

Prerequisites for palliative care provision in intensive care

Towards knowledge translation

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knowledge translation*

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For my great parents and family

(وَمَا أُوتِيتُمْ مِنَ الْعِلْمِ إِلَّا قَلِيلًا)

سورة الاسراء الآية ٨٥

ABSTRACT

Palliative care provision is aimed at improving patients' quality of life when cure no longer possible through healthcare systems, including intensive care. It has been observed that ongoing challenges exist concerning integration of palliative care into intensive care contexts. This necessitates an understanding of the contextual facilitators and barriers. The overall aim of this thesis therefore was to explore the prerequisites of palliative care provision in intensive care contexts. A multimethod approach was employed, including a systematic review, intensive care professionals and managers interviews, as well as a psychometric evaluation of an instrument with potential to be used for assessing intensive care professionals' attitudes in a future evaluation of a knowledge translation strategy. Study I is a mixed-method systematic review identifying factors influencing the integration of palliative approaches in intensive care units. The review included a total of 24 qualitative and quantitative studies and the findings indicated that the prerequisite factors were (a) an organizational structure that facilitates policies and environmental dimensions, and (b) interpersonal factors/barriers, related to the patient and the patient's family, including decision making, multidisciplinary team communication, and prognostication. Study II is an interpretive description design study involving interviews with 36 intensive care professionals, and was designed to explore their perspectives on the provision of palliative care within intensive care settings. The findings illuminated intensive care professionals' perceptions of palliative care within intensive care contexts, their decision-making related to goals for care strategies, and the challenges pertaining to family involvement in care goals. Study III is an interpretive description study exploring the association of organizational structures when integrating palliative care within an intensive care units. The study included interviews with 15 managers and 36 intensive care professionals. The findings show a 'do not resuscitate' policy as a gateway to palliative care, facilitating family members to enable to participation and support, while barriers to palliative care in the intensive care units exists in way intensive care organized. In study IV, a cross-sectional design was applied to measure the differential item functioning of the Frommelt Attitudes Toward Care of the Dying (FATCOD) scale. A convenience sampling method was used, recruiting participants from both Sweden and Saudi Arabia professionally working in intensive care contexts. Ordinal logistic regression was undertaken

to investigate potential differences in the perceptions of the items between different professional groups and in different geographical locations. The results establish that 12 out of 30 items in the FATCOD had significant differential item functioning among the groups. The conclusion derived from this thesis enhances our understanding of the facilitators and barriers of palliative care initiatives, as it illuminates the importance of acknowledging attitudes of death and dying within the professional groups in ways that go beyond the “do not resuscitate (DNR)” decision making as a gatekeeping process and considers the potential of integrating a palliative approach in intensive care.

Keywords: Palliative care, end-of-life care, Saudi Arabia, organizations, health care professionals, perceptions, intensive care units

Sammanfattning på svenska

Palliativ vård syftar till att förbättra patienternas livskvalitet när bot inte längre är möjligt inom hälso- och sjukvården, inklusive intensivvården. Det har observerats att det finns pågående utmaningar när det gäller integration av palliativ vård i intensivvårdssammanhang. Detta kräver en förståelse för de kontextuella facilitatorer och barriärer. Det övergripande syftet med denna avhandling var därför att utforska förutsättningarna för palliativ vård inom intensivvårdssammanhang. En multimetodansats användes, inklusive en systematisk granskning, intervjuer med vårdpersonal och chefer, samt en psykometrisk utvärdering av ett instrument med potential att användas för att bedöma intensivvårdspersonals attityder kring död och vård av döende.

Studie I är en systematisk översikt som identifierar faktorer som påverkar integrationen av palliativa metoder inom intensivvården. Genomgången omfattade totalt 24 kvalitativa och kvantitativa studier och resultaten visade att förutsättningar var (a) en organisationsstruktur som stödjer policyer och vårdmiljön, (b) interpersonella faktorer/barriärer relaterade till patienten och patientens familj inklusive beslutsfattande, multidisciplinär teamkommunikation och prognostisering. Studie II omfattar intervjuer med 36 intensivvårdspersonal, och utformades för att utforska deras perspektiv på tillhandahållandet av palliativ vård inom intensivvårdsmiljöer. Resultatet belyser intensivvårdspersonals uppfattningar om palliativ vård inom intensivvårdssammanhang, deras beslutsfattande i relation till vårdplanen och utmaningarna kring involvering av anhöriga i vården. Studie III utforskar sambandet mellan organisationsstrukturer vid integration av palliativ vård inom intensivvård. Studien omfattade intervjuer med 15 chefer och 36 intensivvårdspersonal. Resultatet visar att "beslutet om att inte återuppliva" (DNR do not resuscitate) är en gatekeeper till palliativ vård, som underlättar för familjemedlemmar att möjliggöra deltagande och stöd, samtidigt som hinder för palliativ vård på intensivvårdsavdelningarna återfinns inom organisationen av intensivvården. I studie IV användes en tvärsnittsdesign för att mäta "differential item functioning" inom FATCOD-skalan (Frommelt Attitudes Toward Care of the Dying). Ett bekvämlighetsurval användes för att rekrytera deltagare från både Sverige och Saudiarabien som arbetar inom intensivvårdssammanhang. Ordinal logistisk regression användes för att undersöka potentiella skillnader i uppfattningen av frågorna inom FATCOD mellan olika yrkesgrupper samt mellan länderna. Resultaten fastställer att 12

av 30 frågorna i FATCOD hade signifikanta skillnader i uppfattningen mellan grupperna. Slutsatsen av denna avhandling förbättrar vår förståelse för underlättande och hinder för palliativa vårdinitiativ, eftersom den belyser vikten av att erkänna attityder för död och döende inom yrkesgrupperna på ett sätt som går utöver "inte återuppliva (DNR)" beslutet och överväger potentialen i att integrera ett palliativt tillvägagångssätt inom intensivvården.

Nyckelord: Palliativ vård, vård i livets slutskede, Saudiarabien, organisationer, vårdpersonal, uppfattningar, intensivvårdsavdelningar

LIST OF PAPERS

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

- I. Alshehri, H. H., Olausson, S., Öhlén, J., & Wolf, A. (2020). Factors influencing the integration of a palliative approach in intensive care units: a systematic mixed methods review. *BMC Palliative Care*, 19(1), 1-18. doi.org/10.1186/s12904-020-00616-y.
- II. Alshehri, H. H., Wolf, A., Öhlén, J., & Olausson, S. Healthcare professionals' perspective on palliative care in intensive care settings: An interpretive description study. Submitted.
- III. Alshehri, H. H., Wolf, A., Öhlén, J., & Olausson, S. (2021). Managerial and organisational prerequisites for the integration of palliative care in the intensive care setting: A qualitative study. *Journal of Nursing Management*. 29(8), 2715-2723. doi.org/10.1111/jonm.13436.
- IV. Alshehri, H. H., Öhlén, J., Sawatzky, R., Olausson, S., & Wolf, A. Attitudes towards death and dying among intensive care professionals: Evaluating culture-related differential item functioning of the Frommelt Attitudes Toward Care of the Dying instrument. *In manuscript*

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ABBREVIATIONS

CIHR	Canadian Institute of Health Research
DIF	Differential Items Functioning
DNR	Do not resuscitate order
EoL	End of life
FATCOD	Frommelt Attitudes Toward Care of the Dying
ICU	Intensive Care units
KSA	Kingdom of Saudi Arabia
MoH	Ministry of Health
OLR	Ordinal Logistic regression
PARiHS	Promoting Action on Research Implementation in Health Services
PEO	Population, Exposure, Outcome
RN	Registered Nurse
SCCS	Saudi Critical Care Sociality
WHO	World Health Organization

INTRODUCTION

An intensive care unit (ICU) is a specialised hospital ward that provides care for critically ill patients under the supervision of specialists. Indeed, ICUs are the most sophisticated medical and technological departments available for numerous specific clinical requirements, not least in terms of their focus on providing lifesaving treatment for the most critically ill patients. Nevertheless, a significant number of patients die during or shortly after hospitalisation in ICUs [1].

Historically, with the development of the intensive care field, evolved most patients had life-threatening yet mainly non-chronic illnesses, such as infections [2], trauma and stroke etc [3-5]. However, as health care has considerably shifted towards management of chronic illnesses, intensive care also now includes chronic illness management occurring in healthcare [6, 7]. Intensive care has needed to adapt and develop treatment strategies for patients with life-threatening conditions, even when there is deterioration in their conditions and illness(es). The concept of palliative care has therefore been increasingly discussed and implemented into the intensive care contexts [8, 9] in order to relieve, ameliorate, comfort and support patients and their family members. In the last few years, palliative care has been widely integrated into different types of care contexts involving intensive care [10-12]. And while there has been research effort invested into knowledge translation of palliative care into intensive care [12], there has been limited success with knowledge translation strategies and models in healthcare systems across the world [13, 14].

Different concepts have been used to describe research designed to make use of new approaches in care practice, such as knowledge translation, implementation, integration, and quality improvement [14]. Palliative care is already embraced by guidelines for intensive care practice in terms of critically ill patients [15]. Nevertheless, obstacles have been encountered by intensive care researchers due to the absence of specialised knowledge about barriers and facilitators of palliative care [16, 17]. This makes it necessary to explore the prerequisites for palliative care provision toward knowledge translation through the perspective and experiences of intensive care professionals and managers in intensive care contexts. The purpose of this

thesis was to explore the prerequisites of palliative care provision to care delivery in intensive care contexts focusing on facilitators and barriers of palliative care provision in intensive care, as a means for developing a future knowledge translation strategy.

BACKGROUND

Intensive Care

Intensive care as a clinical discipline developed after the Second World War, with the primary goal to care for patients who were unconscious [18]. Eventually, the discipline evolved into a specialty aimed at providing care for critically ill patients who were in need of advanced medical treatments. This has promoted a culture that prioritises life-saving acute care and intervention without connection to palliative care.

Intensive care has been described as an organised system staffed by mainly specialist nurses and physicians, with the aim of delivering proactive resuscitative and supportive care for severely and critically ill patients in medical contexts that focus on life-saving interventions, managing hemodynamic instability, as well as life sustainment to support organ deficiency [19]. In the recent years, the intensive care practices have acknowledged the significance of providing dignified, quality-of-life care to patients approaching the end of their lives when the health-care technology fails [19].

Globally, intensive care consists of primary, secondary, and tertiary intensive care levels. The primary level involves higher specialist care competence and staffing targeting, for example, non-invasive respiratory procedures with a higher level of critical care knowledge compared to normal ward level. The secondary level involves delivering invasive monitoring and interventions (such as respiratory support) as part of basic life support for a limited period of time. The tertiary level provides a comprehensive range of monitoring and life support systems, acting as a regional resource for critically ill patients, which may also contribute to the advancement of intensive care medicine through research and education [19]. In the context of Saudi Arabia, these three levels relate to intensive care services in the context of scarce resources (Primary), good resources (Secondary) and relatively plentiful resources (Tertiary). The latter level of service is limited to larger urban areas within the Saudi Arabia, where intensive care has high-tech equipment and facilities [20].

Globally, intensive-care bed capacity differs from country to country. Intensive care beds are almost exclusively found in large urban regions, for example, the city of Boston in the USA has 45 times the number of intensive care beds per 100,000 people than the Republic of Ghana [21]. In Saudi Arabia, intensive-care beds capacity differs across the country. In 2020, Saudi Arabia's Ministry of Health (MoH) noted that there were 6,341 intensive care beds in the country, including 1146 beds in Riyadh [22]. In comparison, intensive care in Sweden is characterized by approximately 551 beds. However, population differences between countries must also be considered [23].

Providing care in intensive care units

The patient in intensive care

Patients receiving intensive care are often severely ill, requiring several treatments that targeted respiratory, multi-organ failure and/or circulatory organ failure [24]. Diverse medical conditions terminology is used to refer to patients' conditions in intensive care, for example, a patient's condition could be classified as acute, severely, chronically and critically ill. Patients with comorbidities of chronic illnesses are increasingly being occupied in the intensive care context, with acute symptoms such as cardiac, pulmonary, neurological, and renal dysfunction, as well as sepsis, diabetes mellitus and multiple organ failure [25-27].

In intensive care, patients with a tracheostomy, or mechanical ventilator or those hospitalised for over twenty-one days are characterised as chronically ill [28]. Chronic critically ill patients' progression is marked by a higher incidence of infection and shock. In particular, these patients exhibit a high prevalence of acute respiratory distress syndrome, and chronic obstructive pulmonary disease (COPD) [29], alongside a longer duration of mechanical ventilation [26, 28]. However, the suffering and vulnerability of some intensive care patients could have been exacerbated by their being sedatives as a result of their condition [30, 31]. Moreover, critical illness, ventilator treatment and sedative usage of convey a lack of voice for the patients, both literally and metaphorically, and a total dependence on the nursing staff. This means that the patients in ICU are a vulnerable group in need of continuous attention, care and treatment [30]. Both during and after intensive care, these patients are at risk of high morbidity, and might be experiencing physical and psychological distress [32]. Regardless, the reality is that the majority

of chronically ill patients are critically ill and fulfil the conditions for receiving palliative care in intensive care [8, 33, 34].

