Patient experiences and nurses' management of pain and discomfort in intensive care during a strategy of analgosedation

- an exploratory study

Helene Berntzen

Thesis for the degree Philosophiae Doctor (PhD)

Department of Nursing Science
Institute of Health and Society
Faculty of Medicine
University of Oslo

May 2020

Series of dissertations submitted to the
Faculty of Medicine, University of Oslo

ISBN 978-82-8377-738-3

Cover: Hanne Baadsgaard Utigard.
Print production: Reprosentralen, University of Oslo.

"It is through comfort and comfort measures that nurses provide strength, hope, solace, support, encouragement, and assistance"

Donahue, 1989 (Donahue, P. Nursing: The finest art)

Foreword

The recent pandemic threatening the world as I write the final pages of this thesis has generated stories from former ICU patients about their experiences as Covid-19 victims. Narratives from intensive care stays resemble the findings in this and many other studies. The knowledge about intensive care environment, treatment, nursing challenges and last but not least the experiences of patients may be regarded beneficial public education. Increased public knowledge may enhance understanding and bring justice to the many patients who have similar experiences independent of the pandemic. Regarding this study, there will be no future need for me to explain to people what intensive care nurses do, what intensive care implies, and why we need research in the field to make these patients' stay as comfortable as possible within the frame of critical illness and care. Already, follow-up hospitals are being established to rehabilitate patients physically and psychologically after Covid-19 ICU stay. "New and interesting" applies well to research, and Covid-19 is both. Several research projects have been established and money has been granted in the wake of the pandemic, including projects on patient outcome, follow-up after intensive care and on experiences of health care workers. It is however important to acknowledge the transferability or generalisability of this research to other ICU-patients.

Although experiences may not differ, specific challenges may nevertheless pertain to Covid-19 ICU patients. Professor Wesley Ely in an interview described Covid-19 as a "delirium factory." Discomfort of being deprived of a functioning mind found in our study may be caused by delirium and worsened from not having close relatives visiting, from being unable to communicate and relate to health care personnel because they are concealed by personal protection equipment. Moreover, because of the severe respiratory distress, Covid-19 patients need high doses of benzodiazepines for sedation and frequently muscle relaxation, neither of them beneficial for protecting the brain. If ICUs are crowded and nurse workload is high, mobilisation, which has been found to counteract delirium, may not be a priority. The deprivation of the functioning mind in our study appeared the most difficult to alleviate, not least due to lack of knowledge about brain dysfunction in intensive care.

In all its horror, we may hope that the spring of 2020, worldwide, will bring focus to the need for research, education, resources, and follow-up care for both patients in intensive care and health care staff, in the interest of all future ICU patients.

Acknowledgement

For the last six years I have been working on this thesis. It has been a privilege, and I am grateful for the opportunity I have been given to do this work at the Department of postoperative and intensive care at Oslo university hospital (OUS). However, this work had not been accomplished without the contribution and support from a lot of people.

First of all, I need to thank the participating patients for sharing their experiences and details from a special and sometimes stressful time in life, and the critical care nurses for letting me study their clinical practice and take part in their deliberations.

I am deeply grateful to my two supervisors on this project; main supervisor Hilde Wøien, intensive care nurse at OUS and Associate professor at the Department of Nursing Science, University of Oslo (UiO), and co-supervisor, Professor emerita, Ida Torunn Bjørk at UiO. Thanks to Hilde for inviting me to conduct this part of your project, for being an inspiration to work hard and to take on challenges, for encouraging and challenging me through honest and comprehensive feedback throughout the project - and for being a friend. Thanks to Ida Torunn for generously sharing knowledge and research experience and for being patient with my long sentences and “inventive” language, and for being an inspiration for many years to come in balancing work and pleasure. You have both believed in me more than I have myself, and your feedback and our discussions have been constructive thanks to the two of you being such a great team. I am going to miss our inspiring discussions accompanied by tea, scones and good laughs.

There is no way I can thank my dear friend, colleague, gatekeeper, co-author and informal supervisor on this project, Ann-Marie Storsveen. Your support has been beyond description and you have been my best companion from start to goal, kept me going with your enthusiasm for ICU patients and nursing, for knowledge, for research in general, and for this project in particular.

Thanks to Sigrid Rannem, head of Department of postoperative and intensive care for believing in me from the start and for making this Ph.d possible. Thank you for greatly supporting research in our department and for proudly presenting our accomplishments. Thanks also to Mimmi Nergård, former head of Postoperative care unit at OUS, Ullevål, for encouraging me at start, and to all my fabulous colleagues at PO who have been caring and supportive when I have returned to clinical work during the summer holidays.

Being a Ph.D student may be long and lonely journey, and I have highly appreciated my other job during this project, in professional development in nursing in our department. Collaborating with all the competent and hard-working nurses in FOU has been inspiring and fun. Thank you all! Special thanks to my closest colleagues and "cheering squad" at the office, Antonija Petosic, Siv Stavseth & Hanne Alfheim for great collaboration and friendship. It definitely helps being in this together.

Many thanks to Professor Tone Rustøen, researchers and fellow Phd-students in the nurse research group at the Division of emergencies and critical care at OUS for discussions and feedback over the years; in particular, all of you who share kitchen and coffee facilities, frustration and joy about refusals, revisions and acceptance of papers. Many thanks also to the PhD-seminar group at UiO for sharing experiences and being a great inspiration, in particular in using qualitative approaches. It has been a privilege to attend these seminars under the leadership of Professors Marit Kirkevold and Professor Anners Lerdal who have set high standards for nursing research and been excellent tutors.

I am grateful to all my friends who make every day a better one for the patients. My admiration for you is enormous and you know that your never-ending engagement has inspired my work. I am grateful also to friends not in health care, who patiently have kept up the interest and challenged me in promoting also the public relevance of my work.

Many thanks to my daughter Eline, for helping out with valuable library and reference works, and my niece Andrea for taking excellent care of layout issues.

Finally, I wish to thank my other and private "cheering squad;" my sister Elise, who is always genuinely interested and caring, my husband, Arne Jan, who has been embarrassingly proud and supportive, and also my best friend and distraction, and my children, Martin, Eline and Hanna; you have been proud of me, but you have made me proud of all your accomplishments over these years. You have become great and independent persons. And Luna; thanks for being there, at my feet – always.

Sammendrag

Rundt årtusenskiftet startet en ny epoke når det gjaldt sedering av intensivpasienter. Mindre sedasjon ble anbefalt som følge av en økende bevissthet rundt komplikasjoner ved dyp sedasjon og samtidige fremskritt i respiratorbehandling og bruk av farmakologiske midler. Implementering av ny kunnskap tar tid, og i 2014 da denne studien ble planlagt, var praksis for sedasjon ved mange intensivavdelinger nasjonalt og internasjonalt fortsatt i liten grad endret. Anbefalinger for sedasjonspraksis og bruk av vurderingsverktøy for smerte og sedasjonsnivå er fortsatt ikke tilstrekkelig implementert.

Analgosedasjon som strategi innebærer å behandle smerte først og gi sedasjon kun når det er nødvendig for å dempe angst og agitasjon. En slik strategi er i overensstemmelse med internasjonale retningslinjer for håndtering av smerte, agitasjon og delir. Både før og etter den anbefalte endringen i sedasjonspraksis har man studert intensivpasienters opplevelser. Til tross for at man har lagt vekt på betydningen av systematisk vurdering og behandling av smerte i mer enn to tiår, blir smerte og ubehag fortsatt rapportert som hovedårsaker til intensivpasienters plager.

Hovedhensikten med denne studien var å få økt kunnskap og forståelse for hvordan pasienter opplever smerte, ubehag og våkenhet under kritisk sykdom i en intensivavdeling der man benytter analgosedasjon. Videre var hensikten å utforske intensivsykepleieres overveielser og handlinger for å lindre smerte og ubehag hos pasienter under de samme forholdene.

Studien var utforskende og bestod av tre delstudier. I del-studie I ble atten pasienter intervjuet etter at de var utskrevet fra intensivavdelingen og ti av disse ble intervjuet igjen etter tre måneder. I del-studie II ble tretten intensivsykepleiere studert ved totalt seksten tilfeller mens de hadde ansvar for en pasient. Det ble benyttet deltagende observasjon etterfulgt av intervjuer om det som ble observert . Alle data ble analysert ved bruk av kvalitative tilnærminger. Del-studie III var en sekundæranalyse for spesifikt å utforske ubehaget i intensivavdelingen, basert på data og funn fra del-studie I og II.

Hovedfunn i studien var at pasientene generelt beskrev at ubehag i større grad enn smerte dominerte opplevelsene deres under intensivoppholdet. Ubehaget resulterte i at mange av pasientene husket intensivoppholdet som en traumatisk del av sykdomsforløpet. Sykepleiernes overveielser og handlinger når det gjaldt smerte var i overenstemmelse med anbefalingene for forebygging, vurdering og behandling av smerte, og i vår fortolkning fungerte den innførte analgosedasjons-protokollen som et kompass som ga sykepleierne retning for smertebehandlingen. Systematikken som protokollen bidro med ga derimot ikke samme fordel når det gjaldt håndtering av annet ubehag enn smerte. Sammenlignet med hvordan smerte ble håndtert, framstod tilnærmingen til ubehag som mer usystematisk, tilfeldig og knyttet til den enkelte sykepleiers formening om hva som var viktig og riktig.

Ved å undersøke fenomenet ubehag mer inngående ut fra hele materialet og perspektivet til både pasienter og sykepleiere , kunne vi beskrive ubehaget som en kompleks, sammenvevd erfaring av å være frarøvet en fungerende kropp, et fungerende sinn og sin integritet. Vi viste også at ubehaget i intensivavdelingen var til dels uunngåelig og beskrev dette som et *komfort-gap* (comfort gap). *Gapet* bestod av ubehaget som gjenstod når både smerte og ubehag var blitt lindret i så stor utstrekning som mulig med tanke på pasientens tilstand, sykepleiernes innsats og påvirkningen fra omgivelsene. Særlig viste ubehaget knyttet til svikt i hjernefunksjon (et fungerende sinn) seg å være vanskelig å lindre.

Komfort-gapet som ble identifisert i denne studien illustrerte at deler av pasientenes ubehag ikke lot seg lindre til tross for at sykepleiernes omfattende innsats. Dette uunngåelige ubehaget så også ut til å belaste sykepleierne som måtte være vitne til, og holde ut, lidelsen hos pasientene mens de forsøkte å balansere det å lindre ubehag og samtidig møte kravene om rehabilitering og framgang. Ved å fokusere på det identifiserte komfort-gapet og hva som utgjør det hos den enkelte pasient, kan sykepleieren bidra til å redusere gapet og forhåpentligvis bedre pasientens erfaringer fra intensivoppholdet.

Ut fra våre funn er pasientkomfort som mål for omsorgen av stor betydning i en intensivkontekst der man tilstreber minimal sedasjon. Når pasientens sederes lettere, gis sykepleier og pasient bedre mulighet til å samarbeide rundt det som er målet med pleien og omsorgen. Sykepleieteorien «Comfort theory» ble benyttet i studien for å belyse hvordan ubehag kunne håndteres individuelt, men likevel systematisk, og har bidratt med begreper som synes nyttige også i klinisk praksis. I «Comfort theory» defineres comfort ved hjelp av de tre begrepene velvære (ease), lindring (relief) og det ”å løfte seg ut av” (transcendence). Av de tre begrepene viste ”transcendence” seg særlig nyttig for oppnå komfort i intensivavdelingen når det ellers synes uoppnåelig.

Å fokusere tydelig på kjerneverdien pasientkomfort i sykepleie, flettet sammen med systematikk, kan bidra til å minske gapet beskrevet i vår studie og derved komme både fremtidige intensivpasienter og intensivsykepleiere til gode.

Summary

A new era of lighter sedation was founded around the turn of the millennium following an increased awareness of the possible complications of deep sedation and along with advances in mechanical ventilation and pharmacological agents. However, implementation of new knowledge takes time and when this study was planned, the benefits of sedation-minimizing strategies, including the application of guidelines and use of assessment tools, was still not routine in intensive care units (ICU). Analgosedation implies treating pain first and providing sedation only when necessary to alleviate anxiety or agitation. As a strategy, analgosedation corresponds well to current international guidelines for the management of pain, agitation and delirium. How patients experience their ICU stay has been studied both before and after the shift in sedation practice. Even though systematic assessment and management of pain have been emphasized for more than two decades, pain and discomfort are still reported as main sources of patient distress.

The overall aim of this study was to provide knowledge important to health care personnel in caring for ICU patients, enabling them to help patients tolerate intensive care treatment in relation to current strategies in managing pain and sedation. More specifically, the purpose was to focus on the pain and discomfort experienced by the patients during ICU stay and how the critical care nurses deliberated and enacted to contribute to reducing pain and discomfort in these patients.

This was an exploratory study including three sub-studies. In sub-study I, eighteen patients were interviewed after discharge from ICU and ten of these were interviewed again after three months. In sub-study II, thirteen critical care nurses were observed by participant observation and interviewed. Data was analysed with qualitative analytic approaches. Sub-study III was a secondary analysis to explore in-depth the discomfort in intensive care, based on data and findings from sub-studies I, and II.

The main findings in this study were that the patients in general described discomforts other than pain as dominating their intensive care experiences. The discomforts however, resulted in patients remembering the ICU as a traumatic part of their illness trajectory. Patients handled the experiences in different ways. The nurses' deliberations and enactments regarding pain related well to the existing recommendations for preventing, assessing and treating pain.

In our interpretation, the analgosedation approach constituted a compass to direct treatment and care regarding pain. The systematics provided by the analgosedation protocol did not to the same extent benefit the nurses in managing other discomforts than pain. Hence, in comparison, the approach to discomforts appeared unsystematic and haphazard. However in navigating, both with and without analgosedation as a compass, the nurses needed to make use of personal and professional skills.

By further investigating the phenomenon of discomfort from the perspectives of both nurses and patients, we described the discomfort as a complex and interwoven experience of being deprived of a functioning body, a functioning mind and of integrity. We also demonstrated an inevitability of discomfort in the ICU, which we described in terms of a comfort gap. The gap constituted the discomfort that was left when pain and other discomforts had been alleviated to the possible extent according to the clinical condition of the patient, the nurses' efforts and environmental factors.

The comfort gap identified in our study seemed to leave the nurses in a position unable to fulfil their patients' needs despite their endeavours to relieve discomfort. This inevitable discomfort appeared to affect and put a strain on the nurses when observing and having to withstand suffering in their patients and when having to balance the need for comfort and the demand for progress in rehabilitation.

However, by paying attention to the comfort gap and to what contributes to its existence in the individual patient, nurses may possibly diminish the gap and thereby ameliorate the patient experience of staying in the ICU. According to our findings, comfort as a goal of care and defined nursing skill appears paramount in contemporary intensive care contexts of minimal sedation. Minimal sedation practices hold the power for nurses and patients to cooperate on the goals of care. Comfort theory has been used in this study to highlight the possibilities of assessing and treating discomforts individually and has provided concepts useful in clinical practice. In particular, by means of dividing comfort in to the types of ease, relief and transcendence, the latter has appeared most useful in achieving comfort in ICU when it seems unattainable. An explicit focus on the core nursing value of comfort, intertwined with systematic approaches, may benefit both patients being cared for and nurses caring for them, and may contribute to diminishing the comfort gap identified in our study.

List of original papers

This thesis is based on the following papers referred to in the text as sub-study I-III

Paper I	Berntzen H, Bjørk IT, Wøien H, "Pain relieved, but still struggling" – Critically ill patients' experiences of pain and other discomforts during analgosedation. *Journal of Clinical Nursing, 2017;00;1-12. https://doi.org/10.1111/jocn.13920*
Paper II	Berntzen H, Bjørk IT, Wøien H, "Having the compass – drawing the map": Exploring nurses' management of pain and other discomforts during use of analgosedation in intensive care. *Nursing Open, 2019;6: 453-62. https://doi:10.1002/nop2.227*
Paper III	Berntzen H, Storsveen, A-M, Bjørk IT, Wøien H, "Please mind the gap": A secondary analysis of discomfort and comfort in intensive care. *Journal of Clinical Nursing, 2020:00:1-14. https://doi:10.1111/jocn.15260*

Abbreviations

CAM-ICU	Confusion Assessment Method for the Intensive Care Unit
CPOT	Critical Care Pain Observational Tool
eCASH	early Comfort using Analgesia, minimal Sedatives and maximal Humane care
ICU	Intensive care unit
ICUMT	Intensive care unit – Memory Tool
LOS	Length of stay
NRS	Numeric Rating Scale.
PAD	Pain, agitation and delirium
PADIS	Pain, agitation, delirium, immobility and impaired sleep
PICS	Post Intensive Care Syndrome
PTSD	Post Traumatic Distress Syndrome
RASS	Richmond Agitation and Sedation Scale
VAS	Visual Analogue Scale
WHO	World Health Organization

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1 INTRODUCTION

"There is no such thing (...) in this world as good memories from an intensive care unit, except from the people working with you being very good, – but staying in an ICU can never be good, can never be positive, that is my opinion"(Patient 5).

These are the words of one of the patients being interviewed in this study. G was a man in his mid-fifties, with a serious heart disease and several stays in hospital and intensive care units (ICU) over the years, making him an experienced ICU–resident. What this patient expresses highlights the main theme of this thesis; the discomforts experienced by ICU-patients and attended to by critical care nurses. To be critically ill implies suffering from pain and many other discomforts. Some of these discomforts may be alleviated, while others may not. More than half of the ICU survivors suffer to some extent from the so-called post-intensive care syndrome (PICS) (Mikkelsen, Netzer, & Iwashyna, 2019; Needham et al., 2012). PICS is manifested as "new or worsening impairments in physical, cognitive or mental health status arising after critical illness and persisting beyond acute care hospitalisation" (Needham et al., 2012). The multifaceted origin of the discomforts in ICU warrants more knowledge about how health care personnel can make an ICU stay less uncomfortable or painful and how to lessen the burden in rehabilitation for those who survive and for their families.

At the onset of this study, there was growing evidence to recommend an analgesia-first approach and light sedation in ICU patients, as maintaining deep sedation is associated with a diversity of adverse patient outcomes (Barr et al., 2013). When awake or lightly sedated, the patients might be able to respond, report pain and mobilize. Furthermore, such an approach increases the ability for health care personnel to cognitively assess patients, communicate and provide comfort and care according to their patients' needs. However, in the mid- eighties, when I started working in the ICU, deep sedation and immobilization was the preferred and accepted approach in patients requiring mechanical ventilation. The sedation was maintained by continuous infusion of analgesics and hypnotic-based sedation, frequently supplemented by neuromuscular blockers (Roberts, Haroon, & Hall, 2012). Pain management was provided with analgesics mixed with sedative agents in fixed proportions. There were no systematic approaches for prescribing, assessing or documenting pain or sedation levels which means we had little idea about how deeply sedated the patients were and whether they were in need of more analgesics. Of course, already at that time, observed pain-related behaviour like grimacing, muscle tension and difficulties in synchronizing with the ventilator triggered the administration of extra medication, however in my experience more often sedatives than analgesics.

At this time, patients' experiences from the ICU stay had been reported by several, revealing pain and distressing experiences (Bergbom-Engberg & Haljamäe, 1989; Gjengedal, 1994; Hafsteindottir, 1996; Hall-Lord, Larsson, & Boström, 1994). While learning to care for the critically ill, a short Swedish film about the experience of being on mechanical ventilation made a great impression on me. The film was recorded from the perspective of the patient, showing the horrors of not understanding and of not being able to communicate. The early interview research by Bergbom-Engberg & Haljamäe (1989) further described these experiences of anxiety and fear related to panic, insecurity and inability to communicate.

The idea of this study arose in 2014, when intensive care nurse, Phd, Hilde Wøien at Oslo university hospital planned a follow-up study of a systematic approach to monitoring pain, agitation and delirium (PAD) (Wøien, 2020; Wøien, Værøy, Aamodt, & Bjørk, 2012). At that time, knowledge proving the positive outcome of being lighter or not sedated was available and highlighted in the international guidelines for the management of PAD (Barr et al., 2013). It was, however, far from routine in intensive care units (ibid). This brought about the need for more knowledge about the adherence to international PAD guidelines and about the experiences of both patients and nurses regarding pain and sedation.

The longitudinal follow-up study compared the effectiveness of the current systematic approach with the supplement of *an analgosedation protocol* (Appendix 1), measured by the adherence to recommendations in the PAD guidelines. Analgosedation implies treating pain first and providing sedation only when necessary to alleviate anxiety or agitation (Devabhakthuni, Armahizer, Dasta, & Kane-Gill, 2012; Kress & Hall, 2006). Introducing new strategies for treating pain and sedation in critically ill patients, called for investigating how patient experiences and nursing practice were affected by the changes. The present study constitutes the qualitative part of this follow-up study.

For decades, we have been aware of patients' memories and experiences from the ICU. However, until the paradigm shift to light sedation we were more or less convinced of the benefit of being deeply sedated and remembering as little as possible. Hence these memories stem mainly from times of improvement and rehabilitation. Similarly, nurses have also faced challenges in communication and physical and psychological recovery issues in their patients. Currently, the ICU patients are expected to be kept awake even when acute and critically ill, and when having an uncertain or poor prognosis. The novelty of this research pertains to the patients' wakefulness and increased ability to report pain during larger parts of their ICU stay, and also in the more acute phase of their illness.

The overall aim of this study was to provide knowledge important to health care personnel in caring for ICU patients, enabling them to help patients tolerate intensive care treatment in relation to current strategies in managing pain and sedation. More specifically, the purpose was to focus on the pain and discomfort experienced by the patients during ICU stay and how the critical care nurses deliberated and enacted to contribute to reducing pain and discomfort in these patients.

1.1 Outline of the thesis

This thesis consists of eight chapters, the sub-studies (I-III), reference list and appendices. In chapter 1, the study is introduced and the outline of the thesis presented. Chapter 2 comprises the background section starting with a historical overview of pain and sedation in the intensive care leading up to the relevance of the study. It continues with a description of central concepts and a review of the literature. The literature review describes the research existing at study start. Updated and relevant research on the topics under study will be accounted for in the discussion section. The aims of the study are presented in chapter 3. In chapter 4, the theoretical perspectives that have inspired the study are presented. In chapter 5, the research design is presented along with the methods used to explore patient experiences and nurses' management of pain, sedation and wakefulness. The findings of the three papers are summarized in chapter 6. Chapter 7, the discussion, is divided into the result discussion, the methodological considerations regarding the study, and the use of theoretical perspectives. Finally, the empirical contribution is presented in chapter 8 along with the implications for clinical practice and further research.

2 BACKGROUND

This chapter will be introduced by an historical overview of the topics relevant to this thesis. Following this, an overview of the concepts central to this study will be presented, and relevant literature existing at the onset of the study will be reviewed.

2.1 Historical overview

Intensive care medicine is a young specialty in medicine established after the 2nd world war. An important antecedent of the establishing of specialized units for intensive care was the polio-epidemic in Scandinavia in the early fifties. In Copenhagen, the anaesthetist Bjørn Ibsen founded a unit to care for polio victims in need of assisted ventilation (Strømskag, 1999). At this time, the patients were awake while being manually assisted in their breathing. Later on, ICU-treatment, in particular mechanical ventilation, required heavy sedation and analgesia to reduce stress, anxiety and agitation, and prevent adverse events (Barr et al., 2013).

A new era of lighter sedation was founded following an increased awareness of the possible complications of deep sedation and along with advances in mechanical ventilation and pharmacological agents. Studies demonstrated the effect of daily sedation interruption (Kress, Pohlman, O'Connor, & Hall, 2000) and the use of a nurse-driven sedation protocol (Brook et al., 1999) in reducing the duration of mechanical ventilation and ICU-length of stay (LOS) (Mehta, McCullagh, & Burry, 2009). This era, starting around the turn of the millennium, is often referred to as a paradigm shift regarding sedation in critical care (Devabhakthuni et al., 2012; Roberts et al., 2012; Wunsch & Kress, 2009). The experience of being an ICU patient has been studied both before and after the shift in sedation practice. Physical and psychological discomfort due to ICU-treatment and care, in particular mechanical ventilation, has been thoroughly documented (Bergbom-Engberg, Hallenberg, Wickstrøm, & Haljamäe, 1988; Gjengedal, 1994; Hafsteindottir, 1996; Hall-Lord et al.,1994). In a review published in 2000, pain and discomforts related to the endotracheal tube, thirst, noise, impaired sleep, being tied down, and to communication difficulties resulting in insecurity, fear, anger, frustration and helplessness were identified (Stein-Parbury & McKinley, 2000). Furthermore, cognitive disturbance, confusion, disturbing dreams, nightmares and hallucinations were reported. Although, these reported experiences are similar to experiences reported in more current research, there are substantial differences in what an intensive care trajectory looked like when these studies were conducted and today. Mechanical ventilation technology was not developed to synchronize with the patient's breathing, allowing them to be more awake and to breathe spontaneously, no short-acting medication was available, and patients were altogether deeply sedated for most of the ICU-stay. This is well illustrated by Granberg et al. who in 1998 described the patient experiences of ICU as a state of chaos starting when the patient fell ill or was injured and continued when regaining consciousness after the ventilation treatment. (Granberg, Bergbom Engberg, & Lundberg, 1998). Moreover, no tools were available to assess or document how deeply these patients were sedated, nor to assess their level of pain. Nevertheless, all patients were awake at some point before or after extubation, and more patients were allowed to rehabilitate longer within the ICU. The change in premises for generating knowledge about patient experiences must be kept in mind when practices following the paradigmatic shift are studied.

In 2000, a national quality improvement collaborative project in adult intensive care medicine took place in Norway, initiated by the Norwegian Medical Association. One focus area in this interdisciplinary "breakthrough project" was sedation and ventilator time. Systematic assessment of sedation supported by the use of a sedation scale was introduced in several Norwegian ICU's, including units in our hospital. As part of the project, the sedative and analgesic infusions were separated allowing the effect of each agent to be assessed and tailored to the patient's need for either of these. Following the research proving positive outcomes from being lightly, rather than deeply, sedated, this project may be regarded as the beginning of the new era of pain and sedation management in Norway. The increasing use of short-acting substances like propofol and remifentanil, brought about another small-scale local quality improvement project (unpublished, Oslo university hospital, Ullevål). The focus of the project was *analgosedation,* a concept central to the present study and in line with recommendations in the shifting sedation practices. Participation in these projects paved the way for my scientific interest in how ICU -patients experience their stay during changes in sedation practice.

In 2002, "Clinical practice guidelines for the sustained use of sedatives and analgesics in the critically ill adult" were published (Jacobi et al., 2002). The use of both pharmacological and non-pharmacological therapies to maintain patient safety and comfort was emphasized. These guidelines were the first to recommend systematic approaches to pain, sedation and delirium, including the use of scoring tools following the paradigmatic shift in sedation practice (ibid). The guidelines included the following recommendation "Sedation of agitated critically ill patients should be started only after providing adequate analgesia and treating reversible physiological causes."

However, implementation of new knowledge takes time and when this study was planned, the published benefits of sedation-minimizing strategies, including the application of guidelines and use of assessment tools, was still not routine, and low adherence in ICUs was reported (Barr et al., 2013; Jackson, Proudfoot, Cann, & Walsh, 2009; Mehta et al., 2009). Updated clinical guidelines in 2013 therefore emphasized the focus on pain management and targeted light sedation, including the use of valid assessment tools to measure pain, agitation, sedation and delirium (Barr et al., 2013) to improve clinical outcomes. The present study was planned in this context of practice and recommendations.

2.2 Central concepts

In this section I will present the patients, the setting and nursing in intensive care to frame the field of this study. Thereafter, I will present the understanding of pain, discomfort, sedation and experiences in the ICU, upon which this thesis builds.

2.2.1 Intensive care patient

An intensive care patient may be defined by the presence of a threatening or manifest acute failure of one or more vital organs, and when the failure is potentially fully or partly reversible (Norsk Anestesiologisk Forening [NAF] & Norsk sykepleierforbunds landsgruppe av intensivsykepleiere [NSFLIS], 2014). Critical illness may have an acute onset, follow trauma, complications to surgery or other treatment or exacerbations of a chronic disease. More than 14000 patients were admitted to Norwegian intensive care units in 2018, and 60% of these were in need of mechanical ventilation (Buanes, Kvåle , & Barrat-Due, 2019). In this study, the term intensive care patient or critically ill patient comprises adult medical and surgical patients admitted to an intensive care unit and who are, or have been, in need of mechanical ventilation.

2.2.2 Intensive care unit

Intensive care units are specialized units aiming to offer continuous and sufficient observation, diagnosis, treatment and care of patients with potentially reversible failure in one or more organ systems, aiming at maintaining, stabilizing and re-establishing normal organ function and preventing further deterioration (NAF & NSFLIS, 2014). The ICU is also characterized by its highly technological environment, frequently surrounding patients with a vast amount of equipment such as monitors, ventilators and other respiratory supporting equipment, infusion pumps and renal replacement therapy machines. Another characteristic of the ICU is the staff, specially educated to treat and care for the critically ill patients. In larger Norwegian ICU's the majority of the nurses have completed their critical care nurse education. Usually in Norwegian and Nordic ICU's, the patient: nurse ratio in ICU is 1:1, but not infrequently, more than one nurse is needed for the sickest patients. Physicians and nurses collaborate closely in Norwegian ICU's and are assisted by consulting physiotherapists. Critical care nurses in Norway are however responsible for the entire bedside care including many tasks, which in other countries are left to different other professions. In this respect, the Norwegian, and to a certain extent, the Nordic ICU's differ from many ICU's in southern Europe and in the USA.

2.2.3 Critical care nursing

According to the Norwegian organization for critical care nurses, NSFLIS, the specialty of critical care nursing is performed on the basis of advanced knowledge, skills and general competencies within the areas of patient treatment, education, professional development, interdisciplinary collaboration and organization (NSFLIS, 2017). Furthermore, "The clinical practice in critical care nursing is evidence-based and embraces health promotion and disease prevention, illness management and rehabilitation as well as comfort and palliative measures. (…..) Comfort and palliative measures require that the critical care nurse performs procedures to relieve symptoms and limit the patient's burden in association with illness, injury and treatment and helps the patient to use his or her own resilience to activate health-promoting processes and assists in dealing with and relieving stress, pain and discomfort"

2.2.4 Pain

The International Association for the Study of Pain (IASP, 2017) defines pain as "an unpleasant sensory or emotional experience associated with actual or potential tissue damage or described in terms of such damage". Important notes to the definition emphasize the subjectivity of pain experience and that an individual's loss of verbal expression of pain does not negate the possibility of pain experience and the need for pain relief (ibid). The subjective experience of pain is consistent with the clinical definition of pain, which states, "Pain is whatever the experiencing person says it is, existing whenever he says it does." (McCaffery,1984, p.14). Loeser & Melzack (1999) offer a multicomponent understanding of pain comprising nociception, perception of pain, suffering, and pain behaviours. Kolcaba (2003) uses pain defined as including sensory, cognitive and affective components as described by Melzack &Wall (1982). The present study is based on these multidimensional understandings of pain and further of pain as one type of discomfort as outlined by Kolcaba (Kolcaba, 1997, 2003).

2.2.5 Discomfort and comfort

Discomfort according to Kolcaba (2003), is an umbrella term that comprises pain, but not every discomfort can be attributed to pain. Both in qualitative and quantitative research, pain and discomfort are frequently described together rather than as two different entities, making the relationship between them unclear. In this study we use *pain and other discomforts* to show the relation between the two concepts, but at the same time distinguish between them in regard to patient experiences. Nurses may also be challenged in distinguishing between pain and discomforts. Separating the two will facilitate the exploration of pain and other discomforts and the different interventions needed when attending to the two. Discomfort is described according to Kolcaba (2003) as "a physical, psychospiritual, sociocultural or environmental detractor from comfort." (p. 253) and comfort as "the immediate experience of being strengthened by having needs for relief, ease, and transcendence met in four contexts (physical, psychospiritual, social, and environmental) (p.14). Comfort is much more than the absence of pain (Kolcaba, 2003) or equivalent to a complete absence of discomfort (Lowe & Cutcliffe, 2005). Hence, it is possible to be in discomfort without having pain, and to be comfortable even with a certain degree of pain or discomfort.

2.2.6 Sedation and wakefulness

Sedation is a broad term indicating both the use of a pharmacological agent and the achievement of a level of sedation defined as the grade of patients' responsiveness (Blanchard, 2002). The level of sedation may range from minimal sedation, to moderate and deep sedation and eventually to anaesthesia (ibid). Sedation in this study refers to the provision of sedative agents (not analgesics) specifically administered to facilitate ICU patients' tolerance to treatment and care and alleviate agitation and anxiety (Devlin et al., 2018). Light sedation is used as a concept throughout this thesis. According to international guidelines, there is no universally accepted definition to this but in studies that use scales such as the Richmond Agitation Sedation Scale (RASS) (Sessler et al., 2002), a score of - 2, equivalent to brief awakening with eye contact to verbal stimuli for less than ten seconds is considered as light sedation (Devlin et al., 2018). Wakefulness as a concept used in this study covers the levels of sedation or consciousness as experienced by the patient.

2.2.7 Experiences and memories

Experiences as a noun may pertain to the act of directly perceiving events or reality, but also to something personally encountered, undergone or lived through (Merriam-Webster, 2020). In this study, experiences refer to what patients have experienced and express as their recall. Experiences may be classified both as real and unreal (Roberts & Chaboyer, 2004), and may be physical, psychological, emotional and existential. Studies on patients' memories refer to experiences, and therefore "memories" is also used in this study to describe the recall of events or experiences (Ringdal, Plos, Ortenwall, & Bergbom, 2010, Zetterlund, Plos, Bergbom, & Ringdal, 2012). Memories from the ICU stay has been divided into factual, delusional and memories of feelings (Jones, Griffiths, & Humphris, 2000a).

2.3 Review of the research

The empirical foundation of the thesis builds upon qualitative and quantitative research findings published until 2014. Literature search was performed in May 2014 at the onset of the study in electronic databases with the assistance of a specialist librarian. The main topics of patient experiences during intensive care and critical care nurses' management, combined with pain, discomfort and sedation formed the basis of the literature search. On-going searches were performed during the course of the study along with keeping relevant alerts from McMaster to trace new publications of interest. A thorough updated literature search was performed in spring 2020 before writing the thesis (Appendix 11). With further assistance from the librarian, I conducted a search in PubMed using Medical Subject Headings (MeSH) and text words including, but not restricted to, critical care, intensive care, critical illness, critically ill, patient experience, psychological distress, emotional distress, discomfort, comfort, pain, analgosedation, nursing management, nursing care, qualitative research, coping, deep sedation, conscious sedation, analgesics, delusion, delirium, memory, mental recall, recollections, wakefulness and well-being.

This section gives an overview of the research and development of pain and sedation in intensive care. In the description of pain, the focus will be on prevalence, characteristics and consequences of pain, assessment, treatment and patient experiences. Accounts of sedation will include the change in sedation practice and use of protocols, how the change has affected the patients' experiences, and memories from the ICU including how these affect patients after the ICU stay. Finally, the nurses' experience of caring for patients being more awake will be accounted for.

2.3.1 Pain

Prevalence, characteristics and consequences

At the onset of this study, pain was reported to represent a great source of stress in ICU, unchanged after more than 20 years of emphasis on pain management (Barr et al., 2013). In quantitative studies, more than 50 % of mechanically ventilated ICU patients report pain both at rest and during routine ICU procedures like endotracheal suctioning, turning and removal of chest tubes (Chanques et al., 2007; Puntillo et al., 2014; Puntillo et al., 2001). Pain has also been related to underlying illness, surgery and trauma (Schelling et al., 2003; Stanik-Hutt, Soeken, Belcher, Fontaine, & Gift, 2001). In a review of 26 studies from 1967 to 1999, pain was the most frequently reported discomfort in ICU-patients (Stein-Parbury & McKinley, 2000).

Pain in critically ill patients has also been reported as under-estimated and under-treated by nurses and physicians (Alderson & McKechnie, 2013; Chanques et al., 2006; Gelinas & Johnston, 2007; Payen, Bosson, Chanques, Mantz, & Labarere, 2009). Under-treatment of pain in the ICU may lead to adverse events like hypertension, tachycardia, increased oxygen consumption in the myocard, hypercoagulation, decreased immune response and persistent catabolism (Lindenbaum & Milia, 2012). Moreover, patients experiencing pain are at increased risk of immobility, anxiety, impaired sleep, possibly causing exhaustion, disorientation and agitation (Chanques et al., 2007; Jacobi et al., 2002; Lindenbaum & Milia, 2012). Insufficiently treated pain in acute care and critical illness has also been associated with the development of chronic pain (Battle, Lovett, & Hutchings, 2013; Kehlet, Jensen, & Woolf, 2006). Assessment of pain followed by adequate analgesic treatment is therefore paramount in intensive care, and an association has been shown between systematic evaluation of pain and agitation and clinical outcomes in adult patients in the ICU (Barr et al., 2013; Chanques et al., 2006). However, the ability to communicate pain may be impaired in critical illness (Alderson & McKechnie, 2013; Chanques et al., 2006; Shannon & Bucknall, 2003).

Assessment and documentation

The gold standard of pain assessment is the patient's own reporting of pain (Herr et al., 2006; McCaffery, 1984). Self-reporting pain intensity in adult ICU patients may be accomplished by applying a Visual Analogue Scale (VAS), a 100 mm horizontal line with sensory extremes anchored at 0 and 100 or a categorical Numeric Rating Scale (NRS), with visual numbering from 0-10 (Jensen & McFarland, 1993), where 0 refers to no pain all and 10 refers to the worst pain imagined. An obstacle to good pain management in the ICU is that critically ill patients are frequently unable to self-report their pain verbally or with other deliberate signs, due to the use of mechanical ventilation, an altered level of consciousness or high doses of sedative or neuromuscular blocking agents (Shannon & Bucknall, 2003). Although systematic clinical assessment and documentation of pain have been regarded of great importance in relieving patients' pain and increase comfort (McGuire, 1992; Puntillo, 1990), clinicians' consolidated beliefs and practices towards treatment of pain has shown to hamper this (Pasero et al., 2009). To accomplish good pain assessment, clinicians therefore need valid and reliable tools or assessment methods to detect and measure pain also in patients with diminished communication abilities. The development of such tools to measure pain has improved the bedside management and evaluation of outcomes of both pharmacological and non-pharmacological interventions (Barr et al., 2013; Chanques et al., 2006; Payen et al., 2009). Prior to the introduction of such tools, critical care nurses' assessment and documentation of pain have related primarily to their own subjective evaluation of the pain of patients unable to self-report, often documented as an NRS value. Research findings before the implementation of valid tools must be regarded as based on the same relatively inadequate assessment and documentation of pain.

Research regarding pain assessment tools has focused on identifying characteristics, behaviour and symptoms specifically related to pain. Facial expression, body movements, muscle tension and synchronized cooperation with the ventilator are categories associated with patients' expression of pain (Gelinas, Fillion, Puntillo, Viens, & Fortier, 2006). Behavioural assessment tools for pain are therefore recommended (Barr et al., 2013). The *Behavioral Pain Scale* (BPS) (Payen et al., 2001) and *the Critical- Care Pain Observation Tool* (CPOT) (Gelinas & Johnston, 2007) are considered the two most valid and reliable behavioural pain scales for monitoring pain in adult ICU patients who are unable to self-report (Barr et al.2013). The tools have proven feasible in medical, postoperative and trauma patients, but being based on observable pain behaviours, they require an intact motor function. Hence, they will not be reliable tools in some neurologic diseases (Arbour & Gélinas, 2010) In addition patients with brain injury or delirium may present atypical behavioural responses to nociceptive stimuli (Teitelbaum, Ayoub, & Skrobik, 2011) and the tools are not validated for these groups of patients (Arbour & Gélinas, 2014).

Behavioural tools however have limitations and cannot determine more than the mere presence of pain as two patients in severe pain behaviourally may express this very differently, i.e. with a different number of behaviours resulting in a total pain score (Pasero, 2009). According to Pasero, these tools should not be mistaken for pain intensity ratings as may be indicated by the score and may represent a pitfall for nurses. Hence, both self-report and behavioural scorings may only indicate pain “yes” or “no” since scores are primarily related to if and to what extent individuals express their pain.

Physiological indicators such as increase in heart rate and blood pressure, dilated pupils, increased respiratory rate and muscle tone, paleness and sweating (McCaffery, 1989) have been used as indicators of pain. However, these may be influenced by a diversity of physiological, psychological and pharmacological factors and has shown low correlation with critically ill patients self-report of pain (Arbour & Gélinas, 2010; Gelinas, Tousignant-Laflamme, Tanguay, & Bourgault, 2011). Based on this, the use of physiological factors solely, in pain assessment in critically ill patients, is not recommended. High quality treatment of pain is dependent on high quality assessment. Regarding the high incidence of pain and the complexity of pain assessment, awake and cooperative patients who are able to communicate, improve the likelihood of succeeding in evaluation and treatment of pain.

Pharmacological and non-pharmacological treatment of pain

Pain management in intensive care aims at relieving or minimizing pain to help patients tolerate treatment and care and allow for rest, and for mobilization when appropriate and possible. Both pharmacological and non-pharmacological treatment of pain is recommended to alleviate pain in the critically ill. Clinical Practice Guidelines for treating pain, agitation, and delirium in adult patients in the ICU were published close to the onset of this study (Barr et al., 2013). The guidelines recommend pre-emptive analgesia and/or non-pharmacological interventions prior to painful procedures such as removal of chest tubes. Furthermore, intravenous opioids are recommended as drug of choice in the treatment of non-neuropathic pain and regarded equally effective when titrated. Pain management goals in critically ill patients may however conflict with other clinical management goals such as organ function stability (Griffiths & Jones, 2007).

Despite relying on a few studies of effectiveness, the non-pharmacological interventions of music therapy and relaxation techniques are suggested in clinical practice guidelines because of their possible pain-alleviating and opioid-sparing impact (Barr et al., 2013, Erstad et al., 2009). Moreover, these interventions are considered safe, low cost and easy to provide. Interventions most frequently used and favoured by patients and nurses in the ICU are music and massage therapies (Chlan et al., 2013; Gelinas, Arbour, Michaud, Robar, & Cote, 2013). Taking into account the multifaceted origin of pain and considering the adverse effects of pharmacological approaches, non- pharmacological approaches represent an important adjuvant in alleviating pain and other discomforts in ICU patients.

Patient experiences of pain and other discomforts

The body of knowledge about patient experiences in ICU consists of a vast amount of qualitative and quantitative research, over the decades, including reviews and meta-syntheses (Cutler, Hayter, & Ryan, 2013; Stein-Parbury & McKinley, 2000; Tsay, Mu, Lin, Wang, & Chen, 2013). Early studies were conducted when deep sedation and immobilization was routine in intensive care and described experiences of chaos, loneliness, insecurity, anxiety, sleep deprivation, fear of death and communication impairment (Bergbom-Engberg & Haljamae, 1989; Gjengedal, 1994; Granberg et al., 1998). Since then, the intensive care context has evolved through lighter sedation, focused pain management, early mobilization and more humane care (Devabhakthuni et al., 2012; Egerod, 2009; Roberts et al., 2012). Despite these advancements, patients continue to report discomforts, often related to mechanical ventilation and including thirst, breathlessness, immobility, incomprehension, delusions, anxiety, inadequate sleep, and communication problems (Guttormson, 2011; Karlsson, Bergbom, & Forsberg, 2012a; Karlsson, Lindahl, & Bergbom, 2012b; Samuelson, 2011a).

In 2013, before the onset of our study, two meta-syntheses reviewing international nursing literature about patient experiences were published (Tsay et al., 2013; Cutler et al., 2013).

Studies included were published from 1970 – 2012 and 1967 – 2011 respectively, and hence includes studies both prior to and after the paradigm shift in sedation practice. Tsay et al. (2013) reported on experiences of being dependent on mechanical ventilation and revealed feelings of fear, loss of control of life, disconnection with reality and impaired embodiment. Cutler et al. (2013) synthesized studies of experiencing critical illness. They described among other things the transformation of perception relating to unreal experiences and dreams, altered perception of the body, dependency, desire for social contact and proximity to death.

2.3.2 Sedation

The change in sedation practice

Traditionally, medication-induced coma has been regarded "humane" for ICU patients and has been the goal of sedation therapy. However, leading to an increase in mortality, prolonged duration of ventilation and length of stay in the ICU, it is no longer recommended (Barr et al., 2013). The paradigm shift has therefore taken place since around the turn of the millennium with a trend towards lighter sedation (Wunsch & Kress, 2009). Compared to the rest of Europe, the Nordic countries have been more prone to adopt the shift (Egerod, Albarran, Ring, & Blackwood, 2013). The current goal of sedation is a patient who purposely follows commands without agitation, although a few patient groups still require deep sedation (Barr et al., 2013). Non-benzodiazepines (propofol or dexmedetomidine) are preferred over benzodiazepines (midazolam) when sedation is needed. Despite the published overall benefits of ICU sedation minimizing strategies, the recommended practice was at the onset of this study not widespread and the use was emphasized in clinical practice guidelines (ibid). Routine monitoring of sedation may improve patient outcome and standardized sedation-assessment scales are recommended (Barr et al., 2013). Validated sedation scales provide clinicians with a common language as it describes the degree of sedation or arousal within defined categories. Furthermore, it may measure changes in sedation level over time, guide administration of sedatives and be useful in sedation protocols (De Jonghe et al., 2000; Jacobi et al., 2002). Preferred sedation- assessment scales according to the clinical guidelines include the Sedation-Agitation Scale (SAS) and the Richmond Agitation–Sedation Scale (RASS). In this study, RASS was routinely used for assessment of sedation. Assessment-driven protocol-based approaches for both pain and sedation management in the critically ill have been recommended, although not strongly, to avoid complications related to over-sedation (Barr et al., 2013).

Protocol use/analgosedation

The analgosedation protocol implemented as part of this study is in line with the current recommendations. The aim is to assess and treat pain first and provide sedatives only when necessary to help patients to rest, and to reduce anxiety and agitation (Devabhakthuni et al., 2012). This strategy has proven feasible to reduce duration of mechanical ventilation, reduce ventilator-associated pneumonia, reduce pain and shorten length of stay in ICU when compared to conventional hypnotic-sedative approaches (Barr et al., 2013; Devabhakthuni et al., 2012; Egerod, Jensen, Herling, & Welling, 2010; Rozendaal et al., 2009; Strøm, Martinussen, & Toft, 2010). Protocols that target pain and aims at lower doses of sedation, i.e. where analgesics are provided before a sedative (analgosedation) have been implemented (Brook et al., 1999; Egerod et al., 2010; Wøien et al., 2012). Even strategies of no-sedation i.e., where analgesics are provided instead of sedatives (analgesia-based sedation) have been used and promoted as beneficial to patient outcome (Strøm et al., 2010), however not without controversies (Brochard, 2010). Protocols have shown also to help members of the ICU team to communicate about management goals and effectiveness of pain and sedation strategies (Brattebø et al., 2002; Brook et al., 1999; Girard et al., 2008). However, individually adapted interventions are often required, and nurses and physicians are challenged in making a distinction between analgesic and sedative needs (Brochard, 2010; Egerod, 2002). Moreover, low adherence to protocols and guideline recommendations has been reported (Mehta et al., 2009; Rycroft-Malone, Fontenla, Seers, & Bick, 2009; Sneyers et al., 2014). Concerns have been reported about patient comfort and safety when treated with sedation-minimizing strategies (Sneyers et al., 2014), and about protocols hampering clinical judgment (Wøien & Bjørk, 2013). Although analgosedation has been shown to result in recall of unpleasant events and delusional memories (Rundshagen, Schnabel, Wegner, & am Esch, 2002), and no-sedation was found to increase agitated delirium (Strøm, 2010), we need more knowledge about how patients are affected by these sedation-minimizing strategies.

Patients' memories from ICU stay

Memories from the ICU differ and have been categorized as factual, delusional or memories of feelings (Jones et al., 2000a), pleasant or unpleasant (Samuelson, 2011b). Patients may however have little or no recall from their ICU stay, sometimes resulting in frustrating gaps in their memory (Capuzzo et al., 2001; Ethier et al., 2011; Granja et al., 2008; Weinert & Sprenkle, 2008). Before the onset of our study, the incidence of factual memories, i.e. recall of real events was reported to highly vary, from 17–83% in earlier studies (Roberts, Rickard, Rajbhandari, & Reynolds, 2007; Rotondi et al., 2002; Rundshagen et al., 2002). Delusional memories, defined as unreal experiences (Jones et al., 2000a) comprising hallucinations, nightmares, dreams and paranoia have been reported in 20-73 % of patients (Guttormson, 2014; Jones, Griffiths, Humphris, & Skirrow, 2001; Ringdal, Johansson, Lundberg, & Bergbom, 2006; Samuelson, 2011b). Emotional memories include recalling pain, anxiety, fear and other feelings also vary greatly in incidence from 9 - 88% (Capuzzo et al., 2001; Jones et al., 2000a; Samuelson, Lundberg, & Fridlund, 2006). Unpleasant memories from the ICU stay may persist over time (Karlsson & Forsberg, 2008; Løf, Berggren, & AhlStrøm, 2008; Roberts, Rickard, Rajbhandari, & Reynolds, 2006; Samuelson, 2011b; Storli, Lindseth, & Asplund, 2008), but patients may also have pleasant recollections (Hofhuis et al., 2008; Samuelson, 2011b; Storli et al., 2008).

