VID
Specialized
University

Avhandling nr. 54
Stine Irene Flinterud

Humanising support and follow-up after critical illness

A qualitative study of the experiences of former intensive care patients, their family members and intensive care nurses

VID

Humanising support and follow-up after critical illness

A qualitative study of the experiences of former intensive care patients, their family members and intensive care nurses

Stine Irene Flinterud

Dissertation Submitted
in Partial Fulfilment of the Requirements
for the Degree of Philosophiae Doctor (Ph.D)

VID Specialized University

2023

© Stine Irene Flinterud, 2023

ISBN: 978-82-8456-063-2, e-version
ISSN: 2535-3071

Dissertation Series for the Degree of Philosophiae Doctor (Ph.D.) at VID Specialized University No. 54

All rights reserved. No part of this publication may be
reproduced or transmitted, in any form or by any means, without permission.

Cover: Dinamo

.

VID Specialized University
post@vid.no

www.vid.no

Foreword

This thesis explores the experiences of support and follow-up after critical illness and intensive care treatment. During the period in which this PhD study was undertaken, we went through a worldwide pandemic. With an increasing number of patients in need of intensive care treatment, this area within the health care system was given a comprehensive media coverage, increasing awareness of intensive care among the general population. However, the data on which this thesis is based were collected before the COVID-19 pandemic; hence, this perspective is not taken specifically into account. It will, however, be discussed when appropriate.

Having worked as an intensive care nurse for several years, my interest grew in how patients and their families are affected by critical illness and intensive care treatment and what follow-up they need. I embarked on this study with a preconception that patients and their family members need more support and follow-up in their post-hospitalisation life than they often receive. In the intensive care unit (ICU) in which I worked, we offered nurse-led follow-up consisting of a patient diary[1] and a follow-up conversation with those patients who had received a diary. Writing a diary was not an obligatory task; rather, it depended on the nurses' interest and enthusiasm. Not all patients received a diary, which meant that not all received an offer to come back to the ICU for a follow-up conversation. Patients who came back to the ICU were often accompanied by a family member, but the conversation was directed toward the patient and their experiences. Embarking on this study, I wanted to explore the area of support and follow-up during and after critical illness and intensive care, from the perspectives of patients, their family members and intensive care nurses.

Acknowledgements

During the period on which I worked on this PhD study, life had its ups and downs, and there are many people to thank for keeping me sane, making me laugh, and helping me get through these years of hard work.

---

[1] A diary written by intensive care nurses for patients treated in an ICU. The diary often consists of descriptions of what has happened to the patients during the day, such as being washed, turned from one side to the other, undergoing examinations such as x-rays, and other facts, such as visits from family members.

First, thanks to the participants! I am grateful to the former patients and the family members for opening up and letting me gain a glimpse of what life may be like when critical illness suddenly strikes, throughout the illness trajectory, and in the everyday life that follows. Thanks to the three participating ICUs and to the ICU nurses for sharing their experiences. A special thanks to my contact persons who helped me recruit participants and extract data from the hospital records.

Thanks to former Haraldsplass diakonale høgskole, now VID Specialized University, for giving me a scholarship, and to all my colleagues and leaders through the years who have cheered me on, facilitated and made it possible for me to work on, and now finish this PhD study.

Sidsel, Asgjerd and Eva. My caring and wise supervisors. Thank you so much for all the support, feedback, discussions, and pleasant company throughout these years. You have all been amazingly supportive and always engaged and interested! Eva, even though you 'pulled out' as a formal supervisor some years ago, you have been to almost every meeting, co-authoring the articles and reading and commenting on my thesis – thank you! Asgjerd, thank you for your engagement, enthusiasm, and wise comments. Sidsel, I could not have asked for a more caring and supportive main supervisor. You have been a tremendous support through these years, and with my health issues during this time, you have not once pushed me beyond my limits but instead have led me through. I am very grateful for having had three such caring and wise ladies as supervisors, thank you all so much – when I grow up, I want to be like you.

I had the opportunity to participate in three different research groups during my PhD study, which gave me inspiration and the possibility of presenting my work and gaining valuable feedback during the process. Thanks to PIFO[2], my research group in VID, the Phenomenological Health Research group in University of Bergen, and POPS[3] in Western University of Applied Sciences. Thanks to Marion Mitchell at Griffith University in Brisbane, Australia, for facilitating and welcoming me and my family for a stay abroad, and thanks to the Norwegian Nurses Organisation (NSF) for giving me funding which made it possible.

Thanks to the best 'scholarship-gang' one could ever wish for. Starting off, years ago, with Marte, Eli, Ann-Kristin, and Tone, and all the other fantastic people who have joined along

---

[2] Pasientopplevelser og utvikling av intervensjoner.

[3] Pasientopplevelser og pasientsikkerhet ved akutt og/eller kritisk sykdom.

the years. We created a safe and caring environment with lots of laughter and some tears – the way it is supposed to be during a PhD journey. Thank you for your care, humour, creativity, knowledge, and engagement!

Thanks to all my friends, old and new, for supporting me and bringing joy into my life with all the planned and unplanned gatherings through the years. These years had not been the same without you! A special thanks to Gro, for always being there even after moving away. The trips to you in Denmark have been both recreation and a lot of fun – a perfect combination! And to Silje, thank you for joining me on hundreds of dog-walks with Ipa, for your interest and discussions, and for sharing life's ups and downs. 'The fabulous four' – Kristin, Marte, and Tone – you are amazing women bringing me daily joy and laughter. You are wise, engaged, and funny, and I am so fortunate to have found friends among colleagues. Tone, my partner in crime. Through these years, you have been a tremendous support and inspiration. You are always there to discuss thoughts and reflections, to laugh or cry if needed – I am so grateful that I have had a best friend joining me on this PhD trip with its highways and bumpy winding roads.

Thank you to my family and in-laws for all your support! Thanks to Mum and Dad for always being there, being interested and cheering me on. A special thanks to Mum who took on the job of transcriber of some of my interviews – I am very grateful! Thanks to my sisters Guro and Sara, for support, discussions and talks.

Last, but not least, thank you so much to my magnificent daughter Mari and my dear Frode. Frode, thank you for your patience, humour, and for putting up with me during these demanding years. And Mari – the sun in my life! You are a fantastic girl, always making me laugh and reminding me of the important things in life. Thank you, both, for love and for bringing joy and laughter into our everyday life. I love you!

Stine Irene Flinterud, Bergen 28.06.2023

Abstract

This thesis is a qualitative study of support and follow-up during and after critical illness and intensive care treatment. A phenomenological approach was taken to exploring the experiences of intensive care nurses, former patients, and their family members. Participants came from three ICUs in Norway. Ten former patients and 11 family members participated in individual interviews, and a total of 20 intensive care nurses participated in three focus group interviews, one in each ICU. All the interviews were analysed using Giorgi's phenomenological methods.

The first article reports on intensive care nurses' experiences of performing follow-up of ICU patients and their family members and their experiences with the patients' and their family members' needs for follow-up. The findings showed how ICU nurses endeavoured to create meaning for patients through the follow-up, personalising patients' diaries throughout their stay in the ICU, and conducting follow-up conversations in the aftermath of the critical illness and intensive care treatment. The follow-up had a twofold meaning. First, the ICU nurses wanted to give meaning to the patients as well as an opportunity to take part in their own history while unconscious and undergoing intensive care treatment. Second, the follow-up gave meaning to the ICU nurses' practice, giving insight and motivation to their continuing work with critically ill patients.

The second article reports on former patients, and what they experienced as limiting and strengthening throughout their illness trajectory, to reveal their needs for support and follow-up. The findings showed that patients gained strength through caring interactions with others. The importance of a caring presence, how they valued being dealt with as unique persons and the importance of being supported when regaining their capacity on the other side of the critical illness are conveyed.

The third article reports on the experiences of family members after they have lived through a close one's illness trajectory from the onset of the critical illness through recovery. The findings showed how the family members strove to find a safe ground for themselves and their close ones during the illness trajectory. The family members needed care as they took on great responsibility for giving their close ones safety and support. The unknown situation

demanded new knowledge so they could gain new understandings during the illness trajectory of a close one.

Through the perspectives of the participants in this study, the importance of caring encounters through a critical and life-threatening situation and onwards toward a new everyday life became apparent. Critical illness may cause a breach in the expected life history of both patients and their family members. Both patients and their family members need to be seen on their own account, and they need individualised support and follow-up to live through this period in the best possible manner. Humanising support and follow-up is suggested, and the nurse-led follow-up reported on seems important for both the patients that receive it and ICU nurses. However, it also needs to be a system that can capture individual needs and offer help and support to each person affected by critical illness.

Sammendrag

Målet med prosjektet var å utforske behovet for støtte og oppfølging under og etter kritisk sykdom og behandling på intensivavdeling. Avhandlingen er en kvalitativ studie hvor erfaringene til intensivsykepleiere, tidligere pasienter og deres pårørende er utforsket gjennom en fenomenologisk tilnærming. Deltakerne i studien ble rekruttert fra tre intensivavdelinger i Norge. Ti tidligere pasienter og elleve pårørende har deltatt i individuelle intervju, og totalt tjue intensivsykepleiere har deltatt i tre fokusgruppeintervju utført på hver av de inkluderte intensivavdelingene. Intervjuene har blitt analysert ved hjelp av Giorgi's fenomenologiske metode.

I første artikkel presenteres intensivsykepleiernes erfaring med oppfølging av tidligere pasienter og deres pårørende, i tillegg beskrives deres erfaring med pasienters og pårørendes behov for oppfølging. Funnene viste hvordan intensivsykepleierne forsøkte å skape mening for pasientene gjennom oppfølgingen, for eksempel gjennom å skrive en personlig dagbok til pasientene underveis i intensivoppholdet samt å utføre oppfølgingssamtaler i etterkant. Oppfølgingen var meningsfull på særlig to ulike måter: Intensivsykepleierne ønsket å gi pasientene muligheten til å ta del i og gi mening til sin tilværelse under intensivbehandlingen. I tillegg ga oppfølgingen mening til intensivsykepleiernes egen praksis ved at den ga innsikt og motivasjon til videre arbeid med kritisk syke pasienter.

I andre artikkel presenteres tidligere pasienters erfaringer av hva de opplevde som begrensende og styrkende gjennom sykdomsforløpet. Funnene viste at pasientene fikk styrke gjennom en omsorgsfull relasjon med andre. Viktigheten av et omsorgsfullt nærvær, hvordan de verdsatte å bli sett som unike mennesker og viktigheten av støtte for å gjenvinne kapasitet i tiden etter intensivoppholdet ble belyst.

I den tredje artikkelen presenteres familiemedlemmenes erfaring etter å ha gjennomlevd en nær persons sykdomsforløp fra starten av den kritiske sykdommen, gjennom intensivbehandling og rehabiliteringsperioden. Funnene viste at pårørende kjempet for en trygg grunn for både seg selv og den nære som var syk, gjennom hele sykdomsforløpet. Familiemedlemmene trengte selv omsorg, samtidig som de tok på seg et stort ansvar for å

støtte og gi trygghet til sin nære. Den ukjente situasjonen de plutselig befant seg i krevde kunnskap for å skape forståelse for den nye situasjonen.

Gjennom deltakernes ulike perspektiv belyses viktigheten av omsorgsfulle møter gjennom kritiske og livstruende situasjoner, og videre mot deres nye hverdag. Den kritiske sykdommen kan gi et brudd i både pasientens og de pårørendes forventede livshistorie, og de trenger individuell støtte og oppfølging for å komme gjennom denne perioden på best mulig måte. Både pasienter og pårørende må bli sett og møtt ut fra egne behov, og de trenger individuell støtte og en oppfølging tilpasset sine behov. Støtte og oppfølgingen må inkludere det å se og ta hver enkelt person på alvor. Sykepleieledet oppfølging virker å være viktig for intensivsykepleierne selv, men også for de pasientene som kommer tilbake til intensivavdelingen. Det trengs imidlertid et system som kan fange opp den enkeltes behov og som kan tilby individuelt tilpasset hjelp og støtte.

List of papers

Flinterud, S. I., Moi, A. L., Gjengedal, E., Narvestad Grenager, L., Muri, A. K., & Ellingsen, S. (2019). The creation of meaning – Intensive care nurses' experiences of conducting nurse-led follow-up on intensive care units. *Intensive & Critical Care Nursing*, 53, 30–36. https://doi.org/10.1016/j.iccn.2019.03.009

Flinterud, S. I., Moi, A. L., Gjengedal, E., & Ellingsen, S. (2022). Understanding the course of critical illness through a lifeworld approach. *Qualitative Health Research*, 32(3), 531–542. https://doi.org/10.1177/10497323211062567

Flinterud, S. I., Moi, A. L., Gjengedal, E., & Ellingsen, S. (2023). Striving for a safe ground-A lifeworld approach of family members' experiences of the critical illness trajectory. *Journal of clinical nursing,* Advance online publication. https://doi.org/10.1111/jocn.16803

Abbreviations and definitions

Aftercare, follow-up: used interchangeably to refer to the offers or measures given by ICUs or other parts of health care systems to provide help for patients and their families in the continuation of life after critical illness.

eCASH concept: early Comfort using Analgesia, minimal Sedatives, and maximal Humane care.

ECMO: extracorporeal membrane oxygenation.

Family member, relative, next of kin: used interchangeably for persons related to the patient who is critically ill.

ICU: intensive care unit.

ICU nurse, intensive care nurse, critical care nurse: used interchangeably for nurses with a formal specialisation or master's degree in intensive care nursing.

PFCC: patient and family-centred care.

PICS: post intensive care syndrome.

PICS – F: post intensive care syndrome – family.

PTS: post-traumatic stress.

PTSD: post-traumatic stress disorder.

Support: the word 'support' is defined in various ways by the Oxford Dictionary: 'to give or be ready to give help to somebody if they need it', 'to provide everything necessary, [especially money], so that somebody/something can live or exist' or 'to hold somebody/something in position; to prevent somebody/something from falling' (Oxford Advanced Learner's Dictionary, 2023). The three definitions highlight different aspects of how support is used within this thesis and how the patients and their family members experience needing somebody's help in their continuing life when the critical illness has thrown their lives of track and placed them in unknown situations.

Close one, loved one: the person who is critically ill.

Table of contents

Foreword i
Acknowledgements i
Abstract iv
Sammendrag vi
List of papers viii
Abbreviations and definitions ix
1. Introduction 12
1.1. Overview of study 13
2. Background and previous research 16
2.1. Nursing and a caring perspective 17
2.2. The intensive care context 20
2.2.1. The prevalence of PICS and PICS-F 22
2.2.2. Patient- and family-centred care 24
2.3. The critically ill patient 25
2.3.1. Survivorship 29
2.4. The families of a critically ill patient 30
2.5. What follow-up offers exist? 33
2.6. ICU nurses encountering critically ill patients and their families 35
3. Aims 39
4. Phenomenology 40
4.1. Phenomenology and the lifeworld perspective 40
5. Methodology and overall design 44
5.1. The researcher's reflexivity 45
5.2. The study 47
5.2.1. Setting and participants 47
5.2.2. Data Collection 50
5.2.3. Analysis 53
5.3. Ethical considerations 56
6. Summary of findings 59
6.1. The intensive care nurses' perspective 59
6.2. The patients' perspective 61
6.3. The family members' perspective 63
6.4. Overall findings 64
7. Discussion 67
7.1. Methodological considerations 67

7.2. Critical illness as potential disruption of the family’s biography 73
7.3. Intersubjectivity in caring healthcare encounters 80
7.4. Humanising support and follow-up.. 83
8. Conclusions and implications for practice... 88
9. References.. 90

Overview of tables

Table 1: Overview of PhD study………………………………………………………………………………..15
Table 2: ICU nurses Characteristics………………………………………………………………………………48
Table 3: Patient Characteristics…………………………………………………………………………………50

Overview of attachments

Appendix 1: Article 1, Article 2, Article 3
Appendix 2: Documentation from Regional Ethics Committee and Norwegian Centre for Research Data AS
Appendix 3: Information and consent forms
Appendix 4: Interview guides
Appendix 5: Background data participants

1. Introduction

'I must have an equal relationship with the healthcare professionals. It cannot exclusively be sorry for me, and I cannot be the only one to feel sorry for. I cannot just be sick and a patient, I have to be human too. There has to be a balance'[4] (Koht, 2022, p. 91). This quotation is from Christine Kohts[5] newest book, 'Dødsfrisk', in which she portrays the serious illness she experienced in 2018 and a few years thereafter and reflects on how it affected her and the people close to her. The quotation comes from a section in which she describes her need to create an interpersonal relationship with the healthcare professionals looking after her, asking them questions about their lives – about their personal problems – to counterbalance the unequal relationship she experienced when she was seriously ill and entirely dependent on them. The book touches upon one of the most important issues in this thesis: the importance of the humanising aspect in healthcare encounters.

Critical illness may strike when least expected, and the threat to life and functioning may be a dramatic life event that turns a person's life upside down. Each year, millions of people worldwide are in need of intensive care treatment, and, according to the Society of Critical Care Medicine, more than five million people are admitted to ICUs in the USA every year (Halpern, n.d.). In Norway, ICUs have treated between 13,000 and 16,000 patients annually over the last decade, with almost 15,000 treated in 2021 (Buanes et al., 2022). Intensive care medicine has seen a tremendous development, and in the USA there was a 35% decrease in mortality in patients admitted to ICUs from 1988 to 2012 even though patients are getting older and have more severe illnesses (Zimmerman et al., 2013). Intensive care treatment is an expensive part of the health-care system, and numbers from the Netherlands show that the healthcare cost of a patient admitted to an ICU are three to five times higher than those of the general population (van Beusekom et al., 2018). Hence, many resources are used

---

[4] Men jeg må ha et slags likeverdig forhold [til helsepersonellet]. Det kan ikke bare være synd på meg, og det kan ikke bare være meg det er synd på. Jeg kan ikke bare være syk og pasient, jeg må være et menneske også. Det må være en balanse. (Sitatet på norsk)

[5] Christine Koth is a famous Norwegian TV-presenter and stand-up comedian who in 2018 suddenly became seriously ill and has been through long hospitalisations and several periods admitted to an ICU during the following years (Wikipedia, 2022).

within the intensive care area, but what about the patients' lives afterwards – what life do we save the patients into?

As an increasing number of patients survives critical illness and intensive care treatments, both former patients and their family members report on a variety of health problems afterwards. The patients may experience cognitive, physical, and/or mental health impairments (Rawal et al., 2017), and their family members may experience psychosocial problems (Haines et al., 2015). In the early 2010s, several stakeholder meetings were held in the USA that aimed at improving the long-term impairments reported after critical illness and ICU stays for patients and their family members (Elliott et al., 2014; Needham et al., 2012). The terms 'post intensive care syndrome' (PICS) and 'post intensive care syndrome – family' (PICS-F) were agreed upon to describe the different problems and impairments that former patients and their families may experience following an ICU stay (Needham et al., 2012). PICS covers the problems patients may experience and includes mental health impairments, such as anxiety, depression, and PTSD; physical impairments, such as physical function, neuromuscular, or pulmonary problems; and cognitive impairments, such as memory, attention, and mental processing speed. For the families, PICS-F mainly covers mental health problems, such as depression, anxiety, PTSD, and complicated grief (Needham et al., 2012).

With an increasing focus on the health problems that affect both patients and their family members after intensive care treatment, measures to humanise the ICU have been implemented in recent decades (Kvande et al., 2022). Such measures are applied both during the intensive care admission (Vincent et al., 2016) and in the aftermath, such as writing diaries and performing nurse-led or multidisciplinary follow-up (Moi et al., 2018; Schofield-Robinson et al., 2018).

1.1. Overview of study

The aim of this PhD study was to explore the experiences of support and follow-up from the onset of critical illness and intensive care treatment through hospitalisation and after patients return home. This thesis is submitted within the PhD programme in diakonia, values, and professional practice at VID Specialized University. The study explored the professional practice of the Norwegian healthcare system, specifically healthcare following critical illness and further recovery. It explored the professional practice of the follow-up offered by three ICUs in Norway. In addition, the study explored the lifeworld of persons affected by critical illness and intensive care treatment, both former patients and their family members.

The PhD study is grounded on two foundational pillars, namely, phenomenology and nursing, the first as ontology, and the second as the theoretical framework. Phenomenology is explicated later in the thesis, and the nursing perspective is presented before the intensive care area is outlined as background. Intensive care is a highly technological area in which advanced medical treatments are performed. In this study, I wanted to go beyond the advanced medical and technical aspects to explore the experiences and lifeworld of former patients and their family members, both when critical illness occurred and in their continuing life, and describe their experience of support and follow-up. In a trajectory running from critical illness and intensive care treatment through recovery and the return home, patients and their family members relate to different kinds of healthcare professionals in the various parts of the healthcare system. However, as an intensive care nurse, my point of departure and foundation has been a nursing perspective within the intensive care area. A brief overview of the study is presented below.

Table 1. Overview of PhD study.

Table 1. Overview of PhD study			
Overall aim	To explore the experiences of support and follow-up during and after critical illness and intensive care treatment		
	Study 1	Study 2	
	Article 1	Article 2	Article 3
Title	The creation of meaning – Intensive care nurses' experiences of conducting nurse-led follow-up on intensive care units.	Understanding the course of critical illness through a lifeworld approach.	Striving for a safe ground – a lifeworld approach of family members' experiences of the critical illness trajectory.
Research aim	To explore and describe the experiences of intensive care nurses providing nurse-led follow-up to patients and their families.	To explore and describe what intensive care patients experience as limiting and strengthening throughout their illness trajectories.	To explore the experiences of family members after they have lived through a close one's illness trajectory starting with critical illness and intensive care treatment, throughout hospitalization and after their return home, and describe what was important and challenging for them during this time
Design	A qualitative design with a phenomenological approach		
Participants	Intensive care nurses	Former intensive care patients	The family members of patients
Data collection	Three focus group interviews	10 individual interviews	Nine individual interviews and one interview with a parent couple
Analysis	Giorgi's phenomenological method		

2. Background and previous research

This section elaborates the background of the thesis, including previous research. The setting for the study is intensive care, and even though the study explores patients' and family members' experiences throughout the illness trajectory, as the onset is the critical illness and intensive care treatment a large part of the background focuses on the intensive care area.

The chapter first outlines nursing and the caring perspective then gives an overview of the intensive care context. A presentation of previous research and an elaboration of what it might mean to become critically ill and be treated in an ICU, for both the critically ill patient and their family member, is then given. Then, the area of support and follow-up for former intensive care patients and their families is described. Experiences of support and follow-up are influenced by the complexity of intensive care; however, as they are also affected by the nurses and the nurse–patient relationship, the last background section is devoted to research reporting on nurses' experiences and the nurse–patient relationship within the ICU.

The area of intensive care is multifaceted and extensive. A comprehensive body of research has been conducted in recent decades aiming at both decreasing mortality and improving long-term outcomes for patients and their family members (Brummel, 2018). As previous research is integrated in the background chapter, the search strategies are also presented here. During this PhD study, searches were conducted in the databases PubMed, CINAHL, and Embase. As the PhD study aimed at covering the entire illness trajectory, from the onset of the critical illness through intensive care treatment and recovery, the search was challenging, and some delimitations were made. I did not undertake searches of different patient groups. Rather, searches were made of three areas: intensive care, support and follow-up, and the participants' experiences. Keywords, MeSH (in PubMed) and subject headings (in Embase and CINAHL) were used. Keywords used when searching the intensive care area were directed towards intensive care – (intensive care, critical care, intensive care units) – and the three populations, namely, the intensive care nurses (intensive care nurse/nursing, critical care nurse/nursing), and the patients (patients, critically ill patients), and their family members (family and caregivers). In addition, searches of the various outcomes affecting patients and their family members were made with the keywords: PICS, PICS-F, PTSD, depression, anxiety, psychological symptoms, and cognitive impairment. Searches of support and follow-up used terms such as follow-up, support, aftercare, diary, rehabilitation, and recovery. Moreover, search terms like experience, phenomenology, humanising ICU, and nurse-patient relations were used in combination with the above-mentioned searches. The reference lists of articles were also checked.

2.1. Nursing and a caring perspective

The PhD study is founded within nursing and draws on a caring perspective. This chapter gives a brief overview of nursing as a tradition and elaborates on the caring perspective within nursing. The caring perspective has informed the analysis, and how this was used is further elaborated on in the analysis section in the chapter addressing methodology and overall design.

Throughout human history, people have fallen ill and been injured, and someone has cared for those in need of help. Over the past 100 years, nursing has developed as a profession alongside medical treatments and the healthcare system. Florence Nightingale is seen as the founder of professional nursing. In the 1850s, Nightingale revolutionised the healthcare facilities available in the Crimean War, and afterwards she established a school of nursing in London and wrote the first theory of nursing. She was a pioneer and the first to write about nursing knowledge and describe the function of the nurse (Alligood, 2018, pp. 2–3). However, in the early 1900s, nurses were mostly seen as physicians' assistants, and the first textbooks written for nurses were written by physicians emphasising the knowledge nurses would need to be good assistants for them (Beedholm & Frederiksen, 2022, pp. 196–198). To found nursing as a scientific discipline and define what constitutes the essence of nursing, nursing theories were developed: Nightingale wrote the first in the late 19th century, and there has been an increasing number of publications since the 1950s (Beedholm & Frederiksen, 2022, pp. 194–196).

The natural sciences and the positivistic paradigm were the leading paradigm within healthcare during the 20th century, with the biomedical model as the dominating tradition (Thomassen, 2006, pp. 145–146). When nursing was developed as a profession in its own right, the positivistic paradigm and the biomedical tradition, with measured and quantifiable data as the primary source, were influential (Thomassen, 2006, pp. 146–150). The first nursing theories developed from the 1950s, in particular bear the mark of this scientific model. For example, the 'nursing-process' is based on concrete observations and investigations of the patients, identifying the central problem, and then defining goals to help, while today's scientific ideal, evidence-based practice, is the prevailing view of valid knowledge in today's healthcare system, namely, that the knowledge is gathered through scientifically confirmed research results (Thomassen, 2006, pp. 148–149). The dominating medical tradition has had a reductionistic view of humans: a person can be divided into dimensions, such as a physical dimension, a psychological dimension, a social dimension, etc.

However, even though the biomedical model influenced nursing practice, there has been a critique of the reductionistic view. A holistic view of humanity has been advocated for whereby the person is seen as more than just the sum of their parts (Alvsvåg, 2022, pp. 41–46). When outlining the foundations of nursing, Per Nortvedt (2008) highlighted how the nurse's professional knowledge has also been grounded in a focus on the patient's experience of being sick, rather than of having a disease. He pointed to Florence Nightingale and how she pointed out in her texts that the nurse needs to understand the patient's experience of being sick (Nortvedt, 2008, p. 16). When encountering a patient, one needs professional knowledge based on both the natural sciences and the human sciences. Knowledge of pathophysiology and diseases is important; however, it is not enough when healthcare provider is caring holistically for a patient. The nurse needs to have a caring attitude and values which take into account the whole person they have before them. The question then arises of what a caring attitude is.

Caring is a core value in nursing, and, as Bradshaw (1997) explicated, 'the roots of nursing have grounded the profession in a firm tradition of enlightened and deliberate caring – an informed compassion' (p. 10). Nurses may partake in all phases of life, caring for each individual person they encounter. Nursing has an inherent ethical dimension, and the international code of ethics for nurses states that they have 'four fundamental responsibilities: to promote health, to prevent illness, to restore health and to alleviate suffering and promote a dignified death' (International Council of Nurses, 2021, p. 2). The

Norwegian Nurses Organisation states in its professional ethical guidelines that the foundation of all nursing should be respect for each person's life and inherent dignity (Norsk Sykepleierforbund, 2023). Hence, nursing has both an inherent ethical dimension and a caring dimension, covering a commitment to respond to the other and take care of the person in need (Kirby, 2003, p. 23).

Kirby (2003) further explicates how nursing is more than just concern: it 'entail commitment – reaching to another intending to care' (p. 24). Caring is a moral commitment; a belief that the person one encounter matter. Benner and Wrubel (1989) highlight how caring occurs when things matter to us. If something or someone matters, we care. We care in a multitude of ways: we may care about our child, our friend, our garden, or our patients (pp. 1-4). Benner and Wrubel (1989) further explicate how caring 'fuses thought, feeling, and action - knowing and being' (p. 1), pointing to the core of how nursing and a caring perspective have been a foundation in this study. Caring is seen as a way of being in a space where the other matters. However, caring, and something or someone mattering to us, will also induce stress. If something is experienced as stressful, it is because we care in the first place. The fact that we care and things matter creates risks and vulnerability, but it also creates possibilities for coping (Benner & Wrubel, 1989, p. 1). In their theory, Benner and Wrubel (1989) draw on a phenomenological view, inspired by Heidegger and Merleau-Ponty, when focusing on the importance of 'the lived experience of being healthy and being ill' (p. 7), highlighting the importance of the lived experience of illness when nurses encounter patients (p. 9).

Arman et al. (2015) summarised the tradition of Nordic caring science in the work of three nurses, theorists and professors in caring science: Kari Martinsen[6], Katie Eriksson[7] and Karin Dahlberg[8]. These three nursing theorists have influenced nursing and caring science in the Nordic countries in recent decades. Caring science has been influential in the nursing profession, and Arman et al. (2015) concluded by establishing that a foundation for a caring

---

[6] Kari Martinsen (b. 1943) is a Norwegian Professor Emerita. Her theory, known as 'the Philosophy of caring', was inspired by philosophers such as Heidegger, Foucault, and Løgstrup (Arman et al., 2015).

[7] Katie Eriksson (b. 1943 – d. 2019) was a Finnish Professor Emerita who developed 'the theory of caritative caring', inspired by philosophers such as Gadamer and Kierkegaard (Arman et al., 2015).

[8] Karin Dahlberg (b. 1952) is a Swedish professor of caring science who has worked on phenomenology and life-world-led perspectives in caring sciences (Arman et al., 2015).

practice has been to care for the patient's world, health, and wellbeing and to alleviate suffering. Nursing as a profession has developed alongside advances in the medical area. Critical care medicine is one of the areas that has seen tremendous development in recent decades, and ICU nurses need advanced knowledge and competencies when working in an ICU. These competencies will be elaborated on in the last part of the next section, but first an overview of the intensive care context is given.

2.2. The intensive care context

Critical care medicine has seen enormous development since its beginnings, and the first modern ICUs were established in the 1960s and 1970s (Brummel, 2018). The intensive care environment is highly technological, and the ICU is a highly specialised ward, treating the most injured and critically ill patients in the hospital (Valentin et al., 2011). Intensive care can be defined as 'a multidisciplinary and interprofessional speciality dedicated to the comprehensive management of patients having, or at risk of developing, acute, life-threatening organ dysfunction' (Marshall et al., 2017, p. 271). The healthcare professionals working in an ICU should have a specialisation in intensive care medicine or emergency medicine (Valentin et al., 2011). The organisation of staffing in ICUs may vary between countries. In Norway, the staff often includes anaesthesiologists with extensive training from an ICU and intensive care nurses with a specialisation or master's degree in intensive care nursing. In addition, there are supporting staff, such as physiotherapists or dietitians. The organisation of ICUs differs from country to country and from hospital to hospital within the same country. ICUs may be specialised units, such as neurosurgical, cardiac, medical, or surgical units, or they may be more general, caring for patients with multiple diagnoses and covering every branch of medicine. What is special about the ICU, however, is the technologies it houses that provide monitoring and support for the function of important organs in the human body when they fail. Examples of this are ventilators supporting the patient's lung function, dialysis or hemofiltration giving renal support, and complex machines such as the extracorporeal membrane oxygenation (ECMO) providing tissue oxygenation in heart and lung failure (Marshall et al., 2017). Marshall et al. (2017) highlight that prevention of physical deterioration during the treatment of injuries or diseases treated is the primary goal of intensive care (p. 271). The patients treated in ICUs are a diverse and heterogeneous group with the common denominator of having life-threatening injuries or diseases causing the dysfunction of one or multiple organs and a need for support.