One of the more common chronic conditions for patients admitted in intensive care is cancer. In the United States, the number of cancer patients admitted to intensive care has grown dramatically over the past decade, with more than one-third of all patients now having a primary diagnosis of cancer [35]. Moreover, in Europe every sixth to eighth patient in intensive care has cancer [36, 37]. It is worth noting that survival rates among these European patients have improved during the last decade [38], whereas cancer patients admitted to the intensive care in Saudi Arabia, have a high mortality rate [39]. This does not exclude aggressive therapy for some for example, vasopressors, sepsis, cardiopulmonary resuscitation and mechanical ventilation are all linked to influences on mortality and changing the coding status to do-not-resuscitate (DNR) is common [39, 40].

Withdrawal/withholding of life sustaining treatment

Intensive care has long been known as a hub of treatment for the critically ill patients. And when the goals of curative care as determined by the patient, family member, and/or doctors are no longer effective, a decision to withhold or withdrawal life-sustaining treatments is not unusual. Withdrawing life-sustaining treatment is described as actively discontinuing such treatments, for example, ventilator support or vasoactive medicines, which are required for the patient's survival [41].

A DNR order is a medical decision which will be made by the treating physician. In certain countries, intensive care strategies include the medical decision of DNR, including in Saudi Arabia. DNR is regularly adopted as part of intensive care clinical practice, and might be combined with palliative care [42, 43]. Prolonging a life with severe chronic disease and suffering may not consistently be in the best interests of the patient. In Saudi Arabia, the local DNR policy indicates that life support measures will not be escalated or withdrawn further. Withdrawing treatments in such patients is no different ethically to withholding them. In either event, every effort will be made to maintain the patient's wellbeing, for instance, by reducing pain and discomfort, and everything less than aggressive resuscitative techniques will be used. DNR does not imply no treatment, and it does not mean the patients should be ignored or abandoned to die in pain [44]. Thus, a DNR order records a decision to not attempted cardiopulmonary resuscitation [45]. For example, life-sustaining treatments, cardiopulmonary resuscitation, ventilator

support and haemodialysis, which may not address the underlying causes of irreversible illnesses, may result in an extension of life, yet impact on quality of life and suffering. This has led to a transformation of how individuals consider the withdrawal or withholding of life-sustaining treatment. Research has evidenced that over 60% of patients classified as receiving withdrawing or withholding life-sustaining orders died within two days in the intensive care contexts [46]. Nevertheless, given that critically ill patients are individuals with a life expectancy of a few months or less, this indicates that withdrawing or withholding life-sustaining orders may have been made too late. On the other hand, research has evidenced that patients were transferred to general wards much more frequently after intensivists were involved in withholding and withdrawing life-sustaining treatment, compared to patients for whom intensivists were not involved [47].

Studies have shown that when intensive care professionals' were willing to support patients by proactively withdrawing life-sustaining therapies in advance of death, with this course of action was significantly linked with improving patients' wellbeing and increasing family knowledge of palliative care [48]. Nevertheless, it seems that intensive care professionals are regularly subjected to unpredictably high levels of tension and conflict, alongside confronting ethical difficulties, while physicians make decisions regarding withdrawing or withholding of life-sustaining treatment [49, 50]. Moreover, the use of life sustaining treatments over a longer period of time and hospitalisation were connected to feelings of regret regarding such decisions among intensive care professionals [51, 52]. In an intensive care context, a conflicts of interest might arise, with some intensive care staff focusing on the management and treatment of symptoms at the expense of being sympathetic to patient's own preferences [53]. However, the literature argues that in palliative care, the patient's preferences should assume priority [54].

The intensive care environment

Patients in intensive care require consistent careful monitoring, highly specialised interventions and expert care, from a variety of specialists [55, 56]. The main goal of intensive care is to return patients to a meaningful existences and to fulfil their life projects [57]. However, the goal of intensive care has also come to embrace providing palliation when the medical intervention is no longer of any benefits for the patient. Traditionally, this curative care culture has contributed to a reluctance to integrate palliative care with the core functions of intensive care. This is due to

intensive care professionals' concern that palliative care might accelerate death by diverting attention from curative care management [58, 59].

The intensive care context may be one of the most impactful and individualised areas of patient care. Intensive care contexts are complex environments equipped with high-tech machines and require the continuous presence of specialised professionals who have experience and knowledge of treating critical diseases [55]. For healthcare professionals, the intensive care environment is increasingly becoming regarded as a challenging and stressful one, which impacts on the quality of their professional work as well as, moral stress and burnout rates [60]. However, the intensive care environment is not only impacts on the healthcare professionals, but also on the families and the patients themselves [61]. Studies have emphasised that stressors, for example, loud noises and strong lighting, windowless rooms, and limited family bedside spaces, all affect patients' quality of life in intensive care [62, 63]. Moreover, research has stressed that just a few modest measures may contribute to developing a more comfortable environment for patients and their families, for instance, by painting and decorating walls, providing single rooms for patients with specific needs, as well as waiting rooms in intensive care [64]. The complex environment of intensive care is believed to have an impact upon palliative care provision and families' experiences of care.

Nurses' role in caring for patients in intensive care

The bedside nurse is the caregiver who spends 24 hours a day with the patients in the intensive care contexts, putting them in a unique position to secure patient safety and wellbeing, as they can quickly detect signs of deterioration or other potential threats. Critical care nursing education and specialisation differs from country to country. For example, in Sweden, registered nurses must have obtained a post-critical care diploma to work in intensive care. In Saudi Arabia, the critical care diploma has been in place since 2006, although it is not an employment requirement in intensive care contexts. Intensive care nurse shortage is a worldwide concern. In Saudi Arabia, the nurses' staffing ratio in intensive care is often referred to as one nurse working for two patients (1:2 ratio) in intensive care, although this varies across ministry of health hospitals. According to research, appropriate nurse staffing in intensive care should be a higher priority for quality of care and enhancing safety [65, 66]. Nurses have a key role in providing care in intensive care together with the multi-professional team. This also includes palliative care provision.

Providing quality care demands a multi-professional strategy that includes physicians, nurses and palliative care experts, such as consultants, psychologists, and spiritual care workers. However, this multi-professional approach may be limited in certain intensive care contexts. Since palliative care has a multidimensional approach to care, to provide this care, healthcare professionals need to possess a variety of care skills to provide it. For example, evidence-based research, covering palliative and care for critically ill patients and their families, has been published by critical care professional organizations [67-69]. The roles and responsibilities of nursing professionals in providing palliative care comprise connections between different healthcare specialties, including managers in intensive care contexts, patients, and the families of patients, all of which help to ensure that patients receive high quality of care [70]. Furthermore, the culture of nursing care within intensive care is multidimensional, for example, nurses have roles involving self-care, patient care, and family care, as well as environmental consciousness [71].

The multi-professional nature of intensive care

The care of patients in intensive care is administered by a diverse range of professionals [72, 73], with the precise nature of the expertise employed varying throughout the world. Intensive care contexts are typically staffed by highly qualified healthcare workers. This ensures improved patient outcomes, given that patients' care requirements in these contexts are complex and unique. For example, patients in a Canadian intensive care unit who were who needed palliative care were looked after by intensive care professionals and specialised palliative care consultants [74]. This had the effect of enhancing the quality of patient-and family-care, while also reducing costs and not affecting mortality rates [75, 76]. In Saudi Arabia, specialised palliative care remains in an early stage of development, and this also includes intensive care contexts [77, 78].

Consequently, according to earlier research of in intensive care contexts, there remain numerous obstacles and challenges for healthcare professionals in managing the transition from curative to palliative care in nations across the world, including Saudi Arabia [79-81]. Moreover, the attitudes, perceptions, and knowledge of the healthcare professionals could have an influence on the implementation of palliative care in the intensive care [82, 83].

Palliative care

According to WHO, the main goal of palliative care is to improve the quality of life for both patients and their families. Palliative care is defined as the provision of care to patients with a life-threatening disease that helps their family at the same time; this relates to physical, psychological and spiritual dimensions of care [84]. To achieve the main goal of maintaining quality of life, palliative care focuses on relieving symptom discomfort and reducing the severity of symptoms, as well as supporting and assisting family members [85]. However, while providing palliative care, challenges may arise in non-specialist palliative care contexts, including intensive care [86]. In certain countries, for example, the United States, it has been reported that a dearth of resources may hinder the ability of healthcare professionals to support families by addressing issues of pain, stress and anxiety [87, 88]. More recently, it has been emphasised that early integrated palliative care, i.e. applying palliative care alongside continuation of condition-specific treatments with a curative intent, may facilitate timely symptom diagnosis and treatment, as well as prolonged emotional support and transition of care. Furthermore, adopting palliative care has been evidenced as increasing patient quality of life while mitigating family stress and life-sustaining interventions at the end of life [89].

Saudi Arabia became the first Middle Eastern nation to establish a palliative care facility at an oncology hospital about 20 years ago [90]. Since its establishment, the facility has developed and strengthened the hospital's palliative care offering [91]. One limitation, however, is that palliative care is currently given to patients with cancer only, and the service is reported to be developing very slowly [91, 92]. This slow development is also reported internationally. For example, a recent review indicated that the majority of European countries are in the development stage of and are still working towards knowledge translation of palliative care into the healthcare system [93]. Nevertheless, there are contradictory assessments of such integration with the Global Palliative Care Atlas, which suggests the majority of the European countries show full integration thereof [94].

Palliative care and end-of-life care in the context of intensive care

Integrating palliative care has become increasingly complex in terms of provision in the intensive care context. Currently, palliative care approaches are guided by the patient's health, well-being and quality of life. It is an approach to care that is receiving attention and increasingly being introduced, in a variety of settings

within hospitals [95, 96], although palliative care outcomes require healthcare professionals to have the required skills and knowledge [97, 98]. Palliative care is a normative concept that refers to how to provide care for patients with a severe life-threatening disease or condition, wherein the principal goal is the enhancement of quality of life for patients and their families [97, 99]. End-of-life (EoL) care on the other hand, is a descriptive concept for care delivered close to death without indication of the care quality provided. Hence, while palliative care and end-of-life care are closely connected, palliative care is not just associated with end-of-life care not least in the case of chronic, deteriorating illness such as chronic heart failure or COPD. Indeed, palliative care can and should be provided alongside treatment and care and other therapies as part of a holistic care approach [69, 100]. Hence, palliative care could be provided for months or even years during a deteriorating stage of a disease.

Intensive care contexts have a higher proportion of critically ill patients who are likely to die [101]. Although intensive care contexts have greater mortality rates than with other contexts, palliative care does not focus solely on dying patients. EoL care is known to consume excessive proportions of resources in intensive care contexts [102, 103]. Palliative care is also recognized as a challenges by healthcare professionals in terms of prognostication, classifying [68, 104], continuity among senior intensivists, conflict between physicians [105], and decision making [83]. According to recent international studies, misconceptions about the aim of palliative care in intensive care means guidelines should be clear on how to integrate palliative care into intensive care, detailing how, when, and by whom care must be initiated and facilitated. This must be done, not only in accordance with the differences in responsibilities of physicians and nurses, but also in accordance with the implications of pertinent national laws and regulations [16, 106].

Two models of palliative care have been identified in intensive care contexts, namely the integrative and consultative models [107]; these reflect the distinction between generalist and specialist palliative care. The generalist palliative care model includes understanding pain and symptom management and the elicitation of preferences and basic discussions about goals of care, which are provided by primary clinicians in integrative palliative care. However, specialised palliative care is suited to patients who require assistance with complicated decision-making, refractory pain and symptom control or those who experience considerable psychological distress and require goal-of-care conflict resolution.

Integrated palliative care provides benefits and value to patients, their families, as well as the overall health-care system [108]. In practice, these models can and should

be combined. Multiple studies point out that although intensive care contexts are equipped for the purpose of prolonging patients' lives or treating life-threatening conditions, intensive care professionals are increasingly finding themselves caring for patients in the end-of-life situations, necessitating palliative care [58, 109, 110]. Thus, it is known that establishing a balance between providing specific medical treatment to patients with a severe illness and providing palliative care towards quality of life is challenging for intensive care professionals [16, 111].

Palliative care: patient- and family-focused

The central premise of palliative care is quality of life that it should focus on the whole patient, not solely on the patient's symptoms. Addressing those symptoms is nevertheless an important part of palliative care, in as much as this will contribute to providing the patient with "wellbeing" [112, 113]. Research from Austria and Demark has emphasised patients' feelings of emotional and physical vulnerability, often in the context of intensive care [114, 115]. Studies suggest it might be better for seriously ill patients in intensive care to benefit from the attention of palliative care specialists together within intensive care specialists [116, 117]. Another important consideration is that each patient's cultural, religious and spiritual needs, and those of their family, should be taken into account when a palliative care plan is devised. This is confirmed by a recent systematic review that emphasises the need to pay attention to measurements of spiritual consequences of palliative care, including developing spiritual competence for knowledge translation [85].

Research into the needs of family members and their experiences of being with their family in intensive care has revealed they encounter difficulties with the use of medical terminology and with obtaining information about administered treatments and the patient's condition [116, 117]. Supporting and comforting the family must therefore be prioritised [118]. Furthermore, the intensive care context can be hindered by a lack of staff training in relation to identifying and assessing specific spiritual needs [119, 120]. Developing a better understanding of the importance of psychological and spiritual needs, particularly in respect to bereavement, may improve care approaches in intensive care [85].

