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Abstract

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This thesis investigates, explores and describes critical care nurses' and family members' experiences of end-of-life care in an intensive care context. Both qualitative and quantitative methods were used. Data was collected through individual interviews with critical care nurses and family members, as well as questionnaires distributed to family members. The analyses employed qualitative content analysis, interpretive description, reflexive thematic analysis, and statistical analyses to provide a comprehensive understanding of the findings. The findings showed that critical care nurses view the integrity of patients as a fundamental component of quality care (studies I, II). However, the concept of integrity was considered elusive, with critical care nurses indicating that their own integrity is essential for recognizing and respecting the integrity of patients (study I). Ethical challenges encountered by critical care nurses ranged from decisions about life-sustaining treatments and the administration of pain relief to considerations regarding patient preferences and organ donation (study II). From the perspectives of family members, overall satisfaction with end-of-life care in intensive care units was reported (studies III, IV). Nonetheless, several deficiencies were identified, particularly a lack of attention to the individual needs, such as the emotional needs of family members. Also, those family members who rated their health as worse compared to a year ago, generally rated lower satisfaction in the decision-making sub-scale (study III). Additionally, family members frequently struggled to recognize the imminence of death and perceived that patients were suffering, despite the provision of pain relief as part of the end-of-life care (study IV).

Keywords

End-of-life, ethical challenges, family members, integrity, intensive care, critical care nurses, palliative care

List of Papers

This thesis is based on the following papers, which are referred to in the text by their Roman numerals.

I. Palmryd, L., Rejnö, Å. And Godskesen, T. (2021). Integrity at the end of life in the intensive care unit: a qualitative study of nurses' views. *Annals of Intensive Care*, 11(23), 1 – 10. Doi.org/10.1186/s13613-021-00802-y

II. Palmryd, L., Rejnö, Å., Alvariza, A. and Godskesen, T. (2024). Critical care nurses' experiences of ethical challenges in end-of-life care. *Nursing Ethics*, Vol. 0(0), 1 - 13. Doi: 10.1177/09697330241252975

III. Palmryd, L., Godskesen, T., Alvariza, A. and Rejnö, Å. (2025). Satisfaction with end-of-life care and self-rated health among bereaved family members; a descriptive cross-sectional study in an intensive care context. (Resubmitted September 25, 2025, in BMC Palliative Care).

IV. Palmryd, L., Alvariza, A., Rejnö, Å. and Godskesen, T. Losing someone close to death in ICU: A thematic analysis of bereaved family members' experiences of end-of-life care. (Resubmitted October 13, 2025, in Intensive and Critical Care Nursing).

Innehåll

Abbreviations

Abbreviation	Term
CCN	Critical Care Nurse
FS-ICU	Family Satisfaction with Care in the Intensive Care Unit
FS-ICU/Care	Family Satisfaction with Care
FS-ICU/DM	Family Satisfaction with Decision-making
ICU	Intensive Care Unit
RAND-36	RAND-36 Health Status Inventory
SPSS	Statistical Package for Social Sciences

Preface

In my career as a registered nurse, I have worked in emergency medical health care and as a specialist nurse in anesthesia and intensive care. Becoming a doctoral student was not a planned path. After several years as a specialist nurse, I graduated with a Degree of Master of Science (120 credits) with a major in Nursing Science where I conducted a study with the aim of highlighting and describing critical care nurses' experiences of patients' privacy in a postoperative unit. The findings showed that patients' privacy was often perceived as important by critical care nurses and that the integrity of the patient was given a lot of attention. However, I wanted to deepen my knowledge in the field based on these results so, together with my future supervisors, a study was conducted on how critical care nurses perceived and maintained patients' integrity during end-of-life care in an intensive care context. It is this study that has formed the basis of this thesis. Furthermore, my experience from working as a critical care nurse during a pandemic, with critically ill patients rapidly approaching death and often without family members being present, has made me interested in the multifaceted nature of life. The challenges of this period have made it clear that it is important to understand how end-of-life care is experienced, from the perspectives of critical care nurses and family members. As a critical care nurse, I have reflected on how other critical care nurses perceive and respond to the challenges that arise in their interactions with patients nearing the end of life and how they provide support to family members. I have also thought about how family members perceive the care and their encounters with critical care nurses and other healthcare professionals. With this background, my desire is to investigate how critical care nurses and family members of patients at the end of life in an intensive care context perceive the care given.

1. Introduction

This thesis focuses on end-of-life care in intensive care and has its place in the research field "The individual in the Welfare Society".

Historical reflections on welfare access reveal that as early as 250-350 AD, deaconesses provided essential support – offering water to the thirsty, food to the hungry, and care to the sick. During the Middle Ages, the Christian church extended its compassion to those who were chronically ill, disabled, or unable to care for themselves, embodying a tradition of mercy and support (Narayanasamy, 1999).

In Sweden, the healthcare system, the social insurance system, and health insurance has been under development for a long period (Rothstein, 2010). Since the 16th century, there has been a rapidly growing state with responsibility for the economy, politics and spirituality (SOU 1993:82). Further, during the 18th century, insurance was created with savings banks for workers, support for families affected by illness or death, and for building widow's and old men's houses. In the event of problems with livelihoods, such as illness, disability or unemployment, help was offered by voluntary organizations and by the municipality or state and health care. However, criticism of voluntary organisations arose because poor care was considered degrading to the needy, and such charity often created a debt of gratitude and a dependency between the donors and the recipients. To promote equality and reduce reliance on poor relief and charity, a key social policy reform introduced general public grants. This shift sparked debate about the distribution of social responsibility among families, society, the state, and municipalities - an issue that gained prominence during the 1928 parliamentary elections and the rise of Social Democratic social policy (SOU 1993:82).

The social policy reform achieved its goal for contemporary health care, which was to create preventive care to reduce the need for health care and, in the event of illness, health care would be given under equal conditions (SOU 1993:82). This reform is still in place today and pervades modern Swedish healthcare, which has been further developed to specific areas of care, where intensive care is the most advanced level of care.

2. Background

2.1. Intensive care

2.1.1. Development, guidelines and criteria for admission

It is now more than 7 decades since the development of intensive care units, hereafter ICU, started in Scandinavia. The concept began with the polio epidemic, which resulted in hundreds of patients with respiratory failure. These patients needed artificial ventilation and in Copenhagen, medical students were utilized to hand ventilate the patient's lungs (Kelly et al., 2014). In Stockholm in 1953, patients with respiratory failure were treated with the Engström Universal Respirator, which provided supplementary oxygen. The treatment with artificial ventilation of the lungs using a respirator led to a significant reduction in mortality. The addition of knowledge about the importance of controlling parenteral nutrition, water and mineral balances meant that intensive care could begin (Engström, 1954). The pioneers of intensive care were in the US, where ICUs were developed through medical and technological advances and with critically ill patients with extensive and complex care needs being cared for in dedicated wards in order to specialize the treatments (Tang & Sun, 2011). In Scandinavia, the anesthesiologist Björn Ibsen started the first ICU in Denmark in 1953, and he is considered the "father" of intensive care in Europe. Sweden followed these developments and started ICUs in Borås and at Karolinska Hospital (Kelly et al., 2014). Since then, intensive care has undergone significant development and is today well defined in terms of medical knowledge and technological equipment (Marshall et al., 2017).

The Guidelines for Swedish Intensive Care are produced by the Swedish Association for Anesthesia and Intensive care (SFAI, 2024), partly based on recommendations from the European Society of Intensive Care Medicine (ESICM, 2025). The Swedish national guidelines aim to provide recommendations for the organizational standards and structure, working methods and competence needs in Swedish intensive care. In the Swedish healthcare system, intensive care is currently divided into three levels (SFAI, 2024). Intensive care is provided by district hospitals at level I, which generally cares for patients with acute failure in all organ systems but lack most of the

surrounding resources. This is followed by county hospitals at level II, which provide intensive care for patients with serious organ failures but lack the most advanced resources. The county hospitals at levels I and II do not have the most advanced monitoring and treatment methods so, when these are required, patients are transferred to ICUs with more specialized medical resources. Intensive care at level III is provided by university hospitals, which are responsible for the most qualified monitoring and treatment methods available for different types of organ failure, often with specialized ICUs. According to the Guidelines for Swedish Intensive Care (SFAI, 2024), the treatments provided either support or replace failing organ functions. Organ support therapies include interventions, such as the administration of moderate doses of circulatory support medications and non-invasive ventilation, aimed at stabilizing physiological function. When organ function is severely compromised, organ replacement therapies are initiated. These include invasive mechanical ventilation, continuous renal replacement therapy, and extracorporeal membrane oxygenation, known as ECMO. Intensive care may also serve the purpose of preserving organ function in potential organ donors.

The criteria for admission to an ICU are based on the presence of potentially reversible conditions that necessitate a level of monitoring and treatment beyond what can be provided in other healthcare settings. Furthermore, the provision of ICU care needs to be of clear benefit to the patient, ensuring that continued life is considered meaningful from the patient's perspective (ESICM, 2025). Importantly, the patient needs to either consent to the treatment or be reasonably presumed to accept it (SFAI, 2024). Each patient's intensive care needs are assessed individually, considering the severity of underlying medical conditions, vital physiological parameters, the necessity for continuous monitoring and advanced treatments, as well as ethical aspects. Typically, patients admitted to the ICU have life-threatening conditions, usually in the lungs, cardiovascular system, or kidneys, that need to be treated with life-sustaining treatment (Marshall et al., 2017). Life-threatening conditions refer to conditions in which the severity of the illness poses an immediate risk to a person's survival, while life-sustaining treatment refers to treatments performed in situations where the primary goal is to preserve life by supporting or replacing essential physiological functions (SOSFS 2011:7). The overarching aim for patients in need of life-sustaining

treatment is clear: to do everything that is possible to maintain vital functions and increase the possibility of survival for critically ill patients. To achieve this, the ICU delivers the most technologically advanced and resource-intensive interventions available, tailored to manage life-threatening conditions resulting from critical illness (Marshall et al., 2017).

Being a patient in need of intensive care typically indicates the failure of one or more organs, leading to complex medical conditions that necessitate resource-intensive treatments (Minton et al., 2018). These conditions often require close monitoring (Eddahchouri et al., 2022), specialized interventions, and the use of advanced medical technologies to stabilize the patient's condition and support organ function (Lee et al., 2016). Within the first 24 hours of the patients' admission to ICU, decisions are made regarding the treatment strategy. These decisions may involve care being provided with full treatment without restrictions. Otherwise, the decisions may include withholding life-sustaining treatment, meaning that certain interventions are not initiated, or withdrawing life-sustaining treatment, meaning that ongoing interventions are interrupted (SFAI, 2012). Among the adult patients admitted to a Swedish ICU during 2024, treatment limitations were documented as follows: approximately 17.0% received a decision to withhold life-sustaining treatment, 0.3% received a decision to withdraw ongoing life-sustaining treatment, and in 5% of cases decisions were made involving both withholding and withdrawing life-sustaining treatments (SIR, 2025).

While medical and technological treatments in ICUs aim to preserve life and improve health, they can also reduce a person's ability to be autonomous and make their own decisions. Patients in ICUs often experience that they are being forced into a dependent role caused by their physical deterioration and need of assistance from other people (Lykkegaard & Delmar, 2013; Yang, 2016). This dependency often leads to feelings of powerlessness (Lykkegaard & Delmar, 2013). Patients deprived of basic functions, such as the ability to breathe independently or communicate verbally due to respiratory support, and being dependent on medical technology and treatments, are often in a position where their survival depends on assistance from other people. This position of dependency can have a clear impact on their experience of lacking their own agency, and lead to them feeling powerless (Yang, 2016). Also, being dependent

on others is often described as uncomfortable or burdensome, and can create complex feelings of shame, and the loss of dignity and private boundaries (Lykkegaard & Delmar, 2013). It may also create a sense of vulnerability, often caused by disorientation and confusion (Yang, 2016). The circumstances patients face during an ICU stay may contribute to the development of delirium, a condition characterized by disorientation, confusion, and disturbances in attention and awareness (Sakusic & Rabinstein, 2025; Savino et al., 2024). Delirium can be hypoactive with symptoms such as apathy, somnolence, withdrawal of attention to external stimuli (Kotfis et al., 2018), or hyperactive with symptoms characterized by restlessness or agitation (Springer, 2024). Delirium can be triggered or intensified by diseases, pain, medications or surgery (Wu et al., 2023). Environmental factors - immobility, sleep disturbances, the presence of urinary catheters, and medical procedures - also play a significant role in its onset (Sakusic & Rabinstein, 2025).

A proportion of patients do not survive their intensive care stay, and the characteristics of these individuals are often higher average age and greater incidence of impaired consciousness upon admission compared to those who survived (Siöland et al., 2024). Such patients frequently require end-of-life care to ensure comfort and dignity during their final stages of life (Bennett & Maccaroni, 2024). In 2024, the majority of the approximately 37,000 adult patients admitted to ICUs in Sweden – where the average length of stay was 2.7 days – showed clinical improvement and were subsequently transferred to lower levels of care, according to the Swedish Intensive Care Register (SIR, 2025). However, a proportion of patients did not survive. In 2024, approximately 6,400 (17.3%) patients died within 30 days of ICU admission, including around 3,100 (8.4%) deaths that occurred during the ICU stay (SIR, 2025). Looking retrospectively, between the years 2008 and 2022, approximately 58,680 (19.8%) of patients died within a 30-day period following admission to an ICU in Sweden (Siöland et al., 2024).

