 2017). Content analysis was applied to identify manifest and latent meanings (Graneheim, Lindgren, & Lundman, 2017; Graneheim & Lundman, 2004). The two videos captured from each patient were the meaning unit for the analysis. At first, the videos were watched several times and transcribed descriptively for both verbal and nonverbal actions and what occurred in the environment, in an Excel sheet. Nonverbal actions, such as eye gaze, movements of the body, noises, facial grimaces and lip movements, were noted. During this process, preliminary codes were made. See Table 2 for an example of a transcript.

From the initial codes, central categories were extracted, reflected upon and discussed more in depth in the research group. Attention-seeking actions became a prominent topic during the analysis. All the situations in which patients attempted to seek attention

TABLE 2 Example of a transcript of the video recordings

Time	Patient (nonverbal)	Nurse (verbal)[a]	What happens in the room[b]	Preliminary codes
02:14:33	Patient moves in bed and taps the bedside, looking at nurse		Alarm goes on the ventilator (Nurses are speaking together)	Attention-seeking action
	Patients coughs some			
	Patient looks at the nurse, grimaces, taps the bedside	*To me, it just looks like you are sick of it all right now.*	Nurse moves towards the patient, lays her hand on the patients' hand and looks at him	
	Patient shakes his head and lifts his hand	*No… is it still difficult to breathe?*		
	Patient nods his head	*Headache yeah, it takes some time before analgesics work. It can take up to ten minutes.*		
	Patient nods his head, bends forward and looks at nurse		Nurse flushes the central venous line, leans towards the patient	
	Patient closes his eyes	*You want a cold cloth in your forehead? No…*	Nurse goes over to the other side of the bed, adjusts settings on the ventilator	
02:15:31		*Now I have given you some more air so you get more support from the machine.*		

[a]Everyone present in the room got their own column in the Excel sheet where what they said was transcribed. The patients' expressions were described mostly with nonverbal behaviour. If a patient used a speech valve during the video recordings, their verbal interaction was also transcribed. [b]Two columns were made with the heading "what happens in the room." This made it possible to describe the actions that went on, when multiple healthcare personnel or relatives were present.

were thus identified, extracted and transcribed as situational descriptions after watching the videos several times, to establish detailed and thick descriptions and to try to understand what the patient wanted to express. The response they got from healthcare personnel was included in the descriptions. By comparing all the attention-seeking actions to explore what the patients expressed, we also examined the content in depth. This was further categorised in the most prevalent overarching domains. The text was reviewed and read numerous times, situations compared against each other, and reflected upon to illuminate differences and commonalities across the patients in the communication and interaction process. Theory about communication and interaction has been used as a tool for discussion (Järvinen & Mik-Meyer, 2005; VanLear & Canary, 2016; Watzlawick, Bavelas, Jackson, & O'Hanlon, 2011). The last step of the analysis included an overall critical analysis, watching the videos again to review the understanding of the themes and the patterns that were identified.

The researcher responsible for collecting and transcribing, coding and presenting preliminary analysis of the data is an intensive care nurse, with extensive experience in one of the ICUs in the study. The three other researchers participated in creating the research design, watching segments of the videos, reading and providing independent feedback on the transcripts and situational descriptions and participated in the analytical phase during regular meetings. There was little disagreement in the analyses, but the researchers contributed with different interpretations of the data and discussed each other's analysis. Agreement was achieved on all main topics and analytical ideas. The principles of transferability, confirmability, credibility and dependability guided the study (Lincoln & Guba, 1985). The information power of the material was extensive, as the video recordings, with their broad representation of communicative episodes, provided rich material to draw upon (Malterud, Siersma, & Guassora, 2016). The analytical thoughts were not discussed with the participants with the direct purpose to confirm or discourage of the findings, although some of them viewed segments of the videos afterwards.

3.4 | Ethical considerations

The study was approved by the South-Eastern Regional Committees for Medical and Health Research Ethics in Oslo, Norway (2015/2012), and was carried out in accordance with the Code of Ethics of the Helsinki Declaration (World Medical Association, 2013). Videos were digitally stored on a server for research data, in accordance with the University Hospital's regulations. Participation was voluntary but seen as a process that was continuously negotiated. The patients' consent while on mechanical ventilation was obtained either with the trained nurse or with other intensive care nurses present to observe the patient's response to the information and to serve as discussion partners when in doubt. The researcher collecting the data also asked questions about the cognitive function of the patient (CAM-ICU, use of sedatives and the nurses' opinions) to make sure the patient would understand the information about the study. The information was given multiple times over several days, and the researcher emphasised sensitivity in the encounters. The video recordings could be experienced as an extra burden or

stressful, so it was important to ensure that the patients were motivated and did not experience any pressure or stress during the recordings. The relatives were informed the day before the video recordings to try to ensure a consent would not be against the patients' will because they had better knowledge about the patients and their preferences. When the video recordings were made, all participants were aware they could request the cameras to be turned off at any time. The nurses were asked to be especially sensitive towards a desire from the patients to turn off the recorder because the patients were considered vulnerable. The patients were told to alert the nurses if they wanted to stop the recordings. The researcher also entered the room at least once during the recordings to ask if everything was okay. The nurses occasionally asked the patients whether video recording was acceptable if they were unsure, especially during sensitive procedures. One of the patients chose to stop the video recording during a procedure and then start it again later. As the researcher who collected data revisited the patients afterwards, she ensured that the patients understood what the study entailed. The patients were asked again if they consented, as participation was not taken for granted and they might feel differently about it afterwards. All patients remembered the researcher at that point of time, which led us to believe they also knew what they consented to while on mechanical ventilation. Patients are severely ill when admitted to ICUs, and mortality is relatively high. Two of the patients included in the study died before signing the written consent form; the relatives then consented on the behalf of the patients to allow the use of the video recordings for research purposes. The ethical committee approved this approach. The relationship with the healthcare personnel was carefully negotiated through reflection and open dialogue both before, during and after the video recordings. Personal details that might disclose the participants' identities were removed in the presentation of the findings.

4 | RESULTS

In total, more than 30 hr of video recordings from 10 patients were collected. The patients had various forms of communication barriers. One of the 10 patients was orally intubated, while the others were tracheostomised. Three of the patients used speech cannula and one used a Trach-Vent for the purpose of weaning off mechanical ventilation during the video recordings. Five of the patients had communication aids such as an alphabet board, emotion board or a stiff board, with paper and pen to write on. Three of the patients had reduced ability to form words with their lips. Four of the patients had visibly reduced strength in either their hands or legs, or a combination of both.

The patients' rooms were quite small, filled with extensive amounts of technological equipment. All of the patients had several continuous infusions, mechanical ventilation, central venous lines, urinary catheters, arterial pressure monitoring, electrocardiography monitoring and saturation probes. Some of them had additional equipment including continuous dialysis, chest or surgical drains, aorta balloon pumps, Swan Ganz catheters, or mobilisation equipment for physiotherapy (e.g., chairs or steps). Personal photographs or gifts from relatives were also present in some of the rooms.

The attempts of patients to attract the attention of others were a major issue due to their limited ability to utter words audibly. This appeared across the observations and was interpreted as attention-seeking actions. In total, 66 situations were extracted from the data set in which the patients tried to seek attention. Four distinct patterns of how the attention-seeking actions evolved were identified: immediately responded to, delayed response or understanding, intensified, or giving up. The ways in which the patients expressed themselves and the content of the attention-seeking actions were intertwined, and the content could not be separated from how it was expressed, responded to or the context. The existential threat of being critically ill was an important background issue that influenced patients' expressions. The content of the attention-seeking actions will be elaborated before the thematic description of the patterns of the attention-seeking actions is provided.

4.1 | The content of the attention-seeking actions

The content of the patients' expressions was classified into four domains: psychological expressions, physical expressions, social expressions and expressions related to the medical treatment. However, the underlying meaning seemed to be hidden and was dependent on the context. For example, the question "*what is happening to me?*" could relate to activities such as mobilisation, bed bathing or nursing procedures, but it could also have a more existential connotation, expressing the patient's experience of uncertainty and desire to talk about the future development of his or her condition. Another example of such context-related interpretation was when patients expressed that they were tired, which could mean a physical tiredness after a heavy mobilisation round, psychological or existential tiredness because they were fighting for their lives, or tiredness due to the intensive treatment or sleep deprivation. Table 3 displays the categories of the content of the patients' expressions.

4.2 | The act of seeking attention and understanding without a voice

Attention-seeking actions were described as four patterns according to how they evolved: immediately responded to, with delayed response or understanding, intensified attempts and giving up. One situation could include several of the patterns, for example, one patient might be immediately responded to by the healthcare personnel, but the attempt to communicate was eventually given up. The patterns will now be presented, and situational descriptions will serve to exemplify and provide more details. In general, it seemed like the patients had a pattern of one or two techniques they used frequently. Hand movements (either waving, pointing or tapping the bedside) and eye gazes were common; attempts to form words with the lips were also observed frequently. Another commonality that could be observed was that the patients often tried to communicate

TABLE 3 The content of the expressions of the patients during mechanical ventilation

Categories of the expressed content	Expressions with content related to psychological domain	Expressions with content related to physical domain	Expressions with content related to social domain	Expressions with content related to the medical treatment
Subcategories	Lack of control, confirmation and hope for the future, desire for human closeness, Intranquillity, anxiety, fear, frustration and comfort	Bodily pain, dyspnoea, suctioning, nausea, dizziness, stomach ache, tiredness, too warm or too cold, replacement in bed, thirst, elimination, headache, thirst and unpleasant sensory experiences	Longing for family, appreciation of healthcare personnel, apologetic statements, humour, specific social activities, desires to undergo/not undergo procedures such as Trach-Vent/mobilisation/ shaving and interest in what is happening outside of the room	Questions about medication, the physical appearance, what has happened, when the physicians will visit, what measures are to be taken in the treatment, when they will be discharged, suctioning, weaning off ventilator and ventilator tubes falling off
Nonverbal utterances	Holds out hand Grabs the healthcare worker's hand Looking around in the room Moving around in the bed frequently Breathing heavily Waving or shaking arms	Grimaces Movements in bed Touching the tracheal tube or stomach Coughing Looking at the vomit bowl, trying to reach it with a hand Making eye movements, trying to spin around the eyes Forming circles next to the face or body Shrugging shoulders Opening mouth Tongue clicking	Looks at the watch on the wall Turns head towards the radio Shakes head and grimaces face Looks towards window Waving with arms Smiling Knocking on the bedside in various ways Raises eyebrows and curls lips	Points to sutures on the stomach Looks at the medication Shaking/nodding head Pointing to the endotracheal tube Looking at specific technical equipment or invasive equipment Grimaces when treatment is mentioned or raises eyebrows Putting up a symbolic stop signal with a hand
Examples of statements (forming words with lips or in written)	"I do not understand what happens or is going to happen" "I cannot take this anymore" "I have no control" "I am tired" "A little resigned and sick of it all"	"It is warm" "I need to go to the toilet" "It hurts" "It is too smooth under me" "Tired" "Tired of not getting enough air" "A little to strong mouth water"	"When will they be here?" "My wife" "He made me do it" "You are nice" "The other nurse is strict" "Sorry that I ask and bother you" "Glasses"	"What is going to happen with (my sutures, my antibiotics, fungus infection, other treatment?)" "When is the medical visit?" "I am feeling exhausted of the breathlessness" "To the other ward Monday?"

looking not at the communicative partner but rather down. This was interpreted as a struggle in delivering the message and encountering the communicative partners' expressions at the same time. Communication boards or stiff writing boards with paper and pen were used 14 times by four of the patients. However, only two patients managed to use them appropriately; four times the patients refused to use them when offered. The writing attempts were unsuccessful two times in terms of achieving understanding because the patient could not write or manage to point at the pictures on the communication board. Table 4 offers an overview of the numbers and distribution of attention-seeking actions among conscious mechanically ventilated patients.