Along with the change in sedation practice with patients being expected to become increasingly responsive, more studies have explicitly focused on ICU-patients' memories or recall in relation to sedation strategies or sedation level (Guttormson, 2011; Samuelson et al., 2006; Samuelson, Lundberg, & Fridlund, 2007; Treggiari et al., 2009; Weinert & Sprenkle, 2008). Ethier et al. (2011) found no difference in patient recall when comparing the use of a sedation protocol and a sedation protocol with daily sedative interruptions. Regarding sedation level, deep sedation has been associated with experiencing amnesia and delusional memories and light sedation with a greater risk of perceiving experiences as stressful and bothersome (Samuelson et al. 2006, 2007). One study, however, did not find associations between sedation level and memories (Weinert & Sprenkle, 2008). Although the relationship between memories and sedation practices or sedation levels is inconclusive, they are important given the current recommendations of light or minimal sedation.

In summary, at the onset of our study, the association between levels of sedation and adverse post-ICU psychological outcomes was unclear, but the improvement in clinical outcome in patients after ICU stay appeared to outweigh the risks of light levels of sedation (Barr et al., 2013).

Memories affecting patients after ICU stay

Memories of ICU treatment have been shown to influence on the development of post-intensive care syndrome (PICS). This syndrome is characterized by "new or worsening impairments in physical, cognitive or mental health status arising after a critical illness and persisting beyond acute care hospitalization" (Needham et al., 2012, p. 502). Delusional and emotional memories have been associated with the development of symptoms of anxiety, depression and posttraumatic stress after ICU discharge (Davydow, Gifford, Desai, Needham, & Bienvenu, 2008; Jones et al., 2001; Kiekkas, Theodorakopoulou, Spyratos, & Baltopoulos, 2010; Ringdal, Plos, Lundberg, Johansson, & Bergbom, 2009; Ringdal et al., 2010). The role of factual memories is however unclear. They have been associated with distress and poorer psychological outcome in some studies (Myhren, Ekeberg, Tøien, Karlsson, & Stokland, 2010; Rattray, Crocker, Jones, & Connaghan, 2010; Samuelson et al., 2007), but in one study, even relatively unpleasant memories of real events during critical illness were found to give some protection from anxiety and development of symptoms of PTSD (Jones et al., 2001). Moreover, along with frightening in-ICU experiences, deep sedation, a high level of sedation with benzodiazepines, and longer duration of sedation have been identified among the risk factors for developing PTSD (Davydow et al., 2008; Jones et al., 2007; Wade, Hardy, Howell, & Mythen, 2013).

Patient experiences of wakefulness

Patients' preferences according to wakefulness and sedation differ. In a qualitative study, Karlsson et al. (2012a) explored patients' unpleasant memories from being awake on mechanical ventilation during ICU stay. They found breathing difficulties, discomfort, pain and suffering related to the endotracheal tube and the tracheostomy. Despite the stressful experiences reported, eight out of twelve respondents in their study would have preferred to be conscious given the choice. They appreciated the positive effects of being aware of what was going on around them and considered consciousness to be preferable to their body function. Guttormson (2011) interviewed patients post ICU on their recall and evaluation of mechanical ventilation and the impact of sedation using the ICU Memory Tool. Of 31 respondents who recalled their ICU stay, more than half of them would not have wished to remember more, indicating they would not want to be more awake. However, one should keep in mind that patients have been asked merely on the basis of what they perceive as the more uncomfortable state, regardless of the medical reasons for promoting light sedation and the possible negative outcome of deep sedation.

Relationship between sedation, delirium and psychological outcome

Delirium, a syndrome characterized by an altered level of consciousness, fluctuation in mental status, inattention or disorganized thinking is prevalent in up to 80 % of mechanically ventilated patients in the ICU (Pandharipande et al., 2008). Delirium is associated with increased mortality in ICU patients, increased hospital and ICU-length of stay (Ely et al., 2004) and post-ICU cognitive impairment (Pandharipande et al., 2013). No direct correlation has been found between delirium and the development of PTSD after ICU-stay (Svenningsen, 2013). Regarding sedation, the provision of benzodiazepines has been associated with the development of delirium, but data are conflicting or inconclusive regarding the use of opioids and propofol (Barr et al., 2013). However, fluctuating levels of consciousness due to sedation has been shown to increase delirium in ICU patients (Svenningsen et al., 2013). Delirium is under-estimated and routine monitoring with valid assessment tools such as the Confusion-Assessment Method for Intensive Care Units (CAM-ICU) and the Intensive Care Delirium Screening Checklist (ICDSC) is recommended (Barr et al., 2013; Ely et al., 2001). According to clinical practice guidelines, prevention of delirium pertains to identifying risk factors, avoiding routine benzodiazepines, promote sleep and exercise, and mobilize patients early. Treatment should include reorientation and familiarizing to the surroundings. When sedation is needed, infusion of dexmedetomidine is preferred (Barr et al., 2013).

2.3.3 Nurses caring for patients being more awake

Decision-making in the ICU is complex because of the patients' critical illness and rapidly changing health status (Bucknall, 2000, 2003), subsequently resulting in the need for simultaneous dealing with aspects of assessment, physiology, and treatment (Aitken, Marshall, Elliott, & McKinley, 2009). Both critical illness, intubation and sedation has traditionally restricted nurse-patient communication. The introduction of sedation-minimizing strategies, allowing even critically ill patients to be more awake, place new demands on critical care nurses. Along with the patients' increased ability to communicate their needs with lighter sedation, nurses' workload is reported higher (Mehta et al., 2012). Assessment tools are innate components in protocols and strategies promoting lighter or no sedation, and the use of tools to guide assessment and interventions regarding pain, sedation and confusion has been found to support nurses' decision-making and to improve the quality of pain control and sedation (Wøien & Bjørk, 2013). Observations aiming to describe and interpret how critical care nurses in practice deal with pain and sedation during the use of protocols or strategies corresponding to current recommendations, may contribute to more knowledge about decision-making in the ICU.

2.3.4 Summary

Ensuring patient comfort in the ICU is a concurrent goal of care, which may sometimes conflict with other clinical management goals regarding organ stability (Griffiths et al., 2007). Even though systematic assessment and management of pain have been emphasized for more than two decades, pain and discomfort are still reported as main sources of patient distress, with moderate to severe pain being reported by more than 50% of patients in the ICU (Chanques et al., 2007, Payen et al., 2007). The introduction of assessment tools both for pain and sedation levels and the change in administration routines may be regarded as a precursor to the analgosedation approach central to this study. The approach implies treating pain first and providing sedation only when necessary to alleviate anxiety or agitation (Devabhaktuni et al., 2012). Analgosedation as a strategy corresponds well to current international guidelines for the management of pain, agitation and delirium (PAD), which recommend lighter sedation and focused pain treatment in ICU-patients to improve clinical outcomes (Barr et al., 2013). Deep sedation, although regarded humane for many patients, has shown to prolong mechanical ventilation and ICU stay, and increase mortality (Shehabi et al., 2012; Tanaka et al., 2014). When patients are awake or lightly sedated, they are more able to respond, report pain and mobilize.

3 AIMS AND RESEARCH QUESTIONS

The research processes in qualitative methodology seek in-depth understanding through the emphasis on the whole, rather than on specific parts of a phenomenon (Polit & Beck, 2017). Although focusing on pain, other discomforts and wakefulness, we were in this study open to every aspect of the participants' experiences, hereby acknowledging the complexity of both the illness experience and the nursing processes relating to these. The study, according to the qualitative methodology is explorative and not hypothesis driven. Despite being hypothesis generating rather than hypothesis testing (ibid), we believe assumptions or anticipations are inevitable parts of a research project designed by clinicians. We assume that being treated according to a protocol aiming at assessing and treating pain first and providing sedatives only when necessary, may increase the patients' ability of expressing their needs, also concerning pain. Concurrently, the nurses may be less challenged in interpreting needs if patients are able to better express these when more awake. Pain treatment may therefore be expected to be more successful. However, without exploring this, we will not know.

Quality decision-making is an important component of good clinical practice (Higgs, 2008). To understand and to improve clinical decision–making it is necessary to understand both the clinical problem and how contextual factors influence on the decisison-making. A study combining observations and interviews with nurses and follow-up interviews with patients shortly after discharge from the ICU, and again after three months will provide new insight into the issue of pain and wakefulness in the ICU. In the following, the specific aims and research questions pertaining to each sub-study will be presented.

3.1 Sub-study I

Patients in the ICU experience pain as one of the major stressors. Introducing a strategy aiming at treating pain first and minimizing sedation might affect the experience of patients in different ways. The aim of sub-study I was therefore *to explore patients' experience of pain, other discomforts and wakefulness during critical illness when treated using the analgosedation approach, and further to explore how patients handled these experiences after ICU discharge.* The research questions were:

When treated using the analgosedation approach

- How do ICU patients describe their experiences of pain, other discomforts, and wakefulness?
- How do patients handle these experiences after discharge from ICU?

3.2 Sub-study II

In sub-study I we found through patient interviews at two different time points after discharge that the analgosedation approach appeared to provide good pain management in ICU. Despite good pain relief, other discomforts resulted in the patients experiencing the ICU as a traumatic part of their illness trajectory. How critical care nurses manage pain and other discomforts will impact on the experience of patients. Thus, the aim of sub-study II was *to explore the characteristics of deliberation and enactment of nurses in relation to pain and other discomforts in critically ill patients after the implementation of an analgosedation protocol.*

3.3 Sub-study III

Discomforts other than pain dominated the experiences of patients in sub-study I, and in sub-study II, the nurses appeared unable to respond to this discomfort in the same systematic manner as they responded to pain. This evoked our interest in further exploring the phenomenon of discomfort. According to the emergent design of the study and based on the findings from the two sub-studies, the aim of sub-study III became; *to explore the complex and persistent, as yet ill-defined phenomenon of discomfort in intensive care.* A secondary analysis of both patient and nurse data was conducted and Kolcaba's Comfort theory was applied as a theoretical perspective. The following research questions were developed:

- What are the characteristic features of discomfort in patients in intensive care derived from patients' descriptions, and how can we use these features to improve our understanding of and response to different types of discomfort?
- How do critical care nurses deliberate about discomfort and intervene to enhance comfort in their patients?
- How can discomfort in intensive care be elucidated using concepts from Kolcaba's Comfort Theory?

4 THEORETICAL PERSPECTIVES

4.1 Kolcaba's Comfort Theory

Comfort Theory is a framework for nursing practice and can be applied to individual practice, units and systems (Kolcaba, 2003). It has been applied to a diversity of patient populations and clinical settings, the perianesthesia or perioperative setting being the closest to the ICU-setting and critically ill patients. Elements in this middle range theory in nursing, have partly guided our conceptual understanding of pain and discomfort in this study. According to Kolcaba (1997, 2003), discomfort is a larger umbrella compared to pain, indicating that pain is included in the discomforts. Pain is regarded as multidimensional, and also pain that has a physical origin is influenced by psychospiritual, sociocultural and environmental factors (ibid). Comfort measures may be applied to alleviate all kinds of discomfort. Antecedents of comfort measures are unmet comfort needs, brought about by pain or other discomforts.

In Comfort Theory, central concepts pertaining to comfort are organized in terms of three types and four contexts of comfort in a taxonomic structure (Table 1). In addition, three types of comfort measures are suggested. The three types of comfort are *relief, ease*, and *transcendence*. According to Kolcaba (1991, 2003), other nursing theories inspired the descriptions of the three distinct types of comfort. Relief was derived from the work of Orlando, ease from Henderson (1961 as cited in Kolcaba, 2003) while transcendence was adopted from Paterson and Zderad (1976, as cited in Kolcaba, 2003). Kolcaba explains the adoption of the terms. *Relief*, as explained by Kolcaba (2003, p. 66-67) in Orlando's interaction theory, represented a patient state of having a comfort need met by a nursing intervention, indicating an effective nurse-patient relationship. This is how relief is presented in Comfort theory. In an intensive care setting, an example of this type of comfort may be to be relieved of pain by a nurse administering an extra bolus of analgesics in response to a behavioural expression of pain, such as grimacing. Henderson described the basic physiological and psychological functions that needed to be addressed in patients to maintain homeostasis. The comfort type or state of *ease,* as Kolcaba derives its use from Henderson's theory, pertains to the patients being calm and content. ICU- patients may for example experience ease in situations when they are comfortable in bed and nurses ensure their ease by thoughtfully repositioning them every 3 or 4 hours. Paterson and Zderad, according to Kolcaba, offered an existential characterization of the comfort term, representing "the freedom to be and become" (Kolcaba, 2003, p. 67) and Kolcaba chose the term “transcendence” after discussion with other theorists arguing that this term was already in use in nursing. The comfort state of *transcendence,* as presented by Kolcaba (2003) occurs when a person rises above their challenges or discomforts, often assisted by the nurse through motivation or facilitation. In the context of intensive care, the comfort type of transcendence may for example apply to when a patient is accepting an intense, but short-lasting pain when being mobilized out of bed, supported and informed by the nurse about the safety of moving and the importance of mobilization to rehabilitate.

The four contexts in which comfort is experienced are *physical, psychospiritual, environmental*, and *sociocultural.* The *physical* context concerns bodily sensations and homeostatic mechanisms. Examples of this may refer to pain, homeostatic imbalance, poor positioning, breathing difficulties, itching, feeling too hot or too cold, nausea and discomfort from tubes and lines (Wilson & Kolcaba, 2004). The *psychospiritual* context pertains to the internal awareness of self, for example anxiety, confusion, incomplete or negative information, threatening diagnoses, fear and prospect of change in health status (ibid). The *environmental* context refers to the external surroundings and conditions such as temperature, light, sound, colour, furniture, landscape and other factors in the background of human experience. The *sociocultural* context refers to interpersonal and societal relationships (Kolcaba & Fisher, 1996), comprising family, societal relationships such as finances, teaching, health care personnel, religious practices, traditions and rituals.

Table 1: Kolcaba’s Taxonomic structure for comfort (Kolcaba, 2003).
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Type of Comfort **Context of Comfort**	**Relief** The state of having a specific comfort need met	**Ease** The state of calm or contentment	**Transcendence** The state in which one can rise above problems or pain
Physical Pertaining to bodily sensation and functions			
Psychospiritual Pertaining to self- esteem, self-concept, sexuality, meaning in one’s life and one’s relationship to a higher order or being			
Environmental Pertaining to the external			
Sociocultural Pertaining to interpersonal, family, and societal relationships			

The three suggested types of comfort measures are *technical, coaching* and *comfort food for the soul*. *Technical* measures pertain to interventions designed to maintain homeostasis and manage pain. *Coaching* comprises interventions designed to relieve anxiety, provide reassurance and information, instil hope, listen and help to plan for recovery. *Comfort food for the soul* is special things, often unexpected by the patient, done by the nurse to make the patient feel cared for and strengthened in a personalized way. Non-technical interventions such as music, back-rub and guided imagery are included in this type of comfort measures (Kolcaba, 2003).

Although we were aware of Kolcaba's work at an early point, the Comfort theory should not be regarded as a theoretical framework as it has not guided the design of the study. However, taking in to account our results in articles I, and II, the Comfort theory may together with existing research in the field of patients' experiences of pain and wakefulness during intensive care and general theories of nursing represent a theoretical underpinning for the thesis.

4.2 Kim's model of nursing processes

According to Kim, nursing science should seek to obtain knowledge to increase "the proportion of rational and explained acts in the total repertoire of what the nurse does in nursing" (Kim, 2010). Knowledge about how nurses reason and act may contribute to improved clinical practice. The study of certain practice complexities may profit from the use of a structure into which data can be organized. Kim's model of nursing processes represents a framework using the terms *deliberation* and *enactment* to describe distinct phases in nursing practice (Figure 1). The phase of *deliberation* involves the phenomena of clinical decision-making including structuring of information, judgment about the meaning of the information and arriving at decisions about how to act. The phase of *enactment* explicitly relates to the nursing intervention or action. The two phases are not linear, nor independent of each other, but interactively connected in practice situations. However, they may analytically be separated for the purpose of understanding nurses' clinical practice (ibid). The connection between the two phases is affected by the nature of the practice setting. The critical care setting often requires immediate responses leaving no time for delay between the phases. The nursing processes of deliberation and enactment are complex as they involve different structural units.

The process of deliberation

The process of deliberation is a continuous process of developing an in-depth understanding of the patient as a unique individual within a specific health care situation. The units comprising of the nurse, the nursing goals and nursing means, the client and the context form a network of interrelated structures that affect the process of deliberation.

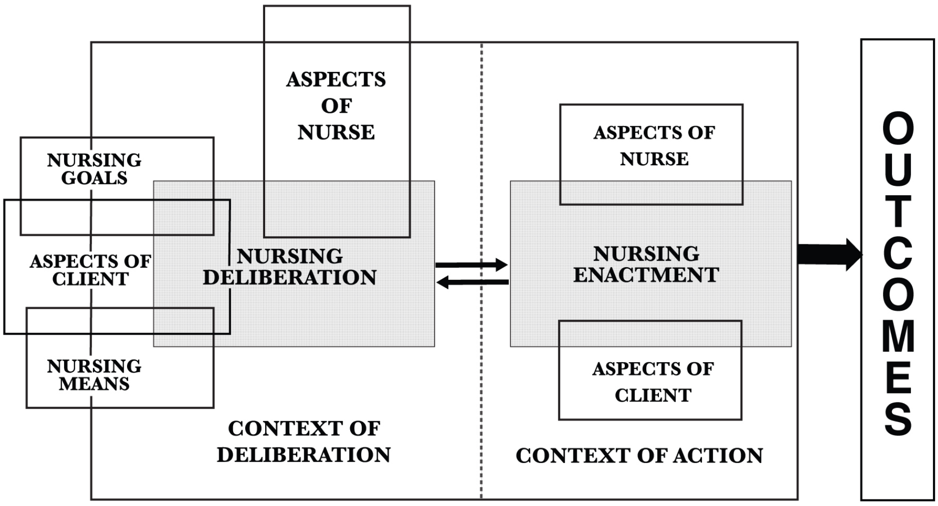

Figure 1: The nursing processes of deliberation and enactment (Kim, 2010). Reprinted with permission.

The aspects of the nurse refer to both general and specific aspects or elements that the nurse brings into the practice setting, such as personal frames of reference, motivation and commitment, values, knowledge and experience. The aspects of the client also encompass general and specific elements pertaining to the patient as an individual and a seeker of health care. The deliberation process of the nurse will be affected by how well she knows the patient. Nursing goals inherent in a clinical situation may be manifest or latent, general such as promotion of health or specific like airway patency. Goals may be defined by the client, by the nurse, or by others. The aspects of nursing means are also divided into general, applied to the patient as an individual, or specific to a health care problem or situation. Furthermore, the nursing means can be divided into those available in the public arena as validated strategies, also labelled “repertoire at large,” into “personal repertoire” describing means related to the individual nurse, or into conjectured means and approaches. These are brought into the process of deliberation juxtaposed with the elements of the structure of nursing goals aiming at interventions that makes practice coherent, meaningful, effective and sensible. The context of deliberation refers to the practice situation comprising of environmental factors, institutional structure, values and culture, nursing workload and other elements influencing on the deliberation process.

The process of enactment

The process of enactment is conditioned by the structures of the nurse, the client and the context of action. The aspect of the nurse, also in this phase referring to what the nurse brings in to the practice situation, and what makes the actions “good or bad, skilful or cumbersome, with passion or without, coordinated or disjointed, organized or disorganized, efficient or inefficient, ethical or unethical, and artful or mundane” (ibid, p.189). The aspects of the client accommodate the enactments of the nurse in the practice situation through how they are presented through behaviours and responses. Both what confines and what allows nursing actions constitute the context of enactment. Adaptation of the enactments to the context is necessary, regardless of the deliberation.

Kim’s model was chosen to guide the exploration of characteristics of ICU-nurses’ practice because it covers the whole nursing process of decision-making *and* interventions. The process of deliberation involves phenomena central to the second sub-study in this thesis such as clinical judgment, clinical decision-making and priority setting. Both the observations and the interviews are expected to reflect this process. The process of enactment relates to the observations of the nurses’ actions. We used the concepts and the processes of deliberation and enactment to obtain a broader picture of how nurses think and what they do in regard to critically ill patients’ pain and other discomforts and to guide the initial analysis of the nursing data.

According to Kim, the two phases need to be separated because actions do not fully or directly follow intentions and intentions do not sufficiently explain actions (Kim, 2010). Complexity is inherent in the nursing processes of deliberation and enactment in the intensive care where a multitude of decisions are concurrently made, evaluated and reconsidered to meet the needs in critically ill patients. Balancing analgesia and sedation according to goals defined by the patient, the nurse or other health care personnel may demonstrate this complexity. The application of a model focusing specifically on the complexity of these processes may assist in understanding the clinical practice in this study involving critically ill patients and highly competent health care personnel.

5 RESEARCH DESIGN AND METHODS

This chapter provides an overview of the methodological choices in the three sub-studies.

5.1 Research design

The purpose of this study was: 1) to increase the understanding of how patients experience pain and wakefulness during critical illness, in the context of a newly implemented analgosedation protocol, and 2) to study how the ICU nurses deliberated and enacted on their patients' pain and wakefulness. A qualitative, exploratory and descriptive design was chosen in this study because it allows insight into and understanding of a phenomenon (Brink & Wood, 1998). The design is considered appropriate when a topic under research is complex in its nature. To gain insight into different aspects of the phenomenon may provide a more complete understanding.

The qualitative research paradigm has its roots in the humanities with its theory of science belonging to the interpretive research tradition (Polit & Beck, 2017). The present study is descriptive, although adapting to methodological techniques from different qualitative traditions rather than being attached closely to one specific methodology. This is in line with the method of *Interpretive description* which has partly inspired the study (Thorne, 2016). Interpretive description was considered appropriate, as it draws on a variety of already known research techniques in the traditions of phenomenology, ethnography and grounded theory, and applies well to the different methods used in this study. The approach differs from other methodologies by constituting a disciplinary conceptual frame that can effectively apply qualitative evidence to practice while maintaining sufficient rigor to ensure academic credibility (Thorne, 2016, Polit & Beck, 2017). Interpretive description is developed to avoid the theoretical assumptions and lack of flexibility embedded in traditional methodologies. In this regard its primary concern lies in developing clinically valuable knowledge rather than adhering to rigid theoretical and process-oriented technical steps in the research process (Thorne, 2016). This methodological stance implies the rejection of *methodological orthodoxy* (Thorne, 1991) or the *tyranny of methods* (Sandelowski, 2000) describing the obligation felt by many researchers to seek epistemological credibility by referring to their work as narrative, phenomenological, ethnographic or as grounded theory while they in fact depict no more than overtones of these methodologies. More than the social sciences, nursing is an applied science and hence pragmatism to a larger extent may be defended. In pragmatism, “what works” or what seems appropriate for the aims of the study is the primary requirement for choosing a methodology (Creswell, 2013). According to Sandelowski (2000), describing the overtones from other methods is preferred to inappropriately naming or implementing those methods. This is in line with how this study was planned and conducted.

The qualitative, exploratory design is emergent, allowing a flexible research process that takes into account findings that emerge during the study (Lincoln & Guba, 1985). When this study was planned, the focus was primarily on patients’ experiences of pain and wakefulness, and the nurses’ management of pain and sedation in the ICU following the implementation of the analgosedation protocol. During the course of the study, there was a shift towards focusing on discomfort rather than pain and wakefulness, both however, strongly related to the experience of discomfort. The shift was based on our findings early in the course, in sub-study I, where the patients reported pain to be of minor concern during and after ICU stay, but discomforts other than pain were highly prominent. In sub-study II, the management of this discomfort, compared to the management of pain became the focus. The results of the two studies indicated that discomfort other than pain appeared ill defined, making it difficult for nurses to assess and appropriately intervene on. Insights emerging from the two studies – in particular the widespread discomfort other than pain revealed by using the qualitative approach – called for a more in-depth exploration of the phenomenon of discomfort. Therefore, in sub-study III we separated the descriptions of pain from other discomforts and re-examined data from both patients and nurses, to search for a deeper understanding of discomfort in intensive care.

An assumption underlying this study, which builds on a naturalistic paradigm (Lincoln & Guba, 1985; Polit & Beck 2017), is that reality is constructed individually, is subjective, and can be interpreted in multiple ways. Texts resulting from interviews and observations hence may have several meanings. In this paradigm, the phenomenon is studied in its natural context and the findings of the study are generated through interaction between the researcher and the participants (ibid). The role of the researcher is further elaborated on in chapter 7.2 Methodological considerations.

5.2 The study

The study was part of a larger study aimed to study the effectiveness of pain relief and improvement in patient level of sedation by comparing a systematic approach care protocol, and this protocol expanded by the addition of an analgosedation approach in the ICU. In a longitudinal study, pain, sedation, delirium and mobilization in ICU were compared at three time-points between 2009 and 2015 (Wøien, 2020). Data from patients' complete ICU stays, encompassing three separate periods of 4–6 months was gathered. The primary outcome was adherence to the current protocol including assessment and documentation of patients' level of pain, sedation and prevalence of delirium at least every 8 hours, early mobilization, and titration towards a light level of sedation. A follow up study comprising a qualitative arm was designed for the third time-point and represents as this thesis. The timeline of the study is shown in figure 2. The present study is included in the third circle.

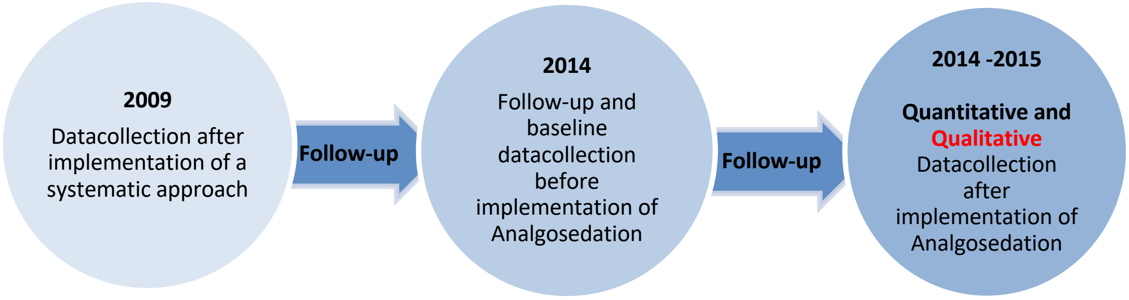

Figure 2: The study timeline of the main study including the present study

The present study constitutes the qualitative arm of the follow up study and was designed to explore both patient experiences and nurses' management of pain and wakefulness after the implementation of the protocol. The analgosedation protocol, as the starting point of this last part of the main study, is considered to constitute part of the *setting* in the present study. The study comprises three sub-studies presented in table 2.

5.3 Overview of the three sub-studies

Table 2: Overview of the method, source and analytic approach in the papers in the thesis.

Paper	Method	Data source	Analytic approach
I	Interviews with patients at two time-points after ICU -discharge	Audio recordings from 28 interviews with 18 patients discharged from the ICU. 18 interviews conducted within the first days after discharge and interviews with 10 of these patients after approximately 3 months	Systematic text condensation (Malterud 2012)
II	Participant observations followed by interviews	Field notes from 16 participant observations and audio recordings from subsequent interviews with each participant; 13 experienced critical care nurses	Thematic Content analysis (Braun & Clarke 2006, Greene & Thorogood, 2013)
III	Secondary analysis of the two datasets from sub-study I and II	Transcripts from interviews with both patients and nurses and field-notes from observations	Abductive qualitative content analysis (inductive & deductive approach). (Graneheim & Lundman 2004, Graneheim, Lindgren, & Lundman 2017)

5.4 Setting

The context of the study was an 11-bed highly specialized, medical-surgical ICU at a university hospital in Norway. The ICU has national responsibilities for treating complex patient cases, and patients are often transferred to other ICU's while still on mechanical ventilation. The unit has approximately 100 nurses employed, nearly all of them with further education as critical care nurses, working closely with the intensivists and anaesthesiologist in charge. Rooms in the unit are either single-rooms or rooms for three beds separated with curtains that are usually closed only during procedures and visiting hours. Nurse-patient ratio is 1:1 on all shifts with the availability of an extra nurse when required depending on the condition of the patient. Besides the nurses and attending physicians, consulting physiotherapists are the only healthcare staff present at bedside. This implies that all care and prescribed treatment during the study was provided by the critical care nurses. Physical restraints were not used.

Prior to the present study, a protocol for analgosedation was implemented and all nurses and physicians took part in educational sessions where it was presented and discussed. Being a university ICU, both personnel and patients are frequently involved in ongoing research projects. Following the implementation of a systematic approach to facilitate adherence to international guidelines for pain and sedation in 2009, the nurses were already familiar with assessing pain, agitation and delirium in their patients using validated tools.

5.4.1 The analgosedation protocol

The analgosedation approach aimed at assessing and treating pain first and providing sedation only when necessary to obtain a calm and cooperative patient. The protocol directed for assessment and documentation of pain, sedation and confusion at least once per shift (x 3/d), provided suggestions for pharmacological treatment and strongly advised for early mobilization.

For pain treatment, the main opioid recommended for continuous infusion was fentanyl. For procedural pain, bolus doses from the fentanyl infusion, ketobemidone and alfentanil were suggested. Acetaminophen (Paracetamol), 1 g x 4 was provided unless contraindicated. For sedation, propofol infusion and bolus were first options, followed by continuous infusion of dexmedetomidine. The provision of benzodiazepines (Midazolam) were mainly restricted to neurosurgical patients with high intracranial pressure. However, some diagnose-specific recommendations were provided as the protocol encompassed both medical and surgical patients including specialties of neurosurgery, haematology and transplantation. The nurses were entitled to titrate prescribed doses of analgesics and sedatives within a range set by the physicians to achieve individually set daily goals. The development of the protocol was greatly influenced by the systematic approach-protocol which was developed in 2009 (Wøien et al., 2012) and the clinical practice guidelines published in 2013 (Barr et al., 2013).

5.4.2 The assessment tools

The assessment tools that were part of the implemented protocol had been validated in international studies and translated into Norwegian. In patients able to self-report pain, the NRS was already in use. For patients unable to self-report pain, the CPOT was translated to Norwegian as part of the project (Appendix 2). It was validated (Storsveen & Hall-Lord, 2016) before it was introduced in the ICU, and implemented in the analgosedation protocol.

The assessment tools RASS for sedation assessment and the CAM-ICU for delirium monitoring, were already in routine use at the onset of this study (Wøien, Værøy, Aamodt, & Bjørk, 2014).

5.5 Participants

Eighteen patients and thirteen critical care nurses participated in the study. Samples used in qualitative studies are relatively small, but information-rich, suitable to reveal different aspects of a phenomenon under study (Polit & Beck, 2012). The qualitative, explorative design assumed a purposive sampling. This type of sampling involves identifying and selecting participants who will mostly benefit the study (ibid), i.e. who are especially knowledgeable about or experienced with a phenomenon of interest. Criterion sampling as one type of purposeful sampling was chosen. In this strategy, cases that meet some predetermined criterion of importance are selected (Patton, 2002).

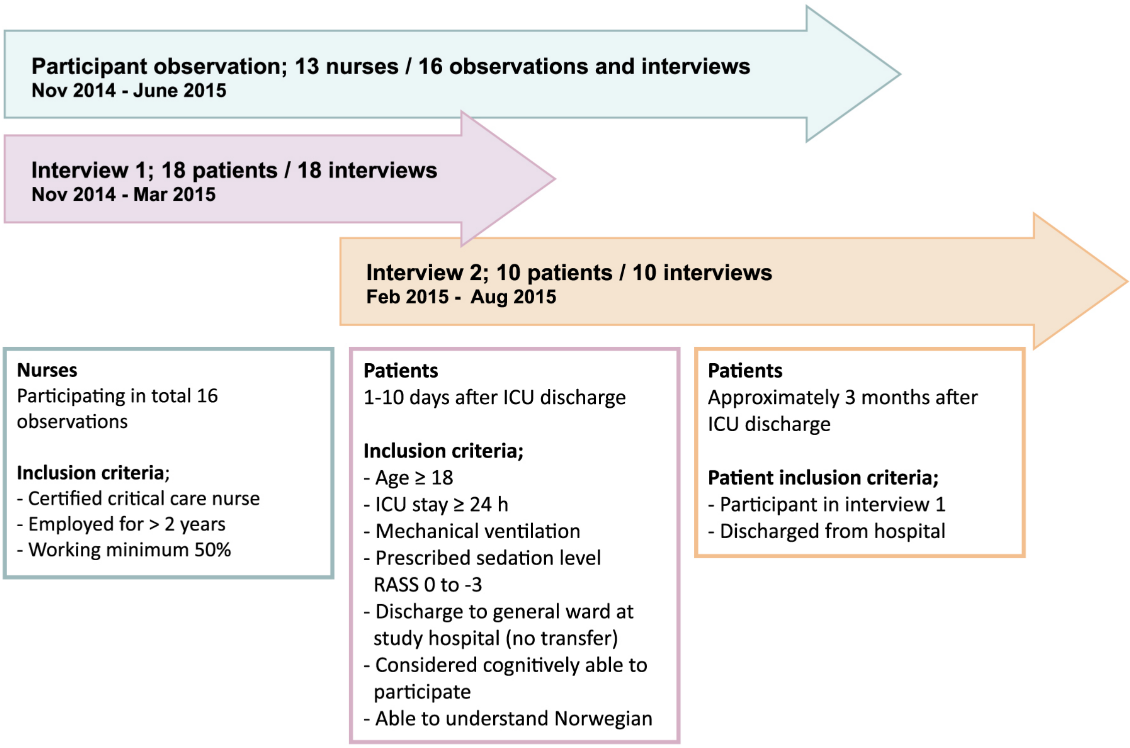

Figure 3: Overview of the studies' inclusion criteria, study time-line and method for generation of data.

5.5.1 Patients

Inclusion and exclusion criteria

All patients to be included were enrolled in the main study and treated according to the analgosedation protocol. They were adults, had been admitted to ICU ≥ 24 hours, were in need of mechanical ventilation on admission, and had a prescribed sedation level (RASS) from 0 to -3, which implies a state of being responsive to verbal stimuli (Figure 3). Patients were *excluded* if they were unable to communicate in Norwegian, had an acute severe intracranial or spinal neurological disorder or were in need of muscle relaxation at the time of inclusion. Finally, for practical reasons and for preventing participants from mixing experiences from different treatment sites, patients transferred to intensive care units in other hospitals were excluded.

Participants

Of the 61 patients included at the third time-point in the main study, 18 were consecutively included in the present study. Figure 4 shows the inclusion and dropouts from the first interview to the second. Patient characteristics are shown in table 3. The majority of the patients had a severe diagnosis of haematological cancer, sepsis, or complications from major surgery. Mean age was 46, mean length of stay in the ICU was 10 days, and mean SAPS 40,2.

Table 3: Patient characteristics

Patient	Gender	Age	Medical Surgical	ICU LOS* Days	Interview I on day x after discharge	Interview II 3-4 months after discharge	SAPS II** score
1	M	46	S	3	2	x	52
2	F	53	S	11	9		44
3	M	27	M	14	1		34
4	F	60	S	14	1	x	37
5	M	58	M	6	1	x	27
6	F	58	S	13	1	x	37
7	F	20	M	3	2		23
8	M	73	M	3	2		46
9	M	22	M	2	1		32
10	M	78	S	48	2	x	65
11	F	65	S	3	2		47
12	F	54	S	9	9	x	57
13	F	71	S	7	1	x	35
14	F	57	S	1	4		36
15	F	40	M	5	2	x	42
16	F	18	S	3	4	x	29
17	M	26	S	18	5	x	34
18	F	29	M	19	2		48

* ICU-LOS: Intensive care unit, Length of Stay
** SAPS: Simplified Acute Physiology Score II

Recruitment

Enrolment of patients from the main study took place at, or after, discharge from the ICU to a general ward. When considered appropriate, the patients were briefly informed about the study by a nurse or a research nurse assistant. Close contact was kept with the nurse in charge on the general wards the following days. When considered physically and cognitively able to participate in an interview lasting approximately half an hour, the patient was asked whether he or she would allow the researcher to inform about the study. Information was given and the interview was conducted after written consent had been obtained (Appendix 7). Due to the patient’s clinical condition at the appointed time, some interviews were postponed, but all patients who consented were interviewed. Using this strategy, the patients were free to decline both the information and the subsequent inquiry about participation. The interviews took place within ten days after discharge, but the majority within the first two days (Table 3). A re-consent was always sought prior to the interview. Recruitment of participants for the two interviews are shown in figure 4.

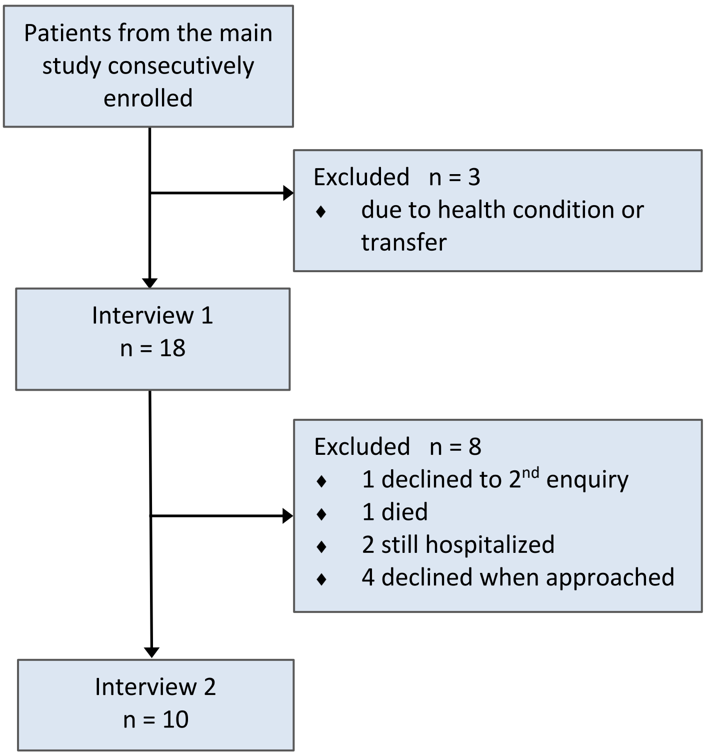

Figure 4: Recruitment and exclusions for the first and second interviews

For the second interview, a preliminary request was made during the first interview. An information letter was sent to the home address, preparing the patients for a telephone inquiry within a couple of days.

For the second interview, 8-10 participants was considered an appropriate number. Therefore, no fixed sample size was planned for the first interview, but the number was guided by the eligibility of patients for the second sample, i.e. the in-depth interviews. According to Malterud et al., saturation of data in exploratory studies is not a realistic goal but may be guided by the concept of informational power (Malterud, Siersma, & Guassora, 2015). This implies seeking to include enough participants to generate sufficient data to meet the objective of the study. According to this, the resulting sample in the second interview was considered adequate. The stepwise inclusion moreover allowed for continued inclusion of participants if the data generated were not considered sufficient.

5.5.2 Nurses

Recruitment

Certified critical-care nurses who had been employed in the study unit for a minimum of two years and worked 50% or more, were recruited. The inclusion criteria of employment and experience were used to ensure a reflection of the pain and sedation management in the study unit where the analgosedation protocol had been implemented. An invitation to participate was distributed along with information about the study in personal mailboxes to all eligible nurses (about 80) (Appendix 9). They were asked to return the form, accepting or declining to participate in an observation session of approximately two hours followed by an interview. Twenty-five female and two male nurses consented by returning the reply form, and six nurses made an explicit decline. The observations were determined by combining the patients and nurses who had consented to participation.

Participants

Thirteen of the nurses, all female, were consecutively included for participation on shifts where observation was scheduled and the nurses were assigned to patients who had consented to the observation, either themselves or by proxy. After 16 observations, data were considered sufficient to meet the aim of the study. The participating nurses were aged between 39 and 59, with a mean age of 47. They had between 3 and 27 years of intensive care experience, mean was 19 years.

5.6 Data generation

All interviews and observations were performed by the Phd-student. Figure 3 shows the data generation time.

5.6.1 Patient interviews

The ICU patients were interviewed using semi-structured qualitative interviews (Kvale & Brinkmann, 2009). Data on memories is recommended to be collected close to ICU discharge (Nouwen, Klijn, van den Broek, & Slooter, 2012) and the choice of time-points for interviews was made on the basis of earlier studies. An interview within one or two weeks after discharge is thought to reflect and reveal immediate reactions to the ICU stay and has appeared to be of value in previous studies investigating memories and experiences (Jones et al., 2001; Samuelson et al., 2006). However, early interviews may be influenced by the illness condition of the patient, and the fact that the patients are still in hospital may prevent them from speaking freely of negative or stressful experiences. The patients may also have problems in distinguishing whether their memories are from the ICU or from the ward. No acknowledged ideal time point for further follow-up exists, but 3 months after ICU discharge has been suggested and chosen in several follow-up-studies (Nouwen et al., 2012; Myhren et al., 2010; Jones et al., 2007). At 3 months participants are expected to have gained a certain distance to the hospitalization and are possibly more comfortable to talk in-depth about their experiences (Granberg et al., 1998). Repeated interviews further provide the opportunity to follow up and confirm evolving interpretations from earlier generated data.

The first interviews

Eighteen semi-structured patient interviews were conducted on different general wards at the study hospital between day 1-9 after the discharge from ICU, although most of them before day 4. The interviews lasted between 10 and 56 minutes (mean 27) according to the condition of the patient and how eager they were to talk. The ICU Memory Tool (ICUMT) (Jones, Humphris, & Griffiths 2000b), was translated into Norwegian (Appendix 3) and was used to structure the interview. The performance of the tool was pilot-tested on a former ICU patient as part of the translation process. The ICUMT is a 14-item questionnaire developed for examining patients' recall of factual events, feelings and delusional memories and had been used both to guide interviews in other studies and for self-reporting memories (Burry et al., 2015; Ringdal et al., 2006). To increase its usefulness in the study, more questions with regard to pain, wakefulness, mobilization and positive memories were added. The tool was however considered a thematic frame rather than a structured guide. The opening question "what can you remember from the ICU?" invited the patients to reflect and to emphasize on experiences important to them. The tool was therefore never intended to generate quantitative data, but to constitute a support to participants who suffered from lack of attention or lack of recall, were weak or short of breath. This appeared to be useful as only about half of the patients were able to provide rich descriptions from their stay despite the approval of the ward nurse. Two patients initially described a total lack of memories from the ICU stay.

During the interview, follow-up questions were used to clarify and by using the checklist that is part of the ICUMT, a short summary was made towards the end of the interview. In addition to confirming the interviewer's perception of the patients' story, the sum-up frequently generated more reflections from the patient about what they had experienced. The patients were in their rooms or in adjacent rooms on the ward if they were mobile or if they shared rooms with other patients. Three patients had a close relative visiting during parts of the interview. If the relatives had any comments, these were not used as data, but may have influenced the statements made by the patients.

The second interviews

Between 3 and 4 months after discharge from ICU, 10 more in-depth interviews were conducted. The time span varied according to patients' preferences and also to their discharge date from the hospital. The interviews lasted between 30 and 63 minutes (mean 49). To facilitate their participation, the patients were left to decide the location for the interview. Four interviews took place at the hospital in connection with a readmission or follow-up, four in patients' homes, one at a patient's workplace and one by "skype" because of a long-term stay abroad.

A thematic interview-guide was used (Appendix 4), with open-ended questions based on findings from previous studies and on data from the first interviews (Thorne, 2016). The guide was adjusted during the course of the data collection to explore relevant input brought in by the interviewees. Between each interview, listening, transcribing and reading the text allowed new aspects to be explored in the upcoming interviews. This is in accordance with the emergent design of the study. Being interested also in change of memories over time, statements from the first interview were used in an explorative, non-confronting manner to allow for inconsistencies in recall.

Since all participants remembered well the first meeting with the researcher, building rapport in the interview situation was facilitated. The participants frequently expressed emotions, which may indicate that they were comfortable with the interview situation. Despite the focus of the interview, participants were allowed to express whatever came to their mind when reflecting upon their ICU stay or their overall illness trajectory. Hence, the second interviews were more conversational in nature than the first, but follow-up questions angled and sharpened the focus towards the purpose of the study. To consider the interviewer a co-constructor of interview data is in line with the understanding of knowledge production through qualitative interviewing (Fog, 2007; Kvale & Brinkmann, 2009).

5.6.2 Other patient data

Various medical data was collected as part of the main study of analgosedation implementation. Data extractions for the patients in the present study about diagnoses, severity of disease, length of stay, medication, measurements of pain, sedation and agitation level and delirium create a contextual frame for the study. Severity of disease in the patients was measured using Simplified Acute Physiology Score (SAPS II) (Le Gall, Lemeshow, & Saulnier, 1993). In general, patients were lightly sedated according to the RASS. Low maximum pain-scores were dominating when assessed with NRS and CPOT. Three patients had a positive delirium score at least once during their ICU stay according to CAM-ICU, fourteen had only negative scores and one patient was documented as impossible to assess at all attempts.

5.6.3 Participant observations and interviews with nurses

To study the deliberations and enactments of critical care nurses, both participant observations and interviews were conducted. Triangulation of methods implies combining methods for data collection with the aim of gaining a broader understanding of a phenomenon (Polit & Beck, 2012). Knowledge and experience may oftentimes be tacit and articulated only following reflection (Hilden & Middelthon, 2002). Observations may contribute to getting beyond what is conscious to the study subjects and may together with conversations or interviews be used as an approach to articulation of such tacit knowledge (ibid). Moreover, admitting the challenge in obtaining good data from the observations, the interviews following the observations were considered valuable in completing the picture of what was going on in the different situations.

Applying both methods allowed the exploration of structural aspects of the nurses' tasks as well as capturing the participants' perspectives and deliberations. In this study the triangulation of methods has been used to capture a more complete picture of the nursing practice of pain and sedation management. The nurses were given the opportunity to elaborate on and discuss the topics of pain and sedation management as well as the more specific challenges relating to the patient they currently were caring for. However, the triangulation of methods by means of utilizing the combination of characteristics to counteract the limitations of each method has been criticised as simplifying the relation between the methods (Atkinson & Coffey, 2003). Atkinson & Coffey claim that interview data should be treated and analysed as independent and distinct reports of acting and not as a contribution to completing inadequate observation data. Neither should observations be used to weigh out inaccuracies in interview data. However, admitting my lack of experience in participant observation, the following interviews were considered crucial to broaden and complete the observation data.

The use of the two methods may sometimes be used to look for contradictions between "what is said" and "what is done". This was not the aim of the triangulation in this study. The strict dualism between what people say and do may according to Atkinson & Coffey (2003) be avoided by acknowledging statements, recall and experiences as enactments having taken place.

Preparations

Access to the field and trust among the staff is essential in participant observation to obtain valid and credible data (Hammersley & Atkinson, 2007). I was not employed in the study unit, but in the same department. In addition to my supervisor who was an employee, I had good colleagues among the staff. Prior to the observations, I took part in planned educational sessions for smaller groups of the staff about the analgosedation protocol. This gave me the opportunity to present both my project and myself as an intensive care nurse and researcher to nearly the entire group of nurses and also many of the physicians.

Not to be mistaken for being at work as a nurse, I dressed in private clothes, but yet wore a white coat not to be mixed up with visiting relatives. On the coat I wore a visible research-nurse badge.

Participant observations

Participant observations was conducted in 16 situations involving 13 nurses caring for 12 different patients (Fangen, 2010; Green & Thorogood, 2014; Hammersley & Atkinson, 2007). Three nurses were observed twice, and two patients were cared for several times, but observations never included the same nurse and patient dyad. The observations lasted 60–150 min (mean 110), and an observation guide was used (Polit & Beck, 2012; Spradley, 1979) (Appendix 5). Naturalistic observation is the preferred method for collecting data on phenomena difficult to explain for individuals taking the phenomenon for granted, such as approaches to problem solving (Polit & Beck, 2012). Observations were scheduled to involve activities like hand-over and shift reports, initial patient assessment and planned procedures possibly requiring deliberations or enactments regarding pain or other discomforts. Non-pharmacological and pharmacological responses to patient cues of pain and other discomforts were specifically observed. The nurses were encouraged to care for patients as usual, but to think aloud when considered relevant to deliberation and enactment concerning pain and other discomforts. I was open-minded to how and to what extent the protocol was applied without putting an emphasis on its use. This was an attempt to avoid a normative influence on how the nurses practiced or talked about the management of pain and other discomfort.

Observation may be non-participant or participant on a continuum from completely covert to overt (Fangen, 2010; Hammersley & Atkinson, 2007). An "observer as participant" approach was adopted (Hammersley & Atkinson, 2007). In this approach, observation is the primary activity, but with some participation and interaction involved. My participation involved small tasks such as fetching things if the nurse was the only nurse in the room and couldn't leave the patient or keeping an eye on the patient if she had to go out for a second. Interactions involved asking informal questions with the purpose of clarifying and validating during observation, for instance the nurses' actions during administration of medication. Some social small talk took place when initiated by the patient or the participating nurse. Occasionally, observations were paused and resumed when appropriate to avoid participant fatigue if the patient was asleep and there was no nursing or patient activity.

Field notes

Short field notes were taken during observation (Polit & Beck, 2012; Fangen, 2010), especially to capture occurring dialogues. On several occasions, two nurses working together created a natural reflective dialogue to be noted. More extensive notes were written after each observation, and with two exceptions prior to the interview to reflect on the questions to ask. The field notes were divided into observational, theoretical (reflective) and methodological notes (Fangen, 2010).

Interviews

Semi-structured interviews were conducted as *reflective dialogues* (Graneheim & Lundman, 2004) on the same shift as the observation. The interviews lasted between 11 and 34 min (mean 21) and a short guide was used (Table 2, sub-study II). The main focus was on clarifying observed behaviours and investigating deliberations and enactments regarding patient pain and other discomforts. However, the opening questions, “What are your thoughts about the pain and discomfort of your patient on this shift?” was posed to encourage narration. The implemented protocol was not specifically discussed, unless initiated by the nurse.