A key requirement in the delivery of palliative care is to develop an understanding of the patient's and family's involvements to inform the assessment and treatment of symptoms that will cause distress, but it should be acknowledged that the acute nature of an illness or condition might make this difficult for intensive care

professionals to achieve successfully. Moreover, gaining an understanding of a patient's wishes might be made more difficult by the fact that certain patients are under sedation [121, 122], in which case attention shifts to consulting with the patient's family members. In this case, the participation in care must be handled by the intensive care professionals and the family of the patient. Introducing communication is an important dimension that facilitates empathising with family members and discussing death and dying a meaningful manner [107]. Enhanced communication can help patients achieve better results, such as fewer psychological symptoms, anxiety, a shorter hospital stay, and wellbeing during the dying experience and death in intensive care [123, 124]. The key to this is to consider and provide palliative care in intensive care and withdraw life-prolonging treatment in an expected manner, rather than as an unpredictable emergency.

Knowledge translation

Knowledge translation is the formal study of ways in which the results of research and other empirical findings can be integrated into clinical practice in order to improve healthcare outcomes [125]. Numerous names have been developed for describing the procedure of putting evidence of knowledge into action. For example, in the United Kingdom and Europe, terminology such as implementation science and research utilisation are typically adopted. The words dissemination and diffusion, research usage, knowledge transfer, as well as uptake, are regularly used in the United States. In Canada, common terms are knowledge transfer and exchange, in addition to knowledge translation [126]. Implementation science is the term given to the scientific study of strategies that encourage the systematic integration of research findings and other evidence-based practices into clinical practice, thereby enhancing health services' quality and efficacy [127]. Moreover, knowledge translation is described as an on-going, multi-faceted process to ensure the evidence-based strategies integrate into specific services or context [128]. However, the Canadian Institute of Health Research (CIHR) offers a broader definition, which emphasises the dynamic and iterative nature of knowledge translation, stressing that it also includes ethical considerations, the integration of research findings from different sources and a strategy for dissemination [129].

This thesis studies the prerequisites for palliative care provision in the intensive care contexts. The research is focused on facilitators and barriers for the purpose of enhancing palliative care knowledge translation in intensive care, which includes the organisational level and intensive care professionals' perceptions of

and management strategies for delivering palliative care in intensive care. Researchers in this field have defined three aspects of palliative care, namely early care services, the integration of palliative care knowledge into practice and the delivery of care to individuals with specific needs [130]. There are, however, gaps in knowledge pertaining to facilitators and barriers of palliative care provision, particularly in non-specialized healthcare contexts, such as the intensive care context. There are different types of frameworks and approaches available that support knowledge translation in practice. Promoting Action on Research Implementation in Health Service (PARiHS) was adopted as the framework for this thesis. The PARiHS framework has notable face validity and conceptual relevance for implementation [131], while also being appropriate to use in relation to different topics and healthcare settings [132].

The PARiHS framework was developed in 1998 [133] and highlights the dynamic interaction between context, complexity and the knowledge translation process when it comes to enhancing evidence-based knowledge uptake within healthcare environments [134]. The PARiHS is a well-known conceptual model [135]. The framework identifies successful research knowledge translation as a function and highlights the relationships among three categories: evidence, context and facilitation. According to Kitson and colleagues (who developed the PARiHS framework) evidence means a combination of evidence or knowledge that is developed from different elements, and this may be derived from research. The prerequisite for knowledge translation's success is that there must be clarity regarding the nature of evidence being utilized. According to the PARiHS framework, considering the quality of the context and culture is critical, for example, understanding the nature of human relationships, clear leadership roles and an organisational approach. Monitoring systems are important and classified as highly important for the successful knowledge translation of evidence, while facilitators can help to make changes easier for individuals. Facilitation itself requires the consensus around and understanding of the evidence, as well as the accessibility in the individual context or setting, for example, familiarity with the resources, culture and values, leadership style and evaluation [136].

Knowledge translation of palliative care within intensive care

Since introduction of palliative care into intensive care, knowledge translation in general has generally been influenced by factors related to either the organisation or the individuals concerned. For example, much palliative care knowledge translation has been employed with the objective of improving care, augmenting

communication [137], and providing comfort through pain medication [138], all of which have different care provisions for the purposes of integrating specialty palliative care into primary teams in intensive care contexts [139, 140]. Existing research indicates that combining palliative care strategies within intensive care is difficult due to the heterogeneous nature of the approaches, and is therefore not successful in all strategic phases. Nevertheless, these knowledge translation strategies in terms of proactive palliative care in intensive care contexts and utilizing consultative or integrated palliative care approaches have been shown to reduce the duration of intensive care stay by transferring patients to the ward whilst simultaneously having no impact on either mortality rates or patient satisfaction [139, 140].

Research indicates that one of the major barriers to the knowledge translation of a scalable based palliative care model within intensive care was the reluctance on the intensive care professionals [11]. This does not simply relate to any specific care professional, but rather reluctance on the part of a whole specialist team for example, in referring oncology patients to palliative care close to their end of life [89, 141]. Research findings suggest that palliative care is a difficult and confounding issue for intensive care professionals because it is inadequately integrated and categorised within intensive care services [142, 143]. This might be due to an absence of policies concerning palliative care or to the fact that hospital administrations do not assume enough responsibility for the development of care approaches that enhance the quality of care for patients and their families in intensive care contexts [144].

Knowledge translations of communicating goals of care have been studied in intensive care. Family members often help as surrogate representatives for those critically ill patients who are unable to speak for themselves. Previous studies emphasise that a team approach to communication [124], formal family meeting [145], a bundled checklist method and the utilisation of advanced practice nurses are successful strategies for improving communication in the intensive care setting [146]. Nevertheless, professional bedside intensive care remains significantly diminished in such approaches, and palliative care provision is essential to establishing and improving effective communication about the goal of care in the intensive care context [146].

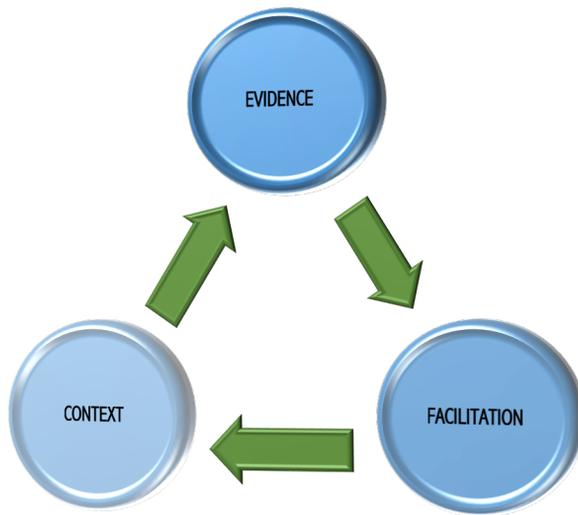


Fig 1: PARIHS framework interrelation of evidence, context, and facilitation

RATIONALE

While intensive care practice emphasises palliative care as essential in the intensive care context, the integration of palliative care into the practice of intensive care presents challenges worldwide. Palliative care services differ widely between countries, as well as between healthcare systems. In Saudi Arabia, for example, palliative care is most typically provided within the regular hospital setting, including the intensive care context, which is primarily associated with oncology. In contrast, palliative care in Scandinavian countries such as Sweden is primarily delivered as an integrated part of a healthcare system and supported by specialised palliative care services. However, when scrutinising a more specialist high-tech hospital setting, such as intensive care, we find the requirements and nature of intensive care to be very similar. In the case of palliative care, the demand for ‘transition care’, in which patients’ care moves from intensive care intervention towards only a palliative care, has increased as professionals have recognised patients’ need for palliative care in intensive care contexts. This transition requires understanding of prerequisites for palliative care provision in order to enable the integration of palliative care in the intensive care. Moreover, due to the use of modern technology and resources by intensive care professionals experts, the treatment of patients in an intensive care context is one of the most advanced, invasive, and most expensive care solutions available. It is therefore essential to recognise alternative ways of providing quality care for patients in need of palliative care, with the objective of enhancing quality by optimising consumption of intensive care resources while also minimising distress and suffering for both the patient and the patient’s family.

There is also a dearth of understanding regarding the meaning of palliative care and approaches in non-specialized contexts, including intensive care. Due to the limited availability of facilities and cultural constraints, there is a general lack of knowledge about managing and adapting palliative care in line with the requirements of critically ill patients. Thus, it is essential to generate knowledge about and develop a better understanding of both the barriers to, and the facilitators of palliative care in the intensive care context, as such knowledge may be utilised to facilitate further research and development in the field, particularly with regard to the prerequisites of initiatives towards knowledge translation in intensive care contexts.

AIMS

Overall aim

The overall aim of this PhD thesis was to explore the prerequisites of palliative care provision in intensive care contexts.

The specific aims of this thesis were:

Study I: To identify factors influencing a palliative approach in intensive care units, as perceived by health professionals

Study II: To explore professionals' perspectives on providing palliative care and end-of-life care within an intensive care context

Study III: To explore the association of organizational structures when integrating palliative care in intensive care units

Study IV: To examine whether the FATCOD-B overall measure has the same meaning across different societal and healthcare contexts, as exemplified by intensive care professionals in Sweden and Saudi Arabia

METHODS

Study design

This thesis encompasses four studies that together try to create a more comprehensive understanding of the prerequisites of palliative care knowledge translation in intensive care contexts from a clinician and provider perspective. An overview of the specific studies is provided in Table 1.

The research paradigm in this thesis was a multimethod approach that combined interpretive and measurement paradigms [147]. The multimethod sequential design was chosen to provide a rich understanding of the prerequisites for palliative care provision towards knowledge translation into intensive care [148]. This includes sequence studies using different designs, data collection methods and analyses. In this thesis, four single studies were used to explore specific prerequisites of palliative care provision towards knowledge translation into intensive care.

Table 1. Overview of the studies

Topic	Study I	Study II	Study III	Study IV
Design	Mixed-method systematic review	Interpretive description	Interpretive description	Quantitative Cross-sectional
Data Collection	Systematic literature search	In-depth interview	In-depth interview	FATCOD scale
Participants	24 published studies/ (8) qualitative, (8) quantitative, and (6) mixed methods studies. healthcare professionals	36 Intensive care professionals	15 Managers 36 intensive care professionals	150 Swedish intensive care and registered nurses/127 Saudi intensive health care professionals
Data analysis	Thematic synthesis	Constant comparative analysis	Constant comparative analysis	Logistic regression analysis

Study I

Mixed Methods Systematic Review

Study I was a mixed method systematic review, with the aim of understanding the factors that shape palliative care approaches in intensive care settings. It contains a structured and systematic search, a quality appraisal, and a data synthesis using thematic analysis. A mixed method in the form of a systematic review (Study I) was conducted as part of this thesis to generate a more refined understanding of the subject, in addition to providing information from recent literature related to the facilitators of and barriers to the delivery of palliative care in intensive care contexts. This method also facilitates the identification of both current knowledge and current knowledge gaps, thereby highlighting areas for future research.

Eligibility criteria

Study I explored the views, perceptions and experiences of intensive care professionals regarding the facilitators and barriers to knowledge translation of implementing or integrating palliative care in an intensive care context. The main inclusion criterium was that the studies should focus on integrating palliative care into intensive care settings. A search was created guided by the population, exposure and outcome (PEO), within the inclusion and exclusion criteria of this study. Qualitative, quantitative and mixed method studies published from January 2007 to January 2018, inclusive, were eligible. A further criterion was that the studies should be written in English and be peer reviewed. Non-empirical studies were excluded, as were settings such as neonatal, and paediatric intensive care, in order to maintain the study's emphasis on adult services.

Search strategy

In Study I, a comprehensive search was undertaken using electronic databases for searching the literature including AMED, PubMed, EMBASE, PsycInfo, Sociological Abstracts, Web of Science, Scopus and Cinahl. The search involved the use of MeSH phrases relating to implementation, palliative care and Intensive Care Units and two professional librarians conducted searches using key terms.

Study selection

A total of 1,843 articles were evaluated, with the selection process undertaken blind by two of the authors in accordance with the inclusion criteria. The duplicated studies were eliminated using Endnote, with 436 being removed during the first round, and a further 113 during in the second round. The online Rayyan software screening tools for systematic review was adapted for the screening and exclusion process [149]. After removing the duplicates, 1,294 studies were screened, the first round, screening the studies' titles and abstracts. This led to 158 studies being included. In the second round, both authors read the full text of the articles included from the first step, with 45 studies remaining. In the third round, the blinding was removed, and the articles were discussed between the two authors and the group of authors. Ultimately, 24 articles were selected that fulfilled the study's inclusion criteria. Quality assessments were performed separately for the quantitative, qualitative and mixed-method studies.

Data analysis

Integrative thematic synthesis techniques were applied to nine qualitative, nine quantitative and six mixed-method studies. There were three steps to the thematic analysis of factors influencing the palliative care process in intensive care were [150]. The initial analysis stage was inductive, involving line-by-line reading of articles several times, with text from the empirical studies being extracted pertaining to pertinent barriers and facilitators. The second analysis stage concentrated on the variables affecting palliative care in the intensive care context, independently derived from the quantitative and qualitative results. During the third stage, the findings were integrated with an emphasis on the factors affecting palliative care in intensive care, from quantitative and qualitative data. The analysis was then double-checked against the papers and each study, meaning that text units and categories were identified. Preliminary analytical inconsistencies were discussed among the authors. The similarities and differences between the influential variables were grouped into overarching analytical categories (types of factors) and more descriptive categories (specific factors) [150]. The final findings were reviewed and double-checked by all authors.