2.2. End-of-life care

2.2.1. Development, definitions and approaches

Traditionally, palliative care has not been integrated into the standard approach in ICUs, where the primary focus is on life-sustaining treatments aimed at managing acute conditions with hope and an expectation of recovery. In the ICU, when recovery for a patient is no longer achievable, and when further advanced treatment is unlikely to provide any meaningful benefit to patients, care shifts to what is referred to as end-of-life care (Kesecioglu et al., 2024). Notably, in the ICU, end-of-life care often takes place over a short period of time and may need to be adapted accordingly (Long et al., 2015). Generally, the concept of end-of-life care is defined as care in the final stages of a person's life, when death is expected within hours to days, and focuses on providing comfort, managing symptoms, and supporting the needs of the patient and their family members from a patient-centered perspective (Schüttengruber et al., 2022). In ICUs, end-of-life care follows a multidimensional approach that not only manages physical symptoms, but also offers comprehensive emotional and social support to both patients and their family members (Kesecioglu et al., 2024). It emphasizes the importance of making compassionate, informed decisions about the limitation of life-sustaining therapies and upholding the dignity of the patient throughout the dying process (Kesecioglu et al., 2024). However, the provision of end-of-life care in all healthcare, as well as in the ICU, should be guided by a palliative care approach. The care provided should be in line with the core principles of palliative care – promoting quality of life through symptom management, effective communication, and the support of family members, delivered by a multidisciplinary team (WHO, 2020).

Palliative care is an approach aimed at relieving symptoms, improving the quality of life for patients with life-threatening diseases, and providing support to family members (WHO, 1990, 2002). The World Health Organization (WHO, 2002) first defined palliative care as preventing and relieving suffering through early detection and treatment of pain and other physical, psychosocial and existential symptoms that may occur in the event of life-threatening illness. Nowadays, palliative care is emphasized as a global ethical responsibility in all health care, extended to encompass intensive care (WHO, 2020). Regardless of whether the

cause of suffering is severe organ failure, severe burns, acute trauma, or frailty in old age, palliative care may be needed and must be available at all levels of care (WHO, 2020).

A consensus-based definition of palliative care is presented by the International Association for Hospice and Palliative Care (IAHPC, 2018). This definition differs from the previous definition by WHO in that, instead of placing focus on life-threatening illness as an indication for the need for palliative care, it highlights that serious health-related suffering itself due to severe illness should be the incentive for palliative care. In the concept of serious illness, IAHPC includes acute or chronic illnesses and conditions that have the potential to result in long-term deterioration, leading to disability or death (Radbruch et al., 2020).

In end-of-life care, conversations are initiated after an overall assessment during which the benefit of possible treatment is weighed against the harm or suffering it may cause the patient. These conversations in ICU often involve critical decision-making about withholding, withdrawing or ending life-sustaining medical treatment (National Board of Health and Welfare, 2018). The aim of the end-of-life conversation is to have a dialogue about the patient's wishes regarding care, taking into account their condition and needs (Myburgh et al., 2016). End-of-life conversations are adapted according to the patient's degree of illness, cognitive ability, cultural background, and desire for participation (National Board of Health and Welfare, 2018). Sometimes, it can be challenging for the healthcare team to have end-of-life conversations with patients in ICUs. This is because some patients are unconscious due to sedation, making it impossible for them to make decisions about their own care and the level of treatment they would like (Feldman et al., 2022). Instead, family members may act as the patient's proxy and become the patient's voice, ensuring that the patient's wishes are respected when they are known or contribute knowledge about what the patient might want (Lind, 2019). Although Swedish law does not give family members the legal authority to make healthcare decisions on behalf of the patient, since that is the responsibility of physicians, they can voluntarily act as proxies and provide information about what they believe the patient's preferences might be. Also, family members of patients who are unable, or have reduced capacity, to provide informed consent, have the right to receive information and to participate in care-related decision-making alongside the patient (Ministry of Social Affairs, 2022). Being involved in

decision-making can range from simply being asked for consent to actively participating in discussions (Lind, 2019). Facilitating the participation of family members in end-of-life conversations and decision-making can improve their satisfaction with the care provided, while fostering a sense of engagement and appreciation for being included in decisions concerning their close person (Sharieff et al., 2024). While doing so, family members might need support to process the decisions being made, even if it is the physicians who make the final decision (Bandini, 2022).

When discussing the transition to end-of-life care with family members in ICU clinical settings, it is essential to clearly explain the current medical situation – with the level of detail tailored to the family members' wishes. Equally important is allowing them time to process the information, ask questions, and come to terms with the situation in their own time (Strøm Darfelt et al., 2025). The transition to end-of-life care in ICUs is guided by the Swedish Guidelines for Life-Sustaining Treatment (SFAI, 2012) and the Consensus for Scandinavian end-of-life care regimes in Intensive Care Units (Strøm Darfelt et al., 2025). According to current guidelines, extubating should be considered to prevent a prolonged dying process, and medications should be administered solely for the patient's comfort or with a palliative intent, particularly when death is anticipated within hours or a few days (Strøm Darfelt et al., 2025). When the patient's life-sustaining respiratory support is withdrawn, spontaneous breathing without supplementary oxygen should be attempted if it does not cause increased suffering for the patient. Furthermore, sedation, pain relief and anxiolytics should be carefully titrated to ensure comfort. Dialysis should be discontinued, pacemakers may be deactivated, and other interventions such as medications, blood transfusions, nutrition and fluid administration should be discontinued. Finally, monitoring and alarms should be reduced to a minimum or discontinued (SFAI, 2012).

2.3. The role of critical care nurses in the ICU

Critical care nurses, hereafter CCNs, play an important role in the multi-professional team in ICUs since they coordinate highly specialized care and treatments for patients. The care is considered complex since it often includes managing highly technological equipment such as ventilators, dialysis machines, as well as extra corporeal membrane oxygenation, known as ECMO (Cho et al.,

2025). At the same time, CCNs provide nursing care to patients who are dependent on their care (Piredda et al., 2024). In this context, patient dignity takes on particular importance, since critically ill individuals are often vulnerable, exposed, and reliant on nurses for even their most basic needs - situations that may be experienced as violating. As a result, dignity is upheld as a core ethical value in all aspects of care (Nyholm & Koskinen, 2017).

The main role for CCNs includes being close to the patients 24 hours a day to provide specific nursing competence when carefully observing and attending to their care needs. The patients are often critically ill and in need of life-sustaining treatments so, through their observations, CCNs support the patients' survival (SFAI, 2024). The workload for CCNs caring for critically ill patients who require intensive support is frequently high, since these patients often suffer from traumatic injuries and multiple organ failures involving vital organs such as the heart, brain, kidneys, or lungs (Nogueira et al., 2014). Through being continuously present, the CCNs can often perceive changes that occur in a patient's condition (Kissel et al., 2025). This is primarily through monitoring patients' vital parameters, such as hemodynamic monitoring, which is a routine yet vital aspect of patient care that demands close attention and precision. During hemodynamic monitoring, CCNs uses key indicators of patients' blood circulation and cardiac function, such as blood pressure and central venous pressure, which are important aspects in their assessment of patients' fluid responsiveness (Barstow et al., 2023; Jeshvaghani et al., 2021). When deterioration is observed and patients need increased interventions or life-sustaining care performed by the multiprofessional team, the CCNs' responsibilities are focused on collaboration. In emergency situations, CCNs are responsible for managing respiratory support and medications, while also performing nursing interventions to help stabilize the patient (Bjurling-Sjöberg et al., 2017).

The specific care provided by CCNs in their daily care routines in ICUs includes being responsible for the medication required for sedation and pain relief, both to give comfort for patients at rest and prior to examinations and treatments. Achieving the optimal level of sedation – ranging from light to deep sedation – is often challenging due to the highly individualized nature of patient needs (Engström, 2016). Maximizing pain relief is of utmost importance but can pose an ethical challenge for CCNs as there is a risk of inadequate pain relief or opioid

overdose (Dieudonné Rahm et al., 2021). Supporting the patients' breathing is another component of CCNs activity (Fasoi et al., 2020), since many patients are intubated to address respiratory failure (Cederwall et al., 2021). CCNs manage the airway during respiratory support, a task that demands precision and fosters trust, as patient's lives often depend on their expertise (Fasoi et al., 2020). The nursing care of patients undergoing dialysis for renal failure is also a common aspect of care. CCNs typically manage the dialysis machine and perform the procedure, which requires particular attention (Cho et al., 2025). The dialysis machine has been described as requiring a lot of attention and this negatively affects the time CCNs have available for caring for patients (Tunlind et al., 2015). In addition, CCNs are also responsible for the care of patients receiving ECMO, a highly complex and resource-intensive therapy (Cho et al., 2025). It has emerged that the equipment used in intensive care sometimes creates stress and frustration among the CCNs due to too much focus being given to technology rather than to the patients (Chang et al., 2024; Yan et al., 2025). The physical environment in ICUs can also contribute to the stress for CCNs, particularly when their colleagues are not within visible range (Keys & Fineout-Overholt, 2024).

Within the complex environment in ICUs, CCNs often face challenges of an ethical nature. Ethics encompasses different ways of interpreting moral life (Beauchamp & Childress, 2019). In this thesis, ethical challenges are defined – following Beauchamp and Childress (2019) - as circumstances where a person faces conflicting moral obligations and cannot fulfill all of them simultaneously. Such ethical challenges may arise for CCNs when differing perspectives come into play, for example, when family members request interventions that are not in line with the patient's best interest or are insufficiently engaged in critical decision-making factors that contribute to delays and potentially increase patient suffering (McAndrew & Hardin, 2020). Respecting a patient's integrity is widely considered to be a fundamental ethical aspect of health care (ICN, 2021). While providing nursing care for critically ill patients in ICUs, CCNs need to be aware of, and observant about, patients' integrity. When possible, it is important to consider a patient's values and preferences regarding personal boundaries. Typically, the ICU patient's preferences and condition guide the CCNs in the planning and implementation of care, except in cases where the patient lacks insight into their own care (Bjurling-Sjöberg et al., 2017). Integrity in health care can, according to

Andersson (1994), be described as an ethical concept centered on respecting patients' values and autonomy. It can be understood in three key ways: wholeness, which reflects a patient's sense of self shaped by their illness and life experiences; personal sphere, which involves respecting the patient's boundaries, values, and wishes; and self-determination, which upholds the patient's right to make decisions, provided they do not infringe on the rights of others (Andersson, 1994). In ICUs, CCNs face particular challenges with protecting a patient's integrity, such as maintaining privacy and protecting the patient's body from the gaze of others (Ozdinc et al., 2023), mainly due to the open environment and shared nature of the ICU setting (Paredes-Garza et al., 2022).

For CCNs, the transition to end-of-life care represents a shift towards palliative care, where their primary focus is the physical, psychological, emotional and family-related palliative nursing care (Omidi et al., 2025). The final hours of life are often considered profoundly significant, and CCNs highlight that a common fear among patients is dying alone (Jang et al., 2019). End-of-life care, therefore, encompasses reassurance through the presence of CCNs, emotional comfort, and spiritual support. CCNs play an important role in accompanying the dying patients through this process and ensuring that they are not left alone but are supported in the final moments of life (Jang et al., 2019). End-of-life care minimizes the active management of medical interventions and, instead, allows the natural progression of the patient's condition to continue. Here, the goal is to create an environment where patients are free from pain, anxiety, and distress (Kesecioglu et al., 2024). In this context, the emphasis moves away from intensive monitoring of vital signs, such as circulation, elimination, and neurological function, and towards a care that prioritizes the patient's comfort, dignity, and overall well-being (SFAI, 2012). During this transition, CCNs follow a treatment strategy which, for example, includes the ventilator support switching from respiration with oxygen to air, and with the lowest possible ventilator support, as long as this does not cause increased suffering for the patient (SFAI, 2012).

CCNs also provide end-of-life care for patients where organ donation may become a possibility (Vanholder et al., 2021). Caring for a potential organ donor is noted as a complex and emotionally challenging task (Moghaddam et al., 2018). This experience is described by CCNs as multidimensional, where grief over the loss of life is interwoven with gratitude for the donated organs and the hope they

bring continued life for someone else (Gripewall et al., 2022). It is essential that the care provided is dignified and grounded in respect for the organ donor and the family members (Simonsson et al., 2020). In this context, the focus of care shifts from intensive care efforts to save the patient's life to preserving the viability of their organs so they may offer life-saving organs to others. This transition requires not only clinical expertise but also emotional resilience, since CCNs need to navigate the delicate balance between loss and the potential for renewed life through organ donation (Moghaddam et al., 2018). When caring for potential organ donors, each encounter with family members is experienced as unique and shaped by the emotional intensity of the situation. The role for CCNs is ambivalent and complex because on the one hand, they provide compassionate support to grieving family members, and on the other, they must act swiftly and systematically to preserve the donor's organs for transplantation (Gripewall et al., 2022).

2.4. Being a family member of a patient at the end of life in the ICU

An integral part of the care provided by CCNs in ICUs during end-of-life care involves encounters with family members to ensure that the treatment and care align with what the patient would have wanted had they been able to make decisions (Noome et al., 2016). In this thesis, an extended definition of family is used, which is "a group of individuals who are bound together by strong emotional ties, a sense of belonging, and a passion for being involved in one another's lives" (Wright & Bell, 2009). These encounters include opportunities for family members to state their understanding, express their thoughts and emotions about death, and be listened to (Buscemi et al., 2024). Sometimes patients have previously expressed their wishes about their care; however, it can become ethically problematic when family members do not want to follow the patient's wishes, for example in questions concerning organ donation, but instead express their own wishes (Sun et al., 2024). When information from family members is absent, CCNs may encounter significant ethical challenges in ensuring that the care provided aligns with the patient's wishes. This situation becomes even more complex when no family member is available, since there is nobody to communicate the patient's preferences. Consequently, meetings with family

members play a crucial role in enabling CCNs to better understand and address the patient's individual needs for support and information (Larsen et al., 2022).

Family members who are in the ICU to stay close to the patient nearing death can sometimes perceive the environment as intimidating due to the presence of many unfamiliar and technologically advanced devices (Hartog & Reinhart, 2018; Timmins et al., 2018). The use of highly technological treatment with, for example, a ventilator symbolizes the efforts to maintain the patient's life but at the same time indicates the patient's proximity to death to family members. Therefore, family members may perceive that ICU care means that all available resources are being offered to save the patient (Choi et al., 2025).