4.3 | Attention-seeking actions immediately responded to

In 53 of the 66 situations, the patients' attempts to establish contact were quickly observed and responded to by the healthcare personnel. Patients mostly used lips, hands or legs, eye gazes, facial grimaces or symbolic gestures to initiate the first contact. The response from healthcare personnel did not necessarily mean that they understood the patient's expressions, but the patients succeeded in establishing a joint awareness that they wanted to express something. The healthcare personnel's response was typically to ask what they wanted and then to respond to what they thought the patient expressed, seeking the patient's confirmation as to whether they were right. The symbolic gestures in the interaction seemed to facilitate the understanding of the attention-seeking actions. Examples of symbolic gestures were touching the tracheostomy (which mostly signified trouble with breathing or mucus), waving the hand (which could mean come over to me), a thumb up (everything is good), tilting the hand from one side to the other or shrugging shoulders (everything is not okay but manageable) and pointing at an object. Eye gazes and tilting of the head towards the radio or clock were examples of nonverbal communicative acts directing the attention of the healthcare personnel towards an object of interest.

TABLE 4 Distribution of attention-seeking actions among the patients and the use of communication aids

Patient Number	Attention-seeking actions	Attention-seeking actions where understanding is not achieved	Use of communication boards such as an alphabet board or emotion board, or pen and paper
Patient 1	11	5	
Patient 2	3		
Patient 3	20	5	2
Patient 4	9	1	4
Patient 5	8	1	7
Patient 6	0		
Patient 7	1		
Patient 8	1		
Patient 9	10	3	1
Patient 10	3		
Total	66	15	14

One patient had very good motor abilities and wrote several messages on paper before he showed them to the healthcare personnel. He clung to the communication board most of the time, holding it in the bed with his hand, and he asked for it repeatedly when it was removed from the bed (i.e., during procedures).

The use of sound was also observed as an efficient method for gaining attention in various situations. This could be either by tongue clicking, banging or tapping on bedsides or even breathing heavily, resulting in alarms from the ventilator. This pattern is exemplified by the following interaction between Alicia and nurse Irene:

> Alicia lies in her bed on her right side facing the window with her eyes closed. Suddenly, she moves her hand slowly up in the air, opens her eyes, and looks around a little before she makes a barely audible clicking sound with her tongue. Irene, who is busy preparing some medications, immediately turns around and walks towards her with the medication in her hand. As she leans towards Alica, she says 'what?' with a calm but questioning tone in her voice. Alicia has already started to move her lips, trying to form words before Irene comes closer, but her eyes are only half open. 'Warm?' Irene asks, looking at her. Alicia opens her eyes completely and forms words with her mouth again, looking at her. Irene says, 'Yes… Then I will check the temperature, you have not had fever. Infection parameters are on their way down, and we have started the antibiotics now.'

4.4 | Attention-seeking actions with delayed response or understanding

Healthcare personnel did not always recognise the patients' signals immediately. In 22 of the 66 situations identified, there was a delay in the response to the patients' communication attempts. Mostly this was due to the lack of visual attention or because the healthcare personnel were busy performing other tasks. A typical response if the healthcare personnel were busy could be to acknowledge the attempt but ask the patient to wait until they were carried out. This could, for example, be during mobilisation or when having to attend to an alarm in the technical equipment.

If the healthcare personnel were busy, some of the patients waited until they had the chance to attract their attention before expressing themselves. They could also try to get attention once the healthcare personnel were close to the bed by grabbing their hands, gazing at them or waving. This was interpreted as a tactical choice to minimise the energy used to obtain attention. Others stopped the healthcare personnel's actions by expressing themselves in the middle of a procedure.

Delays also occurred when the healthcare personnel struggled to understand what was expressed. As a pattern, it could be observed that when the patients' expressions were not understood, the "verbal" interaction was intensified; that is, the patient attempted to form full sentences with the lips, and the healthcare personnel asked the patient to repeat over and over again what they said. The interaction could change into a questioning pattern, where the healthcare personnel often used different approaches or words to find the exact meaning that the patient was attempting to convey. Fiona's interaction with nurses Lydia and Anthony illustrates a typical delayed response to an attempt to obtain attention:

> Fiona raises her right arm as nurse Lydia stands next to the bed looking at the infusion pumps. When Fiona fails to get Lydias attention, she looks at nurse Anthony as he approaches the bed. He rapidly engages in a dialogue with Lydia, asking her to control some medications. Fiona lifts her left arm, gazing at Anthony, then she lays her hand down on her stomach. Anthony and Lydia walk away from the bed still talking about the medication. Fiona gazes a little around the room, moving a little restlessly in bed. She holds her hand up in the air and waves as she looks toward Lydia and Anthony. She then gazes up to the

vomit bag, which is placed on the right side of her pillow, swallowing deeply. She stops waving and waits for some seconds before she eventually waves again. She starts to make circles with her hand, forming words with her mouth, and Lydia approaches her saying 'Hmm?' Fiona points one hand toward her chest and the other toward the vomit bag. 'Nauseous?' Lydia asks, and Fiona forms words with her mouth. 'Okay,' Lydia responds, 'We'll get you further up in the bed in a moment and give you antiemetics.'

4.5 | Attention-seeking actions with intensified attempts

We found that the patients intensified their attention-seeking actions if there was a lack of response from healthcare personnel (in 10 of the 66 situations). The patients increased their activity with, among other efforts, movements and facial expressions. Discomfort became more apparent or intensified physiological reactions occurred, such as a higher respiratory rate, due to their efforts. Sometimes, the alarms also went off on the technical equipment. The patients used what they had available in their immediate presence to obtain attention, such as shaking the bed side with their hands or waving a communication board. The way the intensification expressed itself depended upon the patients' physical capabilities as well as on how urgently they needed help. For one patient, moving her head could be interpreted as an intensification, while for another the intensification took the form of kicking in the bed and attempting to move his body up from the bed in an agitated manner. The intensified attempts required a great deal of energy. The patients showed bodily signs that could be interpreted as emotional resignation, frustration, irritation or exhaustion after having attempted unsuccessfully to achieve attention. They urged the healthcare personnel to help them with, for example, suctioning of mucus, if they felt that they could not breathe. An intensified attempt could therefore be a result of a delayed response from healthcare personnel, or it could occur without prior attempts to achieve attention. George was a patient with many intensified attention-seeking attempts:

> Nurse Sarah and Anna stand by the computer talking to each other. George moves his right hand up and turns his head around and stretches his legs a little with his eyes half open before his hand falls down on the pillow. He lies still for moment before he lifts his arms again. This time they are shaking, and the right arm is placed on the bed side. He starts to move his hand back and forth, making noises with the bed side while looking at Sarah and Anna. He stops for a short moment, and then he shakes the bed side again. He starts to knock on top of the bed side, the bed side makes a different and higher noise than before. 'Can you check what he wants?' Sarah asks Anna. Anna rapidly approaches George, who raises his arm next to his face, pointing upwards. He also forms the words 'higher up' with his lips. Anna says 'higher up' and moves the top of the bed higher so he is in a more seated position. 'Is that enough?' she asks. George nods slightly with his head.

4.6 | Attention-seeking actions when giving up

Due to the patients' limited ability to communicate or healthcare personnel's lack of understanding, the patients sometimes gave up on their attention-seeking attempts. In total, 15 of the 66 situations were unsuccessful in terms of achieving joint understanding, or the patient gave up the attempt even before it was noticed. In the situations where understanding was troublesome, some of the patients intentionally made additional efforts to communicate their messages. For example, they formed their lips more clearly, tried new ways to communicate on their second or third attempts, or used their hands more actively. This was interpreted as a deliberate fight to be understood. There was a thin line between giving up and being understood, and a very fragile moment occurred when there was a lack of understanding between the patients and the healthcare personnel. The patients tried their best, and so giving up was not an easy task. Turning their heads away from the person who communicated with them, avoiding eye contact or dismissing them with a hand wave were observed as a pattern of withdrawal. Suffering was a consequence of not being understood.

When healthcare personnel tried to explore what the patients were attempting to express, sometimes as many as 11 different guesses were presented to the patient. In some of the situations, after several failed attempts and when they were about to give up, understanding was achieved. There were situations where the healthcare personnel gave up trying to understand. Sometimes the nurse would say, "I don't understand you" and made no further attempts to communicate; other times, they gave up after several attempts. This was mostly addressed as "we have to try this again later because we don't understand each other," or they asked other healthcare personnel if they could help them to understand what the patient was attempting to express. They could also direct the conversation to another topic. Dina was one of the patients who sometimes gave up her attempts to be understood.

> Nurse Cristian walks up to Dina's bed to check a nutritional pump. Dina looks at him. He gazes down at her, and she holds her hands out as she forms words with her mouth. 'What are you saying now?' Cristian asks, and Dina forms words with her mouth again. 'I see you are tired today,' Cristian continues, 'but we have plans for the day. The physiotherapist is here… I understand you are tired.' Dina forms words with her mouth, looking at him, 'Hmm?' Cristian responds, leaning a bit closer and placing his hand on

her shoulder. 'Can you write today or… ?' Dina shakes her head, shrugs her shoulders, and looks out into the air.

