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Palliative Care Integration into Critical Care in People with Terminal Conditions

Arielle Westfall
University of Central Florida, ar852839@ucf.edu

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PALLIATIVE CARE INTEGRATION INTO CRITICAL CARE IN PEOPLE WITH TERMINAL CONDITIONS

by

ARIELLE B. WESTFALL

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ABSTRACT

Palliative care is of value to the quality of life in people with terminal conditions when initiated early. The purpose of this literature review was to identify barriers to early initiation of palliative care consultation. The secondary purpose was to examine characteristics that prompt palliative care consultation. The TLC model of palliative care was used to explore palliative care in the critical care setting in people with terminal conditions. The concepts of the model support optimal palliative care as collaborative and comprehensive, with shared decisions made by the patient, practitioners, and loved ones. A literature review was conducted to identify common barriers to early initiation of palliative care consults in the critical care setting for people with terminal conditions. Peer-reviewed articles were retrieved from the EBSCOhost, Medical Literature On-Line (Medline), Cumulative Index to Nursing and Allied Health Literature (CINAHL), and Elsevier databases to evaluate their relevance to palliative care in the critical care setting. Twelve preliminary studies were selected for review per the inclusion criteria. Eleven studies identified education and legal factors as barriers. Six studies identified patient and family perceptions as barriers. Five studies identified practitioner-related bias as a significant barrier to consultation. Of the twelve articles reviewed, ten articles referred to palliative care in the adult ICU setting. Two articles included in the review examined barriers to palliative care in the neonatal and pediatric settings. The analysis of the data identified three categories as barriers to initiation of end-of-life care: practitioner-related bias, patient and family perceptions, and education and legal factors after a synthesis of the relevant literature was performed. Analysis of the articles suggests early identification of potential diagnoses for palliative consultation beginning in the intensive care unit (ICU) can improve symptom management, support, patient-centered care, and quality of life for people with terminal conditions. Barriers related to all three categories dominated the literature, with the most prominent being barriers related to education and legal factors. Results indicate that development and implementation of a palliative care referral tool can increase consultation for patients in the critical care setting with terminal conditions. Further education on the topic can increase understanding of palliative care services and improve provision of palliative care through early referrals and consultation.

DEDICATION

To my grandparents, who inspired me to pursue
a passion of helping people on their worst days.

To my fiancé, Shane, without whose support and encouragement
the completion of this thesis and nursing program
would not have been possible.

To my family, who shaped me into the person that I am today and have
supported me throughout my educational journey.

To the palliative care team at UF Health, thank you for helping me
grow professionally and introducing me to my passion
for palliative and hospice care.

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for encouraging me and showing me that
nothing is impossible if you set your mind to it.

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INTRODUCTION

Palliative care is a form of specialized health care for people who have been diagnosed with a serious illness (National Institute on Aging, 2021). Palliative care prioritizes symptom management and improving a person's quality of life, rather than focusing on their condition or prognosis. According to the World Health Organization, there are 56.8 million people worldwide who require palliative care annually (WHO, 2020). In the United States, 14-20% of people admitted to the Intensive Care Unit (ICU) have a terminal condition which prompts a palliative care consultation (Mercadante et al., 2018). The timing of the initial palliative consultation and the circumstances prompting it are often not recognized in a timely manner.

Palliative care treatments and therapies are of value to the quality of life in people with terminal conditions when initiated early. Palliative care focuses on symptom management and quality of life and can be initiated as early as diagnosis. Early initiation of palliative care can lead to better management of the condition's clinical manifestations, improved quality of life, enhanced caregiver support, and patient-centered care (Allen et al., 2022). Palliative care outcomes support people whether they are receiving life-saving treatments or focusing on comfort care for their illness. Additionally, early initiation of palliative care decreases the number of hospitalizations and reduces healthcare costs for people with chronic and terminal conditions (Allen et al., 2022).

PROBLEM

Terminal conditions can be diagnosed in the primary care setting as well as the acute care setting, depending on the individual's encounter with the healthcare system. Palliative care focuses on managing side effects, clinical manifestations of the condition, and psychosocial issues throughout the duration of a terminal illness and is most commonly received as outpatient therapy (American Cancer Society, 2019). Palliative care can be implemented in the ICU to relieve physical and psychosocial symptoms related to treatment and prognosis, support patients and families, identify patient-centered goals of care, and provide end-of-life care (Mercadante et al., 2018).

Early palliative care consultation can occur in either the inpatient or outpatient setting. Early identification of potential diagnoses for palliative consultation in the ICU can improve symptom management, support, patient-centered care, and quality of life for people with terminal conditions (Allen et al., 2022). Further research is required to explore issues related to early palliative care services in the critical care setting for people with terminal conditions.

PURPOSE

The primary purpose of this review of literature is to identify barriers to early initiation of palliative care consults in the critical care setting. This review will provide a better understanding of current factors that impede early identification and consultation of palliative care services for people who have been diagnosed with a terminal condition. The secondary purpose of this review of literature is to examine characteristics that are currently being used by practitioners to identify patients as a potential candidate for palliative care services.

METHOD

A review of available literature was performed using the Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medical Literature Analysis and Retrieval System Online (Medline), Elton B. Stephens Company (EBSCO) host, and Elsevier databases. Search results were limited to peer-reviewed research articles available from 2000 to 2023 regarding palliative care in the critical care setting. Search terms used independently or in combination included: “palliative care”, “critical care or intensive care or ICU”, and “barriers or obstacles or challenges”. Inclusion criteria consisted of published research articles written in English, articles with full-text availability, and research pertaining to palliative care in the critical care setting. Exclusion criteria consisted of published research articles without full-text availability, research not pertaining to the critical care setting, and research only focusing on end-of-life and hospice care.

Each article was individually reviewed for relevance to palliative care in the critical care setting in people with terminal conditions. All relevant articles were synthesized by the researcher and key findings were extracted. A total of 12 articles were included in this review of literature.

BACKGROUND

Several barriers influence early consultation for palliative care. These barriers to palliative care can be classified into three separate categories: practitioner-related bias, patient and family perceptions, and education and legal factors.