In end-of-life care, family members may endure a difficult time coping with their impending loss, while at the same time dealing with their own grief. This may include a patient's short and rapid dying process when death occurs suddenly without warning due to acute illness or accident. Family members often want to be with the patient and have the chance to say a last goodbye, which might be of importance for the subsequent grieving process (Bandini, 2022). Family members may experience emotional distress because they lack control over the care of the patient and therefore worry about them being uncomfortable at the end of life (Chen et al., 2020). Being present and experiencing support through participating in the care and contributing knowledge about the patient's preferences has been shown to be of great importance for family members' satisfaction with the care provided (Atri et al., 2024; Salins et al., 2024). Family members have been found to sometimes be able to gain a greater sense of participation in care when they have noticed changes in the patient, such as physiological values seen on monitors, the patient's skin color, and by observing the type of treatment patients received in the ICU (Coombs et al., 2016). Previous studies show that if family members do not feel they are allowed to participate in the care, there is a risk that they may experience negative stress (Chen et al., 2020; Fridh & Åkerman, 2020; Maccallum & Bryant, 2019). Additionally, family members may experience anxiety and depression caused by the critical situation of their close person (Onrust et al., 2022). The likelihood of developing psychological symptoms—such as stress, anxiety, and depression—is highest among family members when the patient has a prolonged ICU stay, dies during hospitalization, or when the family member is female (Zhang et al., 2025). Additional factors for family members include

financial insufficiency, prior use of antidepressants within the year before the patient's critical illness, and the level of perceived social support (Hung et al., 2025). Furthermore, stressful symptom states have been associated with poorer physical and mental health outcomes among bereaved family members (Wen et al., 2025).

Family members should be supported in coping with difficulties during and after the death of a close person. Such support should be provided to increase their ability to deal with grief and prevent illness (Ministry of Social Affairs, 2022). The support of family members is included in the concept of palliative care, for example, through conversations during the trajectory of the illness and over a couple of months after the patient's death (Strøm Darfelt et al., 2025). These conversations can be challenging for family members. However, encouraging open and compassionate communication about illness prognosis can help alleviate any concerns. For family members, the conversations allow them to share their thoughts and feelings in the time before, during, and after the death. They can also serve as an opportunity for family members to be referred for continued support if necessary (National Board of Health and Welfare, 2018).

3. Theoretical approach

3.1. Ethics of Care

Ethics of Care is a moral theory that emphasizes relationships, emotional engagement, and context-sensitive caring, rather than the principles of justice (Gilligan, 1982). Rooted in feminist ethics, it challenges traditional ethical theories that prioritize abstract principles, such as autonomy. Instead, it refers to ethical norms regarding what may be morally right or admirable when carrying out practical actions, for example in nursing (Gilligan, 1982). The Ethics of Care underscores the importance of relational values (Gastmans, 2013). By focusing on the nuances of human relationships, and the responsibilities they entail, this theory provides a valuable lens through which to examine moral dilemmas in various contexts, including ICUs where patients are often sedated, intubated, and otherwise unable to express their wishes and preferences. The nurse's role extends beyond the medical interventions and life-sustaining technologies. It involves providing empathy and care that respects the patient's dignity, values, and unique life-circumstances (Gastmans, 2013).

The Ethics of Care, as described by Lindemann (2019), comprises three components that collectively foster responsible nursing practice from a feminist perspective. These components emphasize the importance of nurturing relationships, engaging with patients' autonomy, and taking the individual into account.

The first component of the Ethics of Care (Lindemann, 2019) is that caring both requires and is an expression of a *caring relationship*. It includes providing personal care with genuine concern for the individual's best interest. It is crucial to care about the person you are looking after to prevent caregiving from becoming impersonal, cold, or self-serving. Lindemann (2019) provides an illustrative example: imagine your elderly father's house is in disarray, and he hasn't been eating properly over the last period of time. To avoid appearing neglectful, you hire a housekeeper, but you do not visit your father or think about him much, except when paying the housekeeper's salary each month. While you are technically taking care of your father, you are not doing so in a caring manner.

True care involves feeling concern for the person being cared for, meaning that a caring relationship engages emotions. The Ethics of Care (Lindemann, 2019) places strong emphasis on ensuring that everyone has a voice and is listened to attentively and respectfully. This approach highlights the importance of being responsive in relationships by paying close attention, listening actively, and addressing the needs of the individual. This responsiveness fosters a deeper connection and ensures that care is both meaningful and effective. Sometimes, caring well also means expressing your own emotions such as anger, grief, or frustration, as these emotions will help you stay connected to the person in your care.

The second component of the Ethics of Care (Lindemann, 2019) emphasizes the fact that *a caring relationship requires engagement with another's will.* This means that providing care should be based on the individual's wishes rather than the caregiver's requirements. When you care about someone, you interact with them not merely as an object of your care but as a person with their own wishes, intentions, and desires. You do not impose your own will on the person you are caring for, as that would be an abuse of the power you hold over them. This ethical stance advocates that the patient's own will, when it can be meaningfully discerned, should guide clinical decision-making and the provision of care. To prevent any abuse of power, it is advocated that caregivers practice engrossment, which involves paying close attention to the feelings, needs, and wants of those you care for, and that your own needs are set aside, according to Lindemann (2019). Engrossment is a way of opening yourself up to the person you care for, allowing yourself to be fully attuned to their experiences, who they are, and what they desire.

The third component of the Ethics of Care (Lindemann, 2019) concerns the necessity of *paying attention to the particular* rather than being guided by abstract thinking. With an ethics of care approach, interpersonal relationships are prioritized and information about the details and concreteness in the narratives are sought. By thinking about a person in particular, rather than about morality in general, you may provide the person with morally admirable care. To illustrate the component of paying attention to the particular person according to Lindemann (2019), I will give an example that is relevant to intensive care. Imagine the care of a critically ill patient receiving life-sustaining interventions. During care, the

patient develops delirium, caused by the critical situation. As a CCN, you value the principle of respect for patient autonomy highly and believe that sedation significantly compromises the person's ability to make autonomous decisions. You also believe that it is ethically inappropriate to trivialize the delusions the patient is experiencing due to delirium. During your shift, you observe the patient engaging in a lively and joyful interaction with what appears to be a figure the patient sees on a patterned privacy curtain next to the bed. Based on your commitment to not reinforce the delirium, a course of action might be to gently explain that the experience is not real. However, you recognize that at this particular moment, the delirium is neither painful nor harmful; the patient is content and emotionally calm. Balancing your ethical beliefs with the patient's immediate well-being, you choose not to intervene and allow the interaction to continue.

4. Rationale

The end-of-life care approach emphasizes comfort, symptom management, and support for patients and their family members. In end-of-life care, CCNs often face ethically challenging situations with life and death implications. These circumstances bring ethical considerations to the forefront of clinical practice. Among these challenges, the concept of integrity plays a crucial role. Ethical challenges related to integrity raise important questions – not only about how integrity should be understood and maintained within the clinical context, but also about how it can be preserved in morally demanding situations. There is a lack of comprehensive understanding regarding the ethical challenges that CCNs face in end-of-life care in ICUs. Highlighting these issues is essential to empower CCNs in addressing the needs of patients and their family members with an ethical approach.

Family members of critically ill patients in ICUs are in a vulnerable position, often experiencing emotional distress as their close person hovers between life and death. As the patient's condition deteriorates and they approach death, the need for support often increases. In these critical situations, CCNs may encounter ethical challenges, particularly when the needs of patients and family members are unclear or difficult to interpret. It has been previously noted that when support is inadequate or absent, the grieving process may intensify, potentially leading to prolonged grief that can negatively impact on the long-term health of family members. Consequently, there is a need to understand how family members experience end-of-life care and how they assess their own health during this emotionally demanding period, so that CCNs can provide high-quality end-of-life care that acknowledges and supports the family members' need for support.

This project addresses the need to strengthen CCNs' ability to provide compassionate support to both patients and their family members during end-of-life care in ICUs. By focusing on the ethical challenges of nursing practice, the project seeks to contribute to improved care experiences and outcomes for family members facing the death of a close person in the ICU. Strengthening CCNs' ability to recognize and respond to family members' needs for support is essential in order to foster compassionate support during some of the most emotionally challenging moments in clinical practice.

5. Overall aim

The overall aim of this thesis was to explore end-of-life care in the intensive care context from the perspectives of CCNs and bereaved family members, and to examine the health outcomes experienced by family members following the patient's death.

5.1. Specific aims

I To explore how nurses perceive and maintain the integrity of patients during end-of-life care in the ICU setting.

II To explore the ethical challenges that critical care nurses encounter when caring for patients at the end of life in an intensive care context.

III To investigate bereaved family members' satisfaction with care, decision-making, patients' last hours of life and their own self-rated health in end-of-life care in an intensive care setting.

IV To describe bereaved family members' experiences of end-of-life care following the death of a close person in the ICU.

6. Methods

6.1. Design

The four studies of this thesis are presented in Table 1. The first study, which explored CCNs' experiences of patient integrity at the end of life, revealed that they encountered significant ethical challenges in care. These insights informed the design of Study II. Subsequently, findings from the CCN studies showed that family members also encountered challenges with the care provided. To gain deeper insight into family members' experiences of end-of-life care, Studies III and IV were planned.

Table 1. Overview of the study's design and methods.

Study	**Design**	**Method**	**Participants/ Data collection**	**Data analysis**
I	Descriptive design	Qualitative method	16 CCNs Individual semi-structured interviews	Latent inductive content analysis
II	Interpretive descriptive design	Qualitative method	20 CCNs Individual semi-structured interviews	Interpretive description
III	Cross-sectional design	Quantitative method	141 family members Questionnaire	Descriptive and analytical statistics
IV	Descriptive design	Qualitative method	22 family members Individual semi-structured interviews	Inductive reflexive thematic analysis

6.2. Context

The eight participating ICUs were all located in Stockholm and provided care for adult patients. The ICUs provided specialized neuro-, central/trauma-, and thoracic intensive care, as well as general intensive care for patients with a wide range of medical conditions. The ICU care team usually includes intensive care physicians, CCNs and assistant nurses. Close collaboration concerning patient treatment was maintained between the intensive care physicians and the ward physicians from the patient's home unit. In addition, other professionals such as physiotherapists, counselors and religious leaders were available based on need. The number of beds in the ICUs varied. Usually, single and double rooms were available, although multiple patient rooms were also available in some units. All ICUs had unrestricted visiting policies which allowed family members to visit the patient frequently and also gave them access to a room dedicated to visiting family members where they could rest and eat.

Data collection for study I was conducted before the COVID-19 pandemic, while data collection for studies II–IV were conducted during the ongoing pandemic. The societal restrictions imposed during this period posed significant challenges to collect data through interviews and surveys for studies II–IV.

6.3. Participants and inclusion criteria

Studies I and II involved a total of 36 CCNs. The inclusion criteria required CCNs to be specialist nurses in intensive care, with a minimum of one year of professional ICU experience. Study I included 16 CCNs, 15 of whom were women and one man, with working experience ranging from one to 30 years, median 20 years. Study II included 20 CCNs, 18 of whom were women and two were men, with working experience ranging from one to 35 years, median eleven years.

Study III involved a total of 141 family members. The inclusion criteria were being a family member of an adult patient who had died in an ICU in Stockholm between July 1, 2021, and June 30, 2022; being documented as a primary contact person in the patient's medical journal; being over 18 years of age; and being proficient in the Swedish language. Of the family members, 88 were women and 53 were men, with an age range of 20 to 83 years and a median of 52 years.

In study IV, 22 family members participated. To be included in the study, participants had to meet the criteria for study III and also have returned the questionnaire and indicated their interest in participating in an individual interview.

6.4. Procedures and data collection

The data collection for the four studies began with me contacting the administrative head managers of each ICU via email. The email included information about the studies and an invitation for the departments to participate. Once approval was granted, I contacted the head nurses of the ICUs who acted as liaisons, passing information on to me about CCNs and deceased patients.

In studies I and II, the head nurses of each ICU assisted by distributing invitation letters to the CCNs. The letters contained information about the study and my contact details. CCNs interested in participating contacted me to schedule an interview.

In Study III, I initiated data collection by contacting the head nurses at the ICUs who then provided data on patients who had deceased during the inclusion period. The data collection continued with a search for contact information for family members through the deceased patients' medical records between January 2022 until February 2023. I contacted the documented primary family members by telephone with an invitation to participate by completing a questionnaire available in both digital and paper formats. A total of three contact attempts were made by me, consisting of two telephone calls and one text message. The first contact was made no earlier than four months after the patient's death. Family members who expressed interest in participating provided their postal address or email address to which the questionnaire was sent.

In study IV, the first 50 participants from the questionnaire study (study III) were invited to participate in an interview study. During the initial four months of data collection, 37 of these individuals expressed interest in being interviewed. Once sufficient information had been collected, the interview option was removed from the survey. I contacted family members who had expressed interest in being interviewed in the questionnaire. Contact was made via email or telephone to

inform them about the aim and method of the study and to ask if they wished to participate.

6.4.1. Interview studies I, II and IV

Qualitative methods with individual semi-structured interviews were used for data collection in studies I, II and IV. All interviews in the qualitative studies were personally conducted by me. For each study, a semi-structured interview guide was designed, including open-ended questions, based on literature and clinical experience in intensive care and palliative care. The interview guide in study I was created by me and my supervisor TG together, while the interview guides in studies II and IV were created by me in dialogue with TG. The interview guides focused on how to maintain patients' integrity at the end-of-life (study I), ethical challenges in end-of-life care that CCNs encounter in intensive care (study II), and family members' experiences of end-of-life care in an ICU (study IV). Pilot interviews were conducted to ensure that the interview guides for each study were comprehensive and understandable. In study I, the pilot interviews led to modifications and improvements in the interview guide. In study II, the pilot interviews resulted in the merging of two similar questions into one, while in study IV they led to changes in the wording of a few questions. In the interviews, follow-up questions, such as "Can you tell more about that?", were used to develop and deepen the answers when necessary. All interviews were audio-recorded and transcribed verbatim.

6.4.2. Questionnaire study III

A quantitative method with a questionnaire was used to collect data in study III. The procedure began with me seeking approval for the unit's participation from the administrative head managers of each of the seven included ICUs. After approval, the head nurses of each ICU acted as contact persons for me and forwarded information about the patients who died during the inclusion period. I was then able to obtain information about the names and telephone numbers of bereaved family members from the deceased patients' medical records. I personally contacted family members by telephone and provided information about the study. Those who met the inclusion criteria and were willing to participate received written information about the study from me along with the questionnaire. The questionnaire could be completed via a digital link or in paper

format; family members received a link via email if they chose the digital option. For the paper format, I sent the questionnaire by post together with a pre-stamped envelope.