In Norwegian ICUs, intensive care nurses are the only profession that remains at the bedside continuously. The ICU nurses are responsible for providing holistic care to both the patients and their families. In a newly published meta-ethnography, Henriksen et al. (2021) developed a conceptual framework containing eight core qualities and competencies of ICU nurses. The conceptual framework is based on articles written from the perspectives of patients, families, and ICU nurses and has the theme 'feeling safe and being safe', which includes both how ICU nurses ensure patient safety and ensure patients' feeling of safety, and the subtheme 'creating confidence and motivation'. The eight core qualities and competencies encompass aspects that cover the complexity of the work performed by ICU nurses, from specific skills, such as 'technical skills and biophysical knowledge', 'inter/intra-professional teamwork skills', and 'communication skills' to more relational aspects, such as 'constant and attentive bedside presence', 'creating partnership in care', 'creating confidence through daily care', 'creating a good atmosphere by having a supportive and encouraging attitude', and 'building relationships to maintain self-esteem'.

As the conceptual framework developed by Henriksen et al. (2021) demonstrates, ICU nurses have a wide range of responsibilities and care for both the patients and their family members continuously during an intensive care stay. The patients treated in ICUs need highly advanced technical and medical treatments. However, a recent review by Larsen et al. (2022) found that nursing interventions in the ICU contained both patient-focused and family-focused interventions and concluded that communication and psychosocial interventions are a fundamental part of nurses' interventions when they care for critically ill patients in the ICU.

As briefly described, treating patients in an ICU entails more than just supporting the function of important organs in the human body when they fail and performing technological tasks; ICU nurses encounter patients and their families going through life-changing experiences that may how they continue their lives.

2.2.1. The prevalence of PICS and PICS-F

As briefly mentioned in the introduction, an increasing number of patients survives intensive care treatment. However, during an ICU stay, patients are put through treatments that inflict enormous stress on their bodies, both physically and mentally. Hence, both the patients and their family members are at risk of health problems afterwards. Former patients have reported a high prevalence of depression, anxiety, and PTSD for years after the ICU admission (Bienvenu et al., 2018; Hatch et al., 2018; Huang et al., 2016). In addition, older age, longer continuous sedation, and longer ICU stay have been identified as risk factors in longer physical function recovery (Gandotra et al., 2019). Patients may also experience cognitive impairments: a recent review found cognitive impairment to be common, with incidence ranging from 35% to 81% of patients at three months following ICU discharge (Honarmand et al., 2020). In a review covering patients' experiences of cognitive impairments after ICU treatment, Alrø et al. (2022) identified four main themes affecting the patients: impaired memory, difficulty in managing everyday life, feeling unsupported by the healthcare system, and having strategies for support in their recovery. They concluded that the cognitive impairments that affect patients may cause challenges in their everyday life, affecting their quality of life (Alrø et al., 2022). Co-occurring symptoms are also reported, and a study investigating the co-occurrence of PICS problems in ICU survivors showed that just over 50% reported one or more PICS symptoms while about 20% reported over two such symptoms. Only approximately 5% reported over three PICS symptoms. Hence, most ICU survivors experience symptoms of PICS; furthermore, approximately one in four experience co-occurring problems (Marra et al., 2018).

Becoming critically ill and in need of intensive care treatment is a dramatic event that may inflict a great strain on the family. The family often follows the patient's illness trajectory closely, and may go through a roller coaster of ups and downs during a critical illness trajectory, always fearing the worst-case scenario that the loved one will die. Not surprisingly, family members are also at risk of developing health problems. The burdens of being close to a person in need of intensive care treatment has been reported to cause symptoms of psychological distress (Abdul Halain et al., 2022), with a high prevalence of anxiety, depression, and PTDS (Johnson et al., 2019; Petrinec & Daly, 2016). The prevalence of symptoms varies across different studies, but in general, families of intensive care patients report increased levels of depression (4–94%), anxiety (2–80%) and PTSD (3–62%) (Johnson et al., 2019). The symptoms vary across the illness trajectory, with the highest occurrence being during the intensive care treatment, where the occurrence ranged between 14 and 97% for depression, 0-73% with anxiety and 14%-81% with PTSD (Johnson et al., 2019). The symptoms may also persist in the aftermath of having a family member treated in an ICU, and up to 43% of family members of intensive care patients still reported on symptoms of depression, anxiety, and PTSD at six months after the ICU admission (Johnson et al., 2019). In a Norwegian study, more than half of the family caregivers reported symptoms of PTS during patient admission in the ICU; the symptoms decreased during the following six months, with approximately 25% reporting symptoms of PTS after one year (Alfheim, Hofso, et al., 2019). Factors associated with higher levels of PTS symptoms were being younger, experiencing low levels of hope, comorbidities, and being on sick leave (Alfheim, Hofso, et al., 2019).

Family members may experience various symptoms when they act as family caregivers when a close one falls critically ill. In a study investigating symptoms of family caregivers, Alfheim and Rosseland et al. (2018) reported that the family caregivers experienced a median of nine symptoms, with worrying, feeling sad, difficulty concentrating, difficulty sleeping, feeling nervous, and lacking energy the top six with an occurrence of 60% and above.

With an increasing focus on PICS symptoms, survivorship, and what kind of life patients go back to, measures during intensive care treatments have been implemented that aim at preventing the burdens reported by patients. Various guidelines and bundles have been revised and implemented in recent years that aim at decreasing the prevalence of PICS symptoms. Measures such as reducing sedation, screening and managing delirium, reducing pain, optimalisation of nutrition, enhancing sleep, early mobilisation, the presence of family members, and increasing patient comfort have been implemented (Devlin et al., 2018; Marra et al., 2017; Rousseau et al., 2021; Vincent et al., 2016). The early Comfort using Analgesia, minimal Sedatives, and maximal Human care (eCASH) concept is one example; here, the focus is comfort- and patient-centred care with minimal sedation (Vincent et al., 2016). The goal has been to achieve a more humanising ICU, increasing patient comfort during the ICU admission and decreasing PICS symptoms after intensive care treatment.

2.2.2. Patient- and family-centred care

With an increasing focus on a healthcare service that takes more account of the voices of patients and their family members than used to be the case, the concept of patient- and/or family-centred care has been implemented the last decades (Institute for Patient and Family-Centered Care [IPFCC], 2016).

Within intensive care, guidelines for Family-Centered Care in the Neonatal, Pediatric, and Adult ICU were published in 2017, including 23 recommendations (Davidson et al., 2017). The family's participatory role is highlighted in the guidelines, which cover aspects such as communication with family members, the family's presence in the ICU, different measures to support families, using specialised consultations and ICU team members, and operational and environmental issues. The guidelines point towards the often moderate to low quality of studies. However, they explicate that the guidelines give evidence for best practice and that they have not only been discussed and voted on by 29 experts but that patients and families have validated the outcomes (Davidson et al., 2017).

In addition to these guidelines covering family centred care, patient- and family-centred care (PFCC) has been advocated that aims at enhancing both patients' and their families' care within the ICU. PFCC is defined as 'the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among patients, families, and health care professionals' (IPFCC, 2016, p. 2). In PFCC, four core concepts have been outlined: 'dignity and respect', 'information sharing', 'participation', and 'collaboration' (IPFCC, 2016, p. 2). An integrative review of PFCC in the ICU, which included 42 studies published from 1987 to 2016, found three themes describing their commonalities: 'interacting', 'culture and connection' and 'service delivery' (Mitchell et al., 2016).

The first theme, 'interaction', addresses communication, education, and information. Some studies found minimal cooperation or communication when researching the information given to family members, while the studies in communication described attempts to implement measures that aimed at seeking a dialogue with family members. Education contained studies examining procedures where instructions were used. The second theme, 'culture and connection', brought together studies addressing the physical presence of families as well as some studies investigating psychological support for family members. The third theme, ‘service delivery’, encompassed factors regarding staffing and ICU design. The review highlighted the diversity of research on PFCC; however, it emphasised that most of the included studies only addressed one component from PFCC, pointing toward a lack of PFCC research that addresses multiple components (Mitchell et al., 2016).

Goldfarb et al. (2017) conducted a systematic review and meta-analysis on whether PFCC interventions improved outcomes such as mortality and ICU length of stay or had other beneficial effects. They found improvement in 75% of the PFCC interventions on at least one outcome measure, and they highlighted that the interventions showed increased patient and family satisfaction and decreasing length of stay in the ICU and that the reported mental health status improved (Goldfarb et al., 2017). However, a new systematic review and meta-analysis by Bohart et al. (2022) found moderate to low certainty of evidence for PFCC effect on PICS and PICS-F. Nevertheless, the authors highlighted several ongoing studies investigating this area that need to be included in future reviews.

As shown, patients and their family members report on problems of PICS and PICS-F following intensive care treatment, and measures to decrease these burdens have been implemented. In the following sections, the experiences of patients and their families are explicated in addition to follow-up measures for both groups.

2.3. The critically ill patient

Suddenly becoming critically ill may be a life-threatening and life-changing event, and patients’ experiences have been investigated, researched, and published in books by survivors to an increasing extent over the last 30 years. Patients have reported memories from the ICU for up to 10 years following ICU discharge (Storli et al., 2008; Zetterlund et al., 2012). Both stressful and pleasant memories have been reported that contain physical, emotional, perceptual, and environmental distress and relief and mention the impact and importance of care to alleviate the experienced distress (Samuelson, 2011).

Mechanical ventilation, either through an endotracheal tube or a tracheostomy, is one of the most frequent treatments that patients in ICUs undergo. Some decades ago, patients were heavily sedated when mechanically ventilated. In the Nordic setting, research into patients' experiences during mechanical ventilation and intensive care treatment started in the late 1980s and the early 1990s. Patients spoke of experiencing anxiety, the challenge of not being able to communicate, chaos, and changed perceptions of, for example, time or their body (Bergbom-Engberg & Haljamäe, 1989; Gjengedal, 1994; Granberg et al., 1998). During the later 1990s and into the 2000s, an increasing number of studies reported on patients' experiences. Due to an increasing body of research showing both traumatising and chaotic experiences and an increase in PICS symptoms, regimes of lighter sedation and enhanced pain treatments, among other measures, were developed from the 2000s, as explicated in the previous section. Nevertheless, even though measures to humanise the ICU have been implemented, the life-threatening situation through which intensive care patients live is a significant strain, and patients still report on challenging and burdensome experiences.

Baumgarten and Poulsen (2015) found that mechanically ventilated patients reported on experiencing anxiety, loneliness, and fear when mechanically ventilated and felt totally dependent on healthcare professionals for survival. In another review, Carruthers et al. (2018) conducted a meta-ethnography of studies investigating ICU patients' experiences of being mechanically ventilated. They developed a patient-centred trajectory model consisting of the three stages patients undergo during mechanical ventilation. Stage one, 'alienation', describes the onset of the trajectory and is comprised of five subthemes. When patients woke in a 'hostile and unfamiliar environment', they experienced being 'in a dependent body' that was reliant on technology and others for survival. This period is often described as having a 'blurring of temporality and consciousness', often due to medications or delirium causing nightmares and hallucinations. 'Loss of autonomy' was the fourth subtheme, due to not being able to control one's body, while 'losing one's voice' was the last subtheme, pointing to how challenging it may be to be unable to communicate one's wishes.

Stage two, which the authors called 'hidden work', addresses how patients strive toward recovery in a way which is hidden and remains unseen by others. It contains six subthemes. 'Confronting death' and 'possible futures' point to the existential threat experienced by patients. The next subthemes, 'endurance', 'mental preparation', 'emotional work', and ‘resilience’ point to the mental strength and mental work the patients undergo on their way to recovery.

Stage three in Carruthers et al.’s (2018) findings, namely, ‘recovery’ entails the movement toward a more normal everyday life at home. This stage consists of four subthemes. The first, ‘perception in progress’, point to maintaining hope and motivation that recovery is possible. ‘Re-connecting with others’, ‘regaining autonomy’, and ‘new perspectives’ point to the forward-looking and incorporation of the experiences into a new perspective in their life after the critical illness. Carruthers et al. (2018) also showed how the ‘context of caring’ serves as a foundation throughout this period in which ‘personalisation’ and ‘trust’ are interlinked.

Danielis et al. (2020) conducted a meta-synthesis and meta-summary of studies from 2013 to 2019 due to the changing sedation practices that have led to mechanically ventilated patients being increasingly awake in recent years. They found four themes: ‘the effect of the intensive stress on the body’s system’, which includes experiences of pain and discomfort when awake and mechanically ventilated; ‘the induced negative emotional situations’, which includes feeling both embarrassed due to surrendering oneself to the care of another (e.g., being washed), and frightened, being totally dependent on the ventilator and feeling the presence of death. ‘The feeling of being cared for in a hospital setting’ includes feeling safe and protected by healthcare professionals and finding comfort in other patients being treated in the same room and having the same problems. ‘The perceived support from family and loved ones’ is the last theme and addresses how patients’ loved ones are of great importance, whether present in the ICU or in memories. Interestingly, six of the nine included studies in this review were from one of the Nordic countries, where lighter sedation protocols have been established the last decade. Regardless of the measures implemented to reduce strain and increase patient comfort, these reviews show how the generic content of being mechanically ventilated and treated in an ICU seems to create burdens and uncomfortable situations and that the discomforts and uncomfortable situations the patients report on are still prevalent, albeit experienced slightly differently, when they are awake during mechanical ventilation.

Going through critical illness and intensive care may be a traumatic experience, causing patients pain, delirium, difficulty sleeping, and reduced comfort. ICU patients report on several discomforts during ICU treatment, and a study by Berntzen et al. (2020) grouped the discomforts into three themes: ‘being deprived of a functioning body’, ‘being deprived of a functioning mind’, and ‘being deprived of integrity’. The authors highlighted how there seems to be a gap between the patients’ comfort needs and the nurses’ fulfilling of those needs, even though nurses reported on attending to patients’ discomforts (Berntzen et al., 2020). One of the themes described was ‘being deprived of a functioning mind’, which may point towards the development of delirium. Delirium is a pathological alteration in one’s cognition and has been identified in approximately 30% of critically ill patients (Salluh et al., 2015). Delirium may affect patient outcomes, increasing the risk of death, prolonged hospitalisation, and cognitive impairment after discharge (Salluh et al., 2015). In a meta-ethnography by Gaete Ortega et al. (2020) the lived experience of delirium is outlined. The core theme was ‘a perturbing altered reality’, which had four main themes: ‘disturbed sense of time’, ‘omnipresent feeling of fear, ‘impact of human connection’ and ‘perceiving surreal events’. The themes cover three salient existential areas of uncertainty, self-perceived helplessness, and death (Gaete Ortega et al., 2020).

The existential threat critically ill patients may experience has also been illuminated by Egerod et al. (2015) who conducted a meta-synthesis of 22 Nordic studies. The meta-synthesis showed how patients experience that their existence is at stake and that suffering was evident within the ICU despite the implementation of measures to improve practice. Four themes were found: ‘existing in liminality’, ‘existing in unboundedness’, ‘existing in mystery’ and ‘existing at the threshold’, which cover how patients experience the existential threat of being critically ill. Patients must relinquish control over their own life to healthcare professionals, and losing control might lead them to descend into their inner world (Egerod et al., 2015).

The voices of former ICU patients have not only been reported in research, but several books have been written about the lived experience of critical illness and recovery. Egerod et al. (2020) performed a literal analysis of books published by Danish survivors of critical illness. Using the illness narratives proposed by Frank (2013) (the restitution narrative, the quest narrative, and the chaos narrative), Egerod et al. (2020) analysed the narratives written by intensive care survivors and thematised five themes addressing the existential dichotomies of survival, sanity, identity, values, and independence. These themes explicate the five dichotomies covered in the narratives analysed by the authors: life/death, sanity/madness, before/after, gain/loss, and inner strength/external support. The dichotomies offer a useful way to describe the turning points when life suddenly takes a new direction and one's existence is at stake (Egerod et al., 2020).

This section has briefly outlined some of the experiences reported by critically ill patients during critical illness and intensive care treatment. Patients continue to live their life in the aftermath of critical illness and intensive care and have to deal with their lived experiences. Vester (2022) illuminated how patients need to find themselves anew after the critical illness, a process which incorporates how they must redefine themselves, how they must reintegrate with family, and how they must resume their everyday life after coming home. In a grounded theory study investigating the experience of physical rehabilitation from critical illness, Corner et al. (2019) found that rehabilitation was affected by other factors, such as memory loss, hallucinations, delirium, and fatigue. Their mail finding was that patients must be able to recalibrate themselves to meet their new situation if they are to be able to look towards a desired future. This finding is in accordance with Kean et al. (2017), who found that survivorship after intensive care treatment was like an unscheduled status passage, where one goes on a journey from being on the threshold of life and returning. In one's ongoing life, one incorporates what one has undergone and redefines oneself on the other side of the critical illness.

2.3.1. Survivorship

The term 'survivorship' has been used to describe the recovering patient's situation in their ongoing life. In the early 2010s, Iwashyna (2010, p. 204) commented that ICU survivorship would be 'the defining challenge of critical care in the 21st century. He drew comparisons with cancer survivorship, a term which has been used and incorporated into care, research, and public documents (Iwashyna, 2010). ICU survivorship has not yet been taken into account in public documents to the same extent as cancer survivorship; however, the recent COVID-19 pandemic has increased the focus on ICU survivors and their continuing life.

As Iwashyna (2010, p. 205) rightly emphasised over ten years ago, ‘survivorship care must begin the first day a patient spends in the ICU’, a concept that has been implemented through various measures over the past decade, as mentioned above (Devlin et al., 2018; Rousseau et al., 2021; Vincent et al., 2016). Survivorship after critical illness has been explored in recent years, and a recent review showed how it is organised in three themes: ‘healthcare system’, ‘ICU survivors’ families’ and ‘ICU survivors’ identity’ (Kean et al., 2021). Kean et al. (2021) highlighted that there does not seem to be a common definition or understanding of the term survivorship and therefore proposed the following preliminary definition of ICU survivorship:

> ‘ICU survivorship is a dynamic process which starts with the survival of a critical illness and incorporates changes in self, biography and identity based on the individual patients’ experiences of critical illness and their families. These changes are captured in the process of ‘moving on’.’ (p. 2606)

Survivorship encompasses a patient’s entire life; however, Kean et al. (2021) also explicated that there is life after survivorship as well. Thus, survivorship is used as a term to describe the multifaceted area of critical illness survival.

2.4. The families of a critically ill patient

Being close to a person who falls critically ill and is in need of intensive care treatment may be a tremendous burden that causes uncertainty and stress (Agard & Harder, 2007; Minton et al., 2019; Scott et al., 2019). During the intensive care treatment of their close one, families can do nothing but wait and hope for the best. The waiting period may be a burden, and what waiting means for family members has been outlined in a concept analysis by Björk et al. (2019), who found five attributes in the concept of waiting: ‘living in limbo’, ‘feeling helpless and powerless’, ‘hoping’, ‘enduring’, and ‘fearing the worst’. As waiting is inevitable when a close one is being treated in an ICU, families may experience great strain, and healthcare professionals need to be aware of this when interacting with family members (Björk et al., 2019).

Waiting is a concept covered by the temporal dimension, which comes to the fore when one lives in uncertainty during a close one’s critical illness. This has also been explicated in a review by Imanipour et al. (2019) where the three themes: ‘floating’, ‘probing’, and ‘continuity or closure’ cover family members’ ICU journey. In the theme ‘floating’, experiences of the onset of the ICU admission are described, this being a point when a turmoil of feelings, such as shock, fear, and vulnerability, is imminent. In the next theme, ‘probing’, the families have lived through the first shock and need more knowledge. Information and communication-related difficulties are described, in addition to the need to be included and become more active caregivers to their critically ill loved one. In the last theme, ‘continuity or closure’, the families have adopted somewhat to the hospital setting and experience being settled in a break from their daily lives and more in tune with the routines of the ICU. In this phase, they are more included in decision-making and focus more on the time ahead (Imanipour et al., 2019).

Family members’ experiences and needs have also been summarised in a review by Kynoch et al. (2021), who listed four synthesised findings: ‘family members’ altered psychosocial health’, ‘family members’ proximity and involvement’, ‘information and communication’ and ‘the ICU environment’. The first finding includes and outline of how the uncertain situation develops when a close family member suddenly falls critically ill and how it has a great impact on several aspects of life, such as ‘mental, emotional, spiritual, financial and social well-being’ (Kynoch et al., 2021, p. 1508). The second finding, ‘family members proximity and involvement’, highlights the importance of access to the loved one, especially the importance of being close and able to be involved in the situation of their critically ill family member. The third finding ‘information and communication’, highlights the importance of understanding what is happening and experiencing honest and reliable information that may help people cope with the situation. The last synthesised finding ‘the ICU environment’, explicates the unfamiliar and highly technological environment, which might be experienced as a scary place. In this situation, the relationship with and support from healthcare professionals may be of vital importance (Kynoch et al., 2021).

As noted, being a family member in the ICU may be a great strain, requiring support from the healthcare professionals one encounters. The specific needs of family members have also been a focus of research in recent decades. As early as the late 1970s, Molter (1979) developed a list of family needs during intensive care that has been widely used since. In the early 1990s, internal psychometric properties were examined by Leske (1991) and revised into five dimensions: needs for support, comfort, information, proximity, and assurance. In a recent review outlining families' needs and satisfaction with care, Scott (2019) highlighted four key themes: 'different perspectives on meeting family needs', 'family satisfaction with care in intensive care', 'factors having an impact on family health and well-being and their capacity to cope', and 'psychosocial interventions'. The review showed that the need for information and reassurance was the most prevalent and that, if unmet, it affected family members' satisfaction and mental health (Scott et al., 2019).

The need for information stands out as prominent, and a recent RCT study showed that having daily written care summaries affected the satisfaction and emotional well-being of family members in an ICU (Greenberg et al., 2022). In addition to needing information, family members need support from the health care professionals they encounter. Frivold et al. (2015) highlighted how being a family member in the ICU was experienced as playing both a receiving and a participating role. Prevalent in the findings was the need for informational and supportive care alongside the value placed by the participant on being able to participate, for example, when talking on behalf of the patient or in the decision-making process (Frivold et al., 2015).

As far back as the early 2000s, Gavaghan and Carroll (2002) highlighted how measures such as visitation, information, and needs for assurance, as well as the needs for support and comfort, were important and highly appreciated by the families of critical ill patients. Visitation has been a much discussed issue in recent decades and, with an increasing focus on family centred care, open or flexible visitation is one of the recommendations made by the guidelines (Davidson et al., 2017). In a survey of ICUs in the Nordic countries, Frivold et al. (2022) showed how approximately 80% of the responding Norwegian ICUs had open (41%) or open with an exception of two hours (39%) access for family visits, even though several restrictions exist. In addition, the survey showed that most Norwegian ICUs reported including families in communication and decision-making, while the involvement of families in patient care or ward rounds was reported less frequently (Frivold et al., 2022). Family satisfaction has also recently been examined in two Norwegian ICUs, and the results from this survey show that most families are very satisfied; however, some areas, such as satisfaction with the information they received and the decision-making process, had a lower score (Haave et al., 2021).

In addition to the burden of having a loved one critically ill and treated in an ICU, the family members may take on a great deal of responsibility, potentially causing caregiver strain. A recent grounded theory study described how families experienced ‘being devastated by the critical illness journey in the family’ (Kang, 2023, p. 3). Being devastated encompassed overwhelming experiences in the ICU, how the family took on responsibility during the patient recovery, how the family’s life was devastated by the trauma undergone, and how family members had to balance and make compromises in their own lives after their loved one came home (Kang, 2023). Hence, being a family caregiver may be a tremendous strain, and Van den Born-van Zanten (2016) found that 21% of family caregivers reported caregiver strain due to the provision of care. This finding is accordance with Torres et al. (2017), who found that approximately half of caregivers reported no overburden, whereas 34% reported low overburden and 15% reported moderate to high overburden. In addition, they found that experiencing signs of the psychological dimensions of PICS-F seems to increase the chance of experiencing overburden. When investigating whether caregiver burden was associated with caregiver depression, Beesley et al. (2020) found that approximately 50% reported caregiver overburden three months after ICU admission; however, there was no correlation between caregiver burden and caregiver depression three months after ICU admission.

Both the critically ill patient and their family members may experience a plethora of challenges during and after hospitalisation. As noted, measures have been taken that are directed towards lightening the burden of both the patient and their family member during hospitalisation. In addition, several follow-up offers after intensive care treatment exist; however, these often focus exclusively on the patients.

2.5. What follow-up offers exist?

As outlined in the previous sections, there is no guarantee that a person who survives intensive care treatment, whether the patient or a family member, can continue life as it used to be before the critical illness. New sequelae and challenges may arise due to either the illness itself or the intensive care treatment and the potentially traumatic experience of suddenly having a critical and life-threatening illness. Various aftercare and follow-up offers have been developed, ranging from multidisciplinary ICU follow-up clinics to nurse-led follow-up conducted from the ICU (Svenningsen et al., 2015).

Internationally, there are differences between countries in how follow-up clinics are organised. In some European countries, follow-up clinics developed through the 2000s (Griffiths et al., 2006; Van Der Schaaf et al., 2015) and in the UK, the National Institute for Health (NICE) has published quality standards and guidelines for rehabilitation after critical illness in adults (NICE, 2017). These quality standards highlight four quality statements directed towards important transitions during a critical illness trajectory, the fourth of which addresses follow-up after critical illness discharge. They recommend that adults who stay longer than four days in an ICU with a risk of morbidity should have a follow-up and health assessment two to three months following hospital discharge (NICE, 2017). Other countries have not issued guidelines or recommendations, and a recent survey from Australia found that only two of the responding ICUs organised an intensive care follow-up clinic (Cook et al., 2020).

Nurse-led follow-up has been a prevalent type of follow-up, and a review of nurse-led follow-up showed that it could be divided into three patterns: ward visit in close proximity to discharge, ward visit and consultation at a follow-up clinic, and follow-up visit to the ICU in addition to follow-up by phone (Jonasdottir et al., 2016). In the Nordic countries, follow-up after intensive care has been performed as both a nurse-led and a multidisciplinary follow-up program (Egerod et al., 2013). In Norway, a survey showed that 27 of the responding 39 ICUs offered follow-up to patients and that patient diaries were a frequent part of the follow-up (Moi et al., 2018).

The effect of diaries and follow-up programmes on intensive care patients with PICS symptoms has been much researched and discussed in recent decades. A Cochrane review showed no evidence of either benefit or harm for patients or family members; however, the review only included three studies as other studies were of low quality and did not meet the Cochrane criteria (Ullman et al., 2014). The lack of evidence for diaries and follow-up programmes is supported by other scholars who have found no clear effect on the PICS symptoms of either patients or their family members (Cuthbertson et al., 2009; Jensen et al., 2015; Jonasdottir et al., 2018). Nevertheless, some studies have shown that diaries may have a positive effect on the PICS symptoms experienced by patients and their family members (Backman et al., 2010; Garrouste-Orgeas et al., 2012; Jones et al., 2010; Knowles & Tarrier, 2009), and a recent review of seven RCT studies found reduced rates of PTSD in patients who had received a diary compared with patients who had not (Gazzato et al., 2022). The review, however, found no effect of diaries on depression and anxiety (Gazzato et al., 2022). Nevertheless, several qualitative studies have shown how much patients and their family members appreciate the diaries and follow-up offers (Engstrom et al., 2008, 2015; Ewens et al., 2014; Glimelius Petersson et al., 2015). However, some studies have also shown an ambivalence towards the diaries and that patients report that reading the diary can be challenging and evoke difficult feelings (Engstrom et al., 2009; Ewens et al., 2014; Flahault et al., 2022).

In Norway, national recommendations for diaries in ICUs were published in 2011 (Holme et al., 2020; Storli et al., 2011). Hence, writing diaries for ICU patients has been a large part of the follow-up conducted by Norwegian ICUs (Moi et al., 2018). Diaries have been written as both an act of caring and a means of therapy to help patients in their continuing life after an intensive care treatment (Gjengedal et al., 2010). After the national recommendations were issued, the guidelines for diary practice changed: from the diary being more of an informal gift from the ICU nurses to the patients, it became a formal part of the patients' hospital records (Holme et al., 2020). Although writing a diary is an established routine in Norwegian ICUs (Fålun et al., 2017; Flinterud et al., 2019; Moi et al., 2018; Oslo Universitetssykehus, 2021), there are no current national standards for follow-up of patients and their family members after intensive care treatment. However, a project in Oslo University Hospital received funding after the COVID-19 pandemic and has just started a multidisciplinary outpatient clinic for intensive care survivors (Stoksvik, 2023), which will be interesting to follow.

2.6. ICU nurses encountering critically ill patients and their families

The vast majority of studies covered in this background section have been devoted to areas within intensive care affecting patients and their family members. However, this last section briefly addresses research into ICU nurses working in ICUs taking care of critically ill patients and their family members. As previously noted, measures to humanise the ICU have been implemented aiming to decrease the burdens of PICS, including better pain management, early mobilisation, regimes of lighter sedation, and increasing the presence of family members in the ICU. However, there is an additional factor to the patients' and their family members' experiences during and after intensive care treatment, namely, the interpersonal relationship with the healthcare professionals they encounter.

Intensive care nurses are continuously bedside when patients undergo intensive care treatments, and they are an important factor in the treatment within the ICU. In a recently published editorial, Kitson (2023) stated that: 'there is no cure without care' (p. 1), highlighting how, post-pandemic, there is, amongst other challenges, a shortage of nurses throughout the world. This affects healthcare deeply, and even though we have vaccines, medicines, and advanced equipment to treat and save lives, Kitson (2023) highlighted that nurses must be there to provide personal and fundamental care.

As noted previously, ICU nurses need technical, caring, and interpersonal competencies to ensure both patient safety and patients' feeling of safety (Henriksen et al., 2021). In an ethnographic study of nurses' practice in an ICU, seven discourses covering both impersonal and personal ways of thinking, talking to, and treating patients in an ICU were recognised (McLean et al., 2016). The study showed that nurses moved from being impersonal, thinking and talking about patients as routine work, unstable, a medical case, or a body, to, in the next moment, thinking and talking about them in more personal ways that addressed their needs as social or valued individuals. The study illuminated the complexity of working with critically ill patients and indicate that even though nurses are trained and socialised into a holistic perspective of patients, certain aspects of ICU practice may make it essential to think and talk about patients impersonally so nurses can give them safe and effective care (McLean et al., 2016). The important thing is to balance the impersonal and personal ways of relating to the patient in a way that is appropriate to the patient's situation. As nurses are continuously bedside, research has shown how they view patients as 'their space' and report on experiencing a deep relationship with them that could evoke feelings of love, empathy, and care (Vouzavali et al., 2011). Caring in the ICU has been shown to consist of a holistic approach where the nurses' skills, feelings, and knowledge work together (Wilkin & Slevin, 2004).