5 | DISCUSSION

Through the analysis, the attention-seeking actions of patients on mechanical ventilation in ICUs were contextualised and described in depth to provide further understanding of the patients' efforts to seek joint attention and understanding without a voice. To the best of our knowledge, this is the first study to systematically analyse the patients' initiation of communication in this setting, and it is one of few reported studies using video recordings in ICUs to study interaction and communication (Happ et al., 2011, 2014; Karlsson, Lindahl, & Bergbom, 2012; Meriläinen, Kyngäs, & Ala-Kokko, 2013). The main finding is the way the interaction evolved in the attention-seeking patterns described; the immediately responded to, the ones with delayed response or understanding, the intensified attempts and the attempts that eventually were given up.

5.1 | Establishment of joint attention and joint understanding between patients and healthcare personnel

To date, attention-seeking actions have mainly been described as eye gazes in populations other than intensive care patients, although other techniques have also been mentioned, such as the use of sound (Caruana et al., 2017; Langton, Watt, & Bruce, 2000). Deliberate techniques have been found in intensive care patients on mechanical ventilation, such as creating an alarm by taking off the saturation probe (Engström et al., 2013). As the patients cannot always achieve eye contact with the healthcare personnel, audible signals might be an important and efficient technique for this patient population. This was observed in our study, as the patients utilised tongue clicking, kicking with the legs on the mattress and knocking on the bed side with their hands. An implication of these findings is that intensive care patients should have some kind of sound-activating device close to them to allow them to quickly gain the healthcare personnel's attention without expending excess energy. For patients who lack the strength to push a button, other efficient tools should be developed.

We found that the communication pattern and attempts to achieve attention evolved quite differently than a communication pattern in which the two participants have more equal possibilities to communicate. The healthcare personnel first had to respond to the attempt and then understand what the patients wanted before eventually expressing their understanding verbally for confirmation. Normally, these processes of joint attention and understanding occur almost simultaneously (Langton et al., 2000). The patients or healthcare personnel gave up in their attempts to achieve understanding in 15 of the 66 situations. This is an indicator that unsuccessful attempts at communication occur relatively often for patients on mechanical ventilation. Based on the data from the current study, this issue would be worth exploring in greater depth. In their study, Happ et al. (2011) rated 71.8% of the 747 observed communication exchanges between nurses and patients as successful, but they found a slight decrease in success (63.6% vs. 74.9%) when the patients initiated the exchanges. Our study found that successful achievement of understanding occurred in 51 of the 66 situations, but in 22 of those situations, there was a delayed understanding, meaning that the patients struggled to convey their needs. In the attempts that were given up, we do not know what the patients wanted to express. There were some patients with more unsuccessful attempts than others, which is also worth mentioning.

Previous literature has listed patients' frustration, anger, fear or existential concerns as important consequences of the communication barriers related to mechanical ventilation, making them feel as if they are not part of the same world as the healthcare personnel (Egerod et al., 2015). This study provides further understanding of how negative emotions arise in situations when patients strive to be understood. It is important that healthcare personnel be aware of this issue, as it could affect the outcome of the dialogues and even lead to patients giving up their attempts to communicate. A patient's life world is situated, embodied, temporal, spatial and relational. Meaning is created here and now between the participants who are present in the situation (Heidegger, 1996). For ICU patients, meaningful encounters during the course of their stay is essential, as they may inspire hope, resources and motivation to endure this critical time when their lives are at stake (Baumgarten & Poulsen, 2015; Laerkner et al., 2017). Thus, creating meaningful encounters with the patients should be a goal of healthcare personnel in the ICU. A core premise for achieving such encounters is enhancing the patients' ability to communicate and responding to their attempts to express themselves. Patient participation can improve decision-making in treatment, decrease medical errors and function as a means to improve patient safety (Longtin et al., 2010). In our study, we observed that patients expressed a need for tracheal suctioning due to mucus or signalled that the ventilator tubes had fallen off before the healthcare personnel had become aware of the problem.

5.2 | Consequences of the findings for education and clinical practice

A previous ethnographic study of Laerkner et al. (2017) asked whether initiatives to communicate were not responded to due to inattentive healthcare personnel. An alternative interpretation might be that the healthcare personnel do not perceive the patients' physical movements as an initiative for communication but rather as restlessness or agitation, which is not uncommon in ICU patients. There is also a danger that the initiatives "drown" in the complex and technical environment amid the extensive amount of procedures. Even cues and hints from verbally speaking patients can be hard to identify (Finset, Heyn, & Ruland, 2013). The subtle signs that patients make while on mechanical ventilation require constant awareness on

the part of the healthcare personnel. The evolvement of a type of "guessing-game" dialogue has been described in a previous study (Holm & Dreyer, 2017), but it seems somewhat unproductive and time-consuming for both the patients and the healthcare personnel. Augmentative and alternative communication aids could enhance the patients' possibilities for communication (Carruthers, Astin, & Munro, 2017; Mobasheri et al., 2016; Ten Hoorn, Elbers, Girbes, & Tuinman, 2016). However, healthcare personnel must respond to the patients' attempts to obtain joint attention for meaningful communication, even with aids.

It might be a coincidence that we found patients who refused or did not manage to use their communication aids. When they unsuccessfully attempted to use communication aids and finally gave up, apparent frustration was visible in both their body language and face, and withdrawal was not uncommon. Unsuccessful attempts to use such tools have not been thoroughly described in the literature. We observed that the unsuccessful attempts with aids were mainly due to the patients' lack of motor skills in their arms or to a lack of energy to even point or write. The question, therefore, is if the patients could have a range of aids to choose from, which would be most appropriate for them in their situation? The healthcare personnel should motivate the patients and ensure successful attempts, choosing the appropriate communication aids based on the patients' motoric and cognitive abilities. The healthcare personnel also had varying degrees of knowledge about the patients, and we saw many examples where the healthcare personnel related the patients' expressions to previous situations and experiences with them, which eventually led to mutual understanding. The link between continuity of care and enhanced understanding of the patients could therefore be of interest in future investigations, as this is thought to improve the care and facilitate the interaction in ICUs (Laerkner, Egerod, & Hansen, 2015; Slatore et al., 2012). Knowledge about the different ways the patterns in attention-seeking actions may evolve, can help clinicians identify when the interaction is intensified, or the patient is about to give up their attempts. These patterns are important to recognise, because unsuccessful attempts to communicate may be prevented by redirecting the patient to communicate in a different manner. The way the patient tries to initiate contact may also indicate his/her emotional state. It was a clear difference in the situations observed where the patients tried to express how they felt emotionally compared to asking for water or repositioning; which seemed easier for the healthcare personnel to understand. If the healthcare personnel can grasp the patients' emotions, they can also acknowledge and address, alleviating the patients' feelings of loneliness, frustration and anxiety which has previously been described as consequences of the lack of understanding while on mechanical ventilation (Flinterud & Andershed, 2015; Holm & Dreyer, 2017).

Slatore et al. (2012) reported that most of the communication with ICU patients occurs within a biopsychosocial domain, with a focus on treatment. Holm and Dreyer (2017) claimed that the communication needs may also depend on whether the patients are in a more acute or stabile phase of their ICU stays. In this study, the patients had complex questions about the actual treatments and their relation to their illness as well as about the outcome of their stays. These examples demonstrate information needs in addition to a possible desire for patient involvement and a feeling of control. Our study further revealed patients' existential worries about what would happen to them. The findings indicate a need for the patients to be socially adaptable in an environment where they are completely dependent upon the help of others. The apologetic statements and the gratitude expressed by several of the patients suggest that the patients may view themselves as bothering the healthcare personnel with a lot of needs, and they may be afraid to be seen as overly demanding or ungrateful. This could lead to patients holding back and expressing only their most pressing needs. Language is power, and the patient's lack of verbal language creates an asymmetrical precondition for communication and treatment (Watzlawick et al., 2011). Descriptions of methods of initiating communication should be addressed both in education and in clinical settings for healthcare personnel caring for patients in ICUs. Patient-centred care in an ICU context challenge the current competence, because it requires both advanced communication skills and knowledge about how patients experience being conscious and alert during mechanical ventilation, unable to express themselves. It also requires a constant attention from the healthcare personnel to the subtle signs the patients make to express themselves.

Other premises for good communication are sufficient number of healthcare personnel and adequate time resources to attend to the patients' needs (Laerkner et al., 2015). ICUs are generally constructed for emergencies and unexpected acute care, but they must also be adapted as a humanistic and therapeutic environment of care that stretches over time. Even with good intentions, we observed situations in which the patients had to fight to achieve attention. Staffing in ICUs differs internationally, as does the availability of single rooms and the use of physical restraints and sedation (Egerod, Albarran, Ring, & Blackwood, 2013; Happ et al., 2004), which eventually impacts the patients' ability to communicate and interact. As all the patients were in single occupancy rooms, it would be interesting to replicate a similar study within an open ICU unit with more than one patient in the room. There might be procedures and several dialogues occurring simultaneously, which may impact both the patients' and the healthcare personnel' interaction, experiences and focus on communication.

In a study where nurses were asked to describe their behaviour towards patient participation, the nurses reported that they were more responsive to the patients' needs if they felt such involvement did not hinder them in their daily work (Arnetz & Zhdanova, 2015). Some of the attempts that were delayed in this study could be interpreted to have occurred because of friction between the tasks the nurses had to perform and their ability to respond to the patients' needs. If this friction occurs over time and with many patients, this may cause stress and resignation for the healthcare personnel, as they try to balance their practical tasks while communicating with the patient. This could eventually result in reduced attention to the patients' subtle signals when they are attempting to convey their needs.