Practitioner Related Bias

Practitioner-perceived time constraints with individuals and their families can influence early palliative care consultation. Practitioners believe comprehensive palliative care discussions are difficult to fit into their already full schedules (Enguidanos et al., 2021). Additionally, practitioners can have cultural or personal beliefs leading to reluctance of palliative care consultation or discussion (Enguidanos et al., 2021). Death and dying are considered taboo in many cultures, which can influence a practitioner's motivation to introduce the idea of palliative care to a patient or their family. Professional bias can also lead to practitioners offering false hope when they "foster, or fail to correct, the unrealistic expectations of patients and family" (Gruzden et al., 2012, p. 658). Finally, although palliative care can be given concurrently with disease treatment, practitioners can see palliative care consultation as failure or giving up on the patient (Hawley, 2017). Professional bias can influence patient and family decision-making regarding early palliative care consultation.

Patient and Family Perceptions

Many factors related to the individual and their family can delay palliative care consultation. People in certain living conditions such as homelessness, housing instability, or rural areas can have difficulty or reluctance accepting palliative care due to access issues (Enguidanos et al., 2021). Additionally, families can have financial concerns about the cost of palliative care treatments (Enguidanos et al., 2021). Like practitioners, many also have cultural or personal beliefs about health and dying, discouraging them from palliative care discussions (Enguidanos et al., 2021). Reluctance and cultural beliefs about death and dying can also lead people to have unrealistic beliefs about their disease trajectory, leading to false hope (Gruzden et al., 2012). Similarly, families can have psychosocial factors such as “magical thinking”, or the idea that not referring to death or dying prevents it from happening (Hawley, 2017). Many complex factors can influence decision-making and postpone initial consultation for palliative care in people with terminal conditions. Lack of education and complex legal factors can also discourage families from early palliative interventions.

Education and Legal Factors

Lack of education and knowledge gaps about palliative care can create barriers to early palliative care consultation. One major barrier to early consultation is the public’s lack of education and misunderstanding about palliative care services. According to a qualitative palliative care study by Alcalde and Zimmermann, the participants described themes regarding palliative care stigma including death, hopelessness, dependency, and end-of-life care (2022). The public’s misperception commonly creates pushback against early consultation.

Although the public’s lack of education is a major barrier, the issue also falls on practitioners. Healthcare practitioners possess knowledge gaps and misperceptions about palliative care due to limited education about the topic in their training programs. Although palliative and end-of-life care is mentioned in nursing school and medical school, students spend less than 15 hours overall dedicated to the subject (Dickinson, 2007). Additionally, many practitioners report palliative care as the area of expertise they feel least prepared to deal with (Chiu et al., 2014). A lack of education on palliative care in the public domain and in professional education creates barriers to early palliative care consultation.

Legal barriers to early palliative care consultation can be overwhelming and intimidating for people with terminal conditions. One major barrier is insurance coverage. Although private and public insurance covers part of palliative care costs, the financial burden placed on the person with a terminal condition can vary greatly between prognosis and disease progression (National Institute on Aging, 2021). Additionally, a lack of advance care planning (ACP) and advance directives (AD) can lengthen the time between diagnosis and an initial palliative care consultation. Advance care planning helps people with terminal conditions create guidelines for receiving care which align with their personal goals, values, and preferences (Silviera, 2023). Advance directives are legal documents outlining a person's wishes about treatment decisions in the event of losing decision-making capacity (Silviera, 2023). Completion of ACP and AD documents assists people with terminal conditions in deciding their plan of care, which can lead to an early palliative care consultation. Finally, health care surrogates can impede early palliative care consultation by reluctance to accept palliative care on behalf of their loved one, despite terminal illness. Health care surrogates are intended to make decisions based on their loved one's wishes or best interest, and personal feelings of doubt or uncertainty can prevent surrogates from accepting palliative care (Silviera, 2023).

There are many legal components of palliative care intended to keep an individual's best interests in mind. The legal language can also create hurdles for early palliative care consultation for people with terminal conditions. Understanding of legal jargon, particularly related to health care decision-making at end of life, can be elusive. Legal documents can be complex and include difficult language to understand for individuals not well-versed in legal terminology. Additionally, it can be difficult for individuals and their families to understand ACP documents and the differences between documents such as a living will, Do Not Resuscitate (DNR) order, durable power of attorney, and health care surrogate. A living will outlines a person's desired treatment choices in a situation where they have lost decision-making capacity and can specify which treatments a person does or does not wish to receive as well as under what conditions these choices apply (National Institute on Aging, 2022). This is commonly confused with a DNR form, which is an order signed by the practitioner and patient or health care surrogate indicating a person should not receive cardiopulmonary resuscitation (CPR) in the event of respiratory or cardiac arrest (Florida Department of Health, 2018). A health care surrogate is identified by a person to become their decision-maker on health care treatments if they lose decision-making capacity, which differs from a durable power of attorney. A power of attorney is similar to a health care surrogate and can make health care decisions if a health care surrogate is not identified. They are also able to make decisions regarding financial and legal matters (Palm Beach County Health Department, 2006). Understanding and completing ACP health care documents can be difficult. Obtaining a legal representative for a person with terminal conditions can lead to emotional burdens families are often not prepared to discuss or acknowledge.

Although early palliative care consultation has many barriers, exploring the issues related to bias, education, and legality can improve access to palliative care services for people with terminal conditions.

RESULTS

Twelve articles related to palliative care integration in the critical care setting in people with terminal conditions were included in this review. Study designs included in this review were qualitative-descriptive, cross-sectional, prospective-observational, quantitative-descriptive, quality improvement, and retrospective cohort. While some studies only identified one barrier category, many studies examined a combination of barriers. Eleven of the included studies identified education and legal factors as significant barriers to palliative care consultation in the critical care setting. Six studies identified patient and family perceptions as a significant barrier to palliative care consultation. Five studies identified practitioner related bias as a significant barrier to consultation.