As nurses are continuously by the patients' side, they observe first-hand the traumatic experiences the patients are put through. Hence, several of the follow-up offers described in the previous section started as bottom-up initiatives from intensive care nurses, and nurses play a pivotal role in many follow-up initiatives today (Eaton et al., 2019). ICU nurses report that they value conducting follow-up with former ICU patients, gain better insight into how the critical illness has affected the patients and their family members, and gain valuable feedback on their own practice (Engstrom & Soderberg, 2010). A study performed in Norwegian ICUs highlighted that by conducting follow-up, such as writing a patient diary, nurses became more conscious of the patient as a person (Holme et al., 2020). Doing so also raised their awareness and led them to try to prevent the potential PICS-related problems patients may experience after intensive care treatments (Holme et al., 2020).

As outlined in this background section, the intensive care area is both extensive and much researched. There is no doubt that patients and their family members are at risk of experiencing problems following ICU discharge. However, Brummel (2018) highlighted that the research and tools to assess outcomes need to be more unified. He pointed to a study by Turnbull et al. (2016) that showed that 250 different measurement instruments were used in 425 articles. Other studies have supported this finding in addition to highlighting the methodological challenges in the studies investigating PICS or PICS-F (Johnson et al., 2019; Petrinec & Daly, 2016). A challenge to conducting research in the ICU population is the heterogeneity of the patient group, which may include a wide range of diagnoses and conditions with the common denominator of having single or multiorgan failure in need of organ-supportive treatments if the patients is to survive. Nevertheless, even though there are challenges and differences in outcomes and instruments measuring outcomes after an ICU stay, previous studies have shown that both patients and their family members are at risk of experiencing impairments and problems afterwards.

Moreover, even though the relationship between studies reporting critical care in general and those reporting on critical care survivorship is 40:1 (Brummel, 2018), there is an increasing focus on the survivorship of patients and their families and how they manage in their ongoing lives after intensive care treatment. As noted, research into survivorship has increased in recent decades; however, there seems to be a paucity of studies that take a phenomenological approach to exploring the lifeworld from the onset of critical illness and throughout the illness trajectory into subsequent everyday life for both patients and their family members. In addition, studies often report on one perspective or one area within intensive care, and in this PhD study we wanted to examine support and follow-up through the perspectives of former patients, their family members, and ICU nurses and describe the whole illness trajectory from the onset of the critical illness through recovery and onwards in the patients’ and their family members’ everyday lives at home.

3. Aims

The main aim of this thesis was to explore experiences of support and follow-up during and after critical illness and intensive care treatment. Through descriptions of the lifeworld of former intensive care patients, their family members, and intensive care nurses, we sought to better understand the practice of support and follow-up and explore what was important for the patients and their families from the onset of critical illness and intensive care throughout hospitalisation and after coming home.

In the first article, the perspectives of intensive care nurses were explored, and the aim was to explore and describe the experiences of Norwegian ICU nurses providing nurse-led follow-up. The study had two research questions: how do ICU nurses experience performing nurse-led follow-up? And how do ICU nurses experience ICU patients' and their families' need for follow-up?

In the second article covering former patients' experiences, the aim was to explore and describe what intensive care patients experience as limiting and strengthening throughout their illness trajectories.

In the third article covering families' experiences, the aim was to explore the experiences of family members after they have lived through a close one's illness trajectory starting with critical illness and intensive care treatment, throughout hospitalisation and after their return home, and describe what was important and challenging for them during this time.

4. Phenomenology

As explicated in the background section, intensive care is a highly technological area where the natural sciences play an important part in patients' survival of critical illnesses or injuries. However, the people who encounter intensive care, whether as patients or family members, exist at a point of intersection between the highly technological and advanced medical treatments, on the one hand, and the lifeworld with its human and relational aspects, on the other. Taking a phenomenological approach, I am interested in the participants' lifeworld: how do patients and their family members experience their everyday life during the illness trajectory with regards to support and follow-up? And how do ICU nurses experience the nurse-led follow-up offered from the ICU?

In this thesis, what Herholdt-Lomholdt (2022) call experienced-led phenomenology has been conducted (pp. 173-182). Whereas a phenomenon-led phenomenology would have focused on a specific phenomenon, the current study instead examines the experiences of patients' and their family members' lives during and in the aftermath of critical illness in addition to the ICU nurses' experiences. Herholdt-Lomholdt (2022) described the focus of experienced-led phenomenology as 'how specific events or situations is experienced and active in people's lives' (p.177).[9] Phenomenology is concerned with the first-person perspective and the lifeworld, and it was found appropriate as a means of capturing the participants' experiences of support and follow-up through lived life during an illness trajectory.

4.1. Phenomenology and the lifeworld perspective

Phenomenology is both a philosophical direction and a scientific method (Giorgi, 2009, pp. 87–94). Husserl is seen as the founder of phenomenology, starting in the early twentieth century (Giorgi, 2009, p. 4), with what Dahlberg et al. (2008, p. 24) have described as modern phenomenology. Phenomenology developed in opposition to the positivistic paradigm that was the prevailing theory of science in the early 20th century (Dahlberg, 2019). The positivistic paradigm sees human beings as composed of dual parts and separates the body and the mind. The world is seen as something which is outside of ourselves; something we therefore can measure and weigh. Bengtsson (2006) refers to how Husserl claimed that

---

[9] «Hvordan specifikke begivenheder eller situationer opleves og er virksomme i menneskers liv».

the objective sciences created a gap between science and lived life (pp.20-21). To Husserl, the human consciousness was the onset of knowledge as everything we experience presents itself to consciousness. A distinction was made between the object itself and the act of consciousness – how consciousness is directed towards the object, which he called 'intentionality' (Giorgi, 2009, p. 9). Intentionality refers to how our consciousness is always directed towards something (Zahavi, 2019, p. 16), either thoughts – when thinking of something – or being 'conscious of' something through our senses, for example, when looking at something, feeling something with our hands or tasting something. Phenomenology seeks the experience of what is given to consciousness.

The starting point of phenomenological research is the first-person perspective and an examination of the participants' lifeworld, which was important in this study. Our lifeworld is the world we live in: a pre-theoretical world in which we exist (Zahavi, 2019, p. 51). It is a pre-reflexive and prescientific world that we take for granted, but it is also a social world, where we live in connection to others (Bengtsson, 1999, pp. 16–17). The lifeworld is for us as what water is for fish: it is something that is there and that we (or the fish) take for granted. In the lifeworld, we hold what Husserl called 'the natural attitude' (Dahlberg et al., 2008, p. 33). This is our everyday experience, where we are in the world without reflecting upon the world around us. In everyday life, we relate to the world around us in an immediate way, and the relation we have to our surrounding world is our lifeworld; it is 'a humanly relational world, full of meanings' (Galvin & Todres, 2013, p. 25).

The lifeworld has been explained through different constituents: temporality, spatiality, intersubjectivity, embodiment, and mood. These dimensions have been developed by several philosophers, such as Heidegger, Merleau-Ponty, Van den Berg and Boss (Galvin & Todres, 2013, p. 26). They are not mutually exclusive but, rather, dependent on each other and intertwined in our everyday life. In this study, these lifeworld constituents affect the participants' experiences through an illness trajectory in various ways. Below, I apply Galvin and Todres' (2013, pp. 27–30) definitions when outlining the lifeworld constituents as they emerge through the trajectory of critical illness.

Firstly, the temporal dimension comes to the fore when exploring experiences throughout the illness trajectory. The temporal dimension refers to how we live in a continuum from a past through the present moment toward a future. Time can be both quantitatively and qualitatively experienced. For example, when one is lying in the hospital bed waiting for one's family, the time may go by very slowly; in contrast, when the family arrives, the hours fly by.

The spatial dimension refers to an 'environing world' (Galvin & Todres, 2013, p. 27), and it involves both places and things in relation to closeness or distance. At the onset of the critical illness, the patients and their families enter the intensive care world, which is the world of the ICU nurses. What is important or unimportant, close, or distant is coloured by our lifeworld. When we are critically ill and admitted to an ICU, the world may revolve around things in close proximity, such as the pain we are feeling or the annoyance of the cables connecting us to the equipment. When we get better, the world may open, and we may become more interested in how the family at home is doing or the results from a favourite football team's most recent match.

The intersubjective dimension refers to how we live in relation to others. We live in a social world where we meaningfully relate to other humans through both verbal and non-verbal interaction. Galvin and Todres (2013, p. 28) highlight how our culture and tradition also affect intersubjectivity and thus our being. Through our upbringing, we are shaped and influenced by the relations and ways of being in our culture, which also influences our intersubjective dimension. For example, in the Norwegian culture we shake hands when meeting in a professional setting regardless of gender, while in other cultures one may bring the palms together in front of the chest and bow.

Embodiment refers to how we live with our bodies in a meaningful way in relation to others and the world (Galvin & Todres, 2013, pp. 28–29). When healthy, we do not think about our body: it functions, and we move around as we wish without reflecting on it. In illness however, for example, when waking up after some weeks in bed, our muscles have weakened, making the transfer from the bed to the chair next to the bed almost impossible. Our embodied being is a central part of our lifeworld and is in close connection to the other constituents.

The last constituent described by Galvin and Todres (2013, pp. 29–30) is mood, or emotional attunement. Our lifeworld is coloured by how we feel – our mood or emotional attunement. Our mood influences all the other constituents, and how we feel thus affects our lifeworld. We cannot *not* be in a mood – our mood is always there, albeit varying. Feeling in love or extremely happy will affect our lifeworld in a different way to feeling sad or alone. The constituents that form our lifeworld are always there to a greater or lesser extent, and they are interchangeably related and connected to each other.

As explicated, the current study is grounded in a phenomenological tradition. However, it is not a philosophical study, and phenomenology was used as a way of both seeing the world and entering the research process. The methodological implications of taking a phenomenological approach are further elaborated on in the methodology chapter and in the section addressing methodological considerations.

5. Methodology and overall design

In this thesis, phenomenology is also used as a methodology, with implications on which I elaborate in this section. A phenomenological attitude is one of the preconditions undertaking a research process from a phenomenological starting point, but what does having such an attitude mean? As explicated in the previous section, the natural attitude is our everyday attitude or everyday being, namely, as we are in our everyday life. However, according to Husserl, when philosophical phenomenology is undertaken one has to assume a phenomenological attitude (Giorgi, 2009, p. 87). Within phenomenological philosophy, this is described as the transcendental phenomenological reduction (Giorgi, 2009, pp. 97–100). However, in this study, phenomenological science has been applied, and the phenomenological reduction has been achieved through an open and aware attitude. Throughout the research process, I have striven to be aware of my own natural attitude and encounter the phenomena that appear with a curiosity and openness and without assuming anything based on my 'natural attitude' (Dahlberg et al., 2008 p.54-55; Giorgi, 2009; Zahavi, 2003). I was, however, interested in the participants' lifeworld where they do have a natural attitude, and aimed to capture their naïve being in the world without leading or interpreting what appeared.

In addition to the phenomenological reduction, the bracketing of knowledge and pre-suppositions about the phenomenon or object of our attention, also known as epoché, is important (Giorgi, 2009, p. 91). In epoché, the goal is to meet whatever is 'given' without any preconceptions. We must try to not let former knowledge and thoughts influence us and to see what is given as it is given. Dahlberg and Dahlberg (2019) emphasised the importance of holding back, which they call 'bridling'. When we live in a meaningful world and within the natural attitude, the world around us gives us an immediate meaning. However, when taking a phenomenological approach, I strove to stay open and be in the phase of not understanding; that is, I tried to 'bridle' or 'bracket' my immediate understanding. However, Giorgi (2009), highlighted that 'bracketing' does not mean forgetting everything one knows, but not letting previous knowledge be engaged when deciding on the content of an experience (p. 97). Thus, it means being aware and not letting previous knowledge influence one during research and holding an open view and perspective. I therefore strove to open up and remain curious and open for as long as I could manage without defining or explaining what appeared.

An important aspect in phenomenology is that one needs to be open to the given, that is, the phenomenon of interest, precisely as it presents itself. One tries to leave out the natural attitude whereby we often interpret or add meaning to what we see. At the same time, one is open to what is given, but the focus is on how this given is experienced, not on how the given exists. Husserl was concerned with the presentation of the given and to stay with the given as presented, neither adding nor subtracting characteristics (Giorgi, 2009, pp. 9–11).

According to Giorgi (2009, p. 59), research situations should be similar to lifeworld situations, even though they can never be entirely alike. Within this research, in which the phenomena of interest were support and follow-up, descriptions of everyday events were sought to capture pure experiences as closely as possible without the participants reflecting too much on their own experiences. However, when the participants talked about their experiences, a reflective process will always have happened in addition to their memory of the events, which might be different from what actually occurred.

I have understood the natural attitude as being my everyday life where I am in a 'taken for granted' position and use my knowledge and preunderstanding 'unconsciously'. Through this study, I have striven to attain a consciousness of how I have used my knowledge and pre-understanding. In some parts, such as in the planning, I have used my knowledge and preunderstanding actively. In other parts, however, such as when conducting the interviews or analysis, I have tried to put my pre-understanding in brackets and be open and curious without jumping to conclusions. I have striven for openness and curiosity, to stay open, and, as Dahlberg et al. (2008, p. 121) emphasised, 'to not make definite what is indefinite'. To increase transparency, I now further outline my knowledge base and preconceptions when I embarked on this research.

5.1. The researcher's reflexivity

When embarking on this study, I worked toward making my pre-understanding explicit in order to be able to be aware of it, 'bracket it', and focus on the participants' experience with a naïve curiosity and without being in the natural attitude of taking anything for granted (Husserl, 2002, pp. 58–60). My pre-understanding was shaped by previous experience, my education, and my work. I had been a nurse for 14 years, eight of which I spent as an intensive care nurse. I had been working in an ICU at a university hospital in Norway for six years. I had met and interviewed some former patients treated in an ICU during two other studies. For my master’s degree, I interviewed former patients about their experience of communication while tracheostomised in the ICU, and in another study, I met former patients and performed some tests on and administered questionnaires to them. In several of these encounters, former patients talked briefly about their everyday life after critical illness, and many of them talked about the diary they had received from the ICU. In addition to having different encounters with former patients, I have written in countless patient diaries, but I have never worked explicitly with the follow-up the ICU offered or conducted consultations with former patients or their family members.

My pre-understanding was also affected by the literature I read when preparing for this study. By writing down my pre-understanding, I tried to make explicit what I brought with me into the study in terms of experiences, thoughts, feelings, and meanings. In all, I had a pre-understanding that follow-up from ICUs was important to both patients and their family members, and I had a preconception that several patients and their family members do not receive the follow-up they need to obtain help with their problems following critical illness and intensive care. Both patients and their family members go through extreme experiences, and the former may be hovering between life and death. Even though everyone experiences this in a different way, I thought that both former patients and their family members would benefit from follow-up from the ICUs: that it would be helpful to talk to the intensive care nurses, and sometimes the physicians, who were there throughout their critical illness and intensive care treatment and who knew what they had gone through. By trying to make my pre-understanding explicit, I increased my awareness about what I brought with me, and I hope that this has helped in the process of ‘bracketing’ and that I managed to let go of my natural attitude and open up to the participants’ lifeworld and phenomena that appeared without influencing them with my pre-understanding.

5.2. The study

The study used a qualitative method. Individual interviews and focus group interviews were used as methods for collecting data.

5.2.1. Setting and participants

Three different ICUs were included in the study: one ICU in a university hospital in western Norway, one ICU in a university hospital in eastern Norway, and one local hospital in western Norway. All the units had a follow-up programme for former patients, but the follow-up differed in content; for example, all ICUs wrote diaries for patients, yet they had various inclusion criteria. There was difference in the follow-up offers as well. One ICU invited all patients who had stayed more than five days back to the ICU, whereas the other ICUs invited patients who had received a diary back to the ICU for a follow-up conversation. Different ICUs with different follow-up programmes were included to ensure variation in intensive care nurses' experience of follow-up and in the type of follow-up received by former patients and their family members.

The ICUs were contacted with a request that they participate in the study. When the head of the department had approved the request and the Data protection officer at each hospital had given their recommendation, a meeting was arranged with the contact person in each ICU. The contact persons were informed about the study and their responsibilities during the inclusion process. The contact persons recruited participants. Intensive care nurses were invited to participate in focus group interviews, and information letters were sent to former patients and the family members documented in the patient's hospital records. In addition, the contact persons abstracted data from the journals of those participating former patients who consented.

Participants in the focus group interviews

The first part of the study was the focus group interviews. The inclusion criterion for participating in the focus group interviews was being a certified ICU nurse, and we aimed to recruit nurses with varying lengths of experience as ICU nurses and participants with varying roles and engagement with the follow-up conducted at the ICU. The exclusion criterion was having worked in ICU management during the past three years, as we wanted ICU nurses who had worked ‘hands-on’ with patients, their families, and follow-up. When a satisfactory number of nurses had consented to participate, the contact person and I agreed upon a suitable time for an interview. The contact person arranged the practicalities, such as booking a room for the interview and arranging for the intensive care nurses to be able to participate. The participants signed consent forms and answered a sheet with background information (Appendix 5), which was gathered at the time of interview.

In total, 20 nurses participated, eight in one interview, six in both the others. See Table 2 for participant characteristics.

Table 2. ICU nurses’ characteristics.

Focus group	Interview A	Interview B	Interview C
Age, mean (min–max)	51 (37–64)	55 (52–60)	48 (33–61)
Female/male	7/1	6/0	6/0
Years of experience as an ICU nurse, mean (min–max)	16 (4–27)	25 (19–37)	16 (7–34)
Years of working in the ICU, mean (min–max)	16 (5–21)	22 (2–30)	13 (4–25)

Participants in the individual interviews

The contact person in the ICU sent information letters to eligible participants via post. Letters were sent to both eligible former patients and the persons documented as their next of kin in the hospital records. To participate in the study, the former patients and their family members had to contact me by telephone or e-mail. When they made contact, an appointment for an interview was made.

The inclusion criteria for the former patients were age ≥ 18 years, length of stay ≥ 4 days, mechanically ventilated ≥ 48 hours, and being capable of conducting an interview in Norwegian. At the start of the study, we had an inclusion criterion of having ICU length of stay ≥ 7 days; however, as the recruitment was slowly as there were few eligible participants, the inclusion criterion was modified to an ICU length of stay ≥ 4 days. There were no inclusion criteria regarding reasons for ICU stay. The only inclusion criterion for the family member was that they had been listed as the next of kin in the patient’s hospital record.

Ten former patients and 11 family members participated in the study. There were six men and four women among the former patients, and they were between 26 and 73 years old. The former patients had suffered from one or several conditions: respiratory failure (n = 8), circulatory failure (n = 3), sepsis (n = 2), trauma (n = 2) and gastrointestinal disease (n = 2). All had been intubated through an endotracheal tube, six had been tracheostomised, and five had been treated with non-invasive ventilation during the intensive care treatment. They had been admitted to the ICU for between seven and 68 days and hospitalised for between 17 and 138 days. For more patient characteristics, see Table 3.

Eight of the former patients were either married or lived with a partner, while two were single. All but one had children, and one participant had children under the age of 16. One participant lived alone; the rest lived with family. At the time of interview, two former patients were retired, two worked full time, one was unemployed, two were on partial sick leave, two were fully on sick leave, and one had quit her job and was at home voluntarily. Eight former patients stated that they had had some form of rehabilitation after the hospitalisation, with half of them admitted to a rehabilitation facility. Most stated that they had had some form of either rehabilitation or physiotherapy in the aftermath of the critical illness; however, two former patients stated that they had not received any rehabilitation or physiotherapy afterwards.

Table 3. Patient Characteristics.

	Age	SAPS II[10]	Days mechanically ventilated	Length of stay in the ICU	Length of stay in hospital
Median	54	35,5	12	14	24
Min–max	26–73	32–55	5–60	7–68	17–138
Interquartile range (IQR)	24	19	18	18	28

Of the 11 family members who participated, two were the parents of a former patient, one was the daughter of a former patient, and eight were spouses of former patients. In all but cases, the family members lived with the patient (the parents lived in a house nearby). Their age ranged from 24–63 years; however, due to loss of data, the age of four participants is missing. All but one of the family members had children, and one had children under the age of 16. Of the 11 participating family members, six worked full time, one worked part time, three were retired, and one was on sick leave.

5.2.2. Data Collection

Focus group interviews with the intensive care nurses and individual interviews with the former patients and their family members were conducted. One interview was performed with the two parents together.

Performing focus group interviews

Three focus group interviews with intensive care nurses from the three different ICUs were carried out from November 2016 to January 2017. The focus group interviews took place in a room within the ICU where the participants worked and lasted 90 minutes on average. I moderated the interviews, while my main supervisor co-moderated in two, and one of the co-supervisors co-moderated in one. Focus group interviews are suitable when exploring a group's experience, attitudes, or needs related to the topic at hand. The group interaction is part of the method, and the aim is that discussing and talking about a topic and hearing someone else's views and thoughts might illuminate it comprehensively (Kitzinger, 1995).

---

[10] Simplified Acute Physiology Score II, a score that measures severity of disease in patients admitted to an ICU.

The group dynamic is emphasised and is influenced by various factors related to the participants, such as their personalities, and the setting, such as the culture and work environment in the ICU. These points are further elaborated on in methodological considerations.

At the start of the interviews, my supervisor and I introduced ourselves and reiterated the information in the letter participants had received. I encouraged the participants to maintain confidentiality so that the topics discussed during the interview would stay inside the room. Then, I asked the participants to talk about how the ICU conducted follow-up of former intensive care patients and their family members. Next, three different areas were asked about: their experiences with follow-up, their experiences with former patients' and their families' needs for follow-up, and, lastly, their thoughts about patient participation in the follow-up. See Appendix 4 for the specified interview guide.

During the focus group interviews, we were not interested in individual voices; rather, we wanted to examine the intensive care nurses' experiences of the area under investigation, namely, the follow-up services and their experiences of conducting follow-up with former patients and their family members. As the moderator during the focus group interview, I strove to support the group discussion, ask probing questions, and facilitate everyone to participate in the interviews. The co-moderator observed the interviews, took notes, and summarised and asked questions if anything was unclear at the end of each interview. The three interviews unfolded in different ways. In some, there were discussions and discrepancies while in others, the participants were more unified. Some participants were quiet, while others talked and told more stories from their experience of conducting follow-up.

Performing individual interviews

Individual interviews were conducted with former patients and their family members. In total, 20 interviews were conducted: 19 individual interviews and one interview with both parents together. The interviews were carried out from February 2017 to April 2018. Individual interviews were found suitable to the phenomenological approach, being concerned with the lifeworld and the experiences of the participants during the illness trajectory. Dahlberg et al. (2008, p. 184) highlighted interviews as dialogues that seek to explore the interviewees' lifeworld. The interviews may be a reflective dialogue that prioritises the interviewees' perspective, and as an interviewer I directed the informants towards the phenomenon of interest, namely, their experiences of the critical illness trajectory, to examine the area of support and follow-up and what had been important and challenging for them during the illness trajectory.

The interviews took place where the participants wanted. Mostly, I was invited to the participants homes and interviewed them in a room in their house (n = 13). At the request of the participants, some interviews took place elsewhere, namely, in a room at their workplace (n = 5), or at the hospital (n = 2). The interviews lasted between one hour and two and a half hours, with an average duration of one and a half hours.

Interviews are affected by both the researcher and the informant. Dahlberg et al. (2008) described immediacy in interviews, and when performing the interviews I strove to be attentively present to the interviewee and to what appeared in the interview. Being attentive and striving for an immediacy required that I had an open and curious attitude, constantly bracketing my pre-understanding and knowledge, to let the interviewee lead the interview to where their lifeworld emerged. However, even though I opened up for everything they emphasised in their everyday life and followed their stories, I had an aim in undertaking the interview. Giorgi (2009, p. 123) makes a distinction between 'leading the participants' and 'directing the participants'. When leading, one steers the participants towards specific themes, and this was not my intention. Rather, I tried to direct the participants through certain areas that I wanted to cover and that were made explicit in the interview guide. I strove to be present in the moment, opening up to what the participants were telling me, asking questions to encourage elaboration, and repeating the essence of my understanding at certain point in order to check I had understood what the participants were telling me. The aim was to capture the lifeworld of the other, specifically, how they experienced their everyday life after critical illness.

At the onset of each interview, I introduced myself, told the participants about my background as an intensive care nurse, and reiterated the information they had received by post. Often, the interview setting was the participants' homes, and some everyday conversations about their home, the weather, or things that had happened on my way there were held. After the introduction, I asked them to tell me about the onset of the event causing their critical illness and intensive care treatment. Giorgi (2009) emphasised the importance of descriptions being as concrete as possible (p. 96). Thus, I had prepared myself to ask the participants to describe days or events. I had an interview guide with examples of questions that I could ask the participants. However, my plan was to follow the participants' stories and use the guide as a tool on which I could lean if needed. I soon discovered, however, that it was challenging to follow the interview guide. After some interviews, the guide was revised to contain the areas that I wanted to cover point by point instead of whole sentences, as was the case with the first one. However, in order to be present and able to follow the participants' stories, I focused solely on what the participants were talking about and used the interview guide more as a means of summarising when they had rounded off what they were telling me about. The interviews were structured according to the illness trajectory, even though they often took detours when participants remembered something else that they wanted to tell me about. I experienced the interviews as open and flowing, and the participants seemed to willingly share their experiences with me.

5.2.3. Analysis

Giorgi's (2009) descriptive phenomenological method was used to analyse both the focus group and individual interviews. The method follows Husserl's phenomenological philosophy; however, Giorgi (2009) modified and adapted to serve a scientific purpose. Giorgi (2009) described steps of the analysis that I have attempted to follow (pp. 128-137).

The interviews were recorded on two tape recorders and transcribed verbatim. I transcribed the three focus group interviews and 14 of the individual interviews and had an external transcriber for the remaining interviews. The first step of the method is to read to get a sense of the whole (Giorgi, 2009, p. 128). Then next is to determine the meaning units, hence, dividing the text into parts that are sensitive to meaning. In Giorgi's description (2009), one is to be sensitive to the psychological perspective (pp. 129-130). However, in this study, we did not have a psychological, but a caring, perspective, and the text was divided into meaning units sensitive to the latter. As part of our caring perspective while analysing, we sought an awareness of what the participants gave to others or needed from others. The text was read with a consciousness of what stood out as important when giving or receiving care in the area of support and follow-up. Giorgi (2009) highlighted that the dividing of the meaning units is not a theoretical step; rather, it is a practical means to make the analysis more manageable.

Then, the third step, ‘the heart of the method’, was conducted (Giorgi, 2009, p. 130). In this step, the meaning units were transformed into expressions that were more sensitive to the caring perspective. Each meaning unit was interrogated, and the meaning close to the caring perspective was expressed. The use of free imaginative variations was sought, which means ascertaining higher level categories that contain the same meaning and are sensitive to a caring perspective (p. 132). Giorgi highlighted that this is a laborious step in which one goes back and forth trying out different expressions. This step is to be performed until a level of generality is reached that covers the meaning of the material sensitive to a caring perspective (Giorgi, 2009, pp. 130–133). Below, I elaborate on my process of analysing the focus group and individual interviews.

Analysing the focus group interviews

I started this study by conducting the focus group interviews; hence, this was my first analysis. When transcribing, I gave the different participants nicknames, and I listened to the voices and wrote down what was said. This was sometimes challenging as several participants talked at the same time; however, who said what was not the most important thing in this analysis. As per Giorgi (2009), I was, rather, interested in what was said, that is, the content of the discussion. After finishing the transcripts, I read them several times while listening to the recordings.

I then started analysing each interview separately. First, I divided the text into meaning units in Word, and I then worked on transforming the different meaning units into expressions closer to a caring perspective. When this was done, I transferred the material into a computer software programme, NVivo (QRS International Pty. Ltd., 2020) and tried to continue the analysis using this programme. However, I did not manage to use NVivo as I could not figure out how to organise my material in it, so I continued the analysis in Word. I worked on each interview first, trying out different descriptions. This was a tedious process, and it took me a long time to ‘crack the code’ of how to undertake this analysis. After I had written descriptions sensitive to the caring perspective of each interview, I gathered the interviews and continued to work on higher-order categories to find a structure and the areas of which it consisted (Giorgi, 2009, p. 132).

The analysis was a laborious process with a great deal of pondering, writing, and re-writing, all of which was followed closely by my supervisors, who read and discussed the analysis with me continuously. Through the analysis, we found a general structure consisting of four constituents, which are presented in the findings chapter.

Analysing the individual interviews

When I started the analysis of the individual interviews, I tried NVivo (QRS International Pty. Ltd., 2020) again, and this time I managed to use the programme throughout the entire process of analysis. Having interviewed both former patients and their family members, we wanted to see if the analysis could be applied to dyads (each patient and their family member), with areas or themes from the analysis becoming different articles. Hence, I started analysing the individual interviews separately, first analysing one interview with the former patient and then that with their family member. I continued this analysis until all 20 interviews had been analysed separately. Before continuing the analysis, I had several discussions with my supervisors about the feasibility of continuing the analysis with all participants. We eventually decided to continue the analysis of all the patients together and all the family members together due to the fact that they had very different perspectives, and we feared that it would not do justice to the interviewees to continue analysing them together. I then started analysing the interviews with the former patients.

In NVivo, I sorted the meaning units, gathering those with a similar meaning across the interviews. I wrote second-order descriptions sensitive to the caring perspective and went back and forward trying out different invariant meanings. The process of analysing was continuously discussed with my supervisors, who read and commented on both NVivo and the findings chapter in the articles. One of the advantages of using NVivo was that it enables the researcher, when coding the various meaning units, to go in a few steps from the suggested higher-order categories and the constituents to the individual interview transcripts. Thus, I was able to continuously go back to the transcripts to see if my descriptions were justified and coherent with the participants' descriptions. This analysis process was undertaken with both the former patients and their family members. In each of the analysis, I found a general structure covering the material and consisting of three constituents on which this structure was dependent. This is described in more detail in the findings chapter.

5.3. Ethical considerations

When research is conducted, an ethical awareness is required. Throughout this PhD study, I have maintained ethical awareness, followed the general guidelines for research ethics by Norwegian National Committees for Research Ethics (Norwegian National Research Ethics Committees, 2019), and worked in accordance with the guidelines at VID Specialized University. When the study description was written, ethical approval from the Regional Ethics Committee was sought. However, the study was not regarded as health research under Norwegian legislation and thus did not need ethical approval (Appendix 2). Nevertheless, a recommendation to conduct the study and store personal data was given by the Norwegian Centre for Research Data (Ref. No. 397448) (Appendix 2), and the data protection officer in each hospital gave permission to conduct the study.

