UiT The Arctic University of Norway

Faculty of Health Sciences

Department of Health and Care Sciences

Family care strategies in an unpredictable ICU environment

ICU nurses' and physicians' interprofessional and individual strategies for critically ill ICU patients' families – a qualitative study

Anne Mette Nygaard

A dissertation for the degree of Philosophiae Doctor August 2022

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Abstract

Background: Critical illness not only disrupts the patient’s life, but also the lives of close family members. The care provided by ICU nurses and physicians can reduce the family members’ burden and improve the patient's outcome. Previous research shows that although ICU families generally report high satisfaction, there are several barriers to family care and areas for improvement. Family members miss emotional support and opportunities to become more involved in patient care. They also report problems with inconsistent information and poor communication with clinicians. This indicates that more knowledge is needed of existing ICU family care practices. Therefore, the overall aim of this study was to explore ICU nurses’ and physicians’ individual and interprofessional strategies for providing care to the families of critically ill ICU patients, in order to enhance knowledge of existing ICU practices and hereby improve patient and family care.

Methods: Data were gathered from July 2017 to August 2019, through participant observation, focus groups, dyadic and individual interviews of physicians and nurses from four ICUs in different Norwegian hospitals. In Papers 1 and 2, a constructivist grounded theory approach was used in the data analysis, while thematic narrative analysis was used in Paper 3.

Findings: Papers 1, 2 and 3, respectively, describe how handovers, interprofessional care and an individual approach affect family care in the ICU. Together these articles show that family care in the ICU is an interprofessional responsibility, although an individual approach to families by nurses and physicians is crucial, and continuity in family care must be ensured by good information flow between clinicians. The study also indicates that family care in the ICU is largely based on clinicians’ experiences.

Conclusion: The study demonstrates that ICU nurses and physicians show care and responsibility towards ICU families, although their family care strategies are mainly experiential and tacit. The study also reveals that despite the inherent unpredictability of ICU, family care can be facilitated by developing a family-friendly culture and environment. The ICU management has a vital role to play in enhancing nurses’ and physicians’ individual and interprofessional family care strategies by developing evidence-based guidelines and encouraging interprofessional dialogue and reflection.

Norwegian summary

Bakgrunn: Akutt og kritisk sykdom påvirker ikke bare pasienten, men også pasientens pårørende. Ivaretakelse og omsorg fra intensivavdelingens sykepleiere og leger kan redusere belastningen på pårørende og forbedre pasientens utfall. Tidligere forskning viser at selv om intensivpasienters pårørende generelt rapporterer om høy tilfredshet, finnes det flere barrierer for ivaretakelse av pårørende og områder for forbedring. Pårørende savner emosjonell støtte og å bli involvert i pasientbehandlingen. De rapporterer også om inkonsekvent informasjon og dårlig kommunikasjon med sykepleiere og leger. Dette indikerer at det er behov for mer kunnskap om eksisterende praksis vedrørende ivaretakelse av intensivpasienters pårørende. Studiens overordnede mål var å utforske sykepleieres og legers individuelle og tverrprofesjonelle strategier overfor pårørende til kritisk syke intensivpasienter, for å øke kunnskapen om eksisterende ICU-praksis og dermed forbedre pasient- og familieomsorgen.

Metode: Data ble samlet inn fra juli 2017 til august 2019, gjennom deltakende observasjon, fokusgrupper, dyadiske og individuelle intervjuer av leger og sykepleiere fra fire intensivavdelinger ved ulike norske sykehus. Konstruktivistisk grounded theory ble benyttet i artikkel 1 og 2, mens tematisk narrativ analyse ble benyttet i artikkel 3.

Funn: Artikkel 1, 2 og 3 omhandler henholdsvis hvordan informasjonsoverføring, tverrprofesjonell omsorg og en individuell tilnærming påvirker pårørendearbeidet. Sammen viser artiklene at ivaretakelse av pårørende er et tverrprofesjonelt ansvar, samtidig som sykepleiernes og legenes individuelle tilnærming til pårørende er avgjørende og at kontinuitet i pårørendeomsorgen må sikres gjennom god informasjonsflyt mellom klinikerne. Studien indikerer at ivaretakelse av pårørende i stor grad er basert på klinikernes erfaringer.

Konklusjon: Studien viser at intensivavdelingens sykepleiere og leger viser omsorg og ansvar for intensivpasienters pårørende. Deres pårørendestrategier er imidlertid hovedsakelig erfaringsbaserte og stilltiende. Studien avslører også at til tross for at arbeidshverdagen i intensivavdelingen er uforutsigbar, kan ivaretakelsen av pårørende forbedres ved å utvikle en familievennlig kultur og et familievennlig miljø. Intensivavdelingens ledelse spiller dessuten en viktig rolle i å styrke sykepleieres og legers individuelle og tverrprofesjonelle pårørendestrategier ved å utvikle evidensbaserte retningslinjer og oppmuntre til tverrprofesjonell dialog og refleksjon.

List of papers

Paper I

Nygaard, A.M., Haugdahl, H.S., Brinchmann, B.S., & Lind, R. (2020) Information concerning ICU patients' families in the handover – The clinicians' «game of whispers»: A qualitative study. Journal of Clinical Nursing. 29: 3822– 3834. https://doi.org/10.1111/jocn.15414

Paper II

Nygaard, A.M., Haugdahl, H.S., Brinchmann, B.S. & Lind, R. (2022) Interprofessional care for the ICU patient's family: solitary teamwork. Journal of Interprofessional Care. https://doi.org/10.1080/13561820.2022.2038548

Paper III

Nygaard A.M., Haugdahl H.S., Laholt H., Brinchmann B.S., & Lind R. (2022) Professionals' narratives of interactions with patients' families in intensive care. Nursing Ethics. 29(4):885-898. https://doi.org/10.1177/09697330211050995

Abbreviations

DI: Dyadic interview

FCC: Family-centered care

FG: Focus group

II: Individual interview

ICU: Intensive care unit

PFCC: Patient- and family-centered care

1 Introduction

There is increasing evidence of the significant impact that critical illness has on family members (Alfheim et al., 2019; Davidson et al., 2012; Van Beusekom et al., 2016). Family care unfolds in a complex and fast changing ICU environment where the focus on saving the patient's life (or enabling a dignified death) naturally has highest priority. In the acute phase, ICU patients are generally unable to express their needs due to the critical illness and/or the intensive care. Family members are important spokespeople and caregivers for the patient, while being in a very vulnerable situation themselves, needing care, comfort and support (Mitchell & Wilson, 2019). This places high demands on ICU physicians and nurses in terms of the care they can provide to the patient’s family. Their care can reduce the family members’ burden and improve the patient's outcome (Davidson et al., 2017). Although ICU families generally report high satisfaction (Frivold et al., 2018; Jensen et al., 2017; Scott et al., 2019; Sundararajan et al., 2012), there are several barriers to family care and areas for improvement (Hamilton et al., 2020; Hetland et al., 2018). In particular, family members report problems with inconsistent information and poor communication with clinicians, as well as a lack of emotional support and opportunities to become more involved in patient care (Frivold et al., 2015; Imanipour et al., 2019; Scott et al., 2019; Visser et al., 2014; Wong et al., 2015).

Although we have a broad picture of ICU families’ experience and needs, more knowledge is needed about ICU nurses’ and physicians’ interprofessional and individual strategies with families in order to optimize family care in the ICU.

2 Background

The increased focus on family care in the ICU in recent decades has resulted in more national and international studies on the families of ICU patients. This chapter presents the rationale for this PhD on the basis of existing empirical data, theory, guidelines and legislation. Intensive care and the ICU context are first described to enhance understanding of families' experiences and needs, as well as clinicians' responsibilities, tasks and challenges in family care. Since the study was conducted in Norway, it refers to Norwegian legislation. Finally, patient- and family-centered care (PFCC) is explained, which forms the theoretical foundation of the study.

2.1 The context of ICU family care

Intensive care (also called critical care) is a multidisciplinary and interprofessional specialty which provides treatment to patients with established or potential organ failure, particularly of the lungs, cardiovascular system and kidneys. There are often fine margins between life and death, and intensive care is complex and resource-intensive with a high risk of adverse events. The specialty includes high expertise in pathophysiology and organ support (Marshall et al., 2017). The primary goal of intensive care is to prevent further physiological deterioration while treating the underlying disease (Marshall et al., 2017).

ICUs are characterized by a high-tech and stressful environment, advanced forms of treatment and specialized healthcare personnel (Donovan et al., 2018; Ervin et al., 2018). Marshall et al. (2017) define ICU as:

> *"an organized system for the provision of care to critically ill patients that provides intensive and specialized medical and nursing care, an enhanced capacity for monitoring, and multiple modalities of physiologic organ support to sustain life during a period of acute organ system insufficiency. Although an ICU is based in a defined geographic area of a hospital, its activities often extend beyond the walls of the physical space to include the emergency department, hospital ward, and follow-up clinic"*.

Most Norwegian ICUs are general intensive care units that treat patients of all ages with severe single or multi-organ failure, regardless of their basic condition. Some university hospitals have specialized units for intensive care, such as neurosurgical or pediatric ICUs.

ICUs are divided into levels from 1-3 based on staff qualifications and treatment options (Søreide et al., 2014; Valentin et al., 2011). Level 3, the most advanced intensive care, is provided by university hospitals. ICUs are run by a senior physician and a nurse manager who coordinate staffing and care needs, establish guidelines and priorities for patient care and cooperate to provide high-quality operation of the ICU (Marshall et al., 2017; Søreide et al., 2014).

The number of beds in an ICU varies, but 8-12 beds is thought to be the optimal size (Valentin et al., 2011). ICUs in older hospitals often have a combination of single and multi-bed rooms, while single rooms are recommended in new hospitals (Marshall et al., 2017) to protect patients from noise and other stressful stimuli, ensure privacy and decrease the likelihood of cross-contamination (Søreide et al., 2014; Valentin et al., 2011). However, while single rooms are advantageous for patients and their families, they are expensive to operate (Marshall et al., 2017). ICUs usually have one or more rooms for families, but limited possibilities for overnight stays. Post-ICU follow-up clinics for former patients and their families are not common in Norway.

In 2020, there were 14 398 patients in Norwegian ICUs, with a total of 67 171 ICU days. 41% of the ICU patients were women, 59% men (Buanes et al., 2021). The length of stay ranged from a few hours to several weeks; about 50% of patients stayed for under 48 hours, while around ten percent stayed for a week or more. Ten percent of the patients died in the ICU, and a further 20% during the 30 days following transfer from the ICU. The average age of ICU patients in Norway in 2020 was 62 years (median 68 years) (Buanes et al., 2021). The proportion of elderly ICU patients was higher in mid-range hospitals than in university hospitals.

Intensive care requires interprofessional competence and a large number of staff day and night. ICU nurses and physicians (anesthesiologists/intensivists[1]) constitute the core ICU team, collaborating with physicians from other specialties, physiotherapists, dieticians, social workers, pharmacists and chaplains (Donovan et al., 2018; Ervin et al., 2018; Marshall et al.,

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[1] Norwegian ICUs are primarily staffed by anesthesiologists and/or intensivists. In Norway, an intensivist is defined as an intensive care physician who has completed the further education in intensive care medicine of the SSAI (The Scandinavian Society of Anaesthesiology and Intensive Care Medicine). In this thesis, ICU physician is used as a general term for all physicians working in the ICU.

2017). To some extent, the composition of the ICU team varies between countries and individual ICUs. The typical numbers of nurses and physicians in an ICU vary according to level, and are based on maintaining preparedness for emergency care and providing care to current patients. The typical figures will also vary with the other groups of healthcare staff working in the ICU. In Norway, only physicians and nurses work directly with patients, whereas for example in the USA, respiratory therapists manage the mechanical ventilator (Donovan et al., 2018; Ervin et al., 2018; Marshall et al., 2017), while in Sweden assistant nurses work alongside qualified nurses to provide patient care (Bjurling-Sjöberg et al., 2017). In Norwegian level 2 and 3 ICUs, the nurse-patient ratio is at least 1:1 (Søreide et al., 2014) .

Working in an ICU is challenging and stressful (Van Mol et al., 2015). Not only does the job require intensive care specialization, but it also places great emotional strain on staff, since they deal with patients and their families in a crisis on a daily basis'. Intensive care has saved an increasing number of lives in the last ten years (Milliken & Sadovnikoff, 2020) but it has also involved more ethical dilemmas, especially in relation to decisions to limit life-prolonging treatment (Michalsen & Jensen, 2020) in situations where intensive care gives a patient a very poor quality of life, or painful and prolonged dying. Decisions to limit treatment must be made on an interdisciplinary basis, and information on the patient's and relatives' views must be emphasized (Michalsen et al., 2019; Søreide et al., 2014). However, decisions can create conflicts both within the ICU team and between the team and the patient and family (Michalsen et al., 2019). Moral distress, fatigue and burnout are highly prevalent among ICU nurses and physicians (Epp, 2012; Van Mol et al., 2015). This not only has a negative effect on clinicians, but also on patient and family care and satisfaction (Lamiani et al., 2020).

2.2 The ICU patient's family

According to the Directorate of Health, a patient's "closest person(s)" are one or more people who are in the patient's closest family or who are close to the patient in another way (Helsedirektoratet, 2017). Patients themselves decide whom they consider as their "closest person(s)" (Helsedirektoratet, 2017; Pasient-og brukerrettighetsloven, 1999). This person or persons are generally part of the patient's family[2], but they could also include a good friend or neighbor. The patient’s choice must be respected by other family members and the clinicians. If a patient is incapable of naming the “closest person(s)”, the responsible clinician must clarify this (Helsedirektoratet, 2017).

In Norwegian health legislation (Pasient-og brukerrettighetsloven, 1999), a distinction is made between “family” and “closest family member(s)/person(s)”. The latter have had the most permanent and ongoing contact with the patient (Pasient-og brukerrettighetsloven, 1999). The name(s) of the closest person(s) must be entered in the patient record (Helsepersonelloven, 1999). If a patient is unable to state who the closest person or persons are, clinicians must consult with family members or examine previous information in the patient’s record. Disagreements within the patient's family and/or new family relationships can make this challenging for health professionals if several people consider themselves to be the patient's closest family member.

Family members have varied reactions and different care needs when their loved one is admitted to the ICU, depending on their relationship to the patient, their previous experience and their cultural and socio-economic background. Even members of the same family can react very differently and have different needs (Jensen et al., 2020). The number of family members an ICU patient has will also vary. One or two people are defined as the patient’s “closest persons” in health legislation, but ICU patients may have many relatives such as siblings, children and grandchildren who is affected by the patient's critical illness and admission to the ICU.

2.3 ICU family members’ experiences and satisfaction

The ICU environment is unfamiliar to most families (Imanipour et al., 2019; Wong et al., 2017) and the unfamiliar and unpredictable situation makes families particularly vulnerable (Baumhover & May, 2013; Van Beusekom et al., 2016). Many are afraid that their loved one will die or suffer permanent damage (Imanipour et al., 2019; Wong et al., 2017). Several family members develop psychosocial symptoms such as anxiety, acute stress disorder,

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[2] Unlike the English terms “relatives” and “family”, the Norwegian term “pårørende” can also include close friends. As there is no exact English equivalent to “pårørende”, the terms “family (members)” and “relatives” as used in this dissertation describing the Norwegian context must be understood as including significant others outside the patient’s family in some cases.

posttraumatic stress, sleep deprivation, depression, decreased health-related quality of life and complicated grief (Alfheim et al., 2018; Beesley et al., 2018; Davidson et al., 2012; Van Beusekom et al., 2016). This cluster of complications is called post-intensive care syndrome-family (PICS-F) (Davidson et al., 2012; Schmidt & Azoulay, 2012). The incidence of psychosocial problems is highest during and shortly after admission to the ICU, but some family members develop long-term effects that last for several weeks and months, even years. A Norwegian study (Alfheim et al., 2019) showed that while over 50% of relatives had post-traumatic stress symptoms during the patient's stay in the ICU, as many as 24% still had symptoms one year after the stay. Several risk factors for PICS-F have been identified: female gender, age of family member or patient, low education level, history of anxiety and amount of social support (Beesley et al., 2018; Davidson et al., 2012). If the patient dies or is in a life-threatening condition, relatives who are dissatisfied with communication with clinicians or participation in decision making are at greater risk of developing PICS-F (Beesley et al., 2018; Davidson et al., 2012).

Family satisfaction is one of the internationally recommended quality indicators for ICUs (Rhodes et al., 2012), and is also included in the Norwegian Intensive Care and Pandemic Registry (Buanes et al., 2021). National results (Frivold et al., 2018; Haave et al., 2021) agree with international findings (Heyland et al., 2002; Scott et al., 2019) showing that family satisfaction is generally high, but that there are areas for improvement. While family members are very satisfied with patient care and treatment and the knowledge and skill of ICU clinicians, they are less satisfied with the care they receive themselves and clinicians' communication with them (Carlson et al., 2015; Frivold et al., 2018; Haave et al., 2021; Scott et al., 2019). They lack emotional support and want to be more involved and to be given consistent and up-to-date information (Carlson et al., 2015; Jensen et al., 2020; Scott et al., 2019). Some studies (Frivold et al., 2018; Sundararajan et al., 2012) have shown that families are more satisfied with communication with nurses than with physicians.

Various factors may influence family satisfaction, such as their expectations, their attitude towards life and death, patient-related factors, hospital infrastructure and the care process (Rothen et al., 2010; Stricker et al., 2009). The severity of the patient's illness may also affect the degree of family satisfaction. For example, studies have shown that family members of patients who died in the ICU are more satisfied with support and inclusion in decision-making than family members of survivors (Frivold et al., 2018; Stricker et al., 2009; Wall et al., 2007). Similar results have been reported with regard to mechanical ventilation, where relatives of mechanically ventilated patients were more satisfied than relatives of patients who were not mechanically ventilated (Frivold et al., 2018; Stricker et al., 2009).

2.4 ICU family members’ rights and needs

The rights of family members are subject to health legislation (Helsepersonelloven, 1999; Pasient-og brukerrettighetsloven, 1999) and include the possibility to act in the patient’s best interest. The legislation states that family members’ involvement in healthcare must be expanded and clarified and that clinicians are responsible for ensuring that their rights are met and for supporting them in the ICU (Helsedirektoratet, 2017). Family members must receive respect and care and necessary information and follow-up must be ensured. They are to be considered as a resource and their knowledge should be recognized by clinicians. Particular rules apply to the duties of clinicians when the family members are children (Helsedirektoratet, 2017). Healthcare management is responsible for ensuring compliance with health policy requirements, by e.g. developing internal procedures, routines and tools, training healthcare staff, changing the organizational structure, improving collaboration and developing new services for family members (Helsedirektoratet, 2017) .

ICU patients with decision-making capacity can decide for themselves the degree of involvement of their family members (Pasient-og brukerrettighetsloven, 1999). However, the closest family members have expanded rights to receive information and become involved in the patient’s care and treatment if the patient lacks decision-making capacity (Helsepersonelloven, 1999; Pasient-og brukerrettighetsloven, 1999). However, the closest family members have limited decision-making power (Helsepersonelloven, 1999). This contrasts with for example the USA, where the family can be responsible for a decision to withdraw life-sustaining treatment (Kentish-Barnes et al., 2020). In Norway, as in most other European countries, the final decision-making responsibility is left to the physician (Moselli et al., 2006; Sprung et al., 2003). One reason for this is to prevent family members from feeling additional stress due to responsibility in situations such as limiting life-prolonging treatment (Frivold et al., 2018; Lind, 2019). However, the family must be involved and heard in order to express the patient’s wishes (Pasient-og brukerrettighetsloven, 1999).

The main needs of family members are reassurance and information, while other needs are proximity, comfort, hope and support (Al-Mutair et al., 2013; Molter, 1979; Scott et al., 2019). However, the review by Al-Mutair et al. (2013) shows that family members rank their needs significantly differently from healthcare providers in the ICU. This clarifies how important it is for ICU nurses and physicians to ask family members to state their needs.

In order to help the family to cope with the situation and to prevent psychosocial problems, it is crucial that they understand what happens in the ICU (Frivold et al., 2016; Manias et al., 2019; Wong et al., 2017). The family naturally needs information about the patient's condition and treatment, but also about practical matters such as visiting hours and the possibility of overnight stays. Many families need specific advice on how to handle the new situation and their daily lives. This information must be consistent, repeated, and provided in everyday language (Briggs, 2017; Manias et al., 2019; Wong et al., 2015). It is important for relatives to maintain hope (Al-Mutair et al., 2013; Wetzig & Mitchell, 2017), but it is also essential to provide honest and realistic information (Gutierrez, 2012; Wetzig & Mitchell, 2017; Wong et al., 2015). Information must be given in a considerate manner and nurses and physicians must do their utmost to ensure that the patient's family has understood the information (Helsedirektoratet, 2017). This requires excellent communication skills and cooperative ability on the part of clinicians.

Communication with the patient's family has at least two purposes: the first is to ensure effective and supportive information through reviews of the patient's condition, treatment and prognosis, and to try to maintain a focus on the patient and his or her interests. The second purpose is to help the family members to understand the information, to assist them in reformulating what they know and to elicit their reflections and questions about the situation. In addition, families value explicit acknowledgement of their emotions and need for reassurance (Carlson et al., 2015; Wetzig & Mitchell, 2017; Wong et al., 2015). They fail to comprehend even basic information provided about the illness, treatment and prognosis while still overwhelmed by strong emotions (Wong et al., 2017). Families thus need time to recuperate, and the clinicians must listen carefully to the family because they possess essential information about the patient to enable nurses and physicians to provide optimal patient care (Engström & Söderberg, 2007; McAdam et al., 2008; McDonagh et al., 2004). Relevant information to and from the family must be entered in the patient record or other medical documentation systems (Helsedirektoratet, 2017).

It is vital for family members to be with the patient in the ICU (Al-Mutair et al., 2013; Leske, 1986; Molter, 1979). To see with their own eyes that their loved one is in good hands is crucial for the family's sense of control and understanding of the situation (McAdam et al., 2008; Plakas et al., 2014). It is particularly important to families that the patient receives optimal care and treatment, is seen as a person and treated with respect, and that pain and other discomfort are minimized (McAdam et al., 2008; Nelson et al., 2010). Families want to be involved and to be a resource by supporting and protecting the patient (Haugdahl et al., 2018; McAdam et al., 2008; Nelson et al., 2010; Plakas et al., 2014). This is also important for their feelings of security, trust and cooperation with clinicians. Therefore, open or flexible family presence at the bedside is recommended (Davidson et al., 2017). In addition to improving family members' satisfaction, flexible visiting hours have shown a potential to reduce delirium and anxiety symptoms among ICU patients (Davidson et al., 2017; Nassar Junior et al., 2018). For many patients, family members also increase their sense of security and their motivation; their presence and active involvement in patient care can thus improve the patient's outcome (Davidson et al., 2017; Goldfarb et al., 2017; Mitchell & Wilson, 2019). However, there are several points to consider regarding family presence in the ICU, mainly due to the patient's need for confidentiality and privacy (Mitchell & Wilson, 2019; Ning & Cope, 2020). Although family presence may be important for the patient, it may also cause worry and concern (Halvorsen et al., 2022). For ICU clinicians, flexible visiting hours may increase workload, stress and risk of burnout (Davidson et al., 2017; Nassar Junior et al., 2018). The design of the ICU and its rooms and the severity of the patient's illness will also affect the ability of family members to be present (Ning & Cope, 2020). Although an open visiting policy is recommended and more common, there is great variation between ICUs, both in Norway and globally (Frivold et al., 2022; Nassar Junior et al., 2018). There are still several Norwegian ICUs with visiting hours limited to a few hours daily (Frivold et al., 2022).

It is also important to address the family's physical needs, such as providing comfortable chairs, access to food and drink, a waiting area close to the patient, and the possibility to rest or sleep. They need emotional support and comfort, and the opportunity to be alone and to talk about difficult feelings (Norton, 2018). However, Olding et al. (2016) point out that an exclusive focus on needs may make the family merely passive recipients and less involved in the care of the patient. The degree of family involvement may vary from being bedside to actively participating in decision-making and contributing to care (Olding et al., 2016). Family presence during handovers, the physician's round, invasive procedures and resuscitation are examples of measures aimed to increase families' involvement and to improve the quality of family care (Davidson et al., 2017; Frivold et al., 2022; Olding et al., 2016). However, it has proved difficult to implement such routines and establish a culture where the ICU family is actively involved in patient care (Al-Mutair et al., 2013; Hetland et al., 2018; McAndrew et al., 2020). It is also challenging for ICU clinicians to find the right balance in the family's participation and their feeling of responsibility following participation (Lind, 2019).

2.5 Interprofessional care in the ICU

Interprofessional care is a collaborative, team-based approach to providing optimal care (Paradis et al., 2014) described by Donovan et al. (2018) as:

> *"… care provided by a team of health care professionals with overlapping expertise and an appreciation for unique contribution of other team members as partners in achieving a common goal"*.

In intensive care the importance of the interprofessional team and each individual profession is emphasized to ensure optimal care, treatment and outcome (Ervin et al., 2018; Paradis et al., 2014). The responsibilities and tasks of the individual professions partly overlap with strong mutual dependence in the ICU team (Bjurling-Sjöberg et al., 2017; Donovan et al., 2018). ICU nurses and physicians are jointly responsible for family care under Norwegian legislation (Helsepersonelloven, 1999). This is also reflected in the job descriptions of the professions (NSFLIS, 2017; Søreide et al., 2014) and in ethical guidelines (Den norske legeforeningen, 2015; Norsk Sykepleierforbund, 2012).

Interprofessional care have received increased attention in recent years to prevent adverse events and provide effective, high-quality treatment and care (Paradis et al., 2014; Reeves et al., 2015). An effective ICU team that collaborates well can ensure that families do not receive inconsistent and misleading information (Chen et al., 2018; Reeves et al., 2015; Wong et al., 2015). An additional burden for some family members arises when they experience internal conflicts and unprofessional staff behavior in the care team, within the group of nurses, between nurses and physicians, or between physicians from different units (Azoulay et al., 2009; Fassier & Azoulay, 2010). Clinicians may perceive the patient's condition differently (Halvorsen et al., 2009; Mosenthal et al., 2012), and conflicts and dissent in the team can sow doubt and mistrust about treatment goals and decisions. Unsatisfactory team collaboration and lack of regular meetings to discuss patient and family care are common causes of conflicts between nurses and physicians (Curtis & Shannon, 2006; Puntillo & McAdam, 2006). In the case of ICU nurses and physicians, conflicts may generate moral distress, dissatisfaction, anxiety, perception of inappropriate care and feelings of burnout (Fassier & Azoulay, 2010).

Although teamwork is emphasized in intensive care (Donovan et al., 2018; Ervin et al., 2018), several studies have identified that traditional hierarchies, working in silos, miscommunication and tensions between clinicians still exist (Alexanian et al., 2015; Dietz et al., 2014; Paradis et al., 2014; Reeves et al., 2015; Rodriquez, 2015), which negatively affect the ICU team's work and jeopardize high-quality, safe and effective treatment and care. Generally, physicians have a more positive view of teamwork than nurses (O'Leary et al., 2010). Other studies have also identified a gap between how ICU professionals talk about teamwork and how teamwork is actually practiced (Bjurling-Sjöberg et al., 2017; Rodriquez, 2015).

Recent decades have seen an increasing emphasis on including the patient’s family as an active part of the ICU team (Davidson et al., 2017; Donovan et al., 2018; Ervin et al., 2018). ICU nurses and physicians underline the importance of the family’s role (Rodriquez, 2015). Clinicians can learn a great deal about a patient through collaboration with the patient’s family (Ervin et al., 2018; Rodriquez, 2015). However, by dint of their position, ICU physicians and nurses can to a large extent decide how much the family is involved and can be bedside (Ågård & Lomborg, 2011).

2.6 Patient- and family-centered care in the ICU

The theoretical foundation for this study is family-centered care (FCC) which views the patient’s family as the unit around which care delivery should be organized. This approach recognizes that the patient is part of a larger social unit, *the family*, which is an important factor for mental and physical health (Spooner et al., 2018). FCC is a holistic approach to healthcare that respects and responds to individual families’ values and needs (Burns et al., 2018; Davidson et al., 2017).

FCC emerged in the 1990s, first in neonatal and pediatric nursing, where the inclusion of the family was seen as fundamental to the care of sick children (Mitchell et al., 2016; Mitchell & Wilson, 2019). Later, FCC has been extended to all patients, irrespective of age and level of care (IPFCC, 2016; Mitchell & Wilson, 2019). During the past decade, the FCC concept has been expanded to become patient- and family-centered care (PFCC) (Mitchell et al., 2016; Mitchell & Wilson, 2019), defined as (IPFCC, 2016):

> *"an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families".*

In PFCC, the importance of the patient's and family members' cooperation with healthcare professionals is highlighted (IPFCC, 2016). It is a philosophical approach to care, based on four key concepts: dignity and respect, information sharing, participation, and collaboration, where patients and family members are seen as important allies in enhancing the quality and safety of healthcare (Henneman & Cardin, 2002; IPFCC, 2016). This approach has several advantages: it improves treatment outcomes and care experiences of patients and their families, increases health professionals' job satisfaction and leads to better utilization of healthcare resources (IPFCC, 2016). PFCC interventions can shorten the ICU stay, increase patient and family satisfaction and improve mental health outcomes (Goldfarb et al., 2017).

PFCC is particularly emphasized in the ICU due to the severity of the illness and patients' inability to safeguard their own interests (Davidson et al., 2017; Goldfarb et al., 2017). In addition to providing patient care, ICU nurses and physicians must meet families' needs, reduce the stress of critical illness and prepare families for decisions and care requirements during and after the ICU stay (Davidson et al., 2017; Goldfarb et al., 2017; Henneman & Cardin, 2002).

To optimize clinicians' support of ICU patients' family members, Davidson et al. (2017) have developed evidence-based guidelines for family-centered care in the neonatal, pediatric and adult ICU, with five key recommendations: (1) family presence in the ICU, (2) family support, (3) communication with family members, (4) use of specific consultations and ICU team members and (5) operational and environmental issues. The recommendations are based on a summary of best practices as identified by existing evidence related to supporting families in the ICU. The staff of each individual ICU should review these recommendations and assess which ones are most relevant to their unit, family-centered care practice, their interests, and their available resources (Davidson et al., 2017).

It has proven difficult to implement PFCC in ICUs (Mitchell et al., 2016; Reeves et al., 2019; Van Mol et al., 2015). Lack of a common understanding of teamwork, lack of support from all nurses, visiting policy, work overload, the healthcare provider's attitudes, and inadequate communication between physicians and nurses are examples of identified barriers to PFCC

(Kiwanuka et al., 2019). Implementation of PFCC calls for a comprehensive effort and a common understanding in the ICU. The practice of PFCC is linked to one or more specific interventions, but the PFCC concept is also a holistic approach that needs to permeate the ICU. For example, it does not help to have flexible visiting hours if the staff does not look after and include the families who visit (Henneman & Cardin, 2002). Strong leaders, caring staff and support of a committed multidisciplinary team are features of ICUs that have succeeded in implementing PFCC (Henneman & Cardin, 2002). The vital role of nurses is family care has also been emphasized (McAndrew et al., 2020). Their continuous presence places them in a unique position to lead and support the interdisciplinary ICU team in order to ensure family-centered care (McAndrew 2020). However, there is a complex and dynamic interplay of facilitators and disruptors that affects nurses' efforts to promote family engagement. Important facilitators identified are organizational responsiveness facilitators, unit support facilitators, family adaptation facilitators and ICU nurses facilitators (McAndrew et al., 2020).

2.7 Knowledge gaps

There is broad agreement that PFCC and more active involvement of families must be implemented in intensive care settings (Davidson et al., 2017). Despite considerable research on interprofessional care and teamwork in the ICU, few studies have explored interprofessional *family care* through direct observation and fieldwork. We lack empirical knowledge of how families are involved and how/to what extent the PFCC principles are expressed in clinical practice. Exploring ICU nurses’ and physicians’ interprofessional and individual strategies for family care will enhance knowledge of existing ICU practices and potentially improve family and patient care.

3 Aims

Overall aims:

The overall aim of this study was to explore ICU nurses’ and physicians’ individual and interprofessional strategies for providing care to the families of critically ill ICU patients, in order to enhance knowledge of existing ICU practices and hereby improve patient and family care.

Specific aims:

Paper 1: To explore how information concerning ICU patients´ families was included in ICU clinicians’ daily handovers.

Paper 2: To explore how ICU teams’ interprofessional family care was reflected in their daily work.

Paper 3: To explore ICU nurses’ and physicians’ bedside interaction with critically ill ICU patients´ families and discuss this in light of the ethics of care.

4 Methodology, materials and methods

In this PhD, where the purpose was to explore nurses' and physicians' individual and interprofessional family care approaches in an intensive care setting, a qualitative exploratory design was considered suitable. Qualitative research is used to investigate social phenomena in their natural context, as experienced by the people who have lived experience of them (Creswell & Poth, 2018). The researcher seeks to understand and describe people's characteristics, interpersonal relationships and understandings of the world. A qualitative approach is also suitable for exploring dynamic processes such as interaction and development and providing a holistic perspective (Creswell & Poth, 2018; Malterud, 2017).

Qualitative research involves different working methods and is based on different methodologies (Creswell & Poth, 2018). Constructivist grounded theory was used in Paper 1 and 2, while in Paper 3 thematic narrative analysis was used. The data were triangulated through participant observation, focus groups, and individual and dyadic interviews with physicians and nurses. The rationale for the choices of methods is presented and justified in this chapter. However, first I will present my starting point and preunderstanding in relation to this research project.

4.1 Starting point and preunderstanding

When I started as a research fellow in this project, my main supervisor Ranveig Lind had already designed[3] the research project and applied for and received funding from the Northern Norway Regional Health Authority (Grant No. HNF1365-17). The necessary approvals from the Regional Committee for Medical and Health Research Ethics (Ref.: 2016/1762, Appendix 1) and the Norwegian Centre for Research Data (NSD ref. nr. 49672, Appendix 2) were also obtained.

Lind has extensive experience from the research field, as an ICU nurse, previously the head nurse of an ICU, and as an associate professor and researcher. The main emphasis of her research work, including her own PhD, is on family care in the ICU. Ranveig Lind and one of my co-supervisors Berit Støre Brinchmann had also conducted two focus groups (FG 1 and 2,

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[3] In Paper 1, I mistakenly stated that Berit Støre Brinchmann designed the study with Ranveig Lind. This is incorrect; Ranveig Lind designed the study alone.