5.6.4 Pilot testing

One pilot interview was conducted with a former ICU patient, testing the interview-guides for both the first and the second interview, including the ICUMT that was used during the first interview. The main benefit of the pilot testing was an increased understanding of how to pose the questions to obtain rich descriptions of experiences.

Two pilot observations and interviews with nurses were performed to test and elaborate the guides and to familiarize with the data collection method. The pilot observations aimed to acquaint myself with the routines on the ward and identify the appropriate approach to the observation. The observations were performed with a fellow researcher working part time in the unit. This gave a good opportunity to discuss the experience of observing and of being observed. More specifically, the pilot observations resulted in reflections and refinements of the observation guide, the practice of taking field-notes while observing, and the structure of subsequent interviews. Finally I learned to reflect upon how to handle colleagues interrupting the observations with questions or just to have a chat.

5.7 Data analysis

All interviews in the study were transcribed verbatim by the interviewer. The audio files were listened to both before the transcription to get an overall impression and after for accuracy and to make corrections to both verbal and non-verbal expressions. The software program HyperResearch was used to organize the qualitative data in sub-study I. In sub-study II and III, the more up-to-date solution QSR Nvivo Version 11 was used. Both software solutions appeared useful in the initial coding and organizing of data. However, later in the process the use of the software programs was partly perceived as restrictive and did not become an essential part of the analysis. Different analytic approaches were chosen for the three sub-studies. The research team consisting of the phd-candidate and two supervisors discussed all steps throughout the analytic processes, with substantial contribution from one more researcher from the clinical field in the secondary analysis (sub-study III).

5.7.1 Systematic text condensation (sub-study I)

"Systematic text condensation" as described by Malterud (2011, 2012) was used to analyze the transcribed interviews constituting the patient data. This descriptive and explorative strategy for thematic analysis is inspired by Giorgi's phenomenological analysis and is suitable for cross-case analysis of qualitative data (ibid). The original phenomenological methodology was merely descriptive but evolved to comprise interpretations or hermeneutics (Polit & Beck, 2012). As a novice qualitative researcher in lack of in-depth knowledge or affiliation to one philosophy or theory of science, I was situated where Malterud describes, in between description and interpretation (Malterud, 2012, 2013) - and inspired by phenomenological hermeneutics, or interpretive phenomenology (Lopez & Willis, 2004; Polit & Beck, 2012). Moreover, the strategy is described as being neither unique nor original, but to offer the novice researcher a pragmatic process of analysis while keeping sufficient methodological rigor (ibid). The thorough description of the steps in the analytic process constitutes a frame that kept us close to the original data. This framing may appear restrictive, implying a low interpretation level and a low abstraction level resulting in mere descriptions of category content (Graneheim, Lindgren, & Lundman 2017).

Table 4: Analytic steps in systematic text condensation (Malterud, 2012). Sub-study I.

Analytic steps		Result
1	Identifying themes: reading transcripts to get an overall impression	Preliminary themes
2	Identifying and sorting meaning units. Preliminary themes form the basis for negotiations of codes used to sort meaning units into code groups	Code groups
3	Condensation: dividing code groups into subgroups as means for condensation. Writing artificial quotations (condensates)	Subgroups and Condensates
4	Synthesizing: reconceptualization of condensate content and development of descriptions and concepts	Categories

The analytic steps are described in table 4 and the analytic process illustrated in table 5. Two researchers initially read the transcripts from the first interview independently to get an overview and identify *preliminary themes* relating to the aim of the study. After negotiation, six preliminary themes were agreed upon as a starting point for further organizing the data. In the second step, meaning units of the patients' experiences of pain, discomforts and wakefulness and handling of these, were coded and *code groups* were elaborated from the preliminary themes. The code groups, and the coding were flexible, allowing the code groups to evolve along the process. The first two steps represented *decontextualisation* as the text sorted out was detached from its primary context. In step 3, the *condensation,* the code groups were divided into subgroups and artificial quotations (condensates) were written, one for each code group. The condensates comprised the essence of the sub-grouped codes and included quotes from the informants and concepts from the meaning units.

Table 5: The process of analysis from preliminary themes to overall theme using the steps of systematic text condensation (Malterud, 2012). Bold face illustrates the analytic steps relating to one code group.

Steps 1+2 Decontextualization			**Step 3 Condensation**	**Step 4 Recontextualization**	
Preliminary themes	Meaning units	Code groups	Subgroups	Categories	Overarching theme
Severe discomfort Need to understand and participate Balancing sleep, rest and wakefulness Exercise to get better Being unprepared and unsafe Existentiality	**I woke up on the ventilator and felt I was choking. I did see people, because my wife was there, and the nurses, and I was going to speak, but I was unable to. I took my hands to try and remove the thing, but they took my hands away…. it was terrifying and I thought, “good grief are they going to kill me…” (pat.1/int.2)**	**1. Experiencing pain and other discomforts**	1.1.Experiencing pain relief 1.2 Experiencing pain **1.3 Experiencing other discomforts**	**In discomfort, but rarely in pain**	**Pain relieved but still struggling**
		2. Perceiving reality during changing states of wakefulness	2.1 Distinguishing between delusions and reality 2.2 Perceiving different states of wakefulness 2.3 Remaining in unreal experiences 2.4 Being in a strange place	Struggling to get a grip on reality	
		3. Handling pain and discomfort	3.1 Striving to participate 3.2 Needing to trust others 3.3 Enduring	Holding on	
		4. Handling ICU-experiences after discharge	4. Keeping distance 4.2 Trying to move on 4.3 Searching for recognition 4.4 Describing delusions as internalized experiences	Handling emotionally trapped experiences	

The code groups created from the first interviews were used as a starting point for the analysis of the second interviews. Despite this partly deductive approach, the analytic structures comprising code groups, subgroups and condensates remained dynamic and were expanded by new discoveries during the process of analysis.

In the fourth and final step, *recontextualisation,* the following four categories were formed by comparing and merging the subcategories; “In discomfort, but rarely in pain,” “Struggling to get a grip on reality,” “Holding on” and “Handling emotionally trapped experiences”. Category headings that expressed the most significant interpretations in the in each code-group were chosen. Validation of the category content concerning pain, other discomforts, wakefulness and handling of experiences, was done by rereading all the transcripts. Finally, the overarching theme “Pain relieved, but still struggling” was abstracted from all 4 categories (Malterud, 2011, 2012). An analytic text was written on the basis of each condensate and quotations were chosen to illuminate the patient perspective.

5.7.2 Thematic content analysis (sub-study II)

In sub-study II, thematic content analysis was used (Braun & Clarke, 2006; Green & Thorogood, 2014) to explore the characteristics of deliberation and enactment of nurses in relation to pain and other discomforts in ICU patients. This method is considered useful to identify key features of participants’ accounts. In thematic analysis, themes are abstract labels for parts of the data linked together representing the same thing. The method was considered a good fit for several reasons. It is flexible and not tied to a particular epistemological or theoretical position, it is useful in working with participants as collaborators and offers “thick descriptions” to summarize large data sets (Braun & Clarke, 2006).

In this study, the observation data was considered core data. In the first step all the field notes were individually read by two researchers to get an overall impression (Green & Thorogood, 2014). In the second step five initial codes were identified and agreed upon as relating to the aim of the study. Three of the codes had their origin in field notes relating to elements in the observation guide, and two were identified in the reflective field notes. Then the first one third of the interview transcripts were read. Nurses’ deliberations relating to the initial enactment codes were identified and connecting code groups with similar content were formed. The third step involved to establish a coding scheme and apply this to the rest of the data set. This coding process was dynamic and allowed new codes to be identified and included and new code groups to be formed. In the fourth step, diverging somewhat from traditional thematic analysis, seven categories were formed by comparing and contrasting all the code groups. Although categories are not natural features in the thematic analysis, the label was used in accordance with Graneheim and Lundman (2004), as descriptions close to the data. Themes are described as abstracted interpretations representing threads of meaning throughout the data (ibid). Three themes were abstracted from the categories and the overall theme “Having the compass – drawing the map” resulted from a final abstraction. As an example of the process from initial codes to overall theme, one initial code originating from the transcripts and one from the field notes are shown in table 6.

Although data were coded inductively, the concepts of deliberations and enactments along with other structures of Kim's framework of nursing processes inspired the analysis (Kim, 2010). Patterns across all 16 observations and interviews were identified to elucidate how ICU nurses think and what they do regarding pain and other discomforts. The findings are thought to provide a holistic description of the nursing processes involved and what characterizes these when analgosedation is used.

Table 6: The analytical process showing the initial codes, code-groups, categories and themes pertaining to one theme

Initial codes	Code-groups	Categories	Themes	Overall theme
From transcript: Choosing interventions directed towards pain or other discomforts	Adhering to principles of protocol Using pharmacological interventions Applying non-pharmacological interventions Choosing between pharmacological and non-pharmacological interventions	Ensuring aspects of pain relief and comfort	Balancing conflicting goals	Having the compass – drawing the map
From Field note: Handling other treatment goals along with comfort	Achieving a good balance between goals Experiencing a difficult balance between goals Prioritizing between goals of comfort and pain relief and of rehabilitation Using professional repertoire Using personal repertoire	Ensuring the aspect of rehabilitation		

5.7.3 Abductive content analysis (sub-study III)

The third sub-study was a secondary data analysis (Thorne, 1994; Heaton, 2008; Ruggiano & Perry, 2019) employing a qualitative content analysis (QCA). The methodological approach in QCA, may be inductive, deductive or abductive (Graneheim & Lundman, 2004; Graneheim et al., 2017). Inductive analysis starts with data and codes are defined during the process. This data-driven analysis proceeds from particulars to generalizations. Deductive analysis is concept-driven, by theory, literature or earlier findings and proceed from generalizations to particulars. An abductive approach implies moving back and forth between an inductive and a deductive approach during the process (Graneheim et al., 2017). This approach is also described as combined (Elo & Kyngas, 2008) or directed analysis (Hsieh & Shannon, 2005). It may start with earlier findings or theory to discover meaningful underlying patterns, making it possible to integrate structures on different levels and obtain a more complete understanding of a phenomenon (Eriksson & Lindstrøm 1997 and 1999 as cited in Graneheim et al., 2017). Hence, it appeared useful in this sub-study.

Three analytical steps were conducted, each pertaining to one research question. The first step was inductive, analysing the data in sub-study I. As discomfort was part of the exploration in study one, we started with the condensates based on the code groups and not the raw data. We looked for particular expressions of discomforts according to Kolcaba's definition of discomfort as a detractor from comfort in different contexts (Table 1). We organized all the expressions of discomforts in to the software program NVivo 11, but not according to Kolcaba's different contexts of comfort. Through grouping and discussions on particular patterns of the discomforts, we arrived at three themes; "Being deprived of the functioning body", Being deprived of the functioning mind" and "Being deprived of integrity". We read through all the raw data to confirm that no discomforts had been missed out that could not be placed in either of the three and therefore kept one theme for others, but it was redundant. The overall theme "In need of acknowledgement and alleviation" was abstracted from the three, expressing the patients' needs resulting from the characteristics of their situation as an ICU patient.

Thereafter we turned to the nursing data to deductively explore how the nurses in sub- study II aimed to acknowledge and alleviate the patients' discomforts pertaining to the deprived function of the body, the mind and the integrity. The themes from step 1, thereby functioned as a framework into which the different deliberations and enactments could be placed. An example of one patient theme and the resulting nursing codes and categories are displayed in table 7. Finally, the theme, "In need of and providing acknowledgement and alleviation" was abstracted from the categories, indicating a "match" between the needs of the patients and the nurses' practice.

Table 7: An example of one patient theme with nursing codes, nursing categories and overall theme emerging from the re-analysis of the data

PATIENT DATA STEP 1	NURSE DATA RELATING TO THEMES STEP 2		PATIENT AND NURSE DATA
Themes	**Codes**	**Categories**	**Overall theme**
Being deprived of the functioning mind	• Orientating about time and place • Informing and explaining about the situation • Assessing for delirium • Preparing for procedures • Demarcation of the body boundaries • Reducing environmental stimuli • Reassuring talk • Gentle touch • Soothing speech • Showing empathy	**Recognizing confusion and the need for coherence** **Alleviating apprehension**	**In need of, and providing acknowledgement and alleviation**

In the third step we turned to Kolcaba's Comfort Theory (Kolcaba, 2003). We used elements and concepts embedded in the taxonomic structure (Table 1) deductively to illuminate the phenomenon of discomfort. From the data, we identified how discomforts pertaining to each area of deprivation (body, mind, integrity) corresponded to the different contexts of comfort, the types of comfort and the types of comfort measures. This analytic step is displayed in figure 5.

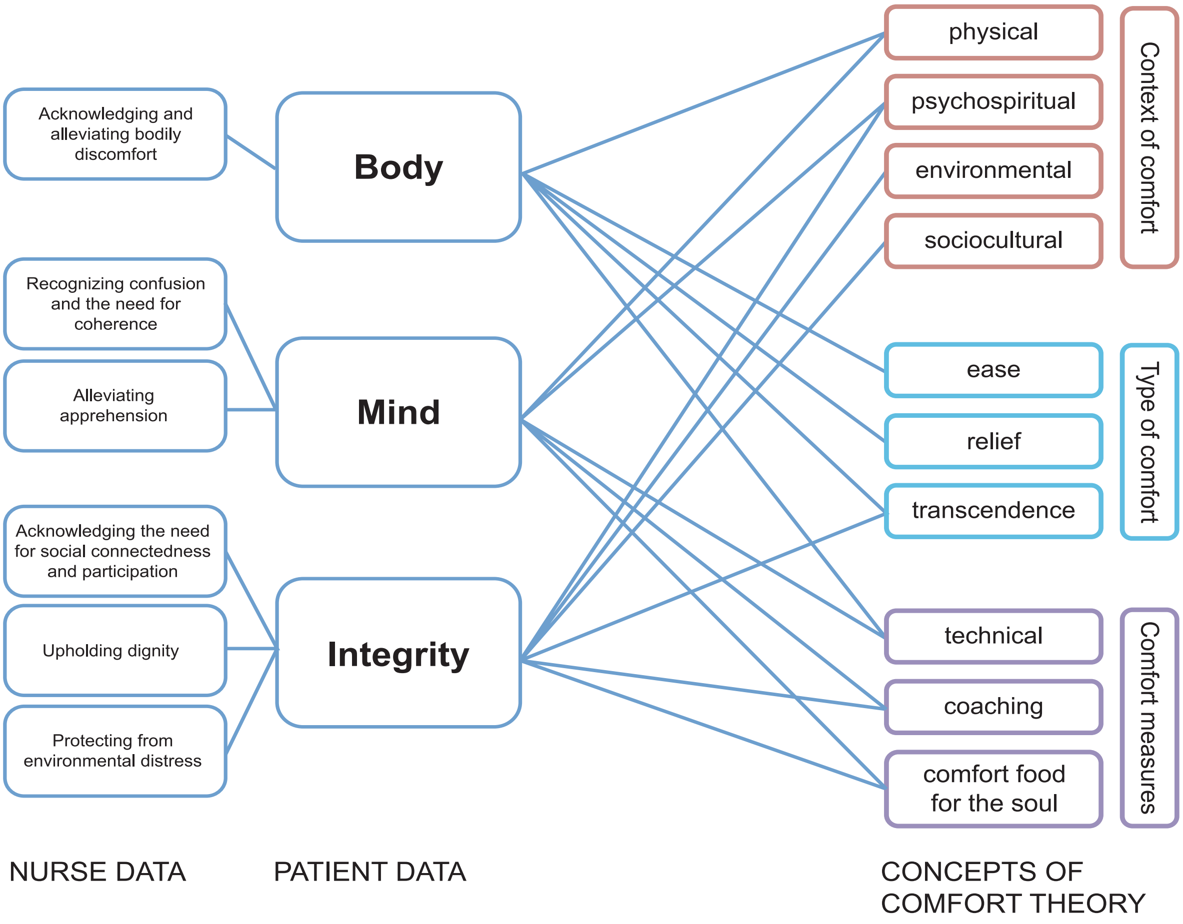

Figure 5: Correspondence in data from steps 1 and 2 in the analysis and concepts in Comfort Theory (Kolcaba, 1997,2003).

5.8 Ethical considerations

The study was designed and conducted according to the Declaration of Helsinki (World Medical Association [WMA], 2013). It was approved by the regional committee for medical research ethics (Health Region East, Norway; Project –ID; 2014/125) and the data protection official at the hospital. Oral and written information was provided all participants and written consent was obtained. All participants were informed about the voluntariness in participation and the possibility of withdrawal at any point during the course. Ethical considerations will be accounted for in regard to vulnerability, voluntariness and the principle of written informed consent.

Vulnerability

Studying patients in vulnerable situations is ethically highly challenging. The patients were recruited and included during the first days after discharge from the ICU. Since patients may be both physically and cognitively impaired after an ICU stay, this required thorough consideration regarding the patient's condition before the interviews. In the pilot interview I tested a screening tool, "the six-item screener" to assess patients' cognitive function. I planned to apply this before the first interview but was instantly convinced of its awkwardness and possibility of jeopardizing the trust and rapport needed in the situation. In two of the eighteen first interviews, the patients appeared somewhat confused and their statements were partly incoherent which made me unsure about their cognitive function. However, through the re-interview three months later, I was reassured and relieved to acknowledge this was more a matter of personality and gift of expression.

Interviewing patients about possibly traumatic experiences also requires ethical consideration. One patient started crying when she realized she didn't have to come to the hospital for the second interview. Her experiences from the admission were traumatic and coming back for her follow-up consultations bothered her.

Several patients were clearly bothered by recalling and speaking of unpleasant or dramatic memories during the interview, in particular delusional memories. I explicitly offered to stop if they appeared bothered, acknowledging the unpleasantness of their recall. Some accepted, but others chose to continue. One woman, who was bothered by her recollections during the first interview, still consented to further contact at 3 months. However, when receiving the information letter she regretted by SMS that she did not want to participate. She was ok she said, but she had to put a lid on her experiences to be able to move on.

Being aware of the possible psychological strain from talking about memories from intensive care (Dyregrov, 2004), all interviews ended with questions about how the participants felt about the interview and whether they thought they might be bothered by any recollections throughout the day. Moreover, I ensured they had someone to turn to after the interview, if they needed to talk. For some patients, I encouraged them to consider a need for follow up by hospital staff, their general practitioner or others. Several, however, expressed appreciation of the interview or conversation, and hence, to some it might have been experienced as a therapeutic intervention. This is supported by the findings of Williams et al. (2009) who found that ICU patients could be helped to recover psychologically by constructing narratives about their experience from their stay.

Voluntariness

Regarding voluntariness in participation of the nurses, my supervisors' position as a colleague at the study unit, and to a much lesser extent my own, some of the employees may have felt obliged to participate. The information letter and consent form was therefore distributed individually, enabling the nurses to accept, decline or ignore the invitation to participate. The rather low response rate (39%) may indicate that to ignore the invitation was an easier choice than declining, but busy shifts and forgetfulness may also explain this. The few explicit declines (5%) were sometimes accompanied by an excuse or explanation of their response. Given the chance of ignoring the invitation, the consents (34%) were considered highly voluntary.

The patients were asked to consent to the interviews by persons on whom they were not dependent or to whom they had a caring relation. A continuous consent to participation was sought by giving the patients opportunity to decline the inquiry of being informed about the study, taking part in the first, and later in the second interview. The voluntariness was emphasized prior to both interviews even though a written consent had been obtained at an earlier time point.

The challenge of obtaining written informed consent

The ethical principle of written informed consent represented a considerable challenge during participant observation in this project. In this part of the data collection, the patients were not included as participants, but as targets for the nurses' deliberations and enactments. Nevertheless, the patients had to make a written consent, or by their proxies if they were sedated (Appendix 8). In addition, all personnel, and relatives if they were present, had to consent to the observation.

In the application for approval of the study from the regional committee for medical research ethics several different consent forms were enclosed. Some of these are available as appendices (Appendix 8-10). The idea was to ensure every possible consent matter pertaining to patients, family members as proxy, and health care personnel. In practice, this became an overwhelming procedure and was proven complicated, unfeasible, and sometimes even unethical. Some of the patients were cared for in rooms with three beds and consulting personnel such as physicians on doctor's rounds occasionally visiting the room, usually for very short periods of time. Retrospectively, to act correctly, I should have obtained eight additional written consents during one hour of observing one nurse. This was considered neither appropriate nor realistic. Many persons were not direct objects for my observations but were nevertheless indirectly involved by being part of the ICU context. To meet the challenge of informed consent, I ended up considering each patient bed and the immediate surroundings, and not the whole room, as the area of observation. I thereby focused on obtaining consent from the nurses directly involved in the care of this particular patient.

The consent form developed for «persons passing-by» was used only a few times, which may be regarded as a pragmatic choice although based on thorough discussion in the research team. In this regard, it felt uncomfortable that not all health care personnel had provided written informed consent. I approached this challenge by providing appropriate and sufficient information about my presence and my mission. All physicians were informed by e-mail about the project and my presence, and about the possibility of being asked to consent to the observation if they were considered to be part of the situation (Appendix 6). All nurses were informed at the changing of the shift, before entering the patient rooms. This provided an opportunity to make objections to my presence. Regarding by-passers, each situation was individually considered, and written consent obtained if deemed appropriate and necessary.

6 FINDINGS

In this section, the main findings from the three empirical sub-studies are summarized.

6.1 Sub-study I

"Pain relieved, but still struggling" – critically ill patients' experiences of pain and other discomforts during analgosedation.

The aim of sub-study I was to explore patients' experience of pain, discomforts and wakefulness during critical illness when treated according to the analgosedation approach. We further aimed to explore how patients handled their experiences after ICU discharge.
Four categories emerged from the analysis and resulted in the overall theme "*Pain relieved, but still struggling.*" (Table 8). The title reveals that even though pain was of minor concern to the patients in this study, they struggled with a lot of other discomforts. The struggle pertained primarily to the mechanical ventilation treatment, to incomprehension and communication difficulties and to unreal experiences. The first category "*In discomfort, but rarely in pain*," indicates that pain was acceptable or less than expected, and that most patients were satisfied with how their pain was attended to. However, discomforts related to the endotracheal tube and to not getting enough air were common. Communication problems evoked feelings of being a "thing" and the discomfort related to a distressing environment was frequently described. The second category "*Struggling to get a grip on reality*", describes how the patients perceived reality during the changing states of wakefulness. How they drifted in and out of sleep or sedation and how they were unable to distinguish what was real and what was not. The experience of feeling confused or of having unpleasant delusions, hence was frequent and created severe discomfort. The third category "*Holding on,*" relates to how the patients described their handling of pain and discomfort in the ICU through participation, trusting in others and by enduring. The last category, "*Handling emotionally trapped experiences,*" pertains to how patients' handled their ICU experiences after discharge. Memories of unreal, unpleasant experiences sometimes appeared to be trapped in the emotions of the patients, hence causing reactions very much in line with real experiences. Reactions to experiences of both real and unreal origin were handled differently, ranging from repression to being expressive and searching for recognition. Some had the experience of being in a realm between life and death

Table 8: Code groups, subgroups, categories and theme, Sub-study I.

Code groups with subgroups	Categories	Theme
Experiencing pain and other discomforts • experiencing pain relief • experiencing pain • experiencing discomforts	In discomfort, but rarely in pain	Pain relieved but still struggling
Perceiving reality during changing states of wakefulness • distinguishing between delusions and reality • perceiving different states of wakefulness • remaining in unreal experiences • being in a strange place	Struggling to get a grip on reality	
Handling pain and discomfort • striving to participate • needing to trust others • enduring	Holding on	
Handling ICU-experiences after discharge • keeping distance • trying to move on • searching for recognition • describing delusions as internalized experiences	Handling emotionally trapped experiences	

6.2 Sub-study II

"Having the compass – drawing the map": Exploring nurses' management of pain and other discomforts during use of analgosedation in intensive care.

The aim of sub-study II was to explore the characteristics of deliberation and enactment by nurses in relation to pain and other discomforts in critically ill patients after the implementation of an analgosedation protocol. In this study we found the implemented protocol to direct the nurses' practice. The metaphor "*Having the compass – drawing the map*" representing the overall theme and title, indicates that the protocol worked as a guide to direct the pain management in a complex setting, however accompanied by a strong dependence on individual interpretation and personal preferences when it came to discomforts other than pain. The overall theme was abstracted from the three themes all representing challenges in the nurses' daily practice and contributing to the complexity (Table 9). The first theme "*Interpreting a complex whole*," shows that interpretation of collected cues and information from different sources was needed to supplement the assessment tools available. The more awake patients required constant attention, but at the same time supported the nurses' deliberations and decision-making. The second theme "*Balancing conflicting goals,"* represents the challenge of ensuring pain relief and comfort along with the aspects of rehabilitation. A wide range of personal skills was revealed in the interventions aiming to achieve the balance needed. Finally, the theme "*Experiencing strain from acting across ideals*," reveals the nurses' experiences of threats to professional ideals and personal standards, arising from trying to balance comfort and rehabilitation. The strain experienced appeared to depend highly on the professional and personal involvement of the nurse. The main finding in this study was that pain was managed quite systematically, but other discomforts were subjected to unstructured and haphazard approaches, based on highly individual assessment, interpretation and interventions. The theoretical perspective that guided the analysis in this study was Kim's model of nursing processes. Using this perspective enabled a better description of how the deliberation and enactment pertaining to pain were different in structure from the processes pertaining to other discomforts.

Table 9: Categories, themes and overall theme, Sub-study II.

Categories	**Theme**	**Overall theme**
• Facilitating tools, but still requiring interpretation • Collecting and combining cues during routines and continuous care • Enacting on information from different sources	Interpreting a complex whole	Having the compass – drawing the map
• Ensuring aspects of pain relief and comfort • Ensuring the aspect of rehabilitation	Balancing conflicting goals	
• Experiencing threats to professional ideals • Experiencing threats to personal standards	Experiencing strain from acting across ideals	

6.3 Sub-study III

"Please mind the gap": discomfort and comfort in intensive care – a secondary analysis.

The aim of sub-study III was to explore further the complex and persistent, as yet ill-defined phenomenon of discomfort in intensive care. The secondary analysis using data from sub-studies I and II, revealed that the discomfort experienced by patients during an ICU-stay could be described in terms of "*Being deprived of a functioning body*," "*Being deprived of a functioning mind,"* and "*Being deprived of integrity,"* abstracted as being "*in need of acknowledgement and alleviation"*. The critical care nurses appeared to attend appropriately to all three areas of discomfort, and their efforts were described in six categories together representing the provision of "*acknowledgement and alleviation."* The overall theme "in need of and providing acknowledgement and alleviation" represents an abstraction of both patient needs relating to, and nurses' management of discomforts. The corresponding categories and themes are shown in table 10. The main finding in this study was the comfort gap revealed between the patients' needs and the nurses' overall achievements in meeting these needs. The comfort gap indicates that the experience of discomfort might constitute an inevitable part of the intensive care stay. Through application of Kolcaba's Comfort Theory in the analysis (Figure 5), we were able to identify the deprivation of the functioning mind as the most difficult part of discomfort to alleviate. Furthermore, the structures and concepts in Comfort Theory appeared feasible when attempting to diminish the existing comfort gap through more systematic planning of care.

Table 10: Patient themes, Nurse categories and overall theme, Sub-study III.

Themes (patient data)	Categories (nurse data)	Overall theme
Being deprived of the functioning body	• Acknowledging and alleviating bodily discomfort	In need of, and providing acknowledgement and alleviation
Being deprived of the functioning mind	• Recognizing confusion and the need for coherence • Alleviating apprehension	
Being deprived of integrity	• Acknowledging the need for social connectedness and participation • Upholding dignity • Protecting from environmental distress	

7 DISCUSSION

7.1 Introduction

The overall aim of this study was to generate knowledge important in caring for critically ill patients in relation to new strategies in managing pain and sedation. We collected data from both patients and nurses to answer questions about the implications of an analgosedation protocol implemented in the clinical setting. We interviewed patients about their experience from ICU with focus on pain and wakefulness, and we observed and interviewed critical care nurses caring for these patients and expected to adhere to the protocol.

Our main findings were that in the context of analgosedation, the patients in general described discomforts other than pain as dominating their intensive care experiences. Furthermore, the nurses attended more systematically to patients' pain than to other discomforts. By further investigating the phenomenon of discomfort from the perspectives of both nurses and patients, we demonstrated an inevitability of discomfort in the ICU, which we described in terms of a comfort gap. The gap constituted the discomfort that was left when pain and other discomforts had been alleviated to the possible extent according to the clinical condition of the patient, the nurses' efforts and environmental factors. However, by paying attention to the comfort gap and to what contributes to its existence in the individual patient, nurses may possibly diminish the gap and thereby ameliorate the patient experience of staying in the ICU.

The emergent design used in this study allowed sub-study III to logically build on the other two, which is reflected in the findings of the study. In this chapter, broader aspects of the results are discussed in light of the *overall aim of the study* and integrated with relevant and updated research literature. This is followed by methodological considerations including the use of theoretical perspectives.

7.2 Discussion of the results

The discussion of the main empirical results is organized around two overarching themes; firstly, why the experience of discomfort in our patients predominantly consisted of discomforts other than pain, and secondly, the different aspects of the identified inevitability of discomfort in intensive care, constituting the comfort gap, including how it possibly can be diminished.

7.2.1 Why did the patients predominantly experience discomfort other than pain?

The central finding that patients in our study reported pain to be of only minor concern is not in line with the current understanding since pain for decades has been regarded a major stressor for ICU patients both at rest and during procedures (Bergbom-Engberg & Haljamae, 1989; Chanques et al., 2007; Puntillo, 1990; Puntillo et al., 2014; Stein-Parbury & McKinley, 2000). Our findings may be regarded as a confirmation of our hypothesis, that the analgosedation approach directing for lighter sedation would enable more patients to communicate their pain and hence receive appropriate pain relief. Nevertheless, the findings may be considered also in light of the study *methodology*, and our *understanding of pain and discomfort*.

The impact of methodology

The quantitative results of the main study which includes the present qualitative arm, revealed low pain scores (Wøien, 2020) corresponding to our qualitative findings of a high degree of pain relief (I). This reflects progress in line with other studies showing the association between increased adherence to international guidelines regarding PAD and improvements in patient outcomes (Pun et al., 2019). The high degree of discomfort experienced by the same patients was however only revealed in the qualitative approach. This approach furthermore allowed us to come closer to aspects such as the meaning of the phenomenon of pain, not only the presence of pain or not. In research, pain and discomfort are frequently measured together, and also used synonymously (Ashkenazy & DeKeyser Ganz, 2019). Particularly in quantitative studies, this is frequent, and unless inquiries are explicitly made about discomfort, there will be no differentiation between the two. During the interviews in our study, the patients were encouraged to reflect on and describe their experiences regarding pain and wakefulness. Pain descriptions were rare, and discomfort was frequently related to the experience of being awake, and also to being somewhere in between asleep and awake (I).

One recent study, however, supports our findings that pain is not necessarily the major concern of ICU patients (I). In a survey, Wåhlin et al. studied 268 ICU patients who rated the importance of their needs and to what extent their needs were fulfilled (Wåhlin, Samuelsson, & Agren, 2017). The study did not focus on whether the patients experienced pain or not, but from an empowerment perspective investigated the importance of having certain needs met, including pain relief. Pain relief was rated to be of *greatest* or *great* importance by 91%.

Furthermore, 98% declared that they received the pain relief they needed all the time (81%) or most of the time (17%). These results, hence, correspond well with our qualitative findings where patients in general did not deny the experience of pain, but emphasized that their pain was acceptable, less than expected or was very well attended to by the nurses (I). The study design and how inquiries are made about pain and other experiences clearly influence the findings in studies along with the understanding or definition of pain and discomfort.

Understanding or defining pain and discomfort

Pain in this study belongs under the umbrella term of discomfort (Kolcaba, 2003) and the two could therefore have been analytically treated as one. However, due to the descriptions dominated by discomfort rather than pain in our patients and acknowledging the different approaches to alleviate the two, we decided to regard pain and other discomfort as two different entities. This allowed us to encounter what actually bothered the patients when they were not explicitly describing their experiences in terms of pain.

Our multidimensional perception of pain (Loeser & Melzack, 1999) allowed pain to constitute whatever pain meant to the patients, encompassing for example nociceptive pain during procedures or following surgery, chronic neuropathic pain due to earlier injury or pain from being away from the patient's beloved ones (I). The latter pertained to the pain dimension of suffering according to Loeser and Melzack (1999). Suffering may thus correspond to *pain distress* or the *emotional component* of pain, as described by Price et al., and as opposed to the physical component reflecting pain intensity (Price, Harkins, & Baker, 1987). Puntillo et al.recently published a study about pain distress measured as the negative emotional dimension of pain in procedures (Puntillo et al., 2018). One example used in their study to exemplify how pain distress may exceed pain intensity, the nociceptive sensory pain, is the endotracheal tube including the tracheal suctioning. This procedure often regarded painful per se (Karlsson et al., 2012a), may also cause a decrease in oxygen level, choking, gagging and shortness of breath (Puntillo et al., 2018). These discomforts included in the pain experience by Puntillo, have in our study been defined as discomfort. I argue that taking an early stance of dividing the phenomena of pain and discomfort for analytical purposes has enabled us to pinpoint that much of what is bothering patients in the ICU should not necessarily be defined, nor treated as pain. This may further indicate that pain in research when reported by a vast majority of the patients in the ICU, comprises much of what we have defined as discomfort. Importantly though, some of the pain described by our patients, such as being kept away from your dearest, should obviously not be treated with opioids, but by applying other comfort measures. This, however, illustrates the complexity of defining, measuring and treating discomfort as distinguished from pain in ICU patients. Nortvedt (2015) argues that pain defies definition because of its complexity. The perception of pain varies and is expressed subjectively according to the perception and embodiment of the individual. The profound subjectivity of pain cannot fulfil the criteria of a definition as a common understanding of the meaning of a phenomenon (ibid).

The concept of discomfort has not been subjected to conceptual analysis until recently when Ashkenazy & De Keyser Ganz (2019) aimed to define discomfort and to differentiate between pain and discomfort. Dividing discomfort in to the two main domains of physical and psychological discomfort, they found that in the research literature, discomfort was predominantly used in the physical sense. Pain was frequently described as the main source of discomfort. Along with the synonymous use of the two concepts (ibid), this illustrates the close relation between them, and partly explains the difficulty in distinguishing between the two. As pain has been regarded a major concern in intensive care for decades, the focus in research has been on assessment and treatment of pain rather than other discomforts.

Our results regarding pain and discomfort are analytically anchored since the patients were not asked to differentiate between the two. One older study included in the concept analysis of Ashkenazy and DeKeyser Ganz (2019) is thus interesting because the ICU patients were asked to separate the levels of pain and discomfort when undergoing 16 different procedures (Morrison et al., 1998). The procedures ranged from having an x-ray taken or being physically restrained, to mechanical ventilation or arterial blood gases. In their results, arterial blood gas sampling was rated severely painful (3 on the 0-4 NRS-scale) but was at the same time rated to generate moderate discomfort (2 on the NRS). Mechanical ventilation on the other hand, generated severe discomfort, but moderate pain. Morrison et al. (1998) hence concluded that the patients were able to discriminate between pain and discomfort; that these could be regarded as distinct entities and differed across procedures or experiences.

Ashkenazy & De Keyser Ganz (2019) concluded that; “discomfort may be physical or psychological and is characterized by an unpleasant feeling resulting in a natural response of avoidance or reduction of the source of the discomfort.” What distinguishes discomfort from pain, according to their concept analysis, is the potential or actual tissue damage. Our study was however inspired by Kolcaba (2003) who in Comfort theory regarded discomfort in relation to *comfort* and hence as “a physical, psychospiritual, sociocultural or environmental detractor from comfort.” This focus implies comfort as the patient-centred goal to all discomfort, including pain. Therefore, in our understanding, neither the clinical nor analytical differentiation between pain and discomfort affect how they should be approached in terms of enhancing comfort. Our study however identified the discomfort bothering the patients the most and being less systematically attended to by the nurses. Kolcaba’s comfort perspective moreover assisted us in reaching our analytical result of the comfort gap and the assumed inevitability of discomfort. Furthermore, it enabled us to identify which constituent parts of the gap could successfully be alleviated within our current knowledge and which were the more inevitable.

7.2.2 The inevitable discomfort constituting the comfort gap

Our finding across the studies in this thesis is that critical care nurses acknowledge and alleviate discomfort relating to all identified areas of discomfort in their patients, although not fully (III). The identified comfort gap resulting from the remaining, unalleviated discomfort, described as inevitable, requires a further discussion. I will therefore discuss the meaning of inevitability pertaining to discomfort, approaches to reduce the inevitable discomfort, how the inevitable discomfort in patients affects the critical care nurses, and finally the significance of *comfort* in diminishing the comfort gap.

The meaning of inevitability pertaining to discomfort

The discomforts resulting from the secondary analysis pertained to the deprivation of the functioning body, the functioning mind and the integrity of ICU patients. All three aspects contributed to the comfort gap, although deprivation of the functioning mind appeared to be by far the most difficult discomfort to alleviate. The confusion, cognitive impairment, delusions and delirium frequently accompanying critical illness contributed to the category “Struggling to get a grip on reality” in our primary analysis (I) and further to the theme “Being deprived of a functioning mind” in our secondary analysis (III). We concluded this to constitute an inevitable part of the comfort gap due to the current lack of knowledge about how the brain is affected in critical illness and thus the causes of delirium and cognitive impairment. Also being awake and alert could cause discomfort. Wakefulness being the primary focus of our study along with pain and impacted by the analgosedation strategy, inevitably caused discomfort in our patients. To be awake and alert but deprived of the ability to move freely, to control breath, to communicate and socialize, to defend privacy, all contributing to the awareness of one's total dependency were among the experiences reported (I). Although being awake also gave the opportunity to participate, take some control and communicate needs, several said they would have preferred to be more asleep.

Similar findings of discomfort were made in an ethnographic study of patients being awake during mechanical ventilation. Lærkner et al.in a Danish no-sedation study, on one hand found that the wakefulness made the patients unpleasantly aware of their powerlessness, the technological and unfamiliar surroundings and activities, inattentive nurses and other patients (Lærkner, Egerod, Olesen, & Hansen, 2017). On the other hand, and dominating their findings more than ours, was however that the ability to interact through the whole illness trajectory provided the patients with an appreciated sense of agency. They were able to initiate, direct and participate in activities and communication. Both Holm & Dreyer and Prime similarly found that patients preferred to be awake in order to be present in their own lives and remain in control despite the inherent discomfort (Holm & Dreyer, 2017; Prime et al., 2016).

Current knowledge does not entail optional deep sedation by choice for the patients in intensive care, thus discomforts pertaining to being awake may be regarded as inevitable. Although patients' preferences according to wakefulness and sedation will differ, the above findings should be highlighted to reassure health care personnel of benefits of minimizing sedation for the patients beyond the improved medical outcome. Therefore, the knowledge important to us is not the preferences of patients regarding sedation level, but the experiences pertaining to being less sedated or awake. This knowledge is crucial for us to develop more patient-centred care in the contexts of new sedation practices, taking in to account the associated challenges for both patients, as outlined above, and for nurses.

Approaches in nursing to reduce the inevitable discomfort

As opposed to discomforts pertaining to the mind in our study, we regarded discomforts related to the body and the integrity less inevitable since both the environment and the nurses' effort in attending to the gap may be regarded as modifiable factors. When we studied the nurses' deliberations and enactments, the nurses found the discomfort ill- defined and difficult to distinguish from pain and hence difficult to assess and treat systematically (II). This is confirmed by the challenges to differentiate between pain and discomfort found by Ashkenazy & De Keyser Ganz (2019).

We found the nurses to use the features of the analgosedation protocol as a direction for managing pain and it appeared to enable a systematic assessment and treatment. The fact that the nurses only occasionally mentioned the use of the protocol, but still enacted according to its content was discussed in light of protocol compatibility with current practice (II). The recently published results from the longitudinal main study (Wøien, 2020) show that the goals of having patients awake, able to cooperate and acceptably pain relieved were achieved gradually over a period of six years. During this period, implementation of systematic approaches to pain, agitation and delirium had been reinforced through follow-up. The analgosedation approach may therefore have been gradually adopted as *usual* practice. The systematic approach comprising common goals of care, the assessment tools and treatment options pertained to pain, but not to discomforts other than pain (II). The nurses attended in general to all three aspects of discomfort identified (III), but their endeavours were closely linked to the individual nurse's experience, knowledge and personal repertoire including creativity, engagement and also certain "specialities" (II). Taking in to account the time it has taken to achieve the goals of pain management mentioned above, hopefully establishing similar goals for managing discomfort may also bear fruit in the longer term. In line with how pain management has evolved to succeed according to our findings, more systematic approaches to other discomforts than pain could possibly enhance patients' comfort.

Even though the personal repertoire, reflecting an individual approach was described as haphazard in our study (II, III), it may comply well with the patients' need for individual care. Patients' positive experiences have been shown to depend on the compassion, attentiveness and companionship of the nurses (Lærkner et al., 2017, Karlsson et al., 2012a). To be treated uniquely, as an individual with personal preferences was highlighted as crucial by patients in the studies by Lærkner et al. (2017), and Olsen, Nester, & Hansen (2017). Lærkner,et al moreover, in their study emphasized that what was perceived as reassuring and comforting to one patient could be disturbing to another (Lærkner et al., 2017). Approaches to discomfort should not standardize care in a way that puts at stake individual needs of patients and individual qualities of nurses but combine systematics and comfort. Checklists or assessment tools to assess patient discomfort or comfort in the ICU exist. Tools such as the Comfort scale (van Dijk et al., 2000), the Inconforts des Patients de REAnimation (IPREA) –questionnaire

(Kalfon et al., 2010) or Numeric Rating Scales for other discomforts than pain, may provide a certain systematic, preferably combined with multicomponent programmes for reducing discomforts (Kalfon et al., 2019; Kalfon et al., 2017). In this study, we have shown that the holistic framework offered through Kolcaba's taxonomic structure may be useful. Within this systematic frame of individual assessment, planning of comfort care in different contexts, and application of appropriate comfort measures, nurses' personal repertoire will be encouraged and valued (III).

The effect of the inevitable discomfort on critical care nurses

The comfort gap identified in our study seem to leave the nurses in a position unable to fulfil their patients' needs, despite their endeavours to relieve discomfort. This inevitable discomfort appeared to affect and put a strain on the nurses when observing and having to withstand suffering in their patients (II). In a recent Danish interview study (Mortensen, Kjaer, & Egerod, 2019) perspectives of expert nurses, defined as having more than 8 years of experience, was compared with perspectives of competent nurses with 2-3 years of experience of caring for non-sedated mechanically ventilated patients in ICU. The nurses in their study described frustration and ambivalence in the context of minimal sedation and expressions of concern about their patients' discomfort. The more experienced nurses expressed more concern and mixed feelings when minimizing sedation than their fellow less experienced nurses who had mostly been working with lightly sedated patients. Although the nurses in our study corresponded, in experience, predominantly to the expert nurse group, with a mean ICU experience of 19 years, the perspective of former sedation practices was not highlighted in our study. However, trying to balance the conflicting goals of comfort and progress in rehabilitation put strain on the nurses. Favouring comfort could impede rehabilitation, and favouring rehabilitation implied discomfort for the patients, putting professional ideals and personal standards at stake (II). The threats to nurses' standards and ideals are in line with findings from Karlsson & Bergbom (2015). Nurses in their study felt they failed and betrayed their patients when unable to alleviate their suffering when conscious on mechanical ventilation. Everingham et al., (2014) found that the "target sedation approach" contradicted the nurses' desire to provide holistic and individualized care.

The challenge of alleviating discomfort related to the deprivation of the functioning mind, assumed to dominate the comfort gap in our study, was highlighted also in Mortensen et al.'s study (2019). In particular, the expert nurses in their study expressed the feeling of being powerless when unable to comfort delirious patients. Le Blanc et al. explicitly studied nurses' experience of caring for patients in delirium and found it exhausting and challenging (LeBlanc, Bourbonnais, Harrison, & Tousignant, 2018). However, when succeeding in helping their patients, the care was perceived positive, making their work meaningful and satisfying. The intertwined, challenging and fulfilling aspects of caring for more awake critically ill patients has been shown by several. The need for being present and alert at all times due to more awake patients' continuous need for attention or surveillance has increased workload and emotional demands on nurses (Everingham et al., 2014; Lærkner, Egerod, & Hansen, 2015). The nurses in our study, however, emphasized how important it felt when patients were able to guide their decision-making about pain and other discomforts. Positive aspects of lighter or no-sedation have been reported in studies, highlighting the satisfaction of being able to interact and involve the patient (Karlsson & Bergbom, 2015; Lærkner et al., 2015; Tingsvik et al., 2013). Lærkner described the dual experience of caring for awake patients on mechanical ventilation as demanding, yet rewarding (Lærkner et al., 2015).

Increasing demands in caring for patients more awake in the ICU deserve organizational attention to foster good practice. It is paramount to support the critical care nurses both practically and emotionally in their struggle to acknowledge and alleviate the discomforts of their patients. The need to know the patient and to take time to learn a new way of caring was emphasized by Karlsson & Bergbom (2015) when interviewing nurses caring for conscious patients on mechanical ventilation.

Patient-centred care is an important framework that may benefit both patient experiences and nurses' satisfaction with work (Jakimowicz, Perry, & Lewis, 2018). As a model of care it is challenged in the ICU in particular regarding the maintenance of patient identity, the establishment of therapeutic relations (Jakimowicz & Perry, 2015) and patient participation in planning treatment and care (McCormack & McCance, 2017). However in my opinion, patient–centred care may be promoted by combining the comfort perspective offered by Kolcaba (2003) and the systematic approach in models for treatment and care such as the *early Comfort using Analgesia, minimal Sedatives and maximal Humane care* (eCASH) (Vincent et al., 2016), described in sub-study II and III.

The significance of comfort to diminish the comfort gap

The inevitability of discomfort in ICU demonstrated in this thesis and constituting the comfort gap, is supported in Puntillo et al.'s recent study about pain distress in procedural pain (Puntillo et al., 2018). The authors claim that procedures are inevitable in ICU, but taking into account the multidimensionality of pain, the associated distress may be decreased by simple measures (Puntillo et al., 2018). By this, they encourage clinicians to minimize the experience of pain in their patients by attending to dimensions of pain available for action. This is in accordance with Kolcaba's view that comfort obtained in one context will always affect comfort in other contexts (Kolcaba & Wilson, 2002). We therefore concluded that even the assumed inevitable discomfort, pertaining to the deprivation of the functioning mind, might be decreased by acknowledging and alleviating discomfort pertaining to the body and the integrity (III). If nurses in the ICU become aware of discomfort in terms of deprivation of the functioning body, the mind and of integrity, they may target their comfort assessment and tailor their comfort measures accordingly. Using the types of comfort offered in Comfort theory, they may discover that comfort as a goal of care, include transcendence as an attainable goal even when discomfort appears inevitable.

Comfort as a goal of care appeared implicit to the nurses, in our study (II), but goals of care need to be made explicit through the interaction between patients and health care personnel (Stanek, 2017). Such interaction and the establishing of goals tailored to the individual was facilitated by patients being more awake, and thus appreciated by the nurses. According to our findings, comfort as a goal of care and defined nursing skill appears paramount in contemporary intensive care contexts of minimal sedation. Minimal sedation practices hold the power for nurses and patients to cooperate on the goals of care. Kolcaba's definition of comfort as “an immediate experience of being strengthened by having needs for relief, ease, and transcendence met in four contexts (physical, psychospiritual, social, and environmental)” (Kolcaba, 1997, 2003) encompasses the three different types of comfort that may be obtained. In our secondary analysis (III) transcendence was found particularly useful as the obtainable type or level of comfort and hence as a goal of care. Assisted by the nurse, patients could achieve transcendence and rise above their discomfort when discomfort was regarded inevitable or direct relief from pain was not attainable. The companionship or fellowship assumed to promote transcendence resembles the act of “standing by,” described by Karlsson et al. as a deep caring action stimulating the patient to use their inner strength to fight for survival (Karlsson et al., 2012a, 2015). “Standing by” implies mediating both calmness and eagerness through attentiveness, friendliness, willpower, courage and other attributes of personal engagement (ibid). Personal engagement may encourage the nurses in their work.

Flinterud et al. (2019), showed that inter-personal relationships with ICU patients and their relatives inspired and motivated nurses in performing nurse-led follow up care such as writing ICU diaries, but also in their general work. Ednell et al., showed that writing diaries for ICU patients contributed to a deeper personal engagement for the nurses (Ednell, Siljegren, & Engstrøm, 2017). This suggests that caring actions, such as diary writing, may mutually benefit both provider and recipient of care. This is in line with our argument that the comfort type of transcendence may not only be valuable in obtaining comfort for patients in the ICU but may concurrently reduce the nurses' feeling of not succeeding in alleviating pain and discomfort in their patients (III). Transcendence furthermore is one of three major assumptions in Parse's theory of human becoming and refers to reaching out and beyond the limits a person sets and that one constantly transforms (Nursing Theory, 2016).

Although the theory has been considered inapplicable to acute emergent care, the aspect of transcendence appears to be much in line with the understanding of transcendence in this study offered through Comfort theory (Kolcaba, 2003). Egerod et al. (2015), referring to Parse's transcendence and to the concept of liminality (Turner, 1967), emphasize the role of caregivers in co-transcending with patients back to life. Back to life refers to transition from the liminal state of facing the choice of life or death experienced in critical illness, also identified in our study. Supported by Kolcaba's view, we may conclude that this co-transcendence may be of great value to both ICU–patients who strive to endure discomfort and nurses who strive to enhance comfort when sedation is minimized.