An ethically conducted study builds on the principles of voluntary participation and informed consent. In the focus group interviews, the contact person in each ICU recruited intensive care nurses to participate. Hence, eligible participants did not feel pressurised by me as a researcher; however, I do not know if they felt pressurised by the contact person. At the start of each interview, I reiterated the information and emphasised the possibility to withdraw at any time. However, they were also informed that if they wanted to withdraw after the interview, their background information, but not what was said during the interview, would be deleted.

When recruiting former patients and their family members, the contact person found eligible participants through their registration system and sent out information letters via post. Participants who wanted to participate contacted me by telephone or e-mail. I knew nothing about how many information letters the contact persons had sent out or to whom.

Working this way facilitated efforts to avoid anyone being pressurised into participation. At the start of each individual interview, I reiterated the information, emphasising the possibility to withdraw at any time during or after the interview.

Ethical considerations regarding the vulnerability of study participants were discussed and considered in the planning of the study. Consideration was given to the fact that former patients and their family members may have been through traumatic experiences. In agreement with the contact person in each ICU, the study participants were informed about an offer to talk to someone from the ICU if they needed after the interview. On one occasion, a participant expressed a wish to talk to someone from the ICU, and I arranged for the person in question to contact the participant after the interview. The ethical issue of including both former patients and their family members was also discussed. Curiosity about the relationship and the desire to see if we could analyse the couples together led to the decision to include both parties. However, at the start of each interview, information was reiterated with an emphasis that they should talk about their own situation and not that of their family member.

To ensure a safe environment during the interviews, I started each one by reiterating a summary of the information letter and asking participants to tell me about the onset of the critical illness. At the end of each interview, I also asked participants how they had experienced being interviewed, and I tried to be aware of and attentive to their body language and non-verbal communication to discover if they had felt unsettled in any way. During and after the interview, I mainly received positive feedback, and the participants told me that it felt good to talk to me about this situation. However, one interview made me feel uncomfortable. This participant had a hard time remembering anything from the first weeks of hospitalisation, and I am not sure if it was due to the challenges of eliciting a story about the whole trajectory or something between us in the interaction, but I felt unsettled both during and after that interview. Nevertheless, I felt that the interviews were rich in content and that the participants opened up to me, and I gained a glimpse of what had been important and difficult for them during the illness trajectory.

During the interviews, the participants decided what and how much they wanted to share. However, I was interested, using verbal and non-verbal signs to show that I wanted the interviewee to continue, or I asked direct follow-up questions to encourage them to elaborate on the topic (Kvale et al., 2015). For participating interviewees, the attention and interest from me, as a researcher, might have been seductive, leading them to tell me more than they were comfortable with later. There was also an asymmetric power relation between me, as a researcher, and the participants in the study (Kvale et al., 2015). Both elements were important to bear in mind and be sensitive about during the interview so that I did not risk violating the participants.

6. Summary of findings

In the following sections, a short summary of the findings from each study is presented in addition to a presentation of overall findings from the perspectives of former patients, their family members, and intensive care nurses.

6.1. The intensive care nurses' perspective

The first article reports on findings from the focus group interviews conducted with intensive care nurses in the three included ICUs. The aim was to explore and describe the experiences of Norwegian ICU nurses providing nurse-led follow-up. The research questions were the following: how do ICU nurses experience performing nurse-led follow-up? And how do the ICU nurses experience ICU patients' and their families' need for follow-up?

The general structure covering the intensive care nurses' experience was 'the creation of meaning', which involved four main areas: 'becoming emotionally moved', 'giving context to patients' lost time', 'risking oneself' and 'increasing insight and motivation'. The structure of creating meaning was illuminated in two ways: how the intensive care nurses strove to give meaning to their patients in their ongoing lives and how the nurse-led follow-up gave meaning to their own practice as intensive care nurses.

In 'becoming emotionally moved', the ICU nurses talked about how they became acquainted with both the patients and their families when they cared for the same patient for a longer period. Continuity of care was highlighted as important, allowing them to develop an interpersonal relationship with patients and their family. The ICU nurses talked about how, when experiencing an interpersonal relationship with patients, they made greater efforts, for example, writing in the diary. The opposite could occur when they had only one shift with a patient or did not experience an interpersonal relationship, that is, the ICU nurses could more easily refrain from writing in the diary.

Under 'giving context to patients' lost time', ICU nurses highlighted the importance of giving the patients an opportunity to give content to the time they had spent in the ICU. ICU nurses conveyed this importance through eager discussion, talking about their experiences with patients who made contact after ICU discharge wanting the diary as quickly as possible. The content of the diary was also talked about, and they spoke of how they individualised this content to create a personalised diary for each patient. This content could be notes on what had happened during the day, pictures of the patients with their family, a summary of a football match from the patient's favourite team, or diary notes written by the family members.

'Giving context to patients' lost time' also covered showing patients a room in the ICU when they returned after discharge. Participants described how they had experienced patients being able to explain dreams or experiences from their ICU stay due to seeing the ICU rooms or hearing the sounds of the equipment.

In 'risking oneself', the nurses described becoming more personally involved. Performing the nurse-led follow-up could involve showing more of their own individuality, beyond their professional role as ICU nurses, which could be challenging. Examples of this could be the mundane style of writing in the patients' diaries, or it could be not remembering patients when they came back to visit the ICU. Knowing how much it meant to the patients, they described feeling upset or uncomfortable when they failed to remember a patient. An additional challenge in 'risking oneself' was the ownership of the diaries. Diaries are seen as belonging to the patients, and the intensive care nurses described protecting them until they were handed over to the patients. However, if a patient died, uncertainty about what would happen to the diary was revealed. Some nurses handed diaries over to the patients' families, while others were more reticent. In addition, the ICU nurses spoke about the experience of one's own name being published in different social media after using it to sign a diary note. This caused discussions about how to sign to protect themselves.

The last area was 'increasing insight and motivation'. The nurse-led follow-up was described to give insight into nurses' own practice as well as a better understanding of patients' and their families' experiences during the ICU stay. Gaining knowledge of how the patients and their families had experienced the ICU stay was seen as instructive, giving the ICU nurses feedback on their own practice that could lead them to change how they performed their work. In addition, the intensive care nurses described how inspiring they found meeting former patients. Such meetings were described as bringing motivation and joy in their continuing work at the ICU.

6.2. The patients' perspective

The second article covers former patients' experiences, and the aim was to explore and describe what intensive care patients experience as limiting and strengthening throughout their illness trajectories to reveal their needs for support and follow-up.

A general structure of 'gaining strength through a caring interaction with others' was found. The structure was dependent on three constituents: 'feeling safe through a caring presence', 'Being seen and met as a unique person', and 'being supported to restore capacity'. The participants described the onset of the critical illness as being in an unpredictable and insecure situation where their familiar lifeworld was threatened. The three constituents were found to be crucial on their path through the different stages in their illness trajectory.

In 'feeling safe through a caring presence', the importance of the presence of both their family and the healthcare professionals was conveyed. Their family was described as their safe anchor whose presence could create a safe space for them in the unsafe situation in which they found themselves. The presence of the healthcare professionals was described with more variety: as both giving them safety but also the opposite, as the healthcare professionals could be present without giving them a feeling of safety. Throughout their illness trajectories, a variety in the significance of certain healthcare professionals was described. Meeting a special other who saw them and cared for them beyond what they expected was highlighted as meaningful and important for their recovery. The form of the caring presence giving them safety changed during their illness trajectory. The importance of support from their family and friends increased after hospital discharge; however, needing help and support could be experienced as challenging as the participants wanted to manage on their own longing for a normal everyday life.

In 'being seen and met as a unique person', the former patients conveyed stories of how important it was to be seen as themselves, with their individual qualities, despite being critically ill patients. Becoming critically ill and in need of intensive care treatment made the participants vulnerable, and being met with respect and taken seriously made their vulnerability easier to handle. The opposite, namely, not feeling respected or taken seriously, was highlighted as challenging and a cause of upset. Being able to show their personalities was described as important, and when they were not able to present themselves as they would in a usual situation, they valued being able to discuss everyday matters such as their faith or use humour in relation to the healthcare professionals. In addition, further on in their life after hospitalisation, receiving attention from and being cared for by family and friends were highlighted as significant. However, the participants also spoke about challenging situations when they met former acquaintances. Not wanting to be associated with the critical incident they had undergone made some take measures to avoid meeting former peripheral acquaintances.

In ‘being supported to restore capacity’, the importance of inner strength and external support was highlighted. The participants described being physically weakened and said that when they motivated themselves to exercise during recovery, personality traits such as being positive or stubborn were essential. In addition, receiving support from their family and social network was important when recovering. Receiving rehabilitation that suited their needs was talked about. However, the participants spoke of the lack of individually tailored programmes after discharge from hospital, such as offers they had received that did not match what they needed. Hence, they were dependent on their own knowledge and persistence when finding their way through the recovery process.

In addition to recovering physically, the participants spoke of their mental recovery. The critical illness and intensive care treatment had been traumatic experiences, and descriptions of needing to talk about these experiences were conveyed. Talking to family and friends were highlighted; however, the need to talk to professionals was also mentioned. Nevertheless, professional offers that could help with the mental problems suffered in the aftermath were lacking, and they talked about finding ways to handle these experiences on their own. The diaries some of the participants had received from the ICU were talked about in contradictory ways. For some, the diary was of great importance in how they coped after hospitalisation, while others described having a more strained relation to it and finding it hard to open and read. Either way, the diaries were described with emotion, regardless of whether they meant a lot to the participants or provoked disturbing feelings. During the restoration of capacity and return to their everyday lives, a flexibility regarding their work was appreciated. Being able to resume their activities of daily living was important. Nevertheless, participants also spoke of regaining their everyday lives in terms of implementing the newfound perspectives they had received from their experiences.

6.3. The family members' perspective

The third article addresses the family members' experiences of a close one's illness trajectory. The aim was to explore the experiences of family members after they had lived through a close one's illness trajectory starting with critical illness and intensive care treatment, throughout hospitalization and after their return home, and describe what was important and challenging for them during this time.

'Striving for a safe ground for themselves and their close one' was found to be the structure covering the participants' experiences. The structure consisted of three constituents: 'in need of care', 'to take on responsibility', and 'to create new understanding'. When their close one suddenly became critically ill and in need of intensive care treatment, family members' world was turned upside down, and they described needing care from those around them. However, while needing care from others, the family members simultaneously cared for their close one and took on a responsibility for making their situation as good as possible. During the illness trajectory, they did their utmost to ameliorate the situation of their close one. When taking on responsibility in the unknown situation, they needed to create a new understanding, and they described being dependent on knowledge about what they should do and how they should act.

In the first constituent, 'in need of care', how the healthcare professionals saw them and managed to create a safe space in the unsafe situation of their close one was important. Receiving individualised help was described, and the importance of being seen in terms of their own needs became apparent, including when it was absent. This was highlighted by a participant who conveyed the need for a conversation with the ICU nurses in a separate room, to be able to talk about her own situation and how she was doing, instead of only answering "I'm ok" when asked in the patient room. In addition to wanting to be seen according to one’s own needs, the participants talked about feelings of vulnerability. Being in a new and vulnerable situation, they described being dependent on how they were dealt with by healthcare professionals. In addition, the care they received from family and friends was highlighted as extremely important, making the social network an important part of handling the situation they were in.

In ‘to take on responsibility’, they described how they wanted to make the situation for their close one as good as possible. Taking on responsibility for both the safety of the patient and speaking on their behalf in the hospital was conveyed. When experiencing events with healthcare professionals that they felt gave their close one suboptimal treatment, some described a need to be there to watch over the patient and make sure they were well taken care of. Later in the illness trajectory, the responsibility they took on changed and they took charge of the whole situation of their close one. They did what they had to in order to make the best of the situation, meeting their close one’s needs. They took on a responsibility for everyday matters, such as exercise, medications, and facilitating visits to different outpatient clinics.

In the third constituent, ‘to create new understanding’, how they needed to gain knowledge and incorporate this into an understanding of the new and uncertain situation was conveyed. To effectively handle the situation, they needed knowledge covering the various situations they were in, such as how to behave within the hospital, information regarding their close one’s medical condition, and how they should behave in relation to their close one after discharge home. Not knowing, they did the best they could, supported by their family and friends, which was of great importance in their challenging situation. Overall, through the different phases of their close one’s illness trajectory, the participants strove to find a safe ground for themselves and for their close ones, and they implemented measures to make the best of the situation in which they found themselves.

6.4. Overall findings

The overall aim of this PhD study was to explore experiences of support and follow-up during and after critical illness and intensive care treatment from the perspectives of former patients, their family members, and intensive care nurses. The three complementing perspectives illuminate support and follow-up during and after critical illness; the patients have a perspective from within, being those experiencing the critical illness which threatens their life; the family members are the spectators on the outside of the life-threatening illness but also experiencing the threat of losing a close one and the known everyday life of their family; and the ICU nurses perform their job and encounter critically ill patients and their families.

Through the experiences of the various participants, both practical issues, including concrete measures such as information, patient diaries, and follow-up conversations, were illuminated, and humanising aspects, such as being seen as unique individuals and the importance of interpersonal relationships were revealed. The patients, family members, and ICU nurses all described, from their individual angles, a disruption of expected life for the patients and their family members due to a sudden and unexpected lifechanging event caused by critical illness that altered their expected future. For the patients and their family members, the critical illness threatened their known everyday life; in contrast, for the intensive care nurses this was 'just another day at the office'. The ICU nurses worked towards saving the patients' lives and implemented measures to help the patients recover in the best possible manner, such as writing in a diary, with the aim of mitigating some of the psychological challenges of having been through critical illness and intensive care treatment.

From the onset of the critical illness and throughout recovery, patients, their family members, and ICU nurses all implement measures to enhance recovery and foster a safe situation. An immanent finding was how family members took on a great deal of responsibility, during the hospitalisation and, in particular, after discharge home. This was an overall responsibility that covered both their critically ill close one, their extended family, and themselves. The ICU nurses, however, focused on their role within the follow-up, writing in the patients' diaries and performing follow-up conversations. However, our findings also reveal the significance of the interpersonal relationship the ICU nurses develop with the patients and their family. Through implementing individualised measures with each patient, the nurses strove to create meaning for the patient in their ongoing life. The patient and the family member likewise conveyed the importance of concrete measures, such as the diary or receiving information. However, they also emphasised the interpersonal relationships with family, friends, and healthcare professionals and the importance of being seen and met as a unique person with individual needs.

Suddenly becoming critically ill and treated in an ICU may be a lifechanging event. What permeates our findings was the importance of interpersonal relationships and the humanising aspects in each encounter between patients, their families, and ICU nurses. This importance was illuminated through experiences of both the presence and absence of these features. In addition to the relational and humanising aspects, the concrete measures of follow-up after intensive care treatment were conveyed. Living on after critical illness may be challenging, and the findings reveal how there is no ‘one size fits all’ – what came across as immanent was the need for follow-up offers individualised to each unique person’s needs. These topics are further explored in the discussion chapter.

7. Discussion

The discussion starts with some methodological considerations. Then, critical illness as a biographical disruption is discussed from the perspectives of all the participants, who, in their own way, work towards mending the disruption with the aim of making a more coherent life story for the patients. Furthermore, the relational aspect and intersubjective dimension are illuminated, and, finally, the discussion highlights the importance of the humanising aspect in support and follow-up after critical illness and intensive care treatment.

7.1. Methodological considerations

Trustworthiness in research relates to the research being presented in a way that makes readers believe and trust the findings. Within qualitative methods, there have been, and still are, debates about the most appropriate criteria for establishing trustworthiness (Morse, 2015; Polit & Beck, 2021; van Wijngaarden et al., 2017). In the mid-1980s, Lincoln and Guba (1985) introduced four criteria adapted to qualitative methods: credibility, transferability, dependability, and confirmability. Van Wijngaarden et al. (2017) highlighted other criteria suited for establishing trustworthiness in phenomenological research, and Giorgi (2009) also explicated ways of enhancing trustworthiness within his phenomenological method. Below, I use criteria from the above-mentioned authors and explicate those relevant to this study, by which I hope to highlight the strengths and limitations in an appropriate way.

Credibility, transferability, dependability, and confirmability

In this study, certain measures have been taken to enhance the credibility of the findings. Lincoln and Guba (1985, pp. 305–307) explicate triangulation as one way of enhancing the credibility of findings. In this study, three different perspectives on support and follow-up during and after intensive care treatment were investigated through the experiences of former patients, their family members, and intensive care nurses. However, the different perspectives were not used to confirm or negate one another; rather, they were seen as perspectives that could elaborate on and illuminate each other and the experiences of support and follow-up during and after critical illness and intensive care treatment. Another notion of enhancing credibility is peer debriefing (Lincoln & Guba, 1985, pp. 308–309) or what Giorgi (2009, p. 134) calls ‘the critical other’. Throughout this PhD study, the project as a whole and the three articles have been discussed in various fora, such as the different research groups I have attended. This has given me valuable perspectives and increased my consciousness when having to explain the choices made. In addition, my supervisors have followed the project closely, read the interview transcripts, and discussed the analysis frequently when I was analysing data writing the articles. In the period in which I analysed the interview transcripts, in particular, and was embraced by the participants’ voices, the opportunity to talk about my thoughts was valuable. In the analysis, it helped in the process of trying out free imaginative variations when working towards the constituents and the general structure (Giorgi, 2009, p. 132).

Transferability relates to the possibility of transferring the results to contexts other than the one being researched. Lincoln and Guba (1985, p. 316) highlighted the importance of what they called ‘thick descriptions’, explicating the context of the research and giving detailed descriptions. I have striven to give thorough descriptions of the various parts of the project. The chapter addressing methodology and overall design presents descriptions of the participants and their demographic variables so readers can more easily assess the transferability to their own context.

In all three studies, we have described the gender composition and explicated the participants’ age and other demographic variables. The intensive care nurses participating had a mean age of approximately 50 years and had spent 13, 16 and 22 years, respectively, working in the ICU, indicating that we have included nurses with extensive experience. For the former patients, we also collected journal data to be able to describe factors such as reason for admittance and severity of disease. In Norway, the ICUs report to the Norwegian Intensive Care and Pandemic Registry so we were able to compare our participant data with the ICU population in Norway. Numbers from this registry showed that the gender distribution in Norwegian ICU patients is approximately 40% women and 60% men (Buanes et al., 2022, p. 7), similar to the participants in our study. The median age of patients admitted to Norwegian ICUs in 2021 was 67.6 years (Buanes et al., 2022, p. 7), while that of the former patients participating in our study was 54. This may indicate that we received other perspectives than those of the general ICU population, as our participants were younger. However, the SAPS II score indicating severity of disease at ICU admittance was 35.5 in this study, equivalent to the number from Norwegian ICUs in 2021 (Buanes et al., 2022, p. 15). The 2021 report from the Norwegian Intensive Care and Pandemic Registry reports on a year in the middle of the COVID-19 pandemic. However, comparison with the pre-pandemic report from 2019 shows that a similar number was reported (Buanes et al., 2020). For the family members, data regarding four participants' age were unfortunately lost. However, other background information, such as their relation to the patient, whether they lived with the patient, and additional information regarding their situation, has been reported.

In addition to describing background data to assess transferability, trustworthiness is assessed based on transparency of the research done. In the articles and throughout this thesis, I have tried to be transparent and describe processes in detail to show the reader how and why I came to the conclusions that I do. I now describe in more detail some of the choices made and how these choices have impacted my findings.

In the first article, we conducted focus group interviews. The use of phenomenological methods in focus group interviews has been debated. However, Bradbury-Jones et al. (2009) highlighted that group discussions about a phenomenon can open new perspectives and encourage discussions; hence, we claim that seeking intensive care nurses' experiences of follow-up offers through focus group interviews was an appropriate method as the phenomenon of follow-up was examined. The nurse-led follow-up conducted in Norwegian ICUs is informed by the recommendations published about a decade ago (Holme et al., 2020); however, these were recommendations only, and each ICU has had the opportunity to shape the practice of follow-up. Through focus group interviews, we then aimed to elicit descriptions of how the follow-up within each ICU was informed and unfolded. An important issue to note is that writing in diaries was a large part of the follow-up in the ICUs. This may have contributed to the extensive focus on diaries in the interviews, and other aspects of follow-up of patients and their family members may have been left out. In addition, as writing patient diaries is voluntarily the offer is based on the enthusiasm and goodwill of the nurses.

To stimulate and facilitate discussions about follow-up, we sought to include participants who had an interest in and experience of the follow-up programmes conducted by the ICUs included. However, we encouraged participants with different opinions and experiences to ensure fruitful discussions and exchanges of opinions in the interviews. Nevertheless, the participants in each interview were from the same ICU, a situation which might have both pros and cons. The participants knew one another, they came from the same culture in the same ICU, and they had worked with the same follow-up programme. In this situation, participants might have followed one line, and some might have been silent about their experiences due to social factors and having to continue the relationship with the other participants after the interview. On the other hand, being colleagues and knowing the other participants might have created a safe space and collegial setting in which the participants felt that they could discuss their ideas and experiences openly.

Stewart et al. (2007) described three categories that may affect group dynamics: intrapersonal and individual differences, interpersonal factors, and environmental factors. We wanted participants with various enthusiasms, interests, and responsibilities for writing diaries and performing follow-up. However, we may very well have recruited participants with an engagement and interest in the follow-up, which might have affected our findings. The intensive care nurses participating had different personalities: some were very outspoken while others were more reserved. Other variables affecting the interview might have been the age and experience of the participating nurses. In some interviews, there was a variety of age and experience while in others the age and experience were more homogenous. The culture and work environment in the ICU might also have affected the group dynamic. One of the interviews was performed in an ICU where I was familiar with some of the intensive care nurses participating. I have not worked in this particular ICU, but in another ICU in the same hospital. I tried to be and act uniformly in each interview, regardless of my knowledge of some of the participants in one interview. Nevertheless, I cannot guarantee that this situation did not influence me or the participants in any way. However, the topic of the interview was one to which the participants related in their professional roles as intensive care nurses working in the ICU, and our knowledge of one another might not have been as influential as if it had been a personal topic.

In the individual interviews, the contact persons in the ICUs were in charge of sending out invitation letters to eligible participants. To keep registration to a minimum, I had no knowledge of the participants until they contacted me. In this way, we tried to minimise the risk of anyone feeling pressurised into participating. Equally, however, I have no overview over how many information letters were sent out to eligible participants. In addition, we asked participants to be interviewed for an estimated 90–120 minutes, which may be quite a strain. It is debatable whether participants who had experienced extensive problems after the critical illness rejected the invitation for this reason. Nevertheless, I experienced a great variety in the participants' stories.

Another important consideration to make regards the motivation of participants to be interviewed. We asked for their experiences during and after they or their close ones had been critically ill and treated in an ICU, and during the interview I tried to be conscious of asking for both positive and challenging experiences. However, across the interviews the participants expressed great gratitude to the ICU where they had been treated for saving their lives, and they conveyed a desire to participate due to gratitude and a wish to give something back. Nevertheless, some participants had had traumatic and troubling experiences and conveyed that they wanted to participate to prevent the things that had happened to them from happening to others.

Openness, meaning and essence

Van Wijngaarden et al. (2017) highlight openness, meaning and essence as appropriate criteria for establishing trustworthiness in phenomenological research. In this section, I discuss these criteria in relation to the PhD study. Within openness, self-reflection and the researcher's openness to being surprised are highlighted. During this research process, I have tried to be aware of my preunderstandings, for example, by writing down my knowledge and preunderstanding when embarking on this research.

During the interviews with the former patients and their family members, I had a preunderstanding of the setting that the participants had undergone, and they were informed through the information letter and at the start of the interview that I was an intensive care nurse. This created a common foundation for the context of the ICU environment, and I used this knowledge during the interviews to ask about the setting that the participants talked about. Throughout this study, I have thought that getting the participants to describe their everyday life throughout their illness trajectory would reveal what was important for them, and how, so this could point towards what kind of support and follow-up they would benefit from. Questions regarding their experiences of support and follow-up were also asked; however, I tried to elicit descriptions of the participants experiences without influencing or steering what the participants spoke about.

An example is the diary some of the participants received at the hospital. The diary may be a book the participants use in their handling of the situation afterwards, but I deliberately did not ask about it before they themselves told me about it as I thought that they themselves would tell me about it if it were important. In addition, not all patients receive a diary in the ICU, and when I informed intensive care nurses about the study in the ICUs before start-up, some were concerned about me revealing that some patients had received one and others had not. They were worried that if I asked former patients about a diary and they had not received one, they would start to wonder why. On one occasion, however, a participant did not mention it, but her husband highlighted how much he thought it meant to her. I do not know why she did not tell me about it: if she did not want to, just forgot, or did not think it was important. I missed an opportunity to hear about her experience with the diary, but at the same time I might have protected others from wondering why they did not receive one.

Even though I tried to be open, being an intensive care nurse and using my knowledge during the interviews may have made me lead the interview in one direction and not ask for elaborations where another researcher without that background could have asked for more detail. However, I tried to be aware of not letting my thoughts and knowledge steer the interviews; rather, I listened carefully to what the participants told me and ask questions to open up what their experiences meant to them. Nevertheless, I came across situations in which 'Stine, the researcher' was put aside, and I became 'Stine, the intensive care nurse'. An example of this was when a participant told me about an event that he had experienced as difficult and I answered him as a nurse would, trying to explain and make him comfortable, instead of asking more about his experience without explaining. Still, during the interviews, I experienced being in a space where the participants felt confidence in me, and several told me that it had been an ‘nice experience’ to be interviewed and that I came across as trustworthy. I can only see my side of the interview setting, but by being open and aware of what was at stake, such as the power relation and the ethical dimension (asking about experiences which might have affected the participants a great deal), I did my best to make it a situation in which the participants were well taken care of while meeting my aim of gaining rich descriptions of their lifeworld.

Openness was also important during the process of analysing. I have analysed three focus group interviews and 20 individual interviews during this PhD study, and I have tried to remain constantly aware of being open to what appears so I do not just find what I was looking for. As noted in the methodology, Dahlberg and Dahlberg (2019) emphasised the importance of staying open for as long as one can manage and working on opening up to what appears without coming to a conclusion to fast.

One example of how my preunderstanding changed during this time concerns the fact that I thought the patients and their family members should receive follow-up from the ICU. However, I found that both patients and their family members want support and follow-up that is tailored towards their individual needs, and who performs the follow-up depends more to what those needs are; thus, it does not always have to be the ICU. In addition, the importance of the relational and intersubjective aspect and how much it affects support and follow-up throughout the illness trajectory has surprised me. These aspects are discussed in the following sections.

7.2. Critical illness as potential disruption of the family’s biography

Critical illness strikes like lightning from a clear sky: patients and their family members suddenly find themselves in uncertainty and chaos and in need of intensive care treatment. Critical illness can be seen as a biographical disruption, which emphasises how the fundamental structures of a person’s life becomes disrupted when they experience critical illness and intensive care treatment (Tembo, 2017). Biographical disruption sees life as a biography, where the present draws on the past and is lived towards the future. The disruption, like the critical illness, may cause a breach in the person’s biography. For the patient, this breach may be caused by the critical illness itself, the treatments, such as sedatives or being intubated, or by psychosocial factors, such as psychological problems or cognitive problems, following the critical illness (Tembo, 2017). For the family member, who is also embraced in this concept, the biographical disruption is a breach of expected family life. Hence, the critical illness may cause a biographical disruption to both the patients and their family members.

Starting with Michael Bury's description of 'chronic illness as "biographical disruption"' in 1982 (Williams, 2000, p. 40), the term has been used to describe illness experiences in both research on chronic illness (Bury, 1982; Williams, 2000) and, more recently, critical illness (Tembo, 2017; Tembo et al., 2012). Bury (1982, p. 169) stated that 'the structures of everyday life and the forms of knowledge which underpin them' is disrupted in illness. He further highlighted the need for chronically ill individuals to re-examine their plans for the future and that illness may cause a dependency on others, such as family and social network (Bury, 1982).

Biographical disruption is often considered in relation to physical illness, and Engman (2019) discusses biographical disruption and embodiment: how one's embodied being is altered due to physical illness, ultimately altering one's habitual behaviour in daily life. In our study, the patients experienced a physical illness that threatened their known embodied being and world. In addition to the critical illness threatening the patient's life and function, the intensive care treatment, with advanced technology and medical treatments, inflicts enormous stress on the patient. As noted in the background section, symptoms of PICS may persist in a considerable number of patients (Vrettou et al., 2022), and one may ask if this can be seen in relation to biographical disruption: the life-threatening illness and strenuous treatments place an immense burden on the patients, breaking their habitual being, causing a breach in their expected life history that they do not manage to overcome, and ending in a biographical disruption.

One of our main findings from the interviews with former patients was how they needed support to restore capacity during their illness trajectory. They described how their being was different from before the illness, both physically and mentally. Engman (2019) highlighted that it is not illness per se that causes a biographical disruption, but rather the ability to live and act in accordance with one's embodied structures: to be and act in familiar ways in one's familiar world. This is in line with our findings, where the participants described physical, psychological, and cognitive deficits influencing their possibility to function as before after waking up and slowly recovering from the critical illness.

A sudden critical illness may cause a biographical disruption as it robs the patient of the possibility to recall a coherent past. It is well known that many patients after ICU discharge can experience symptoms of PICS (Honarmand et al., 2020; Huang et al., 2016; Jackson et al., 2014). In our study, we found how both family members and ICU nurses implemented measures to lessen the burden on critically ill and comatose patients. The family members were at their close one’s side, helping with the challenges that occurred. In addition, the family members were there to talk about what had happened during the period of which the patient had little recollection, helping them make a coherent life story in the aftermath of the hospitalisation. The ICU nurses made efforts through the diary and follow-up conversations to help the patients become aware of their own life biography during the period they had been sedated and critically ill.

Writing diaries for intensive care patients has been much debated over the past decade. As noted in the background section, findings have varied on the effect of diaries on measurable outcomes such as depression, anxiety, and PTSD (Gazzato et al., 2022; Ullman et al., 2014). The same findings has been made for other follow-up measures, such as various kinds of follow-up clinics (Schofield-Robinson et al., 2018). Nevertheless, even though there are conflicting results on statistically significant outcomes on measurable symptoms and diagnoses, an extensive body of research has shown how valuable both diaries and follow-up clinics may be to individual patients (Pattison et al., 2019; Strandberg et al., 2018). Some have also shown an effect on measurable outcomes such as quality of life, anxiety and depression (McIlroy et al., 2019).

In our study, we found that measures were implemented with the aim of helping patients with the problems they might experience after critical illness and intensive care treatment. In the focus group interviews with intensive care nurses, participants described an awareness of the importance of giving patients a chance to have a coherent life story and implemented measures such as writing diaries and inviting patients back to the ICU to talk about their experiences. Patients are critically ill, often sedated, and not able to show or articulate how their lifeworld is at the time in question. The nurses, however, being close to the patients’ existence and having their life in their hands, wanted to give the patients a chance to retrospectively learn about some of the things that had affected them during the critical illness. With their own lifeworld as a starting point, the nurses tried to create meaning for the patients. However, how the patients experience their lifeworld is uncertain; the nurses implement measures based on their own preconceptions. For example, they write content in the diary that they think that the patients would want to know in retrospect.