ICU 1, Table 1) as part of the preparation for the study and the data collection, before I started my PhD.

I started my work in the project by carefully reading the research protocol, including the literature referred to in the protocol. This gave me an overall impression of the research project. I have 20 years' experience as an ICU nurse and have been working full-time in an ICU for over 15 years, followed by a position as an assistant professor in ICU nursing at a university. I considered that this work experience had provided me with good knowledge of the research field and I recognized the preliminary research questions and knowledge gaps presented in the protocol. However, I had little experience of doing qualitative research and using grounded theory. I started to prepare myself for the study and the data collection by reading research method literature and taking PhD courses. I also transcribed and started to analyze the interviews from the focus groups Lind and Brinchmann had conducted.

Another important preparation at this early stage was to write down all my reflections about family care in the ICU. As an ICU nurse, I have taken care of many family members in the ICU and as an assistant professor, I have given lessons and tutored many students in this subject. These experiences have shaped my views and assumptions on family care in an intensive care setting. During my reflections, I asked myself questions such as: *What is good quality care for the ICU patient's family? What are their most important needs? Why is it important to take care of family members? How should physicians and nurses cooperate on family care? How can good family care be learned? What do I find the most challenging aspect of family care? How do I feel about taking care of/meeting family members? Are there things I find difficult or dread, and things I find easy? How does the ICU clinician's attitude and personality influence family care?*

In qualitative research, including constructivist grounded theory, the researcher's reflexivity is emphasized (Charmaz, 2014; Polit & Beck, 2020). By writing down my preconceptions and views about family care, I clarified to myself my assumptions and expected findings. I also made reflections about doing fieldwork and conducting focus groups, such as: *How should I behave during the observations? How much will I influence the data collection? Will I disrupt the clinicians during their work? How can I ask questions in the best possible way?* I consider these reflections as an important and necessary preparation for the data collection and analysis.

4.2 Constructivist grounded theory

Grounded theory consists of both a research method and a result of the research. The researcher uses it as a method to construct a grounded theory (Chun Tie et al., 2019). A grounded theory approach can also be used to gain a deeper understanding of a phenomenon and construct a conceptual framework without producing a grounded theory as a result (Charmaz, 2014). The method is appropriate for open and exploratory research questions in unfamiliar research fields. Grounded theory is well suited for studying structural processes both in social settings and in participants' recollection of events through research interviews. It places priority on the studied phenomenon and explores how participants construct meanings and actions in specific situations (Timmermans & Tavory, 2007). This method was chosen to elicit a broad view of ICU nurses' and physicians' family care practices.

Grounded theory has roots in positivism, pragmatism and symbolic interactionism, developed by the two sociologists Barney G. Glaser and Anselm L. Strauss (Thornberg & Charmaz, 2014). With the development of grounded theory they proposed systematic strategies for qualitative research practice and responded to quantitative researchers who criticized qualitative research as unsystematic, biased, subjective and anecdotal (Charmaz, 2014). They presented a thorough method of qualitative data analysis and theory construction and emphasized that a qualitative study must be transparent, comprehensive and replicable. They aimed to show that findings in qualitative studies could have as much significance as results of quantitative studies (Bryant & Charmaz, 2007).

The methodology combines inductive and abductive strategies to develop concepts and theories grounded in data. Based on inductive data and with the use of iterative and comparative strategies between data and analysis, conceptual categories emerge and data collection and analysis take place in parallel (Bryant & Charmaz, 2007; Charmaz, 2014). The researcher starts with an open mind and searches for the participants' main concern and how this concern can be addressed, expressed in terms of a core category and sub-categories.

In the early 2000s, Kathy Charmaz developed a contemporary version of grounded theory, constructivist grounded theory, in which the researcher's significance for the research process and theory development is emphasized (Charmaz, 2014). Charmaz answered the criticism about the traditional version of grounded theory and moved away from the positivistic and objectivistic perspectives (Charmaz, 2014). In constructivist grounded theory, subjectivity and interaction are highlighted, and neither data nor analysis are seen as neutral. The research and knowledge development are seen in a historical, social and situational context (Charmaz, 2017) . The researcher and the participants are seen as co-constructors of data, influenced by the researcher´s interactions with the participants, their perspective, and the research practice (Charmaz, 2016; Giles et al., 2016). This requires asking in-depth questions about the data and carefully examining the research process and oneself as the researcher (Charmaz, 2017). The researcher’s reflexivity and awareness throughout the research process is emphasized (Thornberg & Charmaz, 2014). Reflexivity clarifies how the researcher influences the research process and results based on his/her previous research experience, interests, decisions and interpretations (Charmaz, 2014). The researcher’s analytical focus is not predetermined; it emerges during the research process (Charmaz & Thornberg, 2021). Although the researcher may have defined some preliminary research questions, he/she must be willing to leave these questions aside when other, more significant and interesting questions emerge from the data (Charmaz, 2014). Crucial insight and detection of analytical connections can emerge at any time during the process (Charmaz, 2014).

Constructivist grounded theory adopts original methodological strategies from classic grounded theory such as simultaneous data collection and analysis, theoretical sampling and saturation, coding and categorizing, the constant comparative method and memo writing (Figure 1) (Charmaz, 2014). This is not a linear step-by-step procedure but a constant back and forth process to construct and generate new concepts (Charmaz, 2014).

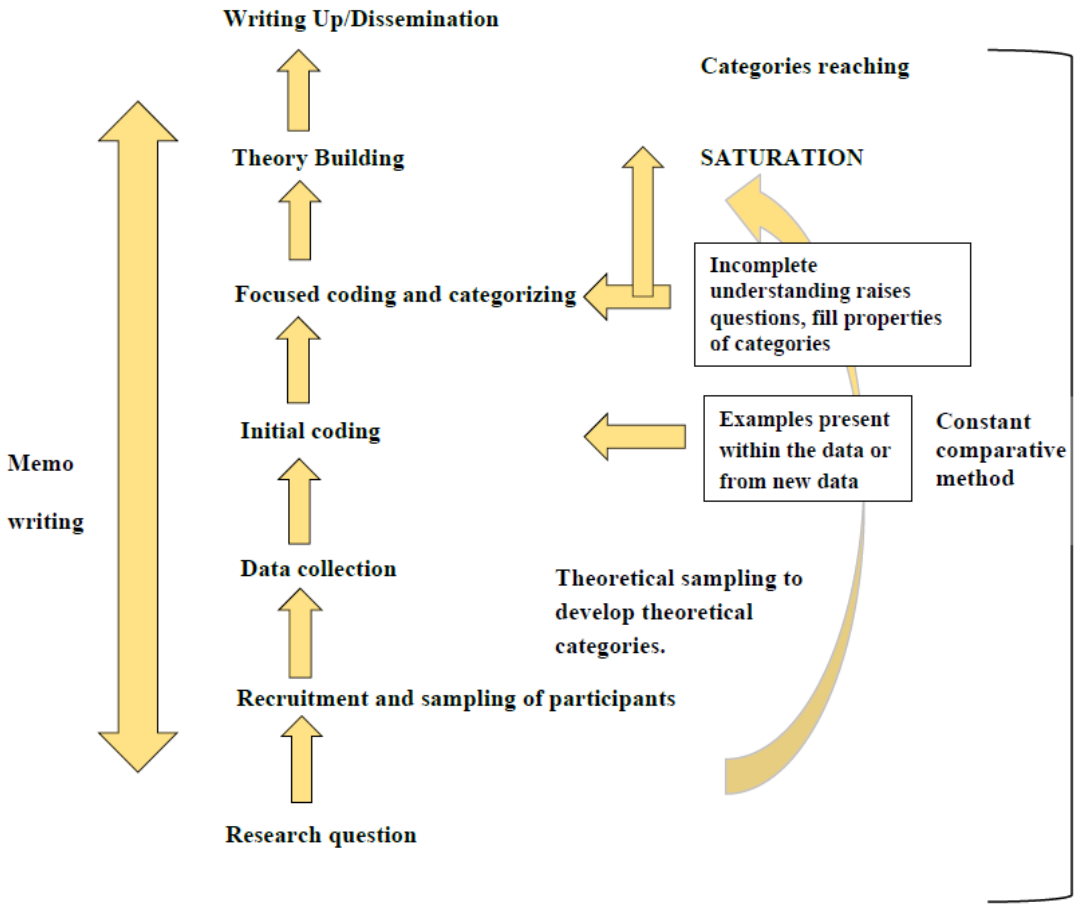

Figure 1: Constructivist grounded theory (Charmaz, 2014)

Simultaneous data collection and analysis is a hallmark of grounded theory, where the data analysis starts immediately after each data collection, helping the researcher to focus on the most significant issues and to develop the conceptual categories gradually (Charmaz & Thornberg, 2021). The categories emerge during the analysis, which moves from the data through initial and focused codes to more abstract categories. Coding means naming a segment of data that categorizes, summarizes, and accounts for each piece of data (Thornberg & Charmaz, 2014). Through coding the researcher defines what is happening in the data and it is the essential link between data gathering and developing an emergent category or theory to explain these data (Charmaz, 2014).

Constructivist grounded theory coding involves initial coding by naming each word, phrase or segment of data and focused coding where the most significant or frequent initial codes emerge. During the initial coding, the researcher remains open to all the possible theoretical directions that may emerge from a careful reading of the data. The researcher then uses the focused codes to sort, synthesize, integrate and organize large batches of data (Charmaz, 2014). The analysis is a back-and-forth process that involves constantly comparing data, codes and categories to successively generate more abstract theoretical/conceptual categories using the constant comparative method (Charmaz, 2014). Based on one or more tentative categories selected from the focused codes, the researcher goes back to the research field and seeks more data to illuminate the category or set of categories and define their properties, boundaries and relevance (Charmaz, 2014). This process, called theoretical sampling, is referred to as (Glaser & Strauss, 1967):

> *"the process of data collection for generating theory whereby the analyst jointly collects, codes, and analyses his data and decides what data to collect next and where to find them".*

When new questions, insights and ideas emerge during the analysis, this may lead the researcher to expand or add new data collection methods (Thornberg & Charmaz, 2014). In grounded theory, all kinds of data can be accommodated. It is not the type of data that determines the direction of the data collection, but the relevance of the data to the theory or the concepts being developed. In this regard, Glaser coined the often quoted maxim "Everything is data" (Thornberg & Charmaz, 2014). Theoretical sampling also involves abduction, where the researcher reflects on possible theoretical explanations of the observed data and the emerging categories and brings these explanations (hypotheses) to the next data collection and analysis by making comparisons and interpretations in a search for patterns and the best possible explanations (Charmaz, 2014; Thornberg & Charmaz, 2014).

Theoretical sampling should not be confused with the initial sampling strategies that the researcher has to consider in the planning phase of the study (Thornberg & Charmaz, 2014). Grounded theorists also have to make these considerations, but once they have started collecting data, the alternation between data collection and analysis takes over, paving the way for the further data collection (Thornberg & Charmaz, 2014). Data are gathered until *saturation*, which refers to the point where the data no longer generate anything new for the emerging categories (Charmaz, 2014).

In grounded theory, the researcher writes informal analytical notes called memos throughout the research process (Charmaz, 2014). This is an essential intermediate stage between data collection, analysis and the written research paper (Charmaz, 2014). The purpose is to capture the researcher's ideas and thoughts. The researcher asks analytical questions of the collected data and notes down ideas and reflections about emerging codes, categories and the relationship between them. Memo writing helps the researcher to start the analysis early and to increase the level of abstraction gradually (Charmaz, 2014).

In contrast to classical grounded theory, which advocated delaying the literature review until after the data collection and the development of the categories (Giles et al., 2013), Charmaz (2014) recommends a preliminary literature review prior to the study, in order to improve understanding of the research topics and provide an initial framework for the study (Charmaz, 2014; Thornberg & Charmaz, 2014). During the analysis, the researcher draws on previous theoretical knowledge, using the literature to see multiple possible approaches in the data. According to Thornberg and Charmaz (2014), researchers' ability to draw good abductive inferences is dependent on their previous knowledge and their ability to be open-minded. A critical and reflective stance is necessary to avoid forcing the research into preconceived categories (Charmaz, 2014).

4.3 Data collection methods

In order to obtain data from the ICU physicians and nurses, we originally decided to combine the methods of participant observation and focus groups for our data collection. Participant observation is suitable when the researcher seeks knowledge about group interactions and activities that make sense of human behaviour and experiences (Polit & Beck, 2020). In this study, I observed physicians and nurses in their natural work environment in various ICUs. Accompanying them throughout their working day brought me close to their reality. It enabled me to examine the nature of professional and interprofessional interactions and exchanges, to identify how healthcare professionals interact in practice, both within and between professional groups (Reeves et al., 2019).

The degree of participation and involvement of the researcher during observation can vary from neither participation nor involvement to complete participation and a high degree of involvement (Spradley, 1980). In this study, I as the researcher used what Spradley (1980) calls “moderate participation”, where I found a balance between being an insider and an outsider. Since I am an ICU nurse, I was able to participate as an insider, as I am very familiar with the ICU environment and the work of ICU clinicians. I have been involved in professional discussions, exchanged experiences and provided simple patient care. At the same time, as a researcher, I was an outsider and observer of the physicians' and nurses' indirect and direct family care (see Chapter 4.6).

In focus groups, data is collected from the talk between the participants in the group. Through a carefully planned discussion, the group dynamics were used to gain insight into the nurses' and physicians' experiences and opinions (Morgan, 2012; Polit & Beck, 2020). The interaction between the participants is central; they react to what is said by the others, thus potentially leading to different viewpoints and deeper understandings from several participants (Morgan, 2012; Polit & Beck, 2020). In this study, we wanted to identify potentially different perspectives between nurses and physicians, but also to explore the interaction and discussions between them. We therefore constructed single-profession focus groups and groups consisting of both nurses and physicians.

During the parallel data collection and analysis, it became clear that physicians from patients' primary wards were also involved in family care in the ICU. On this basis and in line with the principles of theoretical sampling, we decided to include physicians from the primary wards in the study. We also attempted to form focus groups of these physicians, but this was not feasible as they worked in different wards, with a tight schedule that made it difficult to find a suitable time. They were therefore interviewed individually or in pairs.

4.4 Research environment

This study was conducted in four ICUs (ICU 1-4) at four Norwegian hospitals (hospital 1-4), one mid-range hospital (level 2) and three university hospitals (level 3). Each unit treated both medical and surgical critically ill patients, both adults and children. Most of the ICU patients were intubated and needed mechanical ventilation and were often unable to express their wishes and needs. However, the units at the university hospitals offered more advanced intensive care than the mid-range hospital ICU, such as extracorporeal membrane oxygenation and neurosurgical treatment and monitoring. The size of the ICUs ranged from six beds in the mid-range hospital to 11-18 beds in the university hospitals. Two of the units had single rooms only, while the others had both single rooms and rooms with 2-4 beds.

The core ICU team usually consisted of one nurse and one physician from the ICU directly involved in caring for each patient and his/her family. Physicians from the patient's primary ward and other professionals such as physiotherapists, social workers and chaplains supported them if needed and were included in the extended ICU team.

ICU nurses and physicians share responsibility for the ICU patient and family. The nurse-patient ratio was usually 1:1 and the nurses worked bedside in three rotating shifts. Each shift started with a five-minute briefing for all nurses, followed by a bedside shift report. The physicians also worked rotating shifts. Every morning they had a pre-round meeting with the coordinating ICU nurse and physicians from the patients' primary ward. During this meeting, the ICU physicians share the responsibility for the patients among themselves and then do a morning round to one or two patients each. Depending on the procedure in the various ICUs and the patients' condition, the entire group of physicians may also do a short bedside round together. The ICU physicians have shift reports in the afternoon. In the evenings and at night, one senior and one junior physician were generally on duty. How much nurses and physicians communicate during their shifts varied considerably, primarily dependent on the patient's condition. All the ICUs in the study used electronic medical records, with computers readily available in all patient rooms.

Two of the four ICUs had flexible visiting hours for families, while the other two had fixed and more limited hours at 3-4 hours per day. If the patient was a child, the parents could be present continuously and further exceptions from the regulations were made when needed, such as in end-of-life situations. Each unit had one or two waiting rooms for families, and a quiet meeting room where physicians and nurses could talk to the families. However, the possibilities for overnight stays in the unit (at the hospital) were limited, even though many family members had more than a two-hour journey to the hospital.

4.5 Participants

Some assumptions about the sample size were made in the preparatory phase of the research project. We wanted to include both ICU nurses and physicians in focus groups and observations from at least three ICUs in different hospitals. However, the exact sample was primarily determined in line with theoretical sampling and saturation. Apart from ICU 1 (in a mid-range hospital), we chose to invite ICUs at university hospitals in different parts of the country to participate in the study. The invitations to participate were sent to the heads of the ICUs by Ranveig Lind or myself. I had no previous knowledge of or contacts in the included ICUs. Lind has a part-time job in one of the ICUs and was therefore not involved in the data collection there.

The participants in the focus groups were nurses and/or physicians from the same ICU. In each unit, I was provided with a contact nurse who recruited participants to focus groups, orally or by email. No ICU leaders participated in the focus groups. However, as part of my fieldwork, I spoke with the nurse and physician in charge of each ICU.

During the fieldwork, all nurses and physicians in the ICUs were potential participants while they were observed during their daily work. In order to come close to family care situations I usually accompanied the ICU nurse and physician to one or two patients per shift. After going with the clinicians to the same patient for one to three shifts, I changed to another patient to ensure variety in observations, involving different family care situations with different clinicians. All the ICU nurses and physicians had received information about the study by email before the fieldwork started. However, they were also asked if they wanted to be involved in the fieldwork by the contact nurse, coordinating nurse or by myself. None refused except for one coordinating nurse I asked to accompany during a pre-round meeting.

The physicians (surgeons and internists) from the patients' primary ward (from hospitals 3 and 4) were recruited through the heads of their units. For focus groups, individual interviews and observations, participants of different ages, gender and experience were invited as far as possible.

4.6 Data collection

Data were collected from July 2017 to August 2019 (Figure 2). After data collection and the preliminary analysis were completed in one ICU, we contacted the next one. Only one of our requests received a negative response. This ICU withdrew their consent to participate due to a heavy workload after first agreeing, which meant that we had to ask another ICU instead.

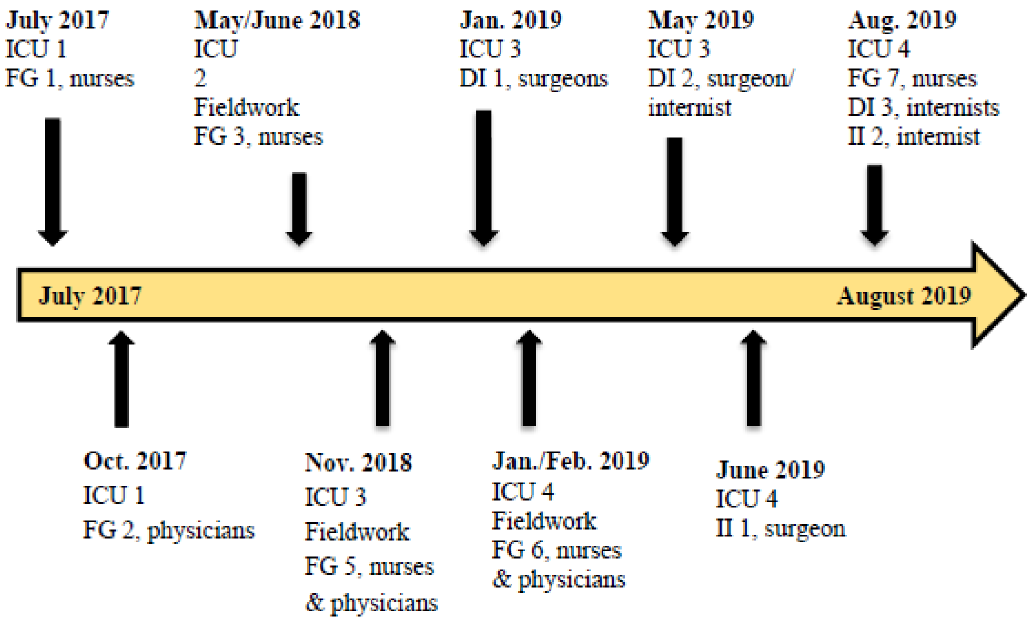

Figure 2: Timeline of data collection with subsequent analysis

The data consisted of 270 hours of participant observation (fieldwork), seven focus groups, two individual interviews and three dyadic interviews (Table 1).

Table 1: Overall data collection

	Participant observation (Fieldwork) (270 h)	**Focus group (FG) (n=7) (Participants per FG)**	**Dyadic Interview (DI) (n=3)**	**Individual Interview (I) (n=2)**
Hospital/ICU 1 (Mid-range Hospital)		FG1: ICU nurses (3) FG2: ICU physicians* (3)		
Hospital/ICU 2 (University Hospital)	76 h	FG3: ICU nurses (5) FG4: ICU physicians (5)		
Hospital/ICU 3 (University Hospital)	97 h	FG5: ICU nurses/ ICU physicians (5)	DI1: Surgeons DI2: Surgeon/ Internist	
Hospital/ICU 4 (University Hospital)	97 h	FG6: ICU nurses/ ICU physicians (5) FG7: ICU nurses (5)	DI3: Internists	II1: Surgeon II2: Internist

40 clinicians participated in focus groups and interviews: 19 ICU nurses, 13 ICU physicians (Table 2) and eight surgeons/internists (Table 3).

Table 2: Focus group participant characteristics

Focus group (FG) (N = 7)	**FG 1**	**FG 2**	**FG 3**	**FG 4**	**FG 5**	**FG 6**	**FG 7**
Hospital No. **Mid-range (M)/ University (U)**	1 M	1 M	2 U	2 U	3 U	4 U	4 U
Intensivists	0	4	0	5	2	2	0
ICU nurses	3	0	5	0	3	3	5
Gender – female/male	2/1	0/4	3/2	1/4	2/3	2/3	5/0
Age – median (range)	52 (37-54)	42 (34-60)	41 (28-54)	60 (33-67)	47 (39-49)	43 (37-54)	35 (34-60)
ICU experience – median (min-max)	18 (8-25)	10,5 (4-30)	10 (2-15)	23 (2-38)	15 (3-20)	9 (4-16)	7 (1-19)

Table 3: Participant characteristics for dyadic and individual interviews

Dyadic/individual Interviews nr.	**Dyadic Interview 1**	**Dyadic Interview 2**	**Dyadic Interview 3**	**Individual Interview 1**	**Individual Interview 2**
Hospital No. **Mid-range (M)/ University (U)**	3 U	3 U	4 U	4 U	4 U
Specialization – surgeon/internist	2/0	1/1	0/2	1/0	0/1
Gender – female/male	0/2	1/1	1/1	1/0	1/0
Age – median (range)	53,5 (36-65)				

The first two focus groups at ICU 1 were conducted in July 2017 (three ICU nurses) and in October 2017 (four ICU physicians). The intention was to test the interview guide and gain experience for further implementation of the study. Since the focus groups also generated interesting data and we had the participants' consent to use the interviews, we included them in the study.

From June 2018 to August 2019, I collected data in ICUs 2-4. In each unit, I started with three weeks of participant observation for eleven to fourteen shifts (day and evening shifts, some at weekends). I was dressed as an ICU nurse with a clearly visible name tag stating that I was a researcher. I spent most of the time in the patients' room, observing the nurses' and physicians' everyday practice with a focus on direct and indirect family care situations. The observations included formal and informal meetings between the clinicians such as shift reports, pre-round meetings, rounds and lunch breaks. With the consent of the families and patients (if possible), I also observed family members visiting and their encounters with clinicians (Appendix 3). No patients or family members refused to have me present.

During my observations, I could closely follow clinical situations where family care was provided, noting the clinicians' communication and actions about and with the family members. Often, I just sat observing in silence, but since I am an ICU nurse, I could also participate in basic nursing care. This made my presence more natural and the observation situation less awkward. I talked a great deal with the clinicians, especially the nurses, with whom I spent the most time. I asked them about their experiences of the organization, policy and approach to family care of their ICU, but they frequently described their experiences without being asked. They often talked about encounters with families who had made a particular impression on them and about what they felt was most important and challenging in family care. Primarily, I observed the physicians' work bedside, during their rounds and other patient-related tasks throughout the day, including their conversations and cooperation with nurses and communication with patients and families. The procedures for physicians' pre-round meetings varied between wards, and I was only able to observe these meetings in ICU 2.

When family members came to visit patients, I always greeted them, explained who I was and asked if I could be present. Otherwise, I tried to keep in the background when visitors were there to enable me to observe without unduly influencing the interaction between clinicians and family. Family members often approached me to ask questions about the study, where I worked and my previous ICU experience. Many told me about the patient and about their experience as family members. If the nurse was busy with other work, it was natural for the family and me to talk.

Throughout and following each shift, I took field notes. As far as possible, after each shift I wrote additional field notes on my computer. In these notes, I distinguished between describing what I saw and heard ("observation notes") and what I thought, felt and reflected on during the observations (“personal notes”). Many of the field notes were written as narratives, marked with a heading that described the observations.

Table 4: Excerpts from field notes (ICU 3)

“I think someone should call them.”

(Observation notes)

This evening I’m walking around with a nurse called Anna. I guess she’s around 30 years old. We say hi and chat as we go into the patient room. We sit down at the desk with the day shift, who starts to report on the patient. The patient has had a planned operation. Towards the end of the operation, they discovered a possible complication and decided to sedate the patient and keep him on a ventilator during the afternoon.

The day shift says she has not spoken to any family members. […]. She does not believe that the family has been informed that the patient is on a ventilator or that there has been a possible complication to the surgery. The anesthesia nurse who had given the day shift the report did not think so either. “I think someone should call them,” she says. “I can call the surgeon,” says Anna. After the report, Anna calls the surgeon to ask if the family has been informed. This has obviously not been done, as Anna then asks if the surgeon can do it. Then she ends the conversation by telling me that the surgeon will come a little later. The surgeon had also said that she could call the family.

[…] After about 20 minutes, the surgeon arrives with a specialist physician. They greet me and Anna. The surgeon states that the patient is on a ventilator. Anna mentions the possible complication, which is why they want to wait until extubation. The surgeon says there was no complication and explains why. Anna asks again if she has called the patient’s family. No, she has not. Anna asks her to call, and the surgeon agrees. Anna produces the telephone number. The surgeon takes it with her and goes out to call. After a few minutes she comes back and says that she has called, and that the family is not going to visit today. Anna nods and says “ok”.

My own thoughts, feelings and reflections

(Personal notes)

[…] I remembered this problem from my own ICU practice. A patient has surgery, gets a complication or is at risk of a complication and it is unclear if anyone has called the patient’s family; the anesthesia nurse does not know and the ICU nurse does not know

either and must call the surgeon to find out. In this case, I had the impression that the surgeon was surprised that the patient was still on a ventilator. I got the feeling that there had been poor communication in the operating room as well. Anna had to ask the surgeon twice to call the family, first over the phone and then when the surgeon entered the patient's room. But perhaps the surgeon wanted to have a look at the patient before calling the family (in fact, I think that is most likely). She did not question the fact that Anna wanted her to call and did so quite quickly. But I still wonder if the surgeon would have called if Anna had not asked her to. It struck me again that it is very important that ICU nurses think about informing the family and take the initiative to facilitate this.

All focus groups were arranged during the last week of the fieldwork. One of the supervisors participated (Ranveig Lind or Hege Selnes Haugdahl). Each focus group consisted of five participants. In ICUs 1 and 2, nurses and physicians were in separate focus groups. This division was chosen to elicit different perspectives between the professions and to take into account power inequalities (within a hierarchical structure). However, we also wished to explore interactions and discussions between the professions, and in ICUs 3 and 4 we therefore held mixed focus groups with participants from both professions. Following the principles of theoretical sampling and saturation, I also conducted five interviews with a total of eight physicians from the patients' primary ward and one final focus group in ICU 4 with only ICU nurses.

Ranveig Lind moderated the focus groups in ICU 1 and the focus group of nurses in ICU 2, while I moderated the rest of the focus groups and the individual and dyadic interviews. In addition, I or one of the supervisors was present in the focus groups as an observer to follow the interaction between the participants and take notes (Table 5).

Table 5: Overview of ICUs, focus groups, moderators and observers

	ICU 1 FG 1	**ICU 1 FG 2**	**ICU 2 FG 3**	**ICU 2 FG 4**	**ICU 3 FG 5**	**ICU 4 FG 6**	**ICU 4 FG 7**
Moderator	RL	RL	RL	AMN	AMN	AMN	AMN
Observer	BSB	BSB	AMN	RL	HSH	RL	HSH

RL=Ranveig Lind, BSB=Berit Støre Brinckmann, HSH=Hege Selnes Haugdahl, AMN=Anne Mette Nygaard

An initial interview guide, based on previous research and designed as a "questioning route" (Krueger & Casey, 2015) was developed and used in the first focus groups (Appendix 4). During the further data generation, this interview guide was modified in accordance with the ongoing analysis and the development of codes and categories. The focus groups lasted from 54 to 96 minutes and the individual/dyadic interviews from 37 to 56 minutes. I recorded the interviews digitally and transcribed them verbatim.

4.7 Data analysis with a constructivist grounded theory approach (Papers 1 and 2)

I followed the guiding principle in grounded theory of parallel data collection and analysis by starting the analysis of the interview transcripts and the observation notes immediately after each data collection. The first transcripts (from ICUs 1 and 2) were read and initially coded line-by-line. In this initial coding phase, I was open to explore "whatever theoretical possibilities" I could find in the data (Charmaz, 2014). Line-by-line coding implies naming each line with a code. Later, in the transcripts from ICUs 3 and 4, I coded less line-by-line, but instead coded and compared the text incident by incident. In grounded theory, we "code for actions" and ask analytical questions of the data: *What are these data a study of? What is actually happening in the data? What do the data suggest, pronounce or leave unsaid? From whose point of view? What might the participant's observed behavior indicate? What is the participant's main concern?* (Charmaz, 2014; Thornberg & Charmaz, 2014). The initial coding made me as the researcher stay close and remain open to the data and prevented me from moving too fast into the analytical process (Charmaz, 2014). The codes should fit the data rather than forcing the data to fit the codes. By going quickly but carefully through the data, I constructed short, simple and spontaneous codes (Charmaz, 2014). In this way, multiple initial codes were produced that represented different experiences and aspects of the nurses' and physicians' family care in the ICU.

Some examples from the initial coding will demonstrate this initial coding process (Table 6). These initial codes represent only a small selection of all the initial codes from the first phase of the analysis.

Table 6: Construction of initial codes after line-by-line reading

Interview excerpt from FG 1 with ICU nurses in ICU 1	**Initial codes (after the first line-by-line reading)**
Anna: *I think the most important thing for family members is to feel seen and heard and that someone understands their situation. And that we actually take the time to listen to them and what they have to say. Very often they seem to be interested in talking about the time before the patient got sick, hanging up pictures and being kind of really proud of them… and we never see that side of the person.*	*Seeing and hearing the family* *Understanding the situation the family is in* *Listening to the family* *Letting the family talk about the time before the patient was sick* *Letting the family show who the patient was before the illness* *Not seeing the healthy patient* *Patients being unable to talk about themselves/their needs*
Kari: *I think a bit of the problem is ... it's ... not often recorded what was said to the family, and then there's no continuity between the physicians, […] we used to have one physician for the ICU, but now they alternate a lot and it could be any of them who talks to the family… and if we're not, I mean if it's not entered in the record what the family was informed about… I think that can make things difficult.* *Another thing is: Who are the family members? ... quite often there are lots of them, not just the closest ones and how do we know if the patient has any contact with these people that we give a lot of information to?* *I've been in some situations where there are conflicts in the family and when the patient wakes up, we find that the person who was given the information shouldn't have had that information at all.*	*Not keeping records of what is said to the family* *Physicians displaying little continuity* *Changing routines in the ICU meant less continuity* *Talking to the family - it could be any physician* *Nurses wanting physicians to document the information they have given to families in the patient record* *Not knowing who the patient's family members are* *Getting no information on the family from the critically ill patient* *Not knowing who are closest of the many relatives, who should have information* *Dealing with challenging conflicts among family members* *Not knowing who should have the information* *Running the risk of giving information about the patient to the wrong person* *Addressing patient interests and wishes*

The next analytical step was focused coding, where the purpose was to synthesize and explain larger segments of the data (Giles et al., 2016). Based on the initial codes, I then concentrated on the most frequent and/or significant codes which I considered made the most analytical sense. These codes were constructed as focused codes (Table 7).

Table 7: Focused codes constructed from initial codes

Initial Code (selected examples)	**Focused Code (selected examples)**
Seeing and hearing the family *Understanding the situation the family is in* *Listening to the family*	*Nurses' awareness*
Letting the family talk about the time before the patient was sick *Letting the family show who the patient was before the illness*	*Families as a source of information*
Not seeing the healthy patient *Patients being unable to talk about themselves/their needs*	*Addressing patient interests and needs*
Not keeping records of what is said to the family	*Documentation practice*
Nurses wanting physicians to document the information they have given to families in the patient record	*Lack of information*
Physicians displaying little continuity	*Poor continuity*
Changing routines in the ICU meant less continuity *Talking to the family - it could be any physician*	*Routines in the ICU*
Not knowing who the patient's family members are *Getting no information on the family from the critically ill patient* *Not knowing who are closest of the many relatives, who should have information*	*Finding out the closest relative(s)*
Dealing with challenging conflicts among family members	*Conflicts among family members*

Not knowing who should have the information *Running the risk of giving information about the patient to the wrong person*	*Addressing patient interests and needs*

Moving from initial coding to focused coding was not a linear process although Table 7 may give this impression. It was a back and forth process using the constant comparative method, comparing data, codes and categories, to find similarities and differences. Using the focused codes, I went through an ever-increasing amount of data. In memos (table 8), I wrote down my thoughts and assumptions about the data, codes and categories and the relationship between them. I made a constant effort to ascertain the participants' greatest challenge or challenges, i.e., their main concern(s). I was trying to find out: What were the participants interested in? What was most important to them? In other words, I was moving away from the preliminary research questions formulated in the research protocol, as emphasized in this method. The participants' main challenge is not defined in advance; it emerges from the data through the analysis. I then decided which codes best captured what I noticed emerge in the data and raised these codes to tentative categories and possible core categories or sub-categories. New insights and questions arose, and I brought these into the next data collection and the further analysis. Then the codes and categories were refined. The memos became more analytical and theoretical, and the level of abstraction increased during the analytical process. The memo writing also helped to clarify and explain the emerging categories and to maintain the analysis process, as I remained open and reflexive throughout the analysis.