5.3 | Strengths and limitations

This study was conducted in a Norwegian ICU. The patients had considerably longer stays on mechanical ventilation and a slightly higher severity of illness score than the average patient in this context (Buanes, 2016). This may have affected the patients' communication abilities, patterns, and needs. It would be useful to conduct a similar study on patients with shorter stays in the ICU, to compare the attention-seeking actions. Data were not collected on the amount of sedation or analgesia previously received, but many of the patients had not been reported as possible candidates for the study prior to inclusion. This may suggest that they did not fit the criteria, being either too sedated or having a positive delirium score. The information power in the data is a strength; a wide range of communication episodes was analysed, with the additional ability to return to the situations through the videos to achieve rich descriptions (Malterud et al., 2016). The number of attention-seeking actions ranged from 0–20 across the patients, making some of the patients more prominent in the data set that was analysed. This depended on a number of factors; for example, some of the patients were connected to speech cannula for periods of the video recordings, and could express themselves. It is not uncommon in qualitative studies that some participants provide richer data than others. Each video recording lasted for hours, to allow the participants to adapt to the cameras, although camera interference was observed from both patients and healthcare personnel on occasion. The pilot helped us find suitable angles to minimise the loss of visual and audible data to enhance validity (Heath et al., 2010). The nurses, however, had control of the lighting, and they often dimmed the lights when the patients needed to rest. Thus, some of the videos have periods with poorer lighting than others, reducing the ability to observe subtle signs, such as forming words with lips and facial expressions. The fact that only one of the patients was orally intubated is worth to mention, as they might communicate in a different manner because the oral tube is more irritating than a tracheostomy and makes it impossible to form words clearly with the lips and close the mouth properly. The patient who was orally intubated made no attempts to seek attention. He received a considerable amount of analgesics to tolerate the tube and sometimes fell asleep making him less active than some of the other patients during the period of the video recordings.

The problematic issues that could occur as the result of being a researcher with an insider perspective and potential cultural blindness were reflected upon during the whole process (Bonner & Tolhurst, 2002; Gair, 2012). The preunderstandings and the role as a novel researcher were acknowledged, and the analysis and discussion of the findings, the reading of the transcripts, and the viewing of the video segments were therefore performed along with more experienced coresearchers. The insider perspective may have impacted the findings, especially the distance/closeness with the participants were reflected upon in each step of the research process. Data challenging preunderstandings or biases, such as deviant cases, were also discussed in the regular meetings. The co-researchers were a strength of this study due to their extensive competence in the fields of communication and qualitative analysis. They were unfamiliar with the ICU context, which allowed openness towards the data.

6 | CONCLUSIONS

The patients' attention-seeking actions varied in form, content and in the way in which they were responded to. The patterns in the attention-seeking actions identified as immediately responded too, those with delayed response or understanding, the intensified attempts or the attempts who were given up evolved depending on the interaction between the patients and the healthcare personnel. It is important for healthcare personnel to recognise and acknowledge the patients struggles to communicate and attention-seeking actions, especially because one of the most prominent characteristics of the communication was how much energy the patients had to use to obtain an initial contact and then achieve understanding. The content of the attention-seeking actions also revealed a more latent quality overall related to the existential threat of being critically ill. This is noteworthy, as it will influence all interactions with the patients and increase the importance that they be understood and attained to. The findings could be used as part of the educational curriculum for professionals working with ICU patients on mechanical ventilation.

7 | RELEVANCE TO CLINICAL PRACTICE

Patient-centred care in an ICU context challenge the current competence, as it requires advanced communication skills in addition to knowledge about how patients experience being conscious and alert during mechanical ventilation, and are unable to express themselves. Also, it requires a constant attention from healthcare personnel to the subtle signs these patients make to express themselves. Our findings are thus relevant in continuous education and quality improvement for ICUs, for nurses as well as for other healthcare personnel working in these settings.

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CONFLICT OF INTEREST

The authors whose names are listed as authors certify that they have no affiliations with or involvement in any organisation or entity with any financial interest, or nonfinancial interest in the subject matter or materials discussed in this manuscript.

CONTRIBUTIONS

MMWK, KH, AF and LGH has allcontributed in the creation of study design, analysis and manuscript preparation. MMWK has been responsible for data collection.

ORCID

Marte-Marie Wallander Karlsen http://orcid.org/0000-0002-0492-8821

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PAPER 3

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Patient involvement in micro-decisions in intensive care

Marte Marie Wallander Karlsen[a,b,c,*], Mary Beth Happ[d], Arnstein Finset[b], Kristin Heggdal[a], Lena Günterberg Heyn[a]

[a] Lovisenberg Diaconal University College, Lovisenberggt 15b, 0456 Oslo, Norway
[b] Institute of Basic Medical Sciences, Faculty of Medicine, University of Oslo, Postboks 1100 Blindern, 0137 Oslo, Norway
[c] Department of Emergencies and Critical Care, Oslo University Hospital, Postboks 4950 Nydalen, 0424 Oslo, Norway
[d] The Ohio State University, College of Nursing, 352 Newton Hall, 1585 Neil Avenue Columbus, OH 43210 USA

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ABSTRACT

Objective: The objective of this study was to explore how bedside micro-decisions were made between conscious patients on mechanical ventilation in intensive care and their healthcare providers.
Methods: Using video recordings to collect data, we explored micro-decisions between 10 mechanically ventilated patients and 60 providers in interactions at the bedside. We first identified the types of micro-decisions before using an interpretative approach to analyze the decision-making processes and create prominent themes.
Results: We identified six types of bedside micro-decisions; non-invited, substituted, guided, invited, shared and self-determined decisions. Three themes were identified in the decision-making processes: 1) being an observer versus a participant in treatment and care, 2) negotiating decisions about individualized care (such as tracheal suctioning or medication),and 3) balancing empowering activities with the need for energy restoration.
Conclusion: This study revealed that bedside decision-making processes in intensive care were characterized by a high degree of variability between and within patients. Communication barriers influenced patients' ability to express their preferences. An increased understanding of how micro-decisions occur with non-vocal patients is needed to strengthen patient participation.
Practice Implications: We advise providers to make an effort to solicit patients' preferences when caring for critically ill patients.

1. Introduction

Patients on mechanical ventilation in intensive care units (ICUs) experience communication barriers due to the endotracheal tube or tracheostomy [1–3]. Patients have described the experience of trying to communicate without a voice as frustrating, terrifying, [4,5] and associated with negative emotions, such as anxiety, anger [6–9] and feeling powerless [4,10]. Current ICU clinical guidelines [11–13] recommend that ventilated patients should be conscious, spontaneously breathing, and mobilized as quickly as possible in a family-engaged environment [13,14]. This has led to an increasing number of conscious patients on mechanical ventilation. Previously the norm was to use substantial amounts of sedatives, making patients unable to communicate. There was also less focus on early weaning from ventilation and increased physical activity, compared to current recommendations [15–17]. A one-way communication style dominated bedside interactions, with healthcare providers being the most active participants [2,18]. In a very critical phase of their lives, patients experience reduced ability to participate in decisions about their treatment and care in ICUs [19–21].

Intensive care treatment is complex and fraught with ambiguity and uncertainty, [22,23] and bedside decision-making is often based on limited information [22]. Ofstad et al. [24] define treatment decisions as an expression from either a provider or the patient to commit to a particular course of clinically relevant action, implying a shared understanding of agreement and patient consent. A decision can also be to withhold treatment or to wait for further assessment of the situation. The American College of Critical Care Medicine and American Thoracic Society describes shared decision-making as "a collaborative process that

* Corresponding author at: Lovisenberg Diaconal University College, Lovisenberggt 15b, 0456 Oslo, Norway.
E-mail addresses: marte-marie.karlsen@ldh.no (M.M.W. Karlsen), happ.3@osu.edu (M.B. Happ), arnstein.finset@medisin.uio.no (A. Finset), Kristin.Heggdal@ldh.no (K. Heggdal), Lena.heyn@ldh.no (L.G. Heyn).

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allows patients, or their surrogates, and clinicians to make healthcare decisions together, taking into account the best scientific evidence available, as well as the patient's values, goals and preferences" [23, p. 190]. Kukla [25] highlights the complexity of making autonomous decisions, and how decision-making relies on previous history, relationships with the providers, and normative expectations of the patient role; therefore, they must be seen as part of a larger context. A self-determined decision can even be to ask providers or relatives to make the decision.

Micro-decisions [26], small-scale decisions made numerous times a day at a patient's bedside, are often not perceived as treatment decisions. Micro-decisions in ICUs may relate to mechanical ventilation (weaning attempts from ventilatory support, use of tracheostomy speaking valve), symptom management, mobilization, or other procedures (i.e. wound care).

There is a paucity of knowledge regarding micro-decisions in ICUs, compared to other decision-making [3,27], such as life-sustaining treatment decisions. A more thorough understanding of the interaction between patients and providers could improve patient participation. In this study we explored how micro-decisions were made between conscious patients on mechanical ventilation and healthcare providers in intensive care with the following research questions:

- What types of micro-decisions are made between patients and healthcare providers in intensive care?
- In what ways does decision-making occur at the bedside in intensive care?
- How are patients on mechanical ventilation engaged in decision-making?

2. Methods

2.1. Study design, setting and data collection

A phenomenological-hermeneutical approach [28–30] was chosen to describe and interpret the participants' interactions and the phenomena of micro-decisions as we observed them. This entails moving between descriptions and interpretations towards the content of meaning in the data collected to achieve a new and deeper understanding of the observed interaction [28–30]. Hence, we used video recordings to collect data, enabling repeated access to the subtle details of natural interaction [29]. It was necessary to capture non-vocal communication since mechanically ventilated patients are unable to produce vocal speech. The study was conducted in two ICUs at a university hospital in Norway. The units had 10 and 11 beds, respectively. Patients had single rooms and a nurse was always present. We installed two surveillance cameras and two sound-recording devices in each patient's room in the morning and left them to run continuously for 3–4 h. The first author stayed outside the patients' rooms making field notes. We collected demographic data from each patient.

2.2. Participants

We purposively recruited patients receiving mechanical ventilation between 2016–2017. The inclusion criteria were patients over the age of 18, mechanically ventilated for at least 48 h, a Richmond Agitation and Sedation Scale [31] score of 0–2, without diagnosed delirium for the previous 24 h, and negatively screened for the Confusion Assessment Method for the ICU (CAM-ICU) [32] at study enrollment. Patients were excluded if they did not speak Norwegian, had severe visual, hearing, or cognitive deficits; or were in end-of-life care.

2.3. Data analysis

The first author watched the videos numerous times to become familiar with the data. The segments of the video recordings related to micro-decisions (the series of scenes that form a distinct narrative unit, connected by the continuity of time, where a specific decision-making process occurs), were first identified and transcribed. We used Ofstad et al.'s [24] definition of decisions to identify the bedside micro-decisions. We then performed a two-step analysis, first grouping the types of micro-decisions that occurred and then analyzing the meaning of the decision processes.