Research shows contradictory effects of diaries on PICS symptoms (Ewens et al., 2014; Gazzato et al., 2022; Ullman et al., 2014); however, patients have reported that they valued diaries and found that a diary might give them a better understanding of a time of which remember little (Strandberg et al., 2018). In our study, the patients conveyed varying feelings towards the diary: for some it seemed to be the most important book they owned; others talked about it as ‘just a book’ they had flickered through; while others talked about how they had put it away and were not sure if they could manage to open it. This finding is supported by Pattison et al. (2019), who showed how the diary gave emotional support in the aftermath of an ICU stay even though some participants in their research also reported wanting to move on and not be reminded of the time they had spent in the ICU. One of our participants talked about being all alone when looking at the diary and experiencing it as extremely traumatic and not helpful. This is important to consider when delivering the diaries and conducting follow-up from the ICU and demands an awareness of patients’ potential conflicted experiences towards the diary.

Most of the Norwegian ICUs that responded in the study by Moi et al. (2018) reported that the diary was handed over as part of the follow-up conversation or when the patient was transferred to another ward. However, the reported numbers show that these situation were mentioned in approximately 65% of the replies, leaving 35% not reported on. The national recommendations for diaries in Norwegian ICUs point out that the handover should be adjusted to each individual patient and should take place during a follow-up consultation (Holme et al., 2020). Oslo University Hospital explicitly states in its guidelines for writing diaries for ICU patients that the diary should not be sent to the patients themselves, but, if that happens, it has to be in accordance with the patient’s wishes and that a nurse must simultaneously have a follow-up conversation with the patient by telephone (Oslo

Universitetssykehus, 2021). This seems like a reasonable practice as, even though the patients want the diary, it may provoke surprisingly strong and traumatic feelings.

For the ICU nurses, writing diaries was an important part of the follow-up while for the patients, the diary was just one of many things helping them in the aftermath of the critical illness. They talked more about receiving support to recover and continue their lives than looking back towards what had happened. This may show the importance of individualising the measures to each patient or family member and finding ways that may help each person meet their specific challenges in their ongoing life.

ICU survivorship takes into account the process of recovering, and it may be seen as a transitional stage. Drew Leder (2019, pp. 173–186) has highlighted 're-possibilizing the world' as recovery after serious illness and names three movements in recovery: 'impossibility' to 'I'm-possibility' to 'I am possibility'. However, explaining that these movements are not stages that unfold in sequence but movements that a person may experience to varying degrees, according to their condition and the situation.

In the first movement, 'impossibility', one may experience impossibility due to the critical illness which suddenly struck. Instead of being up and about, one is tied to a bed and unable to move. However, the illness may not only affect the bodily functions; it may also affect and threaten one's identity (Leder, 2019, pp. 175–178), causing a threat to one's existential being. This suggestion is in line with the proposed definition of survivorship, which incorporates how critical illness may cause 'changes in self, biography and identity' (Kean et al., 2021, p. 2606).

In the second movement, 'I'm possibility', the recovery process has begun, and when recovering one may reclaim one's stance and agency (Leder, 2019, pp. 178–181). Leder (2019) highlights how 're-possibilizing' is a social task and pointed to the importance of support from healthcare professionals, family, and friends when patients are recovering from critical illness, which is strongly prevalent in the phase of 'I'm possibility'. In addition, Leder (2019, pp. 180–181) pointed to how patients in the 'I'm possibility' phase often incorporate the new challenges or limitations into their ongoing life, also explicated by our participants as an important aspect when recovering.

In the last movement, ‘I am’ possibility’, one has the experience of oneself as more than just an embodied being, which can be a way of transcending the body’s limitations (Leder, 2019, pp. 182–184). He highlighted that this may be religious or spiritual; however, it does not have to be. It is a feeling of an ‘I’am-ness’ or awareness that one is something more than just one’s broken body (Leder, 2019, p. 183).

The movement explicated by Leder (2019) as a way of re-possibilizing oneself after serious illness or injury is also touched upon by Galvin and Todres (2013), albeit in a slightly different way. In their lifeworld-led approach, Galvin and Todres (2013) outlined directions for caring in well-being and suffering. Within the lifeworld constituent ‘identity’, they describe how one may alternate between ‘I can’ (pp. 90–91) in a mobility dimension to ‘I am unable’ (pp. 108-109) in the suffering dimension. In ‘I am unable’, Galvin and Todres (2013) highlighted how one may experience the lack of ability, which gives resonance to some of our participants’ descriptions of recovering and is supported in Leder’s (2019) notion of ‘impossibility’. For our participants, not being able to do what they previously could demanded both inner strength and support from others so they could go from ‘I am unable’ to the dimension of ‘I can’. Our findings revealed how the participants worked towards regaining their function and becoming familiar with their new situation, which may be seen as moving from ‘I am unable’ towards ‘I can’, in line with Leder’s (2019) notion of ‘I’m possibility’.

Within intensive care, ‘ICU survivorship’ has been used as a term covering the changes after critical illness and intensive care treatment. ICU survivorship holds the perspective discussed above, as it embraces incorporation of the changes caused by the critical illness to the patient’s self, biography, and identity (Kean et al., 2021). Survivorship is not, however, a life-long state: as Kean et al. (2021, p. 2606) concluded, ‘There is life after survivorship’.

An immanent finding from the interviews with the family members is how they strove to create a safe ground for their close one. The family members in our study described taking on great responsibility for their critically ill close one, both during and after hospitalisation, in line with the findings of a recent systematic review on patients’ and families’ experiences after intensive care (Kean et al., 2021). Being family to a critically ill patient in the ICU and onwards during the recovery trajectory might be a stressful and challenging situation, and caregiver burden has been highlighted previously in the background section. Caregiver burden is prevalent in previous research (Beesley et al., 2020; McPeake et al., 2016; van Beusekom et al., 2016; van den Born-van Zanten et al., 2016), and in our study, the family members highlighted experiencing a stressful situation that could lead to feelings of vulnerability. Experiencing care and support from healthcare professionals or their social network in this situation was of great importance. This finding is supported by a recent international study conducted in the USA, UK, and Australia (Sevin et al., 2021), which reported that family caregivers experienced unmet needs, both emotional and practical, during the illness trajectory of their loved one. Miring-Nordstraa et al. (2023) also highlighted family members experiences through patients' illness trajectory, concluding that there is a lack of guidance of family members during transitions from ICU and onwards through hospitalisation and back home. Watland et al. (2023) has recently tried to accommodate the lack of guidance through the illness trajectory, when developing a model for structuring and individualising follow-up of critically ill patients' family caregivers. The authors suggest 'The caregiver pathway', where family caregivers are offered a digital tool to map needs and challenges, followed by conversation with an ICU nurse before discharge and after coming home, in addition to written information and support (Watland, 2023). 'The caregiver pathway' might be one step towards accommodate the findings from our study that point to a lack of individualised care pathways for family members, and it will be interesting to follow future studies testing the model.

It is interesting to look at the strain, caregiver burden, and unmet needs in relation to biographical disruption. Our main finding was how the family members strove to create a safe ground for both themselves and their close one. The responsibility they took on, helping and supporting the patient throughout the illness trajectory, might be seen as a way of mending the biographical disruption for the patient and reducing the breach in their close ones former and present habitual being. Engman (2019) explicated the connection between embodiment and biographical disruption and how, in illness, one loses one's possibility to enact one's known embodied being in everyday life. As patients are no longer able to enact as they usually would in their normal everyday life, their family members facilitate or take over to mend the disruption. In addition, I argue that this may be what happens to the family member. However, it is not their own illness but, rather, the strain of the whole situation – having a loved one life-threateningly ill and recovering into a new everyday life that threatens the family's everyday life and expected future – that causes psychological strain and a biographical disruption.

However, while experiencing great strain, the patients and their family members conveyed aspects which were of great importance, such as the intersubjective and relational aspects that could relieve the critical situation and make them feel safer despite it.

7.3. Intersubjectivity in caring healthcare encounters

When critical illness occurred, the lifeworld of both the patients and their family members was thrown into chaos, fear, and uncertainty. Within the ICU setting, the intensive care personnel were in charge, with the intensive care nurses continuously by the patient's bedside relating to both the patient and their family members. In the ICU, the patient's and their family's existence is dependent on the intensive care nurses, both literally and metaphorically. The safety the intensive care nurses might create in this uncertain situation during the initial phase in the hospital was highlighted by both the patients and their family members and supported by several recent reviews (Carruthers et al., 2018; Danielis et al., 2020). However, also clearly prevalent in the reviews is how the patients perceive that negative and challenging experiences leave them in vulnerable situations. These are also findings which are recognisable within our study.

Both the patients and their family members described how the presence of the ICU nurses could evoke feelings of safety despite the critical situation; however, this was not always the case. Some patients described ICU nurses who were present by the side of the bed but did not convey a feeling of safety. There seemed to be a quality to the intersubjective dimension between the people encountering each other in the intensive care setting that could either create a safe caring space or not. This might be an example of what Benner and Wrubel (1989) called 'the ability to presence oneself' (p. 13): being in a shared space where understanding and openness to the other's situation is prevalent. Both the former patients and the family members described situations where they experienced a safe space but also situations where they longed for, and needed, such a space. For example, a patient remembered how terrified he was before being intubated as he felt that no one was supporting or comforting him. These findings support the notion that 'the fundamental characteristics of caring become visible when they are absent' (Arman et al., 2015, p. 293), which has been illuminated through the variations in our findings, pointing to the importance of experiencing care through a safe space. In the most dramatic period of critical illness and intensive care treatment, this is important to consider. The main focus is on saving the person's life, but being aware of the importance of being present, or 'presencing oneself', might be a way of reducing the traumatic experiences of being critically ill and treated in an ICU.

The relationship between the people encountering each other was an important finding in our study. In a meta-synthesis of phenomenological research considering the nurse–patient relationship using Heidegger and the notion of 'Being–with', Gullick et al. (2020) showed how nursing may be in what they call a 'they-mode' (an inauthentic mode) or a 'self-mode' (an authentic mode). The authors explicated how the different modes may influence the ability to be present with an increased feasibility for connection to the patients. The 'they-mode' is characterised by a technical being, where nurses perform tasks, and there is a distance between the nurse and the patient. In our findings, both patients and their family members describe experiencing healthcare professionals who were present, performing technical nursing care, but without really *being there* and giving them a feeling of safety. This may be what Gullick et al. (2020) call 'existential abandonment', one of the areas included in the 'they-mode'. The nurses are present in an inauthentic way, without the possibility of giving the patients they encounter sincere care. In contrast to the 'they-mode', nurses in the 'self-mode' are present in an authentic way, being open and seeking connection with the patients (Gullick et al., 2020).

A prevalent finding in our study was how participants spoke of how some persons touched them or saw them as unique individuals. The ICU nurses highlighted how some patients touched them more profoundly, causing them to make greater efforts when writing in their diaries or to seek information after such patients had been transferred to the general ward to find out how they were recovering. The patients and family members likewise spoke about connecting more to some of the healthcare professionals they encountered during their illness trajectory: some still vividly talked about some of the healthcare professionals during the interviews, expressing how much a specific nurse or physician had meant to them during their hospitalisation. One may wonder if these are examples of encounters between the ICU nurses, patients, and families where the nurses are in the 'self-mode' – being openly and sincerely present. The importance of encountering healthcare professionals that can create a safe caring space despite a serious and life-threatening situation is an important finding in this study; hence, one may argue for the importance of healthcare professionals being aware of their 'being' when encountering patients and their family members, both during the most critical times in the ICU and in the continuing trajectory.

Galvin and Todres (2013) highlighted how we are located in an intersubjective space with others and that through shared meanings, we are part of a relational world (p. 28). However, there is more to the intersubjective dimension than people encountering each other. An interesting finding from the focus group interviews is how important the relation that occurred between the intensive care nurses, patients, and family members seemed to be for the follow-up measures performed by the intensive care nurses. The ICU nurses described how they made an extra effort for some patients, especially when they had a good relationship with the patient or their family. Nursing is based on a caring practice, and, as explicated in the background section, nursing theories have been developed to describe and guide nursing practice, from Nightingale in the 18th century until today. However, nursing theories have been accused of being too distant from contemporary nursing practice, and new theoretical frameworks have been suggested for practical nursing as it unfolds today (Mudd et al., 2020).

About a decade ago, Kitson et al. (2014) highlighted how it seemed that something was amiss with nursing care, proposing the Fundamentals of Care (FoC) framework. The framework takes account of a patient's physical, psychosocial, and relational needs in routines and everyday life, which 'form the bedrock of any caring encounter' (Kitson, 2018, p. 100). At the core of the FoC lies the establishing of a relationship between the patient and the nurse. This relationship is the foundation for the fundamentals of care, in which there must be trust, undivided attention to the patient, anticipation of needs, and learning the patient's uniqueness to be able to act in an appropriate way (Kitson, 2018). These are factors both patients and their family members touched upon as important in our findings. Being seen as a unique individual by healthcare professionals was of great importance. The FoC framework is meant to be closer to nursing practice than previous ones. Inherent in this framework is a focus on who the nurse has in front of them and the ability to be emphatic and establish meaningful relationships (Kitson et al., 2013, p. 9), which was illuminated as highly important in our findings.

Being seen and dealt with as a unique person with individual needs was described in various ways by our participants. Their descriptions gave both examples of feeling seen and dealt with in terms of their needs and of the opposite. Heidi Honig Spring's (2022) autobiography tells the story of a hard fight to recover after being run over by a car when she was out for a jog. As a trauma patient, she described her experiences from within the hospital walls, and one of the things she highlighted in her book is all the various ways in which different healthcare professionals encountered her. In one section, she wrote about an encounter with a doctor who sat down and asked her how she was. Positively surprised, she started telling the doctor how much she appreciated her interest. She told about all the various encounters she had had with healthcare professionals who did not seem to be interested in her: healthcare professionals who did not say "hello, how are you" when they entered her room and healthcare professionals who just stopped by her room to give her information, deliver their planned message, and be on their way without conveying any interest in her (Spring, 2022, pp. 88–91). These experiences give resonance to the findings from patients and family members and how they described the importance of being seen and considered as valuable human beings.

7.4. Humanising support and follow-up

The discussion so far has addressed how critical illness may be a biographical disruption, threatening the everyday life of both the patient and the patient's family. In the insecure and challenging situation generated by becoming critically ill, a caring intersubjective space created by healthcare professionals is of vital importance. Samuel Morris Brown, the physician who founded the Center for Humanising Care in the USA entitled his book 'Through the valley of shadows' (Brown, 2016). In it, he highlights how ICU treatment generally gives high-quality medical care but often leaves patients and families 'utterly and even cruelly unsupported as human beings' (p. 5). He calls upon the critical care community to work towards humanising ICU and making a better life for those who survive (p. 157).

In the background section, I have tried to give a short summary of some of the areas affected by critical illness and intensive care treatment. No illness trajectory is the same, and there is a plethora of ways in which each person may experience or be affected by critical illness and intensive care treatments; hence, being considered in their own right and seen in terms of their own unique needs seems, as we find in our study, crucial. As noted, the terms PICS and ICU survivorship have been increasingly used the last decade, increasing awareness about the human lives going through the critical illness and intensive care trajectory. This awareness has led to a development of intensive care treatments that aim at saving the life of the critically ill or injured patient in the ICU and also 'saving' their everyday life after the critical illness and intensive care treatment (Mart et al., 2021). Humanising ICU has been an increasingly used term for making the technical environment and advanced medical treatment more human within the ICU, and, on the basis of our findings, we suggest using the term 'humanising' in reference to support and follow-up as well. The support and follow-up after the critical illness and intensive care treatment, and throughout the illness trajectory, should be made more human in that it should take each person's unique being into consideration.

In their book 'Caring and well-being – A lifeworld approach', Galvin and Todres (2013) argued that something is missing in our current healthcare system. They explicated that care is organised and practised in a technical way in which efficiency and outcome measures seem to be the most important things (Galvin & Todres, 2013). In Norway, the government published a National Health and Hospital Plan 2020-2023 (National Health and Hospital Plan, 2019), in which they highlight what they call 'the patient's healthcare', emphasising the importance of patients being active participants in their own healthcare and experiencing coherence across different services. Those encountering the chain of emergency care should find it a coherent experience, and patients' information should follow their illness trajectory (National Health and Hospital Plan, 2019). This seems like a good plan, even though one of our main findings was that patients did not experience a coherent follow-up with individualised information; that is – healthcare that manages to 'see' each individual patient's needs and accommodate them was lacking.

A humanising follow-up of ICU patients should consider each individual's unique being to accommodate the specific needs of each person, as the needs of former intensive care patients may vary tremendously. As briefly noted in the background section, the humanisation of the ICU has received increasing attention. Moreover, in a recent scoping review, Kvande et al. (2022) highlighted that research on humanising ICU has increased over the last decade, with studies from Spain and Brazil being dominant. There seems, however, to be a lack of consensus as to what ‘humanising care’ comprises. Humanising care is illuminated as ‘holistic care of the patient’, ‘a general attitude of professionals towards the patient’, and ‘an organisational trait towards all subjects of the healthcare system’ (Kvande et al., 2022, p. 500). The focus seems to be on the system, attitudes, or traits of healthcare professionals or the healthcare system. When elaborating on humanisation and outlining their conceptual framework for humanising care, Galvin and Todres (2013) described dimensions of humanisation, but instead of focusing on how the system can be humanising, they asked ‘what makes people feel more human in situation in which they receive care?’ (Galvin & Todres, 2013, p. 9). When describing what it means to be human, they explicated eight dimensions – the qualities that make us human beings – through forms of humanisation and de-humanisation (Galvin & Todres, 2013). However, this is not a dichotomous separation, but, rather, dimensions in continuous interaction located on a continuum.

The eight forms of humanisation/dehumanisation are insiderness/objectification, agency/passivity, uniqueness/homogenisation, togetherness/isolation, sense-making/loss of meaning, personal journey/loss of personal journey, sense of place/dislocation and embodiment/reductionist body (Galvin & Todres, 2013, p. 11). Some of these dimensions are discussed below in relation to our findings with suggestions of how they may inform working towards a humanising support and follow-up.

In the first dimension, insiderness and objectification, the insider perspective of what it means to be human is presented. Our findings show the importance of being taken into consideration and receiving an offer that fits one’s needs. Not receiving any offer of rehabilitation or receiving an offer that was not feasible was prevalent in our findings, in line with a recent review that showed how care pathways do not take into account the individual patient’s survivorship needs (Kean et al., 2021, p. 2599). There needs to be a system that manages to take each individual patient’s needs into account to better tailor a follow-up offer. However, this is not an easy task as there is no follow-up in place for every patient recovering from critical illness. As noted, some Norwegian ICUs have a follow-up offer, but no national recommendations or guidelines exist, in contrast to, for example, the existence of guidelines for rehabilitation after critical illness in adults in the UK (NICE, 2017).

The next dimension, agency and passivity, concerns a person's ability to act and achieve something, have vitality, and be able to do. This dimension is closely linked to dignity, in which the human sense of personhood is connected to the ability to act and achieve. The opposite of agency is passivity: when one is not able to act or achieve, one may be without voice and have to surrender to experts who make choices for you. An interesting example from our study was that one of the participants talked about how he had not received any follow-up offers, emphasising that neither he nor his wife had been capable of asking for help in the period following hospital discharge. This is important to consider, as increasing user involvement has been on the agenda in recent decades. It is important to give patients and family members a say and a voice; however, it is also important to not forget that going through illness may also cause conditions or challenges that require others to actively propose an offer as the patients or family members may not be capable of initiating it themselves.

In uniqueness and homogenisation, how every human is unique, whatever their attributes or characteristics, is explicated. Every human is always more than the sum of their parts, and every human has their own unique individuality. In homogenisation, everyone is equal, and individual uniqueness is lost. The aim of follow-up offers should be to take each person into account and tailor an appropriate follow-up. The various follow-up initiatives may cause someone in need to miss out on the help they need. Of course, the critically ill population is a heterogenous group of people with varying needs, but some sort of follow-up offer where former patients are contacted could be beneficial and enable patients or family members in need of help who may be missed in today's system to be caught.

Togetherness and isolation point to an intersubjective dimension, namely, that every human needs to belong somewhere and to someone. In togetherness, interaction with others is emphasised. Humans are dependent on others, and in our relation to others we are connected to other humans, for example, in a community. In isolation, however, humans are alone and separated from others. A feeling of alienation may lie in this state: one may feel aloneness and become isolated, for example, in dehumanised care. The importance of togetherness is highly prevalent in our findings as ICU nurses, patients, and their family members all spoke of how important the relational dimension was.

In this discussion, I have highlighted essential findings across all three articles and suggested a humanising support and follow-up that take the whole person into account. Throughout the illness trajectory, the encounters between unique persons stand out, and in the challenging and vulnerable situation in which patients and family members suddenly find themselves, how healthcare professionals act and interact with them is of vital importance.

8. Conclusions and implications for practice

The three different perspectives on support and follow-up during and after critical illness and intensive care treatment have illuminated the importance of the humanising aspect through critical illness and onwards to a new everyday life. The critical illness may cause a biographical disruption for patients and their family members, that is, a disruption of their expected life story. Within this situation, the importance of the intersubjective and relational dimensions come to the fore. ICU nurses implement different measures, such as writing diaries or organising follow-up visits to the ICU, which might be seen as means to mend the patients' and their family members' biographical disruption. The survivorship of patients – how they manage in their continuing life – may be influenced by the support and follow-up they receive. However, the measures, such as the information they receive, the diary, or the offer of psychological, physical, or cognitive rehabilitation, need to be customised to each individual person's needs and wishes. This holds true for their family members, who take on a great deal of responsibility throughout the illness trajectory of their loved one without receiving the knowledge they need. Family members highlighted this situation, in particular, when they became informal caregivers at home as their loved one was recovering after the critical illness.

Ensuring patients and family members receive humanising support and follow-up that takes their individual being into account may promote each patient's possibility of survivorship after critical illness and that each family member will be supported and acquire the knowledge they need in their new caregiving role at home. Certain findings from this study need to be taken into consideration in relation to support and follow-up after critical illness and intensive care treatment.

- Intensive care nurses want to help patients in their ongoing life after an ICU stay and write personalised diaries aiming at filling the gaps from the intensive care treatment.
- Healthcare professionals need to consider the importance of the relational and intersubjective dimension when encountering patients and their family members.
- Patients and their family members need to be seen and dealt with as unique persons with individual needs.

- Patients need individualised care pathways tailored to their specific needs.
- Family members take on a great deal of responsibility from the onset of the critical illness through recovery. Healthcare professionals must take this into consideration when supporting and interacting with family members.
- There needs to be a support system for family members taking care of a close one recovering from a critical illness at home.
- Despite the highly technical environment and advanced medical treatments in the ICU, patients and their family members report on the importance of the humanising aspects and the need to consider their humanness.

There seems to be a need for an outpatient clinic or a programme that offers help and manages to catch all the different patients or family members in need of support and follow-up after critical illness and ICU treatment. What kind of programme, and how it should be organised, are not clear; however, the important thing is that patients and their family members receive an offer in which they are listened to, seen as individuals, and meet someone who is curious about their situation and their needs. It will be interesting to follow the new outpatient clinic recently started in Oslo University Hospital, but what is certain is that a more tailored offer that takes each person into account is needed. Whether follow-up should be conducted from the ICU or organised in another way needs further exploration.

9. References

Abdul Halain, A., Tang, L. Y., Chong, M. C., Ibrahim, N. A., & Abdullah, K. L. (2022). Psychological distress among the family members of Intensive Care Unit (ICU) patients: A scoping review. *Journal of Clinical Nursing*, *31*(5–6), 497–507. https://doi.org/10.1111/jocn.15962

Agard, A. S., & Harder, I. (2007). Relatives' experiences in intensive care—Finding a place in a world of uncertainty. *Intensive and Critical Care Nursing*, *23*(3), 170–177. https://doi.org/10.1016/j.iccn.2006.11.008

Alfheim, H. B., Hofso, K., Smastuen, M. C., Toien, K., Rosseland, L. A., & Rustoen, T. (2019). Post-traumatic stress symptoms in family caregivers of intensive care unit patients: A longitudinal study. *Intensive and Critical Care Nursing*. 50, 5-10. https://doi.org/10.1016/j.iccn.2018.05.007

Alfheim, H. B., Rosseland, L. A., Hofso, K., Smastuen, M. C., & Rustoen, T. (2018). Multiple symptoms in family caregivers of intensive care unit patients. *Journal of Pain Symptom Management*, *55*(2), 387–394. https://doi.org/10.1016/j.jpainsymman.2017.08.018

Alligood, M. R. (2018). Introduction to nursing theory: Its history and significance. In M. R. Alligood (Eds.), *Nursing Theorists and their work* (9th ed.). Elsevier.

Alrø, A. B., Nedergaard, H. K., Svenningsen, H., Jensen, H. I., & Dreyer, P. (2022). Patients' experiences of cognitive impairment following critical illness treated in an intensive care unit: A scoping review. *Journal of Clinical Nursing*, 00, 1-17. https://doi.org/10.1111/jocn.16490

Alvsvåg, H. (2022). *Å tenke sykepleiefaglig: Essay i utvalg* [*To think like a nurse: a selection of essay*] (1. utg.). Fagbokforlaget.

Arman, M., Ranheim, A., Rydenlund, K., Rytterström, P., & Rehnsfeldt, A. (2015). The Nordic tradition of caring science: The works of three theorists. *Nursing Science Quarterly*, *28*(4), 288–296. https://doi.org/10.1177/0894318415599220

Backman, C. G., Orwelius, L., Sjoberg, F., Fredrikson, M., & Walther, S. M. (2010). Long-term effect of the ICU-diary concept on quality of life after critical illness. *Acta Anaesthesiologica Scandinavica*, *54*(6), 736–743. https://doi.org/10.1111/j.1399-6576.2010.02230.x

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

Beedholm, K., & Frederiksen, K. (2022). Fra kunnskap til teori. Sykepleieteorier i et historisk perspektiv. [From knowledge to theory. Nursing theories in a historical perspective] In B. Martinsen, P. Dreyer & A. Norlyk (red.) *Sykepleiens superhelter: Sykepleieteoretikere som styrker klinisk praksis* [*The superheroes of nursing: Nursing theorists that strenghten clinical practice*] (1. utg.). Fagbokforlaget.

Beesley, S. J., Hirshberg, E. L., Wilson, E. L., Butler, J. M., Oniki, T. A., Kuttler, K. G., Orme, J. F., Hopkins, R. O., & Brown, S. M. (2020). Depression and change in caregiver burden among family members of intensive care unit survivors. *American Journal of Critical Care*, *29*(5), 350–357. https://doi.org/10.4037/ajcc2020181

Bengtsson, J. (1999). *Med livsvärlden som grund: Bidrag till utvecklandet av en livsvärldsfenomenologisk ansats i pedagogisk forskning*. [*With the lifeworld as a* *foundation: a contribution to developing a life-world phenomenological approach in educational research*] Studentlitteratur.

Bengtsson, J. (2006). En livsverdenstilnæring for helsevitenskapelig forskning. [A lifeworld approach in health science research]. In J. Bengtsson (Ed.), *Å forske i sykdoms- og pleieerfaringer: Livsverdensfenomenologiske bidrag*. [*Doing research in illness- and nursing experiences: a life-world phenomenological contribution*] Høyskoleforlaget.

Benner, P., & Wrubel, J. (1989). *The primacy of caring: Stress and coping in health and illness*. Addison-Wesley.

Bergbom-Engberg, I., & Haljamäe, H. (1989). Assessment of patients' experience of discomforts during respirator therapy. *Critical Care Medicine*, *17*(10), 1068–1072. https://doi.org/10.1097/00003246-198910000-00021

Berntzen, H., Bjork, I. T., Storsveen, A. M., & Woien, H. (2020). "Please mind the gap": A secondary analysis of discomfort and comfort in intensive care. *Journal of Clinical Nursing*, *29*(13–14), 2441–2454. https://doi.org/10.1111/jocn.15260

Bienvenu, O. J., Friedman, L. A., Colantuoni, E., Dinglas, V. D., Sepulveda, K. A., Mendez-Tellez, P., Shanholz, C., Pronovost, P. J., & Needham, D. M. (2018). Psychiatric symptoms after acute respiratory distress syndrome: A 5-year longitudinal study. *Intensive Care Medicine*, *44*(1), 38–47. https://doi.org/10.1007/s00134-017-5009-4

Björk, K., Lindahl, B., & Fridh, I. (2019). Family members' experiences of waiting in intensive care: A concept analysis. *Scandinavian Journal of Caring Sciences*, *33*(3), 522–539. https://doi.org/10.1111/scs.12660

Bohart, S., Møller, A. M., Andreasen, A. S., Waldau, T., Lamprecht, C., & Thomsen, T. (2022). Effect of patient and family centred care interventions for adult intensive care unit patients and their families: A systematic review and meta-analysis. *Intensive and Critical Care Nursing*, *69*, 103156. https://doi.org/10.1016/j.iccn.2021.103156

Bradbury-Jones, C., Sambrook, S., & Irvine, F. (2009). The phenomenological focus group: An oxymoron? *Journal of Advanced Nursing*, *65*(3), 663–671. https://doi.org/10.1111/j.1365-2648.2008.04922.x

Bradshaw, A. (1997). The historical tradition of care. In G. Brykczynska (Ed.), *Caring: The compassion and wisdom of nursing*. Arnold.

Brown, S. M. (2016). *Through the valley of shadows: Living wills, intensive care, and making medicine human*. Oxford University Press.

Brummel, N. E. (2018). Measuring outcomes after critical illness. *Critical Care Clinics*, *34*(4), 515–526. https://doi.org/10.1016/j.ccc.2018.06.003

Buanes, E. A., Kvåle, R., & Barratt-Due, A. (2020). *Norsk intensivregister, Årsrapport for 2019 med plan for forbetringstiltak* (Versjon 1.1). [Norwegian intensive care register. Annual report for 2019 with a plan for improvement measures version 1.1]. https://helse-bergen.no/seksjon/intensivregister/Documents/%C3%85rsrapporter%20i%20NIR/NIR%20%C3%85rsrapport%202019.pdf

Buanes, E. A., Kvåle, R., Helleland, K. F., & Barratt-Due, A. (2022). *Norsk intensiv- og pandemiregister, Årsrapport for 2021 med plan for forbetringstiltak* (Versjon 1). [*Norwegian intensive care- and pandemic register. Annual report for 2021 with a plan for improvement measures (version 1)*]. https://helse-bergen.no/seksjon/intensivregister/Documents/%C3%85rsrapporter%20i%20NIR/NIPaR%20%C3%85rsrapport%202021.pdf

Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health and Illness*, *4*(2), 167–182. https://doi.org/10.1111/1467-9566.ep11339939

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

Cook, K., Bartholdy, R., Raven, M., von Dohren, G., Rai, S., Haines, K., & Ramanan, M. (2020). A national survey of intensive care follow-up clinics in Australia. *Australian Critical Care*, *33*(6), 533–537. https://doi.org/10.1016/j.aucc.2020.03.005

Corner, E. J., Murray, E. J., & Brett, S. J. (2019). Qualitative, grounded theory exploration of patients' experience of early mobilisation, rehabilitation and recovery after critical illness. *BMJ Open*, *9*(2), e026348. https://doi.org/10.1136/bmjopen-2018-026348

Cuthbertson, B. H., Rattray, J., Campbell, M. K., Gager, M., Roughton, S., Smith, A., Hull, A., Breeman, S., Norrie, J., Jenkinson, D., Hernandez, R., Johnston, M., Wilson, E., Waldmann, C., & group, P. R. study. (2009). The PRaCTICaL study of nurse led, intensive care follow-up programmes for improving long term outcomes from critical illness: A pragmatic randomised controlled trial. *British Medical Journal*, *339*, b3723. https://doi.org/10.1136/bmj.b3723

Dahlberg, H., & Dahlberg, K. (2019). The question of meaning-a momentous issue for qualitative research. *International Journal of Qualitative Studies on Health and Well-Being*, *14*(1), 1598723. https://doi.org/10.1080/17482631.2019.1598723

Dahlberg, K. (2019). Den fenomenologiska livsvärlden. [The phenomenological lifeworld] In H. Dahlberg, S. Ellingsen, B. Martinsen, & S. Rosberg (Eds.), *Fenomenologi i praktiken [Phenomenology in practice]* (1 utg.). Liber AB.