Table 8: Excerpt from a memo

Excerpt from memo: 'Talking together' (Sub-category paper 1)
During the fieldwork, I noted that physicians and nurses often made use of their lunchbreak in order to speak about a question or topic related to the patient's family or next of kin. Talking together is clearly vital. This implies that the formal meetings such as the ward round and the bedside handover do not go far enough to cover this need to talk together. Less formal conversations during lunch satisfy the need for off the cuff conversation especially regarding demanding and often unforeseen situations that arise with regard to the patient and their family. My impression is that there is a general willingness to take up such matters despite this being the clinic's 'free time'.

This stepwise analytical process identified areas for missing data that provided direction for the next data collection. As an example, focused codes concerning missing information about families in the clinicians' handover (Paper 1) made me more attentive to the content and activities in the nurses` and physicians` handover in the subsequent data collection. During my observations, I became more aware of the transfer of information about patients' families during reports and physicians' rounds. I also read what was written in the patient record about relatives and I asked the participants specific questions about this topic during observations and interviews.

According to Charmaz (2014), the analysis can take several directions. The researcher may have to follow one direction and finish one paper, and later return to his/her unfinished analysis and write another one (Charmaz, 2014). This was exactly what I did. After analyzing the entire data using initial and focused coding, I had several paths to choose between because a number of challenges stood out as a possible main concern of the participants. I then decided on the problem areas I would concentrate on first, after which I would return to the analysis and data and choose the next issue. Based on what I considered most prominent and significant, I decided to concentrate on the participants' concerns about the transfer of information about families within the treatment team. I was rather surprised that this area stood out; I had not imagined that this would be such a prominent finding. However, this issue appeared relevant right from the analysis of the first transcripts and I followed this path through the subsequent data collection and analysis. When I performed a thorough literature search after the initial and focused coding, I also discovered that the transfer of information about ICU patients' families in handovers had been little studied, which made the findings still more interesting and relevant to present. My review of previous research in the field, in addition to memo writing and regular discussions with the supervision team, helped to develop and construct the final conceptual categories for Paper 1 (see Chapter 5.1).

The core category "a game of whispers" was identified early in the analysis. First as an in vivo code[4] from one of the first focus groups, where a nurse used the phrase to describe how information about families was often lost or changed during handovers. This initial in vivo

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[4] In vivo code = a code that the reseacher adopts directly from the data.

code thus emerged as a core category conceptualizing the missing information about the ICU patient's family during the handover. Together with three sub-categories “documentation dilemmas”, “being updated”, and “talking together,” the core category explains how transfer of family-related information between clinicians is continually processed and resolved.

After writing and submitting Paper 1, I returned to the data and the analysis. The topic of Paper 2, interprofessional family care, was also identified at an early stage as one of the participants’ most prominent concerns and was therefore also a path I had followed from the very beginning. This topic was more in line with my expectations than the topic of Paper 1, considering the main purpose and background of the PhD, but I was unsure of the essence of the clinicians’ challenge in interdisciplinary family care. The participants mainly reported good interdisciplinary collaboration, although a great deal of frustration at collaboration between clinicians was revealed in both the observations and the interviews. In order to make further progress in my analysis, I re-read the entire material and the preliminary analysis with its codes and tentative categories, and then concentrated on all the text, codes and categories that dealt with clinicians’ collaboration on family care. I then conducted a new thorough literature search, which this time concerned interprofessional family care. The search revealed a large number of studies on interdisciplinary collaboration in critical care, but few studies that specifically dealt with interprofessional *family care.* I then worked as I had done in Paper 1, reading the literature, comparing data, codes and categories, writing memos and having discussions with my supervisors. I gradually came to realize the contradiction in the participants’ interdisciplinary family care; they worked in teams and were meant to function as a team, whereas in fact they often worked alone. When I had defined this as the main concern of the participants, the core category of solitary teamwork and the three subcategories proximity and distance, silent interprofessional work and a connecting link were constructed. Paper 2 was then written and submitted (see Chapter 5.2).

4.8 Thematic narrative analysis (Paper 3)

During the data collection, particularly the observations, I became aware of clinicians’ different approaches to families. For example, some provided information to families without being asked for it, while others were more passive and did not give information until family members asked for it. In the focus groups, the participants themselves described how their approach to families was influenced by the personality of the particular nurse or physician involved and by judgment and discretion. Different descriptions of their approaches to families confirmed this impression after the preliminary data analysis; the quality of family care varied and was entirely dependent on the individual clinician. I viewed this as a prominent and important finding in the data, discussed it with my supervisors and decided to continue working on this topic in Paper 3.

In Article 3, I began the analysis in the same way as in the first two articles. After reading the material, I examined preliminary codes and categories, conducted literature searches and wrote memos in order to develop conceptual categories that could clarify the participants' different approaches to families. The material, especially the field notes, contained many stories with detailed and thick descriptions of encounters between clinicians and family members. After further reflection and discussion with the supervision team, I felt that thematic narrative analysis would be most suitable, since constructivist grounded theory is less appropriate for eliciting such rich data (Riessman, 2008). Unlike the analysis strategy in grounded theory where the transcripts are divided up and coded line-by-line or incident by incident, in thematic narrative analysis the researcher makes an effort to keep the narratives intact to preserve the richness of detail. Instead of theorizing across cases, the researchers theorize from each case (Riessman, 2008).

With narrative methods, understanding about human experiences can be revealed through storytelling. Narrative research is an overarching concept; narrative researchers may have different theoretical points of view and use different methods of analysis within a qualitative design. There exists no clear definition of a narrative (Bo, 2016). However, narratives are typically situated in time, place and in a particular setting (Thomsen et al., 2016), and have "essential meaning making structures" where individuals or groups construct their identities (Riessman, 1993, 2008; Thomsen et al., 2016). Narrative inquiry generates knowledge about relational phenomena and complex contexts, which is suitable for this study where we wanted to explore interaction between ICU clinicians and relatives in a complex intensive care setting. The core of narrative analysis is interpretation, where each narrative is open to a diversity of interpretations (Johansson, 2005). Here, I as the researcher was seeking the meaningful "essence" of each story, referred to as the theme (Riessman, 2008). As in grounded theory, emphasis is placed on the role of the researcher and the participants as co-constructors in the research process (Charmaz, 2014; Riessman, 2008). I formulated the narratives on the basis of my observations; they were influenced by my gaze, my background, my views and the goal of my research. In the focus groups and also during the observations, the participants could decide themselves what they wanted to talk about, albeit influenced by my questions and in interaction with the other participants. Further, the stories do not speak for themselves (Riessman, 2008); I have influenced the analysis with my interpretations.

After deciding to change my method of analysis in Paper 3, I re-read the data, and selected all the narratives that described encounters or interaction between ICU clinicians and family members. I then studied the narratives in detail one by one, noting particularly the clinicians' behavior and actions towards families and how this affected the interaction. Again, I asked many questions of the data, such as: *How did nurses receive families when they entered the patient room? Where did they position themselves in relation to the family member(s)? How did the physicians behave? Who started the conversation, clinicians or family? What was said? In what way, in what tone of voice? Did they have eye contact? How did the family respond to the clinicians' behavior and comments? Did the nurse and physician include families in their conversation when they were in the patient room? How did physicians and nurses describe their encounters with families, what was emphasized, what did they feel influenced their behavior and actions?*

For each narrative, I formulated preliminary themes that described the clinician-family interaction. Following this, all the narratives were compared to identify common themes. Tentative themes were discussed with the supervision team and a former ICU relative (Hilde Laholt, who is also a co-author of this article) several occasions. At the end of the analysis, three themes were identified: being attentive, an active approach and degree of tolerance. In the presentation of the papers, specific narratives have been selected to illustrate the themes (see Chapter 5.3).

4.9 Ethical approval and considerations

This study was carried out in accordance with the principles of the Declaration of Helsinki (WMA, 2018). The participating ICUs approved the study, which was also reported to the Norwegian Center for Research Data (NSD) regarding the processing of personal data. The Regional Committee for Medical and Health Research Ethics (REK) waived the duty of confidentiality. Although the project was not covered by the Health Research Act, this was necessary since I gained indirect access to confidential information about patients and family members during the fieldwork. Unconscious or sedated ICU patients were indirectly involved without true capacity to consent. No personally identifiable information about patients or their families was stored. Alert, consenting patients and relatives were informed about the study

(Appendix 5 and 6) and were asked for permission for the researcher to be present to observe the clinicians’ family care. No patients or family members refused. Written information about the study with a photo and contact details of the researcher was hung on the wall at the entrance to the ICU, in corridors and in family rooms/meeting rooms in the unit (Appendix 6) to inform visiting family members and clinicians that the study was taking place.

Acutely and critically ill patients and their family members are in a serious and vulnerable situation. The ICU staff has challenging and rapidly changing working conditions. Situations may therefore arise in an ICU where observation is inappropriate because of the risk of upsetting or burdening the participants. It was therefore emphasized that the PhD student in this project needed experience of critical care, in order to ensure that she could display the necessary ethical sensitivity and discretion.

The ICU physicians and nurses received written information by email before the fieldwork began (Appendix 7). The information was sent out via the unit manager or head nurse. I also gave the same information orally at the beginning of each shift.

Written informed consent was obtained from the participants in the focus groups, and the individual and dyadic interviews (Appendix 8). The participants were told they could cancel their participation whenever they wanted, without giving a reason. To protect confidentiality, field notes and transcriptions from the interviews were anonymized. However, it can be difficult to assure the participants in the focus groups and dyadic interviews of complete confidentiality and anonymity, since the researcher has little control over the participants after the interviews (Sim & Waterfield, 2019). Therefore, at the beginning of each interview, the participants were encouraged not to talk to people outside the group about any of the topics discussed.

The audio files from the interviews were deleted after transcription, and until then they were stored in accordance with the UiT guidelines (UiT, 2022) for data storage. There are no links between participants’ names, audio files or transcripts. The only personally identifiable material from the study is the interviewees’ signed consent forms, which are kept in a locked cupboard in my office. The UiT guidelines state that consent forms must be kept for two years following deletion or anonymization of the personal data.

5 Findings

Three papers have been published based on the empirical data and analyses in this PhD (Table 9).

Table 9: An overview of the papers

	Paper 1	**Paper 2**[5]	**Paper 3**
Subject	Handovers	Inter-professional care	Individual approach
Title	Information concerning ICU patients' families in the handover — The clinicians' "game of whispers": A qualitative study	Interprofessional care for the ICU patient's family: solitary teamwork.	Professionals' narratives of interactions with patients' families in intensive care
Authors	Nygaard, A.M., Haugdahl, H.S, Brinchmann, B.S & Lind, R.	Nygaard, A.M., Haugdahl, H.S, Brinchmann, B.S & Lind, R.	Nygaard, A.M., Haugdahl, H.S, Laholt, H. Brinchmann, B.S & Lind, R.
Journal	Journal of Clinical Nursing Accepted June 2020 Published June 2020	Journal of Interprofessional Care Accepted January 2022 Published March 2022	Nursing Ethics Accepted August 2021 Published February 2022
Method	Qualitative study with constructive grounded theory approach. Participant observation and focus groups with ICU nurses and physicians, dyadic and individual interviews with surgeons/internists	Qualitative study with constructive grounded theory approach Participant observation and focus groups with ICU nurses and physicians, dyadic and individual interviews with surgeons/internists	Qualitative study using thematic narrative analysis Participant observation and focus groups with ICU nurses and physicians

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[5] This paper is referred to as Paper 2 although it was accepted and published later than Paper 3. This is because it was written and submitted before Paper 3.

5.1 Paper 1

The aim of this paper was to explore how information concerning ICU patients´ families was included in the ICU clinicians’ daily handovers. In the analysis, “A game of whispers” emerged as the core category, representing missing information about the patients’ family during the handover. This core category, with the three sub-categories “documentation dilemmas”, “being updated” and “talking together”, explains how the transfer of family-related information between clinicians was resolved (Figure 3).

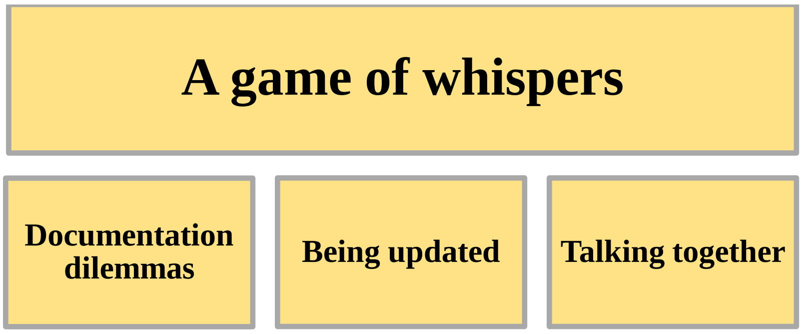

Figure 3: Core category and cub-categories. Paper 1

The findings showed that the handover of information regarding patients’ families mainly took place orally, in “a game of whispers”. This represented a risk of information being altered or lost, and the nurses in particular missed written handover information about the patient's family. In many cases, the written information about family members was incomplete and several dilemmas connected to this were identified. These included uncertainty as to what information about the patient's family to document, how and by whom, physicians or nurses. Since ICU patients are often unable to name their closest family member, clinicians often found it difficult to know and document who this was. The nurses found that family members could give them conflicting information, which posed a dilemma between safeguarding the rights of the patient's family and the patient’s right to confidentiality. Both nurses and physicians highlighted the necessity to talk together and update each other about ICU patients’ families to avoid inconsistent information to and communication with the family members. Talking together and being informed was also important to enable clinicians to help and support each other, especially in difficult patient and family situations.

This study indicates challenges related to appropriate and high-quality handovers concerning

ICU patients´ families. User-friendly handover tools and guidelines for written information that includes family information should be developed.

5.2 Paper 2

The aim of this study was to explore how ICU teams’ interprofessional family care was reflected in their daily work. The analysis revealed “solitary teamworking” as a core category, which suggests contradictory interprofessional work where physicians and nurses experienced supportive collaboration, but still often felt lonely. Traditional hierarchical structures existed between the clinicians, and the nurses missed being more included and involved in the physicians’ discussions. The three sub-categories “proximity and distance”, “silent interprofessional work” and “a connecting link” reveal salient characteristics of nurses’ and physicians’ interprofessional family care (Figure 4).

Figure 4: Core category and sub-categories. Paper 2

The ICU nurses spent most of their time bedside and naturally came close to visiting family members while the physicians were more distanced from the patient's room and family. This distance created frustrations and emotional tensions between the professional groups, even though both physicians and nurses expressed their understanding and respect for each other’s duties. In addition, nurses and physicians expressed a need to keep a certain emotional distance to the families to maintain their professionalism and avoid becoming too personal and emotionally moved. However, it was not always easy to maintain such distance because many family care situations deeply affected them.

Even though the nurses and physicians included information about the patient’s family in their handovers, they had little discussion of family care at a strategic or organizational level. With certain exceptions, there was little facilitation of interprofessional dialogue regarding care of the families. Family care seems based on the clinicians' individual preferences and experience-based approach. The findings also suggest a lack of shared leadership for the ICU nurses and physicians regarding family care.

Moreover, both nurses and family members have essential roles as connecting links in the ICU team to ensure continuity and good information flow. Nurses conveyed messages and facilitated conversations between family members and physicians. The physicians expressed great confidence in the nurses’ assessment of family members’ need for information. However, an ICU team is not formed for a single event, it functions over time and the nurses and physicians in the team often change due to their shift work. Therefore, family members should be included as an active part of the ICU team, since they represent a stable factor in the team, providing their own knowledge about the patient and communication from previous shifts.

The study indicates that interprofessional family care needs strong involvement by an organization that supports and prioritizes family care, includes family members as an active part of the ICU team and emphasizes interprofessional dialogue.

5.3 Paper 3

The aim of this paper was to examine ICU nurses’ and physicians’ bedside interactions with critically ill ICU patients´ families and discuss these in light the ethics of care. Three themes were identified: “being attentive”, “an active approach” and “degree of tolerance” (Figure 5).

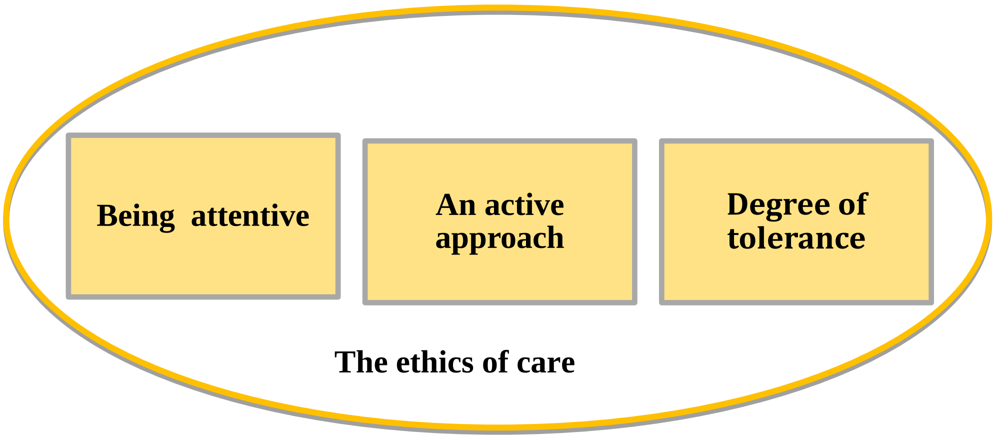

Figure 5: Themes. Paper 3

These findings show that ICU family care varies in quality, depending on the individual clinician’s attitudes, behavior, and personality. The theme “being attentive” describes the ICU nurses’ and physicians’ ability to make sense of family members’ verbal and non-verbal communication including body language, vague hints and covert questions. Attentive nurses and physicians listen to the unspoken words and can imagine and respond to family members’ needs. Conversely, an inattentive clinician can cause family needs to be neglected or overlooked.

The results also showed differences in how active the clinicians were towards family members. “An active approach” involved asking questions, planning for the families and including them in patient care, demonstrated by words and actions. By contrast, passive nurses and physicians do not ask questions, make suggestions or act actively; they wait for the family’s questions, avoid eye contact and pay little attention to the family.

The last theme was related to nurses’ and physicians’ “degree of tolerance” towards families, depending on their workload, stress threshold, robustness, knowledge, and experience. The findings indicated that knowledge and experience made nurses and physicians more tolerant towards family members, but also that older, experienced nurses could be less flexible and tolerant than younger ones. Further, nurses and physicians tended to become less sensitive by caring for critically ill patients over time, thus less tolerant in their assessments of what they considered serious or critical illness. The clinicians’ degree of tolerance was also affected by the increasing ICU workload. They missed time for reflection and talking to colleagues, and several became exhausted over time.

Overall, this paper shows how attentive, active, and tolerant clinicians represent a culture of ethical care that gives families greater freedom of action and active participation in patient care. However, family care seems to be largely based on the individual clinician’s personality and experience, rather than evidence-based guidelines and the ICU culture. Family care is an individual professional responsibility, but it is also a key responsibility of the healthcare organization.

6 Discussion

The overall aim of this study was to explore the individual and interprofessional strategies ICU nurses and physicians use in their approach to critically ill ICU patients' families. The term *strategy* has been chosen in the formulation of the overall aim as it expresses planned and targeted family care. Observations in combination with interviews have given me as a researcher a unique opportunity to be close to ICU clinicians' everyday work and explore how family care is organized and executed. In this chapter, I will discuss the main findings of the study regarding ICU clinicians' family care strategies. I will then present my methodological considerations.

6.1 Discussion of the main findings

The relationship between the main findings and family care in the ICU is illustrated in Figure 6. I first give a brief presentation of this relationship and of the interconnections and common features of the main findings. Papers 1, 2 and 3 describe respectively how handovers, interprofessional care and an individual approach affect family care in the ICU. In summary, the articles show that family care in the ICU is an interprofessional responsibility (Paper 2), although an individual approach to families by nurses and physicians is crucial (Paper 3) and continuity in family care must be ensured through good information flow between clinicians (Paper 1). Although these main findings are explained in the separate articles, it becomes clear when I analyze the material as a whole that these elements depend on and influence each other. For example, effective interdisciplinary collaboration where nurses and physicians listen attentively to each other's information about the family will lay the foundation for a good handover, which in turn will have a positive effect on family care because it creates continuity in the clinicians' work. Figure 6 illustrates this connection: the three elements *handover, interprofessional care* and *an individual approach*, are linked in a circle that surrounds family care in the ICU.

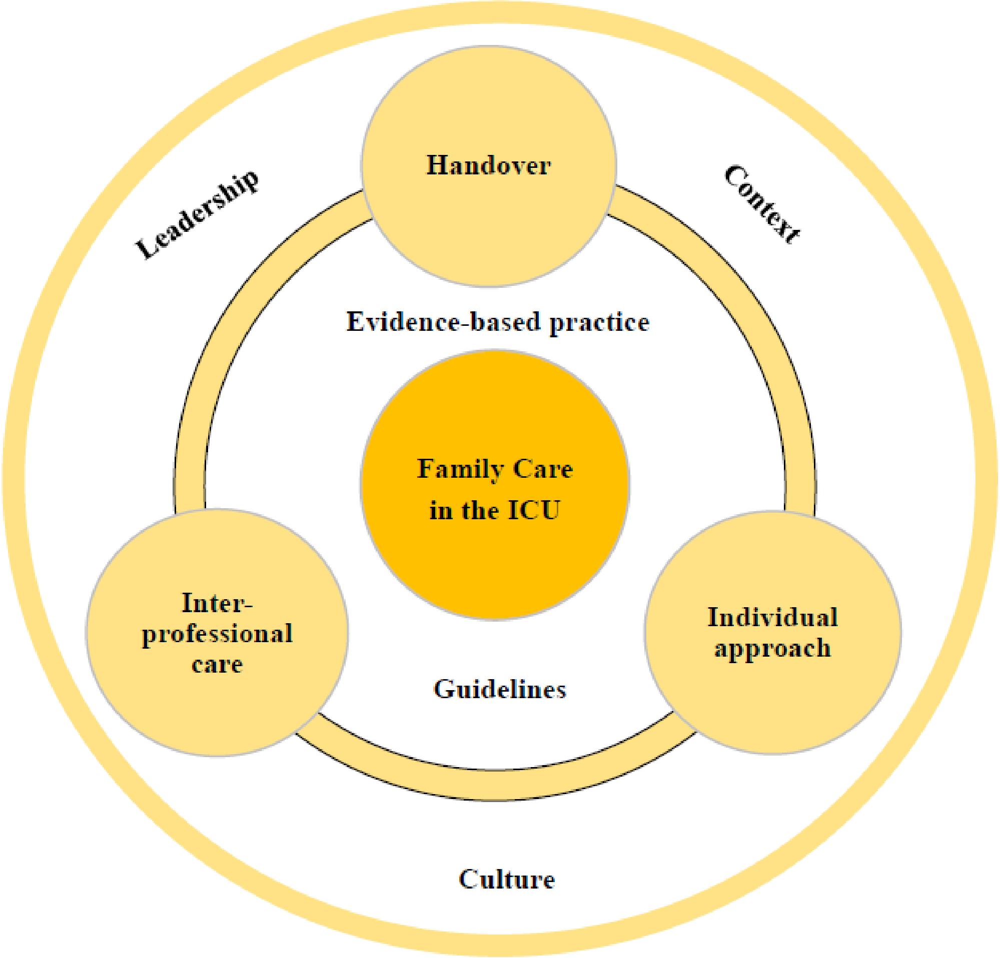

Figure 6: Correlation between the main findings and family care in the ICU

When the articles are considered as a whole, two more interesting findings emerge in this study. One concerns the knowledge that forms the basis for the nurses' and physicians' family strategies, while the other deals with the extent to which their strategies are governed by guidelines. In the figure, these two findings are called *evidence-based practice* and *guidelines*. The study further reveals that the ICU leadership and contextual and cultural factors play a vital role as facilitators or barriers to nurses' and physicians' individual and interprofessional family care strategies. In this way, the study as a whole shows that family care in the ICU is a complex interplay between a number of factors that depend on and influence each other. Based on these main findings, the discussion will now focus on the following three topics: 1. *Family care strategies in the ICU: experience-based and tacit*, 2. *Use of family care guidelines in the ICU*, 3. *Facilitation of family care strategies.* The topics are discussed in relation to the findings of the articles, PFCC and previous research.

6.1.1 Family care strategies in the ICU: experience-based and tacit

The study shows that ICU clinicians' family care strategies are experience-based and generally unspoken or tacit. The nurses and physicians do not talk much about family care at a strategic and organizational level, and the family care strategy of the management seems vague and inexplicit. For example, the participants could express no common reasoning behind the basis for the ICU visiting guidelines (Paper 2) or a common approach to how to document information about families (Paper 1). *Tacit* refers to the way the nurses and physicians had difficulty putting into words their family care strategies, which reminds us of Polanyi's words: "we can know more than we can tell" and his description of *tacit knowledge* (Polanyi & Ra, 2000). Polanyi's notion of tacit knowledge challenged the scientific view of knowledge and has been an important contribution to the theoretical debate on what science and knowledge are (Henry, 2010; Johannessen, 2013). The study participants described how family care was largely determined by discretion and personal judgment that depended on the patient's situation, who the family members were, how they behaved and their needs, in addition to contextual factors such as space, time and resources. Through clinical experience, individual nurses and physicians have found "their own way" to take care of families, where their personal qualities play a key role. This is particularly evident in Paper 3, where we see considerable differences in behavior towards families between individual ICU nurses and physicians, but also in Paper 2, which describes the importance of experienced ICU clinicians for interprofessional family care by providing reassurance and support to less experienced colleagues in demanding family situations. In other words, the most important factor in the nurses' and physicians' knowledge base in family care seems to be the experiential factor, through both trial and error and through "master-apprentice learning". Tacit knowledge is acquired through experience and is typically difficult to articulate, context-dependent, informal and personal (Polanyi & Ra, 2000). This form of knowledge is well known in healthcare, where many skills and much knowledge are acquired through practice. The participants in this study described their family care strategies in the same way; the strategies are linked to the knowledge holder and to the situations in which the knowledge was learned and applied. The risk of knowledge that remains unspoken is that it can become automatic and unconscious. But just as reflection on clinical situations and one's own practice can help to develop a caring ethical family care culture (Paper 3), reflection can also enable nurses and physicians to put their tacit knowledge into words. Reflection can make the knowledge more accessible and explicit, which is necessary for health professionals to learn from each other.

The fact that ICU nurses' and physicians' family care strategies are primarily rooted in experiential knowledge is an interesting finding in light of the debate and requirements of recent decades concerning evidence-based work. Evidence-based practice represents a paradigm shift in clinical practice for healthcare decision-making (Dawes et al., 2005; Polit & Beck, 2020). In addition to research-based knowledge, evidence-based practice also includes clinical expertise and patient values and preferences (Melnyk & Fineout-Overholt, 2011). These three sources of knowledge are emphasized as having equal status (Nortvedt et al., 2021). The purpose of evidence-based practice is that healthcare decisions should be based on the best available, current, valid and relevant evidence (Dawes et al., 2005).

Evidence-based practice has been highlighted as an important advance in clinical practice to improve the quality of healthcare, increase patient safety and improve patient outcomes (Melnyk & Fineout-Overholt, 2011). However, the concept of evidence-based practice has been heavily debated and received much criticism (Djulbegovic & Guyatt, 2017; Polit & Beck, 2020). Critics argue that the benefits of evidence-based practice are exaggerated and that research-based knowledge is overemphasized to the detriment of patient preferences and clinicians' experiences (Djulbegovic & Guyatt, 2017; Polit & Beck, 2020).

In ICU family care, our study suggests that experience-based knowledge carries the greatest weight, while research-based knowledge is poorly integrated into ICU clinical practice. This is despite the recent increase in focus on research on family care and a considerable increase in knowledge about families' needs and experiences (Davidson et al., 2017). According to Bringsvor et al (2014), ICU nurses use many different sources of knowledge in their clinical practice, such as research, theoretical knowledge, workplace culture, clinical expertise and patient participation. However, research primarily influences practice through guidelines and procedures (Bringsvor et al., 2014).

Critics of evidence-based practice warn against underestimating experiential knowledge, emphasizing the importance of health professionals' discretion that has been perfected over time (Djulbegovic & Guyatt, 2017; Wyller & Wyller, 2013). This is reflected in the participants' descriptions of experiential knowledge as an important resource. Experience made clinicians feel more secure and enhanced their ability to act, which then provided more options for families and support for less experienced clinicians in the ICU team. However, the study also shows that experience can make physicians and nurses less sensitive and flexible, which then constrains inclusive family care. There are also limits to what nurses and physicians are able to learn from each other’s family strategies, as they spend much of their time alone with families. Organized exchanges of experience regarding family care, such as debriefing, are not common, particularly between physicians and across professions. Asking families about their experience of the ICU is left to the individual clinician and varies considerably. Therefore, although experiential knowledge is essential for family care in the ICU, the study shows that this form of knowledge also has its limitations. If family care is mainly based on experiential knowledge, it runs the risk of being arbitrary and dependent on the individual clinician.

The participants made little reference to research-based knowledge related to PFCC or other research on ICU family care. My impression from both observations and interviews was that they had little knowledge of this type of research. Some of them stated that they did not really “feel at home” with research, and they may thus have regarded research as scarcely relevant to their family care. The study thus confirms a well-known challenge of evidence-based practice; there is a gap between research evidence and its translation into practice (Melnyk & Fineout-Overholt, 2011) .

The reasons for the difficulty of implementing evidence-based practice in the ICU are many and complex, including clinicians’ lack of knowledge about evidence-based practice, resistance to change from traditional practice and inability to access and evaluate information and evidence (Jordan et al., 2016). According to Renolen et al. (2018), nurses perceive evidence-based practice as an obstacle to good workflow. It comes in addition to their regular work, instead of being an integral part of it (Renolen et al., 2018). Organizational barriers related to support, change and operations have also been identified (Jordan et al., 2016). Nurses and physicians need skills to acquire, evaluate and apply research-based knowledge and integrate it with their experience-based knowledge, to enable information from research to become part of their professional knowledge (Bjørndal et al., 2021). They also need to have a critical attitude to evidence and to their own practice (Dawes et al., 2005). Knowledge management is a common challenge and responsibility, which places great demands on both educational and clinical institutions (Melnyk & Fineout-Overholt, 2011). Professional education must teach students how to evaluate the huge influx of information and new professional knowledge, while clinical organizations must create systems that ensure that new knowledge is used. If research reveals a problem in clinical practice, such as the inadequate transfer of information regarding ICU families seen in Paper 1, ICUs must develop evidence-based and functional guidelines in order to improve practice.

6.1.2 Use of guidelines in the ICU

The ICU’s guidelines determine the overall and common strategies for patient and family care. The guidelines aim to ensure that all patients and families receive equal treatment and that healthcare is of consistently high quality (Grinspun et al., 2011). However, the study reveals several aspects of how the ICU guidelines, or lack thereof, affect family care in a positive or negative way. For example, Paper 1 shows how unclear and missing guidelines for documentation and handovers are detrimental to information flow and continuity in family care. On a positive note, however, the study shows that nurses are careful to ensure that they record the patient’s closest relative(s) and any family members who are children, as stipulated in the guidelines. Another example is how visiting guidelines affect families’ freedom and involvement in patient care (Paper 3). Further, some guidelines and tools appear to be little known or used by ICU clinicians, such as guidelines for talking to adult family members (Paper 2) and the medical record for family information (Paper 1). Some guidelines, such as those for visits, are more familiar to nurses than to physicians, which can lead to frustration and irritation among clinicians.

The need to develop evidence-based guidelines has arisen with the ever-increasing amount of research-based knowledge, coupled with a greater demand for priorities in healthcare (Grinspun et al., 2011; Polit & Beck, 2020). Terms such as procedures, action plans and routines may be used synonymously with guidelines; the concept may also include the use of checklists or other tools to improve care quality and patient safety (Bjørndal et al., 2021). The goal is to develop guidelines systematically, based on the best available evidence, and to reduce unnecessary variation in practice by providing recommendations for clinical decision-making (Grinspun et al., 2011; Polit & Beck, 2020). However, one problem may be that the available evidence is limited or of poor quality (Davidson et al., 2017; Polit & Beck, 2020). This is true of *“Guidelines for Family-Centered Care in the Neonatal, Pediatric, and Adult ICU”* by Davidson et al. (2017). Despite the fact that these guidelines have been developed on the basis of the best evidence available, the recommendations are weak, which emphasizes that this is a relatively new field of research. More research is needed to identify the most effective interventions to improve family-centered care in the ICU (Davidson et al., 2017).

Another effective recommended strategy to translate knowledge into practice is to use care bundles (Palakshappa & Mikkelsen, 2016). This is a group of evidence-based interventions, which when performed together have a better outcome than if performed individually (Horner

& Bellamy, 2012). A relevant bundle in PFCC is the ABCDEF bundle (Figure 7), which improves the ICU patient’s outcome and promotes interprofessional teamwork and collaboration (Stollings et al., 2019). The “F” highlights the importance of involving family members to improve the patient's outcome. The ABCDEF bundle, like PFCC, emphasizes a holistic patient perspective that includes the patient's family. However, both the ABCDEF bundle and the principles of PFCC have proved to be difficult to implement into clinical practice (Balas et al., 2019).

ABCDEF bundle	
A	Assess, prevent, and manage pain
B	Both spontaneous awakening and spontaneous breathing trials
C	Choice of analgesia and sedation
D	Delirium: assess, prevent, and manage
E	Early mobility and exercise
F	Family engagement and empowerment

Figure 7: ABCDEF bundle

We also find several examples of challenges in implementing and complying with guidelines in our data. One involves the use of a guideline for *talking to adult family members* (Paper 2). In connection with a national quality improvement project (Sjøbø, 2017) which was conducted few years before our study, this guideline was introduced as an improvement measure in several of the ICUs included in the present study. This guideline/communication tool is based on the VALUE TEAM template (Curtis & White, 2008), which aims to ensure respectful communication with family members and within the ICU team (Michalsen & Jensen, 2020).