Palliative Care in the Adult Setting

Ten of the studies included in the review of literature examined factors related to palliative care consultation in the adult critical care setting. Six studies exclusively identified and described education and legal barriers. Two studies described barriers from all three categories. While the two remaining studies included in this review of literature both identified barriers related to patient and family perceptions, one also identified education and legal barriers while the other also described practitioner related bias.

Studies Exclusively Identifying Education and Legal Factors

A cross-sectional survey conducted in thirty-three adult ICUs in hospitals across Egypt used questionnaires utilizing the PEOL Care Index to assess palliative care education, practice, and competence among nurses (Eltaybani et al., 2020). Results showed although 96.4 percent of nurses had experience caring for a dying patient, only 29.3 percent had received training or education on palliative and end-of-life care (Eltaybani et al., 2020). This study identifies the lack of education surrounding palliative care for practitioners and suggests providing training and education on palliative care would increase practitioner competence and quality of care in this specialty (Eltaybani et al., 2020).

A retrospective cohort study conducted by Martz et al. found the presence of advance directives increases palliative care consultation, and patients who receive a consult are very likely to accept palliative services (2020). Although less than 50 percent of participants in the study had advance directives on admission, patients who possessed these documents were more likely to receive a palliative care referral (Martz et al., 2020). Possessing advance directives assists patients in assessing their personal goals for their health, care, and quality of life.

One study described a quality improvement project conducted in the Adult ICU of a Cancer Institute in India. The aim of this study was to initiate palliative care referral for at least 50 percent of progressive palliative intent cancer patients in the ICU (Balakrishna et al., 2023). A palliative care trigger tool was developed for the study, which included factors such as symptom management, length of stay, ventilator support, organ failure, neurological insult, request for palliative care, futility of treatment, and a prognosis of less than six months (Balakrishna et al., 2023). Patients were referred if they met at least one of the criteria from the tool, and after implementation palliative care referral increased by 70 percent (Balakrishna et al., 2023). This study suggests implementation of a palliative care referral tool increases palliative care consultation for critical care patients with terminal conditions.

Similarly, Poi et al. conducted a prospective observational study to evaluate the impact of a formal palliative care referral checklist on patients in the ICU (2021). Patients were screened by both the palliative care and ICU teams and would receive a referral if they met at least one of the criteria included in the tool (Poi et al., 2021). The criteria included futility of treatment, symptom management, request to explore supportive care, conflicts regarding treatment, and factors related to neurological, cardiac, or cancer related severe conditions (Poi et al., 2021). After implementation of the referral checklist, 662 patients were referred to palliative care services (Poi et al., 2021). The most common criteria for palliative care referral were low presenting Glasgow Coma Score, consideration of ventilator withdrawal, and multi-organ dysfunction (Poi et al., 2021). This study's findings also suggest the creation of a palliative care referral tool increases consultation for patients who would benefit from palliative services.

A cross-sectional study in India conducted by Kamel et al. aimed to assess house staff's knowledge, attitudes, and perceived barriers of palliative care in the ICU (2013). 23 of the 30 respondents reported receiving some type of training in palliative care, with didactic lectures being the most common form of training (Kamel et al., 2013). Only 7 percent of respondents had completed an elective rotation in palliative care (Kamel et al., 2013). 41 percent would only consider palliative care consultation when a patient is terminally ill or rapidly deteriorating (Kamel et al., 2013). The most common identified barriers were discrepancies in treatment goals between families and medical teams, lack of advance directives, uncertain prognosis, communication with families, and protocols for palliative care (Kamel et al., 2013). The findings illustrate there is limited education provided to house staff, which affects the provision of palliative care for patients in the critical care setting.

One study conducted by Wolf et al. examined the relationship between critical care nurses' perceived knowledge of palliative care and their experiences of moral distress (2019). 167 critical care nurses completed a survey included the Palliative Care Competencies of Registered Nurses survey and Moral Distress Thermometer (Wolf et al., 2019). While most respondents rated each domain of palliative care as "highly important", less than 40 percent rated themselves “highly competent” in any domain (Wolf et al., 2019). The most identified issues of moral distress were unclear goals of care, prolonged dying, inadequate staffing or experience, and providing false hope (Wolf et al., 2019). The study found perception of more adequate use of palliative care services were related to lower levels of moral distress (Wolf et al., 2019).

Studies Pertaining to all Three Barrier Categories

Kennedy et al. conducted a cross-sectional study to assess the views of practitioners on the use of available pain and palliative care specialists at their institution, as well as assess their ability to recognize terminal, non-cancer illnesses (2019). Participants consisted of 90 nurses, nurse practitioners, internal medicine residents, and internal medicine attendings, excluding any pain and palliative specialists (Kennedy et al., 2019). The most common referral reasons were hospice care, terminal cancer, and uncontrolled pain (Kennedy et al., 2019). Over 50 percent of participants were uncertain or disagreed to referral for patients with non-cancer diseases (Kennedy et al., 2019). Most participants reported the appropriate time for consultation was at diagnosis of a terminal illness (Kennedy et al., 2019). The main perceived barrier reported in the study was late involvement of palliative care (Kennedy et al., 2019). Additional barriers identified were attending’s reluctance to consult, patient or family lack of understanding, and the belief that palliative care consultation means discontinuing life-saving care (Kennedy et al. 2019). The findings of this study illustrate the lack of education regarding differentiation between palliative and hospice care and conditions that would benefit from palliative care services.

A qualitative-descriptive study conducted by Vaughn and Salas explored critical care nurses’ perceived barriers and facilitators of palliative care (2022). The study used purposive sampling, and inclusion criteria extended to registered nurses or nurse practitioners with at least one year of experience in critical care (Vaughn & Salas, 2022). The 11 participants identified the main barriers as inconsistent communication, the burden of decision-making on patients and their families, lifesaving mentality and moral distress of practitioners, and lack of education and training in palliative care (Vaughn & Salas, 2022). The main facilitators identified in the study were honest, timely, and patient centered communication, advance care planning, and access to palliative care education (Vaughn & Salas). Findings suggest increased education on palliative care for practitioners would improve palliative care services for critical care patients with terminal illnesses.