Dahlberg, K., Dahlberg, H., & Nyström, M. (2008). *Reflective lifeworld research*. Studentlitteratur.

Danielis, M., Povoli, A., Mattiussi, E., & Palese, A. (2020). Understanding patients' experiences of being mechanically ventilated in the intensive care unit: Findings from a meta-synthesis and meta-summary. *Journal of Clinical Nursing*, *29*(13–14), 2107–2124. https://doi.org/10.1111/jocn.15259

Davidson, J. E., Aslakson, R. A., Long, A. C., Puntillo, K. A., Kross, E. K., Hart, J., Cox, C. E., Wunsch, H., Wickline, M. A., Nunnally, M. E., Netzer, G., Kentish-Barnes, N., Sprung, C. L., Hartog, C. S., Coombs, M., Gerritsen, R. T., Hopkins, R. O., Franck, L. S., Skrobik, Y., … Curtis, J. R. (2017). Guidelines for family-centered care in the neonatal, pediatric, and adult ICU. *Critical Care Medicine*, *45*(1), 103–128. https://doi.org/10.1097/CCM.0000000000002169

Devlin, J. W., Skrobik, Y., Gélinas, C., Needham, D. M., Slooter, A. J. C., Pandharipande, P. P., Watson, P. L., Weinhouse, G. L., Nunnally, M. E., Rochwerg, B., Balas, M. C., van den Boogaard, M., Bosma, K. J., Brummel, N. E., Chanques, G., Denehy, L., Drouot, X., Fraser, G. L., Harris, J. E., … Alhazzani, W. (2018). Clinical practice guidelines for the prevention and management of pain, agitation/sedation, delirium, immobility, and sleep disruption in adult patients in the ICU: *Critical Care Medicine*, *46*(9), e825–e873. https://doi.org/10.1097/CCM.0000000000003299

Eaton, T. L., McPeake, J., Rogan, J., Johnson, A., & Boehm, L. M. (2019). Caring for survivors of critical illness: Current practices and the role of the nurse in intensive care unit aftercare. *American Journal of Critical Care*, *28*(6), 481–485. https://doi.org/10.4037/ajcc2019885

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

Egerod, I., Bøgeskov, B. O., Jensen, J. F., Dahlager, L., & Overgaard, D. (2020). Narrative critical care: A literary analysis of first-person critical illness pathographies. *Journal of Critical Care*, *59*, 194–200. https://doi.org/10.1016/j.jcrc.2020.06.018

Egerod, I., Risom, S. S., Thomsen, T., Storli, S. L., Eskerud, R. S., Holme, A. N., & Samuelson, K. A. (2013). ICU-recovery in Scandinavia: A comparative study of intensive care follow-up in Denmark, Norway and Sweden. *Intensive and Critical Care Nursing*, *29*(2), 103–111. https://doi.org/10.1016/j.iccn.2012.10.005

Elliott, D., Davidson, J. E., Harvey, M. A., Bemis-Dougherty, A., Hopkins, R. O., Iwashyna, T. J., Wagner, J., Weinert, C., Wunsch, H., Bienvenu, O. J., Black, G., Brady, S., Brodsky, M. B., Deutschman, C., Doepp, D., Flatley, C., Fosnight, S., Gittler, M., Gomez, B. T., … Needham, D. M. (2014). Exploring the scope of post-intensive care syndrome therapy and care: Engagement of non-critical care providers and survivors in a second stakeholders meeting. *Critical Care Medicine*, *42*(12), 2518–2526. https://doi.org/10.1097/CCM.0000000000000525

Engman, A. (2019). Embodiment and the foundation of biographical disruption. *Social Science & Medicine*, *225*, 120–127. https://doi.org/10.1016/j.socscimed.2019.02.019

Engstrom, A., Andersson, S., & Soderberg, S. (2008). Re-visiting the ICU. Experiences of follow-up visits to an ICU after discharge: A qualitative study. *Intensive and Critical Care Nursing*, *24*(4), 233–241. https://doi.org/10.1016/j.iccn.2008.03.002

Engstrom, A., Grip, K., & Hamren, M. (2009). Experiences of intensive care unit diaries: “touching a tender wound.” *Nursing in Critical Care*, *14*(2), 61–67. https://doi.org/10.1111/j.1478-5153.2008.00312.x

Engstrom, A., Rogmalm, K., Marklund, L., & Walivaara, B. M. (2015). Follow-up visit in an ICU: Receiving a sense of coherence. *Nursing in Critical Care*. 23(6), 308-315. https://doi.org/10.1111/nicc.12168

Engstrom, A., & Soderberg, S. (2010). Critical care nurses’ experiences of follow-up visits to an ICU. *Journal of Clinical Nursing*, *19*(19–20), 2925–2932. https://doi.org/10.1111/j.1365-2702.2009.03162.x

Ewens, B., Chapman, R., Tulloch, A., & Hendricks, J. M. (2014). ICU survivors’ utilisation of diaries post discharge: A qualitative descriptive study. *Australian Critical Care*, *27*(1), 28–35. https://doi.org/10.1016/j.aucc.2013.07.001

Fålun, N., Oterhals, K., Holm, M. S., Melby, A.-C., & Norekvål, T. M. (2017). Skriver dagbok til respiratorpasienter. [Writing diaries for mechanically ventilated patients]. *Sykepleien*, *3*, 54–59. https://doi.org/10.4220/Sykepleiens.2017.60967

Flahault, C., Vioulac, C., Fasse, L., Bailly, S., Timsit, J. F., & Garrouste-Orgeas, M. (2022). "A story with
gaps": An interpretative phenomenological analysis of ICU survivors' experience. PloS one, 17(3), 1-12. https://doi.org/10.1371/journal.pone.0264310

Flinterud, S. I., Moi, A. L., Gjengedal, E., Narvestad Grenager, L., Muri, A.-K., & Ellingsen, S. (2019). The creation of meaning – Intensive care nurses’ experiences of conducting nurse-led follow-up on intensive care units. *Intensive and Critical Care Nursing*, *53*, 30–36. https://doi.org/10.1016/j.iccn.2019.03.009

Frank, A. W. (2013). *The wounded storyteller: Body, illness, and ethics* (2nd ed.). University of Chicago Press.

Frivold, G., Ågård, A. S., Jensen, H. I., Åkerman, E., Fossum, M., Alfheim, H. B., Rasi, M., & Lind, R. (2022). Family involvement in the intensive care unit in four Nordic countries. *Nursing in Critical Care*, *27*(3), 450–459. https://doi.org/10.1111/nicc.12702

Frivold, G., Dale, B., & Slettebø, Å. (2015). Family members' experiences of being cared for by nurses and physicians in Norwegian intensive care units: A phenomenological hermeneutical study. *Intensive and Critical Care Nursing*, *31*(4), 232–240. https://doi.org/10.1016/j.iccn.2015.01.006

Gaete Ortega, D., Papathanassoglou, E., & Norris, C. M. (2020). The lived experience of delirium in intensive care unit patients: A meta-ethnography. *Australian Critical Care*, *33*(2), 193–202. https://doi.org/10.1016/j.aucc.2019.01.003

Galvin, K., & Todres, L. (2013). *Caring and well-being: A lifeworld approach*. Routledge.

Gandotra, S., Lovato, J., Case, D., Bakhru, R. N., Gibbs, K., Berry, M., Files, D. C., & Morris, P. E. (2019). Physical function trajectories in survivors of acute respiratory failure. *Annals of the American Thoracic Society*, *16*(4), 471–477. https://doi.org/10.1513/AnnalsATS.201806-375OC

Garrouste-Orgeas, M., Coquet, I., Perier, A., Timsit, J. F., Pochard, F., Lancrin, F., Philippart, F., Vesin, A., Bruel, C., Blel, Y., Angeli, S., Cousin, N., Carlet, J., & Misset, B. (2012). Impact of an intensive care unit diary on psychological distress in patients and relatives*. *Critical Care Medicine*, *40*(7), 2033–2040. https://doi.org/10.1097/CCM.0b013e31824e1b43

Gavaghan, S. R., & Carroll, D. L. (2002). Families of critically ill patients and the effect of nursing interventions. *Dimensions of Critical Care Nursing*, *21*(2), 64–71. https://doi.org/10.1097/00003465-200203000-00004

Gazzato, A., Scquizzato, T., Imbriaco, G., Negro, A., Caballo Garrido, M. C., Landoni, G., Zangrillo, A., & Borghi, G. (2022). The effect of intensive care unit diaries on posttraumatic stress disorder, anxiety, and depression: A systematic review and meta-analysis of randomized controlled trials. *Dimensions of Critical Care Nursing*, *41*(5), 256–263. https://doi.org/10.1097/DCC.0000000000000539

Giorgi, A. (2009). *The descriptive phenomenological method in psychology: A modified Husserlian approach*. Duquesne University Press.

Gjengedal, E. (1994). *Understanding a world of critical illness: A phenomenological study of the experiences of respirator patients and their caregivers*. Department of Public Health and Primary Health Care, Division for Nursing Science, University of Bergen.

Gjengedal, E., Storli, S. L., Holme, A. N., & Eskerud, R. S. (2010). An act of caring—Patient diaries in Norwegian intensive care units. *Nursing in Critical Care*, *15*(4), 176–184. https://doi.org/10.1111/j.1478-5153.2010.00402.x

Glimelius Petersson, C., Ringdal, M., Apelqvist, G., & Bergbom, I. (2015). Diaries and memories following an ICU stay: A 2-month follow-up study. *Nursing in Critical Care*. https://doi.org/10.1111/nicc.12162

Goldfarb, M. J., Bibas, L., Bartlett, V., Jones, H., & Khan, N. (2017). Outcomes of patient- and family-centered care interventions in the ICU: A systematic review and meta-analysis. *Critical Care Medicine*, *45*(10), 1751–1761. https://doi.org/10.1097/CCM.0000000000002624

Granberg, A., Engberg, I. B., & Lundberg, D. (1998). Patients' experience of being critically ill or severely injured and cared for in an intensive care unit in relation to the ICU syndrome. Part I. *Intensive and Critical Care Nursing*, *14*(6), 294–307. https://doi.org/10.1016/S0964-3397(98)80691-5

Greenberg, J. A., Basapur, S., Quinn, T. V., Bulger, J. L., Schwartz, N. H., Oh, S. K., Ritz, E. M., Glover, C. M., & Shah, R. C. (2022). Daily written care summaries for families of critically ill patients: A randomized controlled trial. *Critical Care Medicine*, *50*(9), 1296–1305. https://doi.org/10.1097/CCM.0000000000005583

Griffiths, J. A., Barber, V. S., Cuthbertson, B. H., & Young, J. D. (2006). A national survey of intensive care follow-up clinics. *Anaesthesia*, *61*(10), 950–955. https://doi.org/10.1111/j.1365-2044.2006.04792.x

Gullick, J., Wu, J., Reid, C., Tembo, A. C., Shishehgar, S., & Conlon, L. (2020). Heideggerian structures of Being-with in the nurse-patient relationship: Modelling phenomenological analysis through qualitative meta-synthesis. *Medicine, Health Care, and Philosophy*, *23*(4), 645–664. https://doi.org/10.1007/s11019-020-09975-y

Haave, R. O., Bakke, H. H., & Schröder, A. (2021). Family satisfaction in the intensive care unit: A cross-sectional study from Norway. *BMC Emergency Medicine*, *21*(1), 20. https://doi.org/10.1186/s12873-021-00412-8

Haines, K. J., Denehy, L., Skinner, E. H., Warrillow, S., & Berney, S. (2015). Psychosocial outcomes in informal caregivers of the critically ill: A systematic review. *Critical Care Medicine*, *43*(5), 1112–1120. https://doi.org/10.1097/CCM.0000000000000865

Halpern, N. A. (n.d.). *SCCM | Critical care statistics*. Society of Critical Care Medicine (SCCM). Retrieved October 29, 2022, from https://sccm.org/Communications/Critical-Care-Statistics

Hatch, R., Young, D., Barber, V., Griffiths, J., Harrison, D. A., & Watkinson, P. (2018). Anxiety, depression and post traumatic stress disorder after critical illness: A UK-wide prospective cohort study. *Critical Care*, *22*(1), 310. https://doi.org/10.1186/s13054-018-2223-6

Henriksen, K. F., Hansen, B. S., Wøien, H., & Tønnessen, S. (2021). The core qualities and competencies of the intensive and critical care nurse, a meta-ethnography. *Journal of Advanced Nursing*, *77*(12), 4693–4710. https://doi.org/10.1111/jan.15044

Herholdt-Lomholdt, S. M. (2022). At abdicere som konge av seg selv—Om tre fenomenologiske ledestjerner. [To abdicate as king of oneself–On three phenomenological guiding stars] In S. M. Herholdt-Lomboldt (Ed.), *Fenomenologi: Å leve, samtale og skrive ut mot det gåtefulle i tilværelsen* [*Phenomenology: To live, talk and write towards the enigmatic in existence*] (1. utg.). Fagbokforlaget.

Holme, A. N., Halvorsen, K., Eskerud, R. S., Lind, R., Storli, S. L., Gjengedal, E., & Moi, A. L. (2020). Nurses’ experiences of ICU diaries following implementation of national recommendations for diaries in intensive care units: A quality improvement project. *Intensive and Critical Care Nursing*, *59*, 102828. https://doi.org/10.1016/j.iccn.2020.102828

Honarmand, K., Lalli, R. S., Priestap, F., Chen, J. L., McIntyre, C. W., Owen, A. M., & Slessarev, M. (2020). Natural history of cognitive impairment in critical illness survivors. A systematic review. *American Journal of Respiratory and Critical Care Medicine*, *202*(2), 193–201. https://doi.org/10.1164/rccm.201904-0816CI

Huang, M., Parker, A. M., Bienvenu, O. J., Dinglas, V. D., Colantuoni, E., Hopkins, R. O., & Needham, D. M. (2016). Psychiatric symptoms in acute respiratory distress syndrome survivors: A 1-year national multicenter study. *Critical Care Medicine*, *44*(5), 954–965. https://doi.org/10.1097/CCM.0000000000001621

Husserl, E. (2002). *Ideas: General introduction to pure phenomenology*. Routledge. https://doi.org/10.4324/9781315823577

Imanipour, M., Kiwanuka, F., Akhavan Rad, S., Masaba, R., & Alemayehu, Y. H. (2019). Family members' experiences in adult intensive care units: A systematic review. *Scandinavian Journal of Caring Sciences*, *33*(3), 569–581. https://doi.org/10.1111/scs.12675

International Council of Nurses. (2021). *The ICN code of ethics for nurses*. https://www.icn.ch/sites/default/files/inline-files/ICN_Code-of-Ethics_EN_Web.pdf

IPFCC. (2016). *Advancing the practice of patient- and family-centered care in primary care and other ambulatory settings How to Get Started…*. Institute for Patient- and Family-Centered Care. https://www.ipfcc.org/resources/GettingStarted-AmbulatoryCare.pdf

Iwashyna, T. J. (2010). Survivorship will be the defining challenge of critical care in the 21st century. *Annals of Internal Medicine*, *153*(3), 204–205. https://doi.org/10.7326/0003-4819-153-3-201008030-00013

Jackson, J. C., Pandharipande, P. P., Girard, T. D., Brummel, N. E., Thompson, J. L., Hughes, C. G., Pun, B. T., Vasilevskis, E. E., Morandi, A., Shintani, A. K., Hopkins, R. O., Bernard, G. R., Dittus, R. S., Ely, E. W., Bringing to light the Risk Factors And Incidence of Neuropsychological dysfunction in ICU survivors (BRAIN-ICU) study investigators. (2014). Depression, post-traumatic stress disorder, and functional disability in survivors of critical illness in the BRAIN-ICU study: A longitudinal cohort study. The *Lancet Respiratory Medicine*, *2*(5), 369–379. https://doi.org/10.1016/S2213-2600(14)70051-7

Jensen, J. F., Thomsen, T., Overgaard, D., Bestle, M. H., Christensen, D., & Egerod, I. (2015). Impact of follow-up consultations for ICU survivors on post-ICU syndrome: A systematic review and meta-analysis. *Intensive Care Medicine*, *41*(5), 763–775. https://doi.org/10.1007/s00134-015-3689-1

Johnson, C. C., Suchyta, M. R., Darowski, E. S., Collar, E. M., Kiehl, A. L., Van, J., Jackson, J. C., & Hopkins, R. O. (2019). Psychological sequelae in family caregivers of critically iIl intensive care unit patients. A systematic review. *Annals of the American Thoracic Society*, *16*(7), 894–909. https://doi.org/10.1513/AnnalsATS.201808-540SR

Jonasdottir, R. J., Jonsdottir, H., Gudmundsdottir, B., & Sigurdsson, G. H. (2018). Psychological recovery after intensive care: Outcomes of a long-term quasi-experimental study of structured nurse-led follow-up. *Intensive and Critical Care Nursing*, *44*, 59–66. https://doi.org/10.1016/j.iccn.2017.06.001

Jonasdottir, R. J., Klinke, M. E., & Jonsdottir, H. (2016). Integrative review of nurse-led follow-up after discharge from the ICU. *Journal of Clinical Nursing*, *25*(1–2), 20–37. https://doi.org/10.1111/jocn.12939

Jones, C., Backman, C., Capuzzo, M., Egerod, I., Flaatten, H., Granja, C., Rylander, C., Griffiths, R. D., & group, R. (2010). Intensive care diaries reduce new onset post traumatic stress disorder following critical illness: A randomised, controlled trial. *Critical Care*, *14*(5), R168. https://doi.org/10.1186/cc9260

Kang, J. (2023). Being devastated by critical illness journey in the family: A grounded theory approach of post-intensive care syndrome-family. *Intensive and Critical Care Nursing*, *78*, 103448. https://doi.org/10.1016/j.iccn.2023.103448

Kean, S., Donaghy, E., Bancroft, A., Clegg, G., & Rodgers, S. (2021). Theorising survivorship after intensive care: A systematic review of patient and family experiences. *Journal of Clinical Nursing*, *30*(17–18), 2584–2610. https://doi.org/10.1111/jocn.15766

Kean, S., Salisbury, L. G., Rattray, J., Walsh, T. S., Huby, G., & Ramsay, P. (2017). 'Intensive care unit survivorship'—A constructivist grounded theory of surviving critical illness. *Journal of Clinical Nursing*, *26*(19–20), 3111–3124. https://doi.org/10.1111/jocn.13659

Kirby, C. (2003). Commitment to care: A philosophical perspective on nursing. In L. Basford & O. Slevin (Eds.), *Theory and Practice of Nursing—An integrated approach to caring practice* (2nd ed.). Nelson Thornes.

Kitson, A. (2023). There is no cure without care. *Journal of Advanced Nursing*, jan.15623. https://doi.org/10.1111/jan.15623

Kitson, A., Conroy, T., Kuluski, K., Locock, L., & Lyons, R. (2013). *Reclaiming and redefining the Fundamentals of Care: Nursing's response to meeting patients' basic human needs* (Nursing Research Series No. 2). School of Nursing, The University of Adelaide. https://digital.library.adelaide.edu.au/dspace/handle/2440/75843

Kitson, A. L. (2018). The Fundamentals of Care framework as a point-of-care nursing theory. *Nursing Research*, *67*(2), 99–107. https://doi.org/10.1097/NNR.0000000000000271

Kitson, A. L., Muntlin Athlin, Å., Conroy, T., & on behalf of the International Learning Collaborative. (2014). Anything but basic: Nursing's challenge in meeting patients' fundamental care needs. *Journal of Nursing Scholarship : an official publication of Sigma Theta Tau International Honor Society of Nursing*, *46*(5), 331–339. https://doi.org/10.1111/jnu.12081

Kitzinger, J. (1995). Qualitative research. Introducing focus groups. *British Medical Journal*, *311*, 299–302. https://doi:10.1136/bmj.311.7000.299

Knowles, R. E., & Tarrier, N. (2009). Evaluation of the effect of prospective patient diaries on emotional well-being in intensive care unit survivors: A randomized controlled trial. *Critical Care Medicine*, *37*(1), 184–191. https://doi.org/10.1097/CCM.0b013e31819287f7

Koht, C. (2022). *Dødsfrisk: Alle har sitt, stort eller litt*. [*Deadly healthy: everyone has something, big or small*]. Gyldendal.

Kvale, S., Brinkmann, S., Anderssen, T. M., & Rygge, J. (2015). *Det kvalitative forskningsintervju* [*InterViews: learning the craft of qualitative interviewing*] (3. utg., 2. oppl.). Gyldendal akademisk.

Kvande, M. E., Angel, S., & Højager Nielsen, A. (2022). Humanizing intensive care: A scoping review (HumanIC). *Nursing Ethics*, *29*(2), 498–510. https://doi.org/10.1177/09697330211050998

Kynoch, K., Ramis, M.-A., & McArdle, A. (2021). Experiences and needs of families with a relative admitted to an adult intensive care unit: A systematic review of qualitative studies. *JBI Evidence Synthesis*, *Publish Ahead of Print*. https://doi.org/10.11124/JBIES-20-00136

Larsen, M. H., Johannessen, G. I., & Heggdal, K. (2022). Nursing interventions to cover patients' basic needs in the intensive care context – A systematic review. *Nursing Open*, *9*(1), 122–139. https://doi.org/10.1002/nop2.1110

Leder, D. (2019). Re-possibilizing the world: Recovery from serious illness, injury or impairment. In E. Dahl, C. Falke, & T. E. Eriksen (Eds.), *Phenomenology of the broken body*. Routledge.

Leske, J. S. (1991). Internal psychometric properties of the Critical Care Family Needs Inventory. *Heart & lung: the journal of critical care, 20*(3), 236–244.

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

Marra, A., Ely, E. W., Pandharipande, P. P., & Patel, M. B. (2017). The ABCDEF bundle in critical care. *Critical Care Clinics*, *33*(2), 225–243. https://doi.org/10.1016/j.ccc.2016.12.005

Marra, A., Pandharipande, P. P., Girard, T. D., Patel, M. B., Hughes, C. G., Jackson, J. C., Thompson, J. L., Chandrasekhar, R., Ely, E. W., & Brummel, N. E. (2018). Co-occurrence of post-intensive care syndrome problems among 406 survivors of critical illness. *Critical Care Medicine*, *46*(9), 1393–1401. https://doi.org/10.1097/CCM.0000000000003218

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

Mart, M. F., Pun, B. T., Pandharipande, P., Jackson, J. C., & Ely, E. W. (2021). ICU survivorship—the relationship of delirium, sedation, dementia, and acquired weakness. *Critical Care Medicine*, *Publish Ahead of Print*. https://doi.org/10.1097/CCM.0000000000005125

McIlroy, P. A., King, R. S., Garrouste-Orgeas, M., Tabah, A., & Ramanan, M. (2019). The effect of ICU diaries on psychological outcomes and quality of life of survivors of critical illness and their relatives: A systematic review and meta-analysis. *Critical Care Medicine*, *47*(2), 273–279. https://doi.org/10.1097/CCM.0000000000003547

McLean, C., Coombs, M., & Gobbi, M. (2016). Talking about persons—Thinking about patients: An ethnographic study in critical care. *International Journal of Nursing Studies*, *54*, 122–131. https://doi.org/10.1016/j.ijnurstu.2015.02.011

McPeake, J., Devine, H., MacTavish, P., Fleming, L., Crawford, R., Struthers, R., Kinsella, J., Daniel, M., Shaw, M., & Quasim, T. (2016). Caregiver strain following critical care discharge: An exploratory evaluation. *Journal of Critical Care*, *35*, 180–184. https://doi.org/10.1016/j.jcrc.2016.05.023

Meiring-Noordstra, A., van der Meulen, I. C., Onrust, M., Hafsteinsdóttir, T. B., & Luttik, M. L. (2023).

Relatives' experiences of the transition from intensive care to home for acutely admitted intensive care patients-A qualitative study. Nursing in critical care, 10.1111/nicc.12918. Advance online publication. https://doi.org/10.1111/nicc.12918

Minton, C., Batten, L., & Huntington, A. (2019). A multicase study of prolonged critical illness in the intensive care unit: Families’ experiences. *Intensive and Critical Care Nursing*, *50*, 21–27. https://doi.org/10.1016/j.iccn.2018.08.010

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

Moi, A. L., Storli, S. L., Gjengedal, E., Holme, A. N., Lind, R., Eskerud, R., Fenstad, A. M., Kvale, R., & Halvorsen, K. (2018). The provision of nurse-led follow-up at Norwegian intensive care units. *Journal of Clinical Nursing*, 27(13-14), 2877-2886. https://doi.org/10.1111/jocn.14379

Molter, N. C. (1979). Needs of relatives of critically ill patients: A descriptive study. *Heart & Lung: The Journal of Critical Care*, *8*(2), 332–339.

Morse, J. M. (2015). Critical analysis of strategies for determining rigor in qualitative inquiry. *Qualitative Health Research*, *25*(9), 1212–1222. https://doi.org/10.1177/1049732315588501

Mudd, A., Feo, R., Conroy, T., & Kitson, A. (2020). Where and how does fundamental care fit within seminal nursing theories: A narrative review and synthesis of key nursing concepts. *Journal of Clinical Nursing*, 29(19-20), 3652-3666. https://doi.org/10.1111/jocn.15420

National Health and Hospital Plan. (2019). *Meld. St. 7 (2019-2020)—National Health and Hospital Plan 2020-2023*. https://www.regjeringen.no/en/dokumenter/meld.-st.-7-20192020/id2678667/

Needham, D. M., Davidson, J., Cohen, H., Hopkins, R. O., Weinert, C., Wunsch, H., Zawistowski, C., Bemis-Dougherty, A., Berney, S. C., Bienvenu, O. J., Brady, S. L., Brodsky, M. B., Denehy, L., Elliott, D., Flatley, C., Harabin, A. L., Jones, C., Louis, D., Meltzer, W., … Harvey, M. A. (2012). Improving long-term outcomes after discharge from intensive care unit: Report from a stakeholders' conference. *Critical Care Medicine*, *40*(2), 502–509. https://doi.org/10.1097/CCM.0b013e318232da75

NICE. (2017). *Rehabilitation after critical illness in adults*. NICE Clinical Guideline 83; National Institute for Health and Clinical Excellence. https://www.nice.org.uk/guidance/qs158

Norsk Sykepleierforbund. (2023). *Yrkesetiske retningslinjer for sykepleiere*. [*Professional ethical guidelines for nurses*] https://www.nsf.no/etikk-0/yrkesetiske-retningslinjer-sykepleiere

Nortvedt, P. (2008). *Sykepleiens grunnlag: Historie, fag og etikk* [*Foundations of nursing: history, subjects and ethics*] (2. utg.). Universitetsforlaget.

Norwegian National Research Ethics Committees. (2019). *General guidelines for research ethics*.

Oslo Universitetssykehus. (2021). *Dagbok for intensivpasienter—Voksne*. [*Diary for intensive care patients – adults*] https://ehandboken.ous-hf.no/document/45790

Oxford Advanced Learner's Dictionary. (2023). *Support*.

Pattison, N., O'Gara, G., Lucas, C., Gull, K., Thomas, K., & Dolan, S. (2019). Filling the gaps: A mixed-methods study exploring the use of patient diaries in the critical care unit. *Intensive and Critical Care Nursing*, *51*, 27–34. https://doi.org/10.1016/j.iccn.2018.10.005

Petrinec, A. B., & Daly, B. J. (2016). Post-traumatic stress symptoms in post-ICU family members: review and methodological challenges. *Western Journal of Nursing Research*, *38*(1), 57–78. https://doi.org/10.1177/0193945914544176

Polit, D. F., & Beck, C. T. (2021). *Nursing research: Generating and assessing evidence for nursing practice* (11th ed.). Lippincott Williams & Wilkins.

QRS International Pty. Ltd. (2020). *Nvivo* (Released in March 2020) [Computer software]. Lumivero. https://lumivero.com/products/nvivo/

Rawal, G., Yadav, S., & Kumar, R. (2017). Post-intensive care syndrome: An overview. *Journal of Translational Internal Medicine*, *5*(2), 90–92. https://doi.org/10.1515/jtim-2016-0016

Rousseau, A.-F., Prescott, H. C., Brett, S. J., Weiss, B., Azoulay, E., Creteur, J., Latronico, N., Hough, C. L., Weber-Carstens, S., Vincent, J.-L., & Preiser, J.-C. (2021). Long-term outcomes after critical illness: Recent insights. *Critical Care*, *25*(1), 108. https://doi.org/10.1186/s13054-021-03535-3

Salluh, J. I. F., Wang, H., Schneider, E. B., Nagaraja, N., Yenokyan, G., Damluji, A., Serafim, R. B., & Stevens, R. D. (2015). Outcome of delirium in critically ill patients: Systematic review and meta-analysis. *British Medical Journal*, *350*(3), h2538–h2538. https://doi.org/10.1136/bmj.h2538

Samuelson, K. A. (2011). Unpleasant and pleasant memories of intensive care in adult mechanically ventilated patients—Findings from 250 interviews. *Intensive and Critical Care Nursing*, *27*(2), 76–84. https://doi.org/10.1016/j.iccn.2011.01.003

Schofield-Robinson, O. J., Lewis, S. R., Smith, A. F., McPeake, J., & Alderson, P. (2018). Follow-up services for improving long-term outcomes in intensive care unit (ICU) survivors. *Cochrane Database of Systematic Reviews*. https://doi.org/10.1002/14651858.CD012701.pub2

Scott, P., Thomson, P., & Shepherd, A. (2019). Families of patients in ICU: A Scoping review of their needs and satisfaction with care. *Nursing Open*, *6*(3), 698–712. https://doi.org/10.1002/nop2.287

Sevin, C. M., Boehm, L. M., Hibbert, E., Bastin, A. J., Jackson, J. C., Meyer, J., Quasim, T., Bakhru, R. N., Montgomery-Yates, A., Slack, A., Still, M., Netzer, G., Mikkelsen, M. E., Iwashyna, T. J., Haines, K. J., & McPeake, J. (2021). Optimizing critical illness recovery: Perspectives and solutions from the caregivers of ICU survivors. *Critical Care Explorations*, *3*(5). https://journals.lww.com/ccejournal/Fulltext/2021/05000/Optimizing_Critical_Illness_Recovery__Perspectives.4.aspx

Spring, H. H. (2022). *Fortællinger fra stue 62: En traumepatients møde med hospitalsverdenen* [*Stories from room 62: a trauma patient's encounter with the hospital world*] (1. udg.). Fag og Kultur.