Studies II and III

Interpretive Description Methodology

In Study II and III, interpretive description of a non-categorical qualitative design [151] was adapted to generate an in-depth understanding by exploring the provision of palliative care for patients in intensive care. This design was chosen to understand the complexity of palliative care in intensive care from the perspectives of intensive care professionals and managers [151]. Study II aimed to explore professionals' perspectives on providing palliative care and end-of-life care within an intensive care context. Study III highlighted the views of managers and professionals regarding organisational structures related to the integration of palliative care in the context of intensive care.

Settings and participants

The healthcare system in the Kingdom of Saudi Arabia (KSA) has two main providers: 1) the government and 2) the private sector. Healthcare systems include both general and specialist hospitals. The healthcare system also includes three levels of care: Primary, Secondary and Tertiary [19]. MoH hospitals provide 13.1 beds per 1,000 people and, as a whole, there are 1,146 adult intensive care beds [22] in Riyadh, where the data were obtained. Studies II and III, featured four government MoH hospitals in Riyadh. Two of these provided a tertiary level of care, while the other two were classified as offering a secondary level of care.

Study II included participants who were bedside intensive care professionals, while Study III involved participants who were both bedside intensive care professionals and managers. Further inclusion criteria for both Study II and Study III enabled participants from various nationalities and with different backgrounds to take part. As English is the official language of the Saudi healthcare system, it was also stipulated that the participants should be able to speak and understand English. In Study II, purposeful sampling was applied and the number of intensive care professionals taking part was 36, comprising 19 nurses, 12 physicians, four respiratory therapists and a dietician from an allied health group. Moreover, in Study III a theoretical sample was carried out when the author achieved variance between the participants. The total number of participants in Study III was 51,

comprising the 36 intensive care professionals who took part in Study II joined by 15 managers.

Data collection

Studies II and III were performed concurrently, wherein oral and written information was provided to the participants. After securing permission from the heads of the relevant departments in each hospital, a meeting was held with bedside intensive care professionals and managers in order to explain the aims of the research and to confirm their willingness to take part. This also provided an opportunity to finalise the time and location of interviews with the physicians and consultants who had agreed to participate in the study. The interviews were held in an intensive care conference room during the participants' working day.

The method of data collection was in-depth, face-to-face interviews, [152] using open-ended questions on issues relating to palliative care and end-of-life in intensive care (*See appendix*). The interview questions were piloted prior to the study and no major revisions were done. The pilot interviews were not included in the studies. Specifically, interviewees were asked how they provided palliative care for patients in intensive care and, as those patients approached the end of their lives, to describe how they provided care for the patients' family, as well as their personal feelings while providing such care. The managers were asked parallel questions focusing on organizational perspectives and prompted to explain their answers related to palliative care provision for patients in intensive care.

Participants were encouraged to provide further details where necessary, in order to provide the widest possible perspective on their perspectives and experiences [153]. Each interview was recorded, to enable the interviewer to transcribe it word with field notes. The length of the interviews varied from 12 -59 minutes.

Data analysis

A constant comparative analysis was carried out using interpretive description [151] for both Studies II and III. At the core of these studies was the interviewees' views on delivery of palliative care and end-of-life care, in an intensive care context. To minimize bias in the text analysis, an inductive technique was separately employed for each of these studies. The author began with the analysis the Study II before commencing with Study III. The interviews were read and re-read

repeatedly until the data as a whole was known to the author. Each the interview data for each study was analysed separately by using the NVivo 11 software, to code and create a pattern of meanings that were related to each other. After this the interviews were read and re-read once more before widely coded, the data resulting in the creation of greater text segments. This text concerning to how palliative care was provided to patients and their families, as well as identifying organisational facilitators, and barriers to intensive care. The analysis was performed for both studies according to the following interrelated steps:

The first step in the process of analysis was to thoroughly read the transcripts of the interviews several times, after which a synopsis was prepared to describe each participant in the study, with an emphasis on their background and expertise.

The second step in the preparation for the analysis required the researcher to reflect on the assumptions informing the research and to understand how they related to the research objectives.

The third step comprises the establishment of a provisional framework for analysis in order to highlight key organisational facilitators and inhibitors, the relevant personal characteristics of participants, and participant experiences related to the provision of palliative and end-of-life care for patients and care for their families.

The fourth step in the analysis focused on the objectives of Study II and the completion of reflection journals that were written to reduce the risk of any mix-up between the studies.

The fifth step sought to address the objectives of Study III, with the findings emerging from this phase of the research confirming that the evidence provided by healthcare managers had substantially more depth than that obtained from intensive care professionals. The next task undertaken was an analysis of the interviews conducted with managers.

The sixth step in both Study II and Study III was an analysis which comprised the coding and thematic grouping of the text contained in the interview transcripts, with their similarities and differences identified, compared, and contrasted.

The final stage of the analysis involved comparing between the data collected from the intensive care professionals in Study II, as well as that from the intensive care professionals and managers, with all the similarities and differences noted in Study III [151]. After the analysis had been completed and the findings had been

thoroughly discussed within the research team, a final draft of the findings was agreed.

Study IV

Cross-sectional Study Design

The thesis was developed in accordance with the findings of Study IV, regarding the impact of attitudes and different perspectives among the professionals emerging from Studies I-III. In Study IV, a psychometric evaluation of the frequently used the Frommelt Attitudes Toward Care of the Dying (FATCOD-B) scale was performed, with the aim of investigating the instrument's stability across different cultures, experiences and professional groups. This was performed using a cross-sectional design. A cross-sectional study design is one that is undertaken at a single point in time, or within a short timeframe [154].

Settings and Sample

This study was designed to measure the attitudes of healthcare professionals' attitude towards care for dying patients, the intention being to evaluate the psychometric properties associated with the FATCOD-B scale in respect of different intensive care cultures and professional backgrounds and experiences, using Differential Items Functioning (DIF). The sample included registered nurses (RN) studying a critical care master's program, and intensive care nurses from Sweden, and intensive care professionals from Saudi Arabia. In total, 227 respondents from Sweden and Saudi Arabia were included in this study.

Procedure

In Study IV, the data was collected in both Sweden and the Kingdom of Saudi Arabia. In KSA, data was collected at the 11th Annual International Critical Care Conference of the Saudi Critical Care Society, held in Riyadh. The respondents who agreed to participate were required to complete a printed survey comprising FATCOD-B questions (*See appendix*). Participation proceeded once the respondents had provided their informed consent by signing the relevant forms and placing them in a drop box located both in the main entrance and in the Saudi

Critical Care Society booth. The data was collected between 18th and 20th February 2020, after which an online survey link was sent to members who had registered at the Saudi Critical Care Society administration office. The Saudi respondents participated in the survey through this procedure.

Data from Study IV was combined with data obtained from research focusing on Swedish nurses. The information about the study and authors was sent via email to the heads of actual nine intensive care units in hospitals and program directors for critical care masters programmes at seven universities. A total number of 364 critical care nurses were invited to participate in the online survey questionnaire, which included 30 items of FATCOD in Swedish. Information regarding the study and the consent process were provided online before participants began completing the survey. The survey was completed by 118 intensive care RN from seven hospitals. The survey was also completed by nurses with a critical care masters programmes. In total, seven universities were invited, although two universities declined to participate in the survey. The online survey questionnaire was sent to 82 RN studying the critical care masters programmes, with a total 32 students completing the survey.

Data analysis

In Study IV, the FATCOD-B data was analysed using confirmatory factor analysis (bifactor model), descriptive statics and ordinal logistic regression (OLR). Participants' responses were assessed according to their country population, profession and experience level, with factor analysis being applied to confirm the single dimension of the FATCOD-B total score. The Zumbo criteria (1999) [155] was used to evaluate three OLR models, which enabled examination of DIF detection. Analysis of the nonuniform and uniform DIF between models is suggested by comparing the differences between the chi-square, -2 log-likelihood values, as well as the Naglekerke-R-square [155]. Meanwhile, the logistic regression approach is adopted to analyse the extent of data variance in the items within the group. R-squared values in models one and two were compared by considering the unique variance in group differences above and beyond the variables, thus highlighting the significance of DIF. The chi-squared value is obtained for models 1 and 3, enabling a comparison of two degrees of freedom and the distribution function. The chi-squared p-value was calculated and computed using IBM SPSS statistics for Mac version 27 and Excel software.

Ethical considerations

The study was conducted in accordance with the ethical principles of the Helsinki Declaration [156], thus identifying those aspects of the research that concerned human subjects. For example, participant autonomy was considered and respected by the researchers. In Study II and III, participants were informed during data collection that their participation was entirely voluntary and that they had the right to withdraw from the study at any time without the need to offer any reason or explanation. Study IV was an anonymous survey wherein it was not possible to identify individual responses. Nevertheless, a consent form was attached to the questionnaire [156]. To protect the privacy and confidentiality of participant information, the data was securely stored in a password-protected computer file. The written data and digital recordings were kept in cabinets with digital passwords to which only the researcher had access.

Ethical approval for Study II and Study III was sought from and granted by the Ethical Centre Office at the Ministry of Health in Saudi Arabia. The four hospitals were also approved by the research centre. In addition, the data gathering process employed in Studies II and III was approved by the internal ethical IRB committees of each hospital. Written and verbal approval was obtained from participants during the data collection process. Participant information sheets and consent forms were provided for all participants prior to data collection (*see Appendix*). Study I was a systematic review, and therefore ethical approval was not applicable. Due to the nature of the study design being a systematic review, the review was recorded for the protocol registered in the international prospective register of systematic reviews (PROSPERO: CRD 42018099786).

The participants in Study IV were from Saudi Arabia and Sweden. The researcher consequently adhered to the ethical processes and policies applicable in each respective country. The Swedish part for Study IV was approved by the Regional Ethical Review Board in Gothenburg (ID997-15). Ethical approval for Study IV was provided by the chair of the Saudi Critical Care Society to collect the survey during the conference and online. In order to maintain absolute anonymity, the link for the survey was sent to all members of the society through its administrative system. Specifically, anonymity was ensured and consent was presumed when participants consented to participate.

RESULTS

This chapter contains a brief description of individual results of each study, and a comprehensive understanding of all four studies to inform the evolution of palliative care knowledge translation in intensive care.

Study I

In total, 24 studies were included, of which nine were quantitative studies, nine qualitative studies, and six mixed-method studies, with the intention being to identify the factors influencing palliative care in intensive care units, as perceived by healthcare professionals. The majority of studies were performed in western cultures, including the USA, United Kingdom, Netherlands, Germany, Australia, Canada, Brazil and Japan. The included studies were rated as high to moderate, moderate, and low to moderate quality. Four main influencing factors were identified as facilitators and barriers to palliative care in this mixed method review and the main results are presented in the Table 2.

Table 2: Facilitators and barriers of influencing knowledge translation of palliative care in intensive care

Main Influencing factors	Sub-Influencing factors
1- Organizational structure	-Managerial resources -Policy and guidelines -Knowledge and skill -Multidisciplinary team involvement in to care
2- Working environment	-Physical environment -Psychosocial environment
3- Patient and family involvement in the care	-Conflicting with goal of care -Participation with goal of care -Information and communication
4- Palliative care decision making	-Transition of goal of care -Withholding or withdrawal of treatments -Prognostication - Multidisciplinary team communication

Study II

This study involved 36 intensive care professionals, including 19 nurses, 12 physicians, and 5 allied healthcare workers, all of whom were interviewed about their perspectives on providing palliative care and end-of-life care within intensive care. While palliative care has not yet to become part of a systematic approach in care within the participants' intensive care context, the data confirmed that standardised structures exist in connection to DNR policies and end-of-life care at the various intensive care contexts where the participants worked. The findings illuminated three broad themes that reflect the perspectives of various intensive professionals, namely:

- 1) Perceptions of palliative care and end of life care within intensive care, including how the participants practise palliative care and end-of life-care, and their personal views of hospital policy.
- 2) Decision-making regarding the goals of care involving how participants assess patients' eligibility for life-sustaining treatments, and the responsibility for care goals decisions.
- 3) Challenges associated with family involvement in care goals, describing the participants' perspectives on communicating care decisions with the family and facing their emotional burden.

Study III

A total of 51 (36 intensive care professionals and 15 managers) interviews were performed and analysed with intensive care professionals and managers working with patients in intensive care settings. Both managers and intensive care professionals reported that organisational structures were a hindrance to the integration of palliative care into intensive care in respect of differences in hospital policy, routines, and resources in the four hospitals. Three themes were elucidated:

- 1) Do not resuscitate policy as a gateway to palliative care that included practising and organising policy.
- 2) Facilitating family members to enable participation and support.
- 3) Barriers to palliative care in the intensive care unit as a result of intensive care organization including barriers and resources on a personal and environmental level.

Study IV

Study IV was a cross-sectional online and distribution survey of intensive care professionals. In total, 277 intensive care professionals from Sweden and Saudi Arabia responded to the survey, with FATCOD items being used in this research.

Adopting a common attitude scale might enable enhanced comprehension of palliative care provision in relation to knowledge translations strategies. The descriptive analysis data indicated that each group had different responses to the total score. The results evidenced that 12 items had large and moderate DIF values, with the results being presented in Table 3.