The parts of the questionnaire that were used in this thesis are presented below. These included demographic questions about the family members such as sex, age, and reason for the deceased persons' stay in the ICU; the instrument Family Satisfaction with Care in the Intensive Care Unit, FS-ICU 24, which served as the primary instrument of the questionnaire; three items from the instrument FS-ICU 24R; two items from the instrument RAND-36; and open-ended questions where family members could develop their answers and add further information. The questionnaire concluded with a question about whether the family member might consider participating in an individual interview study at a later time. The questionnaire was estimated to take about 30 minutes to answer.

The instrument FS-ICU 24 (FS-ICU.org, 2006) was created by Heyland and Tranmer (2001) with the aim of increasing the quality of intensive care. The English version has been validated showing that the instrument was considered reliable (Wall et al., 2007). A Swedish translation was completed by Söderström (2005); however, this version has not been formally validated and is used as such in the present study. The FS-ICU 24 consists of two subscales: *FS-ICU Care* consisting of 14 questions related to satisfaction with patient care, interactions with healthcare professionals, and support tailored to individual needs; and *FS-ICU Decision-Making* consisting of ten questions related to information provision, the availability of support, and involvement in the decision-making process. A further development of the instrument has been made, FS-ICU 24R (FS-ICU.org, 2019), although this has not been validated, and three questions covering family members' experiences of participation during patients' last hours of life have been used from the updated version.

Two questions from the instrument RAND-36 that measure health and function in everyday life were included based on the WHO's definition of health with a focus on physical, mental and social well-being (Hays & Morales, 2001). The instrument RAND-36 has been translated into Swedish, and validation has shown that it is useful (Orwelius et al., 2017).

Each section was followed by open-ended questions where participants could develop their answers and add further information. The questionnaire concluded with a question about whether they might consider participating in an interview study at a later time.

6.5. Analysis

This chapter provides an overview of the analysis used in the studies.

6.5.1. Qualitative analysis

The qualitative studies employed analytical methods commonly used in nursing research. These methods were thoughtfully selected and adapted by me to meet the specific aims of each study, particularly in terms of the required depth and level of interpretation.

Study I employed qualitative latent inductive content analysis (Graneheim & Lundman, 2004), which enables interpretation at multiple levels – both manifest and latent. Due to the limited research on CCNs' experiences of patients' integrity in end-of-life care in an intensive care setting, this method was chosen by me to allow a broader interpretation. I conducted the analysis from the latent level, which offered a comprehensive understanding of how patients' integrity was perceived and maintained in practice. In the analysis, I followed the steps of qualitative content analysis by Graneheim and Lundman (2004). The analysis began by reading the transcribed interviews several times to capture the depth of the content, and the last author read six interviews. During the reading, meaning units that corresponded to the aim of the study were marked by me, and then collaboratively selected and condensed into a shortened version with the central meaning intact by all authors. In the next step, I coded the meaning units and then grouped them into categories. The final categorization was discussed in the research group until consensus was reached.

In study II, the analysis was inductive, using the specific methodological phases of Interpretive Description (ID) to guide the process (Thompson Burdine et al., 2021; Thorne, 2016). This analysis methodology was chosen by me for its capacity to support a deep and nuanced interpretation of CCNs' experiences with ethical challenges, as conveyed through coherent narratives. The analysis applied ID to

explore and reconstruct how CCNs understood and expressed ethical concerns – what they identified as challenges and what rendered these challenges ethically significant. The focus remained on detailed, real-life accounts in which CCNs described ethically challenging situations, offering insight into their ethical reasoning and judgements. In the analysis, I began by reading the transcripts in parallel with listening to the recorded interviews, and the last author read six transcripts. Text units that were closely related to the study's objectives were then selected by me for further analysis. When reading the transcripts and selecting text units, my preconceived knowledge was included in the process. In the following analysis process, I placed great importance on preserving the essence of the stories as described by Thompson Burdine et al. (2021). In the subsequent phase, I interpreted the text units, which were also discussed within the research group. Through this process, patterns of similarities and variations in the data were identified. Here, ID's interpretive design enabled me to consider the variations that emerged in the data with nurses' experiences and identify shared realities (Thompson Burdine et al., 2021). These were then organized by me into segments with similar content, forming the initial codes, which I discussed with the last author. From the synthesis of these codes, the research team was able to discern recurring patterns and themes in the data. Throughout the process, variations in the participants' experiences were sought to gain broader insight into the results. All authors further discussed the different experiences of CCNs and reached consensus on the final analysis.

Study IV used inductive reflexive thematic analysis by Braun and Clarke (2019). This approach was selected to support the identification of themes related to family members' experiences of end-of-life care, as expressed in interview data. Thematic analysis (Braun & Clarke, 2019) was chosen by me for its capacity to reveal meaningful patterns in relation to the research question, its methodological flexibility, and its emphasis on reflexivity. The reflexive nature of the method included examining my own role, assumptions, and potential influence on the interpretation of family members' experiences of end-of-life care in ICUs. Thematic analysis (Braun & Clarke, 2013; Braun & Clarke, 2019) is an approach used in qualitative research, primarily focused on psychological research but also often used in nursing research. The reflexive nature of the method meant that in the research group, we were reminded to reflect on the research process, including

our own role (Braun & Clarke, 2019). In the analysis, I followed the phases of thematic analysis to support the work of identifying patterns in the data in relation to the research question (Braun & Clarke, 2013). I started by familiarizing myself with the data through simultaneously reading the transcripts and listening to the recorded interviews, and the last author read six transcripts. During my reading of the transcripts, notes and markings were made in the margins. Thereafter, data extracts from the notes and markings that corresponded to the aim were selected by me for further analysis. All extracts were coded by me, and those with similar content were grouped into preliminary themes. I identified patterns and themes in the data using an inductive method, which meant that the patterns that naturally emerged from the data were interpreted and shaped the themes. In the research group, we conducted a collaborative review of the emerging themes to ensure consistency and rigor. This iterative process allowed for refinement and clarification of the themes, ensuring that they were meaningfully connected and distinct from one another. Since we were several researchers involved in the analytical process, the reflexive method, as described by Braun and Clarke (2019), contributed to the analysis developing into a rich and nuanced reading of the data.

6.5.2. Quantitative analysis

In study III, quantitative study, I used descriptive and inferential statistics to analyze data. IBM SPSS Statistics (version 27) and Microsoft 365 Excel were used by me for data analysis. Descriptive statistics were presented as mean value, standard deviation, number, percentages, and minimum-maximum, while the inferential statistics were presented using p-values. A p-value of 0.05 was considered statistically significant.

The statistical analysis and preparation of tables and figures have been carried out by me as first author in consultation with my supervisor ÅR. Prior to the statistical analysis of FS-ICU 24 (FS-ICU.org, 2006), which served as the primary instrument, I rescaled values according to the scoring instructions (FSICU org, year missing). Rescaling means that a linear transformation is performed to standardize the response scale across all items (Wall et al., 2007). All response options followed a Likert scale, with values ranging from 1 to 5, where 1 indicates dissatisfaction, and 5 indicates satisfaction. According to instructions (FSICU org, year missing), the values should be rescaled from 1–5 to 0–100, where 0 is worst

and 100 is best. The response option "not applicable" was classified as "missing" and these answers were excluded. I excluded questionnaires if five or more questions in the subscale FS-ICU/Care were missing, or if four or more questions in the subscale FS-ICU/Decision-making were missing, or if eight or more of the total questions were missing. Thereafter, I calculated summary scores according to the scoring instructions which means that the score, that is the sum of all items for each participant, was divided by the number of items answered. I then calculated the summary scores as the mean value of all the scores.

A simplified scale was used to rank items with the highest proportion of satisfaction and dissatisfaction in the subscales from the FS-ICU 24. This meant that I combined the two response options for satisfaction (Likert 1 and 2) and the two response options for dissatisfaction (Likert 4 and 5), the neutral response option (Likert 3) was retained. Item 22 was omitted from the analysis due to incorrect wording in one of the response options, which could have created ambiguity for the participants when choosing the response option.

I compared the summary score in FS-ICU 24 by using t-test for the variables sex, age and health. For the analysis, a dichotomization of the variable health into two groups: worse, and same/better was carried out.

7. Ethical considerations

This project has followed the Swedish Act concerning the Ethical Review of Research Involving Humans (SFS 2003:460) and ethical standards according to the Declaration of Helsinki (WMA, 2024). Study I was conducted without formal approval as it does not involve any risks of harm to the participants and does not contain sensitive personal data (SFS 2003:460). Ethical approval for studies II – IV has been obtained from the Swedish Ethical Review Authority, Dnr: 2021 – 03364 (approved 2021-08-10). The approval was granted on the condition that initial contact with family members would be made by healthcare professionals, who would then pass on their contact details to the research team. During the period July–December 2021, healthcare professionals asked family members if they would consider participating in the study. Due to the COVID-19 pandemic, which posed additional logistical challenges with a high workload for the ICU staff, only five family members were ultimately included. Therefore, a supplementary application to the Swedish Ethical Review Authority was submitted and approved (Dnr: 2021-06073-02, approved 2021-11-26) which addressed the question of whether I, as a CCN, was permitted to directly contact family members for recruitment into the study.

Ethical considerations are essential in all research, and particularly critical in studies involving human participants. In this thesis, CCNs working closely with patients at the end of life, as well as bereaved family members of deceased patients, have participated. The inclusion of family members, who may be experiencing overwhelming emotions, emphasizes the need for sensitivity and ethical rigor, as they represent a particularly vulnerable population. Therefore, special attention was given during the interviews to their emotional responses, with careful consideration of the risk that they might develop intense emotional reactions.

In conducting the studies, the four principles of biomedical ethics relating to autonomy, non-maleficence, beneficence, and justice have been emphasized (Beauchamp & Childress, 2019). The participant's *autonomy* was protected by providing information about the aim of the studies, that their participation was voluntary, and that they could decline participation at any time without giving a reason and without any consequences. Both CCNs and family members received

written and oral information about the studies and voluntarily gave written informed consent prior to the face-to-face interviews and verbal informed consent was recorded in connection with the interviews conducted by telephone (studies I, II and IV). In study III, family members gave consent by returning the questionnaire.

Non-maleficence concerns not causing harm. During each interview with the participants, I considered whether there could be any risks that could cause harm or whether participation could be burdensome for them. When a risk or burden was identified through reflective analysis during the interview, it was openly discussed with the participant. This was of particular importance in the meetings with bereaved family members. The identified risk, such as overwhelming emotions, was discussed with family members, and three family members expressed that their emotional reactions were intensified by their participation and subsequently chose to discontinue the study. Attention to, and promotion of, their well-being was, therefore, of extra importance to avoid *maleficence*.

Justice must always be maintained when conducting research, and this is the responsibility of the researcher (Beauchamp & Childress, 2019). In this thesis, justice has been considered by offering participation to all CCNs and family members who met the inclusion criteria. In order to ensure that the project remained feasible within the timeframe of a PhD project, the criteria were chosen based on the practical opportunities available to me for data collection, analysis, and reporting.

Further, precautions in accordance with the Declaration of Helsinki have been taken to protect the integrity and confidentiality of research participants. All collected data have been handled carefully to ensure confidentiality by being pseudonymized and used only in coded form (WMA, 2024). Participants were informed about how confidentiality was guaranteed, how data was processed and how the results would be presented. As the first author and data collector in the research group, I am the only person who has access to coded data. I also keep the code key and the identification of the participants in secure storage. The project has been reported to the data protection officer at Marie Cederschiöld University in accordance with EU's General Data Protection Regulations (GDPR, 2016). Data will be archived following the Archives Act (SFS 2019:866).

8. Results

In this section, the results of the respective studies are presented separately.

8.1. Study I

This study aimed to explore how CCNs perceived and maintained the integrity of patients during end-of-life care in the ICU setting. The findings showed that CCNs struggled to define the concept of integrity and to explain what respecting integrity entails in the daily care of patients nearing the end of life. Integrity was consistently regarded as a core value in clinical practice and a fundamental precondition for ethical nursing practice. Respecting patients' integrity emerged as a central theme and a fundamental prerequisite for perceiving patients' integrity was that the CCNs had their own personal integrity. Five categories emerged from the analysis: *Seeing the unique individual*; *Sensitive to patient vulnerability*; *Observant of patients' physical and mental sphere*; *Perspective of patients' religion and culture*; and *Being respectful during patient encounters*.

The CCNs considered the concept of integrity to be elusive. The results described how nurses engaged with patient integrity at the end of life and how they tried to respect and maintain patients' integrity in ICU care. When asked, they found it difficult to define integrity and to explain what respecting integrity entails in the daily care of dying patients. Nonetheless, they repeatedly used notions associated with respect and patient-centered attitudes, such as listening and being sensitive, or they tried to describe good care. The CCNs often equated integrity with respecting the individual and described their strong commitment to carefully seeing the patient as a person through the entire process, from ICU admission to the process of dying. Usually, dying patients in the ICU are sedated and not fully oriented in time and place. In these situations, the CCNs said that they found it important to not lose sight of the patient as a unique person in order to maintain the integrity of the patient. The majority of the CCNs also mentioned that it was important to see the person as unique at the end of life. They noted that patients without a voice or the opportunity to communicate risk being left out - looked at, or talked to, but not communicated with - which might threaten patients' integrity.

The CCNs experienced patients' vulnerability as being related to the patients' strong dependency on the staff when critically ill, their inability to meet their

own basic needs and preserve their integrity. CCNs also experienced the patient's extreme dependency as related to being at the end of life and not being able to exercise autonomous choices directly. As a result, the CCNs found that protecting the patient's vulnerability was important and a way of upholding integrity. CCNs mentioned that for patients, not knowing what was going to happen to them, being subject to others' care decisions, and having no control over time or place during the ICU stay could easily trigger feelings of anxiety and stress in the patients. Also, several CCNs noted that the design of the ICU possibly played an important role in affecting the integrity of patients.