Stewart, D., Shamdasani, P., & Rook, D. (2007). *Focus groups* (2nd ed.). https://doi.org/10.4135/9781412991841

Stoksvik, M. (2023, May 8). Nytt tilbud til intensivpasienter: Føler meg mindre alene. [A new offer to intensive care patients: feel less alone] *VG*. https://www.vg.no/nyheter/innenriks/i/RGlvxa/rikshospitalet-har-etablert-ny-klinikk-for-pasienter-som-har-vaert-innlagt-paa-intensivavdelingen

Storli, S. L., Eskerud, R. S., Gjengedal, E., Holme, A. N., & Synnevåg, H. (2011). *Nasjonale anbefalinger for bruk av dagbok til pasienter ved norske intensivavdelinger*. [National recommendations for diaries in intensive care units]. https://www.barnogsmerte.no/sites/default/files/inline-images/Nasjonale%20anbefalinger%20for%20bruk%20av%20dagbok.pdf

Storli, S. L., Lindseth, A., & Asplund, K. (2008). A journey in quest of meaning: A hermeneutic-phenomenological study on living with memories from intensive care. *Nursing in Critical Care*, *13*(2), 86–96. https://doi.org/10.1111/j.1478-5153.2007.00235.x

Strandberg, S., Vesterlund, L., & Engstrom, A. (2018). The contents of a patient diary and its significance for persons cared for in an ICU: A qualitative study. *Intensive and Critical Care Nursing*, *45*, 31–36. https://doi.org/10.1016/j.iccn.2017.12.004

Svenningsen, H., Langhorn, L., Agard, A. S., & Dreyer, P. (2015). Post-ICU symptoms, consequences, and follow-up: An integrative review. *Nursing in Critical Care*, *22*(4), 212–220. https://doi.org/10.1111/nicc.12165

Tembo, A. C. (2017). Critical illness as a biographical disruption. *Proceedings of Singapore Healthcare*, *26*(4), 253–259. https://doi.org/10.1177/2010105817699843

Tembo, A. C., Parker, V., & Higgins, I. (2012). Being in limbo: The experience of critical illness in intensive care and beyond. *Open Journal of Nursing*, *02*(03), 270–276. https://doi.org/10.4236/ojn.2012.23041

Thomassen, M. (2006). *Vitenskap, kunnskap og praksis: Innføring i vitenskapsfilosofi for helse- og sosialfag*. [*Science, knowledge, and practice: introduction to philosophy of science for health and social sciences*]. Gyldendal akademisk.

Torres, J., Carvalho, D., Molinos, E., Vales, C., Ferreira, A., Dias, C. C., Araújo, R., & Gomes, E. (2017). The impact of the patient post-intensive care syndrome components upon caregiver burden. *Medicina Intensiva (English Edition)*, *41*(8), 454–460. https://doi.org/10.1016/j.medine.2016.12.003

Turnbull, A. E., Rabiee, A., Davis, W. E., Nasser, M. F., Venna, V. R., Lolitha, R., Hopkins, R. O., Bienvenu, O. J., Robinson, K. A., & Needham, D. M. (2016). Outcome measurement in ICU survivorship research from 1970 to 2013: A scoping review of 425 publications. *Critical Care Medicine*, *44*(7), 1267–1277. https://doi.org/10.1097/CCM.0000000000001651

Ullman, A. J., Aitken, L. M., Rattray, J., Kenardy, J., Le Brocque, R., MacGillivray, S., & Hull, A. M. (2014). Diaries for recovery from critical illness. *Cochrane Database of Systematic Reviews*, *12*, CD010468. https://doi.org/10.1002/14651858.CD010468.pub2

Valentin, A., Ferdinande, P., & ESICM Working Group on Quality Improvement. (2011). Recommendations on basic requirements for intensive care units: Structural and organizational aspects. *Intensive Care Medicine*, *37*(10), 1575. https://doi.org/10.1007/s00134-011-2300-7

van Beusekom, I., Bakhshi-Raiez, F., de Keizer, N. F., Dongelmans, D. A., & van der Schaaf, M. (2016). Reported burden on informal caregivers of ICU survivors: A literature review. *Critical Care*, *20*(1), 16. https://doi.org/10.1186/s13054-016-1185-9

van Beusekom, I., Bakhshi-Raiez, F., de Keizer, N. F., van der Schaaf, M., Busschers, W. B., & Dongelmans, D. A. (2018). Healthcare costs of ICU survivors are higher before and after ICU admission compared to a population based control group: A descriptive study combining healthcare insurance data and data from a Dutch national quality registry. *Journal of Critical Care*, *44*, 345–351. https://doi.org/10.1016/j.jcrc.2017.12.005

van den Born-van Zanten, S. A., Dongelmans, D. A., Dettling-Ihnenfeldt, D., Vink, R., & van der Schaaf, M. (2016). Caregiver strain and posttraumatic stress symptoms of informal caregivers of intensive care unit survivors. *Rehabilitation Psychology*, *61*(2), 173–178. https://doi.org/10.1037/rep0000081

Van Der Schaaf, M., Bakhshi-Raiez, F., Van Der Steen, M., Dongelmans, D. A., & De Keizer, N. F. (2015). Recommendations for intensive care follow-up clinics; report from a survey and conference of Dutch intensive cares. *Minerva Anestesiologica*, *81*(2), 135–144.

van Wijngaarden, E., Meide, H. V., & Dahlberg, K. (2017). Researching health care as a meaningful practice: Toward a nondualistic view on evidence for qualitative research. *Qualitative Health Research*, *27*(11), 1738–1747. https://doi.org/10.1177/1049732317711133

Vincent, J.-L., Shehabi, Y., Walsh, T. S., Pandharipande, P. P., Ball, J. A., Spronk, P., Longrois, D., Strøm, T., Conti, G., Funk, G.-C., Badenes, R., Mantz, J., Spies, C., & Takala, J. (2016). Comfort and patient-centred care without excessive sedation: The eCASH concept. *Intensive Care Medicine*, *42*(6), 962–971. https://doi.org/10.1007/s00134-016-4297-4

Vouzavali, F. J., Papathanassoglou, E. D., Karanikola, M. N., Koutroubas, A., Patiraki, E. I., & Papadatou, D. (2011). 'The patient is my space': Hermeneutic investigation of the nurse-patient relationship in critical care. *Nursing in Critical Care*, *16*(3), 140–151. https://doi.org/10.1111/j.1478-5153.2011.00447.x

Vrettou, C. S., Mantziou, V., Vassiliou, A. G., Orfanos, S. E., Kotanidou, A., & Dimopoulou, I. (2022). Post-intensive care syndrome in survivors from critical illness including COVID-19 patients: A narrative review. *Life*, *12*(1), 107. https://doi.org/10.3390/life12010107

Watland, S., Solberg Nes, L., Hanson, E., Ekstedt, M., Stenberg, U., & Børøsund, E. (2023). The Caregiver Pathway, a Model for the Systematic and Individualized Follow-up of Family Caregivers at Intensive Care Units: Development Study. JMIR formative research, 7, e46299. https://doi.org/10.2196/46299

Wikipedia (2022). Christine Koht. Wikipedia, den frie encyklopedi. https://no.wikipedia.org/wiki/Christine_Koht

Wilkin, K., & Slevin, E. (2004). The meaning of caring to nurses: An investigation into the nature of caring work in an intensive care unit. *Journal of Clinical Nursing*, *13*(1), 50–59. https://doi.org/10.1111/j.1365-2702.2004.00814.x

Williams, S. (2000). Chronic illness as biographical disruption or biographical disruption as chronic illness? Reflections on a core concept. *Sociology of Health & Illness*, *22*(1), 40–67. https://doi.org/10.1111/1467-9566.00191

Zahavi, D. (2019). *Phenomenology: The basics* (1st ed.). Routledge.

Zetterlund, P., Plos, K., Bergbom, I., & Ringdal, M. (2012). Memories from intensive care unit persist for several years—A longitudinal prospective multi-centre study. *Intensive and Critical Care Nursing*, *28*(3), 159–167. https://doi.org/10.1016/j.iccn.2011.11.010

Zimmerman, J. E., Kramer, A. A., & Knaus, W. A. (2013). Changes in hospital mortality for United States intensive care unit admissions from 1988 to 2012. *Critical Care*, *17*(2), R81–R81. https://doi.org/10.1186/cc12695

Appendix 1.

Article 1.

Flinterud, S. I., Moi, A. L., Gjengedal, E., Narvestad Grenager, L., Muri, A. K., & Ellingsen, S. (2019). The creation of meaning – Intensive care nurses' experiences of conducting nurse-led follow-up on intensive care units. *Intensive & Critical Care Nursing*, 53, 30–36. https://doi.org/10.1016/j.iccn.2019.03.009

Article 2.

Flinterud, S. I., Moi, A. L., Gjengedal, E., & Ellingsen, S. (2022). Understanding the course of critical illness through a lifeworld approach. *Qualitative Health Research*, 32(3), 531–542. https://doi.org/10.1177/10497323211062567

Article 3.

Flinterud, S. I., Moi, A. L., Gjengedal, E., & Ellingsen, S. (2023). Striving for a safe ground-A lifeworld approach of family members' experiences of the critical illness trajectory. *Journal of clinical nursing,* Advance online publication. https://doi.org/10.1111/jocn.16803

Article 1.

Flinterud, S. I., Moi, A. L., Gjengedal, E., Narvestad Grenager, L., Muri, A. K., & Ellingsen, S. (2019). The creation of meaning – Intensive care nurses' experiences of conducting nurse-led follow-up on intensive care units. *Intensive & Critical Care Nursing*, 53, 30–36. https://doi.org/10.1016/j.iccn.2019.03.009

Abstract

Objective

To explore and describe the experiences of Norwegian intensive care unit nurses providing nurse-led follow-up to patients and their families.

Design and methods

The study had a qualitative design with a phenomenological approach. Three focus-group interviews were conducted with nurses on three intensive care units. Giorgi's phenomenological method guided the analysis.

Findings

The creation of meaning emerged as a general structure describing intensive care nurses' experiences of nurse-led follow-up. When caring for critically ill patients, nurses described becoming emotionally moved, which motivated them to perform nurse-led follow-up procedures, such as writing in patient diaries. A general wish to give context to the patients' time spent in intensive care emerged. When conducting nurse-led follow-up, the nurses made personal contributions, which could be emotionally challenging for them. Overall, nurse-led follow-up was found to increase nurses' insight into and motivation for their own practice.

Conclusion

The performance of nurse-led follow-up appears to be grounded in care for and engagement in individual patients and families. The nurses studied wanted to help patients and families to be able to handle their experiences during an intensive care stay. In addition, nurse-led follow-up gave meaning to the intensive care nurses' own practice.

Article 2.

Flinterud, S. I., Moi, A. L., Gjengedal, E., & Ellingsen, S. (2022). Understanding the course of critical illness through a lifeworld approach. *Qualitative Health Research*, 32(3), 531–542. https://doi.org/10.1177/10497323211062567

Abstract

An increasing number of individuals receive and survive intensive care treatment; however, several individuals experience problems afterward, which may threaten recovery. Grounded in a lifeworld approach, the aim of this study was to explore and describe what intensive care patients experience as limiting and strengthening throughout their illness trajectories. Ten former intensive care patients were interviewed three to eight months after hospital discharge. Using Giorgi's phenomenological analysis, a general structure of gaining strength through a caring interaction with others was revealed. The structure consisted of three constituents: feeling safe through a caring presence, being seen and met as a unique person, and being supported to restore capacity. Being met with a humanistic approach and individualized care appeared to be important, and the findings are discussed within the framework of lifeworld-led care. To facilitate improved aftercare of the critically ill, more tailored support throughout the illness trajectory is needed.

Article 3.

Flinterud, S. I., Moi, A. L., Gjengedal, E., & Ellingsen, S. (2023). Striving for a safe ground-A lifeworld approach of family members' experiences of the critical illness trajectory. *Journal of clinical nursing,* Advance online publication. https://doi.org/10.1111/jocn.16803

Abstract

Aims and Objectives

To explore the experiences of family members after they have lived through a close one's illness trajectory starting with critical illness and intensive care treatment, throughout hospitalisation and after their return home, and describe what was important and challenging for them during this time.

Background

Being family during and after critical illness and intensive care treatment may be traumatic and challenging. An in-depth understanding of family members' lifeworld throughout a close one's illness trajectory is needed.

Design

A qualitative design with a phenomenological approach.

Methods

We held ten interviews with eleven next of kin, nine of which were individual and one with a parent couple. The interviews lasted 90 minutes, on average, and were transcribed verbatim. Giorgi's phenomenological method guided the analysis.

Results

The overall structure was 'striving for a safe ground for themselves and their close one', which was dependent on the three constituents of 'in need of care', 'to take on responsibility' and 'to create new understanding'. Throughout the illness trajectory, the family members required care to increase their feelings of safety in the context of their close one being unsafe. They described taking on responsibility for their close one—a responsibility that increased after hospital discharge—as demanding new knowledge which they were often unable to obtain.

Conclusions

Families of critically ill patients need to be seen on their own behalf. Moreover, when taking on responsibility for their close one, they regularly need more knowledge than they get. There seems to be an absence of a support system for families with caring responsibilities after their relatives are discharged from hospitals.

Relevance to Clinical Practice

This study shows the importance of family carers being considered in their own right, as well as their individual needs throughout a close one's illness trajectory. There seems to be a gap in the knowledge of what family members require when their close one is discharged. Indeed, a better support system is essential for families following a hospital discharge.

Appendix 2.

Documentation from Regional Ethics Committee and Norwegian Centre for Research Data AS.

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	**Saksbehandler:**	**Telefon:**	**Vår dato:**	**Vår referanse:**
REK nord			02.05.2016	2016/704/REK nord
			Deres dato:	**Deres referanse:**
			30.03.2016	

Vår referanse må oppgis ved alle henvendelser

Stine Irene Flinterud
Haraldsplass

2016/704 Oppfølging etter kritisk sykdom og intensivbehandling - en kvalitativ studie av erfaringer fra pasienters, deres pårørendes og intensivsykepleieres perspektiv

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK nord) i møtet 21.04.2016. Vurderingen er gjort med hjemmel i helseforskningsloven § 10, jf. forskningsetikkloven § 4.

Forskningsansvarlig: VID vitenskapelige høgskole
Prosjektleder: Stine Irene Flinterud

Prosjektleders prosjektomtale

Stadig flere overlever kritisk sykdom og behandling på intensivavdeling, men flere rapporterer om fysiske og psykiske problem i etterkant. Ulike oppfølgingstilbud finnes, men det er ingen konsensus om beste modell. For å utvikle og forbedre dagens oppfølgingstilbud er det behov for økt kunnskap om hvordan pasienter og deres pårørende har det i hverdagen etter behandling på intensivavdeling. Ved hjelp av kvalitativ metode vil vi utforske og beskrive opplevelse av oppfølging etter behandling på intensivavdeling fra sykepleieres, tidligere pasienters og deres pårørendes perspektiv. Tre intensivavdelinger i Norge inkluderes. Studien har to deler. I studie A utføres fokusgruppeintervju med intensivsykepleierne, med fokus på hvordan de opplever nåværende oppfølgingstilbudet. I studie B vil dybdeintervju med pasientene og pårørende gjennomføres for å få en økt forståelse for hvordan de opplever sin hverdag i etterkant av behandling på intensivavdeling, og deres behov for oppfølging.

Vurdering

Framleggingsplikt

De prosjektene som skal framlegges for REK er prosjekt som dreier seg om "medisinsk og helsefaglig forskning på mennesker, humant biologisk materiale eller helseopplysninger", jf. helseforskningsloven (h) § 2. "Medisinsk og helsefaglig forskning" er i h § 4 a) definert som "virksomhet som utføres med vitenskapelig metodikk for å skaffe til veie ny kunnskap om helse og sykdom". Det er altså formålet med studien som avgjør om et prosjekt skal anses som framleggelsespliktig for REK eller ikke.

I dette prosjektet beskrives formålet slik at *«For å utvikle og forbedre dagens oppfølgingstilbud er det behov for økt kunnskap om hvordan pasienter og deres pårørende har det i hverdagen etter behandling på intensivavdeling. Ved hjelp av kvalitativ metode vil vi utforske og beskrive opplevelse av oppfølging etter behandling på intensivavdeling fra sykepleieres, tidligere pasienters og deres pårørendes perspektiv. Tre intensivavdelinger i Norge inkluderes. Studien har to deler. I studie A utføres fokusgruppeintervju med intensivsykepleierne, med fokus på hvordan de opplever nåværende oppfølgingstilbudet. I studie B vil dybdeintervju med pasientene og pårørende gjennomføres for å få en økt forståelse for hvordan de opplever sin hverdag i etterkant av behandling på intensivavdeling, og deres behov for oppfølging.»*

Det fremgår videre av protokollen at hovedformålet under del A er oppfølging med tjenestene som intensivpasienten gis etter intensivperioden og under del B man tar sikte på å utforske og beskrive tidligere intensivpasienter og pårørendes erfaring på det mottatte oppfølging etter intensivbehandling, inkludert deres opplevelse av hverdagen etter kritisk sykdom og hva slags oppfølging de ville ha nytte med fokus på deres behov og brukermedvirkning.

Selv om dette er en helsefaglig studie og funnene i studien indirekte vil kunne gi en helsemessig gevinst faller ikke prosjektet inn under definisjonen av de prosjekt som skal vurderes etter helseforskningsloven.

Godkjenning fra andre instanser
Det påhviler prosjektleder å undersøke hvilke eventuelle godkjenninger som er nødvendige fra eksempelvis personvernombudet ved den aktuelle institusjon eller Norsk samfunnsvitenskapelig datatjeneste (NSD).

Vedtak
Etter søknaden fremstår prosjektet ikke som et medisinsk og helsefaglig forskningsprosjekt som faller innenfor helseforskningsloven. Prosjektet er ikke fremleggingspliktig, jf. hfl § *2.*

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

Med vennlig hilsen

May Britt Rossvoll
sekretariatsleder

Kopi til:bard.maland@vid.no

Stine Irene Flinterud
VID Haraldsplass VID vitenskapelige høgskole
Ulriksdal 10
5009 BERGEN

Vår dato: 05.09.2016	Vår ref: 48811 / 3 / AH	Deres dato:	Deres ref:

TILBAKEMELDING PÅ MELDING OM BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 31.05.2016. Meldingen gjelder prosjektet:

48811	*Oppfølging etter kritisk sykdom og intensivbehandling - en kvalitativ studie fra pasienters, deres pårørendes og intensivsykepleieres perspektiv*
Behandlingsansvarlig	*VID vitenskapelig høgskole, ved institusjonens øverste leder*
Daglig ansvarlig	*Stine Irene Flinterud*

Personvernombudet har vurdert prosjektet, og finner at behandlingen av personopplysninger vil være regulert av § 7-27 i personopplysningsforskriften. Personvernombudet tilrår at prosjektet gjennomføres.

Personvernombudets tilråding forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i meldeskjemaet, korrespondanse med ombudet, ombudets kommentarer samt personopplysningsloven og helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.

Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget skjema, http://www.nsd.uib.no/personvern/meldeplikt/skjema.html. Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

Personvernombudet har lagt ut opplysninger om prosjektet i en offentlig database, http://pvo.nsd.no/prosjekt.

Personvernombudet vil ved prosjektets avslutning, 30.11.2019, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen

Katrine Utaaker Segadal

Åsne Halskau

Kontaktperson: Åsne Halskau tlf: 55 58 21 88
Vedlegg: Prosjektvurdering

Dokumentet er elektronisk produsert og godkjent ved NSDs rutiner for elektronisk godkjenning.

Personvernombudet for forskning

Prosjektvurdering - Kommentar

Prosjektnr: 48811

FORMÅL
Prosjektet er opprinnelig blitt vurdert av REK til å falle utenfor helseforskningsloven fordi det er forskning på helsetjenesten. Formålet med studien er å utforske opplevelse av og erfaring med oppfølging etter opphold på intensivavdeling, sett fra tidligere pasienters, deres pårørendes og intensivsykepleieres perspektiv. Studien vil rette seg særlig mot behovet for oppfølging og brukermedvirkning i oppfølgingen. Studien deles i to deler; studie A og B. I studie A vil intensivsykepleiers perspektiv utforskes; hvordan ser de på oppfølgingstilbudet de har, hvilke tanker har de om pasientenes og pårørendes behov for oppfølging og brukermedvirkning i oppfølgingen? I studie B vil pasienter og deres pårørendes perspektiv utforskes; hvordan opplevde de oppfølgingen, hva er deres behov for oppfølging og hvordan ser de på brukermedvirkning i oppfølgingstilbudet?

FØRSTEGANGSKONTAKT OG REKRUTTERING
Førstegangskontakt og rekruttering opprettes via intensivavdelingene. Personvernombudet legger til grunn at taushetsplikten ikke er til hinder for førstegangskontakt og rekruttering. Vi anbefaler at sykehusene/intensivavdelingene formidler kontakten med utvalget, og at de som ønsker å delta av tidligere pasienter og pårørende, samt sykepleiere tar direkte kontakt med forsker. På denne måten ivaretas både taushetsplikten og frivilligheten ved rekrutteringen. Dette er godt beskrevet i meldeskjemaet.

Personvernombudet legger til grunn at klinikkledelsen ved de aktuelle institusjonene godkjenner prosjektet.

UTVALG OG SAMTYKKE
Utvalget i del A består av intensivsykepleiere. Utvalget i del B består av tidligere pasienter og pårørende ved ulike intensivavdelinger.

Utvalgene i del A og B informeres skriftlig og muntlig om prosjektet og samtykker til deltakelse. Informasjonsskrivene motatt 01.09.2016 er godt utformet.

Personvernombudet anbefaler at sykepleiere rutinemessig minnes om at de har taushetsplikt og således ikke kan omtale pasienter og pårørende på en måte som gjør dem gjenkjennbare enkeltvis.

INFORMASJONSSIKKERHET
Personvernombudet legger til grunn at forsker etterfølger VID vitenskapelig høgskole sine interne rutiner for datasikkerhet.

KOMMENTAR
Personvernombudet finner prosjektopplegget bra utformet, men minner rutinemessig om at ved forskning på svake grupper er det flere forhold som må tas i betraktning: Den som foretar datainnsamling bør ha kompetanse

til å gjøre dette på en slik måte at belastningen på deltakerne blir minst mulig. Man bør være forberedt på å håndtere eventuelle problemer som kan oppstå, både underveis og etter datainnsamling. For eksempel kan enkelte informanter ha behov for oppfølging, og forsker må kunne henvise vedkommende til riktig instans, som for eksempel lege eller en støttegruppe. Du kan også lese mer om forskning på svake grupper her http://www.nsd.uib.no/personvern/forskningstemaer/sarbar.html

PROSJEKTSLUTT
Forventet prosjektslutt er 30.11.2019. Ifølge prosjektmeldingen og infoskriv skal innsamlede opplysninger om sykepleierne da anonymiseres. Råmateriale om pasienter og pårørende lagres for mulig oppfølgingsstudier til 30.11.24 og blir anonymisert senest innen denne datoen. Anonymisering innebærer å bearbeide datamaterialet slik at ingen enkeltpersoner kan gjenkjennes. Det gjøres ved å:
- slette direkte personopplysninger (som navn/koblingsnøkkel)
- slette/omskrive indirekte personopplysninger (identifiserende sammenstilling av bakgrunnsopplysninger som f.eks. bosted/arbeidssted, alder og kjønn)
- slette/anonymisere lydopptak

OPPFØLGENDE STUDIE
Dersom det er aktuelt å kontakte deltakerne på nytt for en oppfølgingsstudie minner Personvernombudet om at du må sende meldeskjema med relevante vedlegg før utvalget kontaktes i god tid og seneste 30 dager før prosjektstart.

Appendix 3.

Information and consent forms.

Forespørsel om deltakelse i forskningsprosjektet

"Oppfølging etter behandling på en intensivavdeling"

Bakgrunn og formål

Dette er en invitasjon til deg om å delta i et forskningsprosjekt som handler om behov for oppfølging etter behandling på en intensivavdeling. Målet med prosjektet er å få mer kunnskap om hvordan det går med pasienter og deres pårørende i etterkant av innleggelse på en intensivavdeling, og på bakgrunn av dette belyse behovet for oppfølging og muligheten for å påvirke oppfølgingstilbudet.

Fordi du nylig har vært innlagt på en intensivavdeling ønsker vi å invitere deg til å delta i forskningsprosjektet. En kontaktperson ved avdelingen har identifisert deg som aktuell deltaker og sendt forespørselen. Prosjektleder kjenner ikke din identitet før du eventuelt samtykker til deltakelse.

Prosjektet er en del av en doktorgradsstudie ved VID vitenskapelige høgskole, som også er ansvarlig institusjon. Prosjektet gjennomføres i samarbeid med tre intensivavdelinger i Norge.

Hva innebærer deltakelse i studien?

For å delta i prosjektet må både du og din nærmeste samtykke til deltakelse. Hvis dere ønsker å delta vil dere begge bli intervjuet to ganger etter utskrivelsen fra sykehuset. Første gang etter 3-4 måneder og siste gang rundt 18 måneder etter utskrivelse. Dere intervjues hver for dere, og det er viktig at intervjuet foregår et sted hvor vi ikke risikerer å bli forstyrret. Du kan selv velge hvor intervjuet skal foregå; hjemme, på sykehuset eller annet egnet sted. Det vil bli gjort lydopptak av intervjuene, som så vil bli skrevet ut til tekst som analyseres.

Intervjuet vil vare i cirka 1 ½ - 2 timer. Vi kan dele opp intervjuet i to omganger hvis varigheten blir lang eller du ønsker en pause.

Intervjuet vil starte med spørsmål om hvordan du opplevde det å være innlagt på intensivavdelingen, så kommer vi nærmere inn på hvordan du har det nå i etterkant av sykehusoppholdet. Vi vil også komme inn på ditt behov for oppfølging og dine tanker om det å påvirke din oppfølging i etterkant av innleggelsen på intensivavdelingen. Ettersom prosjektet retter seg mot både ditt og din nærmeste sitt behov for oppfølging vil vi i intervjuene kunne komme inn på hvordan dere opplever den andres behov for oppfølging.

Samtykker du til deltakelse vil vi sende deg et skjema som vi ber deg fylle ut i forkant av intervjuet. Vi ber om at du fyller ut opplysninger som navn, fødselsnummer, telefonnummer, kjønn, sivilstatus, utdanning, jobb, bosituasjon og eventuell rehabilitering etter intensivoppholdet. I tillegg ber vi om å få registrere noen opplysninger om din innleggelse på intensivavdelingen som vi henter fra din journal på sykehuset. Vi vil registrere hvorfor du ble innlagt på intensivavdelingen, eventuelt andre sykdommer du har, alvorlighetsgraden av sykdom ved innleggelse på intensivavdelingen, opplysninger om respiratorbehandlingen, hvor lenge du var innlagt på avdelingen, hvor lenge du var innlagt på sykehuset og om du ble skrevet ut til hjemmet eller rehabilitering.

Hva skjer med informasjonen om deg?

Alle personopplysninger vil bli behandlet konfidensielt. Ditt informerte samtykke og skjemaene med dine opplysninger vil bli gitt en kode, og alt innsamlet materiale vil bli oppbevart innelåst. Det er kun prosjektgruppen som har tilgang til personidentifiserbare data. Dine opplysninger og materiale fra intervjuene knyttes til deg gjennom koden. Datamaterialet anonymiseres når intervjuene omgjøres fra lydopptak til tekst. Ingen enkeltpersoner vil kunne gjenkjennes i publikasjoner.

Doktorgradsprosjektet skal etter planen avsluttes 31.11.2019. Det kan være aktuelt å ta kontakt med deg igjen ved et senere tidspunkt etter prosjektslutt, for å få et lengre perspektiv på hvordan det går etter oppholdet på intensivavdelingen. Du vil da eventuelt motta en ny invitasjon til et oppfølgingsprosjekt. Du krysser av i samtykkeskjemaet om du er åpen for muligheten til at vi kan ta kontakt med deg igjen etter prosjektslutt. Samtykker du til dette vil dine personopplysninger lagres hos Norsk senter for forskningsdata AS (NSD), i inntil fem år etter prosjektslutt, til og med 30.11.24.

Frivillig deltakelse

Det er frivillig å delta i prosjektet, og du kan når som helst trekke ditt samtykke uten å oppgi noen grunn. Dette vil ikke få konsekvenser for eventuell videre oppfølging av deg eller din nærmeste. Dersom du trekker deg fra prosjektet, vil alle opplysninger om deg bli anonymisert og dine personopplysninger slettes.

I forkant av intervjuet 18 måneder etter utskrivelse vil kontaktpersonen ved avdelingen du var innlagt sjekke din journal før prosjektleder tar kontakt for å avtale intervju. Har det oppstått hendelser som fører til at det ikke er mulig å utføre intervju vil kun din nærmeste bli kontaktet.

Dersom du ønsker å delta i studien, eller har spørsmål, ta kontakt med prosjektleder Stine Irene Flinterud på telefonnummer 901 49 286 eller e-post: stine.flinterud@vid.no, helst innen 2 uker etter mottatt forespørsel. Siste side i forespørselen med signert samtykke fylles ut og signeres ved første intervju.

Studien er meldt til Personvernombudet for forskning, NSD - Norsk senter for forskningsdata AS, prosjektnummer 48811.

Med vennlig hilsen

Stine Irene Flinterud
Intensivsykepleier / prosjektleder
Doktorgradsstudent ved
VID vitenskapelige høgskole
Postboks 184 Vinderen
0319 Oslo

Samtykke til deltakelse i studien

(Denne delen fylles ut og signeres ved første intervju)

Jeg samtykker til at dere kan få tilgang til min pasientjournal og elektroniske kurve for å registrere opplysninger som nevnt over.

JA ☐ NEI ☐

Jeg har mottatt informasjon om studien, og er villig til å delta

----

(Signert av prosjektdeltaker, dato)

Jeg samtykker til at mine personopplysninger kan lagres og at jeg kan kontaktes ved et senere tidspunkt etter prosjektslutt, til og med 30.11.2024.

JA ☐ NEI ☐

Vedlegg til tidligere informasjonsskriv for å delta i forskningsprosjektet

«Oppfølging etter behandling på en intensivavdeling»?

På bakgrunn av at EUs personvernforordning (GDPR) ble innført i Norge av det 20. juli 2018 må deltakere i forskningsprosjekt samtykke på nytt, og dette er et vedlegg til forrige informasjonsskriv med informasjon om kommende intervju og dine rettigheter som deltaker i prosjektet.

Formål
Formålet med prosjektet er å få mer kunnskap om pasienter som har vært innlagt på en intensivavdeling og deres pårørende. På bakgrunn av pasienters og pårørendes opplevelse av forløpet i sykehus, fra oppholdet på intensivavdelingen og til utskrivelse, og hvordan det går med pasienter og deres pårørende i etterkant av sykehusopphold ønsker vi å belyse behovet for støtte og oppfølging gjennom sykehusoppholdet og etter utskrivelse.