Studies Identifying Patient and Family Perception Barriers

Patient and Family Perceptions and Education and Legal Factors. A cross-sectional study conducted in India aimed to assess the knowledge, attitudes, and perceived barriers regarding palliative and end of life care among critical care nurses (Walia et al., 2020). 386 critical care nurses participated, with the inclusion criteria of at least one year of experience in critical care (Walia et al., 2020). Although over 80 percent of nurses had a positive attitude towards palliative care, only 7 percent reported having “good” knowledge of the topic (Walia et al., 2020). The perceived barriers identified in the study were family members not accepting poor prognosis, difference in physician opinions about treatment, frequent calls from family requesting information, and family members not understanding the meaning of lifesaving measures (Walia et al, 2020). Findings suggest increasing training and education for practitioners would help bridge the gap between attitudes, knowledge, and practice of palliative care.

Patient and Family Perceptions and Practitioner Related Bias. A quality improvement project was conducted by Hui et al. to assess perceived attitudes and barriers of ICU clinicians related to palliative care and identify criteria for the development of an ICU palliative care trigger tool (2016). 526 clinicians participated in the survey, which utilized the ICU Palliative Care Quality Assessment Tool (Hui et al., 2016). Responses greater than or equal to 4 on the 5-point Likert scale were considered positive (Hui et al., 2016). Results showed the most common perceived barriers were patient and family reluctance, clinician disagreement, and inadequate comfort level, while the most reported triggers for palliative consultation were active stage IV malignancy, patient or family support of palliative care, and request or decision to forego life-sustaining treatment (Hui et al., 2016).

Palliative Care in the Pediatric and Neonatal Settings

Two studies included in the review of literature examined factors related to palliative care consultation outside of the adult critical care setting. Both studies identified barriers to palliative care consultation from all three categories. In a cross-sectional descriptive study, nurses and physicians across seven different hospitals completed a questionnaire utilizing the Neonatal Palliative Care Attitude Scale to compare attitudes of nurses and physicians towards neonatal palliative care, as well as identify barriers and facilitators to palliative care in the neonatal setting (Jung & Ju, 2021). Education and legal related barriers identified in the study included absence of education on palliative care for both practitioners and families, as well as lack of guidelines and policies pertaining to palliative care consultation (Jung & Ju, 2021). Identified barriers pertaining to patient and family perceptions included parental demands for continued life saving measures and unavailable counseling (Jung & Ju, 2021). Attributes related to the physical environment, staffing, time, and team expression of opinions, values, and beliefs were identified barriers related to practitioner related bias in the study (Jung & Ju, 2021).

A qualitative, descriptive study conducted in a single pediatric ICU assessed effectiveness of practitioner communication in family meetings pertaining to palliative care adoption. Data was collected through semi-structured interviews and questionnaires and found ten of the fourteen meetings demonstrated effective communication (Neis et al., 2020). Identified issues related to practitioner related bias were conversations lacking psychological connection, using harsh vocabulary pertaining to the situation, and lack of concern for family feelings (Neis et al., 2020). Findings suggested that while objectivity, clarity of information, and use of understandable language with family are important, they should be used with empathetic communication techniques to be perceived as adequate or effective (Neis et al., 2020). This study also suggests using a feedback technique after family meetings would help negate certain education and perception barriers by assessing what was understood by the family from the practitioner's communication (Neis et al., 2020).

DISCUSSION

The articles analyzed in this literature review identify the major barriers impeding palliative care consultation in the critical care setting for adults with terminal conditions. While there were many complex barriers noted, the most identified barriers from synthesis of the articles were related to education and legal factors. Some of the most common were lack of education for practitioners, patients, and their loved ones, absence of advance care planning and advance directive documents, and the lack of guidelines or set referral criteria to assist practitioners with identifying potential candidates for palliative care consultation.

The reviewed articles suggest an increase in palliative care education provided to practitioners is potentially beneficial in both perceived and actual palliative care consultation and quality outcomes. It is evident from the synthesis that implementation of a formal palliative care referral tool would increase consultation and improve equal access to palliative care services for adults in the critical care setting with terminal conditions. The creation and implementation of a standardized palliative care referral tool would assist providers in identifying candidates for palliative care based on evidenced based characteristics, rather than leaving consultation up to the provider's decision.

Synthesis of the articles showed most practitioners were only comfortable providing a palliative care referral if patients exhibited certain characteristics such as stage IV or terminal cancer, medical futility, rapid deterioration in conditions, and patient or family request to discontinue lifesaving measures or explore supportive care options. Implementation of additional palliative care education would assist providers in discriminating between palliative and hospice care, as well as better identify patients with clinical manifestations or conditions that would benefit from palliative care services.

The most notable limitation identified in the review of literature was sample size. While a few of the studies were conducted in multiple units or hospitals, many were conducted in a single unit and had a limited sample size. Further studies with larger sample sizes and across additional units or hospital systems would be beneficial.

Although these articles identified barriers to palliative care consultation and identified beneficial interventions, further research is needed with larger sample sizes. This will increase the validity of current research findings and the amount of evidence supporting certain palliative care interventions for use in the clinical setting.