Culture and beliefs were another recurring theme that was identified as affecting the integrity of patients. Due to migration and globalization, the CCNs increasingly encountered cultural issues involving faith and religious beliefs that they considered central to the integrity of dying patients and as having significant impact on relatives. The CCNs struggled to understand the patient's cultural values, preferences and beliefs. Respecting patients' integrity was a challenge if family members and staff were unaware of the preferences of ICU patients at the end of life.

8.2. Study II

This study aimed to explore the ethical challenges that CCNs encounter when caring for patients at the end of life in an intensive care context. The findings are described through three themes: *Focusing on relieving suffering*; *Differing or unknown preferences, norms and values*; and *Considerations of organ donation*.

An integral part of end-of-life care for the CCNs was the creation of a comfortable environment in which patients experienced relief from pain and suffering. A difficulty that the CCNs mentioned was balancing the dosage of pain-relieving medication, which was based on the patients' individual pain level. However, this presents a significant ethical challenge since there is the potential for harm associated with administrating high doses of pain-relieving medications, which in a worst scenario, could inadvertently hasten the patients' death. CCNs also described challenges associated with suffering when life-sustaining treatments were continued in patients who had minimal chances of survival. In such cases, the ethical challenges were perceived because the patient's suffering could be prolonged while they were deprived of the right to die, and that family members were given false hope that the patient would survive.

CCNs described ethical challenges in situations where patients were unconscious due to illness and sedation, making direct communication with the patient about care preferences impossible. CCNs expressed challenges when patients' preferences were unknown, which could lead to uncertainty about how the care should proceed. However, some patients remained conscious and were able to express their wishes until the end of their life. In certain cases, these expressed preferences could be in conflict with the CCNs' values. For example, when patients requested discontinuation of life-sustaining treatments, such as breathing support with a ventilator, even though, based on their clinical experience, the CCNs believed that continued care could significantly prolong the patient's life.

Ensuring respectful treatment of deceased patients was not simply a procedural task performed by the CCNs, but a vital expression of the values that defined professional nursing: respect, empathy, and integrity. The care of potential organ donors introduced unique ethical challenges for the CCNs. They described that necessary information about organ donation was provided to family members, and after organ donations were completed, follow-up conversations were held with family members. These conversations provided an opportunity for family members to ask any remaining questions and receive clarification from both CCNs and physicians regarding the donation process. During these conversations, some family members expressed that they were unsure about when the patient had actually died. In such instances, an ethical challenge emerged for the CCNs when family members appeared resistant to the information given due to the crisis they were going through.

8.3. Study III

The aim of this study was to investigate bereaved family members' satisfaction with care, decision-making, the patients' last hours in life, and their own self-rated health in end-of-life care in an intensive care setting. The findings showed that family members experienced overall satisfaction with care in ICUs. The findings are presented using the following scales: *Bereaved family members' satisfaction with care; Bereaved family members' satisfaction with decision-making; Bereaved family members' satisfaction with patients' last hours of life;* and *Bereaved family members' self-rated health.*

Of the 141 bereaved family members who participated, 88.4% (n=122) expressed satisfaction with the care provided by the CCNs to the patients. Additionally, 87.6% (n=120) were satisfied with the way healthcare staff treated patients with courtesy, respect, and compassion, while 86.6% (n=122) reported satisfaction with the courtesy, respect, and compassion shown by healthcare staff towards the family members themselves. Dissatisfaction was reported by 14.2% (n=15) of the family members concerning the atmosphere in the dayroom. Furthermore, 12.3% (n=17) expressed dissatisfaction with the emotional support provided regarding their own needs, and 11.8% (n=14) were dissatisfied with symptom management when assessing and treating the patient's agitation.

In the decision-making, 80.8% (n=114) of the bereaved family members reported satisfaction with the healthcare staff's willingness to answer questions. Additionally, 80.4% (n=111) expressed that the explanations were easy to understand, while 77.1% (n=108) were satisfied with the honesty of the information provided about the patient's condition. Dissatisfaction with the decision-making was reported by 17.1% (n=24) of the family members regarding the information provided about what had happened to the patient and why measures were taken. Similarly, 17% (n=24) expressed dissatisfaction with the control they had over the patient's care, and 14.7% (n=20) reported that the information provided by physicians, CCNs etc. was inconsistent.

Regarding patients' last hours of life, 86.2% (n=119) of the bereaved family members experienced that the patient's life was neither unnecessarily prolonged nor shortened. In contrast, dissatisfaction was reported by 7.3% (n=10) of the family members due to their feeling that the patient had had a very difficult time during their last hours of life, and 2.9% (n=4) expressed that they themselves had felt completely abandoned by the healthcare staff.

Bereaved family members' self-rated scores on the FS-ICU Decision-making related to health showed that there was a statistically significant difference between family members who rated their health as worse (summary score 69.4, SD 26.4) and those who rated their health as same/better (summary score 77.5, SD 21.3) compared to a year ago. This perceived deterioration in health status showed that those family members who rated their health as worse generally rated lower satisfaction with decision-making.

8.4. Study IV

This study aimed to describe bereaved family members' experiences of end-of-life care following the death of a close person in the ICU. The findings are presented in five themes: *Time filled with fear and uncertainty*; *Challenges in understanding critical information*; *Struggling to grasp the imminence of death*; *Fear of patient had suffered at the very end of life*; and *The importance of farewell in the ICU*.

The findings showed that family members entered the ICU during an emotional and turbulent time filled with fear, uncertainty, and sometimes disorientation. Within this medical environment, their own emotional needs often felt invisible. However, family members talked about moments where staff made efforts to acknowledge, comfort, and involve them. These moments were often experienced as being emotionally significant, transforming a space of crisis into one where dignity and human connection could emerge. Family members also found support in non-verbal, practical actions that acknowledged their presence and emotional needs, such as CCNs who made space for physical closeness and comfort, offering chairs, adjusting the patient's position, or simply staying nearby, which allowed family members to feel more connected.

Family members often struggled to recognize the imminence of death. During the moments of a patient's crisis, family members valued the ICU staff's efforts to provide timely and honest information. However, they found it difficult to fully grasp the meaning and implications of what was communicated, especially during the high-stress phases of their close person's illness. Many family members described how the initial shock and emotional overload prevented them from taking in basic information about their close person's condition. Despite receiving updates, family members said that their minds were often elsewhere, filled with fear and confusion. Understanding that their close person was dying did not occur as a sudden realization, but rather as a gradual and emotionally complex process. While family members often recognized that the situation was serious, the transition from active treatment to end-of-life care was difficult to comprehend in practice. Hope for recovery coexisted with subtle or unclear communication about their close person's prognosis, leaving family members emotionally unprepared when death became imminent.

A central emotional concern for family members was whether their close person suffered during the last moments of life. Despite knowing that the CCNs provided pain-relieving medication and sedation, many family members were haunted by doubts and fears that discomfort, fear, or anxiety had persisted. This concern was often tied to family members' longstanding emotional bonds and their deep desire to protect their close person from distress. Even after their close person's death, the uncertainty about whether suffering had truly been avoided lingered as a painful part of their grief. Some family members shared that their fears were shaped by promises made earlier in life. While acknowledging that the staff did everything possible to provide comfort for the patient, some family members still worried about invisible forms of suffering, particularly emotional distress, such as panic or death anxiety, which might not be fully alleviated through medication.

Saying goodbye to a close person who is dying emerged as a meaningful experience for family members. The moments of goodbye, whether they were brief or extended, verbal or physical, were crucial to how family members made sense of the death and began processing their grief. For some family members, physical presence at the moment of death was central to their farewell. Simple acts like touching the body or sitting quietly nearby allowed them to express their love, provide comfort, and begin the process of letting go in a tangible way. Other family members emphasized the importance of shared rituals and symbolic acts during the last moments. For them, creating space for music, stories, or expressions of gratitude transformed the atmosphere from one of loss to one of connection and meaning. While not everyone was present at the exact moment of death, the ability to say goodbye - whether before, during, or after - was what mattered most.

9. Discussion

The results of this thesis present the experiences of CCNs and family members in end-of-life care within the intensive care context. In the discussion, parts of the results of the CCNs' and family members' experiences have been selected for reflection.

9.1. Integrity as a fundamental component in end-of-life care

CCNs struggled to define the concept of integrity and to explain what respecting integrity entails in the daily care of patients nearing the end of life. Maintaining and preserving patient integrity in the ICU was frequently described as challenging, largely due to the prominence of technological aspects and the delivery of care being performed in open spaces with little privacy. Despite these difficulties, integrity was consistently regarded as a core value in clinical practice and a fundamental precondition for ethical nursing practice (study I). When caring for deceased patients, ensuring respectful treatment was not simply a procedural task, but a vital expression of the values, such as integrity, that defined professional nursing (study II). As emphasized by Sun et al. (2024), patients are not merely numbers, they are individuals with unique personalities and spiritual dimensions. In ICUs, patients need to be recognized as a whole being encompassing biology, psychology, society, culture, and spirituality. Providing care in such settings requires fostering a respectful care environment that upholds human integrity while also preserving patient autonomy, as well as recognizing and treating patients as unique individuals (Sun et al., 2024). Recognizing patients as unique individuals is especially important when their ability to make choices, decisions, or take responsibility for their care is impaired, and they depend on others to act in their best interest (Reignier et al., 2019). It is equally important to recognize the role of family members in the ICU. Family members described meaningful moments when CCNs transformed a space of crisis into one where dignity, empathy and human connection could emerge (study IV). This approach resonates with the Ethics of Care, described by Lindemann (2019), which states that caring for the person as a whole should be prioritized. This ethical approach is crucial in preventing caregiving from becoming detached or impersonal.

The CCNs considered the concept of integrity to be elusive (study I), and integrity can indeed be challenging to comprehend. According to Gilligan (1982) it can be likened to an onion - layered and complex, gradually revealed through relationships, context, and moral understanding. In this onion, the outer layers represent the integrity shown to people who are superficially familiar. As you move closer to the core, the layers represent the integrity shown to those who are closest, such as family members. This analogy highlights how different aspects of a person's integrity are revealed based on the depth of their relationships (Gilligan, 1982). A person's integrity can also be violated, for example, in the event of an intrusion into the private sphere. Harming a person - whether living or deceased - violates their integrity (Nordenfelt, 2004). This may occur, for instance, when CCNs focus more on their own emotional experiences and suffering, which may not necessarily align with the wishes or needs of the patient (Laurent et al., 2017). CCNs perceived ethical dilemmas when patients were deprived of their integrity and their right to die, as life-sustaining treatment was continued in patients having minimal chance of survival (study II). Disrespectful handling of the dead constitutes an invasion of the private sphere and a symbolic affront that diminishes the dignity of the deceased person's identity. This perspective affirms that dignity does not end with death but continues to exist and therefore continues to require recognition and protection (Nordenfelt, 2004).

The CCNs often equated integrity with respecting the individual and described their strong commitment to carefully seeing the patient through the entire process, from ICU admission to the process of dying (study I). This perspective is reflected in 87.6% (n=120) of the family members who reported satisfaction with the healthcare staff's courteous, respectful, and compassionate treatment of patients (study III). CCNs also noted that it was important not to lose sight of the patient as a unique person in order to maintain the integrity of the patient (study I). These expressions by CCNs during the care of a dead person's body align with the idea of "engrossment", where close attention is paid to the feelings, needs, and wants of those they care for so that their own needs are set aside, thereby honoring the person's integrity even after death (Lindemann, 2019). When patients have passed away in the ICU, continuing to safeguard the body of a deceased person is a way of preserving their integrity according to de Swardt and Fouché (2017). This commitment reflects a deep ethical and professional

responsibility that CCNs have towards the personhood of the patient, even when the patient is no longer alive. They also noted that CCNs prioritized integrity, ensuring professional and quality care for the deceased and their family members, regardless of their personal feelings about the patient's death (de Swardt & Fouché, 2017).

A fundamental prerequisite for perceiving patients' integrity was that the CCNs had their own personal integrity (study I). The Ethics of Care approach underscores the importance of responsiveness in caring relationships, which involves paying close attention to the needs of the person being cared for, actively listening, and addressing their specific needs (Lindemann, 2019). Nurses' own integrity is seen as crucial to promoting the best interests of patients (de Carvalho & Lunardi, 2009; Moen & Nåden, 2015). Moreover, their personalities, including their integrity, also play a significant role in the quality of care they provide (Verpeet et al., 2005). A crucial aspect of providing compassionate and high-quality care is that nurses are self-reflective, practice self-care, and maintain their well-being (Verpeet et al., 2005). In line with the results in study I, showing that CCNs needed to have their own integrity, Karlsson and Pennbrant (2020) also point out that nurses need to be aware of their own integrity in order to perceive and respond to the integrity of their patients. Achieving this requires self-knowledge and awareness of their approach to the patient (Karlsson & Pennbrant, 2020).

9.2. Critical care nurses navigating ethical challenges

Ethical challenges for CCNs were, for example, associated with suffering when life-sustaining treatments were continued in patients having minimal chance of survival. In these cases, the ethical challenges were perceived as prolonging patients' suffering while depriving them of the right to die and giving family members false hope that the patients would survive (study II). A significant source of distress for CCNs can arise when family members insist on prolonging life-sustaining interventions, even when such measures are no longer in the patient's best interests (Fridh, 2014). Across healthcare settings, patients at the end of life are at risk of experiencing suffering with symptoms such as anxiety, confusion, and nausea (Klint et al., 2019). In an intensive care context, patients may also

experience symptoms such as physical pain, difficulty breathing, and swelling (Ramer et al., 2021). Previous research show that nurses may refrain from providing symptom relief to patients in pain due to fears of unintentionally hastening death and facing potential legal consequences, such as loss of employment, or revocation of their professional license (Willmott et al., 2020). In these complex situations, CCNs need to carefully balance their professional judgement with the emotional and ethical needs of the patient's family members. Guided by Ethics of Care, it becomes essential to prioritize care that aligns with the individual's wishes rather than the preferences or convenience of the caregivers (Lindemann, 2019).