2.3.1. Analysis of the types of micro-decisions

We observed that decisions evolved in several ways, leading to patients' involvement on different levels. Each identified micro-decision segment was therefore analyzed according to a stepwise model for shared-decision making (initiation of dialogue, presentation of options, exploration of patient preferences, and making the decision) [33]. We also described other characteristics such as how the communication unfolded, who was present and what occurred in the room [29]. The situations were compared for commonalities and differences and eventually grouped into types of decisions. Observed non-medical micro-decisions were excluded from the analyses (i.e. morning bath or bed-positioning). This analysis led to a typology of micro-decisions, presented in the results. We used Mangold Interact® 16.4 to organize the visual data [34].

2.3.2. Analysis of the micro-decision processes

The interactions between patients and the healthcare providers were initially interpreted through naïve descriptions of what we observed, focusing on both verbal and non-vocal actions [28–30]. We then analyzed the meaning in the interaction before creating subthemes and themes. An example of this is displayed in Table 1. The first author attained a deeper understanding of the written and visual material, moving between parts of the data and the data as a whole [30], and by watching the selected video segments repeatedly and revising the written analysis accordingly.

The final analytic step involved a review of all the types of micro-decisions and the themes to ensure coherence between presentation and understanding of the data as these were two separate analytic phases. The first and last authors watched an entire three-hour video recording of one patient separately, and discussed differences in their interpretations to ensure rigor and reflection. The other authors watched numerous segments of the micro-decisions and participated in the analysis and discussion of findings via regular meetings. Malterud's concept of information power was applied to evaluate the data from our sample [35]. The information power was considered high as the aim of the study was specific and a considerable amount of interaction relevant to the research questions was collected from key informants. Saturation was reached during the analytic phase by the amount and meaning of micro-decisions that occurred during the 30 h of recordings [29].

2.4. Ethical considerations

The South-Eastern Regional Committees for Medical and Health Research Ethics in Norway approved this study (2015/2012). We performed it in accordance with the Code of Ethics of the Helsinki Declaration [36]. Videos were stored on a digital server following the university hospital's regulations. Participation was voluntary,

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Table 1
This is an example of a micro-decision and how the process unfolded between the provider and the patient. Each type of micro-decision we observed is identified and transcribed in the left column. Then, we captured the essence of the observation in the next column before creating preliminary subthemes. The subthemes were then grouped into the three themes as described in the analysis. We also documented the time the segment occurred to be able to refer to it.

Micro-decision	Interaction as observed	Essence of the interaction	Subthemes
The need for tracheal tube suctioning 01:31:00	Patient Rebecca increases her respiratory rate and it sounds like there is mucus in the tube. Nurse Elizabeth tells her. "I believe we need to suction because you seem bothered by mucus in your lungs." Nurse Elizabeth turns on the suctioning. "Should we go down and remove it?" She asks this as she inserts the catheter down into the tracheostomy. Rebecca looks down and forms words with her mouth and starts to cough several times. "breath calmly," Elizabeth says. After some seconds while Rebecca breathes heavily, Elizabeth says "Is it better, still some left? There is still some left. Should we try once more? Regain your breath first." After some seconds of rest, again Elizabeth says, "Should we try to make you cough properly and I will go down?" She performs the suctioning. After this suctioning Rebecca coughs several times and also spit up some mucus from her mouth which Elizabeth removes with some paper. "There is some left, but I think it must come gradually," she says.	Suctioning to relieve symptoms (deciding together), but it is still ultimately the healthcare provider's decision Decision to withdraw from performing suction Guiding the patient towards tracheal suctioning by explicit statements of the need for it Decision to delay suctioning because of previous actions and the professional's assessment	Information Invitation to participate in decisions Guiding the patient towards agreeing to the decision Balancing decisions up against one other

and the video recordings could be turned off at any time. The patients consented non-vocally (e.g., by nodding) during their ICU-stay. Each participating patient's ability to understand the information provided was systematically ensured (through the use of CAM-ICU, assessment of communication skills and dialogue with the nurses). Each patient was also informed orally several times about the study. After ICU discharge, they signed a written consent form. The nurses were asked to be sensitive to indications from the patients to stop the recordings. The providers involved in the care and the relatives who visited during the video recordings received oral and written information and signed a written consent form.

3. Results

Fourteen patients were invited, and ten agreed to participate in the study (seven and three from respective ICUs). No provider declined participation. A visiting relative was present in two of the videos. In total, we collected 30 h and 23 min of video recordings ranging from 1 h and 7 min to 3 h and 30 min per patient.

The patients were five females and five males of European ethnicity representing a variety of diagnoses. The mean age was 53.6 years (range: 36–72). The median length of days on mechanical ventilation before inclusion was 20 days (range: 4–68). The mean severity of illness score (SAPSII) was 42.0 (Standard deviation [SD]: 13.1). More detailed patient demographics are published elsewhere [37]. Sixty providers (29 nurses, 18 physicians, 9 physiotherapists, and 4 radiographers) cared for the patients during the video recordings. The interactions varied from a few minutes to being present throughout the entire video recording. Most often, physicians visited the patient once (5–25 min), physiotherapists visited for mobilization routines (10–40 min), radiographers visited for X-rays (5–10 min), and nurses spent most of the time at the patients' bedside.

3.1. Types of micro-decisions

We extracted 142 segments from the video recordings that involved micro-decisions (5–28 segments per patient). Patients' involvement in the decision-making was grouped into six communicative patterns. Table 2 presents the types of decisions and the criteria for each group as well as examples of the micro-decisions that were made within each group.

Decisions about the same treatment or procedure unfolded in different ways and varied from patient to patient. More than half of the decisions we observed were non-invited decisions, meaning the decisions were both initiated and decided by the provider, without explicitly asking for the patient's preference. Approximately one quarter were invited decisions meaning that the patients were asked to express their opinion about the decision at stake.

3.2. Bedside micro-decision-making processes

Three themes were identified after observation and further analysis of the patients' and healthcare providers' interactions: 1) being an observer versus a participant in treatment and care, 2) negotiating decisions about individualized care, and 3) balancing empowering activities with the need for energy restoration. The first theme illuminates the patients' involvement in the micro-decisions, the second theme describes how the providers and patients interacted to achieve some type of agreement, and the third theme illustrates how the procedures and intense activity were balanced with rest. The three themes are presented below and illustrated with narrative examples, and references to types of decision-making. Examples of types of decisions across themes are given in appendix 1.

3.2.1. Being an observer versus a participant in treatment and care

Patients' preferences and desires were manifested via non-vocal techniques, such as eye gazes, forming words with their lips, writing, grimacing, or pointing. The patients' capability to express desires non-vocally on one hand, and the degree to which the provider facilitated this communication on the other, influenced the degree of patients' involvement in the micro-decisions. Table 3 illustrates how patient Dina[1] became an observer rather than a participant in the decision-making about the ventilator strategy. Because the provider both initiated and made the decision, and Dina was informed but not asked about her preferences, we categorized this as a non-invited decision.

In other situations, the patients asked treatment-related questions, expressed their preferences, or signaled by pointing (e.g., back to the bed). They expressed reluctance by shaking their heads or moving restlessly around in the bed, which we

[1] The names of all the patients and providers mentioned here have been modified to ensure confidentiality

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Table 2
The definitions illuminate the differences and similarities between the different types of micro-decisions observed. The last column explains the decisions being made within each type of micro-decision more in-depth.

Types of decision-making	Criteria	Identified micro-decisionswithin each type of decision-making
Non-invited decisions	The healthcare provider initiates and makes the decision. Patients may receive information or ask about a specific decision, but the provider does not solicit patient preferences or include the patient in the (final) decision.	The use of a tracheostomy speaking valve Treatment options (various procedures, increase/decrease medication, changes in ventilator-settings, wound care) The timing and type of activity during physiotherapy and mobilization Plans to discharge from the ICU Hygienic procedures (such as disinfection of central venous lines) The need for tracheal suctioning
Substituted decisions	The healthcare provider initiates and makes the decision, indicating knowledge about the patient's preferences and involving the patient in the process via assumed consent.	Ways of performing procedures Treatment options (i.e. increase/decrease of medication) The use of a tracheostomy speaking valve
Guided decisions	The healthcare provider initiates and proposes the decision to the patient, as a decision that the patient would benefit from. Preferences are not actively solicited unless the patient actively expresses something related to the decision. The provider assumes the patient's consent.	Treatment options (i.e. increase/decrease medication) The need for sleep/rest
Invited decisions	The healthcare provider initiates the decision. The provider solicits the patient's preferences by indirectly asking for permission or directly providing options about the decision.	Physicians treatment plan The need for tracheal suctioning The amount and timing of weaning attempts The timing and type of activity during physiotherapy and mobilization
Shared decisions	Either the patient or the healthcare provider may initiate the decision. Both the patient's preferences and the provider's assessment are considered, and the patient takes an active role in the dialogue. Both agree on the final decision.	Long term plans for treatment The amount and timing of weaning attempts and changes in ventilator-settings The need for tracheal suctioning The timing and type of activity during physiotherapy and mobilization
Self-determined decisions	The patient initiates the decision either by communicating non-vocally using communication aids or by physically expressing preferences/needs. The decision is carried out with the assistance of the healthcare provider.	The need for tracheal suctioning The amount and timing of weaning attempts The timing and type of activity during physiotherapy and mobilization

Table 3
BEING AN OBSERVER VERSUS A PARTICIPANT IN TREATMENT AND CARE.

Patient Dina expresses that it feels heavy to breathe when the physicians assess her condition. Physician Victor asks nurse Cristian whether there have been any changes on the ventilator, and he responds looking at the ventilator, "The pressure support and the PEEP have been the same. I raised the oxygen since she had some feeling of dyspnea."
Physician Victor goes over to the ventilator before he looks down at Dina and says, "I will try to make it easier for you to breathe." After making the adjustments, he asks her "Does it feel better?"
Dina forms "a little" with her lips and nods, still breathing heavily.
"I think the setting can be like this; it seems more important that she is comfortable than to reduce the support of the ventilator. Let's wait until the lungs recover," Victor says looking at nurse Cristian. Then he turns around and repeats the same thing to Dina. She looks at him and nods slightly, Victor does not ask her any more questions and leaves the room.

interpreted as a desire to become a participant rather than an observer. Each patient's level of involvement in decisions as well as their overall level of involvement varied across decisions.