CONCLUSION

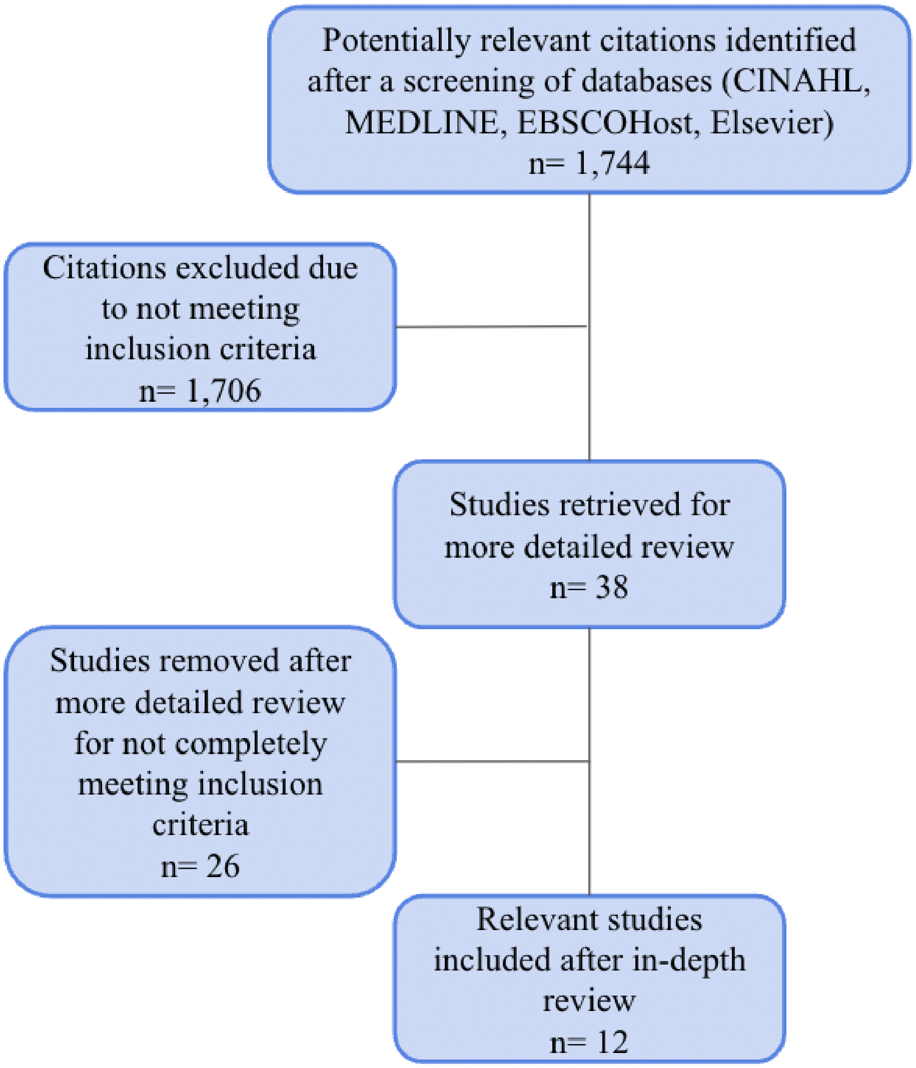
The purpose of this literature review was to identify barriers to early initiation of palliative care consults in the critical care setting. Although a significant percentage of people in the critical care setting could benefit from palliative care services, there are a multitude of complex barriers that impede consultation for people with terminal conditions. Additionally, the timing of initial consultation and the characteristics prompting it are often not recognized in a timely manner. Initiation of palliative care near the time of diagnosis with a terminal condition has been found to improve quality of life, promote patient-centered care, enhance support of caregivers and loved ones, and provide management of difficult to control clinical manifestations.

Initial analysis of the data identified three categories as barriers to initiation of palliative care services: practitioner-related bias, patient and family perceptions, and education and legal factors. Exploring the issues related to bias, perceptions, education, and legality can improve access to palliative care services for people with terminal conditions. Results demonstrated that while there are many complex barriers to palliative care consultation, the most prominent barriers are related to education and legal factors. Lack of education and guidelines surrounding palliative, hospice, and end-of-life care inhibits practitioners from identifying potential candidates for palliative services and providing high quality palliative care.

As the practitioner at the bedside providing patient care, it is essential that nurses are provided sufficient education and training regarding palliative and end-of-life care to provide optimal patient-centered care. Implementation of a standardized referral tool would assist nurses and other practitioners in detecting characteristics that identify a potential candidate for consultation and providing equal access to palliative care services for people with terminal conditions.

Overall, it is evident that many complex barriers influence palliative care consultation in the critical care setting in people with terminal conditions. Interventions are necessary to minimize these barriers and improve palliative care consultation and access. The studies reviewed in this systemic review of the literature suggests interventions such as education, standardized referral criteria, and established guidelines could be beneficial in overcoming the barriers associated with palliative care consultation in the critical care setting.

APPENDIX A: FIGURE 1



Inclusion criteria: peer reviewed research articles, published in English language, publication date between 2000-2023, full-text availability

Search terms: “palliative care” AND “critical care or intensive care or ICU” AND “barriers or obstacles or challenges”

Figure 1: Consort Diagram of Thesis Methodology

APPENDIX B: TABLE 1

Table 1: Table of Evidence

Author(s) Year Location	Study Design & Purpose	Sample Size & Screening Measures	Results	Key Findings & Relevant Barrier Category (practitioner-related bias, patient and family perceptions, education and legal factors)
Balakrishna et al. (2023) India	Quality improvement project, A3 problem solving method, Plan Do Check Act process Initiate palliative care referral for at least 50% of progressive palliative intent cancer patients in the ICU	The QI project was conducted in the ICU of one cancer institute. A palliative care trigger tool was developed for referrals. Any patients that met at least one of the following criteria were referred: difficulty to control physical symptoms, ICU length of stay more than 7 days, ventilator support for more than 5 days, multiorgan failure more than 3 days, major acute neurological insult, more than 1 ICU admission during same hospitalization, oncologist or family request to palliative care, futile treatment, answered "no" to	Palliative care referral increased from 0% to over 70% from November 2019 to March 2020. In 2021 they found that although palliative care referrals from the ICU were decreasing, the patients who met criteria were being moved to different units and getting referred from there.	Introducing a standardized referral criteria tool drastically increased the number of palliative care referrals. This increased access to palliative care for patients with palliative needs. Patients who could benefit from palliative care were being triaged accordingly, decreasing unnecessary stay in the ICU. Barrier categories: education and legal factors