CCNs described ethical challenges in situations where patients were unconscious due to illness and sedation, making direct communication about care preferences impossible (study II). In such cases, the wishes of family members play a significant role. However, 17% (n=24) of the family members reported dissatisfaction with the control that they had over the patient's care (study III). As Giabicani et al. (2025) points out, there can be a discrepancy between what the healthcare team believes is in the patient's best interests and what the family members desire. The need for clear communication is paramount in order to navigate these difficult conversations and to ensure that the patient's dignity and wishes are respected as far as possible (Giabicani et al., 2025). Balancing the ethical considerations and the emotional impact of such decisions can be particularly challenging for the healthcare staff who often perform a supportive role with bereaving family members. It requires careful consideration and sensitivity for cultural and religious beliefs, the need for private space for sensitive conversations and family discussions, as well as support from CCNs who have cared for their close person bedside (Brooks et al., 2025). CCNs, being those closest to patients and family members, sometimes find themselves in positions where they can influence treatment decisions (Kennedy et al., 2025). Their role becomes even more critical when disputes arise over whether to continue or withdraw treatments. CCNs need to navigate the delicate balance between advocating for patients' best interests, supporting family members' emotional needs, and adhering to ethical guidelines (Kennedy et al., 2025).

It has been previously shown that nurses often serve as liaisons between physicians and patients or family members by translating medical language,

advocating for social contexts, and bridging communication gaps. Their involvement frequently enhances person-centered care (Wubben et al., 2021). While nurses contribute valuable insights into decision-making and in general feel heard, their perspective of seeing the whole person is not always considered in decisions (Wubben et al., 2021). Such situations may lead to ethical challenges for CCNs, particularly when they are required to carry out care interventions determined by others that conflict with their own values and professional norms (Falcó-Pegueroles et al., 2015). It was important for the CCNs to not lose sight of the patient as a unique person in order to maintain the integrity of the patient. Therefore, respecting patients' integrity was a challenge if family members and staff were unaware of the preferences of ICU patients at the end of life (study I). These situations can lead to significant moral distress for CCNs, particularly when they feel that the care being provided may not align with the patient's wishes or ethical best practices (Fridh, 2014).

9.3. Family members' experiences of participating in decision-making

Regarding decision-making, family members reported dissatisfaction that concerned the information provided about what had happened to the patient, and why measures were taken (study III). According to Ethics of Care, it is important to actively involve family members in the decisions that are made and ensure that their voices are heard and respected (Lindemann, 2019). Lovell et al. (2023) further emphasized that family members in ICUs do not always absorb the information given and believe that communication regarding the patient's impending death needs to be given both earlier and more clearly to family members.

In study IV, family members valued the ICU staff's efforts to provide timely and honest information. However, they described how the initial shock and emotional overload prevented them from taking in even basic information about the patient's condition (study IV). This emotional state often led to resistance towards the information provided, as highlighted in Study II, reflecting the profound impact of the crisis they were going through. According to Jennerich (2024), preparation is essential to ensure that family members in ICUs can come to terms with the end of their close person's life. In the decision-making process, family

members should receive a clear explanation of what the transition entails, including which treatments or interventions will be discontinued and the monitoring that will occur during the dying process (Jennerich, 2024). It further emphasizes that this information should be communicated continuously throughout the dying process, and also afterwards, allowing family members to fully absorb and understand the information. According to Jennerich (2024), this underscores the importance of clear, compassionate, and easily understandable communication in order to support family members during such challenging times.

A part of the bereaved family members reported that they lacked control over the patients' care (study III). Providing family members with the opportunity to talk about their narratives fosters a more compassionate and inclusive care (Lindemann, 2019). This engagement not only honors patients' autonomy when they themselves cannot communicate directly but also provides family members in ICUs with a sense of agency and inclusion in the decision-making process (Hwang et al., 2025).

A finding shows that family members who experienced a deterioration in health status and self-rated their health as worse compared to a year ago, were generally less satisfied with decision-making (study III). Whether care is provided in ICUs or in other care settings, when family members experience exclusion, they may endure distress, grief compounded by uncertainty, and a sense of powerlessness (Boven et al., 2025; Prigerson et al., 2009). Such emotional burdens can have lasting psychological repercussions, including a risk of prolonged bereavement causing significant impairment with cognitive, emotional, and behavioral symptoms (Boven et al., 2025; Prigerson et al., 2009). Since decision-making that includes withdrawing life-sustaining treatments is profoundly difficult, the process also requires coordination and collaboration within the ICU team (Orr et al., 2022). Kennedy et al. (2025) noted that decision-making in patient care also requires the ICU team to balance their assessment between the patient's expressed wishes and conversations with family members. The decisions need to ensure that the care provided is consistent with the patient's values and best interests, while maintaining ethical and compassionate care (Kennedy et al., 2025).

While family members in study IV often recognized that the situation was serious, the transition from active treatment to end-of-life care was difficult to comprehend in practice. Hope for recovery coexisted with subtle or unclear communication about prognosis, leaving family members emotionally unprepared when death became imminent (study IV). It is, therefore, essential to interact with family members as individuals with their own wishes, intentions, and desires regarding the patient's care and not encounter them merely as objects (Lindemann, 2019). Furthermore, the presence of bereaved family members at the bedside fosters' deeper involvement in the care process, granting family members a sense of control and participation during an emotionally turbulent time (Fridh & Åkerman, 2020; Frivold et al., 2015). However, challenges could arise when neither the family members nor the healthcare staff were aware of the ICU patient's preferences at the end of life (study I). In such cases, offering bereavement support can also be vital in helping family members cope with the emotional challenges of losing a close person in ICU. Supporting family members through this process not only promotes emotional healing but also ensures that end-of-life care remains patient-centered and family-inclusive (Fridh & Åkerman, 2020; Frivold et al., 2015).

9.4. Family members recognition of the imminence of death

This thesis highlights a finding that family members often struggled to recognize the imminence of death (study IV) or when the patient had actually died (study II). This experience may be shaped by the unfamiliar environment and the lack of emotional preparedness for the possibility of death (Chen et al., 2020; Harlan et al., 2020). The difficulty in recognizing the dying process may also be partly attributed to the complex and highly technological environment of the ICU, where visual cues that typically signal the dying process are often obscured (Bennett & Maccaroni, 2024; Donnelly & Psirides, 2015). Both studies found that identifying that a patient is dying can be challenging for family members in ICUs. Donnelly and Psirides (2015) observed that family members might perceive their close person as still breathing due to the rise and fall of the patient's chest, which is often influenced by the advanced technological equipment used in ICUs, such as ventilators. Bennett and Maccaroni (2024) further noted that the use of

equipment in ICUs, such as ventilators and infusion pumps, can mask the natural signs exhibited by a dying patient, including shallow and irregular breathing, poor perfusion, low blood pressure, reduced bowel movements, and decreased urine output (Bennett & Maccaroni, 2024).

There was a notable discrepancy between the experiences of CCNs and bereaved family members regarding the communication surrounding a patient's death. While CCNs reported that they had provided the necessary information (study II), family members felt emotionally unprepared when death became imminent (study IV). This emotional disconnect may be partly explained by ICU family syndrome, characterized by cognitive overload and impaired information processing during times of crisis (Netzer & Sullivan, 2014). In such circumstances, even well-structured communication may be unsuccessful in reaching or being fully understood by family members (Asadi & Salmani, 2024). Additionally, the fact that some family members did not realize that the patient was dead may be due to them experiencing cognitive dissonance (Gyllström Krekula et al., 2018). This condition can occur when family members cannot accept that someone close is deceased and instead convince themselves that the person is still alive because the machines are maintaining the body's functions. The discomfort of cognitive dissonance arises from the conflict between their perception of the patient's condition (that the patient is alive) and the medical reality (that the patient is deceased) (Gyllström Krekula et al., 2018). Regularly updating family members about the patient's condition in a sensitive manner, preparing them for potential outcomes, and offering counseling services to help them cope with stress and emotional challenges, as noted in the Ethics of Care, might lead to family members being more prepared for the outcomes (Lindemann, 2019). Clear and compassionate communication that helps family members make sense of the situation, along with emotional support and a sense of inclusion in the care process, are essential strategies for promoting well-being among bereaved family members (Jennerich et al., 2020). Healthcare professionals play a critical role in fostering this supportive environment through ongoing, compassionate dialogue that prepares family members for the potential outcomes, including death, in a gradual and humane manner (Lindemann, 2019).

Family members' emotional reactions to the death of a close person in ICU can vary widely. Family members described how the initial shock and emotional

overload prevented them from taking in even basic information about the patient's condition. Despite receiving updates, their minds were often elsewhere, filled with fear and confusion (study IV). This emotional strain was also reflected in study III, where 7.3% (n=10) of the family members reported that they felt that the patients had a very difficult time during their last hours of life. Güven et al. (2022) further highlight this reliability, noting that while more than half of family members have what may be experienced as a normal perception of the death, others experience initial shock, denial, and feelings of guilt. Identifying that family members often had difficulty recognizing that death was imminent (study IV) underscores the need for individualized communication and support strategies that are responsive to family members' distinct emotional and informational needs during end-of-life care (Lindemann, 2019).

9.5. Methodological considerations

A variety of research methods have been employed in this thesis. To fulfill the overarching aim of the thesis, three studies utilized qualitative methods while one study adopted a quantitative method. Throughout the research process, transparency regarding the decisions made has been prioritized, with effort given to providing detailed descriptions of the choices made in each individual study. However, there are some considerations that need to be addressed which are presented below.

Participants

When selecting CCNs and family members for interviews, a purposeful method was used to reach individuals with experience of the phenomenon being studied (Creswell & Poth, 2017; Krippendorff, 2019). This targeted approach provided insights from CCNs and family members who had first-hand experience of the emotional and practical challenges of such a loss within ICUs (Polit & Beck, 2021).

One limitation of the inclusion criteria was the exclusion of family members who were not proficient in Swedish, resulting in the valuable perspectives of persons from diverse cultural backgrounds not being collected. Consequently, the study may not fully capture the diversity of experiences and expectations regarding ICU care across various linguistic, ethnic, and cultural groups. This limitation impacts

on the generalizability of the studies' findings, since these may not capture the experiences of all family members (Polit & Beck, 2021).

Recruitment and data collection

In the recruitment of CCNs, it was advantageous to involve the head nurses of each ICU who then provided information about the studies to CCNs who had the appropriate skills and experience. This approach facilitated my efforts to reach suitable CCNs. However, there was an awareness that this selection method could allow head nurses to act as gatekeepers, selectively withholding information from CCNs they felt should not participate based on their knowledge of the staff. This selective dissemination may have limited the diversity of perspectives represented in the studies. Another limitation in the recruitment of CCNs may be the uneven gender distribution among participants, which, while reflective of the actual workforce, resulted in only a few male interviewees. This uneven distribution may have limited the male perspective in the results.

When recruiting family members, data collection was intended to begin no sooner than four months after the patient's death, in accordance with research recommendations that suggest allowing time for initial grief processing (Sque et al., 2014). This approach can be viewed as both an advantage and a limitation. On the one hand, the four-month timeframe may have given family members the necessary time to reflect on their experiences and feel ready to participate in this study. On the other hand, the four-month timeframe may have been too early for others, as some family members indicated that they were still in the midst of their grieving process and chose not to participate. Together with my supervisors, I interpreted this variation in response as being related to the fact that the timing may not have been universally optimal for all participants, potentially introducing selection bias by excluding those for whom the grieving process remained too acute.

In the data collection, I reflected on my role as a professional CCN and took proactive steps to maintain neutrality, ensuring that I did not influence the CCNs and family members. According to Polit and Beck (2021), it is essential for researchers to establish and maintain trust with participants while striving to achieve neutrality. My experience as a CCN helped foster a trusting atmosphere during the interviews. However, it may also have introduced a limitation, since

my familiarity with the context could have led me to overlook or assume certain details. To address this, I made a conscious effort to remain open-minded and consistently asked follow-up questions to avoid drawing premature conclusions.

9.5.1. Qualitative methods

In qualitative research, demonstrating trustworthiness is essential and is commonly established through the criteria of credibility, dependability, confirmability, and transferability (Polit & Beck, 2021). In this thesis, I have aimed to ensure rigor in the qualitative studies by adhering to the trustworthiness framework proposed by Lincoln and Guba (1985). *Credibility*, according to Lincoln and Guba (1985), that the study examines what it intends to examine, is supported by the fact that the deceased patients came from eight different ICUs. The CCNs and family members involved brought diverse experiences from these units and represented a range of ages and both genders. *Dependability* is achieved through the analysis phases in which each study has been carefully described and implemented by myself and my supervisors. In the methods sections of each study, we have made a concerted effort to provide detailed descriptions of the analytical choices and research decisions that were made. This strengthens the possibility of replicating the study in a similar context. *Confirmability* ensures that the conclusions drawn are grounded in the data. In collaboration with my supervisors, I worked to maintain objectivity, critically examining the data and ensuring that the interpretations made were consistent with the data. The *transferability* of the findings may be applicable to other ICUs and care settings where end-of-life care is provided to patients with limited autonomy.

Analysis

In the qualitative analyses, my pre-understanding as a CCN may have influenced the process. This prior knowledge offered a distinct perspective that helped uncover underlying experiences and insights, potentially shaping the interpretation of the data. While this perspective may have permeated the analyses, it also contributed to a more reflective and deliberate interpretation, developed in collaboration with my supervisors.

Using qualitative content analysis as described by Graneheim and Lundman (2004), qualitative data in study I were analyzed from different dimensions, such

as manifest and latent. Although both the manifest and latent content have required interpretation, they differ in depth and abstraction. In the manifest content analysis, I have focused on the explicit, visible aspects of the text and described its obvious components. In contrast, in the latent content analysis my focus has been on the underlying meanings and interpretations of the text. An advantage of qualitative content analysis was its capacity to capture and articulate both manifest and latent content while maintaining consistency and coherence in the analysis. A limitation, however, was that the interpretation was somewhat limited to manifest and latent interpretation where a deeper interpretation of the meaning may be lacking.