3.2.2. Negotiating decisions about individualized care

Patients and providers sometimes negotiated aspects of a micro-decision, such as the timing of procedures, who would be present, the level of assistance, the order of steps to complete the procedure, or whether the procedure was necessary. This was most typically seen in invited, shared, and self-determined decisions (appendix 1). Either the patient or the healthcare provider could initiate a negotiating dialogue. However, the patients tended to indicate opposition either by forming words, making gestures showing reluctance, or shaking their heads ("no") if they disagreed. Patients also used subtle non-vocal signs such as facial expressions (grimacing) or shoulder shrugs to express themselves. An example of how negotiations unfold in this context is provided in Table 4, where patient Raphael negotiated the duration of a nasal cannula procedure. We categorized the situation as a self-determined decision, as Raphael initiated the dialogue and negotiated the timing based on his preferences.

The negotiations led to multiple pathways to manage treatment decisions, exemplified in the various approaches to the use of tracheostomy speaking valves. One of the patients used the tracheostomy speaking valve extensively; however, the physician wanted to ensure that the patient's lungs were sufficiently humidified. After negotiating several alternatives, they agreed upon using another treatment option (Optiflow™) when the patient was resting, to provide humidity. This decision integrated both the patient's desire to communicate and the physician's professional judgment. Another patient expressed feeling anxious using the tracheostomy speaking valve, therefore, she only used it for brief periods. These tailored and shared decisions showed that treatment decisions were adjusted to each patient's needs and preferences.

Raphael made self-determined decisions, as well as being invited into the decision-making by the providers. Fig. 1 illustrates

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Table 4
NEGOTIATING DECISIONS ABOUT INDIVIDUALIZED CARE.

Nurse Benjamin says, "I will now disconnect the tube, and you get this plastic device instead and some extra oxygen supply, and you get the same amount of oxygen as what you get on the ventilator."
Benjamin is holding up the nasal cannula, pointing towards his neck in front of Raphael, who is grimacing.
Nurse Benjamin says, "It is going to feel different to breathe compared to the ventilator, but you are supposed to breathe normally . . . only through the tube in your neck. If it is uncomfortable, I will put you back on the ventilator immediately. I'll be here all the time and won't run away."
Raphael makes first one signal with his right palm out in the air, and then another signal with both hands crossing them as a stop signal as nurse Benjamin is about to connect him to the nasal cannula.
"A time out? No time out now, let's just do this," Benjamin responds and finishes the procedure and disconnects the ventilator.
Raphael makes signals to write, and he writes on the communication board that he is scared.
Benjamin responds, "Yeah, you get scared . . . but you were also scared yesterday, and then I did not hook you up to the device to get you used to the idea."
The dialogue is interrupted by Raphael's coughing, Benjamin removes some mucus from the tracheostomy. Afterward, Raphael writes once more and shows it to Benjamin who reads it out loud standing next to him, "when it stops . . . I get more afraid because it gets so quiet."
Benjamin remains at the bedside and nothing is said for a while. Then Raphael writes again and shows it to Benjamin who responds, "You want to get back on the ventilator? You have been six minutes on the nasal cannula now. Do you want to get connected back to the ventilator?"
Raphael looks at him and nods slightly. Benjamin reconnects him to the ventilator.

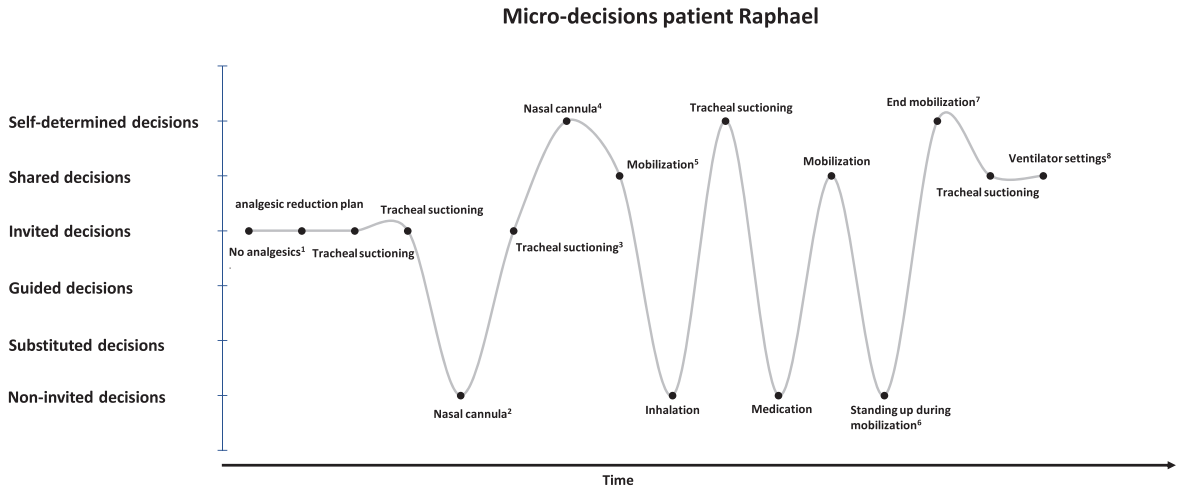

Fig. 1. The figure demonstrates each micro-decisions made in the recording of patient Raphael. The puncutate decision points are illustrated in the types of micro-decision it was grouped within. Further elaboration and exemplification of the decisions that occurred: 1. No analgesics: Patient is asked if he is in pain and needs more analgesics, responds no with lips shaking head. 2. Nasal cannula: Patient is being put on nasal cannula, says no both by shaking head and holding out a hand. Nurse says "I let you off yesterday, today we`ll just do it. I will be with you the whole time." **3.** Tracheal suctioning: Patients coughs, nurse asks If it is okay if he removes mucus and patient nods. 4. End nasal cannula: Patient writes to stop attempt and shows it to the nurse. He puts him back on the ventilator. 5. Mobilization: Patient writes that he would like to sit on bedside if physician allows. Nurse confirms decision. 6. Standing up during mobilization: Patient tries to stand up on his own initiative, gets told by nurse and physiotherapist he cannot do that so quickly and should just sit down on the bedside. 7. End mobilization: Patient tries to lay back in bed on his own initiative signalizing by moving in the bed, assisted by the nurses and physiotherapist. 8. Ventilator settings: Patients express dysponea and nurse adjusts ventilator. Asks afterwards about patient comfort.

how his level of involvement in the micro-decisions varied over time within the types of decision-making identified. We also saw this pattern in other patients.

3.2.3. Balancing empowering activity and energy restoration

The amount and appropriate timing of activities were frequent topics in the videos. Balancing procedures with patients' preferences and need for rest was not easy. Often, plans of care and providers' workflow conflicted with patients' wishes. For example, some patients expressed reluctance towards procedures to wean from mechanical ventilation and to do physiotherapy due to the amount of energy it required. We interpreted these dialogues as the providers trying carefully not to overly pressure the patient, constantly assessing the patients' tolerance for the potentially painful or energy-consuming procedures. Sometimes they pushed patients a step forward in the process of weaning from the ventilator or tried to increase the amount of physical activity, whereas other times they held back, preserving the patients' energy. This contradiction appeared most typically in non-invited and guided decisions, illustrated in the dialogue between patient David and his providers (Table 5). We interpreted the situation as a guided decision, since the providers encouraged David to rest after the activity to benefit his recovery.

The balancing act required the providers to invest time in dialogue and interpret the patients' signs of energy/exhaustion while considering what other activities and procedures would need to be prioritized. Sometimes, limiting the activities was beneficial; whereas other times they expected increased effort and progress. The level of activity seemed to be guided by professional judgment, as decisions about balancing activity and rest were often made without inviting the patient to participate in the decision-making.

4. Discussion and conclusion

4.1. Discussion

The present study provides a novel understanding of ICU patients' involvement in their treatment and care. We found the interaction between patients and the healthcare providers to be

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Table 5
BALANCING EMPOWERING ACTIVITY AND ENERGY RESTORATION.

David has been 21 days in the ICU, struggling with prolonged weaning from mechanical ventilation, ICU-acquired weakness, and postoperative complications. During the physiotherapy, David has worked hard, and physiotherapist Bridget comments as she is about to close the session "Well done, now I think you are tired."
David responds forming "no" with his lips, looking at her shaking his head.
"You never get tired?" Bridget responds laughing, and Davis smiles at her shrugging his shoulders. Bridget then continues "A physiotherapist will be back to get you up on the bedside later, but you`ll get some rest first."
Nurse Oscar comes up to the bedside and says "I thought you would lay on the side and rest a bit. Do you think you will be able to relax some? You have worked out now. It is good to sleep in the morning and not in the evening, to not interrupt the night sleep."
David looks towards Oscar and forms words with his lips and grimaces.
"No? You think it will be painful?" Oscar responds and David nods. "why don't we try, if it is uncomfortable for you, we will change position again?" Oscar asks and David again nods a, a bit slower this time and he looks around.
Bridget and Oscar position David on his right side and make sure he is comfortable. Before Bridget leaves the room, she says "goodbye, rest now it`s been a tough session. Great job!" to David. David forms words with his lips looking at her while he nods.

more varied across and within patients than previously reported both in terms of the types and processes of micro-decisions [18,19,27]. We identified six types of decision patterns: non-invited, substituted, guided, invited, shared and self-determined decisions. The analysis revealed variations in how micro-decisions evolved and were influenced by providers, patients, and other factors such as the disease characteristics. We identified three main features in the decision-making processes: how the patients continuously shifted between being in observer or participant positions when interacting, how the patient and the provider negotiated micro-decisions, and how decision-making was limited by the need for energy restoration. These features have not been addressed in previous studies, which have tended to highlight that patients often feel vulnerable, struggle to communicate, and are isolated from the treatment [18,27].

This study contributes to a more situation-specific understanding of decision-making, in ICUs. Even when patients made self-determined decisions, their physical limitations meant a provider needed to carry them out (e.g., tracheal suctioning). We interpreted patient-initiated communication about treatment or care as self-determined decisions (perhaps an over-statement considering the patient's communication barriers). However, we did observe treatment decisions based on the patients' explicit bodily signals, such as pointing to the tracheostomy.

Our findings illustrate how autonomy is not a fixed state, and that patient involvement must be understood in the cultural, social, physical and embodied practice where it occurs [38]. Kukla argues that autonomy is not necessarily measurable by punctuated decision points but should include several health decisions made over time and considering the degree to which the patients can make a conscientious decision [25]. Thompson [39] interviewed both patients and members of voluntary health care organizations about their involvement in treatment decisions, finding that many prefer providers to make decisions during critical illness. Micro-decisions do not pose the same dilemmas or significance as decisions about life-sustaining treatment; therefore, the severity of the decision may affect the patients' desire to participate in the decision-making. Our study indicates that ICU patients' autonomy depends upon the context, the severity of the illness, the communication barriers, information needs, and the time available to communicate. However, even though the patients were critically ill they also exressed a desire to participate. Patient participation in treatment decisions does not necessarily imply that they should be making only self-determined decisions; however, we recommend that providers invite patients into decision making whenever possible and to explore the patients' preferences.