		"would you be surprised if the patient died within the next 6 months?"		
Eltaybani et al. (2020) Egypt	Cross-sectional survey Assess palliative care education, practice, and perceived competence among adult ICU nurses in Egypt.	N= 33 33 adult ICUs in selected hospitals across Egypt. Inclusion criteria: nurses performing direct patient care in these ICUs. Self-administered, anonymous questionaries using the Arabic version of the PEOL Care Index.	33 nurse managers and 403 staff nurses participated. 97% of the ICUs have restricted visitation, 85% do not have a family meeting room, and 82% do not have institutional standards for end-of-life care. 96.4% of nurses had experience caring for dying patients, but only 29.3% had in-service training on palliative or end-of-life care. Receiving in-service training on palliative care was associated with higher palliative care practice and competence scores.	Although almost all nurses had been put in a position to care for a dying patient, less than 30% of them had training to do so. Training nurses in palliative care increases the perceived quality of palliative care administered to patients by nurses. Barrier Categories: education and legal factors
Hui et al. (2016) United States	Needs assessment survey, quality improvement project	N= 526 Paper and electronic survey with domains	Most common perceived barriers were patient and family	Although almost all participants believed palliative care was important for

	Assess perceived attitudes, issues, and barriers of ICU clinicians related to palliative care and identify suggested criteria for development of an ICU palliative care trigger tool.	from ICU Palliative Care Quality Assessment Tool distributed to full-time ICU clinicians. 5-point Likert scale used, and responses greater than or equal to 4 (agree or strongly agree) were considered positive. 95% believed palliative care was important in patient care. 79% believed they could personally provide palliative care.	reluctance, clinician disagreement, inadequate comfort level. The most reported triggers for palliative consultation were active stage IV malignancy, patient or family support, and request or decision to forego life-sustaining treatment.	patient care, only 79% were confident in their ability to provide it. ICU clinicians were most likely to refer patients to palliative care if they had stage IV cancer, patient and/or family support of palliative care, or a request/decision to forego life-sustaining treatment. Barrier categories: patient and family perceptions and practitioner related bias
Jung, H. N., & Ju, H. O. (2021) Korea	Cross-sectional study, descriptive study Compare attitudes of nurses and physician towards neonatal palliative care and identify barriers and facilitators of neonatal palliative care.	N= 164 112 nurses, 52 physicians across 7 different hospitals Inclusion criteria: nurses who provide direct care in NICU and have at least one year of NICU experience, NICU physicians, pediatric residents, and NICU specialists. Data collected using Neonatal	About 88% of nurses and physicians had not received education in neonatal palliative care, but 89.3% of nurses and 84.6% of physicians reported that education on the topic was necessary. Parents involved in decision making was identified	Nurses identified twice as many barriers as physicians. Main facilitators agreed upon by both groups were parent involvement in decision making, health care team supports palliative care, and parents are informed of palliative care options. Barriers agreed upon by both

		Palliative Care Attitude Scale	as highest scored facilitator. While all the organization items were considered facilitators for physicians, “team can expression opinions, values, and beliefs” was considered a barrier for nurses. All items in the resource category were considered barriers to nurses, but only items related to guidelines or counseling were barriers for physicians. All items in the clinical category were barriers for nurses and physicians.	groups were lack of guidelines/policies for palliative care, unavailable counseling, technological imperatives, and parental demands for continued lifesaving measures. Identified barriers in the study were expression of opinions, values, and beliefs about palliative care, the physical environment, staffing, and time. Nurses were less likely than physicians to believe they could express their opinions and beliefs about palliative care. Absence of education is a barrier to successful neonatal palliative care. Barrier Categories: practitioner-related bias, patient and family perceptions,

				education and legal factors
Kamel et al. (2013) Missouri	Cross-sectional study Assessing house staff's knowledge, attitudes, and identifying perceived barriers while delivering palliative and end of life care in the ICU.	N= 30 Electronic surveys sent to house staff in the ICU at one hospital in St. Louis	23 respondents reported receiving any training in palliative care. Didactic lectures were most common form of training. Only 7% did an elective rotation in palliative care. 41% would only consider palliative care when a patient is terminally ill or rapidly deteriorating. Only 53% reported being comfortable in delivering palliative care in the ICU. Most common identified barriers were discrepancies in treatment goals between medical team and families, lack of advance directives on admission, uncertain prognosis, effective	Not all house staff receive palliative care training, and most of it is not provided through hands-on experience. There is a small amount of house staff that have completed a rotation in palliative care. Lack of education increases discomfort in providing palliative care and decreases chances of patients receiving palliative care. Barrier Category: education and legal factors

			communication with families, and protocol for managing palliative care patients.	
Kennedy et al. (2019) Ohio	Cross-sectional study Assess the views of practitioners of use of available pain and palliative care specialty at their institution, and assess their ability to recognize terminal, non-cancer illnesses.	N= 90 Inclusion criteria: nurses and nurse practitioners of medicine wards and internal medicine residents and attendings. Exclusion criteria: nurses and attending physicians that were pain and palliative specialists Purposive sampling, participants filled out an anonymous questionnaire	Most common referral reasons were hospice care, terminal cancer, and uncontrolled pain. Over 50% of nurses and physicians were uncertain or disagreeable to referral for patients with noncancer, disease causing limiting capacity. Although most respondents believed appropriate time for consult was at point of diagnosis of terminal illness, about 25% of nurses and physicians believed it should be when all interventions are futile. Residents and nurses top perceived barrier to	Practitioners are more likely to provide a palliative care consultation to patients with terminal cancer rather than a noncancer illness. Although most believed that palliative care is most effective at the point of diagnosis, in practice the main perceived barrier was late involvement of care. Lack of understanding. Between palliative and hospice care limits consultation. Although other health care professionals report attendings' reluctance as a major barrier, physicians did not see this as a barrier.