Interpretive description, ID, as described by Thorne et al. (1997) was employed in study II to advance nursing knowledge regarding CCNs' experiences with ethical challenges. This methodology enabled me to generate rich, contextually grounded insights into the emotional, moral, and professional difficulties that CCNs may encounter in highly sensitive and emotionally charged clinical settings. An advantage of ID is that the method has its roots in nursing science. It allows for an understanding that human experiences consist of complex interactions, and that experiences of shared realities are at the core of this disciplinary knowledge. In addition, ID has allowed me to explore phenomena by identifying themes and patterns among subjective perspectives, while also considering individual variations.

By using Reflexive thematic analysis (Braun & Clarke, 2013; Braun & Clarke, 2019) in study IV, patterns within the data have been identified, analyzed, and reported. The reflexivity has generally helped me to pay attention to, and reflect on, my own prejudices and assumptions throughout the analysis process. This step was important to minimize the impact that my own beliefs and values have on the analysis process. Using this method has been advantageous as it has given me the opportunity to critically reflect on my preconceptions during the analysis process, which is also described by Braun and Clarke (2019). However, reflexive thematic analysis also has potential limitations. One limitation is that the analysis does not prescribe a detailed procedure or framework for implementation. I have, therefore, together with my supervisors, thoroughly documented our analytical approach to enable replication and to support the credibility of the findings.

9.5.2. Quantitative method

In the quantitative research using the FS-ICU 24 questionnaire, two things have been of paramount importance in our measurement – validity and reliability (Polit & Beck, 2021). In order to achieve validity (Johnston et al., 2014), family members with direct experience of end-of-life care in ICUs were included, which ensured that the results are rooted in the experiences of individuals relevant to the research topic. A potential threat to validity in this study may stem from discrepancies between the responses of family members in this study and those reported in similar research. Variations in participant responses across studies could influence the interpretation of results. Such discrepancies may have occurred in our data, and they cannot therefore be completely ruled out. Reliability is strengthened by the fact that the original English instrument FS-ICU 24 is validated and has been tested for reliability (Wall et al., 2007).

Analysis

An advantage of using a quantitative method was that it allowed a systematic investigation of data from many participants, offering valuable insights into the diverse experiences of family members. Nevertheless, there were limitations associated with using the instrument FS-ICU 24. First, the Swedish version of FS-ICU 24 has not undergone validation or reliability testing. Second, when interpreting the FS-ICU results across different studies, caution is advised due to ambiguities in the instructions for calculating summary scores for the subscales and the total scale (FSICU org, year missing). In the analysis, we chose to follow the instructions when calculating the result, which meant that the summary score should be calculated as the total sum of all response options divided by the number of responses. Third, variations in question phrasing and response options across different language versions of the FS-ICU 24 necessitate careful comparisons between studies, since these variations may affect the translated instruments' equivalence with the original FS-ICU 24 and with each other.

10. Conclusions and clinical implications

Based on the findings in this thesis, the following conclusions are drawn regarding CCNs' and family members' experiences of end-of-life care in an intensive care context.

CCNs require support in palliative care to navigate the ethically challenging situations they encounter during end-of-life care in the ICU. While they expressed a strong commitment to preserving patients' integrity, many reported uncertainties about how to define integrity as a concept and how to address it in practice. In addition, CCNs frequently faced ethically complex challenges - often involving life-or-death implications - yet had limited influence over decisions and were often unsure about how to respond. These findings highlight the need for enhanced education to strengthen CCNs' understanding of integrity, both as an ethical concept and as a core value in end-of-life care. They also underscore the importance of creating opportunities for ethical reflection and dialogue among colleagues, particularly in situations where moral dilemmas are pronounced.

Bereaved family members faced several challenges during their encounters with intensive care, including inconsistent or insufficient information, unmet emotional support needs, and limited involvement in decision-making. For family members of patients who are cared for at the end of life in the ICU, it is crucial that information is communicated clearly and repeatedly. Healthcare staff, particularly CCNs, should provide individually tailored support to help family members navigate the emotional and ethical complexities in the situation.

The clinical implications are directed at hospital management and managers who should ensure that CCNs receive improved ethical support and training to navigate the complex moral terrain of end-of-life care in intensive care. The ethical challenges CCNs face can serve as a basis for reflective dialogue and guide informed decisions in clinical practice. The difficulty for CCNs in defining and articulating the concept of integrity, despite recognizing it as a core value, further highlighted a gap in ethical discourse and professional guidance. Addressing this gap through targeted education, forums for ethical reflection, and integration of ethical consultation services could strengthen CCNs' ability to deliver ethical end-of-life care. In addition, the findings highlight the need for improved support for

family members during end-of-life care. CCNs require education to proactively assess and respond to the emotional and informational needs of family members during end-of-life care. Creating conditions that enable CCNs to enhance their communication - making it more comprehensive, transparent, and compassionate - is essential. Such improvements not only support family members in coping with the patient's symptoms and the dying process but also contribute to more individualized care.

Future research should prioritize the development and evaluation of strategies to enhance the ethical support and education of CCNs in ICUs. This includes the implementation of ethics education programs, and structured ethical reflection forums. Longitudinal studies would then be needed to assess how these strategies influence CCNs' ethical decision-making, levels of moral distress, and the quality of patient care over time. In addition, further research is needed to explore the ethical support that CCNs receive in relation to integrity during end-of-life care in ICUs. This could inform the creation of practical tools or frameworks to support ethical clarity and consistency in clinical practice. Research should also explore the distinct ethical challenges that CCNs face in an intensive care context to enable the development of support strategies. Equally important is the need for research focused on family-centered communication during end-of-life care. Studies should aim to enhance the clarity, compassion, and effectiveness of communication with family members and identify the best practices for addressing their needs for emotional and informational support. Investigating family members' experiences and satisfaction with end-of-life care in ICUs will also be crucial in designing more responsive and individualized models of care.

Sammanfattning

Denna avhandling undersöker intensivvårdssjuksköterskors och sörjande familjemedlemmars erfarenheter av vård i livets slutskede i en intensivvårdskontext. Både kvalitativa metoder med intervjuer av intensivvårdssjuksköterskor och familjemedlemmar, samt kvantitativ metod med frågeformulär till familjemedlemmar har använts.

Resultatet visar att det var en utmaning för sjuksköterskor att upprätthålla patienters integritet vid vård i livets slutskede. Även om sjuksköterskor såg integritet som ett kärnvärde och en väsentlig förutsättning för etisk omvårdnad, kämpade de ofta med att definiera eller formulera vad det innebar att respektera en patients integritet. Istället beskrev de integritet genom begrepp i linje med respekt och patientcentrerad vård, såsom aktivt lyssnande, känslighet och tillhandahållande av medkännande och högkvalitativ vård. Sjuksköterskorna mötte också etiska utmaningar vid vård av patienter i livets slutskede. Utmaningarna berörde beslut om att avbryta livsuppehållande behandling för patienter med begränsade överlevnadsmöjligheter och hantering av symtomlindring på ett sätt som inte oavsiktligt kan påskynda döden. Ytterligare komplexitet uppstod när patienter valde att avbryta behandling trots potential för förlängt liv. Etiska överväganden inkluderade också vården av den avlidnes kropp, särskilt i samband med organdonation.

Från familjemedlemmarnas perspektiv visar denna avhandling att en övergripande tillfredsställelse upplevdes med vården i livets slutskede. Familjemedlemmar rapporterade att de kände sig stöttade av medkännande vårdpersonal och värdesatte tidig och respektfull kommunikation angående patienters kritiska tillstånd. De värdesatte också möjligheten att välja om de ville vara närvarande vid patientens död eller inte. Resultaten belyser dock också flera utmaningar som familjemedlemmar möter, särskilt svårigheter att inse att döden är nära förestående och avsevärd oro över patienternas upplevda lidande trots att smärtlindring administreras som en del av vården i livets slutskede. Dessutom upplevde familjemedlemmar en brist på konsekvent uppmärksamhet på sina

individuella behov, vilket kännetecknades av otillräckligt emotionellt stöd, inkonsekvent kommunikation och begränsat deltagande i beslutsprocessen.

De kliniska implikationerna tyder på att intensivvårdssjuksköterskor har behov av etiskt stöd och utbildning för att navigera i den komplexa moraliska terrängen kring vård i livets slutskede inom intensivvård. De etiska utmaningar som de möter kan tjäna som en grund för reflekterande dialog och vägleda välgrundade beslut i klinisk praktik. Svårigheten som intensivvårdssjuksköterskor mötte med att både definiera och formulera begreppet integritet, trots att de erkände det som ett grundläggande värde, visade ytterligare på en lucka i etisk diskurs och professionell vägledning. Att åtgärda denna lucka genom riktad utbildning, forum för etisk reflektion och integration av etiska konsultationstjänster skulle kunna stärka intensivvårdssjuksköterskors förmåga att leverera etisk vård i livets slutskede. Dessutom belyser resultaten behovet av förbättrat stöd till familjemedlemmar under vård i livets slutskede. Intensivvårdssjuksköterskor behöver proaktivt bedöma och bemöta familjemedlemmars emotionella och informativa behov. Att förbättra intensivvårdssjuksköterskors kommunikation så att den är mer omfattande, transparent och medkännande är avgörande för att hjälpa familjemedlemmar att hantera patientens symtom och döendeprocessen, vilket i slutändan bidrar till en mer individuell vård.

Framtida forskning bör prioritera utveckling och utvärdering av strategier för att förbättra det etiska stödet och utbildningen för intensivvårdssjuksköterskor. Detta inkluderar implementering av etikutbildningsprogram och strukturerade forum för etisk reflektion. Longitudinella studier behövs för att bedöma hur dessa strategier påverkar intensivvårdssjuksköterskors etiska beslutsfattande, nivåer av moralisk stress och kvaliteten på patientvården över tid. Dessutom behövs ytterligare forskning för att undersöka det etiska stöd som intensivvårdssjuksköterskor får i relation till integritet under vård i livets slutskede på intensivvårdsavdelningar. Detta skulle kunna ligga till grund för skapandet av praktiska verktyg eller ramverk för att stödja etisk tydlighet och konsekvens i klinisk praxis. Forskningen bör också undersöka de olika etiska utmaningar som sjuksköterskor möter i ett intensivvårdssammanhang för att möjliggöra utveckling av stödstrategier. Lika viktigt är behovet av forskning inriktad på familjecentrerad kommunikation under vård i livets slutskede. Studier bör syfta till att öka tydligheten, medkänslan och effektiviteten i kommunikationen med

familjemedlemmar och identifiera bästa praxis för att tillgodose deras behov av emotionellt och informativt stöd. Att undersöka familjemedlemmars erfarenheter och nöjdhet med vård i livets slutskede på intensivvårdsavdelningar kommer också att vara avgörande för att utforma mer lyhörda och individanpassade vårdmodeller.

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Appendices

-Intervjuguider studier I – II, IV

Intervjuguide studie I

Vad innebär det att vårda patienter i livets slutskede inom intensivvård?

Integritet

Hur tänker du kring begreppet integritet?

Vad är integritet för dig som intensivvårdssjuksköterska i din yrkesprofession?

Vilka tankar har du kring integritet i livets slutskede?

Vilka erfarenheter har du om patienters integritet vid vård i livets slutskede?

Hur gör du för att främja eller bevara patienters integritet?

Autonomi

Vilken erfarenhet har du kring patienters självbestämmande vid vård i livets slutskede?

Hur tänker du kring patienters möjlighet till delaktighet vid vård i livets slutskede?

Vill du berätta för mig hur du hanterar patienters delaktighet vid vård i livets slutskede?

Hur reflekterar du kring patienters möjlighet till avskildhet vid vård i livets slutskede?

Vill du berätta hur du hanterar patienters avskildhet vid vård i livets slutskede

-… mot anhöriga?

-… mot avdelningen?

Intervjuguide studie II

Etisk kompetens

Vad är etik för dig i din roll som sjuksköterska?

Känner du dig trygg med dina kunskaper och färdigheter för att hantera utmanande situationer?

Vård i livets slutskede inom intensivvård

Vilka färdigheter och kunskaper anser du att sjuksköterskor behöver för att ge god vård till döende patienter?

Vad anser du är viktigt i vården av patienter i livets slutskede?

Har du mött situationer som känts etiskt problematiska?

Vad har varit mest utmanande för dig i vården av patienter i livets slutskede?

Familjemedlemmars delaktighet, behov av stöd och önskemål

Brukar närstående vara involverade i de beslut som tas?

Har du någon gång känt att närståendes roll är etiskt problematisk?

Vad tror du närstående kan behöva för stöd?

Stöd i arbetet

Diskuterar ni etiska frågor som uppstår i samband med vård i livets slutskede?

Upplever du några hinder för att diskutera etiska frågor?

Intervjuguide studie IV

Omvårdnad i livets slut inom intensivvård

Hur upplevde du den vård din nära anhörig fick i slutet av livet?

Kan du beskriva din upplevelse av vården under de sista timmarna av din nära anhörigs liv?

Fanns det några aspekter av vården som du upplever inte beaktades tillräckligt?

Delaktighet

Hur upplevde du personalens bemötande av dig som närstående?

Hur väl blev du informerad om vad som hände och varför åtgärder sattes in i vården?

Upplevde du dig involverad i de beslut som togs i vården av din anhörige?

Stödbehov

Vilket stöd blev du erbjuden av vårdpersonalen under vården i livets slutskede?

Upplevde du att det stöd som erbjöds var tillräckligt?

Vilket stöd anser du att närstående kan behöva vid vård i livets slutskede?

-Frågeformulär studie III

Till dig som haft en anhörig som vårdats i livets slutskede inom intensivvård

Närstående har ofta en central och viktig roll när en person vårdas inom intensivvård. Samtidigt finns det många som vittnar om att det varit en tung tid med många känslor, inte minst sorg. I denna studie undersöker vi närståendes erfarenheter av vård och det övergripande syftet är att få en ökad förståelse av den vård som ges i livets slut inom intensivvård. Vi har fått information om att du haft en anhörig som vårdats i livets slut inom intensivvården och eftersom vi undersöker just erfarenheter av sådan vård frågar vi om du vill delta med dina erfarenheter.

Att delta i studien innebär inte några följder eller risker för dig. Du behöver avsätta tid för att besvara frågeformuläret (ca 30 minuter). Det är helt frivilligt att delta och genom att sända frågeformuläret i retur samtycker du till att delta. Om du väljer att inte delta eller vill avbryta ditt deltagande behöver du inte uppge varför, utan då kan du bortse från enkäten.