There is reason to believe that the use of this tool could solve some of the problems revealed by our study in terms of inconsistent information to families, lack of continuity and poor collaboration in the ICU team. During the data collection, however, it emerged that the tool was little used in the ICUs involved. The reasons for this are not apparent from the data, but it seems clear that implementation was not entirely successful. According to Ginspun et al. (2011), successful implementation of clinical practice guidelines requires multifaceted and sustained interventions. Essential for the use of guidelines is an ICU culture that supports guideline implementation and adherence, where ICU clinicians share the value of knowledge translation and consider guidelines as crucial to reduce practice variation and achieve best practice (Sinuff et al., 2007). This requires effective leadership and a positive interprofessional team dynamic. Successful implementation also depends on repeated, effective training for all professional groups, follow-up and reminders of use, as well as guidelines in a user-friendly format (Sinuff et al., 2007). ICU nurses have an essential role to play in the implementation of guidelines such as the ABCDEF bundle with their direct role in patient and family care. This requires motivation, knowledge, and skills in translating evidence into clinical practice, and the ability to advocate for important quality and safety initiatives (Balas et al., 2019).

Another important aspect of the development and use of guidelines is the extent to which they allow for flexibility and individual adaptation (Grinspun et al., 2011; Polit & Beck, 2020), which are important principles of PFCC. One example from the study where this appears is related to the visiting rules in the different ICUs. As described in Paper 2, there was great variation between the guidelines and the data revealed key differences in how nurses used them. While some strictly adhered to the set visiting hours, others reported generally not keeping to them. Several participants referred to the fluctuating nature of the ICU as well as patients' and family members' individual needs as determining their visiting practice rather than the guidelines of the ICU. This clearly illustrates the power of nurses as gatekeepers. It was also interesting to observe that regardless of whether an ICU had fixed or flexible visiting hours, the variation in compliance with the guidelines caused frustration and discussion among the nurses.

During data collection, we also noticed how variations in ICU room design and staffing led to differences in visiting policy. In addition, several participants also mentioned that they found it demanding and exhausting to have a great number of family visits, which has also been well documented previously (Davidson et al., 2017; Nassar Junior et al., 2018). This shows that recommendations in a guideline cannot be based on evidence alone. They must also be considered on the basis of the consequences of the proposed measures and in the context of values, resource use, prioritization criteria, laws and regulations (Helsedirektoratet, 2012).

6.1.3 Facilitation of family care strategies

The ICU is by nature unpredictable (Ervin et al., 2018; Marshall et al., 2017). Patients' condition and treatment situation change rapidly, the clinicians never know when the next patient will arrive and patients have a wide variety of diseases. Such unpredictability also affects family care. The study participants pointed this out several times during data collection by referring to contextual factors that they had to taken into account. For example, nurses often had to tell families to wait before they could visit a patient because the patient’s condition had changed (Paper 3) or families had to wait to talk to a physician because the physician was busy with more acute clinical work (Paper 2).

The physical ICU environment, such as the design of patient rooms, and the availability of waiting rooms, parking spaces and accommodation for family members also facilitate or constrain family care. Here, the observations in particular revealed interesting differences between the various ICUs. One illustration of this is how family care was affected by the availability and quality of chairs in patient rooms. One ICU sometimes had no chairs for visitors, leaving the family standing by the bed during the entire visit (described in Paper 3), while another ICU was equipped with at least one comfortable chair in each patient room. A comfortable chair is a sign that the family is welcome, that their natural place is with the patient and that they are part of the team that provides care to the patient. Another example of how the physical environment affects family care is ICUs with private rooms compared to those with shared rooms. Private rooms naturally provide more opportunity to involve the family than shared rooms, where consideration must be given to other patients, families and staff (Paper 2). Single rooms are important for family satisfaction but can also have other positive effects such as reducing stress and anxiety (Jongerden et al., 2013). Family satisfaction and family involvement are also affected by other environmental factors such as colors, sound and light, as well as family facilities such as waiting rooms, accommodation and access to food and drink (Davidson et al., 2017; Jongerden et al., 2013; Ågård et al., 2019). Depending on the design of the ICU environment, rooms will thus be facilitators or barriers to nurses’ and physicians’ family care strategies and PFCC (Hetland et al., 2018; Kleinpell et al., 2018; McAndrew et al., 2020; Ågård et al., 2019).

How the ICU is managed and organized is reflected in its environment and prevailing culture (Aitken et al., 2019). Regardless of the setting, effective leadership implies a clearly expressed vision and motivation of the ICU team to achieve common goals. Without a clear family strategy, the responsibility for family care will be left to the individual clinician, as seen in Paper 3. In this study, one head nurse described herself as especially concerned about the ICU patients’ families (Paper 2). This unit also had flexible visiting hours and generally good facilities for families, and one can thus assume a possible connection between the management’s commitment and the family-friendly impression given by this ICU. Article 3 discusses the ICU management’s role and responsibility in facilitating family care and a family culture based on the ethics of care by offering training and reflection. Such a culture corresponds to a PFCC approach, which requires a change in the mindset of healthcare professionals from a paternalistic attitude to a supportive role (Van Mol et al., 2017). This is not only vital for family care, but also for taking care of vulnerable nurses and physicians. The ICU management has a responsibility to ensure that the nurses and physicians can cope with the unpredictable and stressful work, thus preventing the emotional strain from leading to burnout and distancing from family care. Paper 2 emphasizes that ICU management should address family care more explicitly, and that interprofessional dialogue and staff training must be facilitated.

Another characteristic of the ICU is the large number of nurses and physicians (Ervin et al., 2018; Marshall et al., 2017). Intensive care requires almost equal levels of staffing around the clock, and nurses and physicians work in shifts. This makes it challenging to maintain continuity, communication and collaboration with patients and family, but also between nurses and physicians. Article 2 shows that although many of the participants were satisfied with their interdisciplinary work, there appeared to be limited awareness of each other’s work. The professions worked in silos most of the time and there was little interprofessional dialogue on family care. At the same time, Article 1 shows that ICU clinicians have a great need to talk to and update each other, including in family care. Although ICU nurses are in a unique position to take care of patients’ families (McAndrew et al., 2020), physicians play a crucial role in decision-making processes and in information for families (Michalsen & Jensen, 2020). Without close cooperation and good interprofessional dialogue, there is a risk that communication with families will be vague and inconsistent (Lind et al., 2012).

The study’s overall findings suggest a need for increased awareness of the professions’ joint responsibility to provide family care, not only between individual nurses and physicians, but also at management level. Silo mentality is also reflected in the management structure in Norwegian ICUs, where responsibility for operations is divided between an ICU physician (who organizes the medical work) and an ICU nurse (who organizes the nursing). Leaders must work together to ensure effective operations, professional development, quality and patient safety (Søreide et al., 2014). Examples of this are to facilitate well-functioning documentation systems and the possibility of interprofessional dialogue.

6.2 Methodological considerations

6.2.1 Research in a constructivist perspective

In constructivist grounded theory, people’s meanings and perceptions of reality are at the core of research. Research in a constructivist perspective implies a recognition that there are many different versions of reality. The object of analysis is formed in the encounter with the researcher and is thus fluid, unstable and ambiguous (Järvinen & Mik-Meyer, 2005). According to Berger and Luckmann (2000), everyday life is a reality interpreted by people and created in interaction with others. Interpretations of reality are developed, transmitted and maintained in social situations. Narratives and the context, form and function of observations are emphasized; these are the reality-constructing processes that the researcher wants to gain insight into (Järvinen & Mik-Meyer, 2005). The researcher searches for the meanings and actions of the participants in social situations and discourses about which they may themselves have little or no knowledge or awareness (Lauridsen & Higginbottom, 2014).

The constructivist research perspective is clearly present in this study in the nurses’ and physicians’ different perceptions of reality about ICU family care. These are realities that they have created in interaction with each other and in the family care context. The institutional context is a key factor, and individual perceptions of reality are also colored by the fact that the clinicians mostly provide family care alone and generally do not share their family care strategies with colleagues. In using a constructivist approach, I have not been searching for a universal truth, but for multiple human realities. As a researcher, I have interpreted the nurses’ and physicians’ perceptions of family care and created meanings. This was an interpretation of their reality, not a reproduction of it. The value of eliciting different perceptions of reality is to create a nuanced picture of reality. This is the study’s important contribution to knowledge, which can lead to improvements in practice. The findings are transferable to other ICUs where other nurses and physicians can use the knowledge in their practice, such as in increasing their awareness of how attentive, active and tolerant behavior positively affects family care in contrast to lack of attention, passivity and intolerance. However, the study also shows that the reality of the individual ICU must be taken into account in family care. For example, the need for overnight stays for families will depend on the geographical location of the hospital/ICU.

Critics of constructivism question whether all reality is relativistic and socially constructed (Alvesson et al., 2017). Here, a distinction is made between a strong and a weak variant of constructivism (Fangen, 2010). The weak variant, which I consider to be in line with Charmaz' (2014) view of constructivism, does not deny the existence of objective realities, but points out that the interpretation of these realities must be emphasized. To take the previously mentioned example of comfortable chairs for visitors, we see how a chair represents much more than an object that a visitor can sit on. It represents a common ICU strategy of inclusion and involvement of the family by demonstrating that they are welcome and that space has been provided close to the patient's bed.

6.2.2 Credibility: Research in one's own field

Constructivist grounded theory recognizes the researcher's position and influence on the concepts being constructed (Charmaz, 2014). The researcher is considered as a co-constructor of data, and she must be reflexive and aware of her influence throughout the research process (Thornberg & Charmaz, 2014). The research is affected by the researcher's experience and interpretations. The findings that emerge are not considered objective, but open to several possible interpretations (Lauridsen & Higginbottom, 2014).

My background as an ICU nurse shaped this research project in several ways. It was an advantage to be familiar with the field of research to enable me to focus my observations on family care from the outset. A researcher unfamiliar with the ICU environment would probably have found the high-tech and advanced treatment more of a distraction. My experience as an ICU nurse was also of benefit in establishing trust in my relationships with the participants. Knowledge of the field was important in order to make the necessary discretionary judgments, especially during observations with regard to vulnerable participants (discussed in Chapter 6.2.2). At the same time, my ICU nursing experience probably meant that I took certain ICU procedures for granted and overlooked details of family care. I imagine that another researcher without ICU experience would have emphasized different details in the material and asked different questions. Sometimes I preferred not to ask critical questions because I mostly identified with the participants. I was sometimes worried about drawing the wrong conclusions and misrepresenting the nurses and physicians. I regularly discussed this with my main supervisor. In my memos, I regularly noted down my reflections on both the actual data collection and my analysis of the data. The supervisors have read many memos and we have had useful discussions. They made comments and suggestions on points that I was less aware of, which helped me to focus on my role as a researcher rather than the role of an ICU nurse.

6.2.3 Data triangulation: Combining participant observation and interviews

Data triangulation refers to the use of multiple data sources for the purpose of validating conclusions (Polit & Beck, 2020). Combining participant observation and interviews exploits the strengths of the two methods of data collection, while it can also counteract their limitations (Holstein & Gubrium, 2012). In this study, participant observation allowed me to observe nurse-physician interaction, in addition to clinician-family interaction in the natural context of family care. Following the constructivist research perspective, I combined information from the different methods of data collection in a strategic manner, and used aspects of knowledge I had already acquired to elicit new knowledge. Observation is a suitable data collection methodology to gain insight into tacit knowledge that is difficult to articulate (Zahle, 2012). In observations, the researcher is recommended to focus on participants' appropriate and effective behavior in comparison with their inappropriate behavior (Zahle, 2012). I observed how the actions of an individual nurse or physician received positive or negative sanctions by others (clinicians, patients, or family). This drew my attention to how my actions or words were received by the clinicians and whether I, as an experienced ICU nurse, reacted positively or negatively to their actions (Zahle, 2012).

I deliberately used data from my observations in my questions in the focus groups; this was also important to verify my understanding and interpretations of the observations. In this way, the combination of observations and interviews could reveal any discrepancies between what the clinicians said and what they actually did. This can be difficult to capture by using only interviews without observation. There are several examples of such differences in this study. One is the clinicians' gatekeeping role towards families, which is discussed in Paper 3. Without observation, the clinicians' gatekeeping would have been less visible in the data as a whole.

To sum up, data triangulation has produced rich data on family care in the ICU and the combination of data collection methods strengthens the study's credibility and validity. However, it would probably have further strengthened the study if I had also systematically obtained written data from patient records and data from the families themselves. This idea was considered during the parallel data collection and analysis, but was dismissed due to the already extensive data collection and the framework of the project. However, during my observations I noticed what information about the family was entered in patient records and asked questions about this documentation during both observations and interviews. These aspects of the study were discussed with people with lived experience involved in the project, one former ICU family member and one former ICU patient, and they contributed their expertise on this issue. They had previously been involved during the preparation of the study protocol and during the analysis.

I had limited experience as a researcher when I started my PhD. However, I had considerable clinical experience as an ICU nurse, which mitigated my uncertainty as a novice researcher. I did not know any of the clinicians in the ICUs in the study, but I soon found that I gained their trust. I was an observer, but I also took part in simple nursing care, talked to nurses and physicians in their “language” and demonstrated good understanding of critical care and other work in an ICU. This meant that I soon became familiar with each unit and my presence became more natural and not so much that of an external observer. The clinicians did not appear to feel that they were constantly being watched. However, being observed can be perceived as invasive, and one nurse stated that she did not want to be observed. It also happened that I was presented as an *intern* instead of as a researcher and observer. There were also a few situations I was unable to observe out of consideration for the patient, the family and/or the staff (described in more detail in Chapter 6.2.3).

As a researcher, I was responsible for finding the right balance between the close contact required for data production and the necessary analytical distance that is also required in research (see also Chapter 6.2.5). In some situations, I had the impression that the participants were particularly aware of factors related to families since I was present, but my general impression was that the clinicians behaved as they normally do without an observer in the room. This is also indicated by the results in Paper 3, which partly deal with the clinicians’ behavior. In situations more directly involving families, however, I tried to keep more in the background to avoid disturbing the clinician-family interaction as far as possible. I was a participant insofar as I was in the room with them, listening and observing, but I did not actively participate in the dialogue with the family, without appearing uninterested in them. I answered politely if I was asked a direct question in such situations.

The trusting relationship established during the observations laid a solid foundation for the focus group discussions because most participants already knew me from the observations. There was a pleasant, trusting atmosphere in the interviews. However, the recruitment of participants to the focus groups had taken place via a contact nurse in each ICU; there would thus be no risk of my taking advantage of the trustful relationships to put pressure on the participants to join the focus groups. However, the sample may have been somewhat biased, since those ICU nurses and physicians who were most interested in family care may have been more likely to agree to participate.

Each focus group consisted of five participants, except for the first two, which had three and four. Initially, six clinicians were invited to participate in each group, but their busy schedule did not allow all of them to participate. Apart from focus group 1, which had only three participants, the groups were felt to be large enough and provided rich data when all the participants took part in the discussions to enable a variety of opinions to emerge.

I often found that the participants' discussion in the focus groups revealed various opinions, and I found that it was a friendly research method to help to smooth out any conflicts between parties that could begin to arise. However, I also found that it could be challenging to bring up sensitive topics or express controversial opinions. In some cases, the participants indicated that they preferred not to voice their opinion and that they wanted to avoid being tempted to bring up a topic they did not want to discuss. As the researcher who moderated the interviews, I kept a lookout for any power imbalance between the participants, especially in situations of vulnerability that could arise. However, the participants’ profession, age and experience influenced the group dynamics. Yet it was an advantage that my supervisor(s) and I, who moderated and observed the focus groups, were familiar with the ICU and the terminology used. The observer noted interactions between the participants, while the moderator facilitated the discussion and encouraged participants to speak freely and discuss their experiences and opinions, ensuring that they were all included in the discussions. We were aware of the power imbalance and hierarchical relationship between the participants, especially between the nurses and physicians. The participants in each focus group knew each other and created a trusting, collegial atmosphere. My impression was that the participants felt at ease with each other and spoke freely, partly because several shared experiences from family care that had affected them greatly and been particularly difficult. The observer asked questions and summed up at the end of the interview. This enabled us to confirm or deny our immediate understanding of the participants’ statements and ensured that important questions to the participants had not been omitted. In the focus groups with both physicians and nurses, much of the conversation focused on the physicians' interaction with families and collaboration between physicians and nurses. Since nurses' family care is more comprehensive than this, we conducted a final focus group consisting only of nurses, to find out whether this would provide additional data.

Initially, we wanted focus group interviews with the surgical and medical physicians from the primary ward, but this was not feasible for practical reasons. In retrospect, I realize that based on my insight into the dynamics and schedules of ICUs, I should have planned these interviews better and at an earlier stage. However, conducting individual and dyadic interviews with these physicians was a good substitute for focus groups. I was able to go in depth and elicit important details during these interviews. However, since I had not previously met these participants, I found it somewhat more difficult to get a good dialogue going and I was also more nervous during these interviews.

6.2.4 Ethical considerations: Fieldwork among critically ill patients

My choices of methodology and data collection strategies implied research ethics considerations and challenges that required me to show particular ethical awareness as a researcher. This applied especially during observations among acutely and critically ill patients, but also during the interviews and in management and presentation of the data.

Consideration for vulnerable participants

It was impossible to observe the physicians' and nurses' family care without simultaneously observing patients and families. They thus became indirect participants in the project and, as stated in Chapter 4.9, the REK waived the duty of confidentiality. Family members and alert patients received study information and I asked for their permission to be present and observe the clinicians.

The term vulnerable groups is often used in the literature in medical and health sciences (Fangen, 2010; Johansson & Lynøe, 2008). Such groups are considered vulnerable because it is difficult for them to give informed consent for various reasons (Solbakk, 2014). ICU patients must be considered vulnerable as they often have a lack of or reduced ability to provide consent. Whether it is ethically justifiable to involve vulnerable participants in research has been and is still being debated (Johansson & Lynøe, 2008; Ruyter et al., 2014;

Solbakk, 2014). The Declaration of Helsinki (WMA, 2018) permits research on vulnerable groups, but on certain conditions. The research must be necessary to promote the health of the group to which the participants belong and is only permissible when the research cannot be conducted on others who are less vulnerable, such as healthy people. The more vulnerable a group is, the greater the ethical caution to be exercised (Ruyter et al., 2014). There may be good reasons why people who are very vulnerable, with limited or no capacity to consent, must not be included in research. On the other hand, if very vulnerable people are never included in research, it may further increase their vulnerability (NEM, 2005).

In this PhD project, I feel that the ICU patients were not unduly burdened. Although I provided simple nursing care and observed the clinicians' patient-oriented work, the patients were not directly involved and no sensitive or confidential data about them were collected. As for family members, they are in principle not considered vulnerable as long as they have capacity to consent, i.e., as long as they are adults and cognitively healthy. However, the family members of patients with life-threatening diseases are in particular need of care and support (Helsedirektoratet, 2017). They tend to be under great pressure, are often anxious and are at risk of developing psychosocial disorders (Davidson et al., 2012; Van Beusekom et al., 2016). I have found that this can affect their ability to think clearly and make informed choices. As the patient's spokespeople, they may be asked to make choices on behalf of the patient, which may imply additional strain. Nevertheless, no families refused to allow me to be present to observe the clinicians' family care. Many offered to share some of their experiences with me. They seemed to think my research was important and they wanted to tell me fragments of their experiences as an ICU family.

However, there were a few patient and family situations that I decided not to ask to observe or where the nurses did not think my presence was appropriate. One example was a seriously injured patient who had recently arrived. The injuries were so severe that his life could not be saved and life-prolonging treatment had to be terminated. In this situation, I chose not to be present out of consideration for the patient and family, but also for the sake of the clinicians. I felt that the ethical nature of the situation was challenging for the parties involved, and that my presence could be an additional burden. This example illustrates that even though the levels of stress and vulnerability of the participants were generally not excessive, I had to carefully consider the circumstances in each case.

Informed consent

In health research, the requirement for informed consent is a key principle of research ethics. Informed consent implies that participants in a research project must have received sufficient information about the project to enable them to understand what their participation involves (Ruyter, 2003; Ruyter et al., 2014). This information should ideally be given orally and in writing. Consent must be voluntary and the participants must be able to withdraw from the project without any negative consequences. This requirement is stated in the Health Research Act (Helseforskningsloven, 2008) and is based on the Declaration of Helsinki (WMA, 2018). The aim is to protect the participants from distress and harm, and to safeguard their right to decide for themselves (NEM, 2005). Informed consent alone does not guarantee that a research project is ethical. The responsibility to ensure ethical research always lies with the researcher, not the participants, even if they have given their consent (Ruyter et al., 2014).

In the observational part of this study, it was difficult to provide the information to all the participants. There are a large number of employees in an ICU; it is not uncommon to have 80-120 nurses and 20-40 physicians working shifts in an ICU with about 6-12 inpatients at any given time. It is difficult to estimate the average number of family members per patient, but experience shows that most patients receive regular visits from two to four close family members. How could I inform all these people about the study and obtain their consent to observation?

All ICU employees were sent information by e-mail. In addition, information letters with a picture of the researcher were put up at the entrance to the ICU and in family rooms, staff rooms and corridors. Oral information was given to clinicians, family members and alert patients when I was present in the ICU. Permission to observe given by the management was considered to cover the clinicians, but individual employees were entitled to refuse to be observed. At my first meeting with alert patients and family members, I obtained oral consent. The family consented on behalf of those patients who lacked capacity to consent. This is in itself a research ethics dilemma as one cannot be certain that the family knows whether the patient would have consented. On the other hand, the researcher can only relate to the family when the patient is incapable of giving or refusing consent (NEM, 2005; Ruyter et al., 2014).

A further problem was the content of the information to the various groups of participants. How could I explain in a brief, specific and comprehensible manner about what I would like them to consent to, without placing excessive limitations on my research? Fangen (2010) states that providing full information can unduly constrain the research. It can inhibit the participants and prevent rich and valid data. In participant observation, it can be difficult to provide complete information about what the research will involve for the participants because the researcher does not yet know what she will find and how she will interpret it (Fangen, 2010). This requires a high degree of confidentiality when the researcher presents her findings. Several times during my observations I realized how important it was to make it quite clear why I was present in the ICU. As I was dressed like the intensive care nurses, I could have been seen as one of them. For example, family members asked me about the patient's condition or plans for treatment and care, and one leader introduced me to the staff as an intern, not as a researcher. I found this unpleasant and incorrect since it concealed the real purpose of my presence. I therefore made a conscious effort to state who I was as soon as this was feasible. I also wore a name tag stating that I was an ICU nurse and researcher.

Timing could also pose problems in relation to informed consent. Work in an ICU is hectic and the patient situations change rapidly. It was therefore not always possible to interrupt the clinicians' work and disturb patients and families with my research. I resolved such situations by stating who I was and requesting consent when the situation had stabilized. However, in some cases, as mentioned, I decided not to observe.

Some clinicians who only came sporadically to the ICU, such as surgeons who came during the day, were difficult to reach with information about my position and the purpose of the study. Here, the solution was to inform them as soon as possible without disturbing their work. The information on the walls of the ICU about the ongoing observations was also directed at clinicians who came irregularly. As described in Chapter 4.9, written consent was obtained from participants in individual, dyadic and focus group interviews.

Ensuring the anonymity and confidentiality of the participants

I assured the participants of confidentiality and anonymity. The data were anonymized to ensure that no identifiable information about the participants or the ICUs appeared in the articles or the thesis. Sensitive information was processed with care. The interviewees were given pseudonyms and in my field notes I was careful not to include data that could be linked to a particular patient, family or staff member, such as names of people and places, age, diagnosis and dialect expressions. In focus groups, however, the researcher has little control over the participants following the interview, but as moderators we (Ranveig Lind and I) encouraged all participants not to talk to anyone outside the group about the topics discussed during the interview. The quotes presented in the articles and the thesis were chosen with care, both out of respect for the participants and to ensure their anonymity and confidentiality. Storage and deletion of the data are described in Chapter 4.9.

6.2.5 Choice of analysis methods: Constructivist grounded theory and thematic narrative analysis

Although there is a great deal of research on ICU families, we find few studies of physicians' and nurses' strategies and approaches towards these families. Constructivist grounded theory is a highly suitable method for studying strategies and processes and it provides a broad, inductive approach to the field of research (Bryant & Charmaz, 2007). This method has enabled me to construct concepts and explain relationships and has given me a general overview of clinicians' family care; the study has thus contributed theoretical knowledge to the research field. One important advantage of constructivist grounded theory is the systematic, yet flexible guidelines for collecting and analyzing qualitative data (Charmaz, 2014). In this study, I followed the predetermined methodological steps (cf. Chapter 4.0), and the method allowed me to explore questions and ideas that arose during the process. However, grounded theory is a complex research method that is somewhat time-consuming (Polit & Beck, 2020), which I discovered as an inexperienced grounded theory researcher. It took time to learn to use the method and I found it particularly difficult to grasp the analysis. I closely examined research methodology literature and spent time to understand the concepts used, particularly those used in constructivist grounded theory. The strength of constructivist grounded theory is the systematic and thorough approach, where the researcher's position and influence on the entire research process is acknowledged and emphasized. I made no attempt to conceal my experience as an ICU nurse and the impact of this on the research. Overall, this made the study transparent and more robust.

My initial attempts at analysis were descriptive and not very abstract. I found it difficult to find suitable concepts that were representative of the findings. Gradually, however, I gained a more abstract understanding of the participants' main concerns and core categories and sub-categories emerged. When developing concepts, I found it particularly useful to write memos and to read previous research. At what stage the researcher should review the literature has been debated in grounded theory, as mentioned in Chapter 4.2 (Giles et al., 2013). In the constructivist tradition it is recommended not to postpone this until the very end as in the classical tradition (Giles et al., 2013), and novice researchers in particular are warned not to be influenced by existing theory and preexisting categories (Charmaz, 2014). In addition to my own reflections, it was crucial to have regular discussions with my supervisors. They read many of my memos, challenged me to be clear in my presentation and asked critical questions that constantly improved my analysis and my construction of concepts.

As described in Chapter 4.8, in consultation with my supervisors, I decide to change my method of analysis from constructivist grounded theory to thematic narrative analysis during my work on Paper 3. This was based on a critical assessment of the advantages and disadvantages of the constructivist approach compared to the possibility offered by narrative analysis to produce thick, detailed descriptions (Riessman, 2008). My analysis of the longer narratives in the data focused on how the clinicians' approach and behavior towards families were crucial for the quality of ICU family care. By keeping the narratives intact for interpretive purposes, instead of interpreting each segment of data as in grounded theory analysis (Riessman, 2008), I was able to present findings containing rich, detailed descriptions in Paper 3. A detailed description of the context is important for readers to understand the enabling and constraining factors for high-quality family care. Another advantage of thematic narrative analysis was that we were able to discuss the findings in the light of existing care ethics theory and thus avoid a purely inductive approach in the analysis. However, the steps in thematic narrative analysis are not as clearly and systematically described as in constructivist grounded theory, which may somewhat weaken the transparency of the presentation of the analysis. Riessman (2008) does not provide a blueprint for the analysis procedure, except that the researcher analyzes one narrative at a time while searching for themes. Examples from previous studies in the methodology literature (Riessman, 2008) were useful in learning the method. However, changing the method in the data analysis meant that the constructivist perspective still persisted in the narrative analysis. An example of this is that in the constructivist view "everything is data", including the design of rooms and the location of equipment and people. When a nurse in one of the narratives is described as sitting "with her back to the family", this is an example of a configuration in the room that is not neutral. I would argue that the constructivist perspective specifically helped me in the narrative analysis by enabling me to highlight the ethical aspect of this nurse's position and behavior towards the family.

7 Conclusion

This study shows that the quality of family care in the ICU depends on nurses' and physicians' attitudes, behavior, and personal traits, but also on their interprofessional collaboration and communication. However, the study indicates that nurses and physicians talk little about family care at a strategic and organizational level, and that the family care strategies of the ICU management are vague and inexplicit. Basing family care in the ICU largely on the clinician's personality and experience involves the risk of varied practices, dependent on the individual clinician. The study also shows that even though ICUs are unpredictable by nature, it is possible to facilitate family care in the ICU by developing a family-friendly culture and environment. Here, the ICU management has a vital role to play in enhancing nurses' and physicians' individual and interprofessional family care strategies by developing evidence-based guidelines and promoting interprofessional dialogue and reflection.

7.1 Implications for clinical practice

This study commenced two years before the COVID-19 pandemic broke out and the data were collected before ICUs were generally closed to families. Now, after two years of COVID-19, Norwegian ICUs have fortunately reopened to visitors. However, I fear that the pandemic has reversed some of the progress achieved in involving and caring for families (Fernández-Martínez et al., 2022). The knowledge from this study can thus be important at this point, when procedures for family care and a family-friendly ICU culture need to be re-established. Overall, the study provides a comprehensive picture of the factors that affect nurses' and physicians' family care strategies, which can be useful in clinical practice to understand relationships between the elements involved and provide greater clarity as to where efforts should be directed in order to improve practice. The study shows that family care is considerably more complicated than direct encounters between the individual nurse or physician and the family. For example, the study reveals significant shortcomings and challenges regarding handovers that include information about families. This has been little discussed in previous studies, despite our knowledge that inconsistent information and communication between families and health professionals is a problem. The study also shows that although family care in many respects is the domain of nurses, physicians also have a vital function in this work, and this requires clear interprofessional communication and effective collaboration. Furthermore, the study indicates that the ICU management has a key role to play in a number of areas that affect family care, such as in establishing a clear family care strategy for the unit, improving the physical environment for families and providing staff training and care. The study also presents several good examples to follow, especially in Paper 3, which can be useful in teaching, in reflection on one's own practice and in the promotion of a family culture based on the ethics of care.

7.2 Implications for further research

Overall, this study contains rich and extensive data. During the analysis, as described in Chapters 4.7 and 4.8, I decided to present what most clearly emerged as the nurses' and physicians' main concerns in family care. However, the data also include other interesting and important findings such as caring for children as family members, procedures and facilitation of families' presence in the ICU and room design and facilities for families in the ICU. I plan to analyze these findings in greater detail and present them in later articles, and have already begun work on this.

However, this study also reveals several additional areas that should be explored further. For example, there are a number of problems related to written documentation about families. This is an important finding, which to my knowledge has been little researched. To enhance knowledge of existing documentation practices, notes in medical records and associated trends should be subject to document analysis, which can form the basis for the development and implementation of more appropriate and quality-assured procedures. The study has also demonstrated that the ICU management has a key role and responsibility in family care, although the management's family care strategy currently seems to be vague and not clearly stated. This topic should be further explored by e.g., interviewing the entire ICU management. Further, the study suggests factors that can improve the situation for ICU families, although we know from previous studies that families and clinicians give different weight to certain factors. It would therefore be interesting to explore family members' opinions and experiences in relation to our findings. The study also suggests interventions that should be implemented in ICUs to improve family care, such as handover tools that include family information, regular interdisciplinary meetings and guidelines for talking to families. Such interventions must be implemented in a structured manner and followed up with studies to assess the effects of the implementation.

Paper 1

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Information concerning ICU patients' families in the handover—*The clinicians' «game of whispers»*: A qualitative study

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Abstract

Aims and objectives: To explore how information concerning ICU patients´ families is included in the ICU clinicians' daily handover.

Background: Handover refers to the transfer of information and care responsibility between clinicians. An effective and precise handover are of great importance to ensure quality of care. Although improvements in handovers have received increasing attention in recent decades, little is known about how information about ICU patients' family members is included in handovers.

Design: A qualitative study using Charmaz' constructivist grounded theory approach.

Methods: Data were gathered through participant observation, focus groups, dyadic and individual interviews of physicians and nurses from four ICUs in different Norwegian hospitals. The data consist of 270 observation hours, seven focus groups, three dyadic interviews and two individual interviews. Field notes and transcribed interview data were analysed using constructivist grounded theory approach. COREQ checklist was applied as reporting guideline for this study.

Findings: "A game of whispers" emerged as the core category, representing missing information about the patient's family during the handover. Together with three subcategories: "documentation dilemmas," "being updated" and "talking together," the core category explains how transfer of family-related information between clinicians is continually processed and resolved.

Conclusions: This study indicates challenges related to appropriate and high-quality handover concerning ICU patients´ families. Oral handovers are essential in terms of clinicians' need to elaborate on written information and update each other. However, oral transmission involves a high risk of information loss during the handover. Written documentation about the family seems to be inadequate and poorly structured.

Relevance to clinical practice: The study findings suggest a need for increased awareness in practice and research of the importance of transferring appropriate and reliable information about patients' families between ICU clinicians. User-friendly

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handover tools and patient records that include information on patients' family members should be developed.

KEYWORDS
constructivist grounded theory, family, handover, Intensive care, patient- and family-centred care, qualitative research

1 | INTRODUCTION

A handover is defined as "an explicit transfer of information between clinicians" (Abraham, Kannampallil, & Patel, 2012). Through the handover, professional responsibility and accountability for the patient are transferred from one clinician or a professional group to another (Bakon, Wirihana, Christensen, & Craft, 2017; Merten, Van Galen, & Wagner, 2017; Smeulers, Lucas, & Vermeulen, 2014). To ensure effective and safe patient care, the information transfer must ideally contain all relevant information about the patient (Merten et al., 2017). This also includes information about the patient's family. The family is a fundamental resource and caregiver for the patient and an important collaborator for the health professionals (Davidson et al., 2017). This is especially important in an intensive care setting as most ICU patients are too ill or affected by medication to contribute to their own care and decision-making. For the ICU patient's family, there is also a serious mental strain when a close family member becomes critically ill (Davidson et al., 2017; Mitchell & Wilson, 2019). Consequently, they also need care and information from the clinicians in the ICU team. To ensure continuity and quality of family care, it is necessary to include information about the ICU patient's family in the handover. Improvements in handovers have received increasing attention in recent years in order to enhance quality in communication and continuity of care (Hoskote et al., 2017; Smeulers et al., 2014). These improvements include face-to face communication, structured documentation, patient involvement and use of information technology to support the process (Smeulers et al., 2014). Despite this, some aspects of handovers remain unexplored and appear suboptimal. To our knowledge, few studies have explored how information about ICU patients' family members is included in handovers. Kowitlawakul et al. (2015) showed that only 41% of physicians and nurses included information about the patient's family in the handover when transferring patients in or out of the ICU.