			consultation was attending's reluctance to consult. Physician's main perceived barriers were patient/family lack of understanding and the belief that a consult means discontinuation of life-saving care.	Barrier Categories: practitioner-related bias, patient and family perceptions, education and legal factors
Martz et al. (2020) United States	Retrospective cohort study Identify outcomes associated with palliative care referral for patients with critical illness.	N= 112 Inclusion criteria: adults admitted to the medical-surgical ICU of a community health system in Idaho between September 2017 and March 2018, and patients with positive results on the screening tool. Exclusion: length of stay less than 24 hours Screening tool included disease process information, indirect markers of functional status, patient/family requests for help with decision-	Less than half of participants had advance directives on admission, but these patients were more likely to receive a palliative care consult. 65 did not receive palliative care consultation. Patients who received consult were more likely to be discharged home with hospice or nonhospice institution. All 47 patients referred accepted	The presence of advance directives increases palliative care consultation. Patients who receive a consult are very likely to accept palliative care and continue palliative care treatment after hospitalization. Barrier category: Education and legal factors

		making, and the presence of unrelieved pain or symptoms.	palliative care treatment.	
Neis et al. (2020) Brazil	Qualitative, descriptive study Assess the development of interprofessional team's communication processes when deciding on adoption of palliative care in the Pediatric ICU and analyzing their effectiveness.	N= 14 Inclusion criteria: all families called to meeting with interprofessional team regarding palliative care from January to November 2017 in a single PICU. Semi structured interviews with responsible family member, and questionnaires sent to the medical professional and nurse present at meetings.	10 of the 14 meetings demonstrated communicative efficacy. 4 meetings were considered to have ineffective communication.	Although communication was effective in most situations, some lacked psychological connection, milder words, and concern for family feelings. Objectivity, clarity, and use of understandable language with family are essential, but should be used with empathetic communication to be perceived as adequate. Using a feedback technique can increase communicative efficacy by ensuring the health care professional is aware of what was understood. Barrier Categories: practitioner-related bias, patient and family perceptions, education and legal factors

Poi et al. (2021) Singapore	Prospective, observational study Evaluate the impact of a formal palliative care referral checklist on patients in the ICU	N=662 Ethical approval obtained from the Institutional Review Board. Patients screened by both palliative care and ICU teams were referred if they met ≥ 1 criteria: hypoxic ischemic/anoxic encephalopathy, severe head injury, hemorrhage, or ischemic stroke with poor neurological prognosis, low presenting Glasgow coma score (GCS) ≤ 6, status post cardiopulmonary arrest, intractable chest pain, arrhythmias, or heart failure for which further treatment is futile, end-stage valvular heart disease for which surgical management is no longer possible, active stage IV malignancy, advanced dementia (FAST scale stage 7 or greater), two or more ICU	662 patients were referred. Most common criteria were low presenting GCS, consideration of ventilator withdrawal, and multi-organ dysfunction. Palliative care referrals in the ICU increased from 25 patients in 2013 to 111 patients in 2016.	Study showed that creation of referral criteria drastically increased the number of referrals and assisted patients in meeting their previously unmet palliative care needs. Barrier category: education and legal factors

		admissions within same hospitalization, multisystem organ dysfunction ≥ 2 organ systems, consideration of mechanical ventilator withdrawal expected to result in death, consideration of tracheostomy after intubation ≥ 14 days, difficult-to-control physical symptoms despite usual treatment, complex family dynamics impacting decisions about use of life-sustaining treatments, conflicts about prognosis and/or use of life-sustaining treatments, patients/surrogates wish to explore non-ICU supportive care options, and consideration for terminal discharge		
Vaughn, L., & Salas, A. S. (2022) Canada	Qualitative-descriptive study Explore perceived barriers and facilitators in the	N= 11 Purposive sampling of participants that met inclusion criteria: critical care RN or NP	Main barriers and facilitators identified were communication, end of-life decision making, life-	Nurses believed that these five factors could act as both barriers and facilitators depending on the circumstance.

	provision of palliative care in the critical care setting from critical care nurses' perspectives.	with at least one year of experience in critical care	saving mentality of the ICU, palliative care education, and the critical care environment.	Inconsistent communication, disagreements and burden of decision making, lifesaving mentality and moral distress, and lack of education and training were examples of the barriers nurses noted. Honest, timely, and patient-centered communication, advance care planning, and access to palliative care education and training were examples of the facilitators that nurses noted. Barrier categories: practitioner-related bias, patient and family perceptions, education and legal factors
Walia et al. (2020) India	Cross sectional study Assess knowledge, attitudes, practices, and perceived barriers regarding palliative and	N= 386 Convenience sampling was used Inclusion criteria: RN with at least one year experience in critical care	41.4% of nurses had poor knowledge regarding palliative and EOLC. Knowledge and attitude scores related to palliative care	Although most nurses had a positive attitude towards palliative care, less than 10% had what was considered "good" knowledge of it.

	end of life care (EOLC) among critical care nurses	Majority of participants were female, married, graduates, and had more than 2 years of critical care experience.	were higher in those with additional palliative and EOLC training. 88% of nurses had a positive attitude to palliative and EOLC, but only 7% had good knowledge regarding the topic. Common perceived barriers for providing palliative and EOLC were family members not accepting poor prognosis, difference in physician's opinion about treatment, frequent calls from family asking the nurses for information, and family members not understanding the meaning of lifesaving measures	Perceived barriers were related to patient and physician lack of education on the topic and family perceptions regarding the patient's treatment and prognosis. The study recommends an increase in palliative care training and education for practitioners to bridge the gap between critical care attitudes, knowledge, and practice. Barrier categories: patient and family perceptions, education and legal factors
Wolf et al. (2019) Virginia	Quantitative, descriptive study Examine critical care nurses' perceived	N= 167 Convenience sampling was used, and surveys were sent out to	Majority rated each palliative care domain as highly important, but less than 40%	Most of the participants highly valued palliative care.

	knowledge of palliative care, experiences of moral distress, and the relationship between the two variables.	critical care nurses in 7 ICUs at one institution. The survey included the Palliative Care Competencies of Registered Nurses survey and Moral Distress Thermometer.	rated themselves highly competent in any domain. Most frequent issues of moral distress were unclear goals of care, prolonged dying, inadequate staffing or experience, and providing false hope. No correlation was found between perceived competence and moral distress. Perception of more adequate use of palliative care services were related to lower levels of moral distress.	Nurses are prone to higher levels of moral distress if they feel their patient's palliative care needs are not being met. Barrier Category: Education and legal factors