Studien är godkänd av Etikprövningsmyndigheten (Dnr 2021–03364). Dina svar kommer att behandlas så att inte obehöriga kan ta del av dem. Ansvarig för dina personuppgifter är Ersta Sköndal Bräcke Högskola. Enligt EU:s dataskyddsförordning har du rätt att kostnadsfritt få ta del av de uppgifter om dig som hanteras i studien, och vid behov få eventuella fel rättade. Du kan också begära att uppgifter om dig raderas samt att behandlingen av dina personuppgifter begränsas. Rätten till radering och begränsning av behandling av personuppgifter gäller dock inte när uppgifterna är nödvändiga för den aktuella forskningen. Om du är missnöjd med hur dina personuppgifter behandlas har du rätt att ge in klagomål till Integritetsskyddsmyndigheten, som är tillsynsmyndighet. Resultatet av studien kommer att sammanställas i vetenskapliga artiklar på ett sätt som omöjliggör att du eller din anhörig kan identifieras. Ingen ersättning utgår vid deltagande.

En del frågor kan upplevas som personliga, då de berör dina perspektiv och tankar om den vård din anhörig fått och det stöd du som närstående fått. Om du vill veta mer, eller upplever obehag då du fyller i frågeformuläret och behöver samtala med någon är du välkommen att kontakta ansvariga för

studien. Vi kan också hjälpa dig att få kontakt med sjukvården om du skulle behöva det. Vi svarar gärna på dina frågor.

Bakgrundsfrågor om dig som besvarar enkäten

1. Kön

◯ Kvinna

◯ Man

◯ Icke-binär

2. Ålder

Ange ditt svar:

3. Utbildning

◯ Grundskola

◯ Gymnasium

◯ Högskola/universitet

4. Sysselsättning

◯ Yrkesarbetar

◯ Sjukskriven/-pensionär

◯ Arbetssökande

◯ Studerande

◯ Annat

5. Till din anhörig som avlidit, var du:

◯ Make/maka/sambo/partner

◯ Förälder

◯ Barn

◯ Syskon

◯ Annat

6. Vilken kontakt hade du med din anhörig som avlidit?

◯ Daglig kontakt

◯ 2 ggr/vecka eller fler tillfällen

◯ 1 ggr/vecka

◯ 1 ggr/månad

◯ Mer sällan än 1 ggr/månad

7. Var är du född?

◯ Sverige

◯ Norden

◯ Europa

◯ Utanför Europa

8. Vilket/vilka språk använder du huvudsakligen hemma?

Ange ditt svar:

9. Vad var anledningen till din anhörigs vård på IVA?

◯ Olycka/trauma

◯ Thoraxkirurgi/Hjärt-eller lungsjukdom

◯ Neurokirurgi/Stroke

◯ Infektion

◯ Covid-19

◯ Annat

Frågor om tillfredsställelse med vården

Välj det svarsalternativ som stämmer bäst med din uppfattning. Om någon av frågorna inte stämmer in på dig och din anhörig, välj då ”inte relevant”. Det är viktigt att du fyller i alla frågorna.

10. Hur blev din anhörig som vårdats på IVA bemött av personalen med hänsyn till artighet, respekt och medkänsla?

◯ Utmärkt

◯ Mycket bra

◯ Bra

◯ Ganska bra

◯ Dåligt

◯ Inte relevant

11. I vilken utsträckning bedömde och behandlade personalen din anhörigs symtom med hänsyn till smärta?

◯ Utmärkt

◯ Mycket bra

◯ Bra

◯ Ganska bra

◯ Dåligt

◯ Inte relevant

12. I vilken utsträckning bedömde och behandlade personalen din anhörigs symtom med hänsyn till andningssvårigheter?

◯ Utmärkt

◯ Mycket bra

◯ Bra

◯ Ganska bra

◯ Dåligt

◯ Inte relevant

13. I vilken utsträckning bedömde och behandlade personalen din anhörigs symtom med hänsyn till oro?

◯ Utmärkt

◯ Mycket bra

◯ Bra

◯ Ganska bra

◯ Dåligt

◯ Inte relevant

14. Hur blev du bemött av personalen med hänsyn till dina behov?

◯ Utmärkt

◯ Mycket bra

◯ Bra

◯ Ganska bra

◯ Dåligt

◯ Inte relevant

15. Hur blev du bemött av personalen med hänsyn till känslomässigt stöd?

◯ Utmärkt

◯ Mycket bra

◯ Bra

◯ Ganska bra

◯ Dåligt

◯ Inte relevant

16. Hur var samarbetet mellan all personal på IVA som deltog i vården av din anhörig?

◯ Utmärkt

◯ Mycket bra

◯ Bra

◯ Ganska bra

◯ Dåligt

◯ Inte relevant

17. Hur blev du bemött av personalen med hänsyn till artighet, respekt och medkänsla?

◯ Utmärkt

◯ Mycket bra

◯ Bra

◯ Ganska bra

◯ Dåligt

◯ Inte relevant

18. Hur väl vårdade sjuksköterskorna din anhörig på IVA?

◯ Utmärkt

◯ Mycket bra

◯ Bra

◯ Ganska bra

◯ Dåligt

◯ Inte relevant

19. Hur ofta samtalade sjuksköterskor med dig om din anhörigs tillstånd?

◯ Mycket ofta

◯ Ofta

◯ Ibland

◯ Sällan

◯ Aldrig

◯ Inte relevant

20. Hur väl vårdade läkarna din anhörig?

◯ Utmärkt

◯ Mycket bra

◯ Bra

◯ Ganska bra

◯ Dåligt

◯ Inte relevant

21. Hur var atmosfären på IVA?

◯ Utmärkt

◯ Mycket bra

◯ Bra

◯ Ganska bra

◯ Dåligt

◯ Inte relevant

22. Hur var atmosfären i närståendes dagrum på IVA?

◯ Utmärkt

◯ Mycket bra

◯ Bra

◯ Ganska bra

◯ Dålig

◯ Inte relevant

23. Hur tillfreds var du med omfattningen av den vård som din anhörig fick på IVA?

◯ Mycket missnöjd

◯ Ganska missnöjd

◯ Mestadels nöjd

◯ Mycket nöjd

◯ Helt nöjd

24. Är det något du vill kommentera eller lägga till med egna ord angående frågor nr 10–23?

Ange ditt svar:

Frågor om tillfredsställelse angående beslut i vården

Välj det svarsalternativ som stämmer bäst med din uppfattning. Om någon av frågorna inte stämmer in på dig och din anhörig, välj då ”inte relevant”. Det är viktigt att du fyller i alla frågorna.

25. Hur ofta samtalade läkarna med dig om din anhörigs tillstånd?

◯Mycket ofta

◯ Ofta

◯ Ibland

◯ Sällan

◯ Aldrig

◯ Inte relevant

26. Hur var personalens villighet att svara på dina frågor?

◯Utmärkt

◯ Mycket bra

◯ Bra

◯ Ganska bra

◯ Dåligt

◯ Inte relevant

27. Hur väl gav personalen förklaringar som du förstod?

◯ Utmärkt

◯ Mycket bra

◯ Bra

◯ Ganska bra

◯ Dåligt

◯ Inte relevant

28. Hur ärlig var den information du fick om din anhörigs tillstånd?

◯ Utmärkt

◯ Mycket bra

◯ Bra

◯ Ganska bra

◯ Dåligt

◯ Inte relevant

29. Hur väl blev du informerad om vad som hände din anhörig och varför åtgärder sattes in?

◯ Utmärkt

◯ Mycket bra

◯ Bra

◯ Ganska bra

◯ Dåligt

◯ Inte relevant

30. Hur stor var samstämmigheten i informationen om din anhörigs tillstånd från läkare, sjuksköterskor etc.?

◯ Utmärkt

◯ Mycket bra

◯ Bra

◯ Ganska bra

◯ Dåligt

◯ Inte relevant

31. Är det något du vill kommentera eller lägga till med egna ord angående frågor nr 25–30?

Ange ditt svar:

Frågor om beslutsprocessen

Under vistelsen på IVA fattades många viktiga beslut om din anhörigs vård. Välj det svarsalternativ som stämmer bäst med din uppfattning. Det är viktigt att du fyller i alla frågor.

32. Kände du dig involverad i de beslut som togs?

◯ Jag kände mig helt utestängd

◯ Jag kände mig delvis utestängd

◯ Jag kände mig varken involverad eller utestängd

◯ Jag kände mig delvis involverad

◯ Jag kände mig mycket involverad

33. Kände du att du fick stöd när beslut togs?

◯ Jag kände mig fullständigt övergiven

◯ Jag kände mig delvis övergiven

◯ Jag kände mig varken övergiven eller att jag fick stöd

◯ Jag kände att jag fick stöd

◯ Jag kände att jag fick för mycket stöd

34. Kände du att du hade kontroll över den vård din anhörig fick?

◯ Jag kände att jag inte hade någon som helst kontroll och att sjukvården tog över och dikterade den vård som min anhörig fick

◯ Jag kände att jag inte hade full kontroll och att sjukvården i stor utsträckning tog över och dikterade den vård som min anhörig fick

◯ Jag kände varken att jag hade kontroll eller att jag inte hade det

◯ Jag kände att jag hade viss kontroll över den vård min anhörig fick

◯ Jag kände att jag hade god kontroll över den vård som min anhörig fick

35. När beslut skulle tas, hade du tillräckligt med tid att få uttrycka din oro och få dina frågor besvarade?

◯ Jag hade behövt mer tid

◯ Jag hade tillräckligt med tid

36. Är det något du vill kommentera eller lägga till med egna ord angående frågor nr 32–35?

Ange ditt svar:

Sista timmarna tillsammans

Välj det svarsalternativ som stämmer bäst med din uppfattning. Det är viktigt att du fyller i alla frågor.

37. Vilket av följande beskriver bäst din uppfattning:

◯ Jag upplever att min anhörigs liv förlängdes i onödan

◯ Jag upplever att min anhörigs liv förlängdes något i onödan

◯ Jag upplever att min anhörigs liv varken förlängdes eller förkortades

◯ Jag upplever att min anhörigs liv förkortades något i onödan

◯ Jag upplever att min anhörigs liv förkortades i onödan

38. Under de sista timmarna av din anhörigs liv, vilket av följande beskriver bäst din uppfattning:

◯ Jag upplever att min anhörig hade det mycket jobbigt

◯ Jag upplever att min anhörig hade det jobbigt

◯ Jag upplever att min anhörig mestadels hade det tryggt och bra

◯ Jag upplever att min anhörig hade det mycket tryggt och bra

◯ Jag upplever att min anhörig hade det helt tryggt och bra

39. Under de sista timmarna av din anhörigs liv, vilket av följande beskriver bäst din uppfattning:

◯ Jag kände mig helt övergiven av vårdpersonalen

◯ Jag kände mig något övergiven av vårdpersonalen

◯ Jag kände mig varken övergiven eller inte

◯ Jag kände att jag fick stöd av vårdpersonalen

◯ Jag kände mig väl stöttad av vårdpersonalen

40. Är det någonting du vill kommentera eller lägga till med egna ord angående frågor nr 37–39?

Ange ditt svar:

Frågor om förberedelse inför döden

Välj det svarsalternativ som stämmer bäst med din uppfattning. Det är viktigt att du fyller i alla frågorna.

41. Var du förnuftsmässigt förberedd på att din anhörig skulle dö?

◯ Nej

◯ Ja, till viss del

◯ Ja, till stor del

◯ Ja, helt

42. Var du känslomässigt förberedd på att din anhörig skulle dö?

◯ Nej

◯ Ja, till viss del

◯ Ja, till stor del

◯ Ja, helt

43. När insåg du förnuftsmässigt att din anhörig skulle dö?

◯ Jag insåg det först när det inträffade

◯ Några timmar innan min anhörig dog

◯ Ett dygn innan

◯ Några dagar innan

◯ En vecka innan

44. När insåg du känslomässigt att din anhörig skulle dö i sin sjukdom?

◯ Jag insåg det först när det inträffade

◯ Några timmar innan min anhörig dog

◯ Ett dygn innan

◯ Några dagar innan

◯ En vecka innan

45. Är det någonting du vill kommentera eller lägga till med egna ord angående frågor nr 41–44?

Ange ditt svar:

Frågor om din hälsa

Välj det svarsalternativ som stämmer bäst med din uppfattning. Det är viktigt att du fyller i alla frågorna.

46. I allmänhet, skulle du säga att din hälsa är:

◯ Utmärkt

◯ Mycket god

◯ God

◯ Någorlunda

◯ Dålig

47. Jämfört med för ett år sedan, hur skulle du bedöma din hälsa nu?

◯ Mycket bättre

◯ Något bättre

◯ Ungefär densamma

◯ Något sämre

◯ Mycket sämre

48. Är det någonting du vill kommentera eller lägga till med egna ord angående frågor nr 46–47?

Ange ditt svar:

Tack för ditt deltagande

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End-of-life care in ICU:
Experiences of critical care nurses and family members

The overall aim of this thesis was to explore end-of-life care in the intensive care context from the perspectives of critical care nurses and bereaved family members, and to examine the health outcomes experienced by family members following the patient's death. The thesis is based on findings from two studies involving critical care nurses and two studies involving bereaved family members.

The findings show that critical care nurses require support to navigate the ethically challenging situations they face during end-of-life care in ICUs. They were faced with ethically complex challenges – often with life-threatening consequences – but had limited influence over decisions. They expressed a strong commitment to preserving patient integrity, but also described uncertainties in defining it as a concept and addressing patient integrity in practice.

Bereaved family members were generally satisfied with the end-of-life care. However, they also reported shortcomings in their interactions with healthcare professionals, particularly regarding the provision of information, emotional support and opportunities to participate in decision-making regarding patients' care. Notably, family members who rated their health as worse compared to a year ago, generally expressed lower satisfaction with the decision-making process.

Marie Cederschiöld University offers a PhD programme within the field The Individual in the Welfare Society. The area frames a field of knowledge in which both the individual in care and welfare, as well as societal interests and conditions, are accomodated.

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