The results of the intensive care professionals' responses to the FATCOD items in both Sweden and Saudi Arabia and the factor analysis identified the dominant factor, as well as a few other minor factors. The findings showed 12 items with larger to moderate DIF (namely 1, 8, 12, 15, 16, 18, 20, 21, 24, 25, 29 and 30). The majority of these large DIF items pertained to family questions, for example, item 12- Family involvement in physical care; item 16- Families' emotional support; item 18- Families input into care; item 20- Families' maintenance of normality in the environment; item 24- Family authority, and item 29- Family interferes with care. Additional items related to personal experiences or perceptions, for instance, item 1- Care experiences item 8- Lack of hope from dying person; item 21- Express feelings; item 25- Pain medication, and item 30- Preparation for death. This study revealed that Swedish and Saudi intensive care professionals do not interpret and respond in the same manner to FATCOD items in terms of attitudes towards death care and care for dying patients.

Table 3: The results of Chi-square/P-value and R-square differences related to FATCOD Items from Swedish and Saudi Arabia participants.

FATCOD items	Professional groups from both countries		Registered nurses from both countries		Level of professional experience of registered nurses from both countries		Professional groups within the Saudi Arabian group	
	R-square differences	Chi-square Differences/P-value	R-square differences	Chi-square Differences/P-value	R-square differences	Chi-square Differences/P-value	R-square differences	Chi-square Differences/P-value
1. Care experiences	0,038	8,203/<0.001	0,049	9,281/<0.001	0,007	1,389/0,249	0,022	4,19/0,061
8. Lack of hope from dying person	0,054	26,112/<0.001	0,061	20,267/<0.001	0,016	20,893/<0.001	0,008	1,605/0,224
12- Family involvement in the care	0,274	81,674/<0.001	0,307	63,769/<0.001	0,010	2,522/0,141	0,018	5,911/0,026
15. Personal feelings at time of death	0,029	15,968/0,000	0,045	13,261/<0.001	-0,002	1,138/0,283	0,001	0,438/0,401
16. Emotional support for family	0,136	36,891/ <0.001	0,190	35,757/<0.001	-0,001	0,012/0,497	0,015	2,558/0,139
18. Family input into care	0,096	26,455/ <0.001	0,126	26,610/<0.001	0,002	0,061/0,484	0,009	4,842/0,044
20. Maintain normality in the environment.	0,233	65,985/ <0.001	0,254	48,422/<0.001	0,011	2,048/0,179	0	0,135/0,467
21. Express feelings	0,119	31,711/ <0.001	0,170	27,052/<0.001	0,033	0,545/0,380	0,003	2,376/0,152
24. Family authority	0,279	85,971/ <0.001	0,317	72,124/<0.001	-0,001	0,371/0,415	0,035	6,866/0,016
25. Pain medication	0,135	69,654/ <0.001	0,122	39,479/<0.001	0,005	0,525/0,384	0,730	8,286/<0.001
29. Family interferes with care	0,071	39,224/ <0.001	0,082	31,245/<0.001	0,001	1,879/0,195	0,023	3,034/0,109
30. Prepare for death	0,049	37,103/ <0.001	0,036	31,818/<0.001	0,019	4,241/0,059	0,023	5,081/0,039

Note: (The gray FATCOD items are positively worded questions), light blue represents (Zumbo criteria, R² values moderate (0.045 to 0.070)), while dark blue represents (greater than 0.070 is large). The p-value is less than or equal to 0.01

SYNTHESIS OF RESULTS

The synthesis of the results from Studies I-IV were combined to create a comprehensive understanding of individual study results. For this purpose, the findings were synthesised using the PARIHS theoretical model was that included with three elements (evidence, context and facilitators) from the practical model. The themes in this synthesis were interrelated with the evidence, context and facilitators. Five themes were identified in this synthesis: 1) Organisational structures and environmental barriers to work in intensive care, 2) Intrapersonal factors related to care decisions in intensive care, 3) Family-centred care ambivalence, 4) DNR as a gatekeeping process and facilitators in intensive care, and 5) Stakeholders' perceptions and attitudes. The synthesis is illustrated in Figure 2.

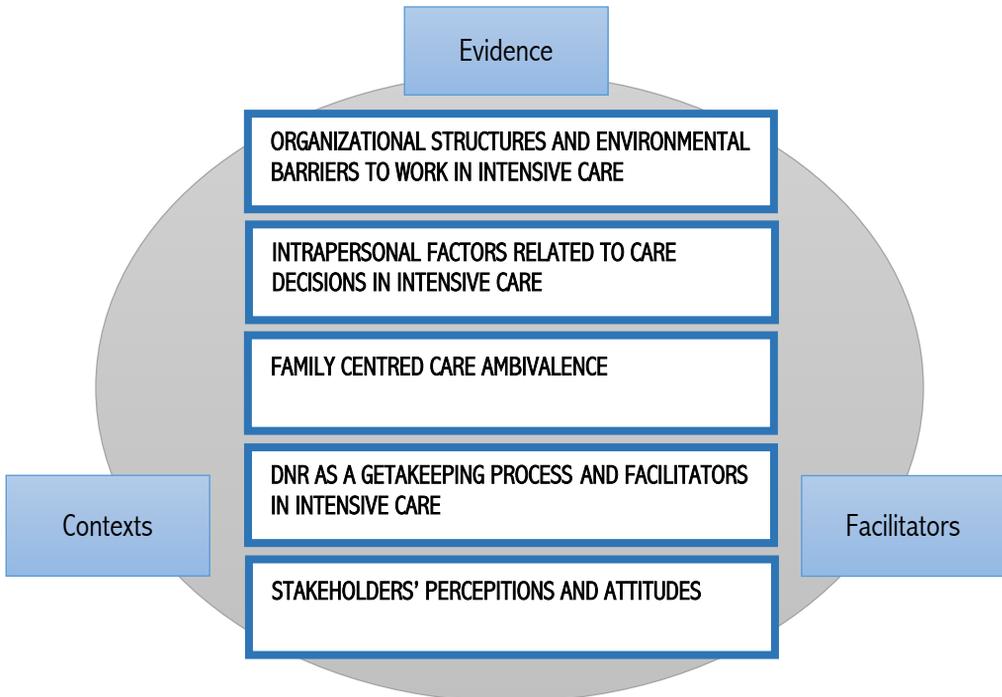


Fig.2 Overview of themes from synthesis of findings

Organisational structures and environmental barriers to work in intensive care

The organisational setting is the main determinate of the delivery of support for knowledge translation into practice. The thematic analysis of the review of factors influencing palliative care approaches (Study I) revealed that there were challenges in managing resources, such as timing and staff workload, due to shortages and barriers. Furthermore, policies and guidelines, multidisciplinary team involvement, and lack of knowledge, and skills were also significant obstacles. This is in line with the findings in Study II, as physicians stated that palliative is not systematically provided in the intensive care context. Moreover, nurses reported that palliative care plan requires a clear policy (study II). However, all the intensive care professionals reported that DNR and end-of-life care was policy applied to patients in intensive care contexts (Studies II & III), indicating that end-of-life and DNR policy are more adhered to more in practice than palliative care policy. Thus, comprehensive palliative care policy is an important organisational tool, although conceptual issues appear to exist.

Intensive care professionals, including managers, stated that the lack of palliative care specialists and the nurse-patient ratio were obstacles to providing palliative care (Study I & Study III). Consequently, among these barriers, managers were dissatisfied with the level of palliative care provided in intensive care (Study III). Despite feeling dissatisfied and criticising the management-staff ratio, the managers explained that patients requiring palliative care are less demanding and require lighter work, and thus care flows are managed by staffing fewer nurses to patients in need palliative care (Study III). Palliative care within intensive care necessitates a multi-professional approach in order to deliver care for both patients and their families. According to nurses and managers, a multi-professional meeting was missing, and communication about goal of care was limited to the physician and family (Study III).

Generally, the structured diagnostic assessment was essential in relation to patients requiring palliative care. However, the emphasis on a lack of prognostication assessment or screening tools was seen as a barrier to the provision of palliative care in intensive care (Study I & II). Thus, Study II revealed that, since palliative care requires assessment or screening tools to identify patients, it was less commonly given and rarely considered by physicians or nurses

in intensive care. Based on these findings, the managers stated that a palliative care training programme was required in intensive care (Study III).

Working environments such as the physical and psychosocial environments of palliative care, were identified as influencing factors (Study I). Physical environmental barriers, such as infrastructure and the nature of the intensive care, and psychosocial environments were linked to moral distress when providing palliative care in intensive care. In the interpretive description studies with intensive care professionals and managers, the physical environment was identified as posing challenges. This included inadequate space for families in intensive care (Study III). Moreover, the environment was challenging because the staff needed to support and care for the family in intensive care. Both intensive care professionals and managers reported that intensive care environments were not designed to facilitate family participation, even if family-centredness was identified as an important aspect of patient care (Study III).

Interpersonal factors related to care decisions in intensive care

In Study I, interpersonal aspects in relation to patients, families and intensive care professional were linked to conflict and communication issues as barriers to the provision of palliative care. Furthermore, these interpersonal aspects were related to decisions about the goals of care. Such interpersonal aspects were highlighted in Study II, wherein nurse participants stated that family involvement with care decisions is principally regulated by physicians. Nevertheless, physicians indicated that families were informed about care goals, although because families may have conflicting care goals they were rarely included in decision-making, thus making it easier to provide palliative care in intensive care. Additionally, several managers confirmed that the physician assumed responsibility for the care goals and decisions because of the challenges associated with involving family members and communicating goals of care (Study III). According to the findings, moral and emotional concerns were addressed by managers and nurses. For instance, managers from various nationalities and backgrounds expressed that their cultural beliefs affect palliative care in intensive care. Thus, cultural beliefs led to moral concerns arising among some managers in study III. Moreover, emotional dilemmas among managers and nurses were confronted while providing palliative care, as a consequence of relationships being established with some of the patients in intensive care contexts (Study III).

In Study II & Study III, exploring the intensive care professional narratives regarding palliative care in intensive care contexts revealed that palliative care was more or less non-existent in intensive care and in practice, the discourse was related to DNR policy. In the interpretive description (Study III) with nurses and managers, patient care was described as life-saving and aimed at maximum support until death. In Study II, some nurses reported that maximum life-support intervention should be provided to all types of patients admitted to intensive care. The majority of nurses' believed that saving patients' lives is part of their job in intensive care. In Study III, most managers and nurses confirmed that they treated patients in intensive care no differently. Accordingly, cardiopulmonary resuscitation for patients is still considered after a DNR decision in care contexts. There were also, differing perspectives regarding care after a decision has been made by physicians. The majority of managers and intensive care professionals, including physicians, remarked that certain physicians continue administering intensive care treatments to patients even when such a decision has been made (Study III). The interviews with some physician participants showed that achieving their intensive care practice objectives was one aspect of their strategies. Nevertheless, they subsequently reflected that maximum care was provided during the initial admission stages (Study II). All participants described the DNR policy and were cognisant of their hospital policy regarding DNR criteria.

Family centred care ambivalence

Family-centred care was highlighted as a challenge in Studies I-III but specifically in the interpretive description studies, for example, in Study II, which concerned the factors influencing the lack of knowledge and seeking of life-saving treatments by family members. In Study III, the majority of intensive care professionals and managers stipulated that family should be involved in care provision decisions, even if they preferred their patients to undergo intensive care treatments. This requirement was due to family members seeking more information from bedside nurses, which was emphasised by many nurses as a challenge of providing care to the family in intensive care (Study II). Ultimately, family emotional aspects appear to be a challenge for intensive care professionals. In Study II, emotional aspects of engagement with family members were regularly expressed by numerous intensive care professionals as posing a challenge or barrier to supporting them in intensive care.

Family beliefs about intensive care treatments were deemed to be a challenge to effectively supporting the family. In Study III, both managers and nurses reflected

on unrealistic expectations of family members regarding intensive care treatment, asserting that these may pose obstacles to providing palliative care in intensive care. Despite describing family expectations of intensive care treatments, most intensive care professionals and managers posited that if families were undecided regarding the DNR goal, intensive care treatment would be provided (Study III). Communication with the patient's family was conveyed as posing barriers to providing palliative care in intensive care. For example, Study III revealed that communication with family members concerning the condition of patients was typically deemed to be a challenging activity for physicians, as stated by managers. Consequently, this necessitated action by intensive care organisations, for example, by enhancing family education regarding palliative care, as well as using standardized tools for dialogue and collaborative teamwork (Study I).

DNR as a gatekeeping process and facilitators in intensive care

Adherence to appropriate palliative care policy, based on enhancing multidisciplinary team meetings including family and other specialists, was identified as facilitating palliative care in intensive care (Study I). Accordingly, one of the principal findings of Study III was the role of DNR policy as a gatekeeper to palliative care. Moreover, DNR was the practice and organisational policy addressed and discussed by the intensive care professionals and managers rather than palliative care policy and/or guidelines (Studies II & III). Decision making in intensive care pertaining to patients requiring palliative care was also identified as a facilitator. In Study I, decision making concerning palliative care was facilitated by adopting a clear prognostic assessment or screening tool. Intensive care professionals described how they screen patients for DNR eligibility (Study II), while clear documentation of the decision and family involvement in consultation was labelled as a facilitator to the provision of palliative care in intensive care (Study I). Meanwhile, the managers in Study III remarked that their role in decision making is to ensure that all documentation relating to the DNR decision is completed and signed by three consultants.