1.1 | Background

In addition to taking care of the patient, ICU nurses and physicians are responsible for helping the patient's family cope during the patient`s ICU-stay and working to reduce the risk of stress-related reactions for the family (Mitchell & Wilson, 2019). This requires that information from and about the family is transferred between health professionals. Close family members know the patient well and should be acknowledged as essential resources in the care of the patient as they commonly are supportive and represent hope and safety (Alexandersen et al., 2019; Haugdahl et al., 2018). In addition, family members have their own needs. They are at high risk of developing psychosocial symptoms such as sleep disorder (Choi et al., 2016), depression, anxiety, posttraumatic stress disorder and complicated grief (van Beusekom, Bakhshi-Raiez, de Keizer, Dongelmans, & van der Schaaf, 2016; Davidson, Jones, & Bienvenu, 2012) and decreased health-related quality of life during the period of critical illness (van Beusekom et al., 2016). Family members need access to ICU to ensure their proximity to the patient and to receive thorough and honest information about the patient's condition (Briggs, 2017; Frivold, Slettebo, & Dale, 2016). Inadequate communication and inconsistent information from ICU nurses and physicians are often the main cause of dissatisfaction in families of ICU patients (Frivold et al., 2016; Jensen et al., 2017). This suggests that the ICU team need to improve their communication and cooperation regarding these families.

The ICU team consists first and foremost of nurses and physicians from the ICU, but the extended team includes health professionals from different disciplines such as physicians from other specialties, physiotherapists, social workers and chaplains (Bjurling-Sjöberg, Wadensten, Pöder, Jansson, & Nordgren, 2017; Donovan et al., 2018). The ICU handover characteristically involves reporting of high medical complexity due to the patient's critical illness and information about the technologically advanced medical equipment in use (Kowitlawakul

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

- Handover including the ICU patient's family is not emphasised in previous research despite family care being an essential part of the ICU team's daily work.
- Oral handovers are essential in terms of clinicians' need to elaborate on the information and update each other, including details about the family. At the same time, oral transmission involves a high risk of information being altered or lost.
- There is a need for user-friendly handover tools and patient records that include information about patients' family members.

et al., 2015). Effective information sharing is essential for an efficient ICU team (Ervin, Kahn, Cohen, & Weingart, 2018). ICU handovers regularly take place several times a day due to changes in medical or nursing shifts, and during transfer of patients in and out of ICU (Rodríguez et al., 2018). Handovers are both intra-disciplinary between nurses or physicians in the shift change and inter-disciplinary between physicians and nurses, for example during rounds. These formal handovers are supplemented with informal information-sharing throughout the day as needed (Ervin et al., 2018).

In general, written notes in the patient record support oral handovers (Collins et al., 2011; Ervin et al., 2018; McFetridge, Gillespie, Goode, & Melby, 2007; Smeulers et al., 2014). Use of checklists, guidelines or other suitable tools is recommended to ensure an effective and structured handover (Bakon et al., 2017; Dutra, Monteiro, Ribeiro, Schettino, & Kajdacsy-Balla Amaral, 2018; Smeulers et al., 2014). These are designed to promote effective communication among clinicians and to rationalise care (Ervin et al., 2018). However, use of these tools is criticised for making the handover too rigid and standardised, risking losing a holistic and individual perspective on care (Hilligoss & Moffatt-Bruce, 2014; Rodríguez et al., 2018; Spooner, Aitken, & Chaboyer, 2018).

ICU handovers generally take place at the bedside or in the clinicians' daily meetings (Ervin et al., 2018). To enhance collaboration and information flow between clinicians and family, it is recommended that family members are present during the bedside handover (Ervin et al., 2018; McCloskey, Furlong, & Hansen, 2019). This is in line with the principles and approach of patient- and family-centred care (PFCC) which recommends that health care be respectful and responsive to patients' and families' values and needs (Davidson et al., 2017; IPFCC, 2010). It might, however, be challenging to allow family presence in the handovers due to the clinicians' need for undisturbed medical discussion and confidentiality in multi-bedded rooms (Davidson et al., 2017; Ervin et al., 2018).

Intensive care is event-driven and time-pressured (Merten et al., 2017) and interruptions and distractions during handovers are common (Ganz et al., 2015; Kowitlawakul et al., 2015; Spooner, Corley, Chaboyer, Hammond, & Fraser, 2015). Further, the ICU team is seldom constant. Due to shift work, in-service training and dynamic changes in patient needs, team members may change from day to day (Bjurling-Sjöberg et al., 2017; Ervin et al., 2018; Hoskote et al., 2017). This instability results in challenging handovers and disruptions in continuity of care for patients and their families.

Although we have a broad picture of clinicians' communication *with* ICU families (Davidson et al., 2017), there are still knowledge gaps regarding how information *about* the family is included in ICU clinicians' daily handover.

1.2 | Aim

The aim of this study is to explore how information concerning ICU patients´ families is included in the ICU clinicians' daily handover.

2 | METHODS

2.1 | Design

A constructivist grounded theory approach was used to explore how ICU clinicians communicate about the patients' families in their everyday practice. According to Charmaz (2014), grounded theory is well suited to investigate both individual and collective actions, and interactions between participants (Charmaz, 2014). The aim of this approach is to conceptualise and understand participants' behaviour and meanings in a particular setting (Charmaz, 2014; Giles, de Lacey, & Muir-Cochrane, 2016). In grounded theory methodology, inductive and abductive strategies are combined to develop theory grounded in data. The researcher seeks out the main concern of the participants using systematic yet flexible guidelines to form conceptual categories (Thornberg & Charmaz, 2014).

Essential principles in grounded theory are simultaneous data collection and analysis, constant comparative method, theoretical sampling and saturation together with memo writing (Charmaz, 2014; Thornberg & Charmaz, 2014). In grounded theory, the researcher has to choose data collection methods based on the research problem and the on-going data analysis (Thornberg & Charmaz, 2014). In this study, participant observation, focus groups, dyadic and individual interviews were chosen.

Constructivist grounded theory has roots in pragmatism and relativist epistemology (Charmaz, 2016; Thornberg & Charmaz, 2014). Knowledge is seen as socially produced, and multiple realities are acknowledged (Charmaz, 2016). Constructivism brings out subjectivity and interaction; neither the data nor the analysis is considered neutral (Charmaz, 2016). The researcher and the participants are perceived as co-constructors of data, influenced by the researcher´s interactions with the participants, their perspective and their research practice (Charmaz, 2016; Giles et al., 2016). The method emphasises researchers' reflexivity and awareness throughout the research process (Thornberg & Charmaz, 2014).

The "consolidated criteria for reporting qualitative research (COREQ)"—checklist (Tong, Sainsbury, & Craig, 2007) was applied as the reporting guideline for this study (Supporting information File S1).

2.2 | Setting and participants

Data were gathered at four ICUs in different Norwegian hospitals—three university hospitals and one mid-range hospital. These ICUs treat both medical and surgical critically ill patients, adults and children. Size ranged from 6 to 18 beds; two had only single rooms, while the others had both single rooms and rooms with 2–4 beds. The nurse–patient ratio was 1:1.

In Norway, close family have legal rights to be informed and included in the care and treatment of the patient. However, they do not have a right to act as a surrogate on behalf of the patient. Patients themselves can decide who should be considered as their family. These persons do not necessarily have to be biological or legal family (The Health Personnel Act, 1999).

In this study, ICU nurses and physicians were the study participants of interest. During data collection and analysis, preliminary findings showed that physicians from the patients' surgical or medical ward were jointly responsible with the ICU staff for providing family members with information and were often involved in the ICU team's handover. They were therefore included in the study.

All nurses and physicians in the participating ICUs agreed to be observed during the fieldwork. To make a thorough observation of the handover, the researcher observed one ICU team daily by following their treatment and care of one or two ICU patients and their families. The observation was continued with the same team, patient and family for one to three shifts before turning to observe another team. The observations typically focused on handover situations in the patient's room and during the clinicians' meetings throughout the shift. Such situations were, for example, nurses' shift reports to another nurse, physicians' daily morning meetings, preround meetings, meetings during rounds and other interdisciplinary meetings. However, nurses and physicians were, in addition, observed during informal meetings, such as dialogues about family care during lunch breaks. With the consent of families and patients (if capable), the researcher also observed when families were visiting and their encounters with the clinicians.

The participants in the focus groups were ICU nurses and physicians; they were colleagues and worked in the same ICU. The participants in the dyadic and individual interviews were surgeons and internists. They knew each other, but belonged to different ward units in the same hospital. In total, 40 clinicians participated in focus groups and interviews: 19 ICU nurses, 13 ICU physicians (Table 1) and eight surgeons/internists (Table 2). As far as possible, participants with different ages, gender and experience were invited to participate. No ICU leaders participated in the focus groups or during the interviews, however, as part of the fieldwork, the observer spoke with both the nurse and the physician in charge of each ICU.

2.3 | Ethical approval

The study was approved by a formal institutional ethics review board (Regional Committee for Medical and Health Research Ethics - Ref.: 2016/1762), and by the participating ICUs. In each unit, the researcher (AMN) was provided with a contact nurse who forwarded information on the study to the ICU nurses and physicians before the fieldwork started. The researcher also informed the clinicians orally at every shift. Although clinicians, rather than patients and family members, were the participants in this study, it was impossible to observe clinicians in the patient's room without simultaneously observing patient and the family. Thus, oral information about the project was provided to alert and consenting ICU patients and to all family members present. Neither patients nor family members refused to have the researcher present. Written information about the project, with a photograph of the researcher, aimed at informing visiting clinicians and all visiting family members was posted at the ICU entrance and in the ICU corridors. Written informed consent was obtained from the participants in the interviews. In the written and oral information, the researcher explained the background, purpose, duration and confidentiality of the study, and about the participants' right to withdraw from the study at any time. The researcher's contact information was included in the written information.

The researcher assured the participants of confidentiality and anonymity. In focus groups, this can be difficult as the researcher has limited control over the participants after the interview (Sim & Waterfield, 2019). At the beginning of each focus group and dyadic interview, the moderator encouraged the participants not to communicate any of the topics discussed outside the group. To protect confidentiality, all transcriptions from field notes and interviews were anonymised.

2.4 | Data collection

Data were collected using a variety of methods and according to the principle of theoretical sampling. Theoretical sampling refers to (Glaser & Strauss, 1967):

> the process of data collection for generating theory whereby the analyst jointly collects, codes, and analyses his data and decides what data to collect next and where to find them.

TABLE 1 Focus group participant characteristics

Focus group (*N* = 7)	Focus g. 1	Focus g.2	Focus g. 3	Focus g. 4	Focus g. 5	Focus g. 6	Focus g. 7
Hospital No.	1	1	2	2	3	4	4
Mid-range (M)/ University (U)	M	M	U	U	U	U	U
Intensivists	0	4	0	5	2	2	0
ICU nurses	3	0	5	0	3	3	5
Gender—female/male	2/1	0/4	3/2	1/4	2/3	2/3	5/0
Age—range	37–54	34–60	28–54	33–67	39–49	37–54	34–60
ICU experience—mean (min-max)	17 (8–25)	14 (5–30)	10 (2–15)	23 (2–38)	12 (3–20)	10 (4–16)	8 (1–19)

TABLE 2 Participant characteristics for dyadic and individual interviews

Interviews Dyadic/individual	Interview 1 Dyadic	Interview 2 Dyadic	Interview 3 Individual	Interview 4 Dyadic	Interview 5 Individual
Hospital No.	3	3	4	4	4
Mid-range (M)/University (U)	U	U	U	U	U
Specialisation—surgeon/internist	2/0	1/1	1/0	0/2	0/1
Gender—female/male	0/2	1/1	1/0	1/1	1/0
Age—range	36–65				

All researchers (AMN, HSH, BSB, RL) are female nurses, including three ICU nurses, all with expertise in clinical practice and teaching. HSH, BSB, RL are widely experienced in qualitative research, leading focus group discussions and with doctoral (HSH, RL) or professorial expertise (BSB). BSB and RL started the data collection by conducting two focus groups in July and October 2017, one with ICU nurses and one with ICU physicians. The participants´ concern about missing information about the ICU patient's family emerged as an initial code already from the analysis of the first focus group. To focus this code and gather richer data about the clinician's handover process, the researchers extended the data collection to participant observations (fieldwork) combined with focus groups. The preliminary data collection and analysis from the first two focus groups were also used to complete the study protocol and organise further steps to accomplish the study.

The fieldwork was performed (by AMN) between June 2018 and August 2019 in eleven to fourteen shifts in each of the three university hospital ICUs. Since the researcher who made the observations is an experienced ICU nurse, she was occasionally included in simple nursing care. This opportunity to follow ICU clinicians during their work enabled the observer to stay close to situations where family care was provided. The researcher made field notes throughout and following each shift.

During the last week in each ICU, focus groups were conducted (by AMN and HSH or RL), with ICU nurses only, with ICU physicians only, and with a mixture of nurses and physicians (Table 1). Each focus group consisted of five participants, except for the first two, which had three and four participants. With consideration to the inequalities of power (within a hierarchical structure) and to identify different perspectives between the nurses and physicians, the first focus groups were conducted with one profession at a time. Then, to explore the interaction and discussions between the professionals, the researchers conducted focus groups with nurses and physicians at hospitals 3 and 4. The researcher's contact nurse in each ICU recruited participants to the focus groups, face-to face or by email.

When it became evident that physicians from the patients' surgical or medical ward were included in the ICU team's handover the data collection was then extended further by arranging five interviews (by AMN) with a total eight of these physicians at hospitals 3 and 4 (Table 2). We tried to schedule focus groups with these physicians as well but due to their busy working days in different clinics, it was not possible. Recruitment of these participants was arranged by email to the head of the surgical and medical clinics. The data collection and analysis showed that nurses were more heavily involved in family care and included more information about the patient's family in their handovers than physicians. To make sure that the emerging conceptual categories were saturated, the researchers conducted one additional focus group in hospital 4 with ICU nurses only.

An interview guide designed as a "questioning route" (Krueger & Casey, 2015) was employed and modified during data generation and the development of codes and categories. All interviews took place in a separate meeting room in the ICUs. Two researchers, a moderator and an observer, conducted each focus group. The moderator chaired the focus group while the observer followed the interactions between the participants, made notes and provided a summary. The dyadic and individual interviews were conducted by AMN. All interviews were digitally recorded and transcribed verbatim by the first author. The data consists of field notes and transcriptions from 270 hr of observation and from twelve focus groups and interviews lasting from 37 to 96 min.

2.5 | Data analysis

Field notes and transcribed interview data were analysed using a constructivist grounded theory approach. In accordance with grounded theory, data collection and data analysis were conducted simultaneously (Thornberg & Charmaz, 2014). Immediately after each data collecting, the analysis and coding process began with line-by-line reading and initial coding of field notes and transcripts. Analytical questions were asked of the data (Charmaz, 2014): What is this data a study about? What do the data suggest, pronounce or leave unsaid? From whose point of view? What might his or her observed behaviour indicate? What is the participant's main concern? As a result of the initial coding, the most frequent and significant codes emerged and were constructed as focused codes. The data analysis was not linear, but a constant back and forth process comparing data, codes and categories, using constant comparative analysis (Charmaz, 2014; Thornberg & Charmaz, 2014). The analysis generated insights, assumptions, aha experiences and questions that the researchers brought to the next data collection. Through memo writing, the ideas about codes, emerging categories and the relationship between them were clarified and explicated. In this way, the level of abstraction increased, and conceptual categories were gradually developed. One core category with three-related subcategories emerged, explaining the participants' main concern.

AMN coded all written text from interviews and field data and wrote memos. HSH, BSB and RL read the data material and contributed to the analysis. The researchers met several times to discuss, select and focus the codes. They contributed ideas and perspectives from their different disciplines, helping the team to identify conceptual categories.

2.6 | Findings

The core category "a game of whispers" first emerged as an in vivo code when a nurse in one of the first focus groups used the concept to describe what happens when information about the family changes with each new member of the ICU team who passes it on:

> ... often it's like a game of whispers; if you meet the nurse who was at the meeting with the relatives, you get a good report, but then you pass on the info to someone else and so on ... that doesn't work so well.
>
> (Emma, ICU nurse, interview 3)

A game of whispers is a well-known children's game. One player whispers a message to a second, the second whispers to a third, and so on. Once the message has gone around everyone and returned to the one who started, it has changed along the way. This indicates how details about a patient's family members get lost during the "game." Only parts of the information will be carried over to the next shift. There is also lack of accurate written documentation about the ICU patient's families. Several nurses called attention to this problem in the focus groups. One of them expressed it like this:

> .... we often read in the patient record that the family have talked to the physician and nurse, ...but about what? What did they talk about? That's not written anywhere. They got information, but what kind of information? That's what I miss ...
>
> (Megan, ICU nurse, focus group 3)

Both oral and written information appeared to have shortcomings. The big picture is missing and ICU physicians and nurses do not receive the necessary information about the patient's family. Further analysis revealed that the information handover process was the participants' main concern. "A game of whispers" emerged as a core category, conceptualising the interdisciplinary interactions, meanings and actions attached to the handover about ICU patients' family members. During the analysis, from the initial coding to the development of the core category, three subcategories were identified and related to the core category: "documentation dilemmas," "being updated" and "talking together."

2.7 | Documentation dilemmas

Written information, primarily in the patient record, is an important part of the daily handover between health professionals. In this study, several dilemmas physicians and nurses face regarding written documentation about ICU patients' family appeared. The subcategory "documentation dilemmas" represents these dilemmas.

The analysis showed that most nurses were at pains to ensure that contact information for the patient's closest family members was correctly recorded in writing. This is essential because it informs decisions as to who is entitled to receive information about the patient, who should be contacted if needed and who is entitled to represent the patient. According to this, the nurses have the challenge of finding: "who actually is the patient's nearest (i.e. rightful) family," since many ICU patients are sedated or too ill to be able to name their nearest family. The nurses have to trust other sources such as the patient's family or previously documented information about the family in the patient records. This could be a dilemma. Nurses experienced that family members could provide them with conflicting information. Disagreements within the patient's family and/or new family relationships made this work even more challenging. "It depends on who you talk to," the nurses explained in bedside situations and during focus groups. It also appeared that the documentation in the patient record could be out-of-date:

> An unconscious patient was transferred to the ICU from the ward as his condition was deteriorating. The patient's nurse repeatedly tried to ring the patient's mother as stated in the patient's record ... but got no answer. Later the patient's father arrived and revealed that the patient's mother died two years earlier. The nurses describe the situation as very embarrassing and unpleasant.
>
> (Field note from ICU 4)

Such mistakes are not just embarrassing and unpleasant for the nurses. They can undermine confidence or result in conflicts between clinicians and the family. For nurses, it clearly represented a dilemma between safeguarding the rights of the patient's family and, at the same time, protecting the patient from unauthorised access to patient information or acting against his/her wishes.

> I've been in situations where there was a family conflict and when the patient woke up, it turned out that the person who was given information definitely shouldn't have got it.
>
> (Karen, ICU nurse, focus group 1)

Another dilemma concerning written information was *how, what and which* information about the ICU patient's family the clinicians ought to document. Beyond formal details, the patient record contained little information about the patient's family. Although nurses and physicians are involved daily in family care, this work is scarcely visible in the written documentation. The patient record often contains only a brief note or a ticked box to say, "the family have been informed" or, "the family have visited the patient." Clinicians argued that it is the patient's record and it is unclear to what extent information about the family actually belongs there. In some patient record systems, there is a separate file to record "information to and from family members." However, this file was rarely used. In the focus groups and the dyadic interviews, the clinicians discussed possible explanations. Some meant that the document is too comprehensive, others were unaware that it existed. In addition, the participants described conflicting views on how and when to use the file. These findings revealed that documentation practices about patients' families vary among clinicians, which can result in missing information. Lack of consensus about a suitable documentation strategy was experienced as a personal and systemic weakness. The dilemma is about how to find a common way of documenting information about the family in a clear and easily accessible manner without using too many words:

> It's an advantage if everyone (i.e. the physicians and nurses) has the same idea of how to do it, so that everyone knows where to look or where to write and when to write it or what to write … so there isn't a lot of writing just for the sake of writing.
>
> (Hans, ICU nurse, focus group 3)

The field observations showed that the family members' reactions and emotions are rarely documented in writing. A common understanding was that such sensory impressions might be challenging to express in a formal, objective way. When experiencing these documentation challenges, it seemed that clinicians just avoided writing anything at all to prevent being misunderstood or misinterpreted. Both physicians and nurses emphasised that the patient and the family (if they had legal access) should have the possibility of reading the patients' record without facing negative or disrespectful content. Thus, they merely communicated the information orally:

> …so many … things are said that we can't just note down in the patient record.
>
> (Eric, senior intensivist, focus group 5)

> Yes, we' re very careful when writing anything about relatives, we're almost a bit nervous about writing, I think that goes for all of us nurses, we write very little. If there are conflicts, we certainly don't write about it, […] I sometimes think it's is a bit arbitrary what you write.
>
> (Lilly, ICU nurse, focus group 5)

Patients' ability to log in to their patient record (from home) is a relatively new opportunity in Norway. This subject generated a lot of discussion in the focus groups and seemed to have an impact on the participants´ willingness to report information about the family in written. Some participants had found that the closest family member provided with the patient's login code had gained access to the patient record system. Just a few participants had heard of or experienced such situations. However, these stories really engaged the participants. Their common opinion was that family members' access to the patient's record influenced the clinicians to be more restrictive and careful with their documentation practices.

On the other hand, the participants recognised the legal value of the documentation as being important for the daily transfer of information, but also for recording purposes. One of the surgeons explained that for them as a profession thorough documentation of family information and of their understanding of the facts was of uttermost importance as a quality- and safety assurance of their work. They would never risk later meeting families who retrospectively said; "Nobody told us."

2.8 | Being updated

The subcategory "being updated" reflects the importance of clinicians´ internal communication of up-to-date and correct information concerning the patient's family. Being updated is fundamental to their ability to pass on consistent information:

> It's desperately important to agree on what we say to the family and that we know what the physicians from the patient's ward unit has said.
>
> (David, senior intensivist, focus group 6)

Being updated is also crucial for the ICU clinicians to function coherently and work as a professional team. It demonstrates interdisciplinary team working and cooperation to the family.

However, this study revealed a discrepancy between the professionals in their desire to be updated: nurses had a greater need to know what physicians told the family than vice versa. Physicians generally inform the family about the patient's diagnosis, prognosis, treatment and the results of various tests. The fieldwork displayed that it was common practice for nurses to attend physicians' formal information meetings with the family. Both physicians and nurses emphasised the practice as a necessity. Nurses should participate as they later have to repeat the information to the family and clarify it for them. The challenge, however, is to keep the rest of the nurses in the ICU team updated as the information was generally just oral and this "game of whispers" could lead to loss of important information.

The physicians usually documented the content of information provided to the family only when they had informed them about something particularly serious or important, such as withdrawing or withholding treatment. Information about everyday ICU issues was considered by the physicians to be familiar to everyone in the team and was usually not documented. On the other hand, the nurses said that they generally needed to know about all aspects of the physician's conversation with the families. In particular, they appreciated being informed if the physician had withheld any information from the family. Without this information the nurses often had to "put on a brave face" in their conversations with the family. They became insecure, vague and afraid to say something wrong. The nurses emphasised that they wanted to be honest, without going beyond their area of responsibility.

The fieldwork showed that nurses provide the family with different kinds of information, without the physician being present. Examples of this are information about the patient's condition and daily treatment plans. In addition, nurses take responsibility for establishing a safe interpersonal climate towards the family, with trust as a cornerstone. In such a trustful relationship, they commonly engaged in small talk and counselling. This kind of information, and other practicalities within their profession, seemed to be of lesser importance in the nurses' handovers and little of this information was documented.

Updates within the ICU team regarding practical information concerning the family, such as agreements and messages (to/from the family), also seemed to be less emphasised. This can cause the flow of information between clinicians to be broken and prevent essential information from reaching the patient's family:

> During the morning report, the day shift nurse asked the nurse from the night shift whether the patient's wife had been told that he had been admitted to the ICU instead of the post-operative ward. The patient needed to be ventilated overnight. The nurse said she did not know if the wife had been informed. Nothing of this was documented in the patient's record or chart.
>
> (Field note, ICU 3)

2.9 | Talking together

The subcategory "talking together" shows the value of physician' and nurses communication in the ICU team. Their talk is crucial for the team to reach agreement and create continuity in family care. Both fieldwork and focus groups showed that physicians and nurses needed to talk together, especially in the case of challenging and serious patient situations or in situations with conflicts with the family, or among them:

> If it is difficult to please the family members [...] or if there's a conflict between the family and us, we actually discuss it. We help each other.
>
> (Christian, intensivist, focus group 2)

The ICU team has daily inter-disciplinary and intra-disciplinary handovers where the clinicians have the opportunity of talking together. Clinicians' team conversations and discussions allow information exchange and give them opportunities to achieve a common understanding and consensus. The issues raised are often serious and complex.

The nurses had their handover at the bedside. They more or less always include oral information about the ICU patient's family. The amount of information varies between situations and from nurse to nurse. Nevertheless, nurses as a profession, due to their extensive daily contact and conversations with the family, were talking more about the patient's family than did the physicians. The nurses described themselves as "a buffer" for the need to involve physicians in family issues, and they decided when to involve a physician. Examples of such situations were when a family member raised questions about medical or prognostic issues beyond the nurses' responsibilities, or when a conflict with the family occurred to be in the offing.

The physicians had their daily handover in a meeting room within the ICU. Sometimes, especially in one of the ICUs, the whole group of physicians carried out their handover during the bedside rounds. The fieldwork showed that the physicians (unlike the nurses) did not regularly include information about the patient's family in their daily handover. The physicians emphasised that they could not spend time on such issues unless there was an extraordinary situation that justified bringing family issues into the agenda. In one focus group, a physician explained that:

> Usually we only talk about family members if someone is angry or has complaints about something, or if it is a difficult situation and we know that this will be troublesome for our colleagues. Beyond this it is not a topic.
>
> (Tom, intensivist, focus group 5)

The fieldwork also confirmed that physicians in situations such as end-of-life discussions or other critical and serious situations discussed family-related questions during handover.

The most important inter-disciplinary handover among the nurses and physicians was the daily bedside round. In these handover situations, as well, it varied whether the clinicians were talking about the patient's family or not. Most often, the nurses were those who included aspects relating to families in the ICU teams' discussions during rounds. However, in the focus groups both physicians and nurses expressed their need for more inter-professional communication about the ICU patient's family. During discussion in one of the mixed focus groups, the nurses suggested that family issues should be a "fixed point" of the daily round. Apart from the patient record and chart, neither the nurses nor the physicians appeared to use any kind of structured handover guidelines or tools.

Observations from the fieldwork showed that both physicians and nurses needed to supplement formal meetings with more informal conversations about the family. The need for talking together was often context-dependent and difficult to plan ahead of the meeting. Such conversations occurred spontaneously when a clinician needed to inform, discuss or consult colleagues. These conversations could take place during lunch break, in the corridor or in the patient room when the family was not present.

> During the fieldwork, I noted that physicians and nurses often made use of their lunchbreak in order to speak about a question or topic related to the patient's family or next of kin. *Talking together* is clearly vital. This implies that the formal meetings such as the ward round and the bedside handover do not go far enough to cover this need to *talk together*. Less formal conversations during lunch satisfy the need for off the cuff conversation especially regarding demanding and often unforeseen situations that arise with regard to the patient and their family. My impression is that there is a general willingness to take up such matters despite this being the clinic's 'free time'.
>
> (Excerpt from memo: 'Talking together')

These informal conversations contained frustration, helplessness and irritation, but also joy. They served as an outlet for clinicians' feelings. Sharing thoughts and listening to good advice and simply the opinions of others reassured them and made them feel better equipped to talk to the family. However, the challenge for physicians and nurses is to find space for talking together under the pressure of limited time, unforeseen incidents and constant interruptions.

The fieldwork showed that bedside handovers and rounds were common practice in the ICUs, but that the patient's family were usually not present. This was also the case in the ICUs with only single bedrooms and with flexible visiting hours. Clinicians mainly justified this on the grounds of efficiency and of their need to speak to their colleagues confidentially and without interruption.

3 | DISCUSSION

In this qualitative study, we wished to explore ICU nurses' and physicians´ handovers concerning ICU patients' families. The core category "a game of whispers" and its three-related subcategories "documentation dilemmas," "being updated" and "talking together," explains how the participant's main concern about transfer of family-related information between clinicians is continually processed and resolved. Information about the patient's family disappeared as if in a "game of whispers" during the handover process. Our findings show that written information about ICU patients' families was sparse, leaving the next shift with fragmented and inaccurate oral information. There was no agreement between the professionals on how family care and information about the family should be documented and reported. Even if improvements in handover have received increased attention in recent times, these findings indicate that routines for how information about the family should be included in the ICU teams' handover are missing, leaving scope for improvement. Earlier research shows the importance of effective and safe handover (Hoskote et al., 2017; McCloskey et al., 2019), which is associated with good workflow, increased focus on patient safety and efficient use of healthcare resources (Abraham et al., 2012; McCloskey et al., 2019).

Lost or inaccurate information is a well-known problem in clinical handovers both within ICU and during transfers between ICU and other hospital ward units (Blum & Tremper, 2009; Dutra et al., 2018; Enger & Andershed, 2018; Ganz et al., 2015; Zakrison et al., 2016). Incomplete handover is associated with medical errors and inadequate care (McCloskey et al., 2019; Smeulers et al., 2014). Our findings indicate that when the information handover within the ICU was lacking about family issues, family members were less likely to receive consistent information from the ICU team. Poor patient- and family-centred care might be the outcome.

Although oral handover has its weaknesses, it also has an important advantage. This study shows that ICU nurses and physicians need to "talk together" and "be updated" to create continuity in the treatment team, establish a common strategy and be consistent when communicating with the family. The findings concur with other studies in showing that oral handovers allow clinicians to inform, ask, discuss and reflect together (Cohen, Hilligoss, & Kajdacsy-Balla Amaral, 2012; Hilligoss & Moffatt-Bruce, 2014; Poletick & Holly, 2010). Handovers may also function as briefing, debriefing, training, and experience exchanges between health professionals (Bakon et al., 2017; Poletick & Holly, 2010). The study participants emphasised that the need to talk together and be updated is greatest in demanding and complex situations with family members. According to Cohen et al. (2012), transmission of information should not resemble a telegram that passes a message passively from one person to another. On the contrary, handovers should be co-constructed and an active process of two-way communication (Blum & Tremper, 2009; Hilligoss & Moffatt-Bruce, 2014). Narratives offer a more detailed and comprehensive understanding of a situation. With narratives, the context is taken into account and critical thinking given space, especially important in complex situations (Hilligoss & Moffatt-Bruce, 2014). This concurs with findings in the present study showing that the participants, in particularly challenging complex situations and otherwise as needed, came together in informal meetings to talk about the actual situation, seeking mutual help and advice.

Oral handovers should be combined with structured documentation (Blum & Tremper, 2009; Smeulers et al., 2014; Zakrison et al., 2016). The patient record is an important tool for creating information flow and communication between health professionals (Collins et al., 2011; Nelson, Walker, Luhrs, Cortez, & Pronovost, 2009). It can also be a tool to structure handovers and make them more effective (Kowitlawakul et al., 2015). This study revealed that many ICU nurses and physicians used information from the patient´s record during the oral handover. Similarly, Kowitlawakul et al. (2015) found that up to 70% of physicians and nurses used the patient record in handovers. However, in relation to family care, the problem, as this study shows, is that the record contains limited information about the patient's family. Nelson et al. (2009) recommend that information about the family is always to be written as a separate entry in the patient record. This provides important information to clinicians who were not present and thus enhance continuity of family care (Nelson et al., 2009). This is also in line with Norwegian legislation regarding patient records, which states that information and advice given to the family must be documented in the patient record (The Health Personnel Act, 1999). The patient record also serves as evidential documentation of the healthcare services provided.

Collin et al. (2011) argue that an inefficient and user-unfriendly patient record system can make clinicians rely more on oral than on written information. This agrees with our findings that the participants did not fully utilise the medical record system and that there were little agreement and structure regarding what should be documented about the patient's family, how and by whom. The dilemmas that arose in relation to how to document information about family members made health professionals communicate this information orally. This lack of documentation means that the considerable time and resources spent by the physicians and nurses in ICU in fulfilling their responsibility for the care of the patient's family goes unrecorded and is more or less invisible.

To ensure effective and structured high-quality transmission of information, handover tools, guidelines or checklists are recommended (Abraham, Kannampallil, Almoosa, Patel, & Patel, 2014; Blum & Tremper, 2009; Graan, Botti, Wood, & Redley, 2016; Hoskote et al., 2017; Kowitlawakul et al., 2015; Merten et al., 2017; dos Santos, Campos, & da Silva, 2018). No such tools were used by the participants in this study. The use of handover tools can save time and prevent large variations in clinicians' handover practices (Hilligoss & Moffatt-Bruce, 2014; dos Santos et al., 2018). However, the design of these tools has been criticised for being too rigid or too extensive (Abraham et al., 2014; Hilligoss & Moffatt-Bruce, 2014; Spooner et al., 2018). In both cases, there is a risk that information transfer between health professionals will be incomplete, with the loss of key information (Abraham et al., 2014). Specific information about the family also appears to play a minor role in such standardised tools (Bakon et al., 2017; Nasarwanji, Badir, & Gurses, 2016; Spooner et al., 2018). The omission of information about the patient's family may thus compromise the holistic patient- and family-centred care perspective (Hilligoss & Moffatt-Bruce, 2014).

In line with the principles for patient- and family-centred care, it is recommended that members of the patient's family are present during bedside handovers (Manias, Geddes, Watson, Jones, & Della, 2016; McCloskey et al., 2019) and during rounds (Davidson et al., 2017; Mørk, Krupp, Hankwitz, & Malec, 2018). This can enhance information flow between the clinicians and the family (Davidson et al., 2017; Ervin et al., 2018) and increase patient and family satisfaction (McCloskey et al., 2019). However, this study showed in accordance with Ganz et al. (2015), that having family members present during handovers was not common. In many clinicians´ opinion, presence of family members during handover can be too time consuming, lead to more interruptions and disturb medical discussion and reflection (Davidson et al., 2017; Ervin et al., 2018; Manias et al., 2016). Consideration for other patients and the need for medical confidentiality are also important factors in determining whether the family can be present during handovers (Davidson et al., 2017; McCloskey et al., 2019). This also concurs with the findings in the present study. However, it is surprising that even the ICUs with only single rooms and with flexible visiting hours usually had restrictions on having visitors present during bedside handovers and rounds.