I dette andregangsintervjuet ønsker jeg å snakke om hvordan det går nå noen år etter innleggelsen på sykehuset. Jeg vil stille deg noen spørsmål omkring tiden etter forrige intervju og hvordan du har det i dag. Videre vil jeg lage en kort oppsummering av hva vi snakket om sist, og du får mulighet for å si hva du tenker om dette nå. Fokuset for prosjektet er på behov for og tilbud om ulik type oppfølging etter et opphold på intensivavdeling, og jeg vil også stille deg noen spørsmål om det tilbudet du har mottatt, og om du eventuelt hadde hatt behov for noe mer som du ikke fikk tilbud om.

Et av temaene som kom frem og som vi gjerne vil undersøke nærmere i neste intervju er behov for individuelt tilpasset støtte og oppfølging, både gjennom sykehusoppholdet og i etterkant. Vi vil gjerne høre hva du ut fra din erfaring tenker er viktig at er med hvis vi skal lage et støtte og oppfølgingstilbud/informasjon om tilbud til både pasienter og pårørende. Eksempler på dette kan være informasjon til pårørende om hvilke hjelp og støtte man kan få til både personlige og praktiske ting underveis i sykehusoppholdet, informasjon og tilbud om fysisk rehabilitering og gjenopptrening for pasienten, pasient og pårørendes behov for å snakke med helsepersonell fra intensivavdelingen igjen, og eventuelt mer psykologisk hjelp til å håndtere det man har vært igjennom for både pasient og pårørende.

Hvem er ansvarlig for forskningsprosjektet?
Prosjektet er en del av en doktorgradsstudie, og VID vitenskapelige høgskole er ansvarlig for prosjektet. Prosjektet gjennomføres i samarbeid med tre intensivavdelinger i Norge.

Det er frivillig å delta
Det er frivillig å delta i prosjektet. Hvis du velger å delta, kan du når som helst trekke samtykke tilbake uten å oppgi noen grunn. Alle opplysninger om deg vil da bli anonymisert. Det vil ikke ha noen negative konsekvenser for deg hvis du ikke vil delta eller senere velger å trekke deg.

Dine rettigheter
Så lenge du kan identifiseres i datamaterialet, har du rett til:
- innsyn i hvilke personopplysninger som er registrert om deg,
- å få rettet personopplysninger om deg,
- få slettet personopplysninger om deg,
- få utlevert en kopi av dine personopplysninger (dataportabilitet), og
- å sende klage til personvernombudet eller Datatilsynet om behandlingen av dine personopplysninger.

Hva gir oss rett til å behandle personopplysninger om deg?
Vi behandler opplysninger om deg basert på ditt samtykke.

På oppdrag fra VID vitenskapelige høgskole har NSD – Norsk senter for forskningsdata AS vurdert at behandlingen av personopplysninger i dette prosjektet er i samsvar med personvernregelverket.

Hvor kan jeg finne ut mer?
Hvis du har spørsmål til studien, eller ønsker å benytte deg av dine rettigheter, ta kontakt med:
- VID vitenskapelige høgskole ved Stine Irene Flinterud, på epost: stine.flinterud@vid.no eller telefon: 901 49 286.
- Vårt personvernombud: Nancy Yue Liu, på epost: personvernombud@vid.no eller telefon: 938 56 277.
- NSD – Norsk senter for forskningsdata AS, på epost: personverntjenester@nsd.no eller telefon: 55 58 21 17.

Med vennlig hilsen

Stine Irene Flinterud
Prosjektansvarlig

Samtykkeerklæring

Jeg har mottatt og forstått informasjon om prosjektet «Oppfølging etter behandling på en intensivavdeling», og har fått anledning til å stille spørsmål. Jeg samtykker til:

- ☐ å delta i intervju
- ☐ at mine personopplysninger lagres etter prosjektslutt, til 30.11.2024.

Jeg samtykker til at mine opplysninger behandles frem til prosjektet er avsluttet, ca. 30.11.2020

(Signert av prosjektdeltaker, dato)

Forespørsel om deltakelse i forskningsprosjektet

"Oppfølging etter behandling på en intensivavdeling"

Bakgrunn og formål

Dette er en invitasjon til deg om å delta i et forskningsprosjekt som handler om behov for oppfølging etter behandling på en intensivavdeling. Målet med prosjektet er å få mer kunnskap om hvordan det går med pasienter og deres pårørende i etterkant av innleggelse på en intensivavdeling, og på bakgrunn av dette belyse behovet for oppfølging og muligheten for å påvirke oppfølgingstilbudet.

Fordi en av dine nærmeste nylig har vært innlagt på en intensivavdeling ønsker vi å invitere deg til å delta i forskningsprosjektet. En kontaktperson ved avdelingen har identifisert deg som aktuell deltaker og sendt forespørselen. Prosjektleder kjenner ikke din identitet før du eventuelt samtykker til deltakelse.

Prosjektet er en del av en doktorgradsstudie ved VID vitenskapelige høgskole, som også er ansvarlig institusjon. Prosjektet gjennomføres i samarbeid med tre intensivavdelinger i Norge.

Hva innebærer deltakelse i studien?

For å delta i prosjektet må både du og din nærmeste som har vært innlagt på en intensivavdeling samtykke til deltakelse. Hvis dere ønsker å delta vil dere begge bli intervjuet to ganger etter utskrivelsen fra sykehuset. Første gang etter 3-4 måneder og siste gang rundt 18 måneder etter utskrivelse. Dere intervjues hver for dere, og det er viktig at intervjuet foregår et sted hvor vi ikke risikerer å bli forstyrret. Du kan selv velge hvor intervjuet skal foregå; hjemme, på sykehuset eller annet egnet sted. Det vil bli gjort lydopptak av intervjuene, som så vil bli skrevet ut til tekst som analyseres.

Intervjuet vil vare i cirka 1 ½ -2 timer. Vi kan dele opp intervjuet i to omganger hvis varigheten blir lang eller du ønsker en pause.

Intervjuet vil starte med spørsmål om hvordan du opplevde det å være pårørende på intensivavdelingen, så kommer vi nærmere inn på hvordan du har det nå i etterkant av din nærmeste sitt sykehusopphold. Vi vil også komme inn på ditt behov for oppfølging og dine tanker om det å påvirke oppfølgingen i etterkant av din nærmeste sin innleggelsen på intensivavdelingen. Ettersom prosjektet retter seg mot både ditt og din nærmeste sitt behov for oppfølging vil vi i intervjuene kunne komme inn på hvordan dere opplever den andres behov for oppfølging.

Samtykker du til deltakelse vil vi sende deg et skjema som vi ber deg fylle ut i forkant av intervjuet. Vi ber om at du fyller ut opplysninger som navn, fødselsnummer, telefonnummer, kjønn, sivilstatus, utdanning, jobb, bosituasjon og noen ulike opplysninger knyttet til din nærmeste sitt sykehusopphold.

Hva skjer med informasjonen om deg?

Alle personopplysninger vil bli behandlet konfidensielt. Ditt informerte samtykke og skjemaene med dine opplysninger vil bli gitt en kode, og alt innsamlet materiale vil bli oppbevart innelåst. Det er kun prosjektgruppen som har tilgang til personidentifiserbare data. Dine opplysninger og materiale fra intervjuene knyttes til deg gjennom koden. Datamaterialet anonymiseres når intervjuene omgjøres fra lydopptak til tekst. Ingen enkeltpersoner vil kunne gjenkjennes i publikasjoner.

Doktorgradsprosjektet skal etter planen avsluttes 31.11.2019. Det kan være aktuelt å ta kontakt med deg igjen ved et senere tidspunkt etter prosjektslutt, for å få et lengre perspektiv på hvordan det går etter oppholdet på intensivavdelingen. Du vil da motta en ny invitasjon til et oppfølgingsprosjekt. Du krysser av i samtykkeskjemaet om du er åpen for muligheten til at vi kan ta kontakt med deg igjen etter prosjektslutt. Samtykker du til dette vil dine personopplysninger lagres hos Norsk senter for forskningsdata AS (NSD), i inntil fem år etter prosjektslutt, til og med 30.11.24.

Frivillig deltakelse

Det er frivillig å delta i prosjektet, og du kan når som helst trekke ditt samtykke uten å oppgi noen grunn. Dette vil ikke få konsekvenser for eventuell videre oppfølging av deg eller din nærmeste. Dersom du trekker deg fra prosjektet, vil alle opplysninger om deg bli anonymisert og dine personopplysninger slettes.

Dersom du ønsker å delta i studien, eller har spørsmål, ta kontakt med prosjektleder Stine Irene Flinterud på telefonnummer 901 49 286 eller e-post: stine.flinterud@vid.no, helst innen 2 uker etter mottatt forespørsel. Siste side i forespørselen med signert samtykke fylles ut og signeres ved første intervju.

Studien er meldt til Personvernombudet for forskning, NSD - Norsk senter for forskningsdata AS, prosjektnummer 48811.

Med vennlig hilsen

Stine Irene Flinterud
Intensivsykepleier / prosjektleder
Doktorgradsstudent ved
VID vitenskapelige høgskole
Postboks 184 Vinderen
0319 Oslo

Samtykke til deltakelse i studien

(Denne delen fylles ut og signeres ved første intervju)

Jeg har mottatt informasjon om studien, og er villig til å delta

----
(Signert av prosjektdeltaker, dato)

Jeg samtykker til at mine personopplysninger kan lagres og at jeg kan kontaktes ved et senere tidspunkt etter prosjektslutt, til og med 30.11.2024.

JA ☐ NEI ☐

Vedlegg til tidligere informasjonsskriv for å delta i forskningsprosjektet

«Oppfølging etter behandling på en intensivavdeling»?

På bakgrunn av at EUs personvernforordning (GDPR) ble innført i Norge av det 20. juli 2018 må deltakere i forskningsprosjekt samtykke på nytt, og dette er et vedlegg til forrige informasjonsskriv med informasjon om kommende intervju og dine rettigheter som deltaker i prosjektet.

Formål

Formålet med prosjektet er å få mer kunnskap om pasienter som har vært innlagt på en intensivavdeling og deres pårørende. På bakgrunn av pasienters og pårørendes opplevelse av forløpet i sykehus, fra oppholdet på intensivavdelingen og til utskrivelse, og hvordan det går med pasienter og deres pårørende i etterkant av sykehusopphold ønsker vi å belyse behovet for støtte og oppfølging gjennom sykehusoppholdet og etter utskrivelse.

I dette andregangsintervjuet ønsker vi å snakke om hvordan det går nå noen år etter innleggelsen på sykehuset. Jeg vil stille deg noen spørsmål omkring tiden etter forrige intervju og hvordan du har det i dag. Videre vil jeg lage en kort oppsummering av hva vi snakket om sist, og du får mulighet for å si hva du tenker om dette nå. Fokuset for prosjektet er på behov for og tilbud om ulik type oppfølging etter et opphold på intensivavdeling, både for pasienten men også for pårørende, og jeg vil også stille deg noen spørsmål om det tilbudet du har mottatt, og om du eventuelt hadde hatt behov for noe mer som du ikke fikk tilbud om.

Et av temaene som kom frem og som vi gjerne vil undersøke nærmere i neste intervju er behov for individuelt tilpasset støtte og oppfølging, både gjennom sykehusoppholdet og i etterkant. Vi vil gjerne høre hva du ut fra din erfaring tenker er viktig at er med hvis vi skal lage et støtte og oppfølgingstilbud/informasjon om tilbud til både pasienter og pårørende. Eksempler på dette kan være informasjon til pårørende om hvilke hjelp og støtte man kan få til både personlige og praktiske ting underveis i sykehusoppholdet, informasjon og tilbud om fysisk rehabilitering og gjenopptrening for pasienten, pasient og pårørendes behov for å snakke med helsepersonell fra intensivavdelingen igjen, og eventuelt mer psykologisk hjelp til å håndtere det man har vært igjennom for både pasient og pårørende.

Hvem er ansvarlig for forskningsprosjektet?

Prosjektet er en del av en doktorgradsstudie, og VID vitenskapelige høgskole er ansvarlig for prosjektet. Prosjektet gjennomføres i samarbeid med tre intensivavdelinger i Norge.

Det er frivillig å delta

Det er frivillig å delta i prosjektet. Hvis du velger å delta, kan du når som helst trekke samtykke tilbake uten å oppgi noen grunn. Alle opplysninger om deg vil da bli anonymisert. Det vil ikke ha noen negative konsekvenser for deg hvis du ikke vil delta eller senere velger å trekke deg.

Dine rettigheter
Så lenge du kan identifiseres i datamaterialet, har du rett til:
- innsyn i hvilke personopplysninger som er registrert om deg,
- å få rettet personopplysninger om deg,
- få slettet personopplysninger om deg,
- få utlevert en kopi av dine personopplysninger (dataportabilitet), og
- å sende klage til personvernombudet eller Datatilsynet om behandlingen av dine personopplysninger.

Hva gir oss rett til å behandle personopplysninger om deg?
Vi behandler opplysninger om deg basert på ditt samtykke.

På oppdrag fra VID vitenskapelige høgskole har NSD – Norsk senter for forskningsdata AS vurdert at behandlingen av personopplysninger i dette prosjektet er i samsvar med personvernregelverket.

Hvor kan jeg finne ut mer?
Hvis du har spørsmål til studien, eller ønsker å benytte deg av dine rettigheter, ta kontakt med:
- VID vitenskapelige høgskole ved Stine Irene Flinterud, på epost: stine.flinterud@vid.no eller telefon: 901 49 286.
- Vårt personvernombud: Nancy Yue Liu, på epost: personvernombud@vid.no eller telefon: 938 56 277.
- NSD – Norsk senter for forskningsdata AS, på epost: personverntjenester@nsd.no eller telefon: 55 58 21 17.

Med vennlig hilsen

Prosjektansvarlig

Samtykkeerklæring

Jeg har mottatt og forstått informasjon om prosjektet «Oppfølging etter behandling på en intensivavdeling», og har fått anledning til å stille spørsmål. Jeg samtykker til:

☐ å delta i intervju
☐ at mine personopplysninger lagres etter prosjektslutt, til 30.11.2024.

Jeg samtykker til at mine opplysninger behandles frem til prosjektet er avsluttet, ca. 30.11.2020

(Signert av prosjektdeltaker, dato)

Forespørsel om deltakelse i forskningsprosjektet

"Oppfølging etter behandling på en intensivavdeling"

Bakgrunn og formål

Dette er en invitasjon til deg om å delta i et forskningsprosjekt som handler om behovet for oppfølging etter behandling på en intensivavdeling, sett fra tidligere pasienter, deres pårørende og intensivsykepleieres perspektiv. På bakgrunn av at du jobber på en intensivavdeling med et pågående oppfølgingstilbud ønsker vi å invitere deg til å delta i et fokusgruppeintervju. Her vil vi belyse intensivsykepleiernes opplevelse av og erfaring med oppfølgingen som pågår, og vi vil snakke om tema som omhandler tidligere pasienter og deres pårørendes behov for oppfølging og mulighet for å påvirke eller involvere seg i oppfølgingstilbudet.

Prosjektet er en del av en doktorgradsstudie ved VID vitenskapelige høgskole, som også er ansvarlig institusjon. Prosjektet gjennomføres i samarbeid med tre intensivavdelinger i Norge.

Hva innebærer deltakelse i studien?

Deltakelse i prosjektet innebærer at du deltar i et fokusgruppeintervju med 6-8 av dine kollegaer ved avdelingen. Intervjuet vil vare i cirka 1- 1 ½ time. Det vil bli gjort lydopptak av intervjuet, som så vil bli skrevet ut til tekst som analyseres.

Samtykker du til deltakelse vil avdelingen kontaktperson, fornavn etternavn, levere ut et skjema med opplysninger som vi ber deg fylle ut før fokusgruppeintervjuet. Vi ber om opplysninger som navn, kjønn, alder, hvor lenge du har vært intensivsykepleier, hvor lenge du har jobbet ved avdelingen og hva slags ansvar du har i nåværende oppfølgingstilbud.

Hva skjer med informasjonen om deg?

Alle personopplysninger vil bli behandlet konfidensielt. Ditt informerte samtykke og skjemaene med dine opplysninger vil bli gitt en kode, og alt innsamlet materiale vil bli oppbevart innelåst. Det er kun prosjektgruppen som har tilgang til personidentifiserbare data. Dine opplysninger og materiale fra intervjuene knyttes til deg gjennom koden. Datamaterialet anonymiseres når intervjuene omgjøres fra lydopptak til tekst. Ingen enkeltpersoner vil kunne gjenkjennes i publikasjoner. Prosjektet skal etter planen avsluttes 31.11.2019. Samtykkeskjema og skjema med dine opplysninger vil da slettes.

Frivillig deltakelse

Det er frivillig å delta i studien, og du kan når som helst trekke ditt samtykke uten å oppgi noen grunn. Dersom du trekker deg, vil alle opplysninger om deg bli anonymisert og personopplysninger slettet. Dersom du senere ønsker å trekke deg kan du kontakte prosjektleder Stine Irene Flinterud.

Studien er meldt til Personvernombudet for forskning, NSD - Norsk senter for forskningsdata AS, prosjektnummer 48811.

Dersom du ønsker å delta, signerer du samtykke på neste side og leverer til avdelingens kontaktperson, fornavn etternavn.

Har du spørsmål til studien, ta kontakt med:
Stine Irene Flinterud, intensivsykepleier / prosjektleder
Doktorgradsstudent ved
VID vitenskapelige høgskole
Telefonnummer 901 49 286 eller e-post: stine.flinterud@vid.no.

Samtykke til deltakelse i studien

Jeg har mottatt informasjon om studien, og er villig til å delta

----

(Signert av prosjektdeltaker, dato)

Appendix 4.

Interview guides.

Interview guide for the focus group interviews.

Intervjuguide for studie A

Åpningsspørsmål: Jeg tenkte først vi kunne starte med at dere forteller meg kort om hvordan oppfølgingen av pasienter og kanskje også pårørende foregår her hos dere. Kom gjerne med eksempler eller situasjoner dere har opplevd som kan belyse det vi snakker om underveis.

Oppfølgingstilbudet:

Hvordan opplever dere det oppfølgingstilbudet dere har?

Oppfølging av pasient:
- (Vil dere fortelle meg om en typisk oppfølging av pasienter?)

Oppfølging av pårørende:
- Vil dere fortelle om situasjoner hvor oppfølging av pårørende har vært aktuelt?

Behov for oppfølging (13.45):

- Hvordan opplever dere pasientenes behov for oppfølging?

- Hvordan opplever dere pårørendes behov for oppfølging?

- Opplever dere at dere klarer å dekke behovene for oppfølging av både pasienter og pårørende?
    - Hva mener dere blir dekket?
    - Hva mener dere ikke blir dekket?

Brukermedvirkning (14.00):

- Hva tenker dere om det at pasienter og pårørende selv kan påvirke eller bli involvert i egen oppfølging?
- Hvordan er det tilrettelagt for at pasientene eller pårørende kan påvirke eller involvere seg i oppfølgingstilbudet?
- Har dere noen tanker om hvordan det at de påvirket eller var delaktig i oppfølgingen kunne sett ut?
- (Hva kan bidra for å fremme muligheten for økt medvirkning/involvering i egen oppfølging?)
- (Hva kan bidra til å hemme eller vanskeliggjøre økt medvirkning/involvering i egen oppfølging?)

Veien videre:

(Hva bidrar til å fremmer/hemmer oppfølging av pasient og pårørende:
- Hva er det som bidrar til å fremme oppfølgingen av pasientene tenker dere?
- Hvilke faktorer er viktig for å få til en god oppfølging av pasientene?
- Hva tenker dere bidrar til å hemme en god oppfølging?
- Er det noen barrierer dere opplever som hemmende i oppfølgingstilbudet?)

- **Noe tanker om hvordan oppfølgingen kan utvikles videre? Ca. 14.15**
    - **Pasient**
    - **Pårørende**

Interview guide with the former patient, first version

Intervjuguidene skal brukes som en hjelp under intervjuet og er kun veiledende. Spørsmålene er eksempler som kan bli brukt ved behov.

Intervjuguide studie B pasienter

Åpningsspørsmål: Før vi kommer inn på hvordan du har det nå etter sykehusoppholdet lurte jeg først på om du ville fortelle meg litt om hvordan det var for deg å være innlagt på intensivavdelingen?
Hvordan har du det i hverdagen nå etter sykehusoppholdet?

- Vil du fortelle meg hvordan en helt vanlig dag er for deg?
    - Fysisk helse, selvhjulpenhet
    - Arbeid/fritid
    - Sosiale aktiviteter
    - Psykisk helse
      (Evt. Vil du beskrive situasjoner hvor du trenger hjelp?)

- Hvordan opplever du at sykdommen eller sykehusoppholdet har påvirket familielivet i etterkant?
    - Vil du beskrive situasjoner hvor du merker at sykehusoppholdet har påvirket familielivet?

- Vil du beskrive din opplevelse av oppfølgingen du fikk etter oppholdet på intensivavdelingen?
    - Hva slags tilbud har du mottatt?
    - Hva tenker du om oppfølgingen du har mottatt?

Behov for oppfølging:

- Hvordan opplever du ditt behov for oppfølging?
    - Oppfølging fra sykehuset/intensivavdelingen?
    - Hva tenker du om ditt behov for oppfølging av andre instanser? (fastlege, fysisk rehabilitering, psykologisk hjelp, kommunehelsetjeneste)

Brukermedvirkning:

- Hvordan ville den optimale oppfølgingen etter sykehusoppholdet sett ut for deg?

- Vil du beskrive hvordan du ser på det å kunne påvirke oppfølgingen selv?

- Hva tenker du om det å kunne påvirke eller involvere seg i egen oppfølging?
    - Hva ville dette betydd for deg?
    - Hvordan ville det sett ut for deg?

- Hva tenker du om påvirkning eller involvering i oppfølgingen du har mottatt?

Interview guide with the former patient, second version

Intervjuguide studie B pasienter

Åpningsspørsmål: Før vi kommer inn på hvordan du har det nå etter sykehusoppholdet lurte jeg først på om du ville fortelle meg litt om bakgrunnen for at du ble innlagt på intensivavdelingen.

- Hvordan var det for deg å være innlagt på intensivavdelingen?
- Hvordan har du det i hverdagen nå etter sykehusoppholdet?
- Hvordan var en helt vanlig dag var for deg rett i etterkant av at du ble skrevet ut?

Hendelsen
Intensivavdelingen
Sengepost
Rehabilitering
Hjemme den første tiden
Hjemme nå noen måneder etterpå

Fysisk
Psykisk
Åndelig
Aktiviteter/jobb
Sosialt

Hva har vært viktig for deg? (i de ulike fasene)
Hva hjalp deg? (i de ulike fasene)
Hva har vært vanskelig/utfordrende? (i de ulike fasene)

Opplever du at sykdommen/sykehusoppholdet har påvirket familielivet?

Oppfølging:

- Har du mottatt noe tilbud fra sykehuset i etterkant? Hva slags tilbud?
- Vil du beskrive din opplevelse av ivaretakelse / oppfølgingen du fikk etter oppholdet på intensivavdelingen/sykehuset?

Behov:
Behov for oppfølging i etterkant? (fastlege, rehabilitering, psykologisk hjelp, kommunehelsetjenesten)
Beskrive situasjoner.

Brukermedvirkning:

- Vil du beskrive hvordan du ser på det å kunne påvirke oppfølgingen selv?
- Hvordan ville den optimale oppfølgingen etter sykehusoppholdet sett ut for deg?
- Hva tenker du om det å kunne påvirkning eller involvering seg i egen oppfølging?

Oppsummering:
Noe annet du tenker har vært viktig i denne perioden?

- Hverdagen
- Behov
- Påvirkning/involvering

Interview guide with the family member, first version

Intervjuguidene skal brukes som en hjelp under intervjuet og er kun veiledende. Spørsmålene er eksempler som kan bli brukt ved behov.

Intervjuguide studie B- pårørende

Åpningsspørsmål: Før vi kommer inn på hvordan du har det nå etter din (manns, kones, samboers, mammas, pappas, sønns, datters osv) sykehusopphold lurte jeg først på om du ville fortelle meg litt om hvordan det var for deg da din (mann, kone, samboer, mamma, pappa, sønn, datter osv) var alvorlig syk og innlagt på intensivavdelingen?
Hvordan har du det i hverdagen nå etter din (mann, kone, samboer, mamma, pappa osv) sykdom / sykehusopphold?

- Vil du fortelle meg hvordan en helt vanlig dag er for deg etter din (mann, kone, samboer, mamma, pappa osv) var innlagt på intensivavdelingen?
    - Arbeid/fritid
    - Sosiale aktiviteter
    - Egen fysisk helse
    - Egen psykisk helse

- Hvordan opplever du at din (mann, kone, samboer, mamma, pappa osv) sykdom/ sykehusopphold har påvirket familielivet deres?
    - Vil du beskrive situasjoner hvor du merker at sykehusoppholdet har påvirket familielivet?

- Vil du beskrive din opplevelse av oppfølgingen du fikk etter oppholdet på intensivavdelingen?
    - Hva slags tilbud har du og din nære mottatt?
    - Hva tenker du om oppfølgingen dere har mottatt?

Behov for oppfølging:

- Hva tenker du om ditt behov for oppfølging i etterkant av din (mann, kone, samboer, mamma, pappa osv) sykehusopphold?
    - Vil du beskrive en dagligdags situasjon som belyser dette behovet?

- Hva tenker du om ditt eget behov for hjelp i hverdagen?
    - Behov for oppfølging fra sykehuset?
    - Behov for oppfølging fra andre?

Brukermedvirkning:

- Hvordan ville den optimale oppfølgingen etter sykehusoppholdet sett ut for deg?

- Vil du beskrive hvordan du ser på det å kunne påvirke oppfølgingen selv?

- Hva tenker du om det å kunne påvirke eller involvere seg i egen oppfølging?
    - Hva ville dette betydd for deg?
    - Hvordan ville det sett ut for deg?

- Hva tenker du om påvirkning eller involvering i oppfølgingen du har mottatt?

Interview guide with the family member, second version

Intervjuguide studie B- pårørende

Åpningsspørsmål: Før vi kommer inn på hvordan du har det nå etter din manns sykehusopphold lurte jeg først på om du ville fortelle meg litt om bakgrunnen for at din pårørende ble innlagt på intensivavdelingen?

- Hvordan var det for deg å være pårørende på intensivavdelingen?
- Hvordan har du det i hverdagen nå etter din pårørendes sykehusopphold?
- Hvordan var en helt vanlig dag var for deg rett etter at din pårørende ble utskrevet?

Hendelsen
Intensivavdelingen
Sengepost
Rehabilitering
Hjemme den første tiden
Hjemme nå noen måneder etterpå

Fysisk
Psykisk
Åndelig
Aktiviteter/jobb
Sosialt

Hva har vært viktig for deg? (i de ulike fasene)
Hva hjalp deg? (i de ulike fasene)
Hva har vært vanskelig/ utfordrende for deg? (i de uilke fasene)

Opplever du at din (mann, kone, samboer, mamma, pappa osv) sykdom/ sykehusopphold har påvirket familielivet?

Oppfølging:

- Har du mottatt noe tilbud fra sykehuset i etterkant? Hva slags tilbud?
- Vil du beskrive din opplevelse av ivaretakelsen / oppfølgingen du/dere fikk etter oppholdet på intensivavdelingen/sykehuset?

Behov:
Behov for oppfølging i etterkant? (fastlege, psykologisk hjelp, kommunehelsetjeneste)
Beskrive situasjoner.

Brukermedvirkning:

- Vil du beskrive hvordan du ser på det å kunne påvirke oppfølgingen selv?
- Hvordan ville den optimale oppfølgingen etter sykehusoppholdet sett ut for deg?
- Hva tenker du om det å kunne påvirke eller involvere seg i egen oppfølging?

Oppsummering:
Noe annet du tenker er viktig i denne perioden?

- Hverdagen
- Behov
- Påvirkning/involvering

Appendix 5.

Background data participants.

Registrering av bakgrunnsopplysninger for intensivsykepleierne

1. Navn:

2. Kjønn:
   Mann ☐
   Kvinne ☐

3. Alder:

4. Hvor lenge har du jobbet som intensivsykepleier:

5. Hvor lenge har du jobbet ved avdelingen:

6. Hva slags ansvar har du i forbindelse med oppfølgingstilbudet?
   Skriver dagbok ☐
   Organiserer oppfølgingssamtalene ☐
   Utfører telefonisk oppfølging ☐
   Er med på oppfølgingssamtale ☐
   Annet/noe du vil utdype:

Skjema for registrerings av bakgrunnsopplysninger, tidligere pasient

Vi ber deg vennligst om å fylle ut skjemaet før intervjuet. Eventuelle spørsmål til utfyllingen av skjemaet kan vi snakke om når vi møtes for intervju.

1. Navn:
2. Fødselsnummer (11 siffer):
3. Telefonnummer:
4. Kjønn: Mann ☐ Kvinne ☐
5. Sivilstatus: Gift ☐ Samboer ☐ Enke / enkemann ☐ Enslig ☐
6. Antall barn:
7. Bosituasjon: Bor sammen med noen ☐ Bor alene ☐
8. Høyeste fullførte utdanning: Grunnskole ☐ Videregående ☐ Høyere utdanning til og med 4 år ☐ Høyere utdanning over 4 år ☐
9. Arbeid per dags dato: Fulltid ☐ Deltid ☐ Arbeidsledig ☐ Pensjonist ☐ Fullt sykemeldt ☐ Delvis sykemeldt ☐ Uføretrygdet ☐
10. Yrke:
11. Rehabilitering i etterkant av sykehusopphold (fysioterapi, organisert trening, annet): Ja ☐ Nei ☐ Hvis ja, besvar spørsmål 12
12. Hva slags rehabilitering? Innlagt på institusjon for rehabilitering etter sykehusopphold ☐ Fysioterapi ☐, antall dager per uke: Annet:

Skjema for registrering av bakgrunnsopplysninger, pårørende

Vi ber deg vennligst om å fylle ut skjemaet før intervjuet. Eventuelle spørsmål til utfyllingen av skjemaet kan vi snakke om når vi møtes for intervju.

1. Navn:
2. Fødselsnummer (11 siffer):
3. Telefonnummer:
4. Kjønn:
   Mann ☐
   Kvinne ☐
5. Sivilstatus:
   Gift ☐
   Samboer ☐
   Enke / enkemann ☐
   Enslig ☐
6. Antall barn:
7. Høyeste fullførte utdanning:
   Grunnskole ☐
   Videregående ☐
   Høyere utdanning til og med 4 år ☐
   Høyere utdanning over 4 år ☐
8. Arbeid per dags dato (kan sette flere kryss):
   Fulltid ☐
   Deltid ☐
   Arbeidsledig ☐
   Pensjonist ☐
   Fullt sykemeldt ☐
   Delvis sykemeldt ☐
   Uføretrygdet ☐
9. Antall dager overnatting på sykehus/hotell i forbindelse med din næres innleggelse på sykehus:
10. Har du oppsøkt lege på grunn av økt påkjenning som følge av din næres sykehusinnleggelse?
    Ja ☐
    Nei☐
11. Antall dager sykemeldt som følge av din næres sykehusinnleggelse:

VID