REFERENCES

Agency for Health Care Administration. (2006). *Health care advance directives.* Palm Beach County Health Department. https://palmbeach.floridahealth.gov/programs-and-services/clinical-and-nutrition-services/registration-forms-clinic-services/_documents/health-care-advance-directives-english.pdf

Alcalde, J., & Zimmermann, C. (2022). Stigma about palliative care: origins and solutions. *Ecancermedicalscience, 16*, 1377. https://doi.org/10.3332/ecancer.2022.1377

Allen, E., Stanek, J., & Lundorf, J. (2022). Early palliative care initiation: Role of the primary care clinician. *The Journal for Nurse Practitioners, 18*(5), 493-495. https://doi.org/10.1016/j.nurpra.2022.01.026

American Cancer Society. (2019). *How and where is palliative care provided and how is it paid for?* American Cancer Society. https://www.cancer.org/cancer/managing-cancer/palliative-care/who-provides-palliative-care.html

Balakrishna, K., Ramasamy, T., & Venketeswaran, M. V. (2023). Initiation of palliative care referral from the intensive care unit for advance state metastatic cancer patients: A quality improvement process from a tertiary referral cancer institute from south India. *Indian Journal of Palliative Care, 29*(4), 412-417. https://doi.org/10.25259/IJPC_267_2022

Chiu, N., Cheon, P., Lutz, S., Lao, N., Pulenzas, N., Chiu, L., McDonald, R., Rowbottom, L., & Chow, E. (2014). Inadequacy of palliative training in the medical school curriculum.

Journal of Cancer Education, *30*(4), 749-753. https://doi.org/10.1007/s13187-014-0762-3

Dickinson, G. E. (2007). End-of-life and palliative care issues in medical and nursing schools in the United States. *Death Studies, 31*(8), 713-726. https://doi.org/10.1080/07481180701490602

Eltaybani, S. Igarashi, A., & Yamamoto-Mitani, N. (2020). Palliative care in adult intensive care units: A nationwide survey. *Nursing in Critical Care*, *26*(5), 315-325. https://doi.org/10.1111/nicc.12565

Enguidanos, S., Cardenas, V., Wenceslao, M., Hoe, D., Mejia, K., Lomeli, S., & Rahman, A. (2021). Health care provider barriers to patient referral to palliative care. *The American Journal of Hospice & Palliative Care*, *38*(9), 1112–1119. https://doi.org/10.1177/1049909120973200

Florida Department of Health. (2018). *What is a do not resuscitate order?* Florida Health. https://www.floridahealth.gov/about/patient-rights-and-safety/do-not-resuscitate/faq-page.html#order

Gruzden, C. R., Richardson, L., D., Major-Monfried, H., Kandarian, B., Ortiz, J., M., & Morrison, R., S. (2012). Hospital administrators' views on barriers and opportunities to delivering palliative care in the emergency department. *Annals of Emergency Medicine, 61*(6), 654-660. https://doi.org/10.1016/j.annemergmed.2012.06.008

Hawley, P. (2017). Barriers to access to palliative care. *Palliative care*, *10*, 1178224216688887. https://doi.org/10.1177/1178224216688887

Hui, F., Kapo, J., & Akgün, K. (2016). Integrating palliative care into the ICU: Experiences, attitudes, and barriers of ICU clinicians. *Journal of Pain and Symptom Management, 51*(2), 321-322. https://doi.org/10.1016/j.jpainsymman.2015.12.138

Jung, H. N., & Ju, H. O. (2021). Comparison of the attitudes of nurses and physicians toward palliative care in neonatal intensive care units. *Journal of Hospice and Palliative Care, 24*(3), 165-173. https://doi.org/10.14475/jhpc.2021.24.3.165

Kamel, G., Paniagua, M., & Uppalapati, A. (2013). Assessing the housestaff knowledge, attitudes, and perceived barriers towards palliative care in the ICU. *Palliative Care and End of Life Issues,* 144(4), 751A. https://doi.org/10.1378/chest.1702426

Kennedy, R., Abdullah, N., Bhadra, R., Bonsu, N. O., Fayezizadeh, M., & Ickes, H. (2019). Barriers to effective use of palliative care services in the acute care setting with emphasis on terminal noncancer diseases. Indian Journal of Palliative Care, 25(2), 203-209. https://doi.org/10.4103/IJPC.IJPC_201_18

Martz, K., Alderden, J., Bassett, R., Swick, D. (2020). Outcomes associated with a nurse-driven palliative care screening tool in the intensive care unit. *Critical Care Nurse, 40*(3), 23-29. https://doi.org/10.4037/ccn2020702

Mercadante, S., Gregoretti, C., & Cortegiani, A. (2018). Palliative care in intensive care units: why, where, what, who, when, how. *BMC anesthesiology*, *18*(1), 106. https://doi.org/10.1186/s12871-018-0574-9

National Institute on Aging. (2022). *Advance care planning: Advance directives for health care.* National Institute of Health. https://www.nia.nih.gov/health/advance-care-planning-advance-directives-health-care

National Institute on Aging. (2021). *What are palliative care and hospice care?* National Institute of Health. https://www.nia.nih.gov/health/what-are-palliative-care-and-hospice-care#palliative

Neis, M., Rocha, C.M.F., & Carvalho, P.R.A. (2020). The communication of palliative care adoption in a pediatric intensive care unit. *Pediatric Nursing, 46*(3), 138-145. https://web.p.ebscohost.com/ehost/detail/detail?vid=2&sid=01bce36c-2867-4a06-ae5f-d147dc53fcea%40redis&bdata=JkF1dGhUeXBlPWNvb2tpZSxzaGliJmF1dGh0eXBlPXNoaWImc2l0ZT1laG9zdC1saXZlJnNjb3BlPXNpdGU%3d#AN=143616622&db=aph

Poi, C. H., Koh, M. Y., Ong, W. Y., Wong, Y., Yow, F. C., & Tan, H. L. (2021). The challenges of establishing a palliative care collaboration with the intensive