4 | LIMITATIONS

Although various opinions on written documentation about the family emerged during data collection, no systematic document analysis was performed to explore this further. This could have been done in accordance with the grounded theory principle of theoretical sampling and may well have strengthened the study´s findings. However, during the fieldwork, observations were made when clinicians made entries in the patient record. The impression from these observations was elaborated in the interviews. The findings from the fieldwork corresponded with the participants' statements during the interviews. The focus groups consisted of five participants, except for the two first focus groups with three and four participants, respectively. Fewer than five participants may be considered too few in a focus group. Other clinicians were invited, but their busy schedule did not allow them to participate.

One challenge for a researcher is to remember all the sayings and doings during observations. This is particularly difficult in a busy and noisy ICU. The researcher runs the risk of not catching all the details, forgetting what was said and misunderstanding observed situations. Therefore, the researcher asked for details and clarifications during the fieldwork and wrote field notes during and after each shift. The researcher also asked questions under the interviews to have her impressions and interpretations from the fieldwork confirmed or rejected. Through the memos, ideas, assumptions and decision-making during the whole research process were documented. A further advantage is that the researcher is an experienced ICU nurse with sound knowledge of ICU practice.

One nurse from each ICU recruited participants to the interviews. The sample may have been somewhat biased, since those ICU physicians and nurses who are most interested in family care may have been more likely to agree to participate. However, observations during fieldwork enabled the researcher to study variations in clinicians' family care, thus providing rich data. Due to research ethics considerations for patients, relatives and health professionals, a few situations arose where the researcher was unable to observe. This could have been because the staff did not want the researcher to observe or because she did not request this herself. Despite the exclusion these situations from the observations the fieldwork gathered rich data.

The researchers who moderated and observed the focus groups were familiar with ICU. It is helpful that an observer notes interactions while the moderator leads the conversation, encourages speaking freely and discussion, encouraging full participation by directing questions at some of the group members. Both moderator and observer were, in the mixed groups, mindful of the power imbalance and hierarchical relationship between nurses and physicians. Age and experience also influenced group dynamics. The group members knew each other and created a collegial atmosphere.

One former relative and one former ICU patient (with valuable experience from his family members) contributed as users in preparation of the study protocol and to the development of codes.

5 | CONCLUSION

The aim of this study was to explore nurses' and physicians´ transfer of information concerning ICU patients' family members during handovers. The findings indicate challenges related to appropriate and high-quality transmission of family-related information between clinicians. Such information was mainly communicated orally. Oral handovers are essential in terms of clinicians' need to elaborate on the information and update each other, including details about the family. At the same time, oral transmission involved a high risk of information being altered or lost as in a "game of whispers." In addition, the study showed that written documentation about the ICU patient's family was inadequate and poorly structured.

5.1 | Recommendations for clinical practice and policy

It appears that few previous studies have emphasised how information about patients' family is transferred between ICU clinicians. The findings of this study suggest a need for increased awareness in practice and research of appropriate and reliable information transfer in the ICU context. User-friendly handover tools and patient records that include information on patients' family members should be developed.

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CONFLICT OF INTEREST

The authors declare no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

AUTHOR CONTRIBUTIONS

RL and BSB designed of the study. AMN, RL, BSB and HSH collected, analysed and interpreted the data. AMN drafted the manuscript. All authors critically revised the manuscript, gave final approval, and agree to be accountable for all aspects of the work to ensure its integrity and accuracy.

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SUPPORTING INFORMATION

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

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Paper 2

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Interprofessional care for the ICU patient's family: solitary teamwork

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Interprofessional care for the ICU patient's family: solitary teamwork

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ABSTRACT

The aim of this study was to explore how interprofessional family care by ICU teams was reflected in their daily work. Data were collected from four ICUs in Norway. Fieldwork and focus groups with ICU nurses and physicians were conducted in addition to dyadic and individual interviews of surgeons and internists. In line with a constructivist grounded theory approach, the core category *"solitary teamworking"* was constructed. Together with three sub-categories, *proximity and distance, silent interprofessional work* and *a connecting link*, this core category conceptualizes interprofessional family care as a form of contradictory cooperation where physicians and nurses alternate between working alone and as a team. The sub-categories reveal three notable characteristics of interprofessional family care: (1) it is emotionally challenging, affected by proximity and distance to the families and between the clinicians, (2) it is silent, at a strategic and organizational level, and (3) nurses and family members have an essential role as a connecting link in the ICU team. Interprofessional family care needs strong involvement by an organization that supports and prioritizes family care, includes family members as an active part of the ICU team and emphasizes interprofessional dialogue.

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Introduction

Family care is an essential part of the ICU team's interprofessional care. Studies (Chen et al., 2018; Reeves et al., 2015; Wong et al., 2015) have shown that efficient and well-functioning interprofessional cooperation, coordination and communication are of utmost importance to the family. The way in which they are cared for affects their satisfaction and ability to cope in a new and stressful situation when their loved one is critically ill (Chen et al., 2018).

Background

Interprofessional care in the ICU is described as *'care provided by a team of healthcare professionals with overlapping expertise and an appreciation for the unique contribution of other team members as partners in achieving a common goal'* (Donovan et al., 2018). Physicians and nurses constitute the ICU team, supported by physicians and professionals from other specialties (Donovan et al., 2018; Ervin et al., 2018). Due to shift work and quick changes in the ICU patient's condition, team members may change from day to day. Interprofessional teamwork is also influenced by contextual, organizational, relational and processual factors such as culture, organizational support, professional power, routines and rituals (Reeves et al., 2019). Unstable team structures and external factors challenge effective team collaboration (Chaboyer & Bergman, 2019; Ervin et al., 2018).

In recent decades, family members have increasingly been acknowledged as a central part of the ICU team (Davidson et al., 2017; Donovan et al., 2018; Ervin et al., 2018). The closest family members usually know the patient well and often act on behalf of the patient, who might be unconscious or too sick to express his/her own preferences (Ervin et al., 2018; McAndrew et al., 2020). In addition to being essential caregivers who can positively affect the patient's condition, family members themselves need caring for in a demanding situation (Davidson et al., 2017; McAndrew et al., 2020; Mitchell & Wilson, 2019).

Family members are vulnerable to inconsistent and vague information from the healthcare team (Lind et al., 2012; Wong et al., 2015). The concept of patient- and family-centered care highlights the importance of family members' participation and collaboration with healthcare professionals in patient care (IPFCC, 2010). With a flexible visiting policy, frequent communication with clinicians and allowing their participation during handovers and medical rounds, they can be included in the ICU team (Briggs, 2017; Davidson et al., 2017; Donovan et al., 2018). Despite convincing evidence of the positive outcomes of patient- and family-centered care, the concept is not well established in ICUs. Several interprofessional-related barriers such as tensions, conflicts and miscommunication between clinicians have been identified (Hetland et al., 2018; McAndrew et al., 2020).

To our knowledge, previous studies have focused little on how physicians and nurses collaborate as a team on family care in the ICU. With the research question "*What are the characteristics of*

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interprofessional family care in the ICU?," this study aimed to explore, through fieldwork and interviews, how ICU teams' interprofessional family care was reflected in their daily work.

Method

The study design is a longitudinal explorative grounded theory approach, employing data triangulation using participant observation and interviews. Data triangulation was chosen to elicit a distinct and complete understanding of the complexities of interprofessional family care. Participant observation provides an inner perspective shedding light on phenomena in their natural setting, while research interviews provide comprehensive insight into clinicians' experiences (Timmermans & Tavory, 2007). Grounded theory is well-suited for studying participants' behavior and interactions in social settings (Charmaz, 2014). Inductive and abductive strategies are combined to develop concepts and theories grounded in data. Based on inductive data and with iterative and comparative strategies between data and analysis, conceptual categories emerge (Charmaz, 2014). This method is suitable for explorative studies in areas with little previous research (Charmaz, 2014). In this study, a grounded theory approach was chosen to elicit a broad view of ICU nurses' and physicians' interprofessional work with ICU patients' families.

Constructivist grounded theory, developed by Charmaz (2016) from Glaser and Strauss (1967) classical grounded theory, adopts original methodological strategies such as coding, memo-writing, theoretical sampling and parallel data collection and analysis (Charmaz, 2016). This version of grounded theory has its roots in pragmatism and relativism, and emphasizes the researcher and the participants as co-constructors of data (Thornberg & Charmaz, 2014). Knowledge is seen as socially produced, reality as fluid, indeterminate and open to multiple interpretations. Subjectivity and interaction are highlighted, data and analysis not seen as neutral. The researcher's reflexivity is emphasized to clarify how his/her previous research experience, interests, decisions and interpretations influence the research process and results (Thornberg & Charmaz, 2014).

Setting

The study took place in four ICUs in Norway, one six-bed unit in a mid-range hospital and three 11–18 bed units in university hospitals with both surgical and medical patients. In each ICU, most patients needed mechanical ventilation. However, ICUs in the university hospitals offered more advanced intensive care than the mid-range hospital, such as extracorporeal membrane oxygenation and neurosurgery.

Two units had only single rooms, the others 1–4 bed rooms. The ICUs practised different visiting regulations independent of room size, from one hour three times a day, to a flexible visiting policy. Parents of children could always be present, and in end-of-life situations, all units made exceptions to their visiting policy.

The "core" ICU team usually consisted of one ICU nurse and one ICU physician directly involved in caring for each patient, supported by physicians from the patient's primary ward. Other professionals like physiotherapists, social workers and chaplains participated in the extended ICU team. Nurses worked bedside in three rotating shifts. The nurse-patient ratio was 1:1. The physicians also worked in rotation. In the daytime, several ICU physicians, primarily senior intensivists, shared responsibility for the patients, normally caring for one or two patients each. In the evenings and at night, generally one senior and one junior physician were on duty, normally also having work outside the ICU.

Nurses start each shift with a five-minute briefing, before a bedside shift report. Physicians make their daily pre-rounds in a meeting room in the ICU, often with the coordinating ICU nurse and physicians from the patients' primary wards present. Sometimes the entire group of physicians takes a short bedside round, or the physicians do their round alone, just to their particular patients. ICU physicians also have afternoon shift reports. All units use electronic health records, with computers available in all patient rooms.

Participants and sampling

ICUs from different parts of Norway participated in the study. Requests were sent to the head of the ICUs by AMN or RL. After completing data collection and the first analysis in one ICU, they contacted the next. In each unit, the researcher (AMN or RL) was given a contact nurse who recruited the participants.

To come close to family care situations, the observer (AMN) followed one ICU team per shift, primarily bedside but also during daily activities such as pre-rounds, briefings and lunch breaks. After following the team in one to three shifts, the observer turned to another patient to ensure variation in observations of family care situations with other clinicians. Nurses and physicians in the ICUs received information about the study by e-mail and gave their consent to be observed directly to the researcher. Participant observations were conducted in 11–14 shifts (day and evening shifts, some at weekends) in each unit.

The researcher's contact nurse recruited participants to focus groups, orally or by e-mail. The participants were nurses and/or physicians from the same ICU. As requested by AMN, surgeons and internists were recruited for interviews through the head of their ward, the appointment confirmed by e-mail. Nineteen ICU nurses, 13 ICU physicians and eight surgeons/internists of different ages, gender and ICU experience participated either in focus groups, dyadic or individual interviews (Table 1).

Table 1. Participant characteristics for focus groups, dyadic and individual interviews.

N = 40	Gender female/male	Age median (range)	ICU experience median (range)
ICU* nurses (19)	14/5	42 (28–60)	10 (1–22)
Intensivists (13)	1/12	44 (33–67)	15 (3–38)
Surgeons (4)	1/3	54 (39–59)	-
Internists (4)	3/1	45 (36–65)	-

*Intensive Care Unit

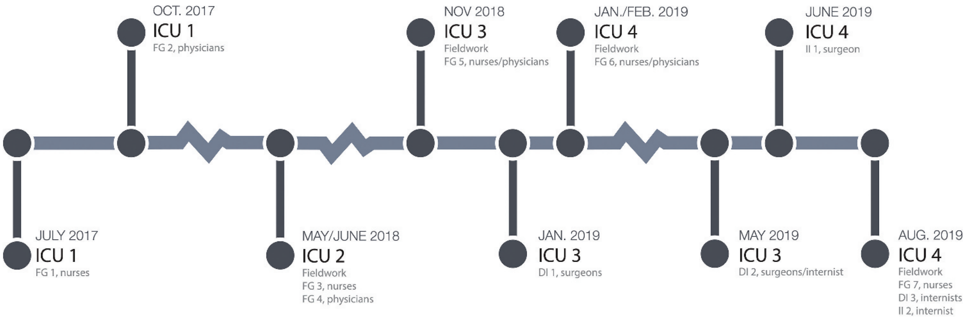

Figure 1. Timeline of data collection with subsequent analysis.

Data collection and analysis

With a constructivist grounded theory approach, the researcher explores the participants' main concern, referred to as core category and sub-categories, and how this concern was addressed. These conceptual categories develop during the analysis from data, initial and focused codes to more abstract categories. With parallel data collection and analysis, the analysis started immediately after each data collection and gave direction to the next where the researcher returned to the field to collect more data to clarify codes, ideas, and assumptions. This process is called theoretical sampling (Glaser & Strauss, 1967). When new questions, insights and ideas emerge during the analysis, the researcher may expand the data collection methods or add new ones (Thornberg & Charmaz, 2014). Using the constant comparative method, the development of categories was an iterative process between data and analysis, comparing data, codes and categories. This included memo writing to focus on and understand the connection between codes and categories (Thornberg & Charmaz, 2014).

RL initiated and planned the project. With BSB, she conducted the first two focus groups, one with three ICU nurses and one with four ICU physicians at the mid-range hospital in July and October 2017 (Figure 1). The intention was to check the original interview guide and plan the rest of the study.

The interviews were transcribed and analyzed by AMN with line-by-line reading and initial coding of the transcripts. By going quickly but carefully through the data, short, simple and spontaneous initial codes were constructed. Based on the most frequent and significant initial codes the researcher constructed focused codes where larger segments of data were synthesized and conceptualized. For example, several initial codes concerning nurses' actions and communication between physicians and family members emerged early during the analysis of data from the first two focus groups. During the study this formed the sub-category "a connecting link."

Following the first data collection and analysis in ICU 1, the researchers expanded the data collection by conducting fieldwork and focus groups in ICUs 2–4 between June 2018 and August 2019 (Figure 1).

The fieldwork consisted of a total of 270 hours of participant observations in the three ICUs (Table 2) at university hospitals, offering the same level of treatment. AMN, who conducted the observations, is an experienced ICU nurse able to participate in basic nursing care and stay close to the realities faced by ICU physicians and nurses providing family care. The researcher observed clinicians throughout the shift (60% daytime and 40% evening shifts) to gain a comprehensive picture of family care. Intensive care is event-driven and time-pressured, often with rapid changes in the ICU patient's condition, which made it difficult to predict when family care situations might arise. Most of the observations were conducted in the patient's room, with clinicians in direct and indirect family care situations. Indirect family care situations included formal and informal meetings between clinicians such as shift rapports, rounds and lunch breaks where they talked about and made agreements concerning the ICU patient's family. Field notes were written during and after each shift. Participant observation enabled the researcher to ask questions and explore impressions in each specific family care situation around emerging codes and categories. Gradually the observations became more focused during the parallel data collection and analysis.

Table 2. Overall data collection.

	ICU* 1 Mid-range hospital	ICU 2 University hospital	ICU 3 University hospital	ICU 4 University hospital
Participant observation	-	76 hours	97 hours	97 hours
Focus group (FG) (Participants per FG)	FG1:ICUnurses (3) FG2:Intensivists (4)	FG3:ICUnurses (5) FG4:Intensivists (5)	FG5: ICU nurses/ Intensivists (5)	FG6: ICU nurses/ Intensivists (5) FG7:ICU nurses (5)
Dyadic interview (DI)	-	-	DI1: Surgeons DI2: Surgeon/ Internist	DI3: Internists
Individual interview (II)	-	-		II1: Surgeon II2: Internist

*Intensive Care Unit

Focus groups were conducted during the last week of the fieldwork, one with ICU nurses, one with ICU physicians (in ICU 2) and two with a mix of ICU nurses and physicians (in ICUs 3 and 4). This composition of the groups was chosen to identify different perspectives between the professions and explore interaction and discussion between them. In focus groups with both professions, the topic was generally physicians' and nurses' collaboration on informing families, in particular the planning and implementation of information sessions between physicians and families. However, since ICU nurses have various tasks (such as arranging visits) and spend most time with families, we decided to conduct a final focus group with nurses only, to ensure that the conceptual categories were saturated.

During the analysis of data from ICUs 1 and 2, focused codes regarding family care collaboration between ICU clinicians and physicians from the patients' primary ward emerged. It soon became clear that the ICU clinicians' collaboration with these physicians was also highly important for family care, especially regarding which clinician was responsible for informing relatives about what. To explore this aspect, data collection was further extended with dyadic and individual interviews with surgeons and internists in ICUs 3 and 4 (Table 2).

An interview guide covering broad topics was developed and used in the first focus groups (ICU 1). During further data generation, the interview guide was modified in accordance with the ongoing analysis and theoretical sampling. One question in the original interview guide was: "How does collaboration between physicians and nurses take place regarding the ICU patient's family?." Then, in the next focus group, we asked more distinct questions about the emerging focused codes. For example, to explore and collect more data about the codes that led to the sub-category *"silent interprofessional work"* one question was: "*Do you (i.e. physicians and nurses) talk to each other before a family meeting?.*"

A moderator (AMN or RL) chaired the focus groups while an observer (AMN, HSH, BSB, RL) observed the participants and made notes. The dyadic and individual interviews were conducted by the first author, using an adjusted interview guide. All interviews took place in a meeting room in the ICU, lasted between 37 and 96 minutes, were recorded digitally and transcribed verbatim by AMN.

During the analysis all authors contributed with their ideas and perspectives by discussing the emerging codes and conceptual categories.

Ethical considerations

The principles of the Declaration of Helsinki (WMA, 2018) were respected and the institutional ethics review board (Regional Committee for Medical and Health Research Ethics – Ref.: 2016/1762) approved the study. Permission was obtained from the head of each ICU. ICU staff received information by e-mail and orally at the beginning of every shift. Posters containing information about the project were posted at the ICU entrance and along the corridors to inform visiting healthcare professionals and family members. The researcher (AMN) informed conscious ICU patients and visiting family members about the study. None refused to have the observer present.

All participants received verbal and written information about confidentiality and their possibility to discontinue participation whenever they wanted, without giving a reason. To protect confidentiality, transcriptions from field notes and interviews were anonymized. The participants have been given pseudonyms.

Findings

In this study, interprofessional family care was highlighted as the participants' main concern. *Solitary teamworking* was constructed as a core category, including three subcategories: *proximity and distance, silent interprofessional work* and *a connecting link*. Family care is an interprofessional responsibility in which clinicians are mutually dependent on, and affected by, each other's actions, views and statements.

Solitary teamworking indicates contradiction-filled interprofessional family care, in which nurses and physicians experience unity of purpose and support from their colleagues, but also have feelings of loneliness and of standing alone. Clinicians shift between working as a team and working alone.

> I envy the doctors, [. . .] it isn't easy to provide information, so they do their best, [. . .] but they inform and then they leave the room. So then we're left with the family for the next few hours.
>
> (Jon, ICU nurse FG 3 ICU 2).

Every ICU has a 'group' of experienced physicians and nurses forming the 'core' of the staff group. They have considerable authority and represent both safety and support for the others. Just as nurses felt safest meeting next of kin with an experienced physician, junior physicians valued having an experienced ICU nurse with them.

Clinicians praised and comforted each other and said spontaneously that they worked well together. Teamwork was most pronounced in complex and demanding situations. Nonetheless, the fieldwork showed that the clinicians spent most of their day engaged in their profession-specific tasks and that traditional hierarchical structures existed between them. The physicians had great authority by virtue of the formal decision-making power of their profession. The nurses were little involved in the physicians' discussions which took place outside the patient's room. They could feel isolated and alone and missed being more included.

> We nurses sometimes feel that we are little involved in those discussions. There's a lot more going on in the meeting room and other places in the unit than where we are as bedside nurses.
>
> (Andrew, ICU nurse, FG 6)

ICU culture and the clinicians' behavior could amplify the inequalities in the balance of power. This appears through the sub-categories.

Proximity and distance

Proximity and distance refers to where physicians and nurses were situated in relation to the family members, the patient and each other, both physically and emotionally.

The nurses were almost always present in the patient's room and in contact with the patient's family, while the intensivists were more distant from the patient's room and family. Unlike the nurses, physicians usually had responsibility for several patients on the same shift. Physicians from the wards had most of their duties there or in the operating theater. Mostly, they were in the ICU only for some minutes each day. Both physicians and nurses expressed their understanding and respect for each other's duties, but the distance created frustrations and emotional tensions between them. Nurses praised the physicians for mostly being willing to talk to family members when asked to by the nurses, but they were frustrated that they had to spend a lot of time '*reeling them in*' (Thomas, ICU nurse FN 2) and waiting for them to come. Physicians praised the nurses for arranging family conferences, but could be frustrated when they rang at '*all hours of the day and night*' (Anna, intensivist FG 4) to ask them to speak to the family.

The distance between the clinicians also appeared in how they referred to each other. Although there was good cooperation between physicians from the patient's ward and the ICU physicians and nurses, clearly the strongest team feeling belonged to the ICU staff. The nurses spoke of ICU physicians as our physicians, whereas the ward physicians came from outside. Team feeling, and confidence, was strongest in relation to those one knew best. Some ICU staff, both nurses and physicians, said that ward physicians were too preoccupied with their own specialty and gave overly optimistic information to family members. Thea, an ICU nurse explained:

> If a surgeon talks to the family, he may say, "the operation went well", despite the patient's health remaining extremely poor.
>
> (Thea, ICU nurse, FG 6)

One surgeon (Carl, Dl 1) said that surgeons became caught up in the intensivists' decisions, even though they were principally responsible for the patient. He had also experienced situations where surgeons had to motivate ICU staff to make additional efforts, and relatives not to give up hope. Although the participants did not describe these situations explicitly as conflictual, they could cause frustration and emotional tensions, both inter- and intra-professionally.

Family care was described as rewarding and integral to the working day. Both physicians and nurses described feelings of satisfaction in helping the family. The nurses were especially close to the families' feelings and concerns, their hopes and their joy. They often got to know them well and strove to build a trustful relationship. However, it was important to ensure that their relationship with the family did not become personal; they needed to maintain a certain distance. If the relationship became too close, it could feel uncomfortable and too private. One nurse (Eva, FG. 3) talked about "*building a wall*" to protect herself. Maintaining distance could be difficult, especially in situations that most powerfully affected them. Very serious and critical situations, particularly those involving children, tore down one's defenses.

> I had a dying patient with a 12-year-old son. I dreaded him coming to visit. I had never met him before, and he was coming to say 'goodbye' to his mother. But I pulled myself together and it went surprisingly well. It was very nice. But you have no idea how you will react, because it does something to you when you have children the same age.
>
> (Christina, ICU nurse, FG 7)

Keeping a certain emotional distance from the family was seen as professional. One ICU physician (Eric, FG 5) spoke about a situation that had touched him "*right in the heart*," describing himself crying with the family members when the father died during his shift. The distance he usually maintained was gone and he felt as though he had '*lost his shield.*' Afterward, he wondered if the family had found him '*unprofessional.*' In several of the interviews, clinicians spoke about similar stories still affecting them deeply – they had tears in their eyes and a lump in their throat in speaking of these.

Several participants touched on the balance between closeness and distance, how their own vulnerability could come as a surprise to them, calling for reflection on their feelings and reactions and their position as a professional. Work pressure was considerable, and they had limited time to dwell on events strongly affecting them. Many clinicians, especially nurses, supported each other in odd moments, throughout the working day. Participants also mentioned talking to a particularly good friend or family member when their feelings weighed heavily on them.

The fieldwork showed how the clinicians' position in the room, where they stood and sat in relation to the family, also indicated their proximity to or distance from them. They could demonstrate closeness by standing at the bedside with the family, putting an arm around their shoulder, giving or receiving a hug. But they could create distance, by sitting behind the computer, avoiding eye contact, or standing far away from, or with their back to, family members. Family members also set limits as to how close health professionals could be. Whilst it might seem entirely natural to *one* to be given a hug, it could be completely rejected by another. Being rejected in this way could be very hurtful, especially in demanding situations where clinicians felt that they had worked hard and given a lot.

Silent interprofessional work

Silent interprofessional work concerns the extent to which the ICU team members talked to each other and planned family care. Both fieldwork and interviews showed that this work was in many respects '*silent.*'

Even though clinicians included information about the patient's family in their handover, they spoke little to each other at a strategic or organizational level about family care:

> . . . there is remarkably little attention paid to that in the physicians' group, we speak about it very little. I don't know what the other physicians do because I do it pretty much my own way. [. . .] We

> don't discuss it much, and perhaps we don't reflect on it so much – at least not together, but on our own. So, there is certainly an unrealised potential.
>
> (Eric, senior intensivist, FG 5)

ounger physicians described having felt that they were '*thrown headfirst*' (Benny FG 6) into conversations with family members when they were inexperienced. Experience brought greater confidence, and over time one developed one's own approach.

Interprofessional debriefing was rarely conducted. However, ICU 4 offered weekly reflection meetings. This unit also had flexible visiting times and generally good facilities for the families. The head nurse was especially concerned about family-centered care and was a driving force in evolving a common "family culture." It was, however, difficult to get all the staff '*on board*' with this since culture change is a long-term project (FN, ICU 4).

The bedside rounds were the best opportunity for physician-nurse communication. These interprofessional dialogs were characterized by '*questions and answers*.' This was in contrast to communication in profession-specific meetings such as the nurses' shift reports and the physicians' pre-rounds comprising discussion and formal clinical talk. This interprofessional dialogue was affected by the way the round took place. In ICU 3, physicians and nurses sat side by side during the round. In other units, it took place either while the nurses were busy with patient-related tasks or when physicians approached the patient, conducted an examination, spoke to the nurse and left the room to write the prescription.

Apart from the rounds, physicians and nurses spoke when necessary, either face-to-face or on the telephone. However, one unit held interprofessional team meetings concerning patients who had been hospitalized seven days or more.

Although clinicians had good experience of interprofessional family meetings, several nurses recalled conferences that had gone badly or led to negative consequences:

> A patient died immediately after he came to intensive care. They phoned the family but did not mention the death over the phone. The ward physician knew the patient best and came to the ICU to speak to the family as soon as they arrived at the hospital. He thought, however, that they had already been told about the death and spoke to them accordingly. The patient's daughter reacted strongly to this. She was very angry. The nurse present described the situation as very unpleasant. She said that she and the physician had not spoken to each other before they went into the meeting. She had thought that the physician knew that the family had not been informed about the death.
>
> (FN, ICU 4)

The nurses mentioned situations where they had been surprised by what the physicians had said to the family and that they subsequently had to "correct a bad impression" (Thea, ICU nurse FG 1). They could be uncertain whether they had misunderstood the situation or wrongly informed the family. Even though the units had guidelines for '*conversations with adult relatives of intensive care patients*' in which a preparatory "pep-talk" within the ICU team was recommended, these were largely unknown and seldom followed. Another example of the organization's strategy for family care being '*silent*' came to light during the focus groups when the guidelines for visits by family members were discussed, revealing that many ICU physicians were largely unfamiliar with these rules. In ICU 3, with the most restrictive visiting times, neither physician nor nurses knew who had imposed the restrictions, or why.

A connecting link

A connecting link refers to the way in which both nurses and family members have an essential role within the ICU team, creating continuity and good information flow.

The observations showed that the ICU team consisted of many clinicians working shifts and taking turns in being with, and taking responsibility for, patients. Family members were often the most stable and present '*facto*r' in the team as patients were often unable say how they were. The family supplemented the clinicians with information about the patient and helped sustain the flow of information from shift to shift. Family members held qualitative information that could often be lost when so many clinicians were involved over time. Family members' role as active participants within the ICU team was little remarked on in the interviews. The impression was given that they were seen as passive recipients of clinicians' information and concerns. It was uncommon for them to join bedside rounds.

Nurses had an important function as the ICU team's link between family members, physicians and themselves. They argued for the family's point of view and were mouthpieces for their wishes. This required both a sense of responsibility and time. The nurses conveyed messages and facilitated dialogue between family members and physicians. If the situation was acute, the family received more frequent information from the physicians than when it was stable. The nurses' function as a link during actual conversations with the family was described as importantly bridge-building:

> The days are, of course, busy [. . .]. If I'm rounding off and ending a difficult conversation, it takes a bit more time, not just in going back to the room with them (the family) and so on, but also finding a way to close the conversation, [. . .]. Then it's really helpful to have a nurse with me who can be a bridge between us and help in rounding off the conversation.
>
> (Siri, senior surgeon, II 1)

The physicians had great confidence in the nurses' assessment of family members' need for information. They explained that they, to a great extent, "*leaned on*" (Tom, intensivist, FG 5) them to say when the family needed to speak to the physician. If the physician took the initiative to talk to the family, it was often in an acute situation with major changes in the patient's treatment, or when there were results of medical tests or examinations.

During daytime, the intensivists were readily available in the unit, and often had ad hoc meetings with family members in the patient's room. However, it could be more difficult and time-consuming to arrange family meetings in the evenings and to include busy ward physicians. Sometimes such attempts caused tensions between clinicians. Although the nurses praised the physicians for being readily available, they described situations where they had to "haul in" or "cover up" for physicians:

> Carrie, the ICU nurse, rings the surgeon and asks if he can inform the daughter of a patient in intensive care about a minor operation the patient had undergone the day before. The surgeon refuses because he spoke to the family pre-operatively. He doesn't see the necessity of providing more information.
>
> After this conversation with the surgeon, Carrie says wearily to the researcher: "That's how it is sometimes. Most would have rung, but not that one. Now, I'll have to smooth things over with the relatives since he won't speak to them."
>
> (FN, ICU 3)

In order to maintain the family's faith in the healthcare staff, the nurse hid her irritation and frustration from them. Without the support of an available doctor, nurses can feel abandoned, uncertain and stressed:

> . . . I often feel that it puts us in a tight spot. [. . .] those of us who are in the room and are left standing there with the relatives. The physician maybe doesn't have enough time or enough information to give them and so we have to start 'tracking down' another physician. It's a bit difficult for us to give information and so we must tell them just to wait.
>
> (Karen, ICU nurse, FG 3)

However, the coordination of family meetings could also be challenging for physicians, especially when nurses contacted them on duty when they had limited time to prepare themselves:

> An unprepared meeting is awful, I hate it. I think it's terribly sad when family members come in the evening and at night. They come from far away, and so the nurse rings at eight in the evening and says: "The family has arrived, and they would like some information". Often, I don't know the patient very well and so I have to 'dig' a little. It's so stupid if it comes from "left field" and I say something that someone else hasn't already said [. . .] That's what I think is worst, people coming in the evening to get information. It's not like when you have time to sit down to look at exactly where we've got to, and exactly what's been done and not done.
>
> (Tom, intensivist, FG 5)

The main challenge was to give consistent and useful information. Family conferences were time-consuming and could disrupt clinicians' workflow. They felt stressed and overstretched. Several physicians felt that family meetings should take place, wherever possible, during the day.

Discussion

We have examined, from an insider's perspective, how physicians' and nurses' family care plays out, over time, in their daily work in the ICU. Interprofessional family care, conceptualized as '*solitary teamworking,*' is a form of contradictory cooperation that can work very well but also be lonely and emotionally challenging. The findings indicate the importance of examining previous family research, as the dynamics of interprofessional practice and family involvement in the ICU are largely absent from the literature (Reeves et al., 2015).

The study shows that family care is a balance between proximity and distance in relation to family members and colleagues, and to oneself as a clinician. Healthcare professionals can feel alone, uncertain, sad and rejected in meetings with family members and in relation to colleagues. They also experience frustration and emotional tensions in relation to the ICU management. Certain situations involving families strongly affect clinicians. They identify with them, and fear acting unprofessionally. This indicates that nurses' and physicians' vulnerabilities may require a certain emotional distance in family care. It is suggested that keeping a distance is a defense mechanism used when the family's distress becomes too overwhelming (Epp, 2012). Distancing oneself can trigger negative emotions and attitudes such as depersonalization, cynicism and detachment and is a significant risk factor for burnout, adversely affecting the quality of family-centered care (Epp, 2012; McAndrew et al., 2020).

A supportive atmosphere and good teamwork help clinicians meet emotional challenges (Epp, 2012; Rydenfält et al., 2018). Our study shows that experienced clinicians supported less experienced colleagues, praising them in particularly demanding situations. The participants, especially the nurses, often instigated "informal debriefing" during lunchbreaks, or in the corridor, where they supported, comforted and advised each other. Such individual approaches are recommended in addition to interprofessional team and system approaches (Costa & Moss, 2018). "*Knowing each other*" also increased the feeling of confidence and of being a team. ICU nurses and physicians clearly had a stronger team spirit among themselves than with the surgeons and internists they collaborated with. Helping families in difficult situations also motivated them.

Interprofessional ICU family care can be characterized as '*silent.*' Despite clinicians including information about the family in their handovers (Nygaard et al., 2020), they spoke little about strategic or organizational family care. With certain exceptions, there is little facilitation of interprofessional dialogue on family care. The ICU leadership's strategy seems vague and inexplicit, and clinicians' work with families seems based on individual preferences and experience-based approaches. The findings also suggest a lack of joint leadership for ICU physicians and nurses regarding family care.

ICU management should address family care more explicitly, establishing better procedures for providing venues for interprofessional discussion and planning of family care approaches. Interprofessional education can enhance attitudes, knowledge, skills and behavior for collaborative practice, leading to improvement in clinical practice (Reeves et al., 2016), including establishing the foundations of a supportive work environment that emphasizes addressing clinicians' emotions and psychological distress, thus attempting to lower the risk of burnout among ICU staff (Costa & Moss, 2018; Epp, 2012). Without an increased focus on, and better routines for, communication, there remains a substantial risk that nurses and physicians will communicate vague information to patients and their family, leaving them uncertain (Lind et al., 2012). The introduction of communication tools such as the "VALUE

TEAM template" (Curtis & White, 2008) to ensure respectful communication in the team and toward the family is recommended (Michalsen & Jensen, 2020). However, our study shows that implementation of these tools needs to be followed closely in a focused process over time, until they are an established part of ICU practice.