The study is one of the first to investigate how micro-decisions are made at the patients' bedsides in ICUs. In a focused ethnography of weaning from prolonged mechanical ventilation, Happ et al. [18] found that 12 out of 30 (40%) patients they observed were involved in making decisions about their care. These decisions included bedside decisions such as weaning procedures and initiation/withdrawal of mechanical ventilation, surgery, feeding tubes, tracheostomy insertions, or withdrawal of dialysis, which is similar to our study. Happ reported that only 19% of the decision-making processes were patient-initiated, and in 55% of the processes, patients were not invited. This concurs with our findings, as many of the observed micro-decision processes were non-invited decisions, and the patients' opinions were not solicited. We do not know whether the patients agreed to the decisions being made or not if they did not express their opinions in the observations.

Negotiations in micro-decisions, such as mobilization, have been reported in other studies [19,40]. Negotiating ways of performing painful and exhausting procedures may be interpreted as patients' ways of gaining control of their somewhat chaotic and uncertain existence [41–43]. These negotiations may challenge providers' professional judgement, which must be incorporated in decision-making in ICUs, but with consideration of the patients' experiences, resources, and cognitive capacity, as well as the best available evidence for the different choices [24,26,44]. Mechanically ventilated patients are completely dependent on the providers' assistance and attention [37], and they lack negotiation power. Encouragement from providers, to become gradually more involved, can lead to patient empowerment [26,27]. Invitation to participate in decisions, by providers, is described by patients in a previous study as a positive act [19] and is empowering over time [19,42,24]. Patient involvement in micro-decisions is therefore an important part of the recovery process [19,42,45]. However, this requires that enough time be spent soliciting patient preferences to ensure correct understanding, due to the communication barriers [44,46].

The negotiations we observed revealed how patients who underwent bedside procedures numerous times (such as tracheal suctioning) gained personal experiences that they subsequently applied in the decision-making. For example, patient Rebecca's (Table 1) previous bad experience with the tracheostomy speaking valve and Raphael's (Table 4) reluctance towards the nasal cannula. Providers can ensure they consider patients' wishes in the micro-decisions over time by both documenting and sharing their preferences with other healthcare team members. Shared decision-making processes often involve soliciting preferences and reaching an agreement from both the patient's and the provider's perspectives [33]. In the "negotiating space" there is potential to involve the patients and to ensure individualized care. The current study shows that micro-decisions can impact important treatment decisions, such as weaning off ventilation, eventually affecting patient outcomes.

For patients on mechanical ventilation, it is difficult to explore options in depth. Exploration of options is an important step in shared decision-making [33]. Facilitative strategies could be to use communication aids, or to involve relatives in the decision-making

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as communication partners. Our study demonstrates the variety of micro decisions in intensive care and that different decision-making processes occur within this healthcare setting. Decision-making must be understood in the context in which it occurs [46].

Our definition of shared decisions (Table 2) is as follows: "Either the patient or the healthcare provider may initiate the decision. Both the patient's preferences and the provider's assessment are considered, and the patient takes an active role in the dialogue. Both agree on the final decision." Our understanding is not focused specifically on eliciting treatment options, such as Stiggelbout el al.'s or others' suggestions [33,47–49], but it is more on the immediate "here and now" agreement with the patient. Nor is it a stepwise model to reach an informed decision where one first focuses on choices, then options, before the final decision stage, as Elwyn et al. recommend [47]. It is a situation-specific understanding of decision-making, not explicitly integrating the best evidence available in the decision [23–25]. Further attention on decision-making is therefore required, especially due to the changes of treatment philosophy in ICUs, with more conscious ventilated patients than before. To reduce the patients' difficulties, communication and decision tools suitable for intensive care are vital [1–3], to foster a systematic approach to patient involvement [49]. The findings from our and former studies [18,19,27,50], reveal that providers seem to lack frameworks to understand and enhance patient participation within a clinical context with non-vocal patients.

This study's main limitations include the risk of participants being affected by the cameras and loss of privacy. We implemented numerous measures to help the participants feel comfortable while being video recorded. A few of the videos contained segments with poor lighting, but most of the data had good audio and visual quality [29,51]. Collection of additional data on the participants' experiences by, for example, interviews, could have contributed to a deeper understanding and strengthened the credibility of the interpretations [52]. Other types of decision-making processes may have occurred over a longer period than we observed.

4.2. Conclusion

The study revealed a variety of ways in which conscious mechanically ventilated patients participate in bedside decision-making, from being an observer of treatment decisions to making self-determined decisions. Decision processes varied considerably between and within patients, and communication barriers influenced patients' ability to express their preferences. Understanding how micro-decisions evolve between patients and providers delivers an opportunity to discuss how shared decisions can be applied bedside in ICUs. Situation-specific decision-making processes, such as guided decisions, should be recognized as important in intensive care.

4.3. Practice implications

Today's standard of care requires a comprehensive understanding and multi-disciplinary approach toward decision-making in intensive care. Our findings reveal the potential for improvement. We would like to emphasize the importance of providers' responsibility to invite patients to participate in decision-making while being mechanically ventilated. Despite the complex communication barriers, providers should create a secure environment for patients to communicate. Continuing education is needed to understand and embrace the negotiating dialogues with the patients to potentially involve them in their treatment and care to promote their recovery and health.

CRediT authorship contribution statement

Marte Marie Wallander Karlsen: Conceptualization, Methodology, Software, Validation, Formal analysis, Investigation, Writing - original draft, Visualization, Funding acquisition. **Mary Beth Happ:** Conceptualization, Methodology, Formal analysis, Validation, Writing - review & editing, Supervision. **Arnstein Finset:** Conceptualization, Methodology, Formal analysis, Validation, Writing - review & editing, Supervision. **Kristin Heggdal:** Conceptualization, Methodology, Formal analysis, Validation, Writing - review & editing, Supervision. **Lena Günterberg Heyn:** Conceptualization, Methodology, Formal analysis, Validation, Writing - review & editing, Project administration, Supervision.

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APPENDIX 1

Communication aids in intensive care units			
Communication aid	**Publication**	**Methods**	**Results**
Above Cuff Ventilation	McGrath, B., Lynch, J., Wilson, M., Nicholson, L. & Wallace, S (2016). Above cuff vocalisation: A novel technique for communication in the ventilator-dependent tracheostomy patient. *Journal of the intensive care society,* 17 (1), 19-26. doi: 10.1177/1751143715607549	Case report, 5 patients testing ACV.	Three of the patients achieved audible voice, one only whispering and the last one none voice at all (due to poor glottic closure, epiglottic and vocal fold edema).
Applications on Ipad/Computer	Kozalinski, R., Tappen, R. M. & Viggiano, D. (2015). Evaluation of Speak for Myself with Patients Who Are Voiceless, *Rehabilitation Nursing,* 40(4), 235-242. doi: 10.1002/rnj.186	Exploratory feasibility Study with 20 patients and testing of *Speak for myself*	All but one patient would have used the *Speak for myself* again, during critical illness. 10 responded they liked it, one "it helped," two "maybe," one "yes a bit" and one "no."
	Miglietta, M. A., Bochicchio, G. & Scalea, T. M. (2004). Computer-assisted communication for critically ill patients: a pilot study, Journal of Trauma, 57(3), 488-493. doi: 10.1097/01.TA.0000141025.67192.D9	Prospective pilot study, patients tested *Life Voice* for 7 days, 35 patients and 42 health care professionals	Patients and healthcare personnel very content with *Life Voice*, 97 % of the patients wanted to continue the use of the device after 7 days. Healthcare personnel reported to strongly agree with the use of the device as improvement of patient care and that it should be used in the care for critically ill patients.
	Rodriguez, C. S., Rowe, M., Koeppel, B., Thomas, L.A. Troche, M.S. (2012). Development of a Communication Intervention to Assist Hospitalized Suddenly Speechless Patients. *Technology Health Care, 20*(6), 519-513. doi: 10.3233/THC-2012-0695	Pilot study with 24 patients to test feasibility and usability of a multi-functional communication system for suddenly speechless patients.	In total the communication system was tested 52 times. 73% of the patients could activate it on command the first day. 27% required re-teaching. The mean score for satisfaction was 1.5 (n=11). They also rated importance highly (mean 1.61, n=11).
	Rodriguez, C. S., Rowe, M., Thomas, L., Schuster, J.,	Quantitative, quasi-experimental, 4-	Participants in the intervention group

	Koeppel, B. & Cairns, P. (2016). Enhancing the Communication of Suddenly Speechless Critical Care Patients. *American Journal of Critical Care, 25*(3), 40-47. doi: 10.4037/ajcc2016217	cohort, with 64 patients and the test of a technology-based communication intervention.	reported lower mean frustration levels (-2.68; SE, 0.17; 95 % CI, -3.02 to -2.34; p < .001) and higher mean satisfaction levels (0.59; SE, 0.16; 95% CI, 0.27 to 0.91; P < .001) with the use of the communication intervention.
	Van den Boogaard, M. & van Grunsven, A. (2004). A new communication aid for mechanically ventilated patients *Connect World Critical Care Nursing 3*, 20-23. doi: 10.1891.WFFCN.3.1	Testing and evaluating a "intelligent" keyboard for communication and communication board, with 9 patients and 7 nurses.	7 of the 9 patient and 6 of the 7 nurses were satisfied with the keyboard. 5 patients reported they used less effort to make themselves understood, and that is was easy to operate.
Communication boards	Patak, L., Gawlinski, A., Fung, N. I., Doering, L., Berg, J. & Hennemann, E. A. (2006). Communication boards in critical care: patients' views. *Applied Nursing Research, 19*(4), 182-190. doi: 10.1016/j.apnr.2005.09.006	Mixed methods study using interviews and survey with 29 patients. Exploring levels of frustration and use of communication tools	Patients judged that perceived level of frustration communicating their needs would have been significantly lower (P <.001) if a communication board had been offered (29.8 %) than if not (75.8 %). Most patients (69 %; n = 20) perceived that a communication board would have been helpful, and they also identified specific characteristics and content for a communication board.
	Otuzoğlu,M. & Karahan, A. (2013). Determining the effectiveness of illustrated communication material for communication with intubated patients at an intensive care unit. *International Journal of Nursing Practice, 20*(5),	Intervention study, in total 90 patients in both study (45) and control group (45). How satisfied patients were with help provided by the	Illustrated material was helpful by 77.8% and partially by 22.8%. Control group patients had more difficulties communicating with the healthcare staff. Using the communication board, 37.8 % of