In intensive care, family support is meant to be a significant component of palliative care provision. Family involvement and participation within a multi-professional team to provide palliative care in intensive care is also deemed as a facilitating factor (Study I). In Study I, the facilitating factor was indicated as being the family's participation in achieving the patient goal of care by collaboration with the intensive care professionals; including them means

respecting their wishes, pre-goal of care decisions and providing them with patient information. Study III revealed that the provision of spiritual and social support to the patients and family was a fundamental consideration for the majority of participants. Nevertheless, providing spiritual care for patients requiring palliative care proved challenging. Reflecting on this difficulty, managers confirmed this is due to the diversity of ethnicities and religious beliefs among intensive care personnel (Study III).

Family meetings arranged by case managers and physicians was described as a means of comforting and supporting the family in intensive care. The majority of physicians and managers stated that the intensive care policy in some hospitals stipulated that they set aside specific time for talking with family members on a daily basis (Study III). Families were also supported by being given time to be with their loved ones in the intensive care context. For example, in Study III, some participants helped families spend more time with patients who had DNRs, not least in relation to the visiting times determined by the consultants and managers (Study III). It seems that DNR is not merely a one-time decision, it is an ongoing process that is constantly impacted by the attitudes of the intensive care professionals, as well as the involvement of the family in the patient's care.

Stakeholders' perceptions and attitudes

Intensive care professionals' attitudes were identified as a significant variable affecting those patients requiring palliative care and end-of-life care, as evidenced in the systematic review (Study I), as well as in the interpretive description results (Studies II & III). Interpersonal issues, for example, disagreements among intensive care professionals concerning palliative care and end-of-life care provision in intensive care, were explored in Studies I & III. In Study IV, the FATCOD scale facilitates use of instruments that may enhance palliative care and end-of-life in intensive care. Although both Studies II and III highlight the importance of symptom control and family involvement, Study IV shows that the largest discrepancy in the attitudes of death and dying between the two countries was linked to attitudes toward family-centred care, such as their involvement in decision making, taking part in the nursing care and supporting the family emotionally. A possible explanation for this is that the concept of family and the involvement of family have different meanings in different geographical contexts (in this study between Sweden and Saudi Arabia). In addition, it would appear that intensive care professional groups could have different perspectives in key areas such as pain management. This was highlighted in Study IV, which shows a

discrepancy between nurses and /other intensive care professionals, including physicians, toward pain management strategies with regards to possible addiction problems among Saudi Arabian group. Hence, at least regarding the usage of the FATCOD, (one of the most used instruments in this specific field) the findings suggest caution when trying to compare outcomes between different countries and contexts (societal/organisational) and professional groups, as the perception of concepts and phenomena related to death and dying seems to differ.

DISCUSSION

The discussion of this thesis centres on a comprehensive understanding of prerequisites (facilitators and barriers) for knowledge translation of palliative care in intensive care. This chapter presents the discussion of the main findings of all the studies included in this thesis and includes methodological “considerations” and reflection on the theoretical framework.

Reflections on the findings

Facilitators for palliative care provision in intensive care

The studies analysed in this thesis identified that palliative care based in the intensive care context is related to DNR policy as a gatekeeper. Gatekeepers include DNR, withholding and withdrawing policies that may be reframed and put into the context of palliative care procedures. The finding of the interpretive description studies have confirmed that palliative care’s development is close to the oncology care, although DNR policy is available within the intensive care context. Interestingly, how we define patients who may require palliative care in intensive care was described as being the physician’s responsibility, with a prognostication scale being adopted to identify patients who are eligible for the DNR policy. In this way, a conceptual reduction of palliative care takes place, since the provision of palliative care primarily involves a series of recommended actions to relieve, comfort and support instead of what-not-to-do as in DNR. Further, this decision has been described as involving a group of physicians who decide what is to be understood as a core teamwork dimension in palliative care. Documenting decision making was a significant determinant for managers who manage patients and family care in the intensive care context. The screening or prognostication assessment tool was adopted to identify patients needing palliative care who have previously been reported as requiring it, thus informing

prognostication assessment tool for palliative care knowledge translation in intensive care [157].

The findings have nevertheless presented the need for systematic usage and a well-defined prognostication scale to identify patients who need palliative care, which may enhance the provision for palliative care by initiating knowledge translation in the intensive care context. Additionally, patient characteristics is one approach to assessing patients requiring palliative care in intensive care, for example, those patients with poor prognosis, multi-organ failure alongside end-stage cancer. Interestingly, this finding is consistent with previous research that shows that patients with cancer are more likely to be admitted to intensive care. This might explain why in the interpretive description findings, the concept of palliative care was focused more on those type of patients [35, 39]. This thesis' findings and those of extant studies have indicated that such characteristics may be associated with chronically ill patients [25-27], as well as being recognised as part of a strategy for knowledge translation to provide palliative care in the intensive care context.

Family involvement and participation in multidisciplinary teams were identified as facilitators in Study I-III. This finding accords with a study identifying that intensive care professionals are willing to support family members of patients receiving life-sustaining treatment [48]. Moreover, family support was described as involving meetings arranged by managers with physicians, with the goal of providing information on a daily basis. Further family support identified in the interpretive description findings was permitting longer family visiting times, which was supported by physicians, managers and nurses. It may be concluded that these facilities were primarily provided for the family's benefit, with less emphasis on patient care. However, in the intensive care context, one of the palliative care dimensions is family support even if the findings are a ambiguous regarding family involvement, as it can also present a challenge to the professionals, for example, the decision for end-of-life care.

One of the essential interpersonal aspects is to measure the attitudes of intensive care professionals. Nevertheless, measuring attitude may be problematic due to the concept of attitude being multidimensional [158]. Furthermore, because personal attitude is a culturally shaped, measuring intensive care professionals' attitudes of death and dying is pertinent to concerns about providing high-quality palliative care in the intensive care context. In this thesis, intensive care professionals' attitudes were identified on the basis of their decisions about the goal of care. In the palliative care field, the FATCOD measure has been implemented and evaluated in relation to the positive effects on palliative care education.

Significantly, this thesis' findings further indicate a challenge with responding to the FATCOD measure in two different societal contexts. This finding emphasised the crucial need to enhance intensive care professionals' knowledge regarding family-centred care and physical practice related to pain management aspects, which are both core palliative care dimensions. Yet, even more so, the findings show that knowledge translations need to be adapted to the social, professional context, as the meaning of, for example, death and dying differs. The findings from this thesis should emphasise that attention should be paid to organisational, policymaker and researcher-related factors in the intensive care context.

Barriers to palliative care provision in intensive care

This thesis' findings have conveyed how organisational structures, for example, managements' resources including lack of policy and guidelines, staff workload, a dearth of bedside nurses, few palliative care consultants, as well as visiting policies are the principal barriers to palliative care provision at the end-of-life in the intensive care context. These findings concur with prior research results that identify challenges relating to palliative care provision in the intensive care context [16]. Moreover, intensive care professionals' knowledge and skills in the intensive care context may also affect palliative care provision. The interpretive description findings highlighted how intensive care professionals discussed DNR policy and end-of-life care, with palliative care considered as potentially being used to reframe the notion of DNR provided in intensive care contexts.

This thesis established that intensive care professionals' perspectives of palliative care provision were more focused on patients with cancer, multiorgan failure and poor prognosis in intensive care. Moreover, they rarely focused on spiritual and psychological needs. This may be linked to their work overload due to working at a 1:2 patient ratio in intensive care, as noted in previous research [119, 120]. It also reveals the significance of palliative care provision in relation to knowledge translation in intensive care, as this necessitates sufficient knowledge and training concerning palliative care practice [119, 120]. Additionally, organisational support is required to clarify the DNR policy for intensive care professionals, specifically nurses and allied healthcare. The results also evidence that the care environment is typically a barrier to palliative care provision in the intensive care context. For example, a family area or place to stay is lacking, as the interpretive description studies' findings showed. However, evidence pertaining to the work environment, whether the physical or psychological environment, should be comprehended and considered while planning for knowledge translation of palliative care provision

in the intensive care context. For instance, one study investigated how patients' rooms were viewed and experienced by family members during critical care, identifying a few small changes that could be made to develop a comfortable environment for both patients and families [64]. This thesis' interpretive description findings have therefore confirmed the presence of a moral dilemma relating to the goal of care and the perception of death and dying in intensive care contexts, and this may be linked to societal, professionals, as well as to some extent religious background. These factors play a significant role in palliative care provision in the intensive care context.

Interpersonal factors, including intensive care professional disagreement, ineffective communication, as well as team and family involvement, are emphasised as barriers to providing palliative care in intensive care. These barriers are associated with evidence from both major western countries in the systematic review study (Study I), in addition to interpretive description studies in the Saudi Arabian context (Study II & III). Nevertheless, in the Saudi intensive care context, the perspectives concerning palliative care provision for patients in intensive care has been challenged, in terms of the goal of care in relation to the DNR policy. Specifically, this challenge concerns ambiguity in of practising the DNR policy, for example, in terms of the involving, communication and agreeing with the family. Moreover, this challenge may be associated with intensive care professionals' preferences [53], in addition to the moral dilemma that has been studied previously [49]. Thus understanding is needed of how a DNR policy affects intensive care professionals and families in relation to the provision of palliative care in intensive care. One finding highlighted that personal factors relating to the natural inclination to save the patient's life in intensive care practice was a barrier to providing palliative care in intensive care [57, 58]. Even so, such challenges may be linked to cultural background, education, as well as family awareness about palliative care. For example, studies have shown that families face challenges with communicating about the treatment being offered to patients because of issues with medical terminology [116, 117]. Moreover, it is crucial to comprehend the role of multi-professional relationships and advanced practice in intensive care in order to provide palliative care in intensive care [159]. Such understanding enables more knowledge to be developed about the context, instead of focusing on each intensive care expert and manager's role in providing palliative care. This concept allows for additional knowledge to be developed about the context from several perspectives. The work of the intensive care nurse has previously been studied as multidimensional [71]. It was suggested that further research be done, and nurses' roles in delivering palliative care in intensive care units should be emphasized in the future.

Methodological considerations

The PARIHS model provided the theoretical framework for this thesis. As previously noted, PARIHS comprises of three major constructs. This thesis discusses the prerequisites for palliative care provision in the intensive care context. The PARIHS model has been previously adopted to analyse research findings [160]. PARIHS provides evidence that informs an appropriate analytical model in Study I. Furthermore, the framework enabled exploration of the context in Studies II and III, by developing the knowledge translation through prerequisites. Analysing the evidence and context through synthesis, this permitted an identification of the facilitators of palliative care provision and an investigation of personal attitude measurements in Study IV. The PARIHS model was advantageous in guiding the synthesis of this thesis' findings. However, it is necessary to comprehend how the PARIHS model may be applied in relation to knowledge translation outcomes [135]. The PARIHS model led to a richer understanding of the facilitators and barriers to palliative care provision in intensive care by assessing elements (evidence, context, as well as facilitators). Nevertheless, there is a dearth of research concerning how successful knowledge translation may be defined through the PARIHS frameworks, which seems to be measure-based [160]. Moreover, this model poses limitations in terms of understanding how the sub elements interact with each other, while it is equally weighted in terms of delivering evidence at varying levels of the organisation [132]. It is nevertheless essential to adopt different models, given the complexity of knowledge translation within the palliative care context. Facilitators and barriers to palliative care provision within the intensive care context have been presented with evidence and in relation to diverse hospital contexts, as well as in light of the of organisational culture of intensive care environments. The findings thus provide significant guidance for developing knowledge translation strategies for palliative care provision in the intensive care context.

The methodological approach employed in this thesis was multimethod, wherein the aim was to examine the prerequisites for palliative care provision in intensive care contexts toward knowledge translation. This multimethod generates a more profound appreciation of the integration of findings from each single study in the search for a conclusion. The international evidence was explored in term of the factors influencing the palliative care approach in intensive care, as perceived by intensive care professionals, and it was crucial to situate the findings within the larger context. A multimethodological design approach may also enhance the necessary triangulation during data gathering and analysis. This approach is ideal for addressing broad research topics, given that it permits an in-depth

comprehension and confirmation of the study findings [161]. By applying an interpretive description for studying how palliative care is provided at the bedside and by organisational management professionals in intensive care, an attempt was made to comprehend the complexity of this research field. Moreover, a multimethod sequential design enhances the clarity regarding the types of variables necessitating further inquiry [148]. This thesis also included a cross-sectional design to examine whether overall scale measure of attitudes towards care for dying people (i.e. the total score) has the same meaning across different societal and healthcare contexts. This enabled the development or construction of a quantitative questionnaire designed to collect data and analyse connections between variables [162].

Trustworthiness of qualitative research findings

The nature of interpretive descriptive design is to address access to an essential kind of knowledge about human subjective experience [151]. To maintain credibility during the data collection and analysis, I had to remain reflexive and transparent throughout the process of collecting data and the analysis. Thorne interpretive description design explains and suggests some guidelines to enhance the credibility of inductive analysis [151]. I took on board the suggestion of tracking reflections by writing notes in a filed notebook on my knowledge, thoughts, and interpretations of the nature of palliative care practice in intensive care. Thorne also recommends documenting “What is happening to you”(pp. 119) through a personal reflection on theoretical engagement within the research [151]. As a novice researcher, I used an interview guide and field notes during the interviews in order to focus on the interview topics rather than on the interaction and engagement, and also not offered the participants ideas during the interview. After each interview, I wrote field notes for each participants in order to grow awareness of the potential impact of the disciplinary as well as professional background of the participants’ findings [151].