Despite increased focus on family-centered care, family members are not really considered as team members by clinicians (Olding et al., 2016; Paradis et al., 2014). Our study shows that family members have an essential role as a connecting link in the ICU team, irrespective of clinicians' awareness of this function. The fieldwork revealed that the family was a stable factor within the team, sharing not only their own knowledge but also decisions and communications from earlier shifts. Our findings demonstrate a more active and participatory messenger role than described in previous research (Olding et al., 2016). This is especially important, as families' interaction with the ICU team is not limited to a single incident, it lasts over time (Ervin et al., 2018; Reeves et al., 2015). The work of the ICU team can extend over days, weeks or months during which the team's physicians and nurses routinely come and go, but the family remains constant. This distinguishes the work of the ICU team from other healthcare teams such as resuscitation or trauma teams (Ervin et al., 2018).

Involving family members and including them in the ICU team has proved challenging in practice (Hetland et al., 2018; Olding et al., 2016; Rodriquez, 2015). Our study shows that family presence during shift reports and bedside rounds is far from common practice. Further, two of the ICUs had fixed, and relatively limited, visiting hours. According to Hetland et al. (2018), several factors influence nurses' assessments of the involvement of family members: clinical environment, family and patient characteristics and ICU culture. Although nurses are especially well-placed to involve families, it is difficult for them to shoulder alone the responsibility for this and to create a good team dynamic (McAndrew et al., 2020; Olding et al., 2016). Olding et al. (2016) point to nurses' limited authority in the ICU as a small part of a much larger and complex healthcare system with considerable medical authority. Our study clearly showed that although the nurses managed the work with the family, they were heavily dependent on successful cooperation with the physicians. Their family care was also influenced by the extent of the organization's facilitation of it, and by whether they had the support of the unit management. McAndrew et al. (2020) emphasize that an organizational culture supporting and prioritizing family care is a prerequisite for nurses' and physicians' engagement with families in ICU.

The findings in this study, in keeping with others (Alexanian et al., 2015; Curtis & Vincent, 2010; Reeves et al., 2015), are that the ICU team members spend most time on their own profession-specific duties. The metaphor of '*silos*' has been used to describe these parallel working environments in which different professions have limited awareness of each other's work and limited possibilities for communication and cooperation (Curtis & Vincent, 2010). According to Reeves et al. (2015), interaction between physicians and nurses can often be terse, with few possibilities for wider interprofessional discussion. Our study shows that the interprofessional dialogue consists more of 'question and answer' than of conversation and discussion. The nurses wanted to take part in physicians' discussions, and both physicians and nurses said that they needed to speak together more. Although the patient record is an important communication tool between clinicians, it contains little information about the family; such information had to be shared verbally (Nygaard et al., 2020). Information technology can hinder interprofessional communication and appeared to foster parallel work practices (Reeves et al., 2015).

Interaction between ICU team members is governed by different professional cultures, hierarchies within and between professions and the medical dominance of the working environment (Alexanian et al., 2015). In moments of clinical crisis, however, clinicians move from working in parallel to working interprofessionally as a team (Reeves et al., 2015). Our study shows that the ICU team's interprofessional family care is no exception. The nurses, working bedside and having daily contact with the family, often care for the family without physicians being involved. They spend much time '*alone*' with the family. Physicians have a more limited but essential role related to their medical responsibility for the patient. The study also shows that the different professional roles overlap and are mutually dependent. Bjurling-Sjöberg et al. (2017) describe the distribution of responsibility amongst the ICU team as '*balanced intertwined responsibility*' aimed at being prepared and flexible in a changing work environment shaped by many influences.

Previous studies (Fassier & Azoulay, 2010; Nathanson et al., 2011; O'Leary et al., 2010), showed that physicians rate the teamwork more highly than nurses do. Nurses can feel outside the decision-making process, and miss being more involved (Alexanian et al., 2015), as this study confirms, despite the participants mostly describing good physician-nurse cooperation. This highlights physicians' authority as responsible for treatment, and their formal decision-making power. Nurses, however, occupy a key position in daily family care, which includes responsibility for mediating contact between physician and family, and they also occupy a position of power. Family members depend on nurses to convey their needs and wishes. Nurses' role as a connecting link requires that they remain aware of their responsibility and of the family's needs, which physicians rely on them to do. This is necessary in an ICU setting where patients remain in acute care day and night, with potential rapid changes in their condition. The findings suggest that clinicians and families could have benefited from physicians and nurses planning times for family meeting better, especially regarding stabilized patients, which should improve continuity of family care, instead of inconsistent information and communication. Better planning, preferably with daily interprofessional family conferences would probably reduce emotional tension and frustration between nurses and physicians (Hamilton et al., 2020).

Limitations

AMN, who conducted the field research, is an experienced ICU nurse. Her stance in the data analysis and construction of conceptual categories will have been influenced by her presence in, and closeness to, the ICUs where she was an observer. However, observation and interviewing demand the capacity for reflection on, and awareness of, one's own preconceptions and prejudices, to enable new lines of approach and critical thinking. The other authors are experienced ICU nurses and/or researchers, able to contribute to nuancing the analysis.

Observation is the recommended data collection method to understand team dynamics of ICU clinicians (Reeves et al., 2019). When participant observation is included in grounded theory, it increases the trustworthiness of the study. Combining observation with interviews enabled the researcher to pose in-depth questions and discuss her observations. This combination also reveals interesting gaps between interview data and observation data. Remembering observed details and events in a noisy and constantly changing critical care environment can be difficult, although detailed field notes were taken during and after each shift.

Conclusion

The study aim was to explore how interprofessional family care is reflected in ICU teams' daily work. With a constructivist grounded theory approach, '*solitary teamworking*' emerged as the core category explaining the contrasts in interprofessional family care; ICU physicians and nurses alternate between working alone and as a team. Family care is experienced as engaging and rewarding, but emotionally challenging, both in contact with the family and in cooperating with colleagues and management. The findings indicate that unit managers must facilitate a culture supporting and prioritizing family care, where family members are included as an active part of the ICU team and interprofessional dialogue is emphasized.

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Professionals' narratives of interactions with patients' families in intensive care

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Abstract

Background: ICU patients' family members are in a new, uncertain, and vulnerable situation due to the patient's critical illness and complete dependence on the ICU nurses and physicians. Family members' feeling of being cared for is closely linked to clinicians' attitudes and behavior.

Aim: To explore ICU nurses' and physicians' bedside interaction with critically ill ICU patients´ families and discuss this in light of the ethics of care.

Research design: A qualitative study using participant observation, focus groups, and thematic narrative analysis.

Participants and research context: Data were gathered from July 2017 to August 2019, in four ICUs in Norway through 270 h of fieldwork and seven focus groups with ICU nurses and physicians.

Ethical considerations: The Regional Committee for Medical and Health Research Ethics and the Norwegian Centre for Research Data approved the study.

Findings: Quality of ICU family care depends on nurses' and physicians' attitudes, behavior, and personality traits. Three main themes were identified: *being attentive*, *an active approach,* and *degree of tolerance*.

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Discussion: The findings are discussed in light of the ethics of care and empirical research from the intensive care environment.

Conclusions: This study shows that attentive, active, and tolerant clinicians represent a culture of ethical care that gives families greater freedom of action and active participation in patient care. Clinicians must not bear sole responsibility for this culture; it must have a firm basis in the hospital and ICU and be established through training, interprofessional reflection, and support of clinicians.

Keywords

Intensive care, critical care nursing, nurses, physicians, family-centered care, care ethics, narrative analysis

Introduction

Critical illness has a significant impact on family members of ICU patients. They are in a vulnerable situation, often worried, insecure, and confused.[1–3] Families are under undue pressure and are often anxious and at high risk of depressive conditions, including acute stress disorder, insomnia, complicated grief, and posttraumatic stress disorder.[4–6]

Clinicians' attitudes and behavior will determine whether family members feel cared for, or alternatively, overlooked and offended. This relationship can be illuminated by the ethics of care, which states that humans in general are dependent on others.[7] In an ICU family care setting the moral aspect lies in a (silent) demand that ICU clinicians act in the family's best interest and are worthy of the family's trust in them.[8,9] This emphasizes the importance of clinician-family interaction in providing high-quality family care.

In this study, we decided to explore nurses' and physicians' approaches towards ICU patients' families and elicit how family care is reflected in ICU clinicians' everyday work. We aimed to examine ICU nurses' and physicians' bedside interactions with critically ill ICU patients´ families and discuss these in light of the ethics of care. This approach can enhance knowledge to improve the care of ICU family members.

Background

Nurses play a pivotal role in ICU family care, being close to patients' families throughout the ICU stay by providing them with information, comfort, and support and in organizing their presence and their contact with the ICU team.[10,11] McAndrew et al.[10] have identified facilitators and disruptors to nurse-promoted engagement with ICU families. Facilitators are at unit and organizational levels, a family adaptation level, and a nursing culture level. Disruptors are system barriers, ethical conflicts, family distress, and family exclusion.[10] Although ICU nurses are responsible for the families' daily ICU contact, physicians play a vital role vis-à-vis families regarding medical information and decision-making. The professional roles partly overlap and are mutually dependent.[12,13] Family care quality therefore depends on good interprofessional cooperation and communication. A family-centered approach to healthcare is recommended in ICUs to mitigate families' psychosocial stress and prepare them for decision-making and caregiving demands.[14] Family-centered care involves a respectful and responsive attitude to families' needs and values, and includes information sharing, participation, and collaboration.[14–16] Family needs have previously been assessed using five dimensions: support, comfort, information, proximity, and assurance.[17,18] However, focusing solely on families' needs might make them passive care recipients, which may be considered an unintentional consequence of the family-centered approach. To date, more research has examined families as care recipients than as active partners.[19] Although family-centered care is often highlighted, it seems to be challenging to implement in ICUs. Information on how it can be translated into daily ICU practice is lacking.[20] Interaction between family members and clinicians must be explored to improve understanding of how clinicians influence family involvement.[20,21]

Care ethics

Care ethics is an ethical approach that emerged in the 1980s, based on relational ontology.[22] It is a context-bound approach, focusing on the interdependence and vulnerability involved in humans' connection to one another. Different traditions of care ethics exist.[23–25] In this article, we reflect upon our findings from a Scandinavian care ethics perspective. The Danish nursing professor Delmar emphasizes a care ethics "thinking horizon" in nursing in order to become more purposeful and attentive in practice.[7] Delmar[7] pursues the thoughts of the Danish philosopher Løgstrup and the Norwegian nursing philosopher Martinsen in addition to her own comprehensive empirical nursing research. According to Løgstrup, people are interdependent and cannot meet without being in a mutual relationship, where they "hand themselves over to each other."[7,26] An "ethical demand" is situated in this interdependence as an appeal emanating from the other to act in the other's best interest.[27] We have something of the other person's life in our power. In a professional caring relationship, however, the power relationship is asymmetrical and care is unidirectional, based on the clinician's solidarity and care for the weak.[28] Care is related to promoting good, but equally importantly, preventing harm. A clinician–family relationship without care, such as when clinicians overlook or ignore relatives, will make relatives feel powerless and left out.

Traditionally, the ethics of care has primarily influenced nursing, not medicine. However, care and moral actions are not limited to nursing.[29] Requirements for caring treatment are found in the Code of Ethics for Doctors,[30] the ICN Code of Ethics for Nurses,[31] and the Health Personnel Act.[32] Although Delmar's caring ethics[7,33] is developed in nursing, this thinking horizon founded on relational ontology may also increase awareness and recognition of care as an ethical perspective in medicine.[34]

Methods

This is a qualitative study with a narrative approach where the story is the object of the inquiry. Storytelling can provide understanding about human experiences. Narratives are situated in time, place, and a particular setting, and have "essential meaning making structures" where individuals or groups construct their identities.[35,36] In this study, narratives were collected in a combination of participant observation and focus groups to elicit a clear understanding of clinician–family interactions. Participant observation provides an inner perspective to illuminate phenomena in their natural settings, while interviews provide comprehensive insight into participants' experiences.[37,38] Data were analyzed using Riessman's[36] thematic narrative approach.

Setting and participants

Nurses and physicians from four Norwegian ICUs (6–18 beds) participated in the study. Three ICUs were in university hospitals with the highest level of intensive care, and one in a mid-range hospital. Recruitment took place orally or by e-mail via a contact nurse in each unit. All ICUs treated both surgical and medical patients, mostly adults. Most patients needed mechanical ventilation and were unable to express their wishes and needs. Visiting hours were flexible in two ICUs and fixed in the other two (3–4 h per day). However, exceptions were made when needed, for example, in end-of-life situations.

Data collection

Data were collected from July 2017 to August 2019. First the researchers conducted two focus groups at the ICU in the mid-range hospital. In the other units, the researcher conducted fieldwork, followed by focus groups during the last week of observations. The fieldwork consisted of 11–14 shifts during 3 weeks in each ICU. Seven focus groups were conducted with 32 participants in all: three groups of nurses, two of physicians, and two of both nurses and physicians. NN_1 performed the observations. A preliminary guide was developed with suggestions for observations: *how the family members were received, what was said, how the clinicians positioned themselves in the room, etc*. The fieldwork provided a unique opportunity to study the clinicians' interaction, and enabled the researcher to ask questions at various points. Field notes with rich descriptions of clinician-family meetings were written during and after each shift. Following clinicians during their everyday work allowed for close contact with their reality. It enabled the examination of professional and interprofessional interactions and exchanges, both within and between professional groups.[20]

Each focus group was moderated by NN_1 or NN_5. A "question route"[37] with open-ended questions was used and participants were encouraged to tell stories from their daily work with families. In addition, an observer (NN_1, NN_2, NN_4, or NN_5) paid special attention to the interaction between participants, took notes, asked supplementary questions, and gave an oral summary at the end. Conducting focus groups after the fieldwork enabled the moderator to ask in-depth questions about the observations. All interviews were digitally recorded and transcribed verbatim by NN_1.

Ethical considerations

The Regional Committee for Medical and Health Research Ethics (Ref. No.), the Norwegian Centre for Research Data (Ref. No.) and the participating ICUs approved the study. Before the fieldwork, the clinicians were informed by email about the purpose and scope of the study. NN_1 also informed them orally on each shift. Written study information was posted at the ICU entrance and corridors to inform visiting clinicians and visiting family members. Further, since it was impossible to observe clinicians' work without simultaneously observing patients and relatives, the researcher also informed conscious patients and visiting family members and requested their permission to observe in the patient's room. None refused this request. Written informed consent was obtained from the focus group participants. Field notes and transcriptions were anonymized.

Data analysis

In thematic narrative analysis, researchers focus on keeping the stories "intact" and analyzing them separately to elicit themes. Themes refer to the meaningful "essence" in the dataset.[39] According to Riessman,[36] in thematic narrative analysis, the content of each story is the exclusive focus. Instead of theorizing across cases, the researcher keeps the story intact by theorizing from each case.[36] NN_1 worked on the narratives one by one, studying and reading them several times, searching for preliminary themes that illuminated clinician–family interactions. NN_1 and NN_5 discussed and refined the preliminary themes and presented and discussed these with the entire research team. All stories were then compared to identify common themes. Specific narratives have been selected to illustrate the themes.

Findings

The analysis shows that ICU family care varies in quality, depending on the individual clinician's attitudes, behavior, and personality. Participants themselves stated that their family care depended on their personality and use of discretion. Three themes were identified: (1) *being attentive*, (2) *an active approach,* and (3) *degree of tolerance*. The narratives presented under each theme reveal contrasts in clinicians' interaction with families.

Being attentive

Being attentive describes ICU clinicians' ability to pay attention, be considerate, listen, concentrate, and be alert and their perception of families' verbal and non-verbal communication.

> Lisa, an ICU nurse, is responsible for a patient in her 70s, admitted for several weeks with severe respiratory failure. She has a tracheostomy. Sometimes she can breathe without a ventilator, but weaning is very difficult. She is alert and can speak with a tube when breathing without a ventilator. She tells Lisa that she doubts if she will recover, she is tired, and the dyspnea attacks make her frightened and desperate. Lisa knows her medical history well and realizes how serious her respiratory failure is.
>
> One day when the patient's family visit, Lisa suspects that they do not really understand how sick she is. Several times they tell her: "You'll soon get better and come home". Later, Lisa asks her: "Does your family understand how sick you are?" "I don't think so," she replies. "That's what I suspected," says Lisa. The patient says that it is difficult to talk to her family about how she is, her thoughts about not living much longer, not wanting to exercise or "fight" to get off the ventilator. Lisa looks at her, listening closely. Later, Lisa discusses her concerns with Eric, the ICU physician. When he sees the patient, he talks to her for some time and finally she repeats to him what she said to Lisa. She feels like giving up. But she also says she has a lot to live for, a husband, children and grandchildren. She is worried about her husband, how he will manage alone. "We can help you to talk to your husband," says Eric. He speaks in a calm voice, looking straight at her, and takes his time. Lisa is sitting with them, listening to them, making comments and nodding.
>
> (Field note, ICU 3)

The nurse's sensitivity to the patient's weak body and words enables her to remain close to the patient's suffering and carefully ask her if she wants to talk about how her family views the situation. Due to her concern about the patient's burden, she discusses it with the physician, and together they support the patient in planning how to communicate this sensitive information to the family. A few days later, during a talk with the family, their suspicion of the family's lack of understanding is confirmed.

> The patient and her husband are sitting close together, holding hands. Eric first talks about the disease. Quite soon the patient exclaims: "I've lost all hope". Her husband is horrified, looks at her and says: "No, you mustn't give up!". The patient says she is afraid and thinks she cannot get out of the situation. Her husband sits quietly with tears in his eyes.
>
> (Field note, ICU 3)

An attentive clinician, like Lisa and Eric, realizes what is most important in this situation. The fieldwork shows that family members' concerns are often expressed as hints. Instead of asking directly, they may ask vague, indirect questions. "So he's wearing a different oxygen mask today?" may express a worry that the patient's condition has worsened. "I can't sleep at night" may mean that the family member is upset. Body language such as "an unfocused look" or sitting "on the edge of the chair" can reveal distress or anxiety.

The opposite of attentive clinicians is those who are bad listeners, make sudden movements, speak sharply, and do not get the details of what is said. They can do patient-oriented work quickly and efficiently, but pay little attention to family members, do not get their hints and thus do not respond to them. In ICU 2 the following situation occurred:

> The patient's brother and sister-in-law are visiting. Hans (the nurse) says hello, then turns his back on them and sits down at the computer. The visitors stand by the bed; there are no chairs. They talk to the patient, but he is tired, does not feel like saying much, closes his eyes and the conversation ends. They stand still, look around and comment on all the "equipment" around the bed. Then it is quiet again. After a few minutes, the sister-in-law says: "I'm glad it was such a success". Hans does not look up from the computer or respond to them. A few minutes later, the visitors say goodbye to the patient. Then Hans turns round and says goodbye before they leave.
>
> (Field note, ICU 2)

As Hans has his back to the visitors, he does not realize they want contact. They are left to themselves and receive no confirmation that the patient is doing well. Without any response, they "give up" and leave. Maybe Hans means well, perhaps he wants to give them time alone with the patient, or he may think they are talking to each other. But he is not attentive; he makes no attempt to find out what they really need or whether he has interpreted the situation correctly.

An active approach

Just as clinicians are attentive to different degrees, we also see differences in how active they are towards family members. An active approach involves asking questions, making arrangements for families, and including them in patient care. It is demonstrated by both words and actions.

> A young man is admitted to the ICU. Oscar, the nurse, is told that he will have a CT scan in 30 min. Oscar rings the patient's father to mention the scan. "I just wanted to tell you in case you were coming here," he says. They agree that the patient's father will come in 1 h, when the scan is over.
>
> The father arrives at the agreed time, gives Oscar a hug, walks over to the bed, looks at his son, touches his arm and strokes his cheek. Oscar is on the other side of the bed. The patient's father says he thought a lot about the information he got the previous evening and slept badly that night. Oscar looks at him, listens, says a few words, but lets him speak. The father has tears in his eyes, his voice is trembling. Oscar explains calmly, precisely and in simple language about the patient's situation now and last night. He also talks about feelings that family members can get in such serious situations, and the visitor talks about how he feels. While they are talking, the physician in charge of treatment arrives. Oscar finishes the conversation and sits down with the physician. They talk quietly while the father is still standing by the bed. He sometimes looks at the doctor and Oscar. Oscar notices this, gets up and goes back to the father. The physician sits at the computer reading the patient record. Oscar tells the father: "If you have any questions, you can ask him [the physician]". The physician gets up, walks over to them, and greets the father. (Field note, ICU 4)

Oscar's active behavior and actions show his care and understanding of the father's situation. He stands by the bed with him, they have eye contact, and he is friendly and accessible. He is proactive in informing the father about the CT scan, providing other important information, and inviting him to come straight in to the ICU. He listens to the father's concerns before speaking, but also makes suggestions and talks about the patient's condition and treatment and about typical thoughts and feelings of family members. His language is direct and simple. Telling the father that he can talk to the physician includes him in the conversation and ensures that he receives the latest information.

The opposite of active clinicians is passive clinicians. They do not ask questions, make suggestions, or act actively; they wait for the family's questions, avoid eye contact, and pay little attention to the family.

> An old patient who is sedated and mechanically ventilated is visited by his wife and daughter. They sit at the end of the bed while the physiotherapist moves the patient's arms and legs. The nurse, Sophie, with her back to the visitors, is busy checking the infusion pumps. The patient's wife puts her face in her hands and sobs quietly, and her daughter hugs her gently. They talk quietly. Sophie sits at the computer without looking at the visitors, updating the patient record.
>
> The visitors follow the physiotherapist's work. When she lifts the patient's injured leg, the wife leans over to look. Neither the physiotherapist nor Sophie say anything about this, perhaps they do not notice it, as they talk about the patient's injuries. The visitors look at the physiotherapist and Sophie. The physiotherapist finishes and talks to Sophie about further treatment without looking at the family members or including them in the dialogue. The

> physiotherapist leaves and Sophie continues at the computer. The visitors walk over to the patient and look at him. The daughter asks Sophie if her mother can touch the patient. "Yes, but don't stroke his arm, that might be unpleasant," she replies quickly and sharply. (Field note, ICU 4)

Sophie is not attentive to the visitors. She avoids eye contact and "does her job." Her passive approach is seen in her lack of response to the family members. They are not involved or informed, and are actually reproached when they suggest touching the patient. The nurse's passivity is also reflected in her position in the room. Unlike Oscar, who stood by the bed with the patient's father, Sophie sat by the computer or stood with her back to the family members. The findings from the fieldwork are supported by stories nurses and physicians told in the focus groups: some clinicians have a more active approach than others.

> One nurse says that she rings relatives if they have not visited the patient for several days. She asks how they are and why they have not come. Can she help them with anything? The other nurses in the focus group are surprised - they do not usually do that.
>
> (Focus group 7, ICU 4)

The active–passive dichotomy is also evident in clinicians' communication with families and how they start the conversation. Active clinicians ask how family members are, if they have any questions, and if they are worried about anything. They also ask them to describe the patient before the illness. An active approach involves letting the family sit by the patient's bed, showing them how to hold the patient's hand, telling them that they can talk to the patient even if he/she cannot reply, and explaining about the equipment and ICU procedures. Passive clinicians mostly talk about the patient's current condition, temperature and blood sample results, and only provide other information when families ask for it.

Degree of tolerance

Clinician–family interaction is also expressed through nurses' and physicians' degree of tolerance towards families. This seems to depend on clinicians' workload, stress threshold, robustness, knowledge, and experience.

Data from fieldwork and focus groups showed that several young, newly trained ICU nurses had difficulty in concentrating on necessary patient tasks when families were present. ICU treatment is advanced, making it difficult to take care of family members simultaneously. Trainee physicians said that as new staff they found it challenging to be "thrown into" difficult conversations with families. Younger, less experienced clinicians could also make relatives feel insecure and afraid.

> A patient's wife talks about what happened the previous night. When she and her son arrived, her husband was very stressed and agitated. They were worried at seeing him in that state. The wife thought the physicians who came to see the patient were "so young, and they said nothing. We got so stressed. Luckily, an experienced doctor came and gave us good information".
>
> (Field note, ICU 3)

Older ICU clinicians said that over the years they had gained more experience and knowledge to enable them to relax more with families. When newly graduated, they were less sure about what to say, and how to help and comfort families.

> Susan has been an ICU nurse for over 20 years. She is responsible for an old patient, acutely admitted a few hours ago. His condition is severe and unstable. Soon after Susan started her shift, the patient's wife, daughter and

> grandson arrived. Susan greets them at the door. She puts out chairs and gives the patient's wife the chair closest to him, telling her that she can hold his hand. She offers them something to drink. Then she talks about the patient's condition, the treatment and the equipment. Later three more relatives arrive. Despite the ward's fixed visiting hours and limited numbers of visitors, Susan welcomes them and fetches more chairs. They all sit around the bed, sometimes talking, sometimes quiet. The atmosphere is peaceful. Susan sits in the background and tells her colleague: "I think this is a nice situation".
>
> (Field note, ICU 3)

Susan is confident and very capable. She can combine caring for a critically ill patient and many family members. She is flexible and ignores the visiting regulations by exercising discretion to meet the family's needs.

Sound knowledge of critical illness and family care gives clinicians confidence when informing families about ICU patients' complex conditions. Oscar, a nurse, said:

> "… it's very important for me to have good knowledge, understand the patient's disease, know the pathophysiology and understand the intensive care provided so I can explain this clearly and simply to families".
>
> (Field note, ICU 4)

However, more experience and knowledge does not necessarily mean better family care. Several participants said that older, experienced nurses could be less flexible and tolerant than younger ones. One nurse said: "*I was better before, now I get tired of them* [families]", while another stated: "*I'm so old, I can't face having relatives around so much*". Younger nurses often showed more commitment and flexibility. Regardless of age and experience, the degree of tolerance was clearly seen in clinicians' behavior towards families. It varied between the extremes of calm, polite, supportive, and inclusive clinicians and abrupt, rude, critical, and dismissive ones.

Participants also stated that caring for critically ill patients over time affected their view of what was really serious. They had experienced so many situations and observed and treated so many ICU patients that they had developed a higher tolerance threshold for what was serious or critical. One ICU physician described this as "*speed blindness.*" A patient situation that seems straightforward to clinicians may be perceived as very serious by families. Several participants also found that the ICU workload was increasing. In one focus group, a nurse described how nurses must go straight "*from end-of-life care to receiving a new patient.*" Clinicians missed time for reflection and talking to colleagues, and several became exhausted over time. However, some family members affected clinicians' emotions in a positive way, motivating them to "*go the extra mile.*. The clinician–family relationship or alliance will affect how much families can be present and involved. Eric, a physician, and Marie, a nurse, discussed this in a focus group.

> Eric: If you feel that families trust you, you're relaxed and then it's ok having them present during a procedure. Then there are those where the alliance has been bad from the start and then I wouldn't take the risk; if they're present, I'd have to focus on them so I don't make mistakes … Marie:… I think it's like that for nurses too. Having a good relationship with the family is fine. But if they're always asking questions, the "wrong questions", it's a bit harder to work … I feel there's a difference at least. With some relatives it's fine, they can be present any time, but with others you just think: "Oh… hope time passes quickly, I want to finish". Eric: …then there are some anxious ones, neurotically wanting to know everything… they need lots of attention and you can't keep focused… Marie: …sometimes there are relatives it's really hard to get along with, you have nothing in common…, no chemistry, while others… you could "invite them home"… it's kind of strange…
>
> (Focus group 5, ICU 3)

Split families with conflicts are viewed as challenging, as are those who are insistent, critical, and ask many questions. There can also be big differences between individual family members. One may be very demanding, while another is very satisfied or very frightened. Clinicians' views of families also vary; one may find a person "tiresome," while another feels very sorry for the same person.

Discussion

The main findings are that ICU clinician–family interaction is related to whether clinicians are *attentive, active,* and *tolerant* towards relatives. This affects care provision and families' freedom of action, which again influences the quality of family care. ICU families expect clinicians to help them handle the new and confusing situation they have been "thrown into." According to Løgstrup, certain phenomena are fundamental to human existence, such as trust, openness, compassion, mercy, and hope.[33] Showing trust is not a choice people make, but an existential phenomenon we are thrown into.[27] However, one may be rejected when reaching out to another person. Thus, in an ethical sense, people are not primarily independent of others and the community.[9] Empirical research, however, reveals a tendency for individualist, liberal values like "autonomy," "independence," and "self-management" to dominate patient and family care, especially in Western countries.[26] Being independent of others' help is also closely connected to integrity and dignity.[7] Even if these liberal values are vital to our modern life, they may have negative outcomes for patients and their families.[7] The fieldwork shows how some clinicians left families to themselves at the patient's bed, failed to inform them, or ignored them. Wong et al.[3] state that families described such experiences as being kept in the dark. Such lack of care can cause harm and represents an important moral concern from a care ethics perspective.[29]

Attention is a core quality in ICU practice. ICU patients' severe condition requires continuous monitoring and assessment.[13] Being attentive is a filtering process where nurses *"separate things of particular significance from less significant things."*[27,40] It requires an intense presence, concentration, and perception of the situation.[27] To ensure safe and high-quality care, bedside nurses must be sensitive to every slight change in the patient's condition and the uniqueness of each situation.[41] Traditionally, ICU clinicians have focused on patients much more than their families.[42] Today, a holistic patient- and family-centered care approach is emphasized and the importance of caring for and involving the family is acknowledged.[19,43] ICU clinicians need to look beyond all the equipment and physical parameters towards the unique needs of the patient and family.[43] Family members' feelings are in turmoil in the ICU setting,[2] but unfortunately many report poor emotional support from ICU clinicians.[44–47] The ICU environment is complex, event-driven, and time-pressured.[48] Several reasons have been suggested for clinicians' lack of support, such as their intense focus on medical care, poor communication and interpersonal skills, and insufficient training in meeting family members' emotional and mental needs.[45,46,49] This was confirmed by the focus group participants, who also mentioned the increased workload and minimal time for discussion and reflection. Bedside nurses may feel torn between treating the patient as their highest priority and caring for the patient's family.[50] However, this study shows how inattention can lead to families' needs being neglected or overlooked. Further, our data demonstrate how clinicians must be attentive to family members' body language, vague hints, and covert questions. ICU clinicians' ability to respond to relatives' concerns is considered supportive and comforting.[49] In the ICU, many family members are afraid of being a nuisance, and are unsure of their caregiver role.[45,49] Being attentive requires sensitivity as a response to a silent demand. An attentive clinician may open up, listen to the unspoken words, and with imagination based on humanity and insight act responsibly and actively as needed.

Clinicians' attitudes towards family involvement in patient care may be barriers or facilitators.[11] This is evident in the narratives describing nurses' and physicians' active and passive approaches to families. While some nurses spontaneously gave families information and encouraged their involvement, others waited for them to express their needs. This shows clinicians' position of power and gatekeeper role, allowing them to decide whether to include relatives. Families are completely dependent on clinicians' decisions and use of power. The power relationship between the two parties is asymmetrical.[8,26] Nurses' and physicians' authority is obvious in their position, uniform, professional knowledge, and personal behavior.[26] Clinicians are probably also subject to a silent demand to diminish the power imbalance and become attuned to the world of the family members.[27]

Gatekeeping depends on discretion, but also on the individual clinician's mood and personal energy.[51] This concurs with our findings showing that clinicians' tolerance and care of family members is affected by their knowledge, professional experience, personal attitudes, behavior, and stress tolerance. Clinicians' professional and personal qualities seem interwoven and difficult to distinguish. According to Page et al.,[50] nurses consistently oscillate between their personal and professional selves. Clinicians can be too close and overprotective but also too distant and paternalistic.[7] An excessively close relationship can become too dependent, leaving families little freedom. A too distant relationship may leave families to themselves without the care they need. Both extremes may imply that clinicians overlook what really matters to a family in a particular situation.[7,8] Professional care differs from private and personal care in requiring professional knowledge and empathetic skills, but also the ability to distinguish between one's own and the family's needs.[27] Awareness of one's own feelings through reflection can help clinicians avoid too close, sentimental feelings or too much distance, which may make care more personal than professional.[8]

This study shows that clinicians' engagement and support for families depends on their degree of tolerance. Some family members are considered particularly difficult, such as those who are very critical, anxious, or emotional. This affects the chemistry and thus communication between clinician and family. Clinicians adapt their communication with families to their ideas of acceptable behavior and the norms and priorities of the ICU.[52] Several studies have identified poor communication between ICU clinicians, especially physicians, and family members.[53–55] Leslie et al.[52] argue for developing communication strategies suitable for all types of relatives. Fortunately, communication is now more in focus, and several studies show promising results of training in communication strategies/skills for nurses and physicians.[53,54,56] Nevertheless, there is a tendency to reduce many of the problems of interaction between physician and patients/family members to poor communication skills even when the (real) problem is to connect with patients/family and understand their needs.[29] This reflects the importance of a care ethics approach focusing on people's interdependence as well as moral attentiveness and contextual sensitivity in relation to how clinicians gain knowledge to act morally.[29]

The findings suggest that ICUs lack a common interprofessional ethical culture for family care. Responsibility for families seems to fall mainly on individual clinicians, particularly nurses, which can cause great variation in family care quality. However, the individual clinician should not have sole responsibility.[10,11,14] Nurses should take a leading role in family care[10,19] and many factors supporting nurses' ability to promote family engagement in the ICU have been identified.[10] Hospital management must facilitate consistent family care. This includes establishing an ICU nursing culture that promotes nurses' moral resilience and enables them to enhance their family nursing skills. If family care is valued and emphasized in the ICU nursing culture, nurses are more likely to promote and prioritize such work.[10] Family care is also dependent on good nurse–physician collaboration.[19] To enhance care ethics thinking, clinicians should reflect on specific clinical situations to improve their attentiveness and judgment.[7,26,34] Such interpersonal skills should also be key topics in ICU specialist education in addition to technical and medical knowledge.[46] Importantly, ICU management needs to initiate closer interprofessional collaboration on specific guidelines for family care.[57]

This study shows that attentive, active, and tolerant clinicians represent a culture of care ethics that enhances families' freedom of action and active participation in patient care. Yet this ethical challenge is little discussed and acknowledged, especially in medical ethics.[29] In nursing, care ethics is more acknowledged[29] but our study shows that even here this perspective needs greater implementation. It is necessary to challenge and supplement the prevailing ideals of detachment and non-interference in medicine.[29] A care ethics approach also aligns with the principles of patient- and family-centered care that emphasize mutually beneficial partnerships among clinicians, patients, and families.[15]

Limitations

Participant observation combined with focus groups resulted in rich data in the form of narratives. Particularly during fieldwork, the researcher was close to ICU clinicians' interactions with families in specific clinical situations. A further strength was the inclusion of both physicians and nurses; although ICU family care is traditionally associated with nursing, physicians also play a vital role, as seen in this study. An additional strength would be to include family members as participants, to verify the researchers' findings that clinicians' attentiveness, active approach, and tolerance are essential for families to feel cared for. However, the research group did discuss the findings with patient representatives, a former ICU relative, and a former ICU patient. The former ICU relative is also a qualified researcher, has participated in the entire research process and is a co-author (NN_3).