	490-498. doi:10.1111/ijn.12190	nurses, communication experiences during the period of intubation.	the patients reported that the staff could sufficiently understand them versus 15.6 % in the control group.
	El-Soussi, A. H., Elshafey, M. M., Othman, S. Y. & Abd-Elkader, F. A. (2015). Augmented alternative communication methods in intubated COPD patients: Does it make difference. *Egyptian Journal of Chest Disease and Tuberculosis, 64*(1), 21-28. doi: 10.1016/j.ejcdt.2014.07.006	Quasi-experimental study, in total 60 participants in both study (30) and control group (30). Testing of a communication board based	40 % of the patients in the study group were very satisfied compared to 6.66 % in the control group. 10 % of the patients in the study group were very dissatisfied compared to 53.33% in the control group.
	Rathi, R. & Baskaran, M. (2015). Communication Board Satisfaction among Clients on Mechanical Ventilator. *International Journal of Nursing Education, 7*(3), 216-221. doi: 10.5958/0974-9357.2015.00168.3	Quasi-experimental study, in total 30 participants.	The study group reported higher satisfaction than the control group (83.5 versus 65).
Electronic voice output communication aids	Happ, M. B., Roesch, T. K. & Garrett, K. (2004). Electronic voice-output communication aids for temporarily nonspeaking patients in a medical intensive care unit: a feasibility study. *Heart and Lung, 33*(2), 92-101. doi: 10.1016/j.hrtlng.2003.12.005	Feasibility study with 11 participants. Qualitative (interviews and observation) and quantitative (questionnaires and document-recordings) approaches. Testing of VOCA (Messagemate & DynaMate)	The patients reported significantly reduced communication difficulties (31.1 versus 17.8, ease of Communication Scale). Patients used VOCA most frequently to communicate with relatives. Barriers to the use was also identified, such as poor positioning, staff constraints and staff unfamiliarity with device.
	Happ, M. B., Roesch, T. K. & Hagan, S. H. (2005). Patient communication following head and neck cancer surgery: A pilot study using electronic speech-generating devices. *Oncology Nursing Forum 32*(6), 1179-1187. doi: 10.1188/05.ONF.1179-1187	Mixed methods design with 10 participants. Participant observation, semi-structured interviews, document recordings) DynaMyte & MessageMate	75 % of the observation communication occurred. Patients ease of communication were compared to a pre-intervention group and was slightly lower (19.8 versus 22.5)

	Shimizu, K., Ogura, H., Irisawa, T., Nakagawa, Y., Kuwagata, Y. & Shimazu, T. (2013). Communicating by electrolarynx with a blind tetraplegic spinal cord injury patient on mechanical ventilation in the ICU. *Spinal Cord 51*(4), 341-342. doi: 10.1038/sc.2012.170	Electrolarynx testing of one participant, tetraplegic and blind.	The testing was successful, producing speech and the participant spoke fluently after a while. Gives a good option for speech when it is not possible for example to use eye-gaze devices.
	Girbes, A. R. J. & Elbers, P. W. G. (2014). Speech in an Orally Intubated Patient. *New England Journal of Medicine, 370*(12), 1172-1173. doi:.1056/NEJMc1313379	Case report, electrolarynx testing of 1 participant	The device restored the speech without the passage of air through the vocal cords on an orally intubated patient.
	Tuinman, P. R., ten Hoorn, S., Aalders, Y.J ., Elbers, P. W. G. & Girbers, A. R. J. (2015). The electrolarynx improves communication in a selected group of mechanically ventilated critically ill patients: a feasibility study. *Intensive Care Medicine, 41*(3), 547-548. doi: 10.1007/s00134-014-3591-2	Electrolarynx testing of 15 participants	In 6 out of 15 patients the use of electrolarynx was effective or very effective producing speech. Delirium was the only factor associated with unsuccessful use.
Eye tracking devices	Garry, J., Casey, K., Cole, T. K., Regensburg, A., McElroy, C., Schneider, E., . . . Chi, A. (2016). A pilot study of eye-tracking devices in intensive care. *Surgery, 159*(3), 938-944. doi: 10.1016/j.surg.2015.08.012	Pilot prospective trial in 3 tertiary ICUs. In total 12 patients. Demographic data and self-reported data from the patients (PIADS).	All the patients could communicate a minimum of basic needs with the system. The psychosocial impact was moderately positive (mean 1,30). 50 % found that the advice moderately or strongly increased their frustration, 50 % of the patients felt it decreased their confusion. Four of the patients were delirium positive the first day, from the third day of use none of the participants were considered delirious.
	Maringelli,F., Brienza, N., Scorrano, F., Grasso, F., & Gregoretti, C. (2013). Gaze-controlled, computer-assisted communication in	Intervention study, in total 15 patients, 15 nurses and 8 physicians. Tobee eye gaze, with PC	Improvement in communication regarding different domains like needs, desired, clinical assessment and a decrease

	intensive care unit: «Speaking through the eyes». *Minerva Anestesiologica, 79*(2), 165-175.	was tested on patients in the ICU. Self-reported questionnaires pre/post.	of anxiety and siphoric thoughts. The nurses and physicians experienced improvement and higher capacity to understand.
Mouthstick stylus and tracheostomy speaking valve	Mitate, E., Kubota, K., Ueki, K., Inoue, R., Momii, K., Sugimori, H., Maehara, Y. & Nakamura, S. (2015). Speaking Tracheostomy Tube and Modified Mouthstick Stylus in a Ventilator-Dependent Patient with Spinal Cord Injury. *Case Reports in Emergency Medicine*, 1-3. doi: 10.1155/2015/320357	Case study, 1 patient with tetraplegia. Speaking valve, testing of both speech valve and a mouthpiece stylus	Improvement in communication, patient could use Vocalaid 10 minutes each time. The mouthstick was modified to be fixed in the maxilla without the need for biting to communicate using communication boards and a touch screen (Vocalaid speaking valve)
Multiple communication interventions	Happ, M. B., Garrett, K. L., Tate, J. A., DiVirgilio, D., Houze, M.P., Demirci, J. R., George, E. & Sereika, S. M. (2014). Effect of a multi-level intervention on nurse–patient communication in the intensive care unit: Results of the SPEACS trial. *Heart and Lung, 43*(2), 89-98. doi: 10.1016/j.hrtlng.2013.11.010	SPEACS trial. Quasi-experimental study in three phases with 89 patients and 30 nurses from two ICUs. Four-hour communication course, supply of AAC material, training and SLP rounds.	Communication frequency and positive nurse communication increased significantly in one of the two ICUs. Patients used more communication aids in the group with both AAC and SLP (p= 0.002) and had more successful communication about pain and other symptoms (p= 0.07).
Tracheostomy Speaking Valve	Freeman-Sanderson, A. L., Togher, L., Elkins, M. R. & Phipps, P. R. (2016). Quality of life improves with return of voice in tracheostomy patients in intensive care: An observational study. *Journal of Critical Care,* 33, 186-191. doi: 10.1016/j.jcrc.2016.01.012	Prospective, observational study. 25 patients tried tracheostomy speaking valve, and self-reported by the use of VASES and EW-5D.	3 of the 25 did not regain voice during their time in ICU. Patients reported an increase in being understood and cheerfulness (both statistically significant). A median difference of all items of VASES scored favored a return of voice.
	Freeman-Sanderson, A. L., Togher, L., Elkins, M. R. & Phipps, P. R. (2016) Return of Voice for Ventilated Tracheostomy Patients in ICU: A Randomized Controlled Trial of Early-Targeted Intervention, *Critical Care Medicine,* 44(6), 1075-1081. doi:	A randomized controlled trial. 30 patients included (15 in intervention, 15 in control group)	

	10.1097/CCM.0000000000001610		
	Kunduk, M., Appel, K., Tunc, M., Alagolglu, Z., Alkis, N., Dursun, G. & Ozgursoy, O. B. (2010). Preliminary Report of Laryngeal Phonation During Mechanical Ventilation Via a New Cuffed Tracheostomy Tube. *Respiratory Care, 55*(12), 1661-1670.	Pilot study descriptive demographic data. 10 patients included.	9 of 10 could achieve sustained phonation. Some patients experienced anxiety, 1 failed making voice. 1 of the patients had a very low voice.
	Leder, S. B., Pauloski, B. R., Rademaker, A. W., Grammer, T., Dikeman, K., Kazandjian, M., Mendes, J. & Logemann, J. A. (2013). Verbal communication for the ventilator-dependent patient requiring an inflated tracheotomy tube cuff: A prospective, multicenter study on the Blom tracheotomy tube with speech inner cannula. *Head and Neck, 35*(4), 505-510. doi: 10.1002/hed.22990	Prospective single group case series, 23 participants	All the participants achieved an audible voice with the Bloom tracheostomy tube.
	Panadian, V, Smith, C. P., Cole, T. K., Bhatti, N. I., Mirski, M. A., Yarmus, L. B. & Feller-Kopman, D. J. (2014). Optimizing communication in mechanically ventilated patients *Journal of Medical Speech Language Pathology, 24*(4), 309-318.	Retrospective chart review of 4 tracheostomized patients' effect of the Portex Blueline ultra suctionaid Tracheostomy Tube (BLuSA)	All four patients managed to speak successfully despite being unable to tolerate cuff deflation. Two of the patients struggled and had some complications, but all improved their ability to communicate.
	Sutt, A. L., Cornwell, P., Mullany, D., Kinneally, T. & Fraser, J. F. (2015). The use of tracheostomy speaking valves in mechanically ventilated patients results in improved communication and does not prolong ventilation time in cardiothoracic intensive care unit patients. *Journal of Critical Care, 30*(3), 491-494. doi: 10.1016/j.jcrc.2014.12.017	Retrospective pre-postobservational study, with 129 patients.	Speaking valve resulted in earlier verbal communication, no effects on ventilator weaning times ($P > .05$) or decannulation times ($P > .05$).

Appendix 1: Communication aids presented alphabetically after category of aid, references within each category of aid listed chronologically after the year of publication. Design of studies according to the authors description.