A recent focus on enhancing comfort in ICU, holds the goal of a comfortable, calm and cooperative patient able to engage with family and caregivers. These principles have been proposed by Vincent and fellow intensivists through the concept of eCASH (Vincent et al., 2016). Comfort, according to the authors, may be achieved through analgosedation, humane and person-centred care and a health-promoting environment, hence corresponding well to the overall aim of our study. However, looking back on the first guidelines for analgesia and sedation in mechanically ventilated ICU patients at the breaking of the paradigm shift in ICU –sedation practice one can find an extensive algorithm with the question "Is the patient comfortable and at goal?" as the starting and ending point (Jacobi et al., 2002). The comfort perspective in this model has unfortunately not been highlighted throughout subsequent guidelines focusing more on the systematic approaches to PAD (Barr et al., 2013). The evident complexity of discomfort other than pain has over the years resulted in research predominantly focusing on the more accessible quantitative measures of pain, sedation and medication. This research seems to have evolved reciprocally with valid assessment tools and clinical guidelines highly valuable in the clinical settings as in research. However, the inclusion of Immobility and Sleep disruption in the updated clinical PAD**IS** guidelines (Devlin et al., 2018) in a promising way acknowledges discomforts other than pain during strategies of light sedation.

The contemporary focus on comfort by means of the eCASH concept (Vincent et al., 2016) has gained much publicity, which may also indicate a warranted attention following and integrating with the paradigm shift in sedation practice. Patient-centred care and interdisciplinary collaboration are key features in the eCASH concept and essential to both the implementation and the delivery of treatment and care as described (ibid). Most important, the re-focusing on comfort intertwined with systematic approaches appears beneficial to both patients being cared for and nurses caring for them, and may contribute to diminishing the comfort gap identified in our study.

7.3 Methodological considerations

According to Thorne (2016), researchers must account for possible biases in the findings of a study. The framework offered by Guba and Lincoln (Lincoln & Guba, 1985) will be used to describe trustworthiness by addressing the criteria of credibility, dependability, confirmability and transferability in the research.

Credibility

Credibility pertains to how one can establish truth of the findings. In this study, the intention was to ensure a coherent study from research questions to conclusions. In chapter 5, I have accounted for the methodology, the context of the study, sampling and recruitment, data-collection and analysis to ensure transparency of the methods. Thick descriptions of the findings and illustrative quotations from participants and field notes have been provided. Some methodological issues however need further consideration to enhance credibility.

Regarding the *study design,* I started this project without a clear presumption of methodological use, but I was devoted to the clinical issues of discovering ways to make the ICU stay better for the patients. During the course of the study, I turned to the methodological literature and realized the challenge of not having admitted to one specific methodology from the start. I attended courses where *method slurring* was a hot topic, referring to researchers, mostly novices like myself, who were unclear and inconsistent about their methodological choices or use. I then discovered the work of professor Sally Thorne through her visit to our university. Through discussions with her and reading her work, Interpretive description came to inspire the study. In hindsight, the flexibility that followed the lack of a rigid methodological choice has contributed to the true emergent design of this study; sub-studies inspired by phenomenological and ethnographic traditions, building on each other, and resulting in a secondary analysis combining data and exploring further already described phenomena. Some of these steps would not have been possible with an initial admittance to one specific methodology. On the other hand, admitting to a specific methodology or abiding more strictly to all aspects of the Interpretive description from the start would have provided stricter prescriptions useful to me as a novice in the research process.

Regarding the *inclusion criteria* determined by the protocol of the main study, I believe that lengthening the required stay in ICU from 24 to 48 hours for the patients could have ensured more intensive care experiences. Some of the patients provided meagre data due to their short stay and others due to their clinical condition. We were however able to continue inclusion until we considered the total amount of data sufficient for informational power (Malterud et al., 2015), an alternative concept to *saturation*. Thorne (2016) claims that the professional mandate of the nursing discipline upon which Interpretive description is built, requires a constant seeking for nuances on diversity to foster individuality in care. She holds a similar claim for the applied research and hence argues towards the use of the concept of saturation as a measure of credibility.

Regarding the *data collection,* the re-interviewing and triangulation of methods in this study may enhance credibility. According to Thorne, Kirkham, & Macdonald-Emes (1997), repeated interviewing of participants enables reconsideration and refinement of developing assumptions. The re-interviewing of patients, and interviews with nurses after observations may have served as member-checks, or bringing raw data back to the informants, as recommended by Guba & Lincoln (1985). Thorne et al. (1997), however, argue that credibility checks might not serve its purpose to demonstrate truth. However, to bring conceptualizations representing the sample rather than the individual, back to the informants for critical consideration might be useful (Thorne et al., 1997). In line with this, we did consider using focus groups of nurses, and possibly ICU patients, to reflect on our findings from sub-study I and II, but the study time did not allow this. Nevertheless, this might have brought interesting perspectives to our findings.

User involvement is required in all current research and may increase the credibility in studies. When I started this project, the requirement of involving user participants was not so explicit. However, the use of a former ICU patient in developing and testing the interview guide was useful. Moreover one former patient was partly involved in discussions about findings in sub-study I, but later in the research process he was unfortunately too ill to participate. It would have been desirable to include a user participant from the start to collaborate through all stages of the research process.

Dependability

Dependability refers to consistency and whether a study could be repeated based on the information given about how the study was conducted. In qualitative studies, the result of a replicated study would not correlate, nor be expected to, but the variance should be traceable (Lincoln & Guba., 1985). Dependability is closely linked to credibility and the thorough accounting for the research process to provide transparency. Furthermore, to enhance rigor in the analysis, and as recommended in interpretive description (Thorne, 2016; Thorne et al., 1997), a reflective journal was kept and perceived valuable throughout the iterative analytic processes. The triangulation of researchers in the analysis involved members with either exquisite academic skills or close clinical affiliation and hence ensured breadth to the analysis.

Regarding the *analysis,* due to the lack of experience with different analytic approaches, no particular plan for choosing the approach for the different sub-studies had been made before study start. Systematic text condensation (STC) (Malterud, 2011, 2012) was chosen in the first sub study. The approach is recommended for novice researcher by the author because it provides a rather simple and rigid procedure. It is inspired by Giorgi's phenomenological approach, although less philosophical, and thus complied well with Interpretive description which also somewhat pragmatically draw on phenomenology among other methodologies. STC, however according to the author, offers "limited space for creative interpretations and elegant conclusions" (Malterud, 2012, p. 804). Findings in this sub-study may thus appear more descriptive than interpretive. In sub-study II where the data consisted of both field notes and interviews, I was eager to move beyond descriptions. Having introduced Kim's model of nursing processes, I started a time-consuming process of both deductive and inductive analytic attempts involving different combination of aspects in Kim's model. Unable to make sufficient sense of this, together with the research team, I turned to thematic content analysis (Green & Thorogood, 2014), and completed the analysis guided by the processes of deliberation and enactment in Kim's model. In sub-study III, we chose abductive qualitative content analysis, a combination of inductive and deductive analyses, to conduct the secondary data analysis (Heaton, 2008; Thorne, 1994, 2016). In this analysis, applying elements from Kolcaba's Comfort theory enabled the identification of central findings of the study. I considered the analytical work in this study a continuous challenge as we have taken on new and more complex approaches during the course of the study. However, this has provided me, as a scholar, varied and valuable experiences of using different analytic approaches. A thorough description of the analytic steps in all parts of the study and supported by tables and figures, provide the readers the opportunity of following the analytic reasoning process.

Transferability

Transferability in qualitative research refers to the applicability of the findings and conclusions to other subjects or other contexts (Lincoln & Guba, 1985) and is left to the reader to evaluate based on the description available in the study. To strengthen the transferability in this study, I have clarified the characteristics of the participants and the context (Ch 5.4, 5.5.1 and 5.5.2). Also, the rich presentation of findings will enhance transferability. Constituting the qualitative arm of the study, we focused primarily the experiences of the patients. We did not consider the correlation between the qualitative and the quantitative data of recorded pain and sedation levels and delirium relevant, taking into account the small sample size. However, the quantitative data from 61 patients in the last cohort in the main study supported the findings by representing the context. Nevertheless, the findings can only represent patients and nurses in *a context of analgosedation*. Neither did we focus normatively on nurses' adherence to the protocol, but to the expected overall principles of analgosedation. The inclusion criteria regarding a sedation level of RASS = 0 to -3, moreover comprise patients less awake than in no-sedation studies where RASS = 0 is frequent. On the other hand, most of our patients have been sufficiently awake during their stay to provide thick descriptions of their experiences and memories.

Confirmability

Confirmability refers to the objectivity or neutrality of the data and the interpretations. The involvement of the research team to prevent bias has been accounted for to enhance confirmability. The epistemological position in the qualitative research paradigm implies that knowledge is not pre-existing but produced in interaction between the participants and the researcher (Kvale & Brinkmann, 2009; Polit & Beck, 2017). Being a contributor to the data and hence the knowledge generation, it is crucial to reflect upon and to be explicit about how my pre-conceptions, motivations, qualifications and familiarity with the field of intensive care might possibly have influenced on the research process.

Being a critical care nurse, I entered the field as a researcher with my personal experience from many years of clinical work. This included a pre-understanding of the critically ill patients' situation and of the practices and procedures relating to pain and sedation. My experience has mainly been related to adult patients in surgical intensive care, including trauma and postoperative patients. I have been part of the changing sedation paradigm, over the years resulting in patients being more awake on mechanical ventilation. Working with cardiac surgery patients in my early career, however, made me reflect on the difference between being prepared and not when waking up with an endotracheal tube. Many of the cardiac surgery patients, well informed, were calm and cooperating, oftentimes smiling or "giving thumbs up" when waking up. Regarding trauma patients and other acutely intubated patients, my experience has been that calming and informing during wake up often works, but that the insecurity of many nurses afraid of the patients' agitation and panic often results in sedation as first choice. My long experience from working in postoperative care has also directed me to a "fast-track" mind-set, implying the planning of discharge already on admission. I believe this facilitated the acceptance and adoption of the analgosedation approach. Over the years, I have reflected upon the personal engagement and empathy shown by most nurses, but lacking in others, acknowledging the extent to which ICU patients are at the individual nurses' mercy.

As a researcher, in addition to my experience from the field, my role was influenced by my limited experience from research when planning this study. However, I had the experience of interviewing from an earlier study where I interviewed close relatives who had consented to organ donation of their deceased family member. Both as a human being *and* a nurse, I had experienced to be affected by the interviewees' stories, their suffering and need for information, alleviation and comfort.

As an interviewer, I reflected on the influence of my ICU experience on the situation. Familiarity with the research field and topic may contribute to sensitivity towards nuances in the responses of the informants. My experience could put me in danger of being insufficiently curious to catch allusions or hints that could have been elaborated on. I could too quickly recognize their experiences according to my own preconceptions. In the present study, my existing knowledge turned out important in grasping and following up patients' responses when their communication was impaired, either due to fatigue or dyspnoea, or if their memories were vague. Despite my clear and repeated information about being a researcher, although an ICU nurse, some patients spoke as if I was an employee and that they were answering some sort of satisfaction inquiry. I assured them of my independent role and encouraged them to speak freely. Furthermore, as an intensive care nurse encountering people suffering, my empathy might have been an obstacle to the distance necessary in research. However, in conducting interviews with bereaved family members in my earlier research, I experienced my background from the field and my knowledge about the topic to be important in building rapport in the interview setting and in comprehending the experiences.

As an observer, the choice of adopting the approach of an "observer as participant" (Hammersley & Atkinson, 2007) was guided by my background. Some participation might be necessary to reduce the influence on the natural situation (Malterud, 2011, 2012). The ideal degree of participation is the one that generates the best quality of data, and the challenge is to combine the participation and the observation to gain an insider perspective yet enabling a proper description to the outsiders (Fangen, 2010). Although being a critical care nurse, I was not acquainted with the specific setting, the patients or the nurses under study with a few exceptions. Nevertheless, I felt my credibility also as a researcher among colleagues assumed some participation during the observations. Navigating in the possibly conflicting roles of being a researcher and a colleague nurse was challenging. I might have missed out on some observations by my eagerness to blend in and make the nurses feel comfortable in my vicinity. Placing myself on a stool in a corner taking notes could have made the nurses insecure and uncomfortable, whereas participating fully as a nurse at work would have interfered with my primary intention of observing. I was explicit about not being normative or prescriptive in my observations, but sometimes the nurses were definitely trying to please me, and my focus on analgosedation practice. Both in informing the nurses prior to the study and during the data collection, I emphasized my assumptions of their enactments to be reasonable and well intended, but I was curious about their deliberations for enacting.

In summary, I was aware of that my experience as an ICU nurse could restrict my exploration, but at the same time contribute to a better understanding of the stories that were being told by both patients and nurses. Regarding participant observations, I was in danger of "going native" and overlooking important issues that a person outside the professional field might have observed and critically questioned (Fangen, 2010; Green & Thorogood, 2014). However, the native or insider perspective provides access to the rationality of things that at first may seem irrational and misguided (Green & Thorogood, 2013). Being a "professional stranger" (Agar, 1980 as cited in Green & Thorogood, 2014), implies maintaining the ability to ask naïve questions despite being an "insider".

7.4 The use of theoretical perspectives

None of the two the theoretical perspectives used in this study, Kim's model of nursing processes (Kim, 2010) and Kolcaba's Comfort theory (Kolcaba, 2003) were used during the initial planning of the study. According to Interpretive description (Thorne et al., 1997), a formal conceptual framework is not considered necessary. Rather, a critical analysis of existing knowledge may constitute an appropriate base for the qualitative inquiry. Moreover, applying theoretical perspectives early in qualitative research is by some researchers considered to possibly bias data collection and analysis (Polit & Beck, 2017).

During the course of our study I was introduced to Kolcaba's Comfort theory, which offers valuable perspectives on comfort as a core value in nursing. As an intensive care nurse, I appreciate such core values, and find them important in times when technology and advancements take more and more place. Advancements that may challenge the well-being of patients, like sedation minimizing strategies, may in particular benefit from structures pertaining to values like comfort. Definitions offered by Kolcaba (2003) and concepts in the taxonomic structure of the Comfort theory including contexts and types of comfort as well as comfort measures, appeared helpful in framing our understanding of pain and discomfort in the intensive care. More specifically, it enabled the identification of which type of discomfort contributed the most to the comfort gap and how transcendence as one type of comfort could be obtained for the patients in intensive care. Comfort theory, however, aims at capturing a truly holistic experience (Kolcaba, 2003). If the theory had been planned to frame the entire study, inquiring about holistic comfort needs in the patients would have been more appropriate, not restricting them to pain and wakefulness. On the other hand, the holistic perspective appeared useful in defining the different aspects of discomfort in our patients to be intertwined to comprise a whole and identifying the nurses' deliberations and enactments to intervene on these.

Kim's model of nursing processes was chosen to frame our exploration of how critical care nurses manage pain and other discomforts during analgosedation. The processes of deliberation and enactment (Kim, 2010) were used to describe nurses' involvement in relevant clinical situations and to guide the initial analysis of the nursing data. Different concepts were however considered in the initial phase. Clinical judgment and decision-making according to Simmons (2010) suggests an endpoint to the thinking process whereas clinical reasoning emphasizes the cognitive processes prior to an endpoint. None of these terms however go beyond the end point of cognition and cover the process of enactment. Kim's model therefore seemed particularly useful in exploring the characteristics of ICU-nurses' clinical practice as it covers the whole nursing process of decision-making *and* interventions. Kim's model might appear somewhat inflexible. Despite the arrows indicating a back and forth process of deliberation and enactment, the use of boxes may be restricting and complicate its use. Despite not being straight forward, we found the model useful to obtain a broader picture of how nurses think and what they do in regard to critically ill patients' pain and other discomforts.

Other models might have assisted us in this part of the study, and both Tanner's clinical judgment model (Tanner, 2006) and the Theory of unpleasant symptoms (Lenz, Pugh, Milligan, Gift, & Suppe, 1997) were taken into consideration.

8 CONCLUDING REMARKS

8.1 Empirical contribution

The empirical contribution of this thesis pertains to the in-depth exploration and description of discomforts other than pain in intensive care, unfolded from the perspectives of both patients and nurses. The findings provide novel insights and improved understanding of the discomforts other than pain overriding the pain experience in the patients' descriptions. The discomfort has been defined as being deprived of the functioning body, the functioning mind, and of integrity.

In this study, pain and other discomforts have been separated for analytical purposes and separately discussed for clinical purposes. In the course of this study it has become clear that pain may be the easier part to assess and manage, other discomforts the more challenging. New perspectives on nursing processes on deliberation and enactment regarding pain and other discomfort have been offered through the uncovering of nurses' systematic approaches to pain, and unsystematic approaches to other discomforts. Earlier findings have been confirmed about how critical care nurses may experience strain from balancing comfort and progress in their patients when abiding to strategies of minimizing sedation.

Specifically, the findings provide a novel insight into the inevitability of discomfort in ICU, demonstrated by a comfort gap. This comfort gap constitutes the discomfort that remains in spite of the nurses' appropriate deliberations and enactments towards meeting their patients' needs. Returning to our analytical and clinical differentiation of pain and discomfort, the two may be re-merged through the application of comfort. The significant core nursing value of comfort intertwined with systematic approaches may contribute to diminishing the comfort gap identified in this study. Pain and discomfort should be assessed in the different contexts of comfort, types of comfort may represent goals of care and treatment, and comfort measures apply to both pain and discomfort. The structures for this application were provided through Comfort theory (Kolcaba, 2003). The comfort types of *ease* and *relief* are fundamentals in nursing care. *Transcendence,* however, has in this study been highlighted as one type of comfort and hence a goal of care, that may benefit both patients being cared for and nurses caring for them. These new perspectives pertain to our overall aim of generating knowledge important in enabling health care personnel to help patients tolerate intensive care treatment in relation to current strategies in managing pain and sedation.

8.2 Implications for clinical practice

The exploratory nature of the research in this thesis provides empirical data to support clinical practice. Highlighting the discomfort overriding experiences of pain in ICU patients in this study should bring attention to the alleviation of this along with pain. Using the three aspects of discomfort identified in the findings may assist nurses in diminishing the comfort gap in their patients both during ICU stay and after discharge. To assess in what way the particular patient is deprived of his or her *functioning body*, *functioning mind* or *integrity* may help to individualize and structure the planning of care to enhance comfort.

Discomfort pertaining to the deprivation of the functioning mind was identified as the major constituent of the comfort gap in this thesis and requires attention. Delirium evidently contributes to this deprivation. Although more research is needed, multi-component nursing care interventions should be considered acknowledging the multifactorial origin of delirium. Consequences of the deprivation of the functioning mind affected many patients, although differently, long after hospital discharge. This confirms the finding of other studies that individual follow up should be offered to help patients come to terms with their memories from ICU stay. Although not offered patients interviewed in this study, intensive care diaries may also help patients to understand their memories and create a coherent story from the illness trajectory.

Currently, systematic approaches are warranted to ensure quality in care. Transcendence as a type of comfort, and goal of comfort, has been introduced in this thesis. Nurses' personal repertoire of engagement, creativity, and "specialties" should be integrated with systematic approaches. Such companionship is appreciated by patients and may enhance comfort. The three aspects of discomfort may also structure clinical education and supervision of nurses and may also be included in curricula on pain and discomfort in intensive care nursing.

8.3 Implications for research

This thesis provides an exploration of discomfort in intensive care and has suggested descriptions and use of concepts pertaining to comfort that may be further explored in critical care research. Using the deprivation of the body, the mind and integrity as a framework to structure future research on both discomfort and comfort may expand the body of knowledge needed to enhance comfort in intensive care. Furthermore, concepts from Comfort theory discussed in this study, may be used to structure research on more systematic approaches to comfort care.

The discomfort of being deprived of a functioning mind, to a large extent pertaining to delirium is highlighted in this thesis. This confirms the need for a better understanding of the causes of brain dysfunction in critical illness and how delirium may possibly be prevented and best treated. Therefore, evidence based knowledge on the role of non-pharmacological interventions to reduce or shorten delirium such as reorientation, cognitive stimulation, improved sleep, reduced immobility and reduced hearing or visual impairment is highly needed.

Comfort in intensive care, a concept partly revived by the strategies of minimizing sedation and highlighted in this thesis presupposes an inter-professional focus (Vincent et al. 2016). This is promising also for inter-professional collaboration in research and may entail new areas of research regarding patient comfort, and comprising both qualitative and quantitative approaches. Follow-up programs for ICU-patients, unfortunately not yet established in our hospital, is warranted. This would also represent an obvious inter-professional research arena possibly involving both nurses, physicians, physiotherapists, occupational therapists and speech-language therapists collaborating on ICU-rehabilitation.

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Reprint of papers I-III

Paper I	Berntzen H, Bjørk IT, Wøien H, "Pain relieved, but still struggling" – critically ill patients' experiences of pain and other discomforts during analgosedation. *Journal of Clinical Nursing, 2017;00;1-12. https://doi.org/10.1111/jocn.13920*
Paper II	Berntzen H, Bjørk IT, Wøien H, "Having the compass – drawing the map": Exploring nurses' management of pain and other discomforts during use of analgosedation in intensive care. *Nursing Open, 2019;6: 453-62. https://doi:10.1002/nop2.227*
Paper III	Berntzen H, Storsveen, A-M, Bjørk IT, Wøien H, "Please mind the gap": A secondary analysis of discomfort and comfort in intensive care. *Journal of Clinical Nursing, 2020:00:1-14. https://doi:10.1111/jocn.15260*

Paper I

Accepted: 4 June 2017

DOI: 10.1111/jocn.13920

ORIGINAL ARTICLE

WILEY Journal of Clinical Nursing

“Pain relieved, but still struggling”—Critically ill patients experiences of pain and other discomforts during analgosedation

Helene Berntzen MNSc, RN, PhD Student[1] | **Ida Torunn Bjørk MNSc, RN, Dr. Polit, Professor Emerita**[2] | **Hilde Wøien MNSc, PhD, RN, Post Doctor**[1]

[1]Division of Emergencies and Critical Care, Oslo University Hospital, Oslo, Norway

[2]Department of Nursing Science, University of Oslo, Oslo, Norway

Correspondence
Helene Berntzen, Division of Emergencies and Critical Care, Oslo University Hospital, Oslo, Norway.
Email: helene.berntzen@studmed.uio.no

Aims and objectives: To explore how critically ill patients treated according to a strategy of analgosedation experience and handle pain, other discomforts and wakefulness.

Background: Patients experience both pain and discomfort while in the intensive care unit. International guidelines recommend focused pain treatment and light sedation. An analgosedation protocol favouring pain management, light sedation and early mobilisation was implemented in our university hospital medical and surgical intensive care unit in Norway in 2014. The analgosedation approach may affect patients’ experiences of the intensive care unit stay.

Design: Exploratory, descriptive design using semi-structured interviews.

Method: Eighteen adult patients treated in intensive care unit >24 hr and receiving mechanical ventilation were interviewed 1–9 days after intensive care unit discharge. Ten patients were re-interviewed after 3 months. Data were analysed using the “systematic text condensation” approach.

Findings: Four main categories emerged from the analysis: “In discomfort, but rarely in pain,” “Struggling to get a grip on reality,” “Holding on” and “Handling emotionally trapped experiences.” “Pain relieved, but still struggling” was the overarching theme. Analgosedation provided good pain relief, but patients still described frequent physical and psychological discomforts, in particular related to mechanical ventilation, not understanding what was going on, and experiences of delusions. To come to terms with their intensive care unit stay, patients needed to participate, trust in others and endure suffering. After hospital discharge, patients described both repression of experiences and searching for recognition of what they had gone through.

Relevance to clinical practice: Despite good pain relief during analgosedation, other discomforts were commonly described. Critically ill patients still experience an intensive care unit stay as a traumatic part of their illness trajectory. Nurses need to attend carefully also to discomforts other than pain.

KEYWORDS
analgosedation, critical illness, experiences, intensive care, interview, nursing, pain, qualitative

1 | INTRODUCTION

A majority of patients experience both pain and discomfort while in the intensive care unit (ICU) (Barr et al., 2013; Puntillo, 1990; Puntillo et al., 2014; Rotondi et al., 2002). Most critically ill patients receive both analgesia and sedation to assist in enduring uncomfortable nursing procedures and medical treatment, including mechanical ventilation (MV). International critical-care guidelines have for some years recommended focused pain treatment and lighter sedation (Barr et al., 2013), reminding clinicians of the importance of the systematic assessment of pain, sedation and delirium with validated tools (Woien, Vaeroy, Aamodt, & Bjork, 2012). Analgosedation involves treating pain and discomfort first and providing sedatives only when necessary to help patients to rest and to reduce anxiety and agitation (Devabhakthuni, Armahizer, Dasta, & Kane-Gill, 2012). Targeting pain and titrating sedation increases patient responsiveness and awareness. When aware, patients may be able to communicate needs, self-report pain and be more cooperative (Kress, Pohlman, O'Connor, & Hall, 2000; Schweickert et al., 2009).

2 | BACKGROUND

Patients' experiences during stays in ICU have been extensively explored in quantitative and qualitative studies (Cutler, Hayter, & Ryan, 2013; Egerod et al., 2015; Jones, Griffiths, Humphris, & Skirrow, 2001; Rundshagen, Schnabel, Wegner, & am Esch, 2002). Studies investigating the relationship between different analgesic and sedative approaches and patients' memories from ICU stays were recently presented in a review (Aitken et al., 2016). However, the results are conflicting, and further studies are needed (ibid). Pain in ICU patients complies with all four categories of pain proposed by Loeser and Melzack (1999): nociception, perception of pain, suffering and pain behaviours. Nociception is the detection of tissue damage by specialised nerve fibres. The perception of pain is the individual awareness of the nociceptive stimuli, and suffering described in the language of pain provokes a variety of pain behaviours. Among these are pain behaviours used for pain assessment in the critically ill, such as grimacing, body movements, muscle tension and compliance with the ventilator (Gélinas & Johnston, 2007; Payen et al., 2001). Suffering may be defined as a negative response not only to pain, but also to psychological states like anxiety, fear or loss of loved ones (Loeser & Melzack, 1999). According to Kolcaba, pain is one type of discomfort. Discomfort is an umbrella term that includes pain, and comfort is an umbrella term covering pain management (Kolcaba, 2003; http://www.comfortline). Kolcaba states that suffering is the opposite of comfort and that comfort measures may be applied to alleviate all kinds of discomfort. Oliveira (2013), in her conceptual analysis, argues that comfort measures are appropriate for use in all healthcare settings. She further refers to the "discomfort of pain", indicating an understanding of pain in line with Kolcaba's. Kolcaba also considers the discomfort of pain to be a significant detractor from comfort (Kolcaba, 2003).

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

- The analgosedation approach provides good pain management in ICU.
- Despite good pain relief, other discomforts are common.
- Patients treated with the analgosedation approach often have delusional memories.
- Patients handle experiences from ICU individually and need to be offered individual follow-up measures.

Delusional memories are defined as unreal experiences (Jones, 2000) and have been thoroughly investigated and reported from ICU stays (Jones et al., 2001; Nouwen, Klijn, van den Broek, & Slooter, 2012; Ringdal, Johansson, Lundberg, & Bergbom, 2006). When treated with analgosedation, patients may experience comfort needs related to their degree of wakefulness. ICU patients' experiences of wakefulness may be linked to, but not necessarily correlate with, sedation levels assessed systematically by ICU nurses. Findings from studies investigating the relationship between the level of sedation and the perception of stressful experiences are still inconclusive. Some studies favour light sedation while other studies report that patients suffer more from delusional memories when they are lightly sedated (Samuelson, Lundberg, & Fridlund, 2006, 2007; Weinert & Sprenkle, 2008). The recall of factual memories in earlier studies has varied highly in incidence (17%–83%) (Roberts, Rickard, Rajbhandari, & Reynolds, 2007; Rotondi et al., 2002; Rundshagen et al., 2002), and despite the priority of pain management and light sedation in two different protocols, one-third of the patients interviewed by Burry et al. (2015) had no recollection of being in ICU, and the degree of recall in those who remembered their stay diminished over time.

The main finding of a metasynthesis of 22 qualitative Nordic studies from 2000–2013 on patient experiences in ICU (Egerod et al., 2015) was that despite a more humane environment, more consistent pain management and lighter sedation, human suffering was still an issue during intensive care. Interpretation of the findings provided a deeper description of patient experiences. However, none of the studies included specifically investigated aspects of pain and discomfort, or included systematic use of protocols for analgesia and sedation. Exploring experiences to better understand patient discomfort, and hence comfort needs, may enhance the quality of care in the ICU (Cutler et al., 2013; Oliveira, 2013).

To our knowledge, no study has specifically explored patient experiences and handling of these when analgosedation was part of the treatment given in ICU.

2.1 | Aims and objectives

We aimed to explore patients' experience of pain, other discomforts and wakefulness during critical illness when treated using the analgosedation approach. We further aimed to explore how patients handled these experiences after ICU discharge.

Our research questions were as follows:
When treated using the analgosedation approach:

- How do ICU patients describe their experiences of pain, other discomforts and wakefulness?
- How do patients handle these experiences after discharge from ICU?

3 | METHODS

3.1 | Design

This study was part of a larger study that investigated the effect of implementing an analgosedation protocol in ICU. An exploratory design was used because it allows insight into and understanding of a phenomenon (Brink & Wood, 1998). The phenomenon is studied in its natural context and the findings of the study are generated through interaction between the researcher and the participants (Polit & Beck, 2008). Interpretive description (Thorne, 2016) formed the theoretical scaffolding of the study. The purpose of this approach is to develop useful nursing knowledge for clinical application by attempting to grasp, describe and interpret practice and its complexity.

3.2 | Setting

The setting was one 11-bed medical and surgical adult ICU in a university hospital in Norway. The unit had single-bed rooms and rooms with three beds separated by curtains. Only the single-bed rooms had windows. The nurse: patient ratio was 1:1 on all shifts, with the availability of an extra nurse if required, depending on the patient's condition. Almost all the nurses in the ICU were certified critical-care nurses. Assessment tools for pain, agitation and delirium were routinely used by the nurses. The ACCM guidelines (Barr et al., 2013) and a Danish analgosedation protocol specified for neurosurgery patients (Egerod, Jensen, Herling & Welling 2010) influenced the development of our analgosedation protocol. The protocol was expanded to also include general medical and surgical patients and to cover some specialties in haematology and transplantation. The analgosedation protocol directs for monitoring patients' symptoms of pain and discomfort continuously with titration of recommended analgesics and sedatives, assessment and documentation of pain, sedation and confusion at least once per shift, and strongly advices for early mobilisation. An awake and cooperative patient is the overall preferred goal. To achieve patients' level of pain and sedation within daily target goals and to detect confusion at an early point, pain and discomfort are addressed first, with supplementary sedative and hypnotic agents only when necessary. In the Norwegian care setting, physical restraints are not used in the ICU. Apart from physiotherapists and attending physicians, no other healthcare staff or therapists are involved in the bedside care and treatment of the patients. ICU nurses are also the primary caretakers of patients' family members.

3.3 | Participants and recruitment

Criterion sampling was used (Patton, 2002). In the larger study, 105 mechanically ventilated patients, aged over 18 and with an ICU stay of >24 hr, responsive to verbal stimuli (RASS level–3 and above) and treated according to the analgosedation protocol were consecutively included. Exclusion criteria were diagnoses of acute severe intracranial or spinal neurological disorder or inability to communicate in Norwegian. Of the 105 patients enrolled, 18 patients discharged to a general ward were included consecutively for interviewing in this study. Of these eighteen, one patient died and one declined further contact. The remaining 16 patients were contacted 3 months later and ten consented to a second interview. Two were still in hospital, three declined and one did not respond to the enquiry. According to the explorative design of the study, all patients included were interviewed regardless of their immediate recollection of their ICU stay.

When considered physically and cognitively able by the ward nurse to be asked for an interview, the researcher informed the patient about the study. When informed consent was obtained, an appointment was made for the first interview. According to Malterud, saturation of data is not a realistic goal in an exploratory study, but it is necessary to include enough participants to generate sufficient data to secure information power (Malterud, Siersma, & Guassora, 2016). The stepwise inclusion in this study allowed for continued inclusion if the data generated were not considered sufficient to meet the aim of the study (ibid, p. 110).

Patient characteristics are shown in Table 1. The mean age was 47 years, and the mean length of stay in ICU was 10 days. To ensure participant anonymity, diagnoses are not displayed, but the majority of the patients had a diagnosis of severe malignancy or developed complications after lung or liver transplantation. In general, patients were lightly sedated. Most patients had low maximum pain scores assessed using the Numeric Rating Scale (NRS) and the Critical Care Pain Observational Tool (CPOT). Three patients had a positive delirium score at least once during their ICU stay according to the Confusion Assessment Method (CAM-ICU), and one patient was documented as impossible to assess at all attempts. Two patients had no recollection at all of being in ICU.

3.4 | Data collection

Data were generated in semi-structured qualitative interviews (Kvale & Brinkmann, 2009). Because it is recommended that data regarding memories should be collected close to ICU discharge (Nouwen et al., 2012), we aimed to conduct the first interview within 1 week after discharge. Repeated interviews provide the opportunity to follow up and confirm evolving interpretations from earlier generated data (Thorne, 2016). All interviews were conducted by the first author between November 2014–August 2015.

TABLE 1 Patient characteristics

Patient	Gender	Age	Medical surgical	Length of stay in intensive care unit days	Interview I	Interview II
1	M	46	S	3	X	X
2	F	53	S	11	X	
3	M	27	M	14	X	
4	F	60	S	14	X	X
5	M	58	M	6	X	X
6	F	58	S	13	X	X
7	F	20	M	3	X	
8	M	73	M	3	X	
9	M	22	M	2	X	
10	M	78	S	48	X	X
11	F	65	S	3	X	
12	F	54	S	9	X	X
13	F	71	S	7	X	X
14	F	57	S	1	X	
15	F	40	M	5	X	X
16	F	18	S	3	X	X
17	M	26	S	18	X	X
18	F	29	M	19	X	

3.4.1 | First interview

Eighteen interviews lasting 10–56 min (mean 27) were conducted on a general ward at the study hospital 1–9 (mean 3) days after discharge from the ICU. An expanded version of the “The ICU Memory Tool” (ICU-MT) (Jones, 2000) was used as an interview guide. This tool is a 14-item questionnaire developed to examine patient recall of factual events, feelings and delusional memories. The tool has been used to guide interviews and in the self-reporting of memories (Burry et al., 2015; Ringdal et al., 2006). The ICU-MT was translated into Norwegian and was expanded with more questions regarding pain, other discomforts and wakefulness. Questions about positive experiences were also added. The performance of the ICU-MT was pilot-tested on a former ICU patient as part of the translation process. Despite the use of a structured guide, the opening question “What can you remember from the ICU?” invited the patients to reflect and to focus on individual experiences. Follow-up questions were used to clarify initial responses.

3.4.2 | Second interview

Ten interviews lasting 30–63 min (mean 49) were conducted approximately 3 months after discharge from ICU. Patients were interviewed by preference: in the hospital combined with readmission or follow-up (4), in their home (4), at their workplace (1) and one on Skype due to a 3-month stay abroad.

TABLE 2 Analytic steps in systematic text condensation (Malterud, 2012)

	Analytic steps	Result
1	Identifying themes: gaining an overall impression	Preliminary themes
2	Coding: identifying and sorting meaning units	Code groups
3	Condensation: dividing code groups into subgroups as means for condensation	Condensates
4	Synthesising: reconceptualisation of condensate content and development of descriptions and concepts	Categories

A thematic interview guide was used, containing open-ended questions and based on data from the first interviews (Thorne, 2016). Our aim was to explore the patients’ recall of experiences after 3 months and the way they handled this. During development, the guide was discussed with the former ICU patient who participated in the pilot testing of the ICU-MT. The guide was adjusted to explore relevant input brought in by the interviewees, still keeping the thematic structure of pain, other discomfort, wakefulness and handling of experiences. The second interviews were more conversational in nature than the first. Follow-up questions directed the focus towards the aim of the study.

3.5 | Ethics

The study was approved by the regional committee for medical research ethics (Health Region East, Norway; Project –ID; 2014/125) and was conducted according to the Declaration of Helsinki (WMA, 2013). Both written and oral information were provided, and informed consent was obtained from the participants before all interviews.

3.6 | Data analysis

Audio-recorded data from the interviews were transcribed verbatim by the interviewer. The software program, HyperResearch®, was used to organise data. Systematic text condensation (STC) was applied as an analytical strategy (Malterud, 2012), aiming for a cross-case thematic analysis of meaning and content. Analytical steps are shown in Tables 2 and 3. Two researchers independently and stepwise read the transcripts from the first interview to gain an overview and identify *preliminary themes* relating to patient experiences in ICU (Step 1).

Meaning units were coded, and *code groups* were formed by negotiating about the meaning of the content of the preliminary themes in relation to the research questions (Step 2). Pain was regarded as part of discomfort, but coded as a pain experience only when actually described as pain by the participants. Codes representing different aspects within each code group were subgrouped and condensed into artificial quotations, or *condensates* (step 3). The condensates contained the essence of the subgrouped codes and were formulated using the participants' own words (Malterud, 2012). All condensates were read by the three authors to confirm coherence with the transcripts.

The analysis of the second interviews was based on the existing code groups from the first interviews. Code groups, subgroups and condensates remained dynamic structures in number and content reflecting new discoveries throughout the analysis. Code groups were named according to final content and were given a category heading expressing the most significant interpretations in each code group (step 4). The recontextualisation resulted in four categories: "In discomfort, but rarely in pain," "Struggling to get a grip on reality," "Holding on" and "Handling emotionally trapped experiences."

All transcripts were reread for validation of category content concerning pain, other discomforts, wakefulness and handling of experiences. Finally, the overarching theme of "Pain relieved, but still struggling" was abstracted from all four categories (Malterud, 2012). An analytical text shown in the results section was written on the basis of each condensate. Quotations originating from each code group were chosen to illuminate the patient perspective. The first author translated quotations into English. All authors discussed all steps throughout the analytic process, and a decision trail was kept. Table 3 visualises the analytic process from preliminary theme to final category. One subgroup (1.1) is exemplified with extracts of meaning units and condensates.

Trustworthiness in this study was sought by applying the Lincoln and Guba framework (Lincoln & Guba, 1985; Shenton, 2004). To enhance credibility, patients transferred to other ICUs were excluded to reduce the risk of memories to be derived from other treatment strategies than the analgosedation protocol. Follow-up questions were used extensively, and a summary of the interviewer's understanding was presented to the patient at the end of each interview to ensure the right comprehension of descriptions. The STC was used to provide a simple and rigid procedure for analysis. The preunderstanding and possible influence of preconceptions on the interpretation of data were based on two of the researchers' extensive experience of working as intensive care nurses and their knowledge of previous research in the field. Credibility is further sought by providing thick descriptions of the patients' experiences, including quotations to emphasise the link to the data. Confirmability is enhanced by involving all three researchers in all steps of the analytic process and by presenting the analytic steps from raw data to results in the text. Dependability is sought by transparency through detailed descriptions of the research process allowing the reader to assess the research practice. Transferability is sought by providing sufficient contextual information about the study site to enable the reader to relate the findings to their own practice.

4 | RESULTS

4.1 | Overarching theme: Pain relieved, but still struggling

The main finding of this study was that patients treated with the analgosedation approach stated that physical pain was not a major concern. However, a number of different discomforts contributed to the struggle of being an ICU patient. Major sources of discomfort were MV, not understanding what was going on, and unreal experiences. The four main categories shown in Figure 1 emerged from the analysis and became the sources for the overarching theme; "Pain relieved, but still struggling." According to Malterud (2012), category headings are expressive statements of each code group.

4.2 | In discomfort, but rarely in pain

Only few patients used the words "pain" or "painful" when describing their experiences in ICU. Discomforts other than pain were

TABLE 3 Process of analysis using the steps of systematic text condensation (Malterud, 2012)

Steps 1 + 2 Decontextualisation			**Step 3 Condensation**	**Step 4 Recontextualisation**
Preliminary theme	Extract of meaning units Brackets indicate patient number/interview number →→→→→→→	Code group (consisting of coded meaning units) →→→	Subgroup and extract of condensate →→→	Category
Severe discomfort	I was treated very well, I think, they gave me regularly (medication) and they were watching me well. When I asked for more, I was given . . .at other times it went automatically—they had this routine (6/1) I was given good pain relief therapy. At that time, I had maximum epidural treatment (..), so there were no symptoms (...) physiological symptoms . . . that was no problem (1/2)	1. Experiencing pain and other discomforts	1.1. Experiencing pain relief They treated me well, and had a routine for pain treatment. I felt no physical pain. Epidural and ketorax ensured that my pain relief was very good *1.2. Experiencing pain* *1.3. Experiencing other discomforts*	In discomfort, but rarely in pain

frequently described. The rare descriptions of pain were usually accompanied by recall of close attention from nurses and good and immediate pain relief:

> *I was treated very well, I think, they gave me regularly (medication) and they were watching me well. When I asked for more, I was given . . .at other times it went automatically – they had this routine.* (6/1)

The experience of pain relief was mostly referred to as type of pain medication or routes of administration. Nonpharmacological measures were rarely mentioned. In some cases, more existential experiences, such as the fear of not surviving and being away from the family, were described in terms of pain:

> *I know in what way I think of pain: it is what is in the heart (her voice trembling). . .to be without your nearest and dearest . . ..* (12/2)

A few patients described severe and all-pervading pain during their time in ICU, and their experience of being taken seriously differed. One patient felt the physicians and nurses did their utmost to try and help relieve the pain without succeeding, whereas another felt she was not provided pain killers when she asked, and another felt misunderstood and treated hard-handedly. These patients were either suffering from chronic pain before admission or from complex medical conditions generating pain that was particularly difficult to relieve. Pain could sometimes trigger a wish to sleep through painful procedures:

> *It kind of hurt all the time; when they changed the sheets, I just wished they would leave me to sleep, because it was so uncomfortable if I had to move the least little bit.* (16/2)

Even though there were few descriptions of pain, some situations clearly triggered other discomforts. Discomfort was related to MV, including both the experience of not being able to breathe and discomfort caused by the endotracheal tube (ET). The discomfort of not understanding and not being able to communicate was evident in many descriptions:

> *I woke up on the ventilator and felt I was choking. I did see people, because my wife was there, and the nurses, and I was trying to speak, but was unable to. I used my hands to try and remove the thing, but they took my hands away. . .. it was terrifying and I thought, "good grief-are they going to kill me. . ."* (1/2)

Being treated badly, lacking influence on their own situation, and not being understood provoked a feeling of being a "nought" or a "thing." Discomforts were also related to lack of protection from distressing stimuli, including other patients and noise, to thirst, to different procedures and to immobility caused by equipment. One patient repeatedly told how terrifying it was to witness a patient in the next bed having an acute situation, which she assumed he did not survive. Coping with the stressful environment when awake, relating to other patients, and enduring discomforts was stressful, and some stated that they would have preferred to sleep more than they did. Discomforts related to unreal experiences or delusions were common.

4.3 | Struggling to get a grip on reality

The fluctuating states of wakefulness seemed to challenge the perception of reality and were described as a struggle to grasp what was real and what was not during the ICU stay, and sometimes after discharge.

Half of the patients had unreal experiences or delusions in ICU in terms of dreams, nightmares, hallucinations or confusion. Most delusions were unpleasant and created severe discomfort. Several recalled feelings, dreams or hallucinations involving constraints, threats against themselves and their family, or about death:

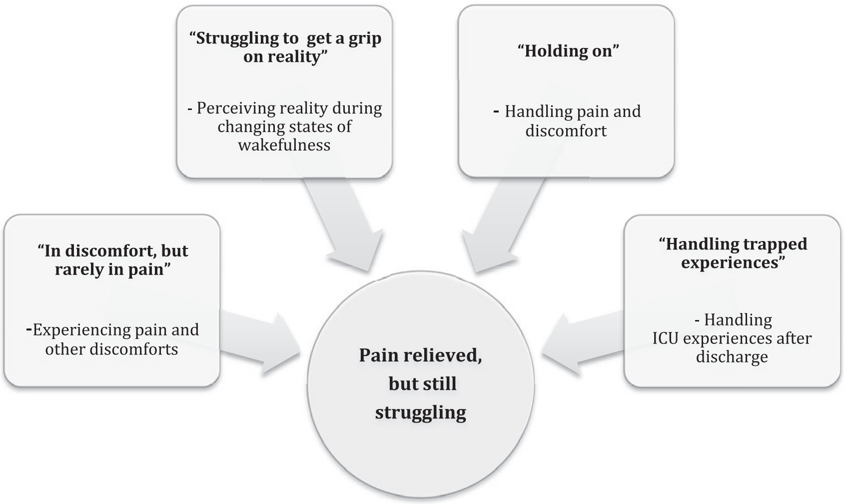

FIGURE 1 The overarching theme and the four categories (bold face), including code group titles

> *I saw things.. I dreamed of people coming to get me, harass me.. put me to death. And I could see people I recognized in the walls; they waved at me, said hello and laughed at me.* (1/1)

Waking up and not being able to make sense of the surroundings was confusing and stressful. Hence, being awake and able to communicate, at least partly understand and sometimes participate in what was going on was highly appreciated:

> *If you perhaps had some more painkillers and were a bit more awake, so that you could make sense of what was going on around you, and didn't wake up with a bang; "Hell, where am I, what am I doing here?" And you panic and you have a million questions – that's tough.* (3/1)

Several patients described how they tried to resist falling asleep, as strange dreams and hallucinations tended to occur when it got dark or when they closed their eyes:

> *A soon as I was trying to sleep.. being asleep is very close to being awake.., and when it's getting dark around you, these people appear and then it goes from bad to worse.* (1/1)

Some were convinced of unreality beyond ICU discharge from ICU and had to be reoriented by family and staff during ward stays. One young patient was, among many other things, so convinced there was a war going on that she never questioned the fact. Little by little, her many delusions were uncovered and eradicated:

> *It was my reality – I was 100% sure of it, just as real as you're sitting there now, so I didn't question it, you see. It was only when I got down here (the ward) that my sister told me what the real situation was – and that I had been dreaming.. so now I have to rearrange it all in my mind.* (18/1)

In a few cases, delusions did not occur until the patients had moved to the ward. Insomnia was capable of precipitating the delusions, which still predominantly appeared at night, or when trying to sleep. Perceptions were frequently woven together with real life events and persons and made some patients struggle with being able to distinguish whether it had been a delusion or reality when telling about it.

4.4 | Holding on

In handling pain and discomfort in ICU, patients described both striving to participate to reduce pain and other discomforts, needing to trust others and enduring in the form of measures to withstand physical and psychological threats. When awake, patients felt in a position to contribute to decisions about their own treatment and care. Several patients had knowledge about and preferences concerning pain management, like restricting opioids to avoid constipation, or being conscious about getting pain medication ahead of mobilisation. One patient demonstrated how he instructed the nurses to apply suction not too deep down his ET by indicating the level on the front of his neck. However, when patients were not invited to take part or were even rejected, it could lead to frustration, anger and resignation:

> *In ICU, at handover…where the nurses stand in the room and go through everything that is wrong and that isn't functioning.. it steals the attention of the whole room in a way..and you listen to this at the beginning of every shift; there it's bleeding, there it's like this and this, and that line is blocked, and so on…three times a day you listen to this… and they never asked if I had something to add.* (17/1)

Some described the importance of relying on visiting family members, and believing in physicians and nurses reassurances when they did not believe in recovery themselves:

> *With my history, my heart can't put up with many more infarctions, so you keep pondering on those things, but a physician came in and said; "We'll make it this time too" and he said it in a way that made me believe it….* (5/1)

Several patients expressed the necessity of endurance to get by, and used expressions like being strong and bracing oneself. A few patients, in particular those suffering from chronic illnesses, used coping strategies, including distraction:

> *You just have to work on yourself, and then you manage.. I put myself in to what I call the "hospital bubble", which is necessary to cope – and with that positive mental attitude, my PMA, I accept that it is something I have to endure.* (5/2)

Some described enduring pain through specific behaviour, such as lying still. Others coped by asking to sleep during possibly painful procedures.

4.5 | Handling emotionally trapped experiences

After discharge, handling of experiences from ICU involved both having been critically ill and having had real and unreal experiences. Experiences frequently seemed to be trapped in the emotions of patients. In particular, recalling unreal experiences was often frightening or distressing. Many patients expressed their attempts to repress or not allow themselves to think of these and other ICU experiences:

> *..but I must have disconnected in a way, because I didn't dare to release it...otherwise I think I could have ended up in a madhouse...* (12/2)

> *As I have said, I'm finished with that shit.. and what is strange is that as time passes, I bloody forget it, which tells me I have really pushed it away – tried to cover it up. That is my nature; I don't gain anything by dragging it on and on and plaguing myself with it.* (10/2)

Keeping distance from both memories and the hospital itself were ways of handling recall, and several patients expressed serious fear of having to go back to ICU and experience again some of what they had gone through. One patient withdrew from the second interview with apologies. She said she did not want to think or talk about her experiences, she just needed to move on. Another patient started crying with relief when she was given the option of being interviewed in her home instead of coming back to the hospital. However, along with the fear of having to go back, patients seemed to acknowledge the necessity of intensive care and expressed gratitude towards the hospital and the healthcare staff:

> *It's like in the newspapers.. those curves...life-curves showing ups and downs...my curve for those six months was very low compared to what it has been, with a zero-point in ICU. It's a closed book, and so you have to look ahead – and hope you won't have to go back there – and if you do, you really need to be there, because that means you're really ill and it's the best place to be.* (1/2)

Some patients had spoken to healthcare staff or relatives about their experiences. Others were reluctant to bother their relatives when their illness itself still was or had been tough for their families to handle. Others felt embarrassed, and some felt crazy or were told by relatives that they might be perceived as crazy if they talked to others about their unreal experiences. While trying to repress their memories, some were also searching for recognition. Reassurance was gained from fellow patients or healthcare staff that their unreal experiences were not uncommon, and they felt relieved by this normalising information:

> *When I spoke to them (the nurses) on the ward, I was told it was not unusual to have these experiences.. – it's comforting in a way, like "okay, I'm not the only one having these problems" – that it is normal, yes – you wish to be as normal as possible.* (1/2)

When comparing findings from the first and the second interview, patients were all in all very consistent in their descriptions. However, many were more articulate and thoughtful in their second interview as they were generally in a much better general state and were more distanced from their experiences. What became evident in some of the second interviews was that descriptions of unreal experiences or events seemed emotionally internalised and were talked about as if they had really happened:

> *Interviewer; You said you went back to see the room, tell me about it; Patient: Well it was a totally different room than ...you see, I used to share the room with two from Syria whose faces were shot to pieces...* (5/2)

Patients still seemed totally rational about these descriptions having their origin in dreams or hallucinations, but the vividness and emotion in the descriptions repeatedly forced the interviewer to ask whether it had actually happened.