Conclusion

High-quality ICU family care that includes family members as active partners in patient care depends on clinicians focusing on families' wishes and needs and being active and tolerant towards families. This represents ethical family care. However, ICU clinicians' family care seems to be largely based on the individual clinician's personality and experience, rather than evidence-based guidelines and a common culture in the unit/hospital. As the study shows, family care is an individual professional responsibility, but it is also a key responsibility of the healthcare organization through training, interprofessional reflection, and support to clinicians to create a common culture of ethical family care in the ICU.

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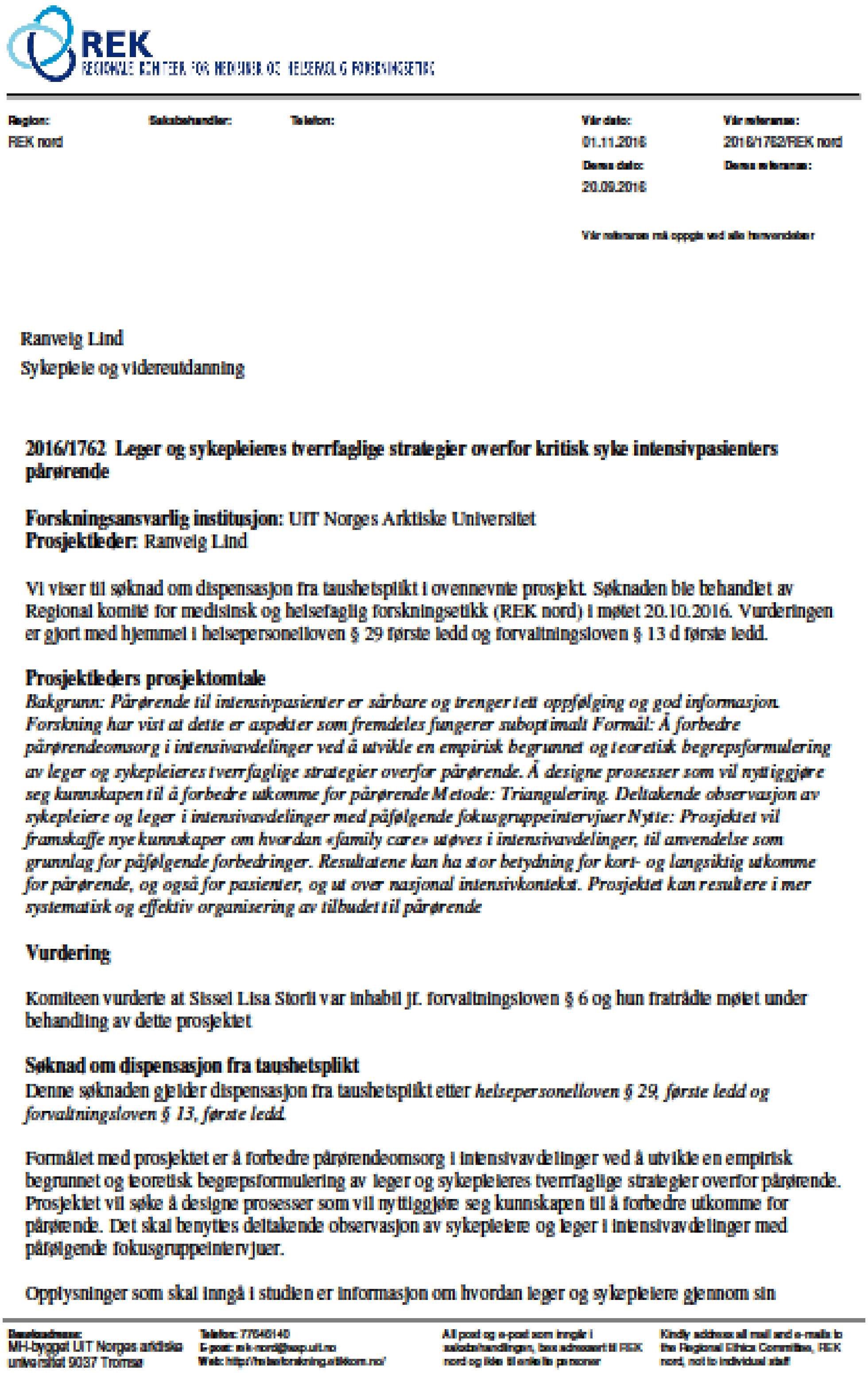
Appendix

Appendix 1



REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK nord			01.11.2016	2016/1762/REK nord
			Deres dato:	Deres referanse:
			20.09.2016	

Vår referanse må oppgis ved alle henvendelser

Ranveig Lind
Sykepleie og videreutdanning

2016/1762 Leger og sykepleieres tverrfaglige strategier overfor kritisk syke intensivpasienters pårørende

Forskningsansvarlig institusjon: UiT Norges Arktiske Universitet
Prosjektleder: Ranveig Lind

Vi viser til søknad om dispensasjon fra taushetsplikt i ovennevnte prosjekt. Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK nord) i møtet 20.10.2016. Vurderingen er gjort med hjemmel i helsepersonelloven § 29 første ledd og forvaltningsloven § 13 d første ledd.

Prosjektleders prosjektomtale
Bakgrunn: Pårørende til intensivpasienter er sårbare og trenger tett oppfølging og god informasjon. Forskning har vist at dette er aspekter som fremdeles fungerer suboptimalt. Formål: Å forbedre pårørendeomsorg i intensivavdelinger ved å utvikle en empirisk begrunnet og teoretisk begrepsformulering av leger og sykepleieres tverrfaglige strategier overfor pårørende. Å designe prosesser som vil nyttiggjøre seg kunnskapen til å forbedre utkomme for pårørende. Metode: Triangulering. Deltakende observasjon av sykepleiere og leger i intensivavdelinger med påfølgende fokusgruppeintervjuer. Nytte: Prosjektet vil framskaffe nye kunnskaper om hvordan «family care» utøves i intensivavdelinger, til anvendelse som grunnlag for påfølgende forbedringer. Resultatene kan ha stor betydning for kort- og langsiktig utkomme for pårørende, og også for pasienter, og ut over nasjonal intensivkontekst. Prosjektet kan resultere i mer systematisk og effektiv organisering av tilbudet til pårørende

Vurdering

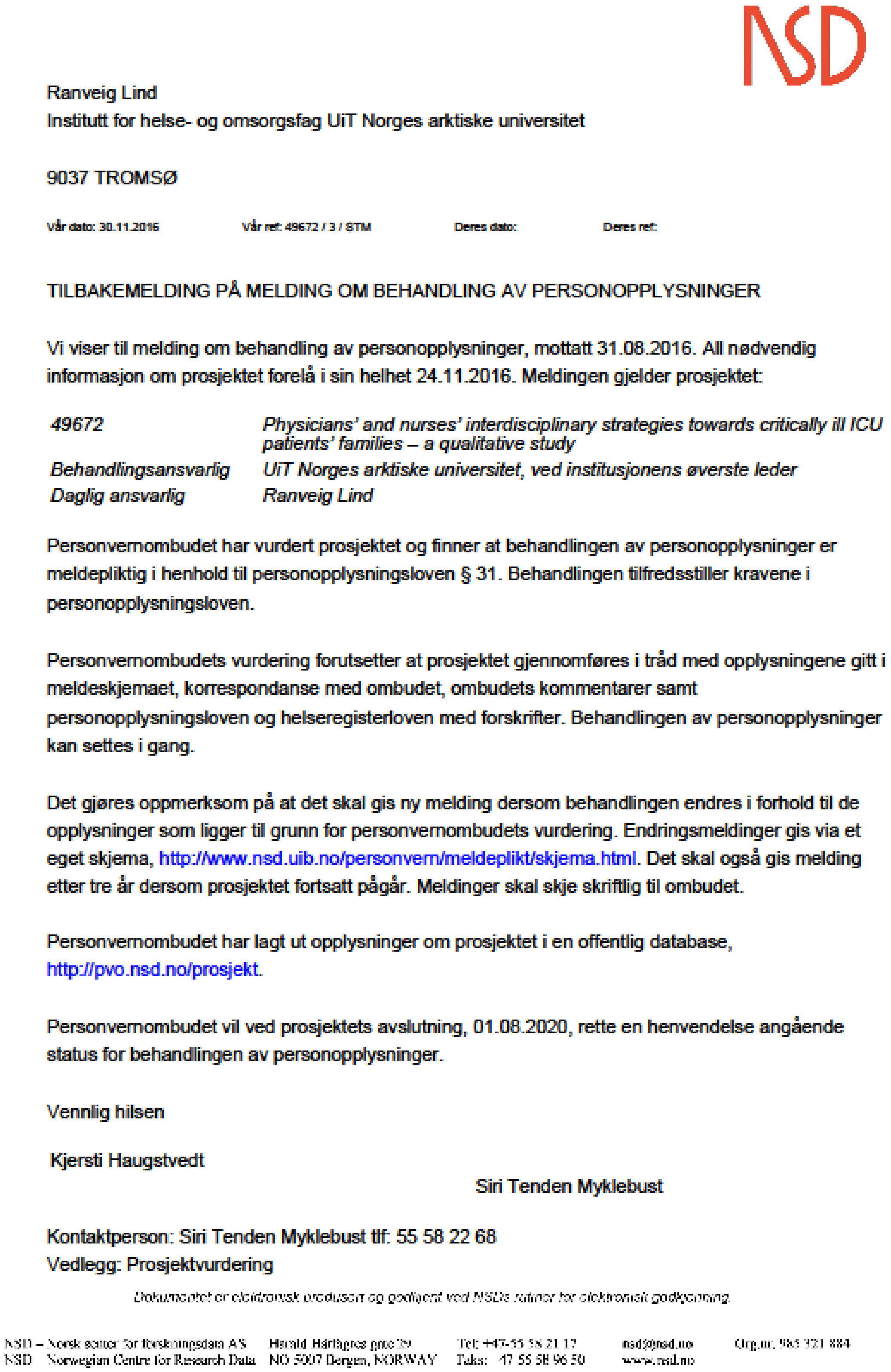
Komiteen vurderte at Sissel Lisa Storli var inhabil jf. forvaltningsloven § 6 og hun fratrådte møtet under behandling av dette prosjektet

Søknad om dispensasjon fra taushetsplikt
Denne søknaden gjelder dispensasjon fra taushetsplikt etter *helsepersonelloven § 29, første ledd og forvaltningsloven § 13, første ledd.*

Formålet med prosjektet er å forbedre pårørendeomsorg i intensivavdelinger ved å utvikle en empirisk begrunnet og teoretisk begrepsformulering av leger og sykepleieres tverrfaglige strategier overfor pårørende. Prosjektet vil søke å designe prosesser som vil nyttiggjøre seg kunnskapen til å forbedre utkomme for pårørende. Det skal benyttes deltakende observasjon av sykepleiere og leger i intensivavdelinger med påfølgende fokusgruppeintervjuer.

Opplysninger som skal inngå i studien er informasjon om hvordan leger og sykepleiere gjennom sin

Appendix 2



NSD

Ranveig Lind
Institutt for helse- og omsorgsfag UiT Norges arktiske universitet

9037 TROMSØ

Vår dato: 30.11.2016 Vår ref: 49672 / 3 / STM Deres dato: Deres ref:

TILBAKEMELDING PÅ MELDING OM BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 31.08.2016. All nødvendig informasjon om prosjektet forelå i sin helhet 24.11.2016. Meldingen gjelder prosjektet:

49672	*Physicians' and nurses' interdisciplinary strategies towards critically ill ICU patients' families – a qualitative study*
Behandlingsansvarlig	*UiT Norges arktiske universitet, ved institusjonens øverste leder*
Daglig ansvarlig	*Ranveig Lind*

Personvernombudet har vurdert prosjektet og finner at behandlingen av personopplysninger er meldepliktig i henhold til personopplysningsloven § 31. Behandlingen tilfredsstiller kravene i personopplysningsloven.

Personvernombudets vurdering 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, 01.08.2020, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen

Kjersti Haugstvedt

Siri Tenden Myklebust

Kontaktperson: Siri Tenden Myklebust tlf: 55 58 22 68
Vedlegg: Prosjektvurdering

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

NSD – Norsk senter for forskningsdata AS Harald Hårfagres gate 29 Tel: +47-55 58 21 17 nsd@nsd.no Org.nr. 985 321 884
NSD Norwegian Centre for Research Data NO 5007 Bergen, NORWAY Faks: 47 55 58 96 50 www.nsd.no

Appendix 3

Observasjonsguide (forslag/eksempler på situasjoner som bør observeres)

Situasjonsbeskrivelse

Hva handler situasjonen om? Generell beskrivelse uten noen identifiserbar informasjon Hvordan er den aktuelle konteksten?

- Tilgjengelige senger/ kapasitet
- Personellsituasjonen
- Stemning i rommet (ro, stille, travelhet, støy etc)

Hvordan foregår prosessene rundt pårørende?

- Gis det rapporter mellom sykepleiere der pårørende nevnes?
- Lager sykepleiere noen form for pårørendekart slik at alle viktige pårørende er inkludert (også barn, dersom familien inkluderer barn som pårørende)
- Hvordan henvender pårørende seg til avdelingen;
  - Gjennom telefonkontakt
  - Via dørtelefon fordi de ønsker å komme inn til pasienten. Blir pårørende møtt/ hentet?
  - Er det adgangsbegrensning /antall inn til pasienten samtidig / andre begrensende faktorer i situasjonen
  - Får de spontan orientering om hvordan det står til med pasienten? Hva skjer videre?
  - Hvordan organiseres deres tilværelse ved pasientsengen (stoler, kaffe/te, oppfordringer til kontakt med pasienten etc)

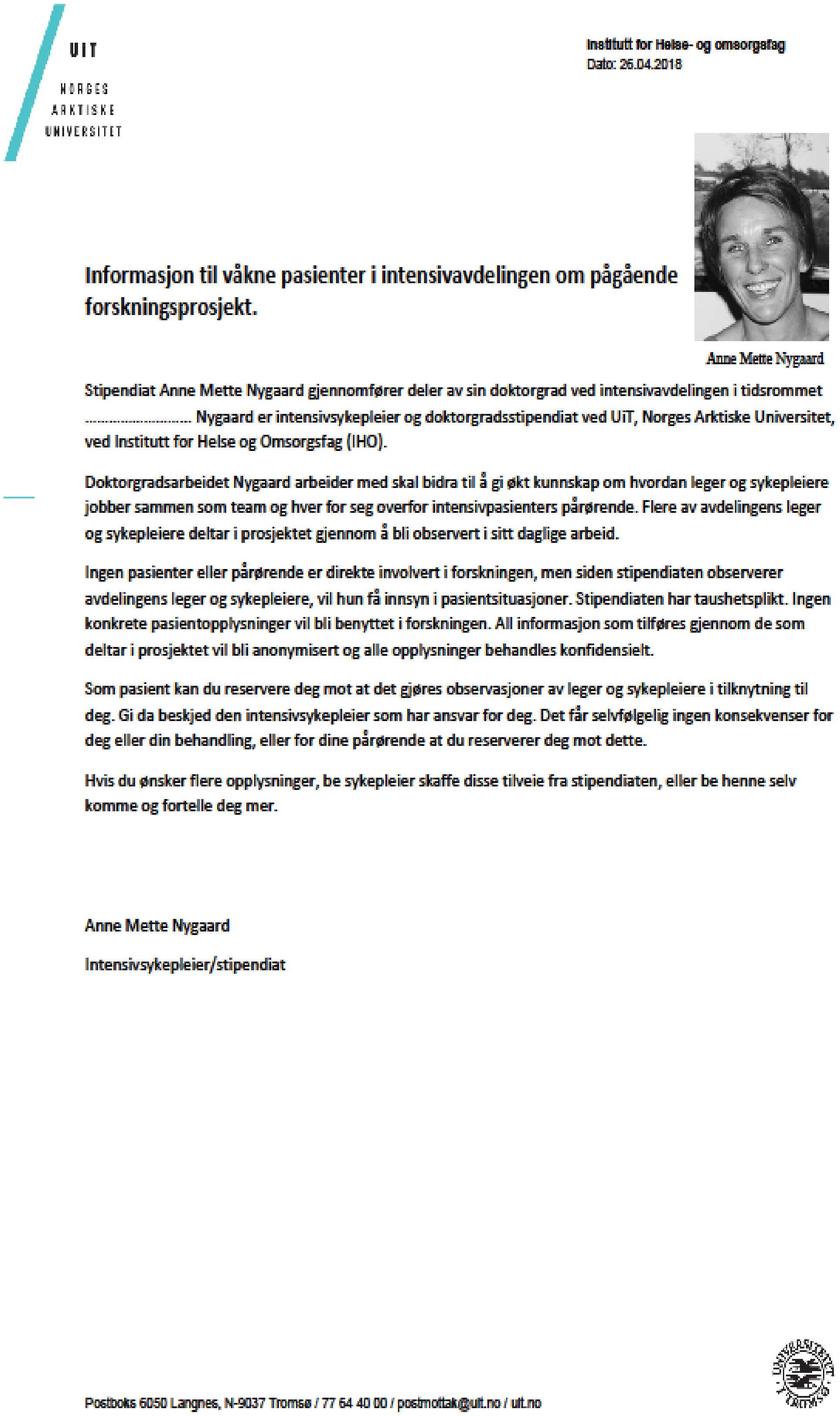
Hvordan foregår samarbeidet mellom lege og sykepleier om pårørende?

- Når snakker de sammen om pårørende? I pasientrommet? I møter i vekk fra sengen?
- Er de opptatt av DEN nærmeste, eller omtales pårørende som flere/ en enhet?
- Deltar sykepleier i previsitter?
- Når avtaler leger og sykepleiere å ha formelle møter der pårørende skal få ny informasjon, evt om endringer?
- Hvordan og hvor foregår forberedelser til slike møter? Brukes det noen form for sjekklister eller prosedyrer? Er det dialog mellom lege og sykepleier på innholdet, evt begrensninger av informasjon som skal gis?
- Hvordan gjennomføres disse (dersom anledning til å observere i slike møter)
  - Tone/ stemning i rommet
  - Følg med på oppgavefordelingen mellom lege og sykepleier
  - Bytter de på å føre ordet?
  - Ser du særegne oppgaver for hver faggruppe?
  - Ser du om partene følger med på og justerer samtalen etter evt reaksjoner hos pårørende?
  - Hvordan avrundes møtene?
  - Gjøres det avtale om nytt møte? Når vil det nye møtet finne sted?
- Hvordan utvikler samarbeidet mellom sykepleiere og leger seg om pårørende seg når pasienten har vært i intensivavdelingen over dager evt uke(r)?
- Kontinuitet av helsepersonell hos pasienter som ligger over tid (og dermed hos pårørende)?

Appendix 4

Questioning route (interview guide)		
	Questions	Probe
Opening	1. Kan vi først ta en runde der vi presenterer oss for hverandre, og fint om dere også sier hvor lenge dere har jobbet i intensivavdeling	Gi gjerne eksempler underveis
Introductory	2. Kan dere beskrive noen trekk i utviklingen i arbeid med pårørende til intensivpasienter fra dere startet å jobbe i intensivavdeling og fram til i dag?	Status i deres avdeling
Transitions	3. Kan dere fortelle om det beste/det viktigste med arbeidet rettet mot pårørende? 4. Hva er spesielt utfordrende?	Barn som pårørende, pårørende til barn, døende pasienter, våkne pasienter? Helsepersonell står langt fra hverandre? Tid?
Key Questions	5. Kan dere fortelle om et vanlig forløp i arbeidet med pårørende fra pasienten kommer inn i avdelingen? 6. Hvordan utvikler dette arbeidet seg ettersom dager og eventuelt uker går og pasientens tilstand svinger? 7. Hva er legers og sykepleieres fokus i arbeidet med pårørende? 8. Hvordan foregår samarbeidet mellom leger og sykepleiere vedrørende pårørende? 9. Hvordan foregår samarbeidet om pårørende med leger fra moderavdelingen? 10. Hvis dere skulle foreslå noen forbedringer, hva er da det viktigste?	Samtale, informasjon, visittid Kontinuitet, dokumentasjon, interesse for pasienten, etiske hensyn Tilnærming, har leger/sykepleier ulikt fokus? Ansvarsforhold Beslutningsprosesser, ansvarsforhold, informasjon
Ending questions	11. Er det noe dere vil fortelle om i relasjon til tema pårørende, som vi ikke har snakket om?	

Appendix 5



UIT
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Institutt for Helse- og omsorgsfag
Dato: 26.04.2018

Informasjon til våkne pasienter i intensivavdelingen om pågående forskningsprosjekt.

Anne Mette Nygaard

Stipendiat Anne Mette Nygaard gjennomfører deler av sin doktorgrad ved intensivavdelingen i tidsrommet .... Nygaard er intensivsykepleier og doktorgradsstipendiat ved UiT, Norges Arktiske Universitet, ved Institutt for Helse og Omsorgsfag (IHO).

Doktorgradsarbeidet Nygaard arbeider med skal bidra til å gi økt kunnskap om hvordan leger og sykepleiere jobber sammen som team og hver for seg overfor intensivpasienters pårørende. Flere av avdelingens leger og sykepleiere deltar i prosjektet gjennom å bli observert i sitt daglige arbeid.

Ingen pasienter eller pårørende er direkte involvert i forskningen, men siden stipendiaten observerer avdelingens leger og sykepleiere, vil hun få innsyn i pasientsituasjoner. Stipendiaten har taushetsplikt. Ingen konkrete pasientopplysninger vil bli benyttet i forskningen. All informasjon som tilføres gjennom de som deltar i prosjektet vil bli anonymisert og alle opplysninger behandles konfidensielt.

Som pasient kan du reservere deg mot at det gjøres observasjoner av leger og sykepleiere i tilknytning til deg. Gi da beskjed den intensivsykepleier som har ansvar for deg. Det får selvfølgelig ingen konsekvenser for deg eller din behandling, eller for dine pårørende at du reserverer deg mot dette.

Hvis du ønsker flere opplysninger, be sykepleier skaffe disse tilveie fra stipendiaten, eller be henne selv komme og fortelle deg mer.

Anne Mette Nygaard

Intensivsykepleier/stipendiat

Postboks 6050 Langnes, N-9037 Tromsø / 77 64 40 00 / postmottak@uit.no / uit.no

Appendix 6

UIT
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Institutt for Helse- og Omsorgsfag
Dato: 26.04.2018

Informasjon til pårørende og besøkende i intensivavdelingen om pågående forskningsprosjekt

Anne Mette Nygaard

Stipendiat Anne Mette Nygaard gjennomfører deler av sin doktorgrad ved intensivavdeling i tidsrommet .... Nygaard er intensivsykepleier og doktorgradsstipendiat ved UiT, Norges Arktiske Universitet, ved Institutt for Helse- og Omsorgsfag (IHO).

Doktorgradsarbeidet Nygaard arbeider med skal bidra til å gi økt kunnskap om hvordan leger og sykepleiere jobber sammen som team og hver for seg overfor intensivpasienters pårørende. Flere av avdelingens leger og sykepleiere deltar i prosjektet gjennom å bli observert i sitt daglige arbeid.

Ingen pasienter eller pårørende er direkte involvert i forskningen, men siden stipendiaten observerer avdelingens leger og sykepleiere, vil hun få innsyn i pasientsituasjoner.

Stipendiaten har taushetsplikt. Ingen konkrete pasientopplysninger vil bli benyttet i forskningen. All informasjon som tilføres gjennom de som deltar i prosjektet vil bli anonymisert og alle opplysninger behandles konfidensielt. Studien er har fått innvilget dispensasjon fra taushetsplikt for deltakende observasjon fra Regional komite for medisinsk og helsefaglig forskningsetikk (REK Nord 2016/1762) og er meldt til Norsk senter for forskningsdata (Prosj.ID 49672).

Som pårørende kan du reservere deg mot at det gjøres observasjoner av leger og sykepleiere i tilknytning til en av dine nærmeste. Gi da beskjed til ansvarshavende intensivsykepleier eller den intensivsykepleier /sykepleier som har ansvar for ham eller henne du er pårørende for.

Hvis du ønsker flere opplysninger, ta gjerne kontakt med stipendiaten når du ser henne.

Anne Mette Nygaard

Postboks 6050 Langnes, N-9037 Tromsø / 77 64 40 00 / postmottak@uit.no / uit.no

Appendix 7

UIT
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Institutt for Helse- og Omsorgsfag
Dato: 26.04.2018

Generell informasjon til sykepleiere og leger i intensivavdelingen om pågående doktorgradsprosjekt:

Physicians' and nurses' interdisciplinary strategies towards critically ill ICU patients' families – a qualitative study

Anne Mette Nygaard

Stipendiat Anne Mette Nygaard vil gjennomføre deler av sitt doktorgradsarbeid ved intensivavdelingen i tidsrommet .... Nygaard er intensivsykepleier og doktorgradsstipendiat ved UiT, Norges Arktiske Universitet, ved Institutt for Helse- og Omsorgsfag (IHO).

Hensikten med forskningen er å få økt kunnskap om leger og sykepleieres tverrfaglige strategier overfor pårørende. Forskningens resultater kan senere anvendes til å designe prosesser som vil nyttiggjøre seg kunnskapen til å forbedre utkomme for pårørende.

Det er gitt tillatelse fra ledelsen ved .... til å benytte Intensivavdelingen ved .... som forskningsfelt. Det skal til sammen gjøres empirisk arbeid ved tre norske intensivavdelinger.

Forskningssubjekter er intensivsykepleiere og intensivleger tilknyttet intensivavdelingen, og som er involvert i arbeid med pasienters pårørende. Datamaterialet vil samles inn via deltakende observasjon og fokusgruppeintervju (intervju /dialog med 4-6 deltakere samtidig). Observasjonens hensikt er å vinne innsikt i hvordan sykepleiere og leger organiserer og gjennomfører sine tilnærminger til og kontakt med pårørende, og hvordan deres samarbeid om pårørende utvikler seg over den tiden pasienten er innlagt i intensivavdelingen. Intervjuenes hensikt er å få bedre innsikt i intensivsykepleiere og legers erfaringer fra pårørendearbeid, og hvilke tilnærminger de selv opplever som hensiktsmessige.

Tillatelse til observasjon er gitt fra avdelingens ledelse. Dere vil bli spurt om å være respondenter. Ved forespørsel vil det foreligge mer utfyllende informasjon om prosjektet, samt samtykkeerklæring. Tillatelse fra avdelingens ledelse anses som et felles samtykke til observasjon i avdelingen, men du kan reservere deg mot å bli observert ved å si ifra til undertegnede.

Ytterligere informasjon kan også fås gjennom å ta kontakt med stipendiat Nygaard i avdelingen, eller på mobiltlf. 99552152 eller epost Anne.Mette.Nygaard@uit.no

Prosjektet er tilknyttet UiT Det Arktiske Universitet, Institutt for Helse – og omsorgsfag (IHO), og er ledet av Førsteamanuensis Ranveig Lind, PhD, som også er hovedveileder. Biveiledere er Professor Berit Støre Brinchmann og Førsteamanuensis Hege Selnes Haugdahl.

Studien er har fått innvilget dispensasjon fra taushetsplikt for deltakende observasjon fra Regional komite for medisinsk og helsefaglig forskningsetikk (REK Nord 2016/1762) og er meldt til Norsk senter for forskningsdata (Prosj.ID 49672).

Med vennlig hilsen

Anne Mette Nygaard

Intensivsykepleier/Stipendiat

Postboks 6050 Langnes, N-9037 Tromsø / 77 64 40 00 / postmottak@uit.no / uit.no

Appendix 8

Forespørsel om deltakelse i forskningsprosjektet:

Physicians' and nurses' interdisciplinary strategies towards critically ill ICU patients' families – a qualitative study

Dette er et spørsmål til deg om å delta i et forskningsprosjekt som vil utforske legers og sykepleieres strategier og tilnærminger i arbeidet med intensivpasienters pårørende, og hvilke hensyn som tas i dette arbeidet. Bakgrunnen for studien er tidligere forskning på helsepersonell og pårørende. Pårørendes erfaringer fra kvalitative studier og fra tilfredshetsundersøkelser, viser at de er fornøyd med omsorg og behandling, men slik de ser det, finnes det forbedringspotensial i kommunikasjon og informasjon. Tidligere pårørende og tidligere pasient er brukermedvirkere gjennom hele forskningsprosjektet.

Vi vet ikke nok om hvordan leger og sykepleiere i intensivavdelinger tilnærmer seg pårørendearbeidet. Du forespørres fordi du er *anestesilege/intensivsykepleier*, og med minst to års klinisk erfaring fra intensivavdeling. Tre intensivavdelinger fra ulike sykehus deltar i studien.

Ansvarlig for forskningsprosjektet er Førsteamanuensis Ranveig Lind, intensivsykepleier PhD

Hva innebærer studien for deg?

Studien innebærer deltakelse i et fokusgruppeintervju sammen med 2-3 leger, 2-3 sykepleiere og to forskere. I fokusgruppeintervju går samtalen mellom deltakerne etter korte spørsmål fra intervjuer, som her ofte kalles moderator. Denne personen vil være stipendiat Anne Mette Nygaard. Hun er doktorgradsstudent (PhD) og en erfaren kliniker fra intensivavdeling. I intervjuet deltar Ranveig Lind som observatør/sekretær. Det er utarbeidet en intervjuguide som omhandler spørsmål om typiske møter med nyankomne intensivpasienters pårørende, videre forløp, informasjon som gis pårørende og kommunikasjon, kompetanse, samarbeid innen profesjon og mellom profesjonene og beslutningsprosesser. Intervjuet vil også ta opp spørsmål framkommet gjennom PhD-studentens deltakende observasjon i intensivavdelingen.

Hva skjer med informasjonen?

Intervjuene vil bli analysert med Grounded Theory som metodisk tilnærming. Brukerrepresentantene, en tidligere intensivpasient og en tidligere pårørende, vil bistå forskerne med innspill i analysen. Resultater fra studien planlegges publisert som artikler i internasjonale tidsskrift med fagfellevurdering, som foredrag og poster i internasjonale og nasjonale konferanser, og som populærvitenskapelige foredrag for å nå tidligere intensivpasienter og deres pårørende. Det vil ikke være mulig for andre enn du selv og de som deltok i fokusgruppen å identifisere deg eller arbeidsstedet i resultatene av studien når den publiseres. Deltakerne i gruppen vil bli anmodet om å forholde seg til det som blir sagt under intervjuet som om det var omfattet av taushetsplikt.

Mulige fordeler og ulemper

Å komme sammen med kollegaer med erfaringer fra å ha arbeidet med samme type pasienter og deres pårørende, kan bidra til at man i rolige omgivelser får gitt uttrykk for egne erfaringer og kanskje også lære av andres. Studien kan vekke minner fra situasjoner der arbeidet ble løst på en god måte, men man kan også risikere å bli påminnet mindre gode erfaringer.

Intervjuet planlegges gjennomført på et møterom på …………………, en hverdag, med varighet på ca. 1 time. Det gis dessverre ingen kompensasjon for tidsbruk som går med til intervjuet.

Frivillig deltakelse

Det er frivillig å delta i studien. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke til å delta. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side.

Rett til innsyn og sletting av opplysninger

Hvis du sier ja til å delta i studien, har du rett til å få innsyn i intervjumaterialet. Om du nå sier ja til å delta, kan du senere trekke tilbake ditt samtykke. Dersom du trekker deg fra prosjektet, kan du kreve å få slettet ditt bidrag i intervjuet, med mindre opplysningene allerede har inngått i analyser eller er blitt brukt i vitenskapelige publikasjoner. Dersom du senere ønsker å trekke deg, eller har spørsmål til prosjektet, kan du kontakte Ranveig Lind, tlf.: 911 84 108/ 77058285, Ranveig.Lind@uit.no eller Anne Mette Nygaard, tlf.: 99552152, Anne.Mette.Nygaard@uit.no

Personvern

Intervjuet vil bli tatt opp på digital lydopptaker, og deretter skrevet inn i word. Deltakerne vil bli gitt fiktive navn. Ingen andre personidentifiserende kjennetegn vil registreres. Alle data, også lydfiler vil bli lagret på passord-beskyttet område på UiTs forskningsserver. Lydfiler på opptaksenhet vil slettes umiddelbart etter overføring til PC.

Studien er ikke meldepliktig til Regional Etisk Forskningskomité for Medisinsk og Helsefaglig forskning (behandler ikke helseopplysninger eller biologisk materiale, jfr. Helseforskningsloven §10). REK har innvilget dispensasjon fra taushetsplikten for deltakende observasjon i intensivavdelingen. Studien er meldt til Norsk Senter for Forskningsdata SND.

Dersom du bestemmer deg for å delta i studien, kan din signerte samtykkeerklæring legges i vedlagte frankerte konvolutt adressert til prosjektleder Ranveig Lind, og sendes som vanlig post. Den kan også leveres til Ranveig Lind eller Anne Mette Nygaard ved intervjuets start.

Harstad 05.06.2018

Ranveig Lind	Anne Mette Nygaard
Prosjektleder	Stipendiat

Samtykkeerklæring

Jeg er villig til å delta i prosjektet

Physicians' and nurses' interdisciplinary strategies towards critically ill ICU patients' families – a qualitative study

Sted og dato		Deltakers signatur

Deltakers navn med trykte bokstaver,
Yrkesgruppe