The interpretive description design followed credibility criteria that included: epistemological integrity, representative credibility, analytic logic and interpretive authority. Firstly, epistemological integrity means that the reader should get the sense that there is a “defensible line of reasoning from the assumptions made about the nature of knowledge through to the methodological principles by which judgments concerning the research process are explained when it comes to epistemological integrity”(pp. 233) [151]. It is also important that the findings are

credible in the sense that the researcher makes clear logical interpretations of the data. Moreover, the research method must present a study phenomenon that is dependable with an affirmed epistemological standpoint and interpretive strategies [151]. Throughout the qualitative studies, I discussed with experienced qualitative researcher the selection of interpretive methodologies that fit logically with the research objectives. I also discussed the process of developing the research questions with my supervisors to ensure that my thoughts and reasoning corresponded with interpretive description. Additionally, as a critical care nurse, I was grounded in the disciplinary knowledge required for interpretive description. By acknowledging the critical role that such aligning plays in the conduct and implementation of this research thesis, this groundedness in the practical field of critical care improves the study's epistemological integrity.

Secondly, it is essential to demonstrate representative credibility in interpretive description studies. The phenomenon under study was sampled by meaningful analysis of the data, consistent with evolving theoretical claims. In interpretive description studies, intensive care professionals and managers of different kinds and personalities are anticipated to provide a variety of experiences and perspectives to the study findings. The credibility of the findings was strengthened by the fact that the interpretive description research was carried out in four separate hospitals. Nevertheless, theoretical claims cannot be made based on findings from two interpretive description studies concentrating on one societal context. To approach the variations, different nationalities with the different backgrounds were included in interpretive description Studies II and III. In this way, the findings from the interpretive description studies could reflect a variety of perspectives in the different cultural groups. Due to the study's sample and particular cultural and organisational context, the reader should proceed with caution when applying the findings to other contexts and populations. Moreover, as this was a PhD study with a affected time by the Covid-19 pandemic and its impact on the ICU community during 2020-2022. This may have negatively affected the study's credibility because it is critical to have a long engagement with the phenomena.

Thirdly, according to Thorne (2016), analytic logic can be explained as follows: "all qualitative research reports should represent an analytic logic that makes clear the researcher's reasoning from the obvious forestructure to the interpretations and knowledge claims created on the basis of what was obtained in the research" (pp.234) [151]. The reader ought to be able to confirm or reject the research's credibility based on the reasoning of evidence logic offered in the research. To enhance the credibility of research, certain techniques were utilized in interpretive

description Studies II and III, for example, to keeping track of the inductive reasoning process, creating an audit trail was created using analytic memos for each participant, field notes, and a reflective notebook after data collection and throughout analytical entries. These strategies assisted in describing the study's relevant context and provided an audit trail showing how the analysis developed. In addition, I used some verbatim quotes in the findings within the data. This was accomplished by discussing the data with my supervisors in order to construct a code that was consistent with the information gathered.

Interpretive authority is the fourth important requirement in interpretive description studies [151]. As a novice researcher and critical care nurse, I kept a reflective notebook to confirm my preconceived opinions and possible significant forestructures, thus enabling trustworthy interpretations of the data. Interpretive authority is also recognised by “validity-as-reflexive-accounting”(pp.235); this means we should aim to convince our reader or audience of the truth about the research process [151]. In the interpretive description (Studies II and III), several strategies were used when collecting and analysing the data in order to be accountable and transparent about my research interpretations: field notes, writing in a reflective journal before and after data collection, and writing analytic memos throughout the data analysis process. Feedback from supervisors before and after the interviews and data analysis process was also obtained.

Validity and reliability of the FATCOD scale

In Study IV, the quantitative research focus is typically on reliability and validity in terms of method strength and weakness. A cross sectional-benefit is that it allows to assess more than one variable and an analysis of multiple outcomes [154]. However, given that the data in Study IV was collected using both a paper-based survey before the covid-19 pandemic, and then via an online survey, during the initial Covid-19 pandemic in 2020, time was limited. Additionally, data was obtained from each participant only once, per participants meaning that the relationship between a factor and a result may be biased. Thus, it is crucial to consider the data collection techniques' (instruments) validity and reliability. In Study IV we choose to analyse the FATCOD questionnaire as it aims to investigate attitudes towards care for dying people and is deemed a valid instrument [163, 164].

An instrument's reliability is the second measure of quality during quantitative inquiry. Essentially, this is the extent to which a study instrument produces

consistent results when employed in the same context on multiple occasions. Internal consistency pertains to assessments using Cronbach's alpha, which is the most commonly used test for identifying internal consistency. The FATCOD instrument was tested in different cultures, for example, Swedish FATCOD had a Cronbach's alpha of .506, which increased after item number 25 was omitted to .701 [165]. Additionally, FATCOD was tested in the Japanese context, with an internal consistency Cronbach's alpha of .85 [166]. Even so, the psychometric properties of Study IV suggested an aspect of dimensionality that might be associated with validity and reliability that requires further assessment in future. FATCOD was evaluated using a cross-sectional study, including anonymously distributed papers and online links in order to minimise bias. However, this may be limited given that the sample included both intensive care professionals, as well as registered nurses studying a critical care masters programmes who may not currently work in the intensive care context. Moreover, a large number of participants were nurses, and the majority from Sweden. This was also particularly true of the Saudi sample, which included more nurses than other health professionals. The Swedish language was used within the Swedish sample, with the FATCOD validated and translated [165]. However, for the Saudi sample, the original English FATCOD scale was used. Accordingly, the findings may be limited. The OLR recommend the sample size to be a minimum of 250 per group [155, 167]. Although this was achieved in Study IV, the sample is limited.

Conclusion

This thesis' findings provide critical information that may be adopted so that patients and their families can receive optimal palliative care and end of life care in the intensive care context, both today and in the future. Future knowledge translation initiatives targeting the integration of palliative care should concentrate on organisational and educational efforts aiming to strengthen human relationships and partnerships, not least in relation to patient and family involvement in decision making in addition to (i.e. before, during, after and supplementing) for example a DNR process. Training and education are important for intensive care professionals and managers, in order to ensure that obstacles are successfully resolved through the facilitating factors that are available, hopefully further optimising intensive care in ways that mean palliative care will be provided to all patients and families who need it.

Future Perspective

This thesis has highlighted the dearth of observational studies aiming to comprehend the palliative care and end-of-life care process provided to patients in the intensive care context, while the results were more focused on family support and DNR policy. Current concepts pertaining to palliative care, end-of-life care, as well as life-sustaining treatment are crucial to understand via individual empirical study in relation to each specialised intensive care professional role, because each speciality comprises different activities that require additional evidence.

This doctoral thesis does not comprehensively cover the stakeholders (patient and family) insights, which is important to investigate in the future to obtain in-depth understanding of the organisational culture in general and the context. Additionally, individual factors such as cultural background and type of speciality, gender and educational level are variables of interest.

Increasing comprehension of the significance of psychological and spiritual needs, especially pertaining to patient care and family support, may enhance palliative care and end-of-life care in the intensive care context. Consequently, it is essential to develop the provision of palliative care knowledge translation strategies according to facilitators and barriers, based on the evidence and context of this thesis, for example, by using the PARIHS framework for designing and evaluating an implementation study. Nevertheless, it is crucial to obtaining an in-depth understanding of palliative care provision by studying the major dimensions of palliative care and focusing on pain management and family-centred care is crucial.

Further research should be undertaken to analyse to further analyse the impact of professional background and societal context on the healthcare professionals' attitudes towards caring for dying persons in larger populations.

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Appendix

Appendix 1

A- Interview questions for healthcare professionals

- 1- Can you tell me how you provide care for patients about to die or in need palliative care in intensive care units?
 - Can you explain the care processes for these patients?
 - How do you work to identify the patient about to die in intensive care unit? Do you have specific prognostic procedure? Can you give an example of the last case you have cared for?
 - While you providing care to patients about to die in intensive care unit: could you tell me how you feel?
 - What are resources or routines that helps you to provide care for patients about to die in intensive care unit? Can you give an example?
 - How about the challenges? Can you give an example?
 - How do you manage these challenges?
- 2- How do you experiences providing care for patient's family who is about to die or in need palliative care in intensive care unit?
 - How do you support families?
 - How do you communicate prognosis and the goal of care with families' members? Explain
 - Can you described how you involve families in care for patients about to die in intensive care unit? Example?
- 3- Do you have any additional information you want to tell me?

B- Interview questions for Managers

- 1- Can you tell me how do you provide care for patients about to die or in need palliative care admitted to intensive care units? From your organisational point view?
 - From your work background: Can you tell me about your though of working process of caring for patients about to die or in need palliative care and their families in intensive care unit? Can you give an example?
 - How do you support families?
 - Would you describe the decision-making process for patients about to die in an intensive care unit? Example?
 - How about teamwork?
 - How do you feel when you work with care process for patients about to die and their families?
- 2- What are the challenges of supporting and providing care for patients about to die or in need of palliative care in the intensive care unit? From your organisational point view Can you give an example?
 - Could you tell me about how do you manage these challenges in your workplace? Can you give an example?
 - Give examples of, when and how you organize caring for a patients at about to die in intensive care ?
 - How do you follow up with your staff if they are applied care for patient about to die in the intensive care unit?
 - Can you tell me about you thoughts regarding the utilisation of management's resources in your workplace for patients about to die in intensive care unit?
- 3- Do you have any additional information you want to tell me?

Appendix 2a

A- Participant information

Research title: Palliative care processes and challenges in the ICU setting: Healthcare professionals' perspective in the context of Saudi Arabia.

1. About the Study

This is a scientific research project carried out to collect data for my PhD degree in critical care nursing at the University of Gothenburg, Gothenburg, Sweden. This study is supervised by Professor Dr Joakim Öhlen (RN, PhD), Associate Professor Dr Axel Wolf (RN, CRNA, PhD), and Assistant Professor Dr Sepideh Olausson (RN, CCRN, PhD). The responsible project coordinator and national investigator for the survey and interview studies will be Dr Tariq Saleem Alharbi, an Assistant professor at the Umalqra University in KSA.

Findings from the research will be presented at conferences, published in peer review journals and in the PhD thesis.

2. Aims and Objectives

The main questions in this research project is to explore healthcare professionals' experiences of providing care for patients who are dying and their families in an ICU. I hope that this study will explore ways of improving the quality of care delivered to patients and improve patient safety.

3. Inquiry concerning participation

We are inviting healthcare professionals who are working with the critically ill patient in intensive care units. I will conduct semi-structured interviews, which will take around 30-45 minutes. I will write notes and use audio record the interviews.

4. Confidentiality and researcher responsibility

The authors pay attention to preserve your participant's rights and respect your dignity. You have right to withdraw at any time from the research. Informed consent will be taken before interview. All these recordings will be handled confidentially. The data will be destroyed Following the University of Gothenburg ethical guideline. Any data collected linking to individuals will be kept confidential in the study. Only researchers will have access to the data.

5. What if participants want to withdraw from the interview?

Participants will have the right to withdraw at any stage of the interview without giving any reason or justification.

- 6.** What are the risks from the study?
 No risks are anticipated from the study.

Personal information (Please check the appropriate spaces):	
Age:
Gender:	<input type="radio"/> Male <input type="radio"/> Female ^[SEP]
Nationality:	<input type="radio"/> Saudi <input type="radio"/> Non Saudi (please specify) ^[SEP]
Profession:	<input type="radio"/> Nurse <input type="radio"/> Physician <input type="radio"/> Respiratory therapist <input type="radio"/> Psychologist <input type="radio"/> Other (please specify) ^[SEP]
Highest degree held:	<input type="radio"/> PhD Degree <input type="radio"/> Master's Degree <input type="radio"/> Bachelor's Degree <input type="radio"/> High School Diploma <input type="radio"/> Other <input type="radio"/> (please specify) ^[SEP]
Specialties education	<input type="radio"/> Critical care specialty <input type="radio"/> Trauma care specialty <input type="radio"/> None <input type="radio"/> Other please specify.....
Type of Intensive care units (ICU) you work on	<input type="radio"/> Medical ICU <input type="radio"/> Surgical ICU <input type="radio"/> Cardiac ICU <input type="radio"/> Neuro ICU <input type="radio"/> Intermediate ICU <input type="radio"/> Other (please specify)
<p>• Do you work as manger within your bedside work If yes? please ecify.....</p> <p>Contact information Hanan Hamdan Alshehri RN, CCRN PhD student at university of Gothenburg, Sweden Mobile: +96652723707 Email : hanan.hamdan.alshehri@gu.se or hhs401@hotmail.com</p>	

Appendix 2b

B- Managers

Research title: Palliative care processes and challenges in the intensive care setting: Healthcare professionals' perspective in the context of Saudi Arabia.

7. About the Study

This is a scientific research project carried out to collect data for my PhD degree in critical care nursing at the University of Gothenburg, Gothenburg, Sweden. This study is supervised by Professor Dr Joakim Öhlen (RN, PhD), Associate Professor Dr Axel Wolf (RN, CRNA, PhD), and Assistant Professor Dr Sepideh Olausson (RN, CCRN, PhD). The responsible project coordinator and national investigator for the survey and interview studies will be Dr Tariq Saleem Alharbi, an assistant professor at the Umalqra University in KSA.