Some described more or less explicit unreal experiences of being in a realm between life and death:

> *And so they showed me a door: if you go through that you may stay, but if you come with us there is no going back, and it was great there: very luxurious and beautiful ladies, but I told them I still had quite a few things to finish off, so I would stay put... I know it sounds dramatic, and I am a bit embarrassed to talk about it, but this was my experience.* (5/2)

5 | DISCUSSION

The main finding of this study was that only a few patients described discomfort during their ICU stay in terms of pain. Other central findings were the patients' thorough descriptions of other discomforts. Some discomforts were influenced by the patients' changing states of wakefulness. We also found that some patients handled their experiences after discharge by repressing them, while others also sought reassurance and recognition of what they had gone through.

The few descriptions of actual pain are in contrast with the current understanding of pain as a frequently reported, stressful experience in ICU (Barr et al., 2013; Chanques et al., 2007; Payen et al., 2007; Puntillo, 1990; Samuelson et al., 2007). Because our focus was on an analgosedation regimen, pain was considered as distinct from other discomforts in our analysis and was restricted to what the patients themselves described as pain. The few descriptions of pain correlated well with Loeser and Melzack (1999) pain categories of nociception and perceptions of pain, like when patients expressed a wish to sleep through painful procedures. The language of pain was also used to describe the grief of being away from loved ones, correlating with the category of suffering. In handling pain, the last category of Loeser and Melzacks, pain behaviours, was evident when patients described lying still in bed to endure or avoid pain.

The analgosedation approach, as intended, might have enabled the generally lightly sedated patients to communicate pain and thereby receive better pain treatment. When responding to questions about pain, patients often emphasised that pain was present but acceptable, much less than expected, or was being treated very satisfactorily. In quantitative studies, the incidence of pain has been reported in more than 50% of both medical and surgical ICU patients (Chanques et al., 2007; Payen et al., 2007). When investigated quantitatively, pain may be reported using rating scales or even simple yes–no responses. This counting of the incidence and severity of pain and investigating pain and discomfort together, which is common, might result in more extensive reporting of pain. Qualitative studies, in contrast, enable the exploration of the meaning of pain, which is often reported in terms of factors not restricted to pain, but comprising other types of discomfort (Cutler et al., 2013; Samuelson, 2011).

Three months after discharge from ICU, we found that a few patients who had not reported pain during the first interview now described pain in retrospect in terms of not being able to move in bed or not wanting to be awake during turning because of pain. This may indicate that acute pain was experienced as a very specific but not persistent feeling, recalled mainly in terms of consequences. Various expressions of enduring both pain and other discomforts communicated by several patients in terms of a value or an attitude may possibly explain why patients did not emphasise the experience of pain. Hence, it might indicate that patients did have pain experiences, but endured them as a part of their illness.

Suffering as one of four broad categories of pain (Loeser & Melzack, 1999) has, according to Morse, two behavioural states: enduring and emotional suffering (Morse, 2001). Kolcaba's description of comfort as an outcome measure consisting of *relief*, *ease* and *transcendence* (Kolcaba, 2003) complies with Morse's definition of comfort being the patient-centred outcome of good nursing care (Morse, 1992). Patients experience *relief* when severe discomfort is alleviated, in our patients, for example, when they were given pain medication. Patients are at *ease* in situations that allow them to be calm and content, such as when they are being helped to find a comfortable position in bed. The state of *transcendence* occurs when persons rise above their discomforts. This may be exemplified by patients accepting intense pain of short duration when being mobilised out of bed, motivated by the importance of mobilising to rehabilitate (Kolcaba & Wilson, 2002). Kolcaba states that comfort is more than the absence of pain, and that comfort measures may support the patients' mastering, enduring or transcendence when discomforts cannot be alleviated (Kolcaba, 2003). Our category "holding on" comprising elements of participation, endurance and trust in others might be interpreted as correlating with transcendence, one of Kolcaba's aspects of comfort.

A further finding was the many descriptions of discomforts other than pain, possibly dominating because descriptions of actual pain were rare. The majority of these discomforts have been reported on and presented in reviews of the qualitative literature (Cutler et al., 2013; Egerod et al., 2015; Tsay, Mu, Lin, Wang, & Chen, 2013). We found that well-known discomforts relating to MV, communication difficulties, comprehension and experiencing delusions were often triggered or aggravated by how the patients fluctuated between states of wakefulness. We defined wakefulness on a continuum from being asleep or sedated to being fully awake. When asked, several patients said they would have preferred to be more sedated or to be fully awake, indicating that somewhere in between was not a preferred state. The category of "struggling to get a grip on reality" involved the perception of reality when not being fully awake, confused or hallucinating. This seems comparable to Cutler et al. (2013) description of "transformation of perception." The inability to distinguish between reality and hallucination and dreams and the experience of struggling their way in and out of sleep were described in our study. Furthermore, the experience of being situated somewhere between life and death, categorised by us as "handling emotionally trapped experiences," was described by some. This seems in line with descriptions in two of the abstracted themes in Egerod et al. (2015). The themes "existing in liminality" and "existing on the threshold" described experiences of reality merging with imagination, and being on a threshold between life and death. The concept of liminality was used by van Gennep et al. to explore states of transition and further described by Turner as being neither here nor there, yet in both places (Turner, 1967). Turner also used the concept of being "betwixt and between" to describe the transitional state of liminality as existing somewhere between "recognised fixed points in space-time structural classification" (Turner, 1967). Liminality and different states of this transitional concept have also been used in discussing the illness–recovery–survivorship trajectory of critical illness (Kean et al., 2017). The distress of altered perception, possibly caused by the fluctuation between different states of wakefulness described by patients in our study, may conceptually correspond to descriptions of liminality and to being "betwixt and between," neither classified as being asleep, nor being awake. In the review by Cutler et al. (2013), factual recall and the altered perception or sense of reality was identified as an overarching theme, stated to possibly affect all memories and interpretations of ICU patients' experiences.

Our patients were generally lightly sedated, and all except two had factual memories. Delusional memories in our patients were very common and remained constant over time. Descriptions of discomfort frequently accompanied both factual and delusional memories. This is in line with van de Leur et al. (2004) who reported discomfort from ICU to be positively related to factual recall, but that also hallucinations represented a source of discomfort. The content of the delusional memories in our study did not seem to differ from earlier studies, being strange, scary and life-threatening, but yet closely related to real life events (Svenningsen, Egerod, & Dreyer, 2016; Wade et al., 2015). Aitken et al. (2016) concluded that deep sedation in ICU patients often led to amnesia and delusional memories, whereas lightly sedated patients had more stressful experiences.

An important finding in our study was that delusional memories persisted, and even became internalised as real, resulting in the category of "handling emotionally trapped experiences". In contrast with our findings and the findings of Jones et al. (2001), Burry et al. (2015) found that the delusional memories lessened over time. Our interpretation of unreal experiences becoming internalised or trapped in the emotions of patients may support the perspective of Storli, Lindseth, and Asplund (2007) who question the classification of experiences as factual or delusional according to the ICU-MT. In their opinion, delusions might be expressions of the individual's life experience and hence should not be dismissed as unreal. Only how the individual is affected by the experience, real or unreal, is what matters (Storli, Lindseth, & Asplund, 2008; Storli et al., 2007). How patients in our study were affected might be expressed through how they handled their experiences after ICU. Several described how they distanced themselves from experiences by staying physically away from the hospital and the ICU, and by avoiding thinking or talking about what they had gone through. This was also an attempt to keep their wits, not be regarded as crazy, and to try to move on. The repression may correlate to Morse's concept of enduring, described as "holding on, focusing on the present—a state to block out the horror" (Morse & Penrod, 1999, p. 147). Other patients expressed the need to share their experiences and to be reassured and recognised. Reassurance, both during the ICU stay and afterwards, was an overarching theme in a follow-up study from 2007 (Pattison, Dolan, Townsend, & Townsend, 2007). Storli et al. (2008) described both the repression and the need to talk about the experiences in an interview study 10 years after critical illness. Cutler et al. (2013) also described the need of patients to put the critical illness and ICU stay behind them and addressed the attempt of patients to restore meaning in life and reconcile with their experience.

Some of the patients in our study clearly had traumatic experiences, and they described individual reactions to their experiences and individual ways of handling these. The need and demand for care after critical illness are well established as survivors of critical illness may suffer from significant physical, cognitive and psychological problems, collectively known as postintensive care syndrome (PICS), which may affect their quality of life (Jones, 2013; Needham et al., 2012). Neither follow-up consultations nor ICU diaries were offered to our patients. The effects of these widely offered interventions are, however, still unclear. Evidently, one size does not fit all when it comes to meeting the needs of these patients to improve recovery. The authors of a recent grounded theory study on ICU survivorship concluded that current follow-up strategies are too narrow in scope, focusing on functional outcomes and missing the complexity in these patients' attempt to leave their unpleasant experiences behind them (Kean et al., 2017). Our findings support the use of a structured pathway of rehabilitation as described by Jones (2013) where therapeutic interventions are targeted to meet individual patient needs.

5.1 | Methodological considerations

Nouwen et al. (2012) recommend documenting data on patient memories soon after ICU discharge (Nouwen et al., 2012). One week after discharge is thought to be adequate to reflect and reveal immediate reactions to the ICU stay, and was of value in previous studies investigating memories and experiences (Karlsson, Bergbom, & Forsberg, 2012; Samuelson et al., 2006, 2007). Early interviews, however, may be influenced by the condition of the patient. In addition, the fact that patients are still in hospital may prevent them from speaking freely about negative or stressful experiences.

Three months after discharge, participants can be expected to have gained a certain distance from the hospitalisation and may be more comfortable talking in-depth about their experiences (Granberg, Bergbom Engberg, & Lundberg, 1998). According to a recent systematic review on follow-up regarding emotional consequences after ICU, no acknowledged ideal time point exists, but 3 months is suggested and has been chosen in follow-up studies (Nouwen et al., 2012).

The first interviews in our study were performed only a few days after discharge from ICU as recommended (Nouwen et al., 2012). Including eligible patients consecutively according to inclusion criteria resulted in some interviews with weak patients and occasionally rather "thin" descriptions, whereas more detailed and evocative "thick" descriptions are the hallmark of qualitative research (Kvale & Brinkmann, 2009; Thorne, 2016). Including only the most articulate subjects able to provide detailed rich descriptions of their experiences may threaten the validity of the study (Sandelowski, 1986). However, actions must be taken to secure a total richness of the material when participants have difficulties in providing detailed accounts of their experiences (Kirkevold & Bergland, 2007). Using ICU-MT as a guide for the first interview enabled patients who were weak, short of breath or suffering from lack of attention or lack of recall to contribute nevertheless. In interviews with talkative patients in a good general state, the ICU-MT functioned as a thematic frame.

Performing a second interview after transcribing the first enabled us to further investigate issues and interpretations we experienced as unclear in the first interview. To ensure rich descriptions in total, the second interviews were analysed as a continuation of the first interviews, and we aimed to find changes over time between the first and second interview.

The analgosedation protocol was used within a mixed ICU patient population. Restricting the study to one patient group with more specific pharmacological recommendations could have revealed differences in experiences related to different medications. Still, ICU patients with the same diagnosis differ widely and would require a much larger sample and a different design, preferably a randomised controlled trial.

6 | CONCLUSION

Even though pain descriptions were rare in our study, the growing focus on patient comfort, pain relief and lighter sedation did not seem to prevent the experience of staying in ICU from becoming a traumatic part of the patients' illness trajectory. Discomforts other than pain, caused by MV treatment, not understanding events, communication difficulties, delusional memories and indeed merely by being critically ill were prominent in our study. The ICU stay resulted in experiences of real and unreal origin seemingly trapped in the emotions of patients. This “trapping” was handled by patients both through repressing and talking about experiences, as strategies to move on. It was evident that opportunities to follow-up on and talk about experiences after discharge should be provided.

One suggested area of research in the field of intensive care has been to examine whether a shift in pain and sedation practice contributes to a reduction in delusional memories and hallucinations (Jones, 2007). We have contributed to this body of knowledge by showing that dramatic delusional memories frequently occur in patients treated using the analgosedation approach.

7 | RELEVANCE TO CLINICAL PRACTICE

Conclusions from this and many other studies have in common the great discomfort of being an intensive care patient. The nuances of discomfort seem important to describe in order to assist nurses in the detection and understanding of the torments and challenges experienced by individuals during their ICU stay. Good pain management is essential, but nurses need to attend carefully also to other discomforts. The insight from this study may stimulate our clinical imagination and direct us to look for certain behaviours and reactions in patients, enabling us to suggest possible interpretations of what we see. In this way, we are able to come closer to applying individual comfort measures to relieve and ease discomfort and help patients to achieve transcendence. By attending to possible precursors of disturbing memories from ICU, and thereby contribute to making the ICU a better place to stay, one might hope to facilitate improved rehabilitation from critical illness. Further research on more specific comfort measures such as adapting the ICU environment better to patient needs and applying nonpharmacological measures for discomforts seen in this and other studies will be necessary to guide future ICU nurses in everyday clinical practice.

ACKNOWLEDGEMENTS

We would like to thank the participants for sharing their experiences, C. Jones for collaboration during the translation of the ICU-MT and A-M Storsveen for continuous discussions about the findings.

CONTRIBUTIONS

Study design: HB, ITB, HW; data collection: HB; analysis: HB, ITB, HW; and manuscript preparation:HB, ITB, HW.

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How to cite this article: Berntzen H, Bjørk IT, Wøien H. "Pain relieved, but still struggling"—Critically ill patients experiences of pain and other discomforts during analgosedation. *J Clin Nurs*. 2018;27:e223–e234. https://doi.org/10.1111/jocn.13920

Paper II

Received: 26 May 2018 | Revised: 10 October 2018 | Accepted: 12 November 2018
DOI: 10.1002/nop2.227

RESEARCH ARTICLE

WILEY NursingOpen Open Access

"Having the compass–drawing the map": Exploring nurses' management of pain and other discomforts during use of analgosedation in intensive care

Helene Berntzen[1,2] | Ida Torunn Bjørk[2] | Hilde Wøien[1,2]

[1]Department of Postoperative and Intensive Care, Division of Emergencies and Critical Care, Oslo University Hospital, Oslo, Norway
[2]Department of Nursing Science, University of Oslo, Oslo, Norway

Correspondence
Helene Berntzen, Division of Emergencies and Critical Care, Oslo University Hospital, Oslo, Norway.
Email: helene.berntzen@studmed.uio.no

Abstract

Aim: To explore the deliberation and enactment processes of nurses in relation to pain and other discomforts in the critically ill patients after the implementation of an analgosedation protocol.

Background: Nurses in intensive care units (ICU) face great challenges when managing pain and other discomforts and distinguishing between patients' needs for analgesics and sedatives. An analgosedation protocol favouring pain management, light sedation and early mobilization was implemented in a university hospital ICU in Norway in 2014. Changing sedation paradigms resulting in an increasing number of awake patients during critical illness is expected to affect nursing practice.

Design: Exploratory, single-unit study in a mixed adult ICU.

Methods: Data collection with participant observation and semi-structured interviews in sixteen clinical situations in 2014 and 2015. Thirteen experienced certified critical care nurses were included. Thematic content analysis was conducted.

Results: An overall theme "*Having the compass–drawing the map*" emerged from the analysis. The protocol or strategy of analgosedation appeared to provide a direction for treatment and care, although requiring extensive interpretation of needs and individualization of care, often in challenging situations. The overall theme was abstracted from three themes: *"Interpreting a complex whole," "Balancing conflicting goals" and "Experiencing strain from acting across ideals."*

Conclusion: Nurses seem to attend adequately to patient pain, but the approach to discomforts other than pain appears unsystematic and haphazard. More explicit goals of care and strategies to handle discomfort as distinct from pain are needed. More research is needed to identify effective comfort measures for ICU patients.

KEYWORDS
analgosedation, clinical decision-making, critical care, nursing process, observation, pain management

1 | INTRODUCTION

Clinical decision-making is a principal nursing skill and is highly complex in the context of critical care (Aitken, Marshall, Elliott, & McKinley, 2009). According to Bucknall (2000), nurses in intensive care units (ICU) face a decision or judgement every 30 s. Nurse decision-making in the ICU related to pain and other discomforts often relies on variables other than self-reporting. The patient's ability to communicate needs is often impaired due to critical illness, sedation, mechanical ventilation (MV) and cognitive impairment. Deep sedation in ICU patients has been associated with poor long-term outcomes for mortality and psychological recovery (Shehabi et al., 2012). International recommendations of light sedation (Barr et al., 2013; Strøm, Martinussen, & Toft, 2010) aim to contribute to more awake patients able to communicate pain and other needs. Many patients, however, suffer from procedural pain (Puntillo et al., 2014) and other discomforts (Berntzen, Bjørk, & Wøien, 2018). Unrelieved, pain may have serious physiological and psychological consequences (Jones et al., 2007; Sessler, 2009).

Analgosedation as a strategy complies with current recommendations of light sedation by aiming at assessing and treating pain first and providing sedatives only when necessary to help patients to rest and to reduce anxiety and agitation (Devabhakthuni, Armahizer, Dasta, & Kane-Gill, 2012). Valid assessment tools are crucial in making appropriate decisions about pain in ICU patients unable to communicate (Barr et al., 2013; Gelinas & Johnston, 2007). Indicators of pain in such tools are facial expression, body movements, muscle tone and ventilator compliance (ibid).

This study aimed to explore the management of patient pain and other discomforts by ICU nurses after implementation of an analgosedation protocol.

1.1 | Background

Decision-making by ICU nurses is complex because the patients are seriously ill and their health status changes rapidly (Bucknall, 2000, 2003), often requiring nurses simultanously to deal with aspects of assessment, physiology and treatment (Aitken et al., 2009). Clinical decisions are influenced by the nurse's individual knowledge and experience (Bucknall, 2000, 2003; Shannon & Bucknall, 2003). Lack of knowledge and inappropriate assessment procedures partly explain the continuing reports of under-treatment of pain and over-sedation in ICU patients (Gelinas, 2016; Pasero et al., 2009). The importance of systematic assessment of pain and sedation with validated tools has therefore been emphasized (Barr et al., 2013; Payen et al., 2007; Wøien, Værøy, Aamodt, & Bjørk, 2012).

Pain is experienced by medical, surgical and trauma patients at rest and during medical and nursing procedures and is considered a great source of stress (Barr et al., 2013). A wide range of other discomforts also identified as distress or stressful experiences are also reported, including delusions, anxiety, immobility, inadequate sleep and communication problems, frequently related to MV (Berntzen et al., 2018; Karlsson, Lindahl, & Bergbom, 2012; Samuelson, 2011; Stein-Parbury & McKinley, 2000; van de Leur et al., 2004). In this study, we define discomfort according to Kolcaba, as an umbrella term including pain (Kolcaba 2003, www.thecomfortline.com).

According to Vincent et al (2016), a multi-professional approach to patient comfort in ICU is needed. Vincent and intensive medicine fellow researchers claim that the main goal is a comfortable, calm and cooperative patient, able to engage with family and caregivers. To achieve this, analgosedation should be provided and care should be humane and person-centred to ensure a health-promoting environment (ibid). It is paramount that nursing practice in ICU continues to reflect these recommendations.

Protocols may assist nurses and other healthcare professionals (HCP) in making decisions, also with regard to provision of analgesia and sedatives (Brattebø et al., 2002; Brook et al., 1999; Minhas, Velasquez, Kaul, Salinas, & Celi, 2015). However, low adherence to protocols and guideline recommendations (Mehta, McCullagh, & Burry, 2009; Rycroft-Malone, Fontenla, Seers, & Bick, 2009; Sneyers, Laterre, Perreault, Wouters, & Spinewine, 2014) has been related to concerns about patient comfort and safety when treated with no sedation or light sedation (Rose et al., 2015; Sneyers et al., 2014) and concern that protocols might hinder clinical judgement (Wøien & Bjørk, 2013).

Customizing strategies when implementing recommended practices requires an understanding of practice patterns and beliefs (Rose et al, 2015). To understand and improve care and thus enhance comfort for critically ill patients, nurses need a comprehensive understanding of the clinical issues that contribute to pain and discomfort and how contextual factors influence decision-making regarding comfort. Thompson, Aitken, Doran, and Dowding (2013) emphasize the need to access the logic behind decisions to be able to “unpack the quality of a choice” (p. 1,722).

In Kim's framework of nursing practice (Kim, 2010), the terms “deliberation” and “enactment” describe distinct processes in nursing practice. Deliberation involves the process of clinical decision-making including structuring of information, judgement about the meaning of the information and arriving at decisions on how to act. Enactment describes the nursing intervention or action. In the framework, the two basic processes encompass a complex series of actions involving different structural units (Figure 1). The processes are not linear and sometimes overlap, but they may be analytically separated for the purpose of understanding nurses’ clinical practice (Kim, 2010).

Kim's framework and concepts seemed useful in exploring and describing nurses’ involvement in clinical situations.

According to Kim, nursing science should seek to obtain knowledge to increase “the proportion of rational and explained acts in the total repertoire of what the nurse does in nursing” (Kim, 2010, p. 191).

2 | THE STUDY

2.1 | Aim

The aim of this study was to explore the characteristics of deliberation and enactment by ICU nurses in relation to pain and other discomforts in critically ill patients after the implementation of an analgosedation protocol.

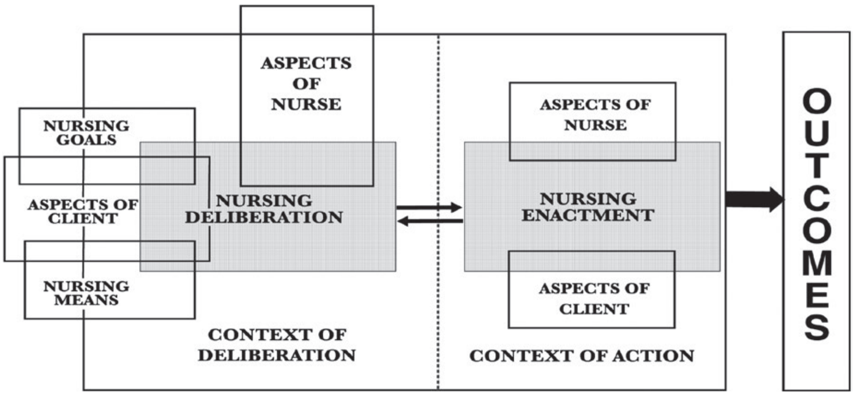

FIGURE 1 The processes of deliberation and enactment (Kim, 2010). (Reprinted with permission)

2.2 | Design

This study was part of a larger implementation study with the overall aim to follow the progression of pain, agitation and delirium (PAD)—practice after implementation of an analgosedation approach. An exploratory design with naturalistic observation and semi-structured interviews was used. Naturalistic observation provides data on phenomena difficult to understand as it gives access both to what people do and what they say they do (Green & Thorogood, 2013). This method can provide a more complete understanding of the complexities of a situation.

2.3 | Setting and participants

The study was conducted in a Norwegian university hospital. The characteristics of the setting are provided in Table 1. Patients treated in this study were aged 18–78 years and had various diagnoses, predominantly cardiorespiratory complications. Some were awake and some deeply sedated, in general with low pain scores.

Criterion sampling was used (Patton, 2002). Certified critical care nurses working permanently in the study unit 50% or more and for a minimum of two years were recruited. Inclusion criteria of employment and experience were used to ensure a reflection of the practice in the study unit where the analgosedation protocol had been implemented. An invitation to participate was distributed to all eligible nurses (approximately 80). Twenty-five female and two male nurses consented by returning a reply form. Thirteen of these, all female nurses, were then consecutively included for participation, on shifts where observation was scheduled and the nurses were assigned to patients who had consented. After 16 observations, data were considered sufficient to secure *information power* (Malterud, Siersma, & Guassora, 2015). According to Malterud, saturation of data is not a realistic goal in an exploratory study, but the design of the study allowed for continued inclusion if the data generated were not considered sufficient to meet the aim of the study.

2.4 | Data collection

Data were collected between November 2014–June 2015 in 16 situations using participant observation and semi-structured interviews (Green & Thorogood, 2013; Hammersley & Atkinson, 2007) involving 13 nurses and 12 patients. Three nurses were observed twice and two patients were cared for several times, but situations never

TABLE 1 Setting

ICU	11-bed mixed adult ICU Single rooms and rooms with three beds separated by curtains
Staffing	Nurse:patient ratio 1:1 An extra nurse was available when required
The analgosedation protocol implemented before this study	Assessment of pain, agitation, sedation and confusion with valid tools at least every 8 hr or once per shift, • Numeric Rating Scale (NRS) for pain assessment for patients able to self-report and Critical-Care Pain Observation Tool (CPOT) for patients unable to self-report • Richmond Agitation-Sedation Scale (RASS) for agitation and sedation. • Confusion Assessment Method (CAM-ICU) for confusion and delirium Analgesia provision first, sedation only when necessary Suggestions for a range of pharmacological treatments for different patient categories Short-acting medication for procedures Advise early mobilization

TABLE 2 The interview guide

Introduction
- What are your thoughts about pain and discomfort of your patient on this shift?

Assessment
- Can you tell me about how you assess pain and other discomforts?
- What would you say influences how you assess?

Interventions
- What are your goals when intervening towards pain and other discomforts?
- Can you tell me about any interventions you made today?
- What would you say influences how you intervene?

General
- Prompting questions
- Clarifications/elaborations specifically related to the observations?

included the same nurse and patient dyad. All data were collected by the same experienced interviewer. She was an experienced ICU nurse who had no familiarity at the study unit. In the present study, we were not explicitly aiming to explore the negative or positive implications of using the analgosedation protocol and therefore the protocol itself was not a main concern during interviews and observations. We were open-minded to how and to what extent the protocol was applied without putting an emphasis on the use, thus avoiding to normatively influence on how the nurses practiced or talked about the management of pain and other discomforts.

2.4.1 | Observations

The nurses were observed for 60–150 min (mean 110). An observation guide was used. Observations focused on activities like handover and shift reports, initial assessment of patient and planned procedures possibly requiring deliberations or enactments regarding pain or other discomforts. Non-pharmacological and pharmacological responses to patient cues of pain and other discomforts and adherence to the implemented protocol were specifically observed. Nurses were encouraged to care for patients as usual, but to think aloud when relevant regarding pain and other discomforts. Short field notes were taken during observation, especially to capture any occurring dialogues. Extensive notes were written after each observation.

An "observer as participant" approach was adopted (Hammersley & Atkinson, 2007), implying that observation was the primary activity, yet involving some participation or interaction. Informal questions and small-talk conversations were used to enhance trust and promote rich data. The observer wore private clothes, a white coat and a research-nurse badge to blend in, but to avoid being mistaken for a nurse at work.

2.4.2 | Interviews

Semi-structured interviews lasting 11–34 min (mean 21) were conducted as reflective dialogues (Graneheim, Lindgren, & Lundman, 2017), focusing on clarifying observed behaviours and investigating deliberations and enactments regarding patient pain and other discomforts. All interviews were conducted during the observation shift and in all but two cases, field notes were written before the interview to reflect on the questions to ask. A short interview guide supplemented these questions (Table 2) and opening questions like: "What are your thoughts about the pain and discomfort of your patient on this shift?" were posed to encourage narration. The implemented protocol was not specifically discussed, unless initiated by the nurse. Interviews were recorded and transcribed verbatim by the interviewer.

2.4.3 | Pilot study

Two pilot observations and interviews were performed to test and elaborate the guides and to familiarize with the data collection method. The guides, however, were continuously developed throughout the study, to sharpen the focus on the process of deliberation and enactment.

2.5 | Ethical considerations

The study was approved by the regional committee for medical research ethics (Health Region East, Norway; Project –ID; 2014/125) and conducted according to the Declaration of Helsinki (WMA, 2013). Written and oral information was provided and written informed consent was obtained from participating nurses and from patients enrolled in the study (or from their closest relatives).

2.6 | Data analysis

A thematic content analysis was conducted (Green & Thorogood, 2013). Data were coded inductively, but Kim's framework of nursing processes was used as a scaffold, to assist in searching for patterns, similarities and inconsistencies in nurses' deliberation and enactment. NVivo Version 11 (QSR International Pty Ltd., 2015) was used to organize data. As we considered that the observations contained the core data, two researchers individually read the field notes several times to familiarize with the data and to obtain an overall impression (Green & Thorogood, 2013). The second step involved identification of initial codes encompassing enactments related to the research questions. Five initial codes were agreed on through elaboration and discussion (Table 3). The first three codes came naturally as a consequence of data obtained using the observational guide and the latter two emerged from data in the reflective field notes. Six of the interview transcripts were then read thoroughly to identify deliberations connected to each enactment code. For each initial code, groups of codes with similar content were established and a coding scheme was created. The third step involved coding of the remaining interviews in a dynamic process to allow identification of new codes, rearrangements and creation of new code-groups. The final step, comparing and contrasting the code-groups across the whole data set, resulted in seven categories. Three abstracted themes were

TABLE 3 The analytical process showing the initial codes, code-groups, categories and themes (Green & Thorogood 2013)

Initial codes	Code-groups	Categories	Themes	Overall theme
Assessing pain and other discomforts	Using valid tools Challenges and barriers to assessment Schedule of assessment Assessing other measures not captured by tools	Facilitating tools, but still requiring interpretation Collecting and combining cues during routines and continuous care Enacting on information from different sources	Interpreting a complex whole	Having the compass–drawing the map
Combining information	Using available information Interpreting Attending to patient preferences			
Choosing interventions directed towards pain or other discomforts	Adhering to principles of protocol Using pharmacological interventions Applying non-pharmacological interventions Choosing between pharmacological and non-pharmacological interventions	Ensuring aspects of pain relief and comfort Ensuring the aspect of rehabilitation	Balancing conflicting goals	
Handling other treatment goals along with comfort	Achieving a good balance between goals Experiencing a difficult balance between goals Prioritizing between goals of comfort and pain relief and of rehabilitation Using professional repertoire Using personal repertoire			
The cost of professional and personal involvement	Acting at variance with professional conviction Acting at variance with personal standards Observing and withstanding patient discomfort and suffering	Experiencing threats to professional ideals Experiencing threats to personal standards	Experiencing strain from acting across ideals	

identified through exploration of the relationship between all categories. A final abstraction constituted the overall theme "*Having the compass–drawing the map.*" Table 3 illustrates the process of analysis showing the steps from initial codes to the overall theme.

This analytical approach enabled the elucidation of how ICU nurses think and what they do, from patterns across all 16 observations and interviews. In this way, the presentation of findings involves a holistic description of the characteristics of the processes of deliberations and enactments regarding pain and other discomforts when analgosedation is used.

2.7 | Rigour

Lincoln and Guba's framework is used to describe trustworthiness (Lincoln & Guba, 1985). Triangulation of research methods was used to obtain in-depth data and enhance *credibility*. *Dependability* was sought by describing the role of the researcher and the data collection details. All analytical steps were performed by more than one researcher to ensure different perspectives and to enhance *confirmability*. The process of analysis was described and displayed in a table, and the findings were discussed with ICU nurses to confirm recognition of categories and themes. *Transferability* to similar contexts was sought through descriptions of the setting and the participants and by rich descriptions of the findings, accompanied by illustrative quotations.

3 | FINDINGS

The study participants were aged 38–59 and had been working in ICU for an average of 19 years. The overall theme "*Having the compass–drawing the map*" indicates that the implemented strategy of analgosedation provided a direction for treatment and care, although it was seldom explicitly referred to or discussed by the nurses during observations or interviews. Extensive interpretation of patient needs and individualization of care was still required, often in complex situations. The overall theme was abstracted from the following themes: "*Interpreting a complex whole,*" "*Balancing conflicting goals*" *and* "*Experiencing strain from acting across ideals*" (Table 3).

3.1 | Interpreting a complex whole

In spite of the strategy implemented, the nurses were required to collect and combine cues and make interpretations to make decisions and act. Valid assessment tools for pain and sedation levels were widely used and perceived to facilitate a systematic approach to assessment, reduce subjectivity and enhance more consistent reporting. Often elements from tools were incorporated into continuous assessment. Usability was also reflected in comments indicating that tools were just a new wrapping:

> The way the CPOT is built, it is actually based on things we used to assess from before, but now exactly what to do and what points to give is more specified. (..) And earlier, even though you would observe facial expression and cooperation with the ventilator, it was more open to individual interpretation. (interview 1)

Despite the availability and usability of valid tools, sedation and impaired communication and cognition often required interpretation beyond scoring. Sometimes messages were conflicting regarding patient self-reporting of pain and the patient behaviour observed. Other times the scoring alternatives seemed too confining to cover the level of pain or sedation and to reach a common understanding:

> Nurse: "How bad is your pain right now?" Patient's eyes are closed. She hesitates…"ehm..3…" Nurse; "But can you perhaps live with it?" Patient: "But it really hurts." Nurse: "but 3 isn't that much on the scale… maybe it is more?" Patient: "4?" (with a questioning tone). (field note 6)

In general, it was not clear how the nurses deliberated to distinguish between pain and other discomforts and no systematic assessment of discomforts other than pain was evident. However, one way of describing discomfort was mild pain or a precursor of pain requiring an enactment. There was general agreement that no patient should be in pain, but that not all discomfort could be eliminated. However, when nurses were unable to decide on what was pain and what was discomfort, the assessment and the decision about when and how to intervene were challenging.

> Nurses discuss patient distress at handover
>
> - But it is agitation, not pain?
>
> - Who knows? I don't know why she was crying, I can't get eye-contact because she's too sedated in a way, but at the same time in distress. (field note 16)

To know the patient well added depth to the deliberation but did not necessarily facilitate the decision about what to enact. This nurse had been caring for a young man with cancer and septicemia even before he was sedated and intubated:

> …and when he has expressed a wish to die - and believes he is going to die, what is agony, what is discomfort, what is pain? I mean what is what? It is really difficult. (interview 2)

The nurses assessed pain as part of a daily routine, such as when starting the shift, during daily care and often specifically when turning the patient. The assessment included combining scorings and other measures or input not captured by the tools. Vital signs and other physiological measures like lacrimation and restlessness were used along with information from patient records and from handover and inter-professional rounds. Patient history, current medication and the reporting nurse's perceptions contributed to interpreting the pain situation in patients who were unable to self-report. Frequently nurses deliberately performed turning or repositioning without any pre-emptive or extra medication "to obtain a better impression" of the pain and sedation level:

> I thought I had to …ehm .. allow myself to see how he actually is – and how it turns out before I decide in a way, because at first I thought I had to give both ketorax and propofol beforehand, but if I give it before I start, I don't really know anything about him. (interview 2)

Several nurses described the demanding situation of having more awake patients on MV requiring constant attention and surveillance, frequently disrupting workflow. However, most emphasized the importance of being guided by patients' responses in making decisions about pain and other discomforts. The nurses felt safer doing the right thing when patients could respond:

> The patient is clearly grimacing when they turn her over. The nurse asks whether she is in pain. She frowns and shakes her head. "Discomfort?" the nurse asks. The patient nods. The nurses discuss whether to give more analgesia or propofol (sedative). The nurse turns to the patient and asks whether she just wants something to make her relax. She nods again and they give her 10 mg propofol. (field note 4)

3.2 | Balancing conflicting goals

The second theme reflects how the nurses needed to prioritize between different and sometimes conflicting goals of relieving pain and other discomforts, yet ensuring goals of progress and rehabilitation. An effort to outweigh the pain and discomfort was made by use of pharmacological and non-pharmacological interventions and evident in both observations and interviews. Pharmacological treatment was mainly directed towards possibly painful procedures like endotracheal suctioning, repositioning and mobilization in or out of bed:

> I feel very anxious about my patients being in pain, so the pharmacological options are often the first priority. (interview 8)

Even though the previously implemented analgosedation protocol itself was seldom mentioned, the nurses gave a general impression of good understanding and adherence to the principles of analgosedation as a general direction for treatment and care. There was, however, a concern about how the goal of keeping patients more lightly sedated or awake was experienced by the patients:

> The patients are supposed to be more awake …even though it may result in a bad experience (..) it's for better or worse I think….but I hope we have sufficient tools to capture whether they can tolerate it. (interview 11)

Nurses acknowledged to a large extent the non-acute pain and discomfort resulting from being critically ill, insecure and frightened, immobilized and awake. A caring approach using continuous information, therapeutic touch and soothing speech was observable as the enactment in caring for patients who were sedated. A personal repertoire of skills was observed in balancing the aspect of comfort and the rehabilitative aspect when patients were more awake. The skills encompassed creativity, humour, motivational skills, "standing by" and recognition of the individual:

> When you have someone awake like her, you can't keep going at 110, …you need to slow down and work at a different pace… (interview 7)

The overall goals of rehabilitation sometimes caused the nurses to withhold analgesics or sedatives to accomplish planned or prescribed events such as waking patients who had been sedated, weaning from the ventilator, maintaining spontaneous breathing or mobilizing in or out of bed:

> It is this knife-edge we are balancing on – when I provide too much analgesics, I get a sedated patient who is not coughing and who is not moving and who does not communicate. (interview 6)

Other times "balancing" implied cancelling physiotherapy and mobilization and letting the patient rest to recover. Such a balance was not always achieved and the nurses sometimes had to handle challenging situations across their ideals of care.

3.3 | Experiencing strain from acting across ideals

Nurses were affected by witnessing and withstanding patient discomfort and suffering and by sometimes having to disregard their professional ideals and personal standards to balance the comfort and rehabilitation of patients.

The strain experienced by the nurses seemed linked to their professional and personal involvement. To abide strictly by professional standards might challenge the nurse's personal standards of care. Despite being given both analgesia and tranquillizers, a woman cared for in one situation continuously expressed pain verbally. Because of her reduced respiratory function, withholding intravenous opioids was prescribed:

> Nurse: "The case is that you got pain medication a while ago and it is important that you don't get too sleepy"…. she goes on telling the patient that she is aware that she is being pushy, which is difficult because she needs to act according to her heart – not to be a torturer……"but we will work our way through this together – You and I!". (field note 6)

Personal involvement with the patient situation, the history of the patient and the relatives seemed to contribute to vulnerability towards the suffering of a patient. However, the experience and knowledge of specific situations helped nurses withstand better patient discomfort and suffering:

> You need a balance to get to an extubation for instance … like if we can manage this short, but steep hill, we can extubate and then things will be much better – then I think I can put up with a bit more. (interview 1)

Working towards common goals together with the patients when possible, and involvement of fellow nurses and physicians in their deliberations supported the nurses in their enactments.

4 | DISCUSSION

A central finding in this study was that analgosedation principles were clearly visible in the management of pain and other discomforts in critically ill patients, although the ICU nurses involved seldom referred to the implemented protocol. This finding may indicate that the analgosedation principles are easily adopted and merge well with current clinical practice. We also found that the elements of the pain assessment tools used formed a "natural part" of the nurses' routine assessments. Although interpretation beyond the tools was needed, there was fair agreement on how to assess and treat pain and that no patient should be in pain. Discomfort, however—although agreed on by the nurses as something that could not be fully eliminated in critically ill patients—seemed ill defined and difficult to distinguish from pain, in line with the findings of Gerber, Thevoz, and Ramelet (2015). The challenge of distinguishing between pain and discomfort in ICU patients also shown in our study complicate nurses' deliberations and enactments. Berntzen et al. (2018) explored the experience of pain and other discomforts as separate entities in ICU patients treated with analgosedation. They found that the patients' pain was largely relieved, but that they struggled with other discomforts, mainly due to MV, incomprehension and experiencing delusions. Lærkner, Egerod, Olesen, and Hansen (2017) found that being awake during critical illness increased the ICU patient's awareness of the severity of their illness and increased their discomfort and sense of incapacity.

Despite constantly considering discomforts like pain, anxiety, incomprehension, immobilization, constipation and equipment attached, nurses in our study seemed to lack systematic deliberations about discomforts other than pain. However, there was a tendency to consider discomfort as mild pain or as a precursor to pain, precipitating pharmacological interventions, mainly increasing of the opioid infusion rate or bolus injections. Non-pharmacological interventions were applied to prevent or relieve both pain and other discomforts, but no systematic deliberation preceding the enactments was observable or articulated. Sometimes the nurse's deliberation about sources of discomfort was communicated at handover. In Kim's (2010) structure for nursing deliberation, the availability of nursing means is divided into “repertoire at large” which mainly applies to validated strategies and into “personal repertoire” or “conjectured means or approaches” (p. 186) related to the individual nurse. Nurses in this study approached pain through deliberation using valid assessment tools and adhering to treatment principles from a protocol, a practice corresponding to Kim's “repertoire at large.” The approach to both deliberating and enacting for discomforts other than pain, however, seemed highly based on individual or personal comprehension or interpretation of the patient situation, corresponding to Kim's “personal repertoire.”.

In a focus group study, although ICU nurses recognized the usefulness of pain and sedation assessment tools, they relied more on their personal knowledge and experience (Wøien & Bjørk, 2013). Clinical decision-making based primarily on the personal repertoire and conjectures based on individual professional and personal standards reflect a haphazard or intuitive rather than an intentional practice (Kim, 2010). In a normative perspective, nurses should aim at delivering competent, timely, relevant and efficient nursing measures according to prescriptions or strategies (Kim, 2010). Considering the extent to which ICU patients experience discomforts other than pain (Berntzen et al., 2018), it seems necessary to aim at a more structured process of both deliberation and enactment to enhance patient comfort.

Structured processes need explicit goals. According to Kim, a set of goals can be identified in every situation involving nursing actions (2010), but one problematic aspect of the deliberation process is how the nurse perceives and prioritizes the different goals. Patient comfort in our study seemed to constitute an implicit goal of care (GOC). According to Stanek (2017), GOCs are ideally established and made explicit through interaction between a patient and healthcare professionals, but are frequently taken for granted and not explicitly articulated. A critically ill patient's ability to express comfort needs may be impaired, hindering the establishment of explicit goals of comfort. Kim divides the orientation of nursing goals into those defined by the client, by the nurse and by others. In our study, the nurses appreciated the support in decision-making obtained through the awake patient's ability to express their needs. The nursing goals and hence means were then tailored to the patient's own preferences or goals. Juxtaposing elements of nursing means and nursing goals in the process of deliberation is necessary to make nursing practice coherent, meaningful, strategically effective and sensible (Kim, 2010, p. 187).

Over the past few years, strategies and bundles of treatment and care, representing evidence-based guidance for clinicians, have been introduced and implemented in many ICUs. Focusing on comfort, the e-CASH concept (early Comfort using Analgesia, minimal sedatives and maximal humane care) pursues the goal of a calm, cooperative and comfortable patient (Vincent et al., 2016). These goals of caring for critically ill patients in ICUs need to be operationalized to have the potential to help nurses structure deliberation and subsequent enactment, also for discomforts other than pain. Puntillo et al (2010) assessed ICU patients at a high risk of dying with a 10-item checklist for the presence and intensity of symptoms and concluded that symptom assessment could lead to more focused interventions and reduce patient suffering. Chanques et al suggested the daily evaluation of five common stressful symptoms in ICU patients able to communicate: pain, thirst, anxiety, dyspnoea and poor sleep (Chanques, Nelson, & Puntillo, 2015). In a review of existing instruments to assess patient comfort during hospitalization, Lorente et al found moderate methodological quality and low reported utility of the tools (Lorente, Losilla, & Vives, 2017). None of these instruments, however, were developed specifically for the critical care context.

A systematic approach with strategies or tools may aid nurses in assessing and handling discomfort as distinct from pain. The lack of sensitivity in current tools may result in overestimation of pain and underestimation of other discomforts. Analgosedation as a strategy promotes pain assessment and treatment first and will enable more patients to express their needs. We need to ensure, however, that other discomforts are not mistaken for pain and treated as such in patients unable to communicate. Despite the need for tools and strategies to avoid haphazard deliberations and enactments, our study shows that nursing practice in intensive care is inevitably dependent on the nurses' personal and professional engagement, skills and standards.

4.1 | Limitations

There are several limitations to this study. Firstly, the single-unit study design may reflect a local culture in the practice of decision-making and therefore reduce transferability to other units. The nurse:patient ratio is considered high in Nordic ICUs (Egerod, Albarran, Ring, & Blackwood, 2013) and workload issues may influence the deliberations and enactments of nurses. However, no other healthcare staff or therapists are involved in the direct bedside care of the patient. Secondly, all the participants were female and a mixed sample might have revealed gender differences in decision-making. However, most nurses in general and at the study site are female and comparison between genders was not part of the study aim. Thirdly, the data collector's familiarity with the field may have impaired the objectivity of the observations and analysis. Attempting to consciously balance between closeness to the field and the nurses, while focusing on the nature of the nurses' deliberations and enactments, hopefully provided what is described as a creative insight using both an “insider” and “outsider” perspective (Hammersley &

Atkinson, 2007). The collaboration of three researchers in the analysis, one without any relation to ICU nursing, may have counteracted the danger of a skewed analysis based on the preconceptions of the experienced ICU nurse collecting the data.

5 | CONCLUSION

In this study, the use of Kim's framework to guide the analysis contributed to highlighting the differences between the structure of deliberations and enactments with regard to pain and other discomforts in ICU nursing practice. We showed that the processes of deliberation and enactment regarding pain adopted by the nurses, to a large extent relate to existing recommendations for preventing, assessing and treating pain. Protocols or strategies, reflected in our study by the analgosedation protocol, may be regarded as a compass to indicate the direction of treatment and care in nurses' decision-making. The "compass" adds to the metaphor "the landscape of critical care" used by Bucknall (2003) in exploring influences on nurse decision-making. The valid tools, goals of pain treatment, guidelines and prescriptions may represent landmarks for nurses to find the "path." However, the complex landscape of the critical care context will always compel nurses to use both personal and professional skills to navigate. Concerning discomforts other than pain, the landmarks to guide nursing practice are sparse. This results in extensive individual interpretation and judgement in nursing deliberations and enactments, as to whether or when to apply pharmacological or non-pharmacological measures, often in situations lacking explicit or established goals. To avoid haphazard clinical practice in the ICU, new assessment methods that capture discomforts other than pain should be developed and effective comfort measures to relieve discomforts other than pain should be identified and implemented. Knowledge about ICU patients' discomforts other than pain should be used to describe more explicit goals of care and ensure patient comfort.

ACKNOWLEDGEMENTS

We would like to thank the participants for letting us study their clinical practice, and ICU nurse Ann-Marie Storsveen for valuable discussions about the findings. The study was financially supported by Oslo University Hospital, Division of Emergencies and Critical Care, Department of Postoperative and Intensive Care

CONFLICT OF INTEREST

All authors declare no conflict of interest.

AUTHOR CONTRIBUTIONS

HB, ITB, HW: Study design, analysis and manuscript preparation. HB: data collection.

ORCID

Helene Berntzen https://orcid.org/0000-0001-5262-7911

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How to cite this article: Berntzen H, Bjørk IT, Wøien H. "Having the compass–drawing the map": Exploring nurses' management of pain and other discomforts during use of analgosedation in intensive care. *Nursing Open*. 2019;6:453–462. https://doi.org/10.1002/nop2.227

Paper III

Received: 19 December 2019 | Revised: 1 March 2020 | Accepted: 23 March 2020
DOI: 10.1111/jocn.15260

ORIGINAL ARTICLE

Journal of Clinical Nursing WILEY

"Please mind the gap": A secondary analysis of discomfort and comfort in intensive care

Helene Berntzen RN, MNSc, Phd-student[1,2] | **Ida Torunn Bjørk RN, Dr. Polit, Professor Emerita**[2] | **Ann-Marie Storsveen RN, MNSc**[1] | **Hilde Wøien RN, PhD, Associate Professor**[1,2]

[1]Department of Postoperative and Intensive Care, Division of Emergencies and Critical Care, Oslo University Hospital, Oslo, Norway

[2]Department of Nursing Science, University of Oslo, Oslo, Norway

Correspondence
Helene Berntzen, Department of Postoperative and Intensive Care, Division of Emergencies and Critical Care, Oslo University Hospital, 0027 Oslo, Norway; Department of Nursing Science, University of Oslo, Oslo, Norway.
Email: helene.berntzen@studmed.uio.no

Funding information
Departmental funding only.

Abstract

Aims and objectives: To explore in depth discomfort in intensive care as experienced by patients and attended to by critical care nurses.

Background: Discomfort in illness is complex and persistent, and its alleviation is a challenge for nurses working in intensive care units (ICU). In previous studies, we showed that ICU patients described little actual pain but suffer from much discomfort. Critical care nurses had a systematic approach to the treatment of pain, but were more haphazard in dealing with other types of discomfort.

Design: Secondary qualitative analysis of data from two previous exploratory studies.

Methods: Content analysis was used on existing data from 28 interviews with ICU patients, and 16 field notes and interviews with critical care nurses. Kolcaba's Comfort Theory was applied for further analysis. The COREQ checklist was used.

Results: Three themes, "Being deprived of a functioning body", "Being deprived of a functioning mind" and "Being deprived of integrity" characterised the discomfort experienced by ICU patients. The nurses appeared to attend to all areas of discomfort expressed by patients. In need of, and providing acknowledgment and alleviation became a common overarching theme. We identified a comfort gap caused by the discrepancy between the patients' needs and the nurses' achievements in fulfilling these needs.

Conclusions: A gap exists between ICU patients' comfort needs and nurses' achievements in fulfilling these, indicating that discomfort currently is an inevitable part of the critical illness trajectory. Increased knowledge about how the brain is affected in ICU patients and more systematic approaches to assessing comfort needs and enhancing comfort may support nurses in fulfilling patient needs and possibly diminish the existing comfort gap.

Relevance for clinical practice: An increased understanding of the complex experience of discomfort in ICU patients may bring about more systematic approaches to enhance comfort and direct for education and further research.

KEYWORDS
critical care nursing, critical illness, discomfort, intensive care unit, needs, nursing, qualitative, secondary analysis

1 | INTRODUCTION

Patients in the intensive care unit (ICU) experience physical and psychological discomfort, including pain, and this is well documented (Egerod et al., 2015; Puntillo, 1990; Puntillo et al., 2014; Samuelson, 2011a, 2011b). The discomfort is related to treatment and care, environmental factors and the mere experience of being critically ill. Since the days of Florence Nightingale, nurses have been judged by their ability to make patients comfortable, both physically and mentally (Goodnow, 1935, as cited in Kolcaba, 2003). Critical care nurses in the complex context of intensive care frequently need to make decisions about pain and other discomfort based on factors other than self-reported variables. ICU patients are frequently unable to report their pain verbally or with other deliberate signs because of an endotracheal tube, an altered level of consciousness or sedative agents (Shannon & Bucknall, 2003). Assessment tools for pain in noncommunicating patients are available and recommended (Gelinas, Fillion, Puntillo, Viens, & Fortier, 2006; Payen et al., 2001). Corresponding valid assessment tools for discomfort other than pain are, however, lacking. If nurses are assisted in appropriately matching care with physical and psychological patient discomfort, patient suffering may be reduced and comfort in critically ill patients may be enhanced. In this regard, a better description and understanding of discomfort in intensive care is required. The purpose of this study was to expand our knowledge about discomfort other than pain in the ICU from the perspectives of both patients and nurses.

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

- Discomfort in ICU is a complex and interwoven experience of deprivation of a functioning body, a functioning mind and integrity.
- The discrepancy between the patients' comfort needs and the nurses' overall success in meeting these needs indicates that discomfort is an inevitable part of critical illness and that this is reflected in a *comfort gap*.
- Nurses in intensive care may be assisted in diminishing the identified comfort gap in their patients by keeping in mind the three types of discomfort outlined in this study.

2 | BACKGROUND

Discomfort – the essential concept in this study – pertains to Kolcaba's description of discomfort as a detractor from comfort (Kolcaba, 2003). Pain, as one type of discomfort, is regarded as multidimensional, comprising nociception, perception of pain, suffering and pain behaviour patterns (Kolcaba, 1997, 2003; Loeser & Melzack, 1999). In the ICU, the presence and intensity of pain is either self-reported by patients or assessed with validated tools comprising behavioural variables (Gelinas et al., 2006; Payen et al., 2001), and recommended in international guidelines (Barr et al., 2013; Devlin et al., 2018).

Current international clinical guidelines recommend strategies for focused pain treatment, and lighter or targeted sedation (Devlin et al., 2018). Deep sedation in ICU patients is associated with adverse short-term and long-term outcomes (Devlin et al., 2018; Tanaka et al., 2014). Such strategies allow patients to stay awake and alert, maintain cognitive function, and interact and communicate pain and other discomforts. When these abilities are maintained or regained, nurses may rely more on ICU patients' expressions to intervene appropriately and enhance patient comfort. However, similar to other organ systems, an ICU patient's brain suffers from dysfunction. When the patient is cognitively impaired, the abilities to communicate and interact diminish and make it difficult for the patient to communicate discomfort and comfort needs. This brain dysfunction in ICU patients may be explained partly by pathophysiology related to critical illness, but also by long-acting sedatives, and possibly by impaired sleep (Kamdar et al., 2013; Pandharipande et al., 2017). The patients may experience all these factors as kinds of discomfort. ICU delirium is one frequent manifestation of brain dysfunction that has been associated with increased length of stay, mortality, cognitive decline and long-term psychological sequelae (Pandharipande et al., 2013, 2017).

Discomfort was a prominent finding in patients in the qualitative part of a combined quantitative and qualitative study where we addressed the implications of implementing a systematic approach to pain, agitation and delirium (PAD); (Berntzen, Bjørk, & Wøien, 2018, 2019). The systematic approach was supplemented by an analgosedation protocol in line with the, at that time current international recommendations (Barr et al., 2013). Such a change in practice may affect both patients' experiences and nurses' management of discomforts in patients who are more awake.

The quantitative study showed a significant decrease in sedation levels, sedatives administered and in number of patients unable to be assessed for delirium (Wøien, 2020). The delirium prevalence, however, remained unchanged and pain scores were low. The results reflect progress in line with other studies showing the association between increased adherence to international guidelines and improvements in patient outcomes (Pun et al., 2019). In the qualitative studies – including interviews of patients after ICU discharge and observing and interviewing critical care nurses – we also found that in general the degree of pain relief was good. However, the interviews revealed that the patients experienced a high degree of other types of discomfort during their ICU stay (Berntzen, Bjørk, & Wøien, 2018). The critical care nurses attended systematically to patient pain, but the approach to discomfort other than pain appeared to be haphazard, largely depending on the individual nurse's experience, knowledge and personal repertoire of enactments (Berntzen, Bjørk, & Wøien, 2019). The results of the two studies indicated that discomfort other than pain appeared ill-defined, making it difficult for nurses to assess and intervene appropriately. Insights from these studies – in particular, the widespread discomfort other than pain revealed by using the qualitative approach – called for a further exploration of discomfort. By separating the descriptions of pain from other discomforts and re-examining data both from patients and nurses, we searched for a deeper understanding of discomfort in intensive care.

2.1 | Aims and research questions

The aim of the study was to explore the complex and persistent, as yet ill-defined phenomenon of discomfort in intensive care. We addressed the following research questions:

1. What are the characteristic features of discomfort in patients in intensive care derived from patients' descriptions, and how can we use these features to improve our understanding of and response to different types of discomfort?
2. How do critical care nurses deliberate about discomfort and intervene to enhance comfort in their patients?
3. How can discomfort in intensive care be elucidated using concepts from Kolcaba's Comfort Theory?

3 | METHODS

3.1 | Design

This was a qualitative secondary data analysis (SDA) exploring two original datasets to undertake a more in-depth analysis aimed at increasing the understanding of the phenomenon of discomfort in ICU. A SDA can be used to investigate new or additional research questions to those initially explored from a dataset (Ruggiano & Perry, 2019). Several forms of SDA have been proposed (Heaton, 2008; Thorne, 1994, 2016). Supplementary analysis (Heaton, 2008) or analytic expansion (Thorne, 1994) implies undertaking a more in-depth analysis of an emergent aspect in the primary study that deserves further elaboration through a new or revised research question. Amplified analysis (Heaton, 2008) or amplified sampling (Thorne, 1994, 2016) implies secondary analysis by comparing and combining two or more existing datasets to extend aspects within a wider context of what was originally studied. The secondary analysis applied in this study pertains to a combination of the two forms of SDA described. The Consolidated Criteria for reporting qualitative studies (COREQ Checklist; Tong, Sainsbury, & Craig, 2007) was used (Data S1). Some criteria are reported only in the primary studies due to the nature of the SDA.

3.2 | The primary studies

The setting for the primary studies was a medical-surgical adult university hospital ICU, with national responsibilities to treat patients with critical illness in need of advanced treatment. In the study unit, a systematic approach including an analgosedation protocol had been implemented to facilitate adherence to international guidelines and recommendations for focused pain treatment and light sedation. The nurse:patient ratio was 1:1, and the patient rooms were either single or three bedded.

Participants in the two qualitative studies included in the secondary analysis were 18 adult ICU survivors and 13 critical care nurses with more than 2 years' experience in ICU. The patients had been treated for more than 24 hr in the ICU and been on mechanical ventilation. Recruitment was driven by criterion sampling (Patton, 2002). Ten of the patients were female, mean age was 47 (range 18–78), mean length of ICU stay was 10 days (range 1–48) and 11 patients were surgical patients. In the electronic patient records, both the self-reported pain scores and those assessed by nurses with the Critical Care Pain Observational Tool (CPOT) for nonverbal patients were low. The mean sedation level scored with the Richmond Agitation and Sedation Scale (RASS) was −2, i.e. lightly sedated and able to respond to verbal stimuli. Only three of the 18 patients had a positive delirium score using the Confusion Assessment Method for the ICU (CAM-ICU); 14 had no positive scores and one was not assessable for delirium at any time during the stay.

The first study involved the ICU patients. All 18 patients were interviewed in the first week after ICU discharge. Ten of the patients underwent second interviews after approximately 3 months, which explored more in-depth how they retrospectively experienced pain, other discomforts and wakefulness during their ICU stay. In the second study, the critical care nurses were observed during patient care on 16 occasions and subsequently interviewed to explore deliberation and enactment processes in relation to patient pain and discomfort. All data were collected during autumn 2014 and spring 2015 by the first author, a female critical care nurse and doctoral student who worked at the hospital, but not at the study unit.

Interviews with patients and observations and interviews with nurses were performed within the same time period. This means that some patients who had been cared for by nurses under observation were also interviewed after discharge. Although the participant observations in general may have influenced the interviewer, patients being cared for during the observations were considered context, not participants. Therefore, no questions were asked during the patient interviews on the basis of a clinical situation involving the actual patient. In the primary data analysis, systematic text condensation (Malterud, 2012) was used to analyse the patient interview data. Content analysis (Green & Thorogood, 2018) was used for the observational and interview data from the nurses.

3.3 | Ethics

The study was approved by the regional committee for medical research ethics (Project –ID; 2014/125) and conducted according to the Declaration of Helsinki (World Medical Association [WMA], 2013). Additional approvals were not necessary for the secondary analysis as no data were shared. The fourth researcher, formally participating only in the secondary analysis, had access only to already de-identified data. The purpose of the study was within the framework of what had already been consented to by the participants.

Studying vulnerable groups including unconscious or confused ICU patients is ethically highly challenging. Informed consent had to be obtained from all patients even when they were not included as participants, but as targets in the nurses' deliberations and enactments in the second study. Some of these patients were sedated and consent to the observation was obtained through their next of kin. Patients were considered participants only in the first study and were interviewed post-ICU discharge. In this regard, they were all able to consent and free to share their experiences of confusion or delirium.

3.4 | Secondary data analysis

3.4.1 | Process of data analysis

Abductive qualitative content analysis was used in the SDA of the qualitative studies (Graneheim, Lindgren, & Lundman, 2017; Graneheim & Lundman, 2004). This analytical strategy implies moving back and forth between inductive and deductive approaches during different stages in the analysis. We performed three analytical steps – each pertaining to one research question. The first two steps pertained to the primary data in the specific context of intensive care. In the third step, Kolcaba's Comfort Theory was applied to the results of the preceding two analytical steps. Three authors actively took part in all three steps of the analysis.

3.4.2 | Step 1 – Reanalysis of the patient data

We used Kolcaba's view of discomfort as a detractor from comfort (Kolcaba, 2003) to identify expressions of discomfort. This approach covers the physical, psychospiritual, environmental and sociocultural contexts, reflecting the holistic nature of comfort. We therefore searched for expressions of discomfort in all these contexts in the patient descriptions.

The first step in the re-analysis was to read the *condensates* from the patient data several times to identify any patterns of discomfort. A condensate is a reduction in all meaning units of a subgroup into an artificial quotation kept in the terminology of the participants (Malterud, 2012). The condensates were based on all the transcribed interviews with the patients. As our focus was on discomfort in the ICU, condensates of subgroups from the primary analysis pertaining to experiences *after* ICU discharge were excluded. Three themes that characterised different aspects of discomfort emerged from the analysis: "Being deprived of a functioning body", "Being deprived of a functioning mind" and "Being deprived of integrity." Primary descriptions of the themes were noted. With these descriptions in mind, the full transcripts were re-read to validate the themes and to confirm that all relevant data have been selected for analysis. Figure 1 illustrates the entire range of types of discomfort resulting from this analysis, and also shows how the different themes were interrelated. An example of interrelation is how both deprivation of a functioning body (e.g. speech) and a functioning mind (e.g. comprehension) can contribute to the deprivation of integrity (e.g. expressing and guarding the self). Expressions of discomfort that did not fit into any of the three themes were to be classified as "others". However, all meaning units identified could be assigned to one or more themes and no meaningful data were left over. Going back and forth between the condensates and the thematic descriptions, we composed a thorough description of each theme. Finally, we abstracted the overall patient theme, "In need of acknowledgement and alleviation" (Table 1).

Integrity as a concept requires explanation because of its complexity. It is an important concept in nursing ethics (Beauchamp & Childress, 2001) and is closely linked to other key concepts such as autonomy, dignity, privacy and identity (Fjellstrøm, 2005). However, different conceptual interpretations of integrity exist (Fjellstrøm, 2005; Pellegrino, 1990). In this study we understand the integrity of a person to be *having a whole self and guarding and expressing this in practice resulting in a sphere of personal wholeness* (Fjellstrøm, 2005). We consider inability to guard and express this self, deprivation of integrity.

3.4.3 | Step 2 – Re-analysis of the nurse data

We aimed to answer research question 2 in light of understanding discomfort as being deprived of a functioning body, a functioning mind and of integrity. We began with the three themes and analysed all field notes and interviews with the nurses to identify deliberations and enactments that aimed at alleviating discomfort associated with each theme. Meaning units were then coded according to similar content and grouped together in six categories (Table 1), thereafter abstracted into the nurse theme "Providing acknowledgement and alleviation." Together with the overall theme from the patient data, the common overall theme "In need of, and providing acknowledgement and alleviation" was formulated (Table 1). Table 1 shows the two steps in the re-analysis of the data. The first step involving analysis of the patient data resulted in the themes in the first column derived from codes in Figure 1. Step 2 comprised codes

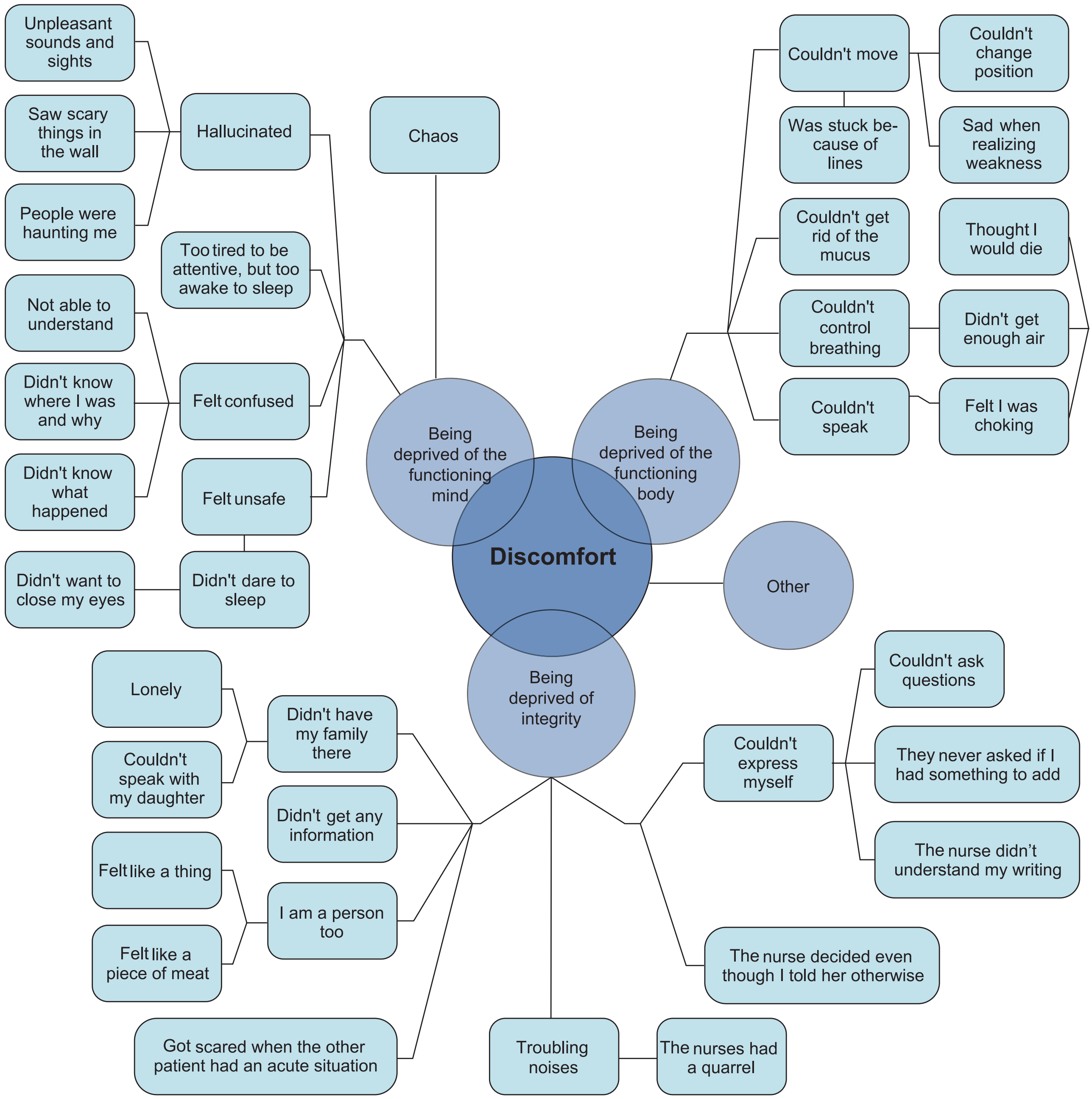

FIGURE 1 Analysis, step 1; A complex and inter-related wholeness of discomforts experienced by patients in the ICU

and categories from the nurse data identified as pertaining to the themes from step 1. In accordance with Graneheim and Lundman (2004), abstracted interpretations representing threads of meaning throughout the data form themes, whereas descriptions closer to the data form categories.

3.4.4 | Step 3 – Application of Comfort Theory

The third research question was approached by applying Kolcaba's Comfort Theory in terms of the taxonomic structure for comfort (Table 2) and types of comfort measures (Table 3) to the themes and adjacent categories resulting from steps 1 and 2 in the analysis.

The understanding of discomfort as a detractor from comfort and comfort as an outcome are elements of Comfort Theory (Kolcaba, 2003). This middle-range theory may offer perspectives important in intensive care where discomfort is prominent. As a framework for nursing practice, it has been applied to different patient populations and clinical settings, the peri-anaesthesia setting being the closest to the ICU setting, and to critically ill patients (Kolcaba & Wilson, 2002; Wilson & Kolcaba, 2004). Specific

TABLE 1 Patient themes, nursing categories and overall theme emerging from the re-analysis of the data

PATIENT DATA STEP 1	NURSE DATA STEP 2		PATIENT AND NURSE DATA
Themes	**Codes**	**Categories**	**Overall theme**
Being deprived of the functioning body	• Attentive positioning • Preventive positioning • Managing respiratory distress • Facilitating participation • Supporting physical functions • Acknowledging inability to speak • Balancing activity and rest	Acknowledging and alleviating bodily discomfort	In need of, and providing acknowledgement and alleviation
Being deprived of the functioning mind	• Orientating about time and place • Informing and explaining about the situation • Assessing for delirium • Preparing for procedures • Demarcation of the body boundaries • Reducing environmental stimuli • Reassuring talk • Gentle touch • Soothing speech • Showing empathy	Recognising confusion and the need for coherence Alleviating apprehension	
Being deprived of integrity	• Including and involving family • Facilitating communication • "Standing by" • Facilitating patient decision making • Involving patient • Facilitating participation • Negotiating • Motivating • Instilling hope • Using personal knowledge about patient • Recognition of person or personality • Engaging in patient former life and interests • Standing up for the patient • Using personalised distraction • Promoting dignity • Respecting patient needs • Defending privacy • Protecting from noise	Acknowledging the need for social connectedness and participation Upholding dignity Protecting from environmental distress	

concepts pertaining to comfort are organised in a taxonomic structure with three types and four contexts of comfort (Table 2). The three types of comfort are *relief*, *ease* and *transcendence* and the four contexts of comfort comprise *the physical*, *the psychospiritual*, *the environmental* and *the sociocultural*. Furthermore, three types of comfort measures are described: *technical*, *coaching* and *comfort food for the soul*. The application of these elements in Comfort Theory in this exploratory study may contribute to a deeper understanding of discomfort in intensive care that may guide critical care nurses in their everyday practice.

The themes emerging from the analysis of the patient data comprised what we consider to be a multifaceted and holistic representation of discomfort or unmet comfort needs. Figure 2 displays how the themes from our data appear to correlate with contexts and types of comfort, and types of comfort measures in Comfort Theory. Explanations of the interpretations are given in the results section. As an example, in Figure 2 the lines display that discomforts representing the deprivation of the functioning body correspond to the physical context of comfort in Comfort Theory. All three types of comfort may be obtained in this area of discomfort, and primarily by application of technical comfort measures.

3.5 | Trustworthiness

The framework offered by Lincoln and Guba may be used to describe trustworthiness also in secondary analyses (Lincoln & Guba, 1985; Shenton, 2004; Thorne, 1994). *Credibility* in this study is ensured through triangulation of data collection methods involving observations and different types of interviewing, and data sources involving both patients and nurses, and documents to provide a background. Furthermore, thick descriptions of the phenomenon under investigation are provided and interpretations of the findings have been discussed with bedside critical care nurses. *Transferability* to similar contexts is sought by describing the studies on which the SDA was

TABLE 2 Kolcaba's Taxonomic structure for comfort (Kolcaba, 2003; Kolcaba & Fischer, 1996). Adapted and printed with permission

Type of Comfort Context of Comfort	Relief **The state of having a specific comfort need met**	Ease **The state of calm or contentment**	Transcendence **The state in which one rises above one's problems or pain**
Physical Pertaining to bodily sensations and functions			
Psychospiritual Pertaining to self-esteem, self-concept, sexuality, meaning in one's life and one's relationship to a higher order or being			
Environmental Pertaining to the external			
Sociocultural Pertaining to interpersonal, family and societal relationships			

TABLE 3 Types of comfort measures suggested in Comfort Theory (Kolcaba, 2003)

Comfort measures generally are of three types: (Kolcaba, 2003)
1. Technical comfort measures to maintain homeostasis and control pain
2. Coaching to relieve anxiety, provide reassurance and information, instill hope, listen and help to plan for recovery
3. Comfort food for the soul are those special things that nurses can do to make patients feel cared for and strengthened, such as massage or guided imagery

built and highlighting the context and the population. *Dependability* is sought by transparency and detailed description of the analytic process, also displayed in tables and figures, allowing the reader to assess the research practice. Finally, to prevent researcher bias, all steps in the analysis were performed both individually and as a team. Several meetings were held and the different perspectives of the researchers discussed and negotiated to ensure *confirmability*. One of the researchers has no experience in working with ICU patients. Her outsider perspective may have prevented bias from the other researchers more emic position from many years of work with this patient group.

4 | RESULTS

The overall theme "In need of, and providing, acknowledgement and alleviation" represented a common description pertaining to both patient discomforts or unmet comfort needs and the nurses' provision of care aiming to meet these needs. In the following we present content from the three themes of deprivation from the patient data under the headings, "The Body", "The Mind" and "Integrity." A field note description involving both a patient and a nurse introduces each theme. Derived from the observations and interviews with nurses, corresponding categories of nurses' attention in each area of deprivation are described after each heading. We also describe our interpretation of the correspondence with concepts in Comfort Theory shown in Figure 2.

4.1 | The body

> *A young man is half sitting in bed. He looks tense but makes no movements. He speaks through a tracheostomy, speaking valve and says he all of a sudden finds the bed totally wrong. The nurse straightens the wrinkled sheets, fixes the pillow behind his head and neck, tucks his feet in, which he wants to be done in a very special way, and which requires many attempts before he approves*
>
> *(field note 16)*

4.1.1 | Being deprived of a functioning body

The loss of bodily functions experienced by the patients pertained mainly to respiratory distress, and inability to move and speak. Not being able to reposition him- or herself, because of weakness or restriction by tubes or lines was a distinct discomfort that made the patients experience loss of control of their body. This loss of bodily function could be accompanied by an experienced loss of integrity in terms of dependency and indignity. Not being able to control breathing, feeling choked by not getting enough air and not getting rid of mucus were devastating experiences leading to anxiety and loss of control. Loss of speech caused by the endotracheal tube and being unaware of the speechlessness being temporary could be traumatising as illustrated by this young patient; *"Can I speak again?? Oh God I was relieved when I realized that (…) it meant the whole world to me - I was really, really, really relieved".* Even though some patients were able to communicate by using a spelling board or paper and pencil, attempts were frequently unsuccessful and led to even more frustration when they were not able to make themselves understood.

When applying Comfort Theory, comfort needs that are evoked by being deprived of a functioning body clearly pertain to the *physical* context of comfort. "Acknowledgement and alleviation of bodily discomforts" a category deriving from our nurse data may relate to

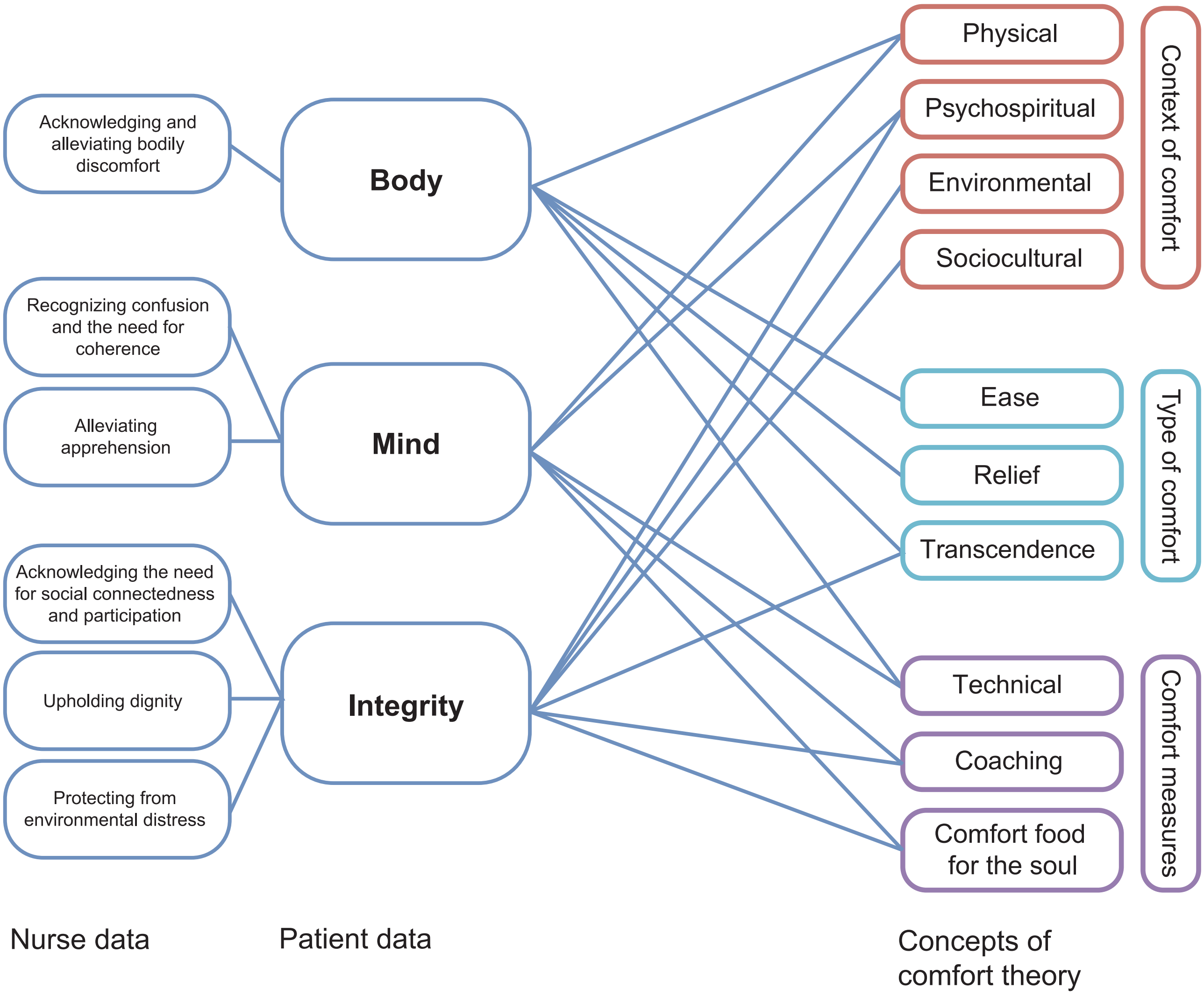

FIGURE 2 Correspondence in data from steps 1 + 2 in the analysis and concepts in Comfort Theory (Kolcaba, 2003)

all three types of comfort. *Relief* may be obtained by managing respiratory distress, *ease* by being attentive or preventive in positioning patients to make them comfortable in bed and *transcendence* by balancing activity and rest when promoting rehabilitation. These nursing deliberations and enactments aiming at “the body” belong mainly to the *technical* comfort measures in Comfort Theory. These comfort measures are described as being designed to help patients maintain or regain physical function and comfort, and prevent complications.

4.2 | The mind

> *A nurse is standing at the bedside close to the patient's head, holding the young woman's arm, speaking to her in a low and soothing voice. She tells her what day it is, where she is and why she is in hospital, and tells her about the monitoring procedures she is about to perform. She asks her to squeeze her hand, carefully opens her eyes and uses a small torch to examine her pupils. She puts a stethoscope on her chest and her abdomen, asking if she is in pain. The patient does not respond, but her heart rate decreases from 120 to 113 while the nurse potters about her*
>
> *(field note 9)*

4.2.1 | Being deprived of a functioning mind

Patients struggled to keep their wits and maintain connection to the real world while in ICU. Contributing to the confusion and delusions were the absent sense of reality, the fluctuating state of wakefulness and the lack of information and hence incomprehension of what was going on. The inability to speak which complicated communication reinforced the experience of incomprehension.

Delusions were common, frequently unpleasant, and often appeared at dusk or when the patients closed their eyes, thereby impairing sleep. Dreams and hallucinations mixed up the real and unreal. The presence of close relatives appeared to form an anchor to reality and contributed to alleviation of the unfamiliar and sometimes scary environment. This alleviation was illustrated by a young male patient who said: *"everything in the room changed – absolutely everything, except for my dad."*

Discomfort from feeling unsafe and being anxious may correspond to the *psychospiritual* context in Comfort Theory. However, the deprivation of the functioning mind relating to cerebral dysfunction, e.g. confusion and delirium, corresponds more to the *physical* context. In our nursing data, the comfort needs pertaining to the mind were met by "alleviating apprehension" and by "recognizing confusion and need for coherence." These categories comprise comfort measures of all three types according to Comfort Theory: *technical* when assessing delirium, *coaching* when informing, explaining and instilling hope and *comfort food for the soul* when using gentle touching, soothing speech and reassuring talk. Nursing interventions directed towards the deprived function of mind in terms of delirium or confusion, however, might not help in obtaining comfort to an extent of either type mentioned in Comfort Theory. A patient who is hallucinating about being haunted may not experience *relief* or *ease* or *transcendence*, no matter how great the efforts of the nurse to acknowledge and alleviate his fears.

4.3 | Integrity

> *Towards the end of the multidisciplinary daily round, held in a meeting room on the ward, the nurse speaks warmly about the patient, and the other meeting participants look surprised. One of them comments that there has been nothing but complaints about this patient for a long time, and that caring for him is exhausting. The nurse reports on his mental capacity, and his commitment and skills in different areas. Witnessing this, I both as an ICU nurse and a researcher, reflect on how seldom these meetings entail this kind of information and how hard it may be for ICU patients to show who they are and be acknowledged in terms other than those of being a 'patient'*
> *(field note 10)*

4.3.1 | Being deprived of integrity

Even though the lack of a normally functioning mind was most unpleasant, being awake and aware of oneself and the situation could also be difficult. The experience of incapacity could compromise the patient's dignity, even the feeling of being a person. The deprivation of speech function could be scary but was only one part of the discomfort of being voiceless. The patients were also deprived of the ability to communicate needs, participate and present themselves as a person, which could lead to a feeling of loneliness, and a feeling of not being included or even respected. To a young female who tried to write her needs on paper, everything was crystal clear, but the nurse could not read her writing and made no further effort to understand. She felt rejected and told how she tried to write; *"why are you treating me like this? I am a person too."* Integrity seemed deprived by the loss of ability to maintain autonomy, the disempowering experience of not feeling like, or not being treated like a person and by being deprived of meaningful relations with family and others. To witness other patients and situations, staying in crowded patient rooms and experiencing a noisy and unfamiliar environment deprived the patients of privacy. One patient said; *"When your bowels haven't moved for days and suddenly they do, and you are in a room with several others - it is not exactly what you wish for".*

Having chosen a complex description of integrity in our study, the deprivation of this in the patient data appears to correspond to three different contexts of comfort in Comfort Theory: the psychospiritual, the environmental and the sociocultural. Nurses intervened in the deprivation of integrity through "Acknowledging the need for social connectedness and participation", "Upholding dignity" and by "Protecting from environmental distress." The content of these categories pertains to Kolcaba's comfort measures either *coaching* or *comfort food for the soul*. *Coaching*, for example, could include using motivation or facilitating patient involvement, and *comfort food for the soul* could imply recognition of the person or personality, engaging in the patients' life and interests, reducing environmental stimuli and including and involving the family. According to Kolcaba (2003), the *comfort food for soul* targets the *transcendence* type of comfort through memorable connections between the nurse and the patient or family. These connections strengthen the patient in healing and rehabilitation.

5 | DISCUSSION

This secondary analysis of primary data showed that discomfort in ICU patients may be characterised by being deprived of a functioning body, a functioning mind and of integrity. The discomfort experienced constituted a complex and inter-related wholeness described by the overall theme of *needing* acknowledgement and alleviation. Furthermore, nurses were attentive to aspects of discomfort experienced by patients in all three areas of deprivation. The nurses' deliberations and enactments regarding discomfort resulted in six categories constituting the overall theme of *providing* acknowledgement and alleviation.

A central finding in this study was *a comfort gap* evident in that our ICU patients expressed a high degree of discomfort despite the endeavours of critical care nurses to alleviate these. The comfort gap correlates with findings of the critical care nurses' perceptions that discomfort experienced by ICU patients cannot be fully eliminated

(Berntzen et al., 2019). This may indicate that nurses are not capable of fulfilling all comfort needs identified. Furthermore, the existence of this comfort gap is supported by Kolcaba's argument that a state of being comfortable rarely applies to stressful health care situations (Kolcaba, 2003). It also aligns with a contemporary conceptualisation of comfort as not pertaining to a complete absence of discomfort, but rather a matter of achieving an acceptable level of comfort (Lowe & Cutcliffe, 2005). A discrepancy similar to the gap we identified was also described by Aro, Pietila, and Vehvilainen-Julkunen (2012) and Wåhlin, Samuelsson, and Ågren (2017). Wåhlin et al. used an empowerment questionnaire to investigate different topics in ICU, rated according to importance to the patient and to what extent these topics were met. The study, however, did not specifically focus on needs, or on discomfort or comfort. The largest difference found between what was rated important and what was met, pertained to the patients' "need to look forward" and to "strengthen life spirit." In their descriptive survey of ICU patients' needs, Aro et al. (2012), however, found a good correlation between the perceived importance of needs and how these needs were met. Of most importance and best met were the needs for physical comfort, feeling safe, being respected and emotionally supported and informed. The gap – although not labelled as such in their study – therefore contained unmet needs evaluated as least important by the patients. In our study, the qualitative and dual perspective of both nurses and patients on discomfort and unmet comfort needs may further elucidate the gap and what contributes to its existence.

Confusion was one prominent feature of the comfort gap identified and a factor contributing to the characteristic "being deprived of a functioning mind", sometimes accompanied by other cognitive impairment. Applying Comfort Theory to our results made it clear that the deprivation of a functioning mind was the most difficult area in which to obtain comfort of either type mentioned. According to Wilson and Kolcaba (2004), cognitive impairment is one variable for which little improvement in comfort may be obtained. Maintaining or regaining comfort related to functioning of the body and of integrity, however, appears attainable, although this depends highly on the nurses' commitment, resources available and the use of existing knowledge. Regarding the deprivation of a functioning mind, the measures to enhance comfort might have a limited impact and depend heavily on the nature of the discomfort. If a patient is hallucinating about the outbreak of World War III or about people wanting to hurt their children (examples from our primary patient data), it seems unlikely that attempts at reassurance will be successful.

Taking this into account – together with the existing lack of knowledge about how the brain is affected in critical illness – the further discussion will focus on this area of deprivation and on how the comfort gap may be diminished.

In our primary study, a large part of the discomfort reported was related to incomprehension and delusions (Berntzen et al., 2018). Similarly, in a review and synthesis of qualitative studies of critical illness experiences, the theme "transformation of perception: unreal experiences and dreams" was an overarching theme affecting all informants' memories and interpretations of such (Cutler, Hayter, & Ryan, 2013). The deprivation of the functioning mind was also reflected in Wåhlin et al.'s study where staff failed to adequately assist the patients to maintain contact with reality (Wåhlin et al., 2017). Moreover, the topics "visit by next of kin" and "staff positive to visitors" were rated to be of great importance. In our study, the importance of family presence represented an important connection to reality, illustrated well by the young man who experienced his entire surroundings to change except for his dad.

The multiple descriptions of unpleasant delusions in our study seem incompatible with "feeling safe," which was identified as an overarching need in ICU patients by Hupcey and Zimmermann (2000). This was also supported by findings both in Aro's study (2012) and by Wåhlin et al. (2017) where it was described as "have trust in staff." In this respect, the lack of knowledge about how the brain is affected in critical illness is of major concern. Delirium is the manifestation of a highly prevalent acute brain dysfunction and organ failure in ICU patients and has to be accounted for when discomforts are assessed and treated. Delusions as part of delirium are common and may severely affect patients during and after the ICU stay (Jones, Griffiths, Humphris, & Skirrow, 2001; Nouwen, Klijn, van den Broek, & Slooter, 2012; Olsen, Nester, & Hansen, 2017; Wade et al., 2015). However, cognitive failure, such as impairments in memory and problem-solving abilities, has also been found in nondelirious ICU patients (Jones, Griffiths, Slater, Benjamin, & Wilson, 2006) and hence also requires attention.

Regarding our findings, more knowledge about the brain and the mind in critical illness is needed to establish how best to reduce the comfort gap identified. The first step ought, however, to be the implementation of existing knowledge in clinical practice, both regarding assessment and interventions. The assessment of confusion and delirium has been facilitated in patients being more awake and by valid assessment tools, but studies show that recommended tools are not sufficiently in use in current clinical ICU practice (Morandi et al., 2017). According to a recent review, various factors need better understanding: the relationship between sleep and delirium, the use of the electroencephalograph (EEG) in delirium monitoring and the role of nonpharmacological interventions like early mobilisation, enhanced communication and family presence (Pandharipande et al., 2017). The last update of the guidelines encompassing pain, agitation/sedation and delirium (PAD) in the ICU introduces approaches towards improving immobility and impaired sleep, resulting in the PADIS guidelines (Devlin et al., 2018). This appears to be a promising expansion of recommendations to address discomforts other than pain contributing to the comfort gap in this study. In 2009, Schweickert et al. had already shown a significant positive effect on its reduction and functional outcome from providing physical and occupational therapy in the initial phase of critical illness (Schweickert et al., 2009). Specifically, early mobilisation, which is facilitated by strategies of light or no sedation, has been considered an important nonpharmacological intervention to restore cognitive function and combat delirium (Baron et al., 2015; Needham et al., 2010; Schaller et al., 2016). Early occupational therapy interventions in the ICU, including multisensory stimulation, positioning, cognitive stimulation and basic training in activities in daily life also, significantly reduce delirium (Alvarez et al., 2017; Tobar, Alvarez, & Garrido, 2017). Recent reviews, however, show insufficient evidence regarding interventions to reduce the incidence and duration of delirium in critically ill patients, and more research is warranted (Bannon et al., 2019; Burry et al., 2019; Herling et al., 2018). Inconclusive research may hamper the implementation of new knowledge and interventions that might further reduce the comfort gap.

Furthermore, in our patients, the presence of family members was important to maintain the connection to reality. Not surprisingly, other studies have found that delirious patients feel greater trust towards family members than towards health care personnel (Storli, Lindseth, & Asplund, 2008; Svenningsen, Egerod, & Dreyer, 2016). In a worldwide survey, 74% of ICUs reported that family members were allowed to visit for less than 5 hr a day (Morandi et al., 2017). A greater involvement of close relatives, including open or flexible visiting hours may be another crucial intervention to support ICU patients during delirium. Morandi et al. (2017) also found that interventions to reduce or treat delirium were more frequent when family members were actively involved. Moreover, family presence also enhanced early exercise and mobilisation in the patients.

Different types of discomfort pertaining in particular to the mind in our study appear to be inevitable at present, taking into account the existing lack of knowledge about the causes of cognitive impairment in ICU, including delirium (Pandharipande et al., 2017). However, important in Comfort Theory is that comfort obtained in one context will always affect comfort in the other contexts (Kolcaba, 2003; Kolcaba & Wilson, 2002). Hence, optimising comfort in other areas may affect the discomfort pertaining to the mind. Morse et al. argue that when comfort is unobtainable, nurses must still recognise the discomfort experienced by patients and be innovative in assisting them to find comfort to whatever level possible (Morse, Bottorf, & Hutchinson, 1994). Levels of comfort may be reflected in patients experiencing a sense of *relief* when their individual comfort needs are met, such as when analgesics are provided towards pain. Patients are at *ease* in situations enabling them to be calm or content, such as when being positioned comfortably in bed. The comfort state of *transcendence* occurs when a person rises above challenges or discomforts, often assisted by the nurse through motivation or facilitation according to Kolcaba (2003). In our primary study, one patient told how he managed the discomfort of being an ICU patient by putting himself into what he called “the hospital bubble”. This bubble may not have relieved discomfort but represented comfort by means of transcendence.

An interesting finding arising from applying Comfort Theory in this study was the feasibility of regarding transcendence as an obtainable type or level of comfort in intensive care. When a certain amount of discomfort is regarded inevitable – also with regard to the deprivation of a functioning body and integrity – nurses may apply comfort measures to help patients rise above their discomforts, i.e. achieve transcendence. If physical discomfort is inevitable during mobilisation despite the provision of pain medication, the nurse may help the patient to rise above this by reassuring the patient of the safety of mobilising, and by acknowledging the existing discomfort. Furthermore, transcendence may be sought by focusing on how the exercise may contribute not only to “medical” goals but also to personal goals, such as participating in a future family event or going hiking. In an earlier study, we found that nurses may experience strain from witnessing patient discomfort when trying to balance rehabilitation and comfort in their patients (Berntzen et al., 2019). To regard transcendence as one type of comfort may even reduce the nurses’ feeling of not doing their best for their patients.

A central finding was the comfort gap that exists in spite of the nurses’ endeavours to alleviate discomfort and attend to comfort needs. This may also reflect the finding that unsystematic approaches were used to alleviate discomfort other than pain in our primary study (Berntzen et al., 2019). The nurses’ endeavours were closely linked to their own personal knowledge and their personal repertoire of interventions including things close to their heart or ‘specialities’. Clearly, multicomponent programmes for discomfort reduction (Kalfon et al., 2017, 2019) and bundles of care like the E-cash (Vincent et al., 2016) and the ABCDEF-bundle (Marra, Ely, Pandharipande, & Patel, 2017; Pun et al., 2019) may contribute to a more individualised and also less unsystematic approach. However, having applied Kolcaba's Comfort Theory in this study, we argue that assessing and planning intensive care according to the taxonomic structure might represent a feasible systematic approach. Securing the assessment of individual comfort needs, defining goals of care relating to comfort of either type, and thereafter planning the care by choosing the appropriate comfort measures may enhance patient comfort. Furthermore, within the frame of systematic assessment and planning, nurses in the ICU will be welcome to use their personal repertoire, including their ‘specialities’, to achieve the common goals of care.

5.1 | Methodological considerations

Reuse of datasets obtained from vulnerable populations may be justified to maximise the use of collected data (Hinds, Vogel, & Clarke-Steffen, 1997), and secondary analyses offer an important possibility of fully exploiting valuable human data (Thorne, 1994). However, qualitative secondary analyses raise a number of issues regarding rigor and ethics (Heaton, 2008; Ruggiano & Perry, 2019; Thorne, 1994), although some apply primarily to the lack of first-hand knowledge of data and ethical issues of informed consent and confidentiality in sharing of datasets. As we reused self-collected data and the purpose of the study did not deviate from what the participants had consented to in the parent studies, these issues were considered not to apply to our study.

A pivotal concern with secondary analyses is the problem of fit between the data and the research question if the data were collected with a different purpose (Heaton, 2008; Thorne, 1994, 2016). In our study, data in both parent studies were collected on pain, other discomforts and wakefulness. The emphasis, however, was on pain experience in the context of the analgosedation protocol implemented. Discomfort was studied by separating pain and discomfort for analytical purposes. A central finding of an overwhelming presence of discomfort other than pain in the data gave rise to this study's research questions which were considered sufficiently close to the original purpose to maintain fit for the secondary analysis.

6 | CONCLUSIONS

Our in-depth exploration of what characterises discomfort in ICU revealed a complex, interwoven experience of being deprived of a functioning body, a functioning mind and integrity, leaving the patient in need of acknowledgment and alleviation. The nurses' acknowledged and alleviated all types of discomfort experienced. However, a comfort gap between the patients' needs and the nurses' overall achievement in meeting these needs indicates that discomfort is an inevitable part of critical illness in ICU. Applying Kolcaba's Comfort Theory to our results contributed to identifying the deprivation of a functioning mind as the least accessible area for nurses' comfort measures. To diminish the gap identified, existing knowledge about the assessment of cognitive function and dysfunction must be implemented. Furthermore, increased knowledge is needed about delirium and other cognitive impairment in intensive care patients. The discomfort from these conditions may not be alleviated, but comfort in other areas may also enhance comfort issues regarding the mind. Using Kolcaba's taxonomic structure and concepts in Comfort Theory may ensure a better competency to assist nurses in enhancing comfort in ICU patients. Furthermore, transcendence as one type of comfort may be obtainable when direct relief from discomfort is not possible. Including transcendence in the comfort repertoire may offer critical care nurses an option to define attainable comfort goals and choose appropriate comfort measures.

7 | RELEVANCE TO CLINICAL PRACTICE

Knowledge of what is important to ICU patients is pivotal in diminishing the comfort gap revealed in our study. This knowledge might guide nurses when deliberating about care structures that will offer patients comfort to whatever level possible.

In the intensive care setting, the distinct focus has been on managing pain and discomfort, including the use of pain assessment tools for noncommunicating patients, and protocols for sedation and analgesia. As discomfort has not usually been regarded as distinct from pain, systematic approaches have evidently concentrated on relieving pain more than on enhancing comfort. Structuring the approach to the familiar – still ill-defined – phenomenon of discomfort as part of the ICU illness trajectory may help nurses in their endeavours to alleviate discomfort in the clinical setting. Familiarity with the concepts of Kolcaba's Comfort Theory in relation to discomfort in ICU may also assist nurses in assessing comfort needs, determining more appropriate goals of care and intervening to alleviate discomfort experienced by their patients.

Minding the gap identified in our study may increase the focus on discomfort other than pain and enhance comfort in patients during their stay in ICU. Different, novel perspectives on discomfort may open up new approaches to the training of critical care nurses and new avenues of research.

ACKNOWLEDGEMENTS

Oslo University Hospital, Division of Emergencies and Critical Care, Department of Postoperative and Intensive Care financially supported this study

CONFLICT OF INTEREST

All authors declare no conflict of interest.

AUTHOR CONTRIBUTIONS

Study design, analysis and manuscript preparation: HB, ITB and HW; data collection: HB.

ORCID

Helene Berntzen https://orcid.org/0000-0001-5262-7911

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

How to cite this article: Berntzen H, Bjørk IT, Storsveen A-M, Wøien H. "Please mind the gap": A secondary analysis of discomfort and comfort in intensive care. *J Clin Nurs*. 2020;00:1–14. https://doi.org/10.1111/jocn.15260

APPENDICES

PROTOKOLL

Introduksjon til analgo-sedasjon

for voksne intensivpasienter

Generell Intensiv 1, avdeling Rikshospitalet, Akuttklinikken,

Oslo Universitetssykehus

Oktober 2014

Protokollen er basert på *"Klinisk vejledning for analgo-sedation"* (2008) ved
Neuroanæstesiologisk Klinik, Rigshospitalet, København og utviklet av:
Overlæge Karen-Lise Welling, ph.d.
Seniorforsker Ingrid Egerod, sygeplejerske, cand.cur., ph.d.
Klinisk udviklingssygeplejerske Suzanne Herling
Intensivsygeplejerske Malene Brorsen Jensen

Protokollen er bearbeidet og videreutviklet av:
Post dok Hilde Wøien
Avdelingsleder Smerteklinikken Audun Stubhaug dr.med
Fagsykepleier Ann-Marie Storsveen
Doktorgradsstipendiat Helene Berntzen

Og gjennomgått og anbefalt til bruk i studien av :
Overlege anestesi Hilde Norum, A-teamet GI 1, OUS
Overlege anestesi Tor A. Aasmundstad, B-teamet GI 1, OUS
Overlege anestesi Jon Narum, C-teamet GI 1, OUS

Bakgrunn for protokollen

Vårt arbeid med smertelindring og sedasjon til intensivpasienter som har foregått ved Generell Intensiv 1 (GI 1), Rikshospitalet, har bidratt til en mer systematisk tilnærming til fagområdet. Intensivpasientene blir vurdert flere ganger daglig for både smerte, sedasjon og forvirring, det settes daglig mål for sedasjonsnivå, og eventuell behandling settes inn på bakgrunn av pasientens dokumenterte smertelindrings- og sedasjonsnivå. Kvaliteten på dette arbeidet kan imidlertid forbedres ved at vurderinger og dokumentasjon utføres oftere, ved at plan og mål blir tydeligere, og ved at flere pasienter sederes ”lettere” og dermed unngår oversedasjon. [1;2] I 2013 kom det ut nye og oppdaterte retningslinjer for behandling, diagnostisering og forebygging av smerter, agitasjon og delirium hos intensivpasienter (Barr et al). [3] Disse retningslinjene støtter i stor grad det arbeidet vi på GI 1 har utført på dette feltet, men viser oss også tydelig hvilken vei vi bør gå for at intensivpasienten sikres tilstrekkelig behandling. På denne bakgrunn velger vi å innføre analgo-sedasjon i vår avdeling, og å bygge en protokoll som tar hensyn til de publiserte anbefalingene fra 2013, samt annen gjeldende forskningslitteratur på området. Vi retter en stor takk til Neuroanæstesiologisk Klinik ved Rigshospitalet i København og deres arbeidsgruppe som har utarbeidet ”Klinisk vejledning for analgo-sedation” (2008), og som har gitt oss muligheten til å bygge vårt arbeid på deres gjennomarbeidede og testede protokoll.

Klassifiseringen av kvaliteten av vitenskapelig evidens for hver anbefaling i retningslinjene til Barr et al [3] er inndelt fra A- C, der A gir høy evidens for en påstand, B moderat evidens og C lav eller svært lav evidens. Videre er anbefalingene i disse retningslinjene klassifisert etter styrke; – sterk (1) eller svak (2) – samt enten for (+) eller mot (–) en intervensjon. I denne protokollen henvises det til graden av evidens på anbefalingene basert på ovennevnte retningslinjer.

Formål med protokoll over introduksjon til analgo-sedasjon

- Å utføre smertelindring og sedasjon sikkert og i henhold til internasjonale retningslinjer
- Å øke kvaliteten og minske variasjonen av smerte- og sedasjonspraksis til intensivpasienter
- Å optimalisere pasientens velvære, og lindre smerte og ubehag
- Å forebygge langvarig kognitiv svikt og posttraumatisk stress
- Å opprettholde pasientens mobiliseringsevne

Hva er analgo-sedasjon?

Begrepet analgo–sedasjon innebærer at det først og fremst utføres tiltak for smerte og ubehag, men med supplerende sedasjon og hypnotisk medikamenter der det er nødvendig.[4;5] Analgo-sedasjon er en strategi, hvor pasienten først og fremst smertelindres, og deretter kun hvis det er nødvendig, sederes. Ved analgo-sedasjon er det ofte mulig å etablere spontan respirasjon under respiratorbehandling og å fremskynde avvenning på respirator. Blant fordelene ved analgo-sedasjon i forhold til konvensjonell sedasjon er: Kortere respiratortid, mindre risiko for ventilasjons assossiert pneumoni (VAP), kortere liggetid på intensivavdeling og redusert morbiditet. [6-8]

Analgo-sedasjon erstatter ikke menneskelig kontakt eller menneskelig behandling (f.eks fri besøkelsesstid, dempet lyd og lys, normalisert døgnrytme og pasientmedvirkning). Hver dag skal det tas stilling til om pasienten har smerter, og om sedasjon er nødvendig. De individuelle mål med analgo-sedasjon vurderes daglig, og det skal legges en plan for prosedyrerelatert analgo-sedasjon (f.eks ved tracheostomi, sykepleietiltak som stell og leieendring og ved mobilisering). [9]

I. Analgesi

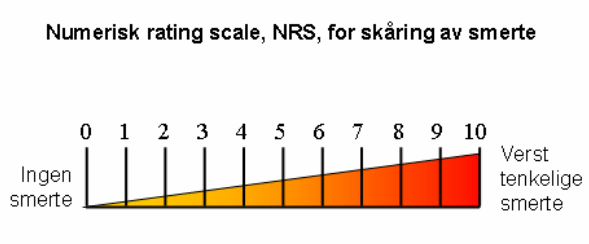
Hva er anbefalingene for smertevurdering?
Smertevurdering og vurdering av terapeutisk respons utføres regelmessig ved hjelp av et valid vurderingsverktøy og dokumenteres systematisk (+1) grad B.

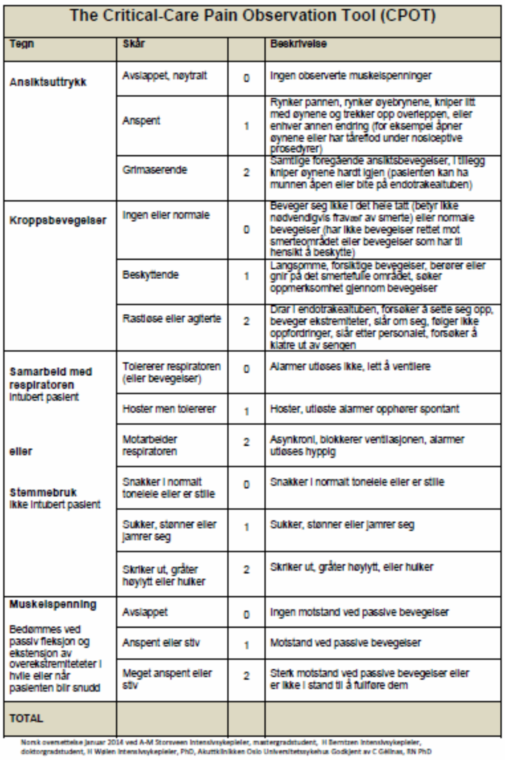
Når pasienten er i stand til at samarbeide og kommunisere sin smerte, vurderes smertenivået ved hjelp av en Numerisk Rating Skala (NRS) (1) grad B.

Når pasienten ikke er i stand til å kommunisere, vurderes smertenivået ut fra smerterelatert adferd (bevegelser, ansiktsuttrykk og uro) ved hjelp av smertevurderingsverktøyet Critical Care Pain Observation Tool (CPOT)(1) grad B

Praktiske forhold ved smertevurdering

- Smertevurdering gjennomføres senest innen 2 timer etter vaktskifte og minst 1 gang per vakt, uavhengig av om det administreres analgetika.
- Smertevurdering dokumenteres systematisk i Metavision.
- Numeric Rating Scale (NRS) anvendes til kooperative patienter, hvor 0 = ingen smerter og 10 = verst tenkelige smerter.[10;11]
- Critical Care Pain Observation Tool (CPOT) anvendes til pasienter som ikke er i stand til å kommunisere verbalt.[12]





The Critical-Care Pain Observation Tool (CPOT)

Tegn	Skår		Beskrivelse
Ansiktsuttrykk	Avslappet, nøytralt	0	Ingen observerte muskelspenninger
	Anspent	1	Rynker pannen, rynker øyebrynene, kniper litt med øynene og trekker opp overleppen, eller enhver annen endring (for eksempel åpner øynene eller har tåreflod under nosioeptive prosedyrer)
	Grimaserende	2	Samtlige foregående ansiktsbevegelser, i tillegg kniper øynene hardt igjen (pasienten kan ha munnen åpen eller bite på endotrakealtuben)
Kroppsbevegelser	Ingen eller normale	0	Beveger seg ikke i det hele tatt (betyr ikke nødvendigvis fravær av smerte) eller normale bevegelser (har ikke bevegelser rettet mot smerteområdet eller bevegelser som har til hensikt å beskytte)
	Beskyttende	1	Langsomme, forsiktige bevegelser, berører eller gnir på det smertefulle området, søker oppmerksomhet gjennom bevegelser
	Rastløse eller agiterte	2	Drar i endotrakealtuben, forsøker å sette seg opp, beveger ekstremiteter, slår om seg, følger ikke oppfordringer, slår etter personalet, forsøker å klatre ut av sengen
Samarbeid med respiratoren Intubert pasient	Tolererer respiratoren (eller bevegelser)	0	Alarmer utløses ikke, lett å ventilere
	Hoster men tolererer	1	Hoster, utløste alarmer opphører spontant
eller	Motarbeider respiratoren	2	Asynkroni, blokkerer ventilasjonen, alarmer utløses hyppig
Stemmebruk Ikke intubert pasient	Snakker i normalt toneleie eller er stille	0	Snakker i normalt toneleie eller er stille
	Sukker, stønner eller jamrer seg	1	Sukker, stønner eller jamrer seg
	Skriker ut, gråter høylytt eller hulker	2	Skriker ut, gråter høylytt, eller hulker
Muskelspenning Bedømmes ved passiv fleksjon og ekstensjon av overekstremiteteter i hvile eller når pasienten blir snudd	Avslappet	0	Ingen motstand ved passive bevegelser
	Anspent eller stiv	1	Motstand ved passive bevegelser
	Meget anspent eller stiv	2	Sterk motstand ved passive bevegelser eller er ikke i stand til å fullføre dem
TOTAL			

Norsk oversettelse januar 2014 ved A-M Storsveen Intensivsykepleier, mastergradstudent, H Berntzen Intensivsykepleier, doktorgradstudent, H Wøien Intensivsykepleier, PhD, Akuttklinikken Oslo Universitetssykehus Godkjent av C Gélinas, RN PhD

Gelinas et al 2006: CPOT- A Validated Approach to Evaluating Psychometric Properties of Pain Assessment Tools for Use in Nonverbal Critically Ill Adults

Oversatt til norsk av Ann-Marie Storsveen, Helene Berntzen og Hilde Wøien.
Norsk oversettelse godkjent av Celine Gelinas.

Hva er anbefalingene for smertebehandling?
Alle kritisk syke pasienter har rett til tilstrekkelig smertebehandling (2) grad A.

En behandlingsplan med mål for smertebehandlingen utarbeides for hver pasient og gjøres tilgengelig for sykepleierne og legene (+1) grad B.

Alle tilgjengelige intravenøse opiater er like effektive, når de titreres til like smerteendepunkt (1) grad C.

Ved mistanke om neuropatisk smerte anbefales gabapentin eller pregabalin i tillegg il iv opioider (1) grad A.

Faste eller kontinuerlige doser opioid foretrekkes over "ved behov"- regimer for å sikre konsistent smertelindring (2) grad B.

Forebyggende smertelindring anbefales ved fjerning av toraksdren (+1)grad C og ved smertefulle prosedyrer (+2) grad C

Praktiske forhold ved smertebehandling
- Analgesi påbegynnes alltid forut for sedasjon. I mange tilfeller kan sedasjon unngåes, hvis pasienten er tilstrekkelig smertelindret (f.eks. ved tubetoleranse).
- Kontinuerlig opioidinfusjon skal forordnes av lege og minimaliseres mht. infusjonshastighet og infusjonsperioder.
- Infusjonshastighet vurderes og justeres minst 1 gang per vakt, da lang infusjonsperiode og høy dose gir abstinenser og (for fentanyl) akkumulasjon.
- Ved prosedyrerelatert smerte kan det suppleres med bolusdoser av analgetikum eller økning av infusjonshastigheten av fentanyl / remifentanil.
- Ved bruk av opioider ordineres peristaltikkfremmende laksantia. Det skal alltid samtidig ordineres osmotiske laksantia (se tarmfunksjonsalgoritme).
- Paracetamol skal forordnes og administreres med en generell forsiktighet ved leversvikt, lever-TX, leverreseksjoner, og ved hematologi med multiorganaffeksjon. Det skal også taes hensyn til pasientens alder. Der det er indikasjon ordineres Paracetamol fast til alle pasienter x 4/døgn (15mg/kg x 4).
- Clonidine anbefales brukt ved opiat nedtrapping og som forebyggende i forhold til utvikling av opiat abstinens i kontinuerlig infusjonsdose 60-90 mikrog/t.
- Clonidine og Dexmedetomidine kan benyttes som adjuvans ved smertebehandling.
- Epidural analgesi er indisert der pasienten trenger smertelindring uten sedasjon og respirasjonsdepresjon. Pga infeksjonsfaren (epidural abcess) bør epiduralkateter ikke ligge ut over en uke. Ved behov for videre epiduralanalgesi byttes til nytt innstikksted (i nytt nivå).
- I utgangspunktet unngåes NSAIDs på grunn av påvirkning av nyrefunksjon og økt blødningstendens.

Hvilke spesielle anbefalinger gjelder for smertebehandling av intensivpasienter med hjerte- og/eller lungesvikt?
- Akutte smerter/ Postoperative smerter: Som hovedregel følges smertebehandlingsplanen forordnet av den legen som har bedøvet pasienten (oftest standard postoperativ plan). Bolus alfentanil (Rapifen) / ketobemidon (Ketorax) / PCA-bolus i.v. supplert med paracetamol, eller evt. kortvarig økning av opiatinfusjon (25 %).

- Lette smerter: Paracetamol til ubehag og lettere smerter. Ved ubehag fremkalt av trakealtube, katetre, immobilisering m.m. kan det administreres bolus opiat (alfentanil (Rapifen), ketobemidon (Ketorax), PCA-bolus i.v., eller evt. en bakgrunnsinfusjon med lav dose remifentanil.
- Prosedyrer som kan medføre smerte eller stress (f.eks. fjerning av dren, sårstell eller fysioterapi): Evt. forutgående supplement av enkeltdoser analgetikum alfentanil (Rapifen) eller evt. kortvarig økning av opiat /remifentanil infusjon.
- Kroniske smerter (pasienter i fast behandling med sterke analgetika): Behandlingen individualiseres under hensyn til vanlig behandling, evt. langtidsvirkende opioid (oxynorm i sonde el per os, oxycontin per os).
- Andre stressrelaterte smerter: Evt. ikke-farmakologisk stressterapi: Faste hviletider, rolig stemmeføring, tilstedeværelse av nærmeste pårørende, rolig musikk m.m.
- Utskrivning fra Generell Intensiv: Ett til to døgn innen utskrivelse kan det skiftes til oxycodonhydroklorid (Oxynorm ved opioidkrevende smerter, som gies i.v. intervalldosert x 2-6/døgn med dose 0.05-0.15 mg/kg. Peroral dose 2,5-3,0 x parenteral dose. Langttidsvirkende oxycodon som OxyContin kan også benyttes og gies i individuelle doser x 2/døgn. Det første døgn titreres opiatbehovet på bakgrunn av smertevurdering (jamfør NRS- eller CPOT-skåring).

Hvilke spesielle anbefalinger gjelder ved valg av opioider til intensivpasienter med hjerte- og / eller lungesvikt?

- Fentanyl er første valg til disse intensivpasientene.
- Remifentanilinfusjon skal høyst gies 3-5 døgn; ved fortsatt behov skiftes til fentanyl. Remifentanil kan redusere behovet for parallell sederende behandling med opp til 50%.
- Oxycodonhydroklorid (Oxynorm): ekvianalgetisk dose 0,3-0,5 x morfin, har færre bivirkninger og foretrekkes frem for morfin.

Hvilke spesielle anbefalinger gjelder for smertebehandling av gastrokirurgiske intensivpasienter?

- Akutte smerter / Postoperative smerter: Som hovedregel følges smertebehandlingsplanen forordnet av den legen som har bedøvet pasienten (oftest standard postoperativ plan). Bolus alfentanil (Rapifen)/ ketobemidon (Ketorax) / PCA-bolus i.v. supplert med paracetamol, eller evt. kortvarig økning av opiatinfusjon (25 %).
- Lette smerter: Paracetamol til ubehag og lettere smerter. Ved ubehag fremkalt av trakealtube, katetre, immobilisering m.m. kan suppleres med bolus opiat alfentanil(Rapifen), ketobemidon (Ketorax), PCA-bolus i.v. eller evt. en bakgrunnsinfusjon med lav dose remifentanil.
- Prosedyrer som kan medføre smerte eller stress (f.eks. fjerning av dren, sårstell eller fysioterapi): Evt. forutgående supplement av enkeltdoser analgetikum alfentanil (Rapifen) eller evt. kortvarig økning av opiatinfusjon.
- Kroniske smerter (pasienter i fast behandling med sterke analgetika): Behandlingen individualiseres under hensyn til vanlig behandling, evt. langtidsvirkende opioid i sonden (oxynorm, oxycontin).
- Andre stressrelaterte smerter: Evt. ikke-farmakologisk stressterapi: Faste hviletider, rolig stemmeføring, tilstedeværelse av nærmeste pårørende, rolig musikk m.m.
- Utskrivning fra Generell Intensiv: Ett til to døgn innen utskrivelse kan det skiftes til oxycodonhydroklorid (Oxynorm ved opioidkrevende smerter, som gies i.v. intervalldosert x 2-6/døgn med dose 0.05-0.15 mg/kg. Peroral dose 2,5-3,0 x

parenteral dose. Langttidsvirkende oxycodon som OxyContin kan også benyttes og gies i individuelle doser x 2/døgn. Det første døgn titreres opiatbehovet på bakgrunn av smertevurdering (jamfør NRS- eller CPOT-skåring).

Hvilke spesielle anbefalinger gjelder ved valg av opioider til gastrokirurgiske intensivpasienter?

- Fentanyl er første valg til disse intensivpasientene.
- Remifentanilinfusjon skal høyst gies 3-5 døgn; ved fortsatt behov skiftes til fentanyl. Remifentanil kan redusere behovet for parallell sederende behandling med opp til 50%.
- Oxycodonhydroklorid (Oxynorm): ekvianalgetisk dose 0,3-0,5 xmorfin, har færre bivirkninger og foretrekkes frem for morfin.

Hvilke spesielle anbefalinger gjelder for smertebehandling av hematologiske intensiv pasienter?

- Akutte smerter/ Postoperative smerter: Som hovedregel følges smertebehandlingsplanen forordnet av den legen som har bedøvet pasienten (oftest standard postoperativ plan). Bolus alfentanil (Rapifen/ ketobemidon (Ketorax) / PCA-bolus i.v. supplert med paracetamol, eller evt. kortvarig økning av opiatinfusjon (25 %).
- Lette smerter: Paracetamol til ubehag og lettere smerter (se anmerkning s.7, Prakstiske forhold ved smertebehandling; forsiktighet ved visse tilstander). Ved ubehag fremkalt av trakealtube, katetre, immobilisering m.m. kan suppleres med bolus opiat alfentanil (Rapifen), ketobemidon (Ketorax), PCA-bolus i.v. eller evt. en bakgrunnsinfusjon med lav dose remifentanil.
- Prosedyrer som kan medføre smerte eller stress (f.eks. fjerning av dren, sårstell eller fysioterapi): Evt. forutgående supplement av enkeltdoser analgetikum alfentanil (Rapifen) eller evt. kortvarig økning av opiat/remifentanilinfusjon.
- Kroniske smerter (pasienter i fast behandling med sterke analgetika): Behandlingen individualiseres under hensyn til vanlig behandling, evt. langtidsvirkende opioid i sonden (oxynorm, oxycontin).
- Andre stressrelaterte smerter: Evt. ikke-farmakologisk stressterapi: faste hviletider, rolig stemmeføring, tilstedeværelse av nærmeste pårørende, rolig musikk m.m.
- Utskrivning fra Generell Intensiv: Ett til to døgn innen utskrivelse kan det skiftes til oxycodonhydroklorid (Oxynorm ved opioidkrevende smerter, som gies i.v. intervalldosert x 2-6/døgn med dose 0.05-0.15 mg/kg. Peroral dose 2,5-3,0 x parenteral dose. Langttidsvirkende oxycodon som OxyContin kan også benyttes og gies i individuelle doser x 2/døgn. Det første døgn titreres opiatbehovet på bakgrunn av smertevurdering (jamfør NRS- eller CPOT-skåring).

Hvilke spesielle anbefalinger gjelder ved valg av opioider til hematologiske intensivpasienter?

- Fentanyl er første valg til disse intensivpasientene.
- Remifentanilinfusjon skal høyst gies 3-5 døgn; ved fortsatt behov skiftes til fentanyl. Remifentanil kan redusere behovet for parallell sederende behandling med opp til 50%.
- Oxycodonhydroklorid (Oxynorm): ekvianalgetisk dose 0,3-0,5 xmorfin, har færre bivirkninger og foretrekkes frem for morfin.

Hvilke spesielle anbefalinger gjelder for smertebehandling av nevrointensive pasienter?

- Akutte smerter/ Postoperative smerter: Som hovedregel følges smertebehandlingsplanen forordnet av den legen som har bedøvet pasienten (oftest standard postoperativ plan). Bolus alfentanil (Rapifen)/ketorax i.v. supplert med paracetamol, eller evt. kortvarig økning av opiatinfusjon (25 %).
- Nevropatiske smerter: Start med tricykliske antidepressiva f.eks. amitriptylin (eks Sarotex) 25 mg x 1-3 p.o. daglig. Alternativ er Remerom smeltetabletter 15-30 mg. Er dette ikke tilstrekkelig er neste valg antikonvulsiva f.eks. gabapentin (Neurontin) 300 mg x 3 p.o. stigende til maksimalt 3600 g/døgn. Alternativt pregabalin (Lyrica) 75 mg x 2 stigende til maksimalt 300 m g x 2 p.o. Hvis ikke effekten av disse medikamentene er tilstrekkelig, kan forsøkes et syntetisk opioid fx tramadol 50 mg x 2 p.o. stigende til maksimalt 100 mg x 4 p.o.
- Lette smerter: Paracetamol til ubehag og lettere smerter. Ved ubehag fremkalt av trakealtube, katetre, immobilisering m.m. kan suppleres med bolus opioid, alfentanil (rapifen), ketobemidon (Ketorax), PCA-bolus i.v. eller evt. en bakgrunnsinfusjon med lav dose remifentanil.
- Prosedyrer som kan medføre smerte eller stress (f.eks. fjerning av dren, sårstell eller fysioterapi): Evt. forutgående supplement av enkeltdoser analgetikum alfentanil (Rapifen) 7-15 mikrog/kg eller evt. kortvarig økning av opiat/remifentanilinfusjon.
- Kroniske smerter (pasienter i fast behandling med sterke analgetika): Behandlingen individualiseres under hensyn til vanlig behandling, evt. langtidsvirkende opioid i sonden (OxyContin).
- Andre stressrelaterte smerter: Evt. ikke-farmakologisk stressterapi: Faste hviletider, rolig stemmeføring, tilstedeværelse av nærmeste pårørende, rolig musikk m.m.
- Utskrivning fra Generell Intensiv: Ett til to døgn innen utskrivelse kan skiftes til oxycodonhydroklorid (Oxynorm ved opioidkrevende smerter, som gies i.v. intervalldosert x 2-6/døgn med dose 0.05-0.15 mg/kg. Peroral dose 2,5-3,0 x parenteral dose. Langttidsvirkende oxycodon som OxyContin kan også benyttes og gies i individuelle doser x 2/døgn. Det første døgn titreres opiatbehovet på bakgrunn av smertevurdering (jamfør NRS- eller CPOT-skåring).

Hvilke spesielle anbefalinger gjelder ved valg av opioider til nevrointensive patienter?

- Fentanyl er første valg til nevrointensive pasienter, inkludert pasienter med alvorlig hodetraume og med stor risiko for å utvikle intrakraniell hypertensjon.
- Remifentanil er første valg til alle nevrointensive pasienter samt pasienter med lettere hodetraume og mindre risiko for å utvikle intrakraniell hypertensjon, og hvor det forventes, at pasienten skal vekkes innen kort tid, eller hvor tubeintoleranse er fremtredende. Remifentanil kan erstatte fentanyl hos pasienter med mer alvorlig hodetraume og avtagende intrakraniell hypertensjon 1 døgn forut for forventet vekking. Remifentanilinfusjon skal høyst gies 3-5 døgn; ved fortsatt behov skiftes til fentanyl. Remifentanil kan redusere behovet for parallell sederende behandling med opp til 50%.
- Oxycodonhydroklorid (Oxynorm): ekvianalgetisk dose 0,3-0,5 xmorfin, har færre bivirkninger og foretrekkes frem for morfin.

Se skjema 1: Anbefalinger ved administrasjon av opioider
Se skjema 2: Anbefalinger ved administrasjon av remifentanil

II. Sedasjon

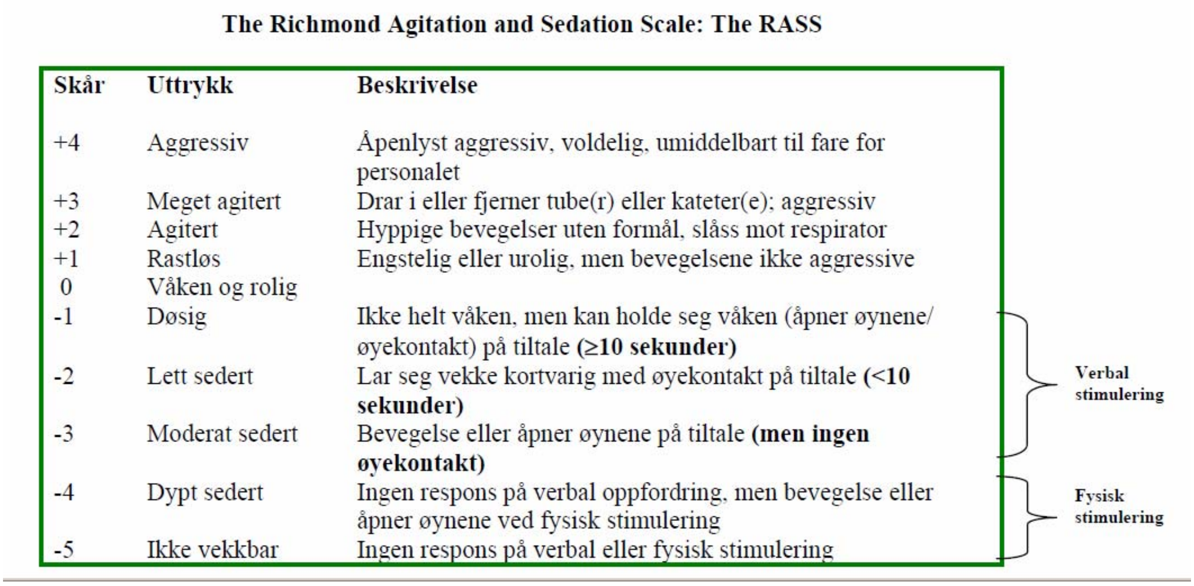
Hva er anbefalingene for sedasjon?
Sedativa titreres til et lett fremfor et dypt sedasjonsnivå der det ikke er kontraindisert (+1) grad B

Sedasjon av agiterte kritisk syke patienter bør kun initieres etter tilstrekkelig analgesi og etter at reversible fysiske tilstander er behandlet (2) grad C.

Det bør jevnlig fastsettes et mål for sedasjon for hver enkelt pasient, og sedasjonsnivået og den terapeutiske respons bør regelmessig dokumenteres (+1) grad B.

Hvordan vurderes sedasjonsnivået?

- Sedasjonsnivå vurderes vha Richmond Agitation and Sedation Scale (RASS) [13] og dokumenteres i Metavision.
- Sedasjonsnivå vurderes senest innen 2 timer etter vaktskiftet og minst 1 gang per vakt (minst hver 8. time).
- Sedasjonsnivå=0 tilstrebes normalt. RASS-nivå= minus 4 eller -5 tilstrebes primært ved forhøyet ICP eller marginal oxygeneringsevne med behov for ekstreme respiratorinnstillinger.
- Sedasjon legeordineres og gjennomføres på spesifikk indikasjon.
- Indikasjon for sedasjon vurderes løpende for å unngå oversedasjon.



The Richmond Agitation and Sedation Scale: The RASS

Skår	Uttrykk	Beskrivelse
+4	Aggressiv	Åpenlyst aggressiv, voldelig, umiddelbart til fare for personalet
+3	Meget agitert	Drar i eller fjerner tube(r) eller kateter(e); aggressiv
+2	Agitert	Hyppige bevegelser uten formål, slåss mot respirator
+1	Rastløs	Engstelig eller urolig, men bevegelsene ikke aggressive
0	Våken og rolig	
-1	Døsig	Ikke helt våken, men kan holde seg våken (åpner øynene/ øyekontakt) på tiltale **(≥10 sekunder)**
-2	Lett sedert	Lar seg vekke kortvarig med øyekontakt på tiltale **(<10 sekunder)**
-3	Moderat sedert	Bevegelse eller åpner øynene på tiltale **(men ingen øyekontakt)**
-4	Dypt sedert	Ingen respons på verbal oppfordring, men bevegelse eller åpner øynene ved fysisk stimulering
-5	Ikke vekkbar	Ingen respons på verbal eller fysisk stimulering

Hvordan vurderes bevissthetsnivået?

- Vurdering av bevissthetsnivå ved Glasgow Coma Score (GCS)
- GCS og RASS supplerer hverandre og dokumenteres under fanen CNS i Metavision.

Hva er anbefalingene ved valg av sedativa?
Propofol eller dexmedetomidine foretrekkes fremfor benzodiazepiner (+2) grad B

Propofol velges når der ønskes rask vekking (f.eks. vurdering av bevissthet/nevrologisk tilstand eller ekstubasjon) (2) grad B.

Benzodiazepiner benyttes ved behov for dyp sedasjon, kramper og alkoholabstinens

Sedativa titreres til et bestemt sedasjonsnivå for å unngå langtidseffekter (1) grad B.

Risiko for abstinenser etter bruk av sedativa og opioider bør vurderes. Sedativa bør gradvis avtrappes (?) grad B.

Nonfarmakologiske metoder må inkluderes for å sikre pasientens søvn (2) grad B.

Praktiske forhold ved sedasjon

- Sedasjon påbegynnes aldri forut for analgesi. I mange tilfeller kan sedasjon unngåes, hvis pasienten er tilstrekkelig smertelindret (f.eks. ved tubetoleranse).
- Pasienter til hypotermi etter hjertestans trenger dyp sedasjon i tillegg til tilstrekkelig analgesi og muskelrelakserende behandling.
- Nevrokirurgiske pasienter skal ikke sederes lettere enn forordnet RASS-nivå
- Bolusdoser og kontinuerlig infusjon av sedasjon skal forordnes av lege og minimaliseres mht. hyppighet og dosering ved intervall, samt ved infusjonshastighet og infusjonsperioder.
- Infusjonshastighet justeres minst 1 gang per vakt, da lang infusjonsperiode og høy dose gir forlenget respiratortid.

Hvilke spesielle anbefalinger gjelder for sedasjon av nevrointensive pasienter?

- Propofol er første valg for nevrointensive pasienter og midazolam er annet valg.
- Propofol (20 mg/ml) gies som infusjon til maks dose 2 mg/kg/time.
- OBS: Fentanylinfusjon potenserer propofoleffekten.
- Ved utilstrekkelig sedasjon og propofol infusjonshastighet på 4 mg/kg/t suppleres med **bolus** midazolam. Er dette utilstrekkelig etter 6-12 timer, erstattes propofol med midazolaminfusjon (alltid bolus først, da respiratortiden forlenges etter oppstart av midazolaminfusion).
- Ved midazolamdose > 0,3 mg/kg/time suppleres med pentobarbital (mebumal) i gjentatte doser.
- ”Thiopenthal-coma” er en av de ultimate behandlinger til pasienter med svært forhøyet ICP eller Status Epilepticus – og i utgangspunktet ikke et valg for sedasjon.

Se skjema 3, 4 og 5: Administrasjon av sedativa

Hvilke spesielle forhold gjelder for propofol til intensivpasienter?

- OBS: Kjent allergi
- OBS: Hypertriglyceridemi.
- Eldre intensivpasienter trenger lavere doser propofol enn andre. Anbefalt kontinuerlig dose er ca 80% av doser til voksne.
- Overvektige intensivapsienter trenger også lavere doser propofol enn normalvektige.
- Propofolindusert hypotensjon behandles primært med volum substitusjon.

- Reversibilitet er redusert etter 36-72 timers infusjon.
- Propofolinfusjonssyndrom (acidose, rhabdomyolyse [nedbrydning av muskelfibre], leverpåvirkning) kan ses ved doser >5 mg/kg.
- Propofol kan anvendes som et anti-krampemiddel
- Propofol inkluderes i kalorieregnskabet (inneholder 1 kcal/ml eller 0,1 g fett/ml). Ved for stor kalorieinntak eller hypertriglyceridemi, som ses ved doser > 2 mg/kg/time (svarer til anbefalt daglig lipiddoser på 0,5 g fett/kg), måle Se-triglycerid.
- Grønnfarging av urinen kan forventes.

Se skjema 6: Sedasjon til spesielle nevrointensive sykdomsgrupper
Se skjema 7: Skjema til avtrapping av sedasjon

III. Delirium

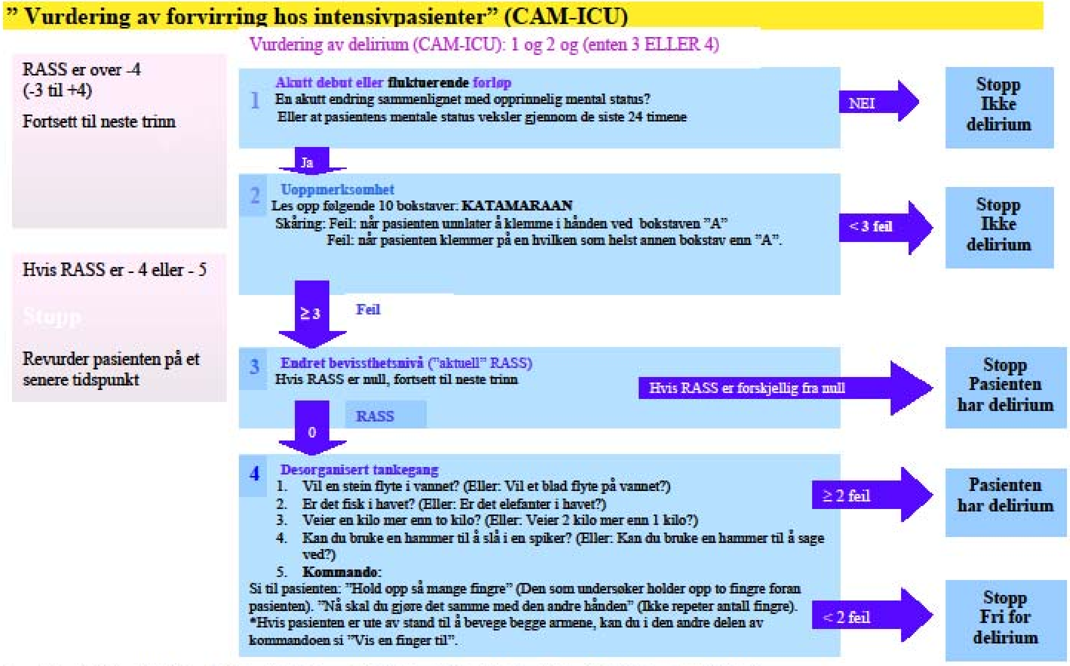
Delirium er en akutt hjernedysfunksjon og en svært vanlig komplikasjon hos kritisk syke pasienter. Det er forbundet med økt morbiditet og mortalitet samt forlenget tid i respirator og liggedøgn, med økte pleie- og behandlingsomkostninger som følge. Studier viser at varigheten av delirium er en uavhengig risikofaktor for nedsatt kognitiv funksjon på lang sikt (opptil ett år). Deliriumanfallene varierer ofte i løpet av døgnet, og det er rapportert om at alt fra 15 til 80 % av intensivpasientene opplever delirium på et tidspunkt mens de er innlagt på intensivavdeling. Delirium er ikke alltid lett å oppdage, da de fleste tilfellene er hypoaktivt delirium (cirka 43,5 %) eller blandet delirium (54,1 %). Bare 1,6 % har rent hyperaktivt delirium – utelukkende agitasjon.[14]

Hva er anbefalingene for vurdering av delirium?
Delirium er forbundet med økt mortalitet og forlenget liggetid på intensivavdeling og sykehus. Nedsatt kognitiv funksjon ses også i økt frekvens hos disse pasientene etter intensivopphold (+1) grad A.

Delirium bør overvåkes rutinemessig hos voksne intensivpasienter (+1) grad B

Praktiske forhold ved vurdering av delirium

- Vurdering av delirium gjennomføres minst 1 gang per vakt.
- Vurdering av delirium dokumenteres systematisk i Metavision.
- Confusion Assessment Method for the ICU (CAM-ICU) benyttes som vurderingsverktøy[3;15]



” Vurdering av forvirring hos intensivpasienter” (CAM-ICU)

Vurdering av delirium (CAM-ICU): 1 og 2 og (enten 3 ELLER 4)

RASS er over -4
(-3 til +4)
Fortsett til neste trinn

Hvis RASS er - 4 eller - 5
Revurder pasienten på et senere tidspunkt

1 **Akutt debut eller fluktuerende forløp**
En akutt endring sammenlignet med opprinnelig mental status?
Eller at pasientens mentale status veksler gjennom de siste 24 timene

2 **Uoppmerksomhet**
Les opp følgende 10 bokstaver: **KATAMARAAN**
Skåring: Feil: når pasienten unnlater å klemme i hånden ved bokstaven ”A”
Feil: når pasienten klemmer på en hvilken som helst annen bokstav enn ”A”.

3 **Endret bevissthetsnivå ("aktuell" RASS)**
Hvis RASS er null, fortsett til neste trinn

4 **Desorganisert tankegang**
1. Vil en stein flyte i vannet? (Eller: Vil et blad flyte på vannet?)
2. Er det fisk i havet? (Eller: Er det elefanter i havet?)
3. Veier en kilo mer enn to kilo? (Eller: Veier 2 kilo mer enn 1 kilo?)
4. Kan du bruke en hammer til å slå i en spiker? (Eller: Kan du bruke en hammer til å sage ved?)
5. **Kommando:**

Si til pasienten: "Hold opp så mange fingre" (Den som undersøker holder opp to fingre foran pasienten). "Nå skal du gjøre det samme med den andre hånden" (Ikke repeter antall fingre). *Hvis pasienten er ute av stand til å bevege begge armene, kan du i den andre delen av kommandoen si "Vis en finger til".

Oversatt til norsk i 2008 av Hilde Wøien, MScN, Anne Kathrine Langerud MScN, Hanne Alfheim MN, Audun Stubhaug Dr Med, Rikshospitalet HF, Oslo, Norway

Hva er anbefalingene for behandling av delirium?

Det gis ingen anbefaling for legemidler eller en kombinasjon av ikke-farmakologisk og farmakologisk behandling for å forsøke å forebygge delirium, da det ikke finnes tilstrekkelig (0) grad C.

Tidlig mobilisering anbefales for å redusere forekomsten av delirium (+1) grad B.

Det foreligger ikke publisert evidens for at behandling med haloperidol reduserer omfanget av delirium i intensivavdelinger for voksne pasienter (0 evidens).

Delirium sees i sammenheng med analgesi og sedasjonspraksis. Analgo-sedasjon, bruk av protokoller samt bruk av validerte vurderingsverktøy til smerte, sedasjon og delirium i et tverrfaglig team anbefales (+1) grad B

Det anbefales at delirium som ikke er relatert til alkohol- eller benzodiazepinabstinens, behandles med deksmedetomidin fremfor benzodiazepiner når pasienten trenger sedasjon (+2, Evidens B).

Hvilke spesielle anbefalinger gjelder for delirium hos intensivpasienter?

Rutinemessig daglig sedasjonsstopp eller definert mål om et lett sedasjonsnivå anbefales (+1) grad B. Daglig mobilisering bidrar til redusert liggetid på intensiv og på sykehus, samt at det også kan gi økt styrke og funksjonell status.[16,17] I tillegg til en analgesibasert sedasjon anbefales også optimalisering av intensivpasientens søvn, ro og hvile ved at alle aktiviteter samles i puljer (+1) grad C. Bruk av benzodiazepiner kan være en risikofaktor for utvikling av delirium, men sammenhengen er foreløbig uklar.[3]

Skema 1. Anbefalinger ved administrasjon av opioider		
Legemiddel	**Dosehastighet**	**Handling**
Fentanyl	Startdose voksne 1-6 mikrog/kg/time	Dose justeres uti fra smertenivå. Ved uro/agitasjon suppleres med propofol bolus opp til 0,5 mg/kg eller infusjon 0,5 mg/kg/time.
Remifentanil	Startdose = 0,05-0,1 mikrog/kg/min Vedlikeholdsdose 0,05-0,1 mikrog/kg/min	Dose justeres hvert 5 minutt med 25 % uti fra smertenivå og respirasjonsfrekvens. *Må ikke gies som bolus!*
	Hvis dose >0,03 mikrog/kg/min (Se skjema 2)	Ved fortsatte smerter økes med 0,03 mikrog/kg/min til effekt Ved uro/agitasjon suppleres med propofol bolus opp til 0,5 mg/kg eller infusjon 0,5 mg/kg/time
Alfentanil (Rapifen)	Startdose = 0,25-0,1 mikrog/kg/min Vedlikeholdsdose 0,25-0,1 mikrog/kg/min	Dose justeres uti fra smertenivå. Ved uro/agitasjon suppleres med propofol bolus opp til 0,5 mg/kg eller infusjon 0,5 mg/kg/time.

Skjema 2. Anbefalinger ved administrasjon av remifentanil (60 mikrog/ml)
Infusjonshastigheten velges ut fra pasientens vekt og den ønskede dosering. **OBS: Remifentanil må IKKE gies som bolus. Startdose: 0,05 mikrog/kg/min** **Sett til propofol ved dose høyere enn 0,15 mikrog/kg/min** **Maks. dose 0,15 mikrog/kg/min**

Skjema 3: Anbefalinger ved administrasjon av propofol (20 mg/ml)
Startdose: 1 mg/kg/time **Skal suppleres med analgetikainfusjon, senest når dose kommer opp på 2 mg/kg/time** **Maksimum 4 mg/kg/t (overveie skift av sedativa eller supplement med midazolam)**

OBS! Det skal taes hensyn til pasientens alder og eventuell overvekt ved bruk av propofol.
OBS. Remifentanil kan redusere behovet for samtidig sederende behandling med opp til 50%.
Propofol og remifentanil må gjerne gå i samme venflon eller CVK, selv om det gies bolus Propofol.

Skjema 4: Anbefalinger ved administrasjon av midazolam (5 mg/ml)
Start alltid med **bolus** midazolam (0,03-0,1 mg/kg). Midazolaminfusjon forlenger respiratortiden. **Startdose: 0,03-0,1 mg/kg/time** **Maks. dose >0,3 mg/kg/t**

Skjema 5: Anbefalinger ved administrasjon av sedativa

Legemiddel	**Dosehastighet Se skjema**	**Handling**
Propofol (10mg/ml eller 20 mg/ml)	1 mg/kg/time	Startdose
	< 3 mg/kg/time	Vurdering av ønsket sedasjonsnivå for det kommende døgn.
	3 mg/kg/time	Supplere evt. med remifentanilinfusjon ved utilstrekkelig sedasjon. Remifentanil kan redusere behovet for annen samtidig sederende behandling med opp til 50 %.
	> 4 mg/kg/time	Supplere eller erstatte propofol med midazolam
Midazolam (5 mg/ml)	0,03-0,1mg/kg/time	Startdose bolus er 0,05-0,1 mg/kg. Det forutsettes, at pasienten samtidig behandles med analgetika (typisk fentanyl). Bolus behandling med midazolam forkorter respiratortiden sammenlignet med infusjon av midazolam.
	< 0,3 mg/kg/time	Hvis pasienten får analgesi med fentanyl, suppleres med remifentanil infusjon ved utilstrekkelig sedasjon. Remifentanil kan redusere behovet for annen samtidig sederende behandling med opp til 50%.
	0,3 mg/kg/time For 60 kg svarer det til >18 ml/t	Supplere evt. med fenemal (bolus 0,5-1 mg/kg)
Dexdor	0,2-1,4 mikrog/kg/min	Hos monitorerte intuberte intensivpasienter som har vært sederte kan startdosen være 0.6 mikrog/kg/min. Under opptrappingsfasen opp mot ønsket effekt, kan det gies bolusdose med propofol.
Thiopental		Thiopental 5-10 mg/kg i bolus Deretter ved behov infusjon 5 mg/kg/t i 3 timer fulgt av 1-3 mg/kg/t
Fenobarbital		Bolus 0,5-1 mg/kg. Sjeldent nødvendig med fenobarbital (fenemal). Anvendes ved alvorlig epilepsi og evt. i abstinensbehandling.

Skjema 6: Sedasjon til spesielle nevrointensive sykdomsgrupper		
Sykdomsgruppe	**Tilstand**	**Valg av analgetika/sedativa**
SAH	Før kirurgisk behandling	Fentanyl / alfentanil (ev.Remifentanil) / propofol
	Etter kirurgisk behandling	Fentanyl / alfentanil (ev.Remifentanil) / propofol (1. og 2. døgn) ev Midazolam
Akutt medullær skade		Remifentanil /propofol (lav dose) kombinert med bolus oxynorm/morfin.
Generalisert status epilepticus	Trinn 1 Behandlingsmål er EEG til burst suppression (kontinuerlig EEG monitorering tilstrebes)	Remifentanil (dosert som i skjema 2) / propofol (inntil 2mg/kg/t)
	Trinn 2	Midazolam bolus, evt. –infusjon (dosert som i skjema 4), propofoldose reduseres eller seponeres helt
	Trinn 3 (Obs hypotensjon)	Thiopental 5-10 mg/kg over 30 minutter 5 mg/kg/time i 3 timer fulgt av 1-3 mg/kg/t
Nevromuskulær sykdom		Alminnelig tubetoleranse kan som regel oppnåes med analgesi (fentanyl eller remifentanil). Hvis ikke det er nok, anvendes Propofol kombinert med bolus oxynorm/morfin. Husk behandling for nevrogene smerter.

Skema 7. Skjema til avtrapping av sedasjon	
Stoff eller stoffkombinasjon	**Handling**
Remifentanil/propofol	Propofol halveres i 1 (-2) timer. Deretter avsluttes. Remifentanil avtrappes deretter med 25% hver 10 minutt, forutgått av bolus morfin / oxynorm i.v. (45 minutter før)
Fentanyl/propofol	Propofol halveres i 1 (-2) timer, deretter avsluttes. Fentanyl reduseres så til 0,5 mikrog/kg/t eller avsluttes, avhengig av smertevurdering.
Fentanyl/midazolam	Midazolam avsluttes. Fentanyl reduseres til 0,5 mikrog/kg/time

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Appendix 2

The Critical-Care Pain Observation Tool (CPOT)

Gélinas, C., Fillion, L., Puntillo, K. A., Viens, C., & Fortier, M. (2006). Validation of the Critical-Care Pain Observation Tool in adult patients. *American Journal of Critical Care, 15* (4), 420-427.

Tegn	**Skår**		**Beskrivelse**
Ansiktsuttrykk	Avslappet, nøytralt	0	Ingen observerte muskelspenninger
	Anspent	1	Rynker pannen, rynker øyebrynene, kniper litt med øynene og trekker opp overleppen, eller enhver annen endring (for eksempel åpner øynene eller har tåreflod under nociseptive prosedyrer)
	Grimaserende	2	Samtlige foregående ansiktsbevegelser, i tillegg kniper øynene hardt igjen (pasienten kan ha munnen åpen eller bite på endotrakealtuben)
Kroppsbevegelser	Ingen eller normale	0	Beveger seg ikke i det hele tatt (betyr ikke nødvendigvis fravær av smerte) eller normale bevegelser (har ikke bevegelser rettet mot smerteområdet eller bevegelser som har til hensikt å beskytte)
	Beskyttende	1	Langsomme, forsiktige bevegelser, berører eller gnir på det smertefulle området, søker oppmerksomhet gjennom bevegelse
	Rastløse eller agiterte	2	Drar i endotrakealtuben, forsøker å sette seg opp, beveger ekstremiteter, slår om seg, følger ikke oppfordringer, slår etter personalet, forsøker å klatre ut av sengen
Samarbeid med respiratoren Intubert pasient	Tolererer respiratoren (eller bevegelser)	0	Alarmer utløses ikke, lett å ventilere
	Hoster men tolererer	1	Hoster, utløste alarmer opphører spontant
eller	Motarbeider respiratoren	2	Asynkroni, blokkerer ventilasjonen, alarmer utløses hyppig
Stemmebruk Ikke intubert pasient	Snakker i normalt toneleie eller er stille	0	Snakker i normalt toneleie eller er stille
	Sukker, stønner eller jamrer seg	1	Sukker, stønner eller jamrer seg
	Skriker ut, gråter høylytt eller hulker	2	Skriker ut, gråter høylytt, eller hulker
Muskelspenning	Avslappet	0	Ingen motstand ved passive bevegelser
Bedømmes ved passiv fleksjon og ekstensjon av overekstremiteteter i hvile eller når pasienten blir snudd	Anspent eller stiv	1	Motstand ved passive bevegelser
	Meget anspent eller stiv	2	Sterk motstand ved passive bevegelser eller er ikke i stand til å fullføre dem
Total			

Norsk oversettelse januar 2014 ved A-M Storsveen intensivsykepleier mastergradstudent, H Berntzen intensivsykepleier doktorgradstudent, H Wøien intensivsykepleier PhD, Akuttklinikken Oslo Universitetssykehus. Godkjent av C Gélinas, RN PhD

Kortfattet beskrivelse av hver adferdskomponent i CPOT

Ansiktsuttrykk: Ansiktsuttrykket er en av de beste adferdsindikatorer for smertevurdering. Skår = 0 blir gitt når det ikke observeres muskelspenninger i pasientens ansikt. Skår = 1 innebærer et anspent ansiktsuttrykk, noe som vanligvis uttrykkes ved rynket panne, eller øyenbryn. Skår = 2 referer til grimasering, som er en sammentrekning i hele ansiktet inkludert gjenknepne øyne og stramme kinnmuskler. I noen tilfeller vil pasienten åpne munnen eller, dersom hun eller han er intubert, bite på endotrakealtuben. Enhver annen endring i ansiktsuttrykk bør beskrives i kurven/journalen og bli gitt skår =1 dersom dette skiller seg fra et avslappet (0) eller grimaserende (2) ansikt.

Kroppsbevegelser: Skår = 0 blir gitt når pasienten ikke beveger seg i det hele tatt eller når sykepleieren bedømmer pasientens bevegelser som normale. Skår =1 refererer til beskyttende bevegelser, i den betydning at pasienten gjør langsomme og forsiktige bevegelser, forsøker og nå eller berøre det smertefulle området. Skår =2 blir gitt når pasienten er rastløs eller agitert. Her gjør pasienten gjentatte bevegelser, forsøker å dra i ledninger, prøver å sette seg opp i sengen eller samarbeider ikke. **Merk**, kroppsbevegelser regnes som mindre spesifikk smerteatferd, men er likevel viktige i den helhetlige evalueringen av pasientens smerte.

Samarbeide med respiratoren: Begrepet samarbeid med respirator benyttes når pasienten respiratorbehandles. Skår = 0 blir gitt når pasienten er lett å ventilere. Pasienten verken hoster eller utløser alarmer. Skår = 1 betyr at pasienten hoster eller utløser alarmer som opphører spontant uten at sykepleieren trenger å gjøre tiltak. Skår = 2 blir gitt når pasienten motarbeider respiratoren. Pasienten kan hoste og utløse alarm, og det kan observeres en asynkroni med respiratoren. Sykepleieren må gjøre tiltak for å berolige pasienten eller administrere medikamenter for å roe ned pasienten.

Stemmebruk: Stemmebruk benyttes hos ikke-intuberte pasienter, som er i stand til å lage lyd. Skår = 0 refererer til at pasienten er stille eller snakker i normalt toneleie. Skår =1 blir gitt der pasienten sukker, stønner eller jamrer seg og en skår = 2 når pasienten skriker ut (ai-au), gråter høylytt eller hulker.

Muskelspenning: Muskelspenning er også en meget god indikator på smerte, og betraktes som den nest beste i CPOT. I hvile bedømmes muskelspenning ved å utføre en passiv fleksjon og ekstensjon av pasientens arm. Under snuprosedyren kan sykepleier enkelt føle om pasienten gjør motstand. Skår = 0 blir gitt når det ikke kjennes noen motstand ved passive bevegelser eller snuing. En skår =1 refererer til motstand under bevegelse eller snuing, med andre ord at pasienten er anspent eller stiv. Skår = 2 innebærer sterk motstand. Her kan sykepleieren være ute av stand til å fullføre passive bevegelser eller pasienten motsetter seg bevegelse ved snuing. Pasienten kan også knytte nevene.

Norsk oversettelse januar 2014 ved A-M Storsveen intensivsykepleier mastergradstudent, H Berntzen intensivsykepleier doktorgradstudent, H Wøien intensivsykepleier PhD, Akuttklinikken Oslo Universitetssykehus. Godkjent av C Gélinas, RN PhD

Instruksjoner for bruk av CPOT

1. Pasienten må observeres ett minutt i hvile for å få en baseline (grunnverdi) på CPOT.

2. Deretter bør pasienten observeres under nociseptive prosedyrer (f.eks snuing, sårstell) for å oppdage enhver endring i pasientens smerteatferd.

3. Pasienten bør vurderes før og ved forventet maksimal effekt av analgetika for å evaluere om medikamentet var effektivt i forhold til å lindre smerte**.**

4. I forhold til tallfestingen med CPOT, skal pasienten gis den høyeste skår som er blitt observert i løpet av observasjonsperioden.

5. Pasienten tilskrives en skår for hver enkel atferdskomponent inkludert i CPOT og muskelspenning skal evalueres til slutt, spesielt når pasienten er i hvile, ettersom stimulering og berøring i seg selv (når det utføres passiv fleksjon og ekstensjon av armen) kan føre til endringer i atferd.

Observasjon av pasient i hvile (baseline)

Sykepleieren observer pasientens ansikt og kropp i ett minutt for å merke seg alle synlige reaksjoner. En skår gis for alle komponenter unntatt muskelspenning. På slutten av denne ett-minutts perioden holder sykepleier pasientens arm med begge hender, en ved albuen og den andre benyttes til å holde pasientens hånd. Deretter utfører sykepleier en passiv fleksjon og ekstensjon av overekstremiteten, og kjenner etter om pasienten gjør motstand. Dersom bevegelsene utføres lett, anses pasienten som avslappet og uten motstand, skår = 0.

Dersom bevegelsene fortsatt kan utføres, men med bruk av mer styrke, konkluderes det med at pasienten viser motstand mot bevegelsene, skår =1. Hvis sykepleieren kjenner sterk motstand og ikke kan fullføre bevegelsene, gis skår = 2. Slik motstand kan observeres hos pasienter som er spastiske.

Observasjon av pasient i forbindelse med snuing

Også under snuprosedyren kan sykepleieren vurdere pasientens smerte. Mens sykepleieren snur pasienten på siden, observeres pasientens ansikt for å legge merke til alle reaksjoner, som rynket panne eller grimasering. Reaksjonene kan være kortvarige, eller vare lenger. Sykepleieren ser også etter kroppsbevegelser. Det ses for eksempel etter beskyttende bevegelser som at pasienten forsøker å nå eller berøre det smertefulle området (f.eks. operasjonssnitt, skadet område).

Hos respiratorpasienten er sykepleieren oppmerksom på alarmer og hvorvidt de opphører spontant eller krever tiltak (f.eks. berolige eller å gi medikamenter)

I forhold til muskelspenning kan sykepleieren kjenne hvorvidt pasienten gjør motstand mot bevegelsen eller ikke. Skår = 2 blir gitt når pasienten gjør motstand mot bevegelsen og forsøker å komme i ryggleie.

Norsk oversettelse januar 2014 ved A-M Storsveen intensivsykepleier mastergradstudent, H Berntzen intensivsykepleier doktorgradstudent, H Wøien intensivsykepleier PhD, Akuttklinikken Oslo Universitetssykehus. Godkjent av C Gélinas, RN PhD

Appendix 3

Minneskjema fra intensivopphold (ICU Memory Tool*)

C. Jones, G. Humphris, RD. Griffiths. Preliminary validation of the ICUM tool: a tool for assessing memory of the intensive care experience. Clinical Intensive Care. 2000;11(5):251-255.

(Vennligst sett ring rundt det svaret som passer)

1.	**Husker du at du ble innlagt på sykehuset ?**	Tydelig Utydelig Ikke i det hele tatt
2.	**Kan du huske tiden på sykehus før du ble innlagt på intensivavdelingen?**	Alt Noe av det Ingenting
3.	**Husker du at du var på intensivavdelingen?**	Ja/Nei
4a.	**Husker du hele oppholdet klart?**	Ja/Nei

4b. **Hva husker du ? (sett ring rundt det du husker)**

Familie*
Alarmer*
Stemmer*
Lys*

Ansikter*
Tube/pusterør*
Suging i tuben*
Ubehag†

Mørke*
Klokke*
Rør/sonde i nesen*
Legevisitt*

At du følte deg forvirret†
At du følte deg nedfor†
At du følte deg engstelig/redd†
At du følte at noen forsøkte å skade deg‡

Hallusinasjoner‡
Mareritt‡
Drømmer‡
Panikk†
Smerte†

4c. **Dersom du hadde noen form for følelse av at noen forsøkte å gjøre deg vondt deg eller å skade mens du var i intensivavdelingen, kan du beskrive disse følelsene nedenfor.**

…………………………………………………………………………………………......
……………………………………………………………………………………………
……………………………………………………………………………………………

TIL ADMINISTRATIV BRUK

Skår for underkategorier:
* faktiske minner
† minner om følelser
‡ uvirkelige minner

Norsk oversettelse oktober 2014; Helene Berntzen, intensivsykepleier, doktorgradsstudent, Hilde Wøien, intensivsykepleier, PhD, Ann-Marie Storsveen, intensivsykepleier, mastergradsstudent. Akuttklinikken, Oslo universitetssykehus. Godkjent av C. Jones

4d. **Dersom du hadde mareritt eller hallusinasjoner mens du var på intensivavdelingen, kan du beskrive disse:**

…………………………………………………………………………………………......
……………………………………………………………………………………………
……………………………………………………………………………………………

5.	**Husker du at du ble overflyttet fra intensivavdelingen til sengepost?**	Tydelig Utydelig Ikke i det hele tatt
6.	**Har du hatt noen uforklarlige følelser av panikk eller uro?**	Ja/Nei

6a. Hvis ja: **Hva gjorde du når disse følelsene oppstod?**

…………………………………………………………………………………………......
……………………………………………………………………………………………
……………………………………………………………………………………………

7.	**Har du hatt noen påtrengende eller plagsomme minner fra tiden på sykehuset eller fra hendelsen som førte til din innleggelse?**	Ja/Nei

7a. Hvis ja på 7: **Hva gjorde du når du disse påtrengende /plagsomme minnene oppstod?**

…………………………………………………………………………………………......
……………………………………………………………………………………………
……………………………………………………………………………………………

7b. Hvis ja på 7: **Hva bestod disse minnene av (f.eks skremmende mareritt)?**

…………………………………………………………………………………………......
……………………………………………………………………………………………
……………………………………………………………………………………………

8. **Har du snakket om hva som skjedde med deg på intensivavdelingen med:**

Et familiemedlem

En sykepleier ved avdelingen

En venn

En lege ved avdelingen

Fastlegen din

Norsk oversettelse oktober 2014; Helene Berntzen, intensivsykepleier, doktorgradsstudent, Hilde Wøien, intensivsykepleier, PhD, Ann-Marie Storsveen, intensivsykepleier, mastergradsstudent. Akuttklinikken, Oslo universitetssykehus. Godkjent av C. Jones

Intervjuguide 2 – Semi-strukturert dybdeintervju

Informant nr:	Varighet:

Forklare kort og deretter forsikre meg om at informanten er innforstått med studiens hensikt og samtykket som er signert. Forklare om lydopptak og om hva som vil skje med innsamlede data. Til slutt presisere tema for intervjuet, men understreke at de også kan snakke om annet som opptar dem;

Innledningsspørsmål

- Hvor lenge har du vært hjemme?
- Hvordan har det generelt gått siden utskrivelsen og siden vi sist møttes.
    - Dette intervjuet handler mest om smerte, men også om det å være våken under intensivoppholdet og om det å kunne bevege seg – eventuelt få hjelp til dette. Vi har snakket litt om dette forrige gang vi møttes, men jeg vil gjerne få spørre om noen av de samme tingene og om noe andre ting. Jeg ønsker først å snakke med deg om det å være våken på respirator.

Våkenhet

- Kan du si noe hva du husker av det å være våken mens du lå på respirator?
- Opplevde du det å være våken som en god ting?
- I så fall på hvilken måte?
- Opplevde du noen gang det å være våken som en belastning?
- I så fall på hvilken måte?
- Har du noen minner om det med søvn mens du lå på respirator?
- Oppfølgingsspørsmål som utdyper

Er det noe du har tenkt på i ettertid (eller nå) som kunne gjort det bedre for deg i den situasjonen ?

Dersom du mot all formodning skulle havne i en lignende situasjon igjen, ville du da ønske å være mer våken eller mindre våken enn det du var ?
Hvorfor ?

Mobilisering

- Kan du huske om du kunne bevege deg i senga mens du lå på respirator?
- hvis ikke– hvorfor kunne du ikke det? og hvordan opplevde du det ?
- Kan du huske at du satt på sengekanten, at du stod opp, at du satt i stol på intensivavdelingen?
    - o fortell om dette ?
    - o hva husker du og hvordan opplevde du det ?

Smerter

Smertehukommelse?

- Kan du fortelle om du kan huske om du hadde smerter mens du lå på intensivavdelingen?
- Hvis ingen minner om smerte – minner om ubehag ?

Smertens natur?

- hva slags smerter var det – kan du beskrive dem på noen måte?
- hvor hadde du smerter ?
- kan du huske når eller i hvilke sammenhenger du opplevde smerter eller ubehag ? beskriv

Smerteformidling/kommunikasjon

- opplevde du at det ble forstått når du hadde smerter?

        - hvis nei fortell om dette ….
- Kan du huske hvordan du formidlet at du hadde vondt ?
- kan du huske at du ble spurt om du hadde vondt? Hvordan ble du spurt ?
- har du noen formening om dette var på intensivavdelingen eller senere

Er det noe du har tenkt på i ettertid (eller nå) som kunne gjort det bedre for deg ?

Smertelindring?
- opplevde du at det var noe som lindret smertene du hadde ?
- Utdypende spørsmål

Er det noe du har tenkt på i ettertid (eller nå) som kunne gjort det bedre for deg ?

Vedvarende smerter
- Har du vært plaget med noen form for smerter før du ble syk – kan du i så fall fortelle om dette
    - Hvordan har det vært med smerter etter at du ble utskrevet fra sykehuset ?
    - Dersom smerter
    - kan du beskrive hva slags smerter?
    - I hvilken grad opplever du at smertene er knyttet til den aktuelle sykdomssituasjonen eller oppholdet på sykehuset ?
    - Påvirker eventuelle smerter deg i det daglige eller i aktiviteter?
    - Hva betyr dette for deg?
    - Bruker du smertestillende medikamenter?
    - Gjør du andre ting for å håndtere smerten du fortsatt har?

Smertehukommelse og håndtering
- Hvis du husker smertefulle episoder – er dette noe du tenker på nå i ettertid – i så tilfelle kan hun/han fortelle om dette – hva det betyr i dag?
- Hvordan opplever du disse minnene om å ha hatt vondt?
- Hvis minnene er plagsomme, gjør du noe for at det skal være bedre?

Avslutningsspørsmål?
- Er det noe vi ikke har kommet inn på som du har lyst til å snakke om?
- Hvordan har det vært for deg å delta i dette intervjuet?

Generelle utdypende spørsmål/oppfølgingsspørsmål;
Kan du fortelle litt om..?
Kan du si litt mer om …?
Du nevnte at…kan du forklare det litt nærmere…?
Kan du beskrive mer nøyaktig….?
Hva tenker du om det du beskrev nå ?

Bekreftende spørsmål
Er det slik å forstå at ….?
Forstår jeg deg rett når?

Observasjonsguide
deltagende observasjon / interaktiv observasjon

Bakgrunn/kontekst;

PASIENTEN/OMGIVELSER/PERSONER.

Beskriv pasienten, situasjonen, omgivelsene, personene til stede.
Noter hvordan omgivelsene kan påvirke smertevurdering eller smertehåndtering; lyder, forstyrrelser, andre personer (tolkning)

Hovedfokus:

HENDELSER

Beskriv alle hendelser og situasjoner, planlagt og uplanlagte, som kan tenkes å ha betydning for smerteopplevelsen hos pasienter;

- prosedyrer
- stell og pleie
- mobilisering (leieendring, bevegelse)
- hoste, hikke, skjelvinger
- besøk
- berøring
- uventede situasjoner

Beskriv pasientens utseende (uttrykk) inkludert non-verbal kommunikasjon/tegn
Beskriv sykepleierens aktiviteter/atferd knyttet til **vurderinger** av smerte i forbindelse med hendelser og situasjoner;

- kommunikasjon med pasienten (sitater hvis mulig)
- diskusjoner med kolleaer/visitt
- bruk av smerteskåringsverktøy

Beskriv sykepleierens aktiviteter/atferd knyttet til **håndtering/tiltak** vedrørende smerte i forbindelse med hendelser og situasjoner,

- medikamentelle
- ikke-medikamentelle
- avbrytelser og forsinkelser i vurdering eller håndtering av smerte
- evaluering av tiltak
- hva som skjer dersom tiltakene ikke synes å ha tiltenkt effekt -
- Utforske i intervju det som observeres og undersøke om at det jeg f.eks beskriver som tiltak er intensjonelt

INTERAKSJONER

Beskriv sykepleierens verbale og non-verbale kommunikasjon
Beskriv ***interaksjoner*** *som kan ha tilknytning til smerte, våkenhet, mobilisering mellom personer tilstede*
Beskriv tegn pasienten gir for å initiere en interaksjon
Beskriv tegn fra pasienten som sykepleieren responderer på
Når det kommuniseres om smerte, noter sitater når mulig

TID

Sekvenser á 30 – 120 minutter avhengig av situasjon og aktivitet. Kan også være kortere dersom situasjonen tilsier – eller deles opp hvis dette er hensiktsmessig. Dette har en todelt funksjon; observasjonstiden blir bedre utnyttet data blir mer kondensert og belastning på miljøet og de som observeres reduseres.

Organisering av notater;
inkludere korte narrative beskrivelser av personer, interaksjoner, situasjoner, handlinger, hendelser, tid, uttrykte følelser i feltnotatene og de analytiske notatene

<table>
<tr><td colspan="4">Observasjon nr : Spl nr: Klokkeslett:
Ant. minutter :</td></tr>
<tr><td>Observasjonsnotater inkl kontekstnotater
Hendelser – hva er involvert hver gang spl gjør noe ifht smerte/sedasjon/forvirring /mobilisering</td><td>Refleksjoner /Fortolkninger</td><td>Spørsmål til intervju
Fortolkninger som bør sjekkes ut</td><td>Metoderefleksjoner
- andre tilnærminger, tidspunkt, situasjoner
- Noe jeg må lese om/diskutere
- Reaksjoner hos meg</td></tr>
</table>

Oslo universitetssykehus

Til alle leger med tilknytning til generell intensiv 1;

Kort informasjon om forskningsprosjekt med oppstart oktober 2014

Del-studie/doktorgradsprosjekt; "Intensivsykepleieres håndtering av smerte hos intensivpasienter, og intensivpasienters erfaringer med smerte og våkenhet ved analgosedasjon; en feltstudie." *Prosjektet er en del av det allerede oppstartede prosjektet; "Innføring av en protokoll for analgosedasjon på intensivavdeling og en studie av pasienters erfaringer med smerte og våkenhet."*

Bakgrunn

Intensivpasienter rapporterer både smerte og ubehag i forbindelse med behandling, og har ofte behov for både analgesi og sedasjon. Studier viser at smerte underbehandles og at pasientene får mer sedasjon enn det er behov for, noe som kan øke liggetiden på intensiv og risikoen for komplikasjoner under og etter kritisk sykdom. Analgosedasjon er en anbefalt strategi som innebærer først og fremst å smertelindre intensivpasienten og deretter gi sedasjon ved behov. Hensikten med analgosedasjon er å bidra til en mer våken, kommuniserbar og mobil pasient som kan bruke egne respirasjonsmuskler, og der kognitiv funksjon kan overvåkes. Hensikten med hovedstudien er å få mer kunnskap om effekten av at intensivpasienter behandles etter prinsippene for analgosedasjon.

Hensikt

I denne del-studien er hensikten 1) å få økt kunnskap om hvordan sykepleiere vurderer og behandler smerte etter implementering av analgosedasjon som en strategi ved GI1, og 2) hvilke opplevelser og erfaringer intensivpasienter har ved analgosedasjon vedrørende smerte og våkenhet, forvirring og evne til bevegelse.

Hva innebærer studien?

Vi vil observere og studere hvordan intensivpasientens smerte blir vurdert og håndtert av intensivsykepleiere, og utforske intensivpasientenes opplevelser og erfaringer fra intensivoppholdet etter ca. en uke og etter tre måneder.
I studien vil det bli benyttet feltobservasjoner og påfølgende intervjuer med intensiv-sykepleiere og intensivpasienter. Feltobservasjoner vil foregå fra og med november 2014. Observasjonene har ikke til hensikt å evaluere arbeidet som utføres som bra eller mindre bra, men utforske vurderinger og tiltak i forbindelse med smertebehandling og sedering av intensivpasienter.
Konkret vil undertegnede være tilstede på pasientstuen sammen med sykepleiere som har samtykket til deltagelse, og som aktuelle dager har ansvar for pasienter som er inkluderte i hovedstudien. Sykepleierne vil bli observert i perioder på 30 min – 2 timer i situasjoner som passer med studiens formål. Det vil bli innhentet samtykke i forkant fra pasienter (evt. pårørende) og sykepleiere, og i etterkant fra eventuelle andre som er tilstede i observasjons-situasjonene.
Du vil altså kunne oppleve at undertegnede er tilstede i pasientrommet, eventuelt overvær diskusjoner rundt planer for pasientbehandlingen. Dersom du anses som deltagende i situasjonen, vil du bli spurt om samtykke til å benytte observasjonsdata. Det registreres ingen opplysninger om deg utover nedtegnelser i løpet av observasjonene. Observasjonene knyttes med en kode til pasienten du behandler.

Som observatør vil undertegnede være kledd i hvit frakk over privat tøy og ha skilt merket "Forskningssykepleier. "Pasientintervjuene vil foregå på sengepost og etter utskrivelse fra sykehuset.

Dersom du har spørsmål, kan du kontakte doktorgradsstipendiat Helene Berntzen på telefon 92263592 eller prosjektleder og veileder Hilde Wøien på telefon 91380768.

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Forespørsel om deltakelse i forskningsprosjekt (del-studie – intervju 1)

Intensivsykepleieres håndtering av smerte hos intensivpasienter, og intensivpasienters erfaringer med smerte og våkenhet ved analgo-sedasjon

Bakgrunn og hensikt

Under oppholdet på intensivavdelingen deltok du i en forskningsstudie som du samtykket til (eller dine pårørende dersom du selv var for syk til dette). Studien innebar at sykepleierne flere ganger i døgnet registrerte grad av smerte, våkenhet og forvirring hos deg, og i hvilken grad du fysisk var i stand til å bevege deg i eller ved sengen. I tillegg ble det samlet opplysninger fra pasientjournalen og de elektroniske overvåkningsskjemaene som benyttes i avdelingen. Disse opplysningene omfatter alvorlighetsgraden i sykdommen da du ble lagt inn på intensivavdelingen, hvor langt oppholdet på intensivavdelingen og i sykehuset for øvrig har vært, hvor lenge du trengte respiratorbehandling og hva slags medisiner du fikk. Vi ønsker i en del-studie å finne ut mer om hvordan intensivsykepleiere vurderer smerte og gjør tiltak overfor pasientene, og hvilke opplevelser og erfaringer intensivpasienter har fra intensivoppholdet vedrørende smerte og våkenhet, forvirring og evne til bevegelse.

Hva innebærer studien?

I denne del-studien ønsker vi å be deg delta i et intervju. Intervjuet vil foregå på sengeposten med undertegnede som er intensivsykepleier og forsker/doktorgradsstipendiat i løpet av den første uken etter utskrivelse fra intensivavdelingen. Intervjuet vil vare i underkant av en halv time og med ditt samtykke bli tatt opp på lydopptaker. Eventuelt vil vi be om å få kontakte deg for et nytt intervju etter tre måneder. Du forplikter deg ikke til dette. Det siste intervjuet vil i så tilfelle foregå hjemme hos deg, på sykehuset eller pr. telefon etter hva som passer deg best. Tema for samtalene vil være minner og erfaringer fra intensivoppholdet, med hovedvekt på smerteopplevelser.

Mulige fordeler og ulemper

Det er ingen umiddelbare fordeler for deg personlig å delta i denne studien. Resultatene av studien kan derimot bidra til at smertebehandlingen og pleien til intensivpasienter blir bedre. Mange har minner og erfaringer fra intensivoppholdet som de synes det er vanskelig å dele med andre, og det vil derfor kunne oppleves godt å fortelle noen om opplevelsene sine. For andre kan det å dele minner oppleves som en belastning.

Hva skjer med informasjonen om deg?

Alle opplysninger som fremkommer under intervjuet vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger, men en kode knytter deg til en navneliste som i hoved-studien. Det er kun undertegnede doktorgradsstipendiat og veiledere som har adgang til navnelisten og som kan finne tilbake til deg.

Frivillig deltakelse

Det er frivillig å delta i studien. Du binder deg heller ikke til videre deltagelse om du samtykker, og du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke. Dette vil ikke få konsekvenser for din videre behandling. Dersom du er villig til å delta, undertegner du samtykkeerklæringen på siste side, og undertegnede vil få beskjed og ta kontakt med deg. Har du spørsmål eller senere ønsker å trekke deg fra studien, kan du kontakte doktorgradsstipendiat Helene Berntzen på telefon 92263592 eller prosjektleder Hilde Wøien på telefon 91380768.

Kapittel A- utdypende forklaring av hva studien innebærer

Bakgrunn for studien
Det er gjort en god del forskning rundt pasienters erfaringer og minner fra intensivopphold og tiden på respirator. Imidlertid er det få studier som viser sammenhenger mellom det pasienten husker og hvilke medikamenter han eller hun har fått som smertestillende og som sovemedisin, og om hvor våken pasienten er blitt vurdert til å være underveis i forløpet. Vi ønsker å finne ut mer om dette og om hvordan erfaringene med smerte og våkenhet oppleves etter en stund for i fremtiden å kunne tilby den behandlingen som er best under selve intensivoppholdet, og i tiden etterpå.

Som deltaker har du ikke ansvar for noe i løpet av perioden. Du kan eventuelt bli kontaktet når det er tid for et nytt intervju slik det er beskrevet.

Det gis ingen økonomisk kompensasjon for deltagelsen i denne studien, men dersom du velger å komme til sykehuset for å bli intervjuet, kan rimelige reisekostnader dekkes.

Kapittel B - Personvern

Alle opplysninger, inkludert navnelister som muliggjør identifisering av deg vil bli slettet når prosjektet er fullført, senest i 2020. Resultatene av studien vil bli publisert i internasjonale tidsskrifter for leger og sykepleiere. Det vil ikke være mulig å identifisere deg i artikler som publiseres.

Oslo Universitetssykehus ved administrerende direktør er databehandlingsansvarlig.

Rett til innsyn og sletting av opplysninger om deg og sletting av prøver
Som deltaker i studien, har du rett til å få innsyn i hvilke opplysninger som er registrert om deg. Du har videre rett til å få korrigert eventuelle feil i de opplysningene vi har registrert. Dersom du trekker deg fra studien, kan du kreve å få slettet innsamlede opplysninger, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner.

Informasjon om utfallet av studien
Alle deltakere har rett til å få informasjon om utfallet/resultatet av studien.

Oslo
universitetssykehus

Samtykke til deltakelse i forskningsprosjekt – del-studie (intervju 1)

Jeg samtykker til å bli intervjuet i forskningsprosjektet og jeg har fått en kopi av dette samtykkearket og den skriftlige informasjonen om studien.

Navn på den som samtykker: ________________________________

Dato: ________________ Signatur: ________________________________

Navn på den som har gitt muntlig og skriftlig informasjon om studien: ____________________

Dato: ________________ Signatur: ________________________________

Oslo universitetssykehus

Forespørsel om deltakelse i forskningsprosjekt (del-studie)

Intensivsykepleieres håndtering av smerte hos intensivpasienter, og intensivpasienters erfaringer med smerte og våkenhet ved analgo-sedasjon

Bakgrunn og hensikt

Vi ønsker i en del-studie å finne ut mer om hvordan intensivsykepleiere vurderer smerte og gjør tiltak overfor pasientene, og hvilke opplevelser og erfaringer intensivpasienter har fra intensivoppholdet vedrørende smerte og våkenhet, forvirring og evne til bevegelse.

Hva innebærer studien?

I denne del-studien inngår en **observasjon** av deler av behandlingen som utføres mens din pårørende er intensivpasient og behandles med respirator. En av undertegnede som er intensivsykepleier og forsker/doktorgradsstipendiat vil en eller flere ganger mens din pårørende er innlagt i intensivavdelingen være tilstede i pasientrommet for å observere hvordan sykepleierne vurderer hans/hennes behov for smertelindring og sovemedisin, og hvilke tiltak som gjøres. Eventuelt kan det senere bli aktuelt å intervjue din pårørende rundt erfaringer og minner vedrørende smerte og våkenhet, forvirring og evne til å bevege seg under intensivoppholdet. Et slikt intervju vil selvsagt skje med samtykke fra pasienten selv. Behandlingen din pårørende får vil ikke på noe tidspunkt avhenge av om han/hun er deltager i studien.

Mulige fordeler og ulemper

Som i hoved-studien.

Hva skjer med informasjonen om din pårørende?

Alle opplysninger som fremkommer under observasjonsperiodene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger, men en kode knytter din pårørendes opplysninger til en navneliste som i hoved-studien. Det er kun undertegnede doktorgradsstipendiat og veiledere som har adgang til navnelisten og som kan finne tilbake til din pårørende.

Frivillig deltakelse

Som i hoved-studien. Har du spørsmål eller senere ønsker å trekke ditt samtykke, kan du kontakte doktorgradsstipendiat Helene Berntzen på telefon 92263592 eller prosjektleder Hilde Wøien på telefon 91380768

Kapittel A- utdypende forklaring av hva studien innebærer

Bakgrunn for del-studien

Det er gjort en god del forskning rundt pasienters erfaringer og minner fra intensivopphold og tiden på respirator. Imidlertid er det få studier som viser sammenhenger mellom det pasienten husker og hvilke medikamenter han eller hun har fått som smertestillende og som sovemedisin, og om hvor våken pasienten er blitt vurdert til å være underveis i forløpet. Vi ønsker å finne ut mer om dette og om hvordan erfaringene med smerte og våkenhet oppleves etter en stund, for i fremtiden å kunne tilby den behandlingen som er best under selve intensivoppholdet og i tiden etterpå.

Kapittel B - Personvern

Alle opplysninger som muliggjør identifisering av din pårørende vil bli slettet når prosjektet er fullført, senest i 2020. Resultatene av studien vil bli publisert i internasjonale tidsskrifter for leger og sykepleiere. Det vil ikke være mulig å bli identifisert i artikler som publiseres.

Oslo Universitetssykehus ved administrerende direktør er databehandlingsansvarlig.

Rett til innsyn og sletting av opplysninger om din pårørende og sletting av prøver

Å samtykke på vegne av din pårørende gir ikke automatisk rettighet til innsyn i opplysninger som er registrert. Dersom du trekker samtykket tilbake, kan du kreve å få slettet innsamlede opplysninger, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner.

Informasjon om utfallet av studien

Som deltaker i studien har din pårørende rett til å få informasjon om utfallet/resultatet av studien.

Oslo universitetssykehus

Stedfortredende samtykke til deltakelse i forskningsprosjekt/ del-studie

Jeg har mottatt skriftlig og muntlig informasjon og jeg vet nok om hensikt, metode, fordeler og ulemper til å gi mitt samtykke.
Jeg vet at det er frivillig å delta og at jeg når som helst kan trekke mitt samtykke tilbake uten at min pårørende mister sine nåværende eller fremtidige rettigheter til behandling.

Jeg gir samtykke til at ____(pasientens navn) deltar i forskningsprosjektet og jeg har fått en kopi av dette samtykkearket og den skriftlige informasjonen om studien.

Opplysning om min tilknytning,/slektskap til pasienten:

____

Navn på den som gir stedfortredende samtykke: ______________________________

Dato: _______________ Signatur: ______________________________

Navn på den som har gitt muntlig og skriftlig informasjon om studien: _______________

Dato: _______________ Signatur: ______________________________

Oslo
universitetssykehus

Forespørsel om deltakelse i forskningsprosjekt

Del-studie/doktorgradsprosjekt; "Intensivsykepleieres håndtering av smerte hos intensivpasienter, og intensivpasienters erfaringer med smerte og våkenhet ved analgosedasjon; en feltstudie." *Prosjektet er en del av det allerede oppstartede prosjektet; "Innføring av en protokoll for analgosedasjon på intensivavdeling og en studie av pasienters erfaringer med smerte og våkenhet."*

Bakgrunn

Intensivpasienter rapporterer både smerte og ubehag i forbindelse med behandling, og har ofte behov for både analgesi og sedasjon. Studier viser at smerte underbehandles og at pasientene får mer sedasjon enn det er behov for, noe som kan øke liggetiden på intensiv og risikoen for komplikasjoner under og etter kritisk sykdom. Analgosedasjon er en anbefalt strategi som innebærer først og fremst å smertelindre intensivpasienten og deretter gi sedasjon ved behov. Hensikten med analgosedasjon er å bidra til en mer våken, kommuniserbar og mobil pasient som kan bruke egne respirasjonsmuskler, og der kognitiv funksjon kan overvåkes. Hovedhensikten med studien som utføres ved Generell Intensiv 1 ved OUS, Rikshospitalet, er å få mer kunnskap om effekten av at intensivpasienter behandles etter prinsippene for analgosedasjon.

Hensikt

I denne del-studien er hensikten 1) å få økt kunnskap om hvordan sykepleiere vurderer og behandler smerte etter implementering av analgosedasjon som en strategi ved GI1, og 2) hvilke opplevelser og erfaringer intensivpasienter har ved analgosedasjon vedrørende smerte og våkenhet, forvirring og evne til bevegelse.

Hva innebærer studien?

Det du som intensivsykepleier blir forespurt om samtykke til innebærer en observasjon av vurderingene som gjøres og smertebehandlingen som utføres hos intensivpasienter du har ansvar eller medansvar for. Konkret vil undertegnede, *uten å delta i pleien*, be om å være tilstede i pasientrommet sammen med deg på aktuelle dager der du har ansvar eller medansvar for pasienter som er inkluderte i hovedstudien. Du kan bli observert en eller flere ganger i perioder på 30 min – 2 timer i situasjoner som passer med studiens formål, for eksempel stell, mobilisering og andre sykepleieprosedyrer. Uformell samtale rundt vurderinger og tiltak vil inngå i observasjonen, og det vil være viktig å supplere feltnotatene med korte intervjuer med deg i etterkant av observasjonen. Ved disse intervjuene vil det bli benyttet lydopptaker for å få best mulige data.
Observasjonene har ikke til hensikt å evaluere arbeidet du utfører som bra eller mindre bra, men utforske de vurderinger og tiltak du gjør i forbindelse med smertebehandling og sedering av intensivpasienter. Feltnotater vil bli skrevet etter og delvis under observasjonene, og bli supplert med opplysninger fra pasientens journal og elektronisk kurve. Dersom du samtykker til å delta vil du være blant dem som kan bli forespurt ved vaktens start dersom du har ansvar for en av studiens inkluderte pasienter. Behandlingen pasienten får vil være i tråd med avdelingens protokoll for analgosedasjon og ikke avhenge av om vedkommende er deltager i studien.

Opplysninger du gir om antall år du har arbeidet som intensivsykepleier registreres, men ingen personidentifiserende opplysninger. Utover dette registreres kun nedtegnelser i løpet av observasjonene og en kode knytter observasjonene til pasienten som behandles. Anslagsvis vil totalt 20 -30 observasjoner bli gjennomført.

Mulige fordeler og ulemper

Det er ingen umiddelbare fordeler for deg personlig å delta i denne studien, men resultatene av studien kan derimot bidra til å øke kunnskapen om sykepleieres vurdering av smertebehandling til intensivpasienter. For mange vil det kunne oppleves verdifullt å kunne bidra til slik kunnskap, og noen vil oppleve det positivt å formidle egne vurderinger om faglige problemstillinger. For andre kan det oppleves som en belastning. Observasjonene skal ikke gå utover arbeidet ditt eller pasienten, og påfølgende intervjuer vil bli gjort innenfor arbeidstid med avløsning fra en annen sykepleier.

Hva skjer med informasjonen om deg?

Det som observeres og det du formidler vil bli behandlet uten tilknytning til deg som person. En kode knytter feltnotatene og pasientdata fra journal og elektronisk kurve til en navneliste. Resultatene av studien vil bli publisert i internasjonale tidsskrifter for leger og sykepleiere. Det vil ikke være mulig å identifisere deg eller pasienten i materialet som publiseres.

Frivillig deltakelse

Det er frivillig å delta i studien, og du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke. Dersom du er villig til å delta, undertegner du samtykkeerklæringen på siste side og legger i merket skap utenfor intensiv så snart som mulig. Dersom du har spørsmål eller senere ønsker å trekke deg fra studien, kan du kontakte doktorgradsstipendiat Helene Berntzen på telefon 92263592 eller prosjektleder Hilde Wøien på telefon 91380768.

Kapittel A- utdypende forklaring av hva studien innebærer

Bakgrunn for studien
Det er gjort en god del forskning rundt vurderingsprosesser hos sykepleiere, og rundt smertevurdering, men få studier er spesifikt rettet mot intensivsykepleie der bruken av observasjon som metode er benyttet. Når det gjelder intensivpasienter, finnes en del forskning om pasienters erfaringer og minner fra intensivopphold og tiden på respirator. Vi ønsker spesielt å finne ut mer om hvordan erfaringene med smerte og våkenhet oppleves etter en tid for å kunne tilby den behandlingen som er best under selve intensivoppholdet, men også i tiden etterpå.

Kriterier for deltakelse i studien er at du er fast ansatt ved avdelingen og har arbeidet med intensivpasienter i minimum 2 år.

Kapittel B - Personvern

Personopplysninger om deg begrenser seg til demografiske data; alder, kjønn, utdannelse og arbeidserfaring. Pasienten du har ansvar for knyttes til en navneliste med en kode. Kun undertegnede og veiledere i prosjektet vil ha tilgang til datamaterialet i delprosjektet det samtykkes til.

Oslo Universitetssykehus ved administrerende direktør er databehandlingsansvarlig.

Rett til innsyn og sletting av opplysninger om deg og sletting av prøver
Dersom du trekker deg fra studien, kan du kreve å få slettet innsamlede opplysninger, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner.

Informasjon om utfallet av studien
Alle deltakere har rett til å få informasjon om utfallet/resultatet av studien.

Oslo universitetssykehus

Samtykkeskjema forskningsprosjekt

”Intensivsykepleieres håndtering av smerte hos intensivpasienter, og intensivpasienters erfaringer med smerte og våkenhet ved analgosedasjon; en feltstudie”

For at vi skal vite at du har fått invitasjon til å delta, ville det være fint om du fyller ut uansett om du samtykker til å delta eller ikke. Da unngår du å få flere forespørsler.
Svarslippen legges i merket kasse på vaktrommet, generell intensiv 1

SETT RING;

JA jeg er villig til å delta

NEI jeg vil ikke delta

Navn: ______________________________

Dato: _______________ Signatur: ______________________________

Appendix 10

Oslo universitetssykehus

Kort informasjon og forespørsel om samtykke ved forskningsprosjekt

Del-studie/doktorgradsprosjekt; "Intensivsykepleieres håndtering av smerte hos intensivpasienter, og intensivpasienters erfaringer med smerte og våkenhet ved analgosedasjon; en feltstudie." *Studien er en del av det allerede oppstartede prosjektet;" Innføring av en protokoll for analgosedasjon på intensivavdeling og en studie av pasienters erfaringer med smerte og våkenhet."*

Bakgrunn og hensikt

Vi vil gjerne be om tillatelse til å benytte observasjoner gjort i en pasientsituasjon der du har vært tilstede i rommet som helsepersonell eller pårørende. Observasjonene inngår i datasamlingen til en studie som er en del av et større forskningsprosjekt der hovedmålet er å studere effekten av innføring av analgosedasjon ved Generell Intensiv 1 ved OUS, Rikshospitalet. Analgosedasjon er en anbefalt strategi som innebærer først og fremst å smertelindre intensivpasienten og deretter gi sedasjon ved behov. Hensikten med analgosedasjon er å bidra til en mer våken, kommuniserbar og mobil pasient som kan bruke egne respirasjonsmuskler, og der kognitiv funksjon kan overvåkes. Hensikten med hovedstudien er å få mer kunnskap om effekten av at intensivpasienter behandles etter prinsippene for analgosedasjon. I del-studien skal vi studere intensivsykepleieres vurderinger og tiltak vedrørende smertebehandlingen og videre hvilke erfaringer og minner akutt-og kritisk syke pasienter har om smerte fra oppholdet i en intensivavdeling.

Observasjonene har ikke til hensikt å evaluere arbeidet som utføres som bra eller mindre bra, men utforske vurderinger og tiltak i forbindelse med smertebehandling og sedering av intensivpasienter. Noen av pasientene vil senere bli intervjuet om sine opplevelser og erfaringer fra intensivoppholdet.

Det registreres ingen opplysninger om deg utover nedtegnelser fra observasjonene som knyttes til den situasjonen som ble observert. Observasjonene knyttes med en kode til pasienten du har behandlet eller besøkt. Kun undertegnede stipendiat og veiledere vil ha tilgang til det innsamlede datamateriale.

Oslo Universitetssykehus ved administrerende direktør er databehandlingsansvarlig.

Frivillig deltakelse

Det er frivillig å delta i studien, og du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke. Dersom du samtykker til at vi kan benytte observasjonene, undertegner du samtykkeerklæringen. Dersom du har spørsmål eller senere ønsker å trekke deg fra studien, kan du kontakte doktorgradsstipendiat Helene Berntzen på telefon 92263592 eller prosjektleder Hilde Wøien på telefon 91380768.

Informasjon om utfallet av studien

Alle deltakere har rett til å få informasjon om utfallet/resultatet av studien.

Navn på den som gir samtykke: ______________________________

Dato: _______________ Signatur: ___________________________

Detailed literature search strategy 24.01.2020

In PubMed, I conducted a search using Medical Subject Headings (MeSH) and text words including, but not restricted to: critical care, intensive care, critical illness, critically ill, patient experience, psychological distress, emotional distress, discomfort, comfort, pain, analgosedation, nursing management, nursing care, qualitative research, coping, deep sedation, conscious sedation, analgesics, delusion, delirium, memory, mental recall, recollections, wakefulness, well-being.

«Norske» artikler som ikke kommer med på søket over:
https://www.ncbi.nlm.nih.gov/pubmed/?term=31685257+30478708+30069988+29633421+29567559+28238055+26106928+24380660+23075027+22999498+21885286

Literature search for: "Patient experiences and nurses management of pain and discomfort in intensive care during analgosedation"

Below you find a search in PubMed for identifying articles on “intensive care”, restricted to articles published last 20 years in English, Swedish, Danish or Norwegian language (excluding children, excluding animal research, but including articles that also are about adults, humans):

(Critical Care[Majr:NoExp] OR Intensive Care Units[Majr:NoExp] OR Critical Illness[Majr] OR Critical Care Nursing[Majr] OR intensive care[Title] OR critical care[Title] OR critically ill[Title] OR critical illness[Title] OR serious illness[Title] OR seriously ill[Title] OR acute care[Title] OR ((intensive[Title] OR critical[Title]) AND (unit[Title] OR units[Title])) OR icu[Title] OR Respiration, Artificial[Majr:NoExp] OR Ventilators, Mechanical[Majr:NoExp] OR (mechanical*[Title] AND ventilat*[Title]) OR (patient*[Title] AND ventilat*[Title])) **AND** "last 20 years"[PDat] AND (Danish[lang] OR English[lang] OR Norwegian[lang] OR Swedish[lang]) NOT ((child[Title] OR children[Title] OR infant*[Title] OR newborn*[Title] OR neonat*[Title] OR pediat*[Title] OR paediat*[Title] OR nicu[Title]) NOT adult*[Title]) NOT (((Animal Experimentation[Mesh]) OR Animals[Mesh]) NOT Humans[Mesh])

The search above retrieves 71 355 articles pr. 24. January 2020.

It is then restricted to this search sentences combined as follows:

1 OR (2 AND 3) OR 4 OR 5

1.
"Psychological Distress"[Mesh] OR "Patient Comfort"[Mesh] OR discomfort*[Title/Abstract] OR comfort*[Title/Abstract] OR psychological distress[Title/Abstract] OR emotional distress[Title/Abstract] OR distressed[Title/Abstract] OR "Pain"[Majr:NoExp] OR "Acute Pain"[Majr] OR "Pain, Procedural"[Majr] OR "Pain Management"[Majr] OR "Pain Measurement"[Majr] OR analgosedat*[Title/Abstract] OR analgo-sedat*[Title/Abstract] OR patient experienc*[Title] OR patients experienc*[Title] OR "Qualitative Research"[Mesh:NoExp]

2.
"Nursing Care"[Majr:NoExp] OR "Nursing Assessment"[Majr:NoExp] OR "Nursing Staff, Hospital"[Majr] OR Patients/psychology[Majr] OR "Inpatients/psychology"[Majr] OR "Survivors/psychology"[Majr] OR "Patient Satisfaction"[Majr] OR "Adaptation, Psychological"[Majr:NoExp]

3.
"Critical Care/psychology"[Majr] OR "Critical Illness/psychology"[Majr] OR "Deep Sedation"[Majr] OR "Conscious Sedation"[Majr] OR "Hypnotics and Sedatives"[Majr:NoExp] OR "Analgesics"[Majr:NoExp] OR "Delusions"[Majr] OR "Confusion"[Majr:NoExp] OR "Delirium"[Majr:NoExp] OR "Memory"[Majr:NoExp] OR "Mental Recall"[Majr] OR "Wakefulness"[Majr] OR "Anxiety"[Majr:NoExp] OR "Stress, Psychological"[Majr:NoExp]

4.

(Nurs*[Title] AND (management[Title] OR caring[Title])) OR "nursing care"[Title]

5.

(patient[Title] OR patients[Title] OR inpatient*[Title] OR survivor*[Title]) AND (experience*[Title] OR recall*[Title] OR recollect*[Title] OR memor*[Title] OR coping[Title] OR cope[Title] OR copes[Title] OR adapt*[Title] OR wakefulness[Title] OR awake*[Title] OR pain[Title] OR wellbeing[Title] OR well-being[Title]) **NOT medline[sb]**

The complete search is here ready to be copied and pasted into PubMed, yelding 3334 articles pr. 24. January 2020:

(((Critical Care[Majr:NoExp] OR Intensive Care Units[Majr:NoExp] OR Critical Illness[Majr] OR Critical Care Nursing[Majr] OR intensive care[Title] OR critical care[Title] OR critically ill[Title] OR critical illness[Title] OR serious illness[Title] OR seriously ill[Title] OR acute care[Title] OR ((intensive[Title] OR critical[Title]) AND (unit[Title] OR units[Title])) OR icu[Title] OR Respiration, Artificial[Majr:NoExp] OR Ventilators, Mechanical[Majr:NoExp] OR (mechanical*[Title] AND ventilat*[Title]) OR (patient*[Title] AND ventilat*[Title])) AND "last 20 years"[PDat] AND (Danish[lang] OR English[lang] OR Norwegian[lang] OR Swedish[lang]) NOT ((child[Title] OR children[Title] OR infant*[Title] OR newborn*[Title] OR neonat*[Title] OR pediat*[Title] OR paediat*[Title] OR nicu[Title]) NOT adult*[Title]) NOT (((Animal Experimentation[Mesh]) OR Animals[Mesh]) NOT Humans[Mesh]))) AND ((((("Psychological Distress"[Mesh] OR "Patient Comfort"[Mesh] OR discomfort*[Title/Abstract] OR comfort*[Title/Abstract] OR psychological distress[Title/Abstract] OR emotional distress[Title/Abstract] OR distressed[Title/Abstract] OR "Pain"[Majr:NoExp] OR "Acute Pain"[Majr] OR "Pain, Procedural"[Majr] OR "Pain Management"[Majr] OR "Pain Measurement"[Majr] OR analgosedat*[Title/Abstract] OR analgo-sedat*[Title/Abstract] OR patient experienc*[Title] OR patients experienc*[Title] OR "Qualitative Research"[Mesh:NoExp])) OR ((("Nursing Care"[Majr:NoExp] OR "Nursing Assessment"[Majr:NoExp] OR "Nursing Staff, Hospital"[Majr] OR Patients/psychology[Majr] OR "Inpatients/psychology"[Majr] OR "Survivors/psychology"[Majr] OR "Patient Satisfaction"[Majr] OR "Adaptation, Psychological"[Majr:NoExp])) AND ("Critical Care/psychology"[Majr] OR "Critical Illness/psychology"[Majr] OR "Deep Sedation"[Majr] OR "Conscious Sedation"[Majr] OR "Hypnotics and Sedatives"[Majr:NoExp] OR "Analgesics"[Majr:NoExp] OR "Delusions"[Majr] OR "Confusion"[Majr:NoExp] OR "Delirium"[Majr:NoExp] OR "Memory"[Majr:NoExp] OR "Mental Recall"[Majr] OR "Wakefulness"[Majr] OR "Anxiety"[Majr:NoExp] OR "Stress, Psychological"[Majr:NoExp]))) OR ((Nurs*[Title] AND (management[Title] OR caring[Title])) OR "nursing care"[Title])) OR ((patient[Title] OR patients[Title] OR inpatient*[Title] OR survivor*[Title]) AND (experience*[Title] OR recall*[Title] OR recollect*[Title] OR memor*[Title] OR coping[Title] OR cope[Title] OR copes[Title] OR adapt*[Title] OR wakefulness[Title] OR awake*[Title] OR pain[Title] OR wellbeing[Title] OR well-being[Title]) NOT medline[sb]))

Comments:

- Majr: (Mesh Major Topic). Mesh= Medical Subject Headings. MeSH terms are "exploded" automatically to retrieve citations that carry the specified MeSH heading as well as the more specific terms indented beneath it in the MeSH hierarchy.

- [Majr:NoExp]= turns off the automatic “explode” - does not include MeSH terms found below this term in the MeSH hierarchy.

- NOT medline[sb] = An additional search has been carried out in PubMed in order to retrieve articles which have not yet been entered into MEDLINE.