Findings from the research will be presented at conferences, published in peer review journals and in the PhD thesis.

8. Aims and Objectives

The question in this research project is to describe healthcare professionals and managers' organizational and structural challenges regarding the provision of palliative care approach for critical patients in an ICU and their families. I hope that this study will explore ways of improving the quality of care delivered to patients and improve patient safety.

9. Inquiry concerning participation

We are inviting healthcare manager who are working with an intensive care units. We will conduct semi-structured interviews, which will take around 30-45 minutes. I will write notes and I will use audio record the interviews.

10. Confidentiality and researcher responsibility

The authors pay attention to preserve your participant's rights and respect your dignity. You have right to withdraw at any time from the research. Informed consent will be taken before interview. All these recordings will be handled confidentially. The data will be destroyed following the University of Gothenburg ethical guideline. Any data collected linking to individuals will be kept confidential in the study. Only researchers will have access to the data.

11. What if participants want to withdraw from the interview?

Participants will have the right to withdraw at any stage of the interview without giving any reason or justification.

12. What are the risks from the study?

No risks are anticipated from the study.

Personal information (Please check the appropriate spaces)	
Age:
Gender:	<input type="radio"/> Male <input type="radio"/> Female ^[SEP]
Nationality:	<input type="radio"/> Saudi <input type="radio"/> Non Saudi (please specify) ^[SEP]
Profession:	<input type="radio"/> Nurse <input type="radio"/> Physician <input type="radio"/> Respiratory therapist <input type="radio"/> Psychologist <input type="radio"/> Other (please specify) ^[SEP]
Highest degree held:	<input type="radio"/> PhD Degree <input type="radio"/> Master's Degree <input type="radio"/> Bachelor's Degree <input type="radio"/> High School Diploma <input type="radio"/> Other (please specify) ^[SEP]
Specialties education	<input type="radio"/> Critical care specialty <input type="radio"/> Trauma care specialty <input type="radio"/> None <input type="radio"/> Other please specify.....
Type of Intensive care units (ICU) you work on	<input type="radio"/> Medical intensive care unit <input type="radio"/> Surgical intensive care unit <input type="radio"/> Cardiac intensive care unit <input type="radio"/> Neuro intensive care unit <input type="radio"/> Intermediate intensive care unit <input type="radio"/> Other (please specify).....
What kind of management position do you have:	<input type="radio"/> Manager of intensive care unit <input type="radio"/> Head of intensive care unit <input type="radio"/> Charge of intensive care unit <input type="radio"/> Supervisor of intensive care unit <input type="radio"/> Clinic instructor of intensive care unit <input type="radio"/> Other (please specify) ^[SEP]
<p>• Do you work as bedside staff within your management role If yes? please specify </p> <p>Contact information Hanan Hamdan Alshehri RN, CCRN PhD student at university of Gothenburg, Sweden Mobile: +96652723707 Email : hanan.hamdan.alshehri@gu.se or hhs401@hotmail.com</p>	

Consent form

Study title: Palliative care processes and challenges in the ICU setting: Healthcare professionals' perspective in the context of Saudi Arabia.

I have received sufficient information about the study and agree to participate in the interview study.

I understand that

- I can decide to stop at any time
- Taking part in this study is voluntary
- The interview will be recorded for the purpose of analysis
- My personal information will be kept confidential
- The research result will be presented at conferences, published in peer review journals and in the PhD thesis.

Participant signature:.....

Researcher Name: Hanan Hamdan Alshehri

Signature:.....

Contact information

Hanan Hamdan Alshehri RN, CCRN PhD student at university of Gothenburg, Sweden
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Email: hanaan.hamdan.alshehri@gu.se or hhsd01@hotmail.com

Appendix 3

Prerequisites for the implementation of palliative care in intensive care: a Saudi Arabian perspective

The purpose of this scientific project is to explore the prerequisites of palliative care for critically ill patients in intensive care settings. This study will identify the professional's preconceptions and attitude towards death/dying, as well as the care of patients who are in an ICU to receive care towards the end of their life. By exploring the area and highlighting the challenges that may exist, healthcare professionals can acquire additional knowledge that will be necessary for improving care for those patients who require palliative care.

Instructions

The survey consists of two scales: the Attitude Toward Care of the Dying Scale (FATCOD), and demographical data. The survey will take approximately 15 minutes to fill in. Please answer as honestly and frankly as possible, by choosing one answer to each statement or question. Participation in this study is voluntary and your identity will remain anonymous. In light of this, please do not write your name in the questionnaire, to ensure your privacy anonymity. Please do not hesitate to contact me if something is unclear or clarification is needed. Your participation is much appreciated.

Yours Faithfully

Hanan Hamdan Alshehri

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halshehri@pnu.edu.sa

Part one: personal information

Please check the appropriate spaces:

1. Age: _____
2. Gender: Male _____ Female _____
3. Religion: Muslim _____ Christian _____ Other _____
4. Nationality: Saudi _____ Other _____ (please specify)
5. Working country:
 - Saudi
 - Outside Saudi; specify _____
6. Member of SCCS
 - Yes
 - No
7. Profession:
 - Nurse
 - Physician
 - Respiratory therapist
 - Psychologist
 - Other (please specify) _____
8. Highest degree held:
 - PhD Degree
 - Master's Degree
 - Bachelor's Degree
 - High School Diploma
 - Other (please specify) _____
9. Specialist education/training
 - Critical care specialty
 - Trauma care specialty
 - None
 - Other please specify _____
10. Level of experience in the ICU
 - 0 year - 2 years
 - 2 years - 5 years
 - 6 years -10 years
 - More than 10 years
11. Type of hospital you work in
 - Ministry of health hospital
 - Military hospital
 - University hospital

- National guards' hospital
- Private hospital
- Other (please specify) ____

12. Type of Intensive care units (ICU) you work in

- General ICU
- Cardiac ICU
- Neuro ICU
- Intermediate ICU
- Other (please specify) ____

13. Language proficiencies

- English only
- Arabic only
- English and Arabic
- Other (please specify) ____

14. Do you hold a managerial position?

- Yes
- No (If no, please continue to question 16)

15. If yes, what type of managerial position do you hold?

- Head of ICU
- Charge of ICU
- Supervisor of ICU
- Clinic instructor of ICU
- Other (please specify) ____

16. Previous education on death and dying:

- I have taken a course in death and dying previously.
- I have not taken a specific course on death and dying, but material on the subject was included in other courses.
- No education dealing with death and dying was previously presented to me.

17. Do you have primarily religious or non-religious beliefs to your outlook on life?

A. I have primarily religious beliefs to my outlook of life, and

- my religious beliefs make a strong influence on my attitude toward death and dying
- my religious beliefs make a minor influence on my attitude toward death and dying
- my religious beliefs make do not influence my attitude toward death and dying.
- I have no religious beliefs

B. I have primarily non-religious beliefs to my outlook of life, and

- my non-religious beliefs make a strong influence on my attitude toward death and dying.
- my non-religious beliefs make a minor influence on my attitude toward death and dying.
- my non-religious beliefs make no influence on my attitude toward death and dying.
- I have no religious beliefs

18. Previous experience in caring for persons living close to death:

- I have previously cared for persons who are dying and their family members' previously.
- I have had no experience caring for persons who are dying and their family members previously.

19. Previous experience with loss:

- I have lost someone close to me within the past year; specify relationship:
 - Immediate family (partner, mother, father)
 - significant other
 - child
- I have no previous experience with the loss of someone close to me.

20. Present experience:

- I am presently anticipating the loss of a loved one.
- I presently have a loved one who is life-threateningly and incurably ill (life expectancy one year or less).
- I am not dealing with any impending loss at the present time.

Part two: questions

Please select the statement that corresponds to your own personal feelings about the attitude.
Please answer all 30 questions on the scale.

1. Giving care to the dying person is a worthwhile experience
 1. Strongly disagree
 2. Disagree
 3. Uncertain
 4. Agree
 5. Strongly agree
2. Death is not the worst thing that can happen to a person.
 1. Strongly disagree
 2. Disagree
 3. Uncertain
 4. Agree
 5. Strongly agree
3. I would be uncomfortable talking about impending death with the dying person.
 1. Strongly disagree
 2. Disagree
 3. Uncertain
 4. Agree
 5. Strongly agree
4. Caring for the patient's family should continue throughout the period of grief and bereavement.
 1. Strongly disagree
 2. Disagree
 3. Uncertain
 4. Agree
 5. Strongly agree
5. I would not want to care for a dying person.
 1. Strongly disagree
 2. Disagree
 3. Uncertain
 4. Agree
 5. Strongly agree
6. The nonfamily caregivers should not be the one to talk about death with the dying person.
 1. Strongly disagree
 2. Disagree
 3. Uncertain
 4. Agree
 5. Strongly agree
7. The length of time required giving care to a dying person would frustrate me.
 1. Strongly disagree
 2. Disagree
 3. Uncertain

- 4. Agree
 - 5. Strongly agree
8. I would be upset when the dying person I was caring for gave up hope of getting better.
- 1. Strongly disagree
 - 2. Disagree
 - 3. Uncertain
 - 4. Agree
 - 5. Strongly agree
9. It is difficult to form a close relationship with the dying person.
- 1. Strongly disagree
 - 2. Disagree
 - 3. Uncertain
 - 4. Agree
 - 5. Strongly agree
10. There are times when the dying person welcomes death.
- 1. Strongly disagree
 - 2. Disagree
 - 3. Uncertain
 - 4. Agree
 - 5. Strongly agree
11. When a patient asks, "Am I dying?" I think it is best to change the subject to something cheerful.
- 1. Strongly disagree
 - 2. Disagree
 - 3. Uncertain
 - 4. Agree
 - 5. Strongly agree
12. The family should be involved in the physical care of the dying person.
- 1. Strongly disagree
 - 2. Disagree
 - 3. Uncertain
 - 4. Agree
 - 5. Strongly agree
13. I would hope the person I'm caring for dies when I am not present.
- 1. Strongly disagree
 - 2. Disagree
 - 3. Uncertain
 - 4. Agree
 - 5. Strongly agree
14. I am afraid to become friends with a dying person.
- 1. Strongly disagree
 - 2. Disagree
 - 3. Uncertain
 - 4. Agree
 - 5. Strongly agree

15. I would feel like running away when the person actually died.
 1. Strongly disagree
 2. Disagree
 3. Uncertain
 4. Agree
 5. Strongly agree
16. Families need emotional support to accept the behavior changes of the dying person.
 1. Strongly disagree
 2. Disagree
 3. Uncertain
 4. Agree
 5. Strongly agree
17. As a patient nears death, the nonfamily caregiver should withdraw from his/her involvement with the patient.
 1. Strongly disagree
 2. Disagree
 3. Uncertain
 4. Agree
 5. Strongly agree
18. Families should be concerned about helping their dying member make the best of his/her remaining life.
 1. Strongly disagree
 2. Disagree
 3. Uncertain
 4. Agree
 5. Strongly agree
19. The dying person should not be allowed to make decisions about his/her physical care.
 1. Strongly disagree
 2. Disagree
 3. Uncertain
 4. Agree
 5. Strongly agree
20. Families should maintain as normal an environment as possible for their dying member.
 1. Strongly disagree
 2. Disagree
 3. Uncertain
 4. Strongly agree
 5. Agree
21. It is beneficial for the dying person to verbalize his/her feelings.
 1. Strongly disagree
 2. Disagree
 3. Uncertain
 4. Agree
 5. Strongly agree
22. Care should extend to the family of the dying person.

1. Strongly disagree
 2. Disagree
 3. Uncertain
 4. Agree
 5. Strongly agree
23. Caregivers should permit dying persons to have flexible visiting schedules.
1. Strongly disagree
 2. Disagree
 3. Uncertain
 4. Agree
 5. Strongly agree
24. The dying person and his/her family should be the in-charge decision-makers.
1. Strongly disagree
 2. Disagree
 3. Uncertain
 4. Agree
 5. Strongly agree
25. Addiction to pain relieving medication should not be a concern when dealing with a dying person.
1. Strongly disagree
 2. Disagree
 3. Uncertain
 4. Agree
 5. Strongly agree
26. I would be uncomfortable if I entered the room of a dying person and found him/her crying.
1. Strongly disagree
 2. Disagree
 3. Uncertain
 4. Agree
 5. Strongly agree
27. Dying persons should be given honest answers about their condition.
1. Strongly disagree
 2. Disagree
 3. Uncertain
 4. Agree
 5. Strongly agree
28. Educating families about death and dying is not a nonfamily caregiver responsibility.
1. Strongly disagree
 2. Disagree
 3. Uncertain
 4. Agree
 5. Strongly agree
29. Family members who stay close to a dying person often interfere with the professional's job with the patient.

- 1. Strongly disagree
- 2. Disagree
- 3. Uncertain
- 4. Agree
- 5. Strongly agree

30. It is possible for nonfamily caregivers to help patients prepare for death.

- 1. Strongly disagree
- 2. Disagree
- 3. Uncertain
- 4. Agree
- 5. Strongly agree

Part 3 question

- Which challenges do you encounter while providing care for patient who are dying? Please explain?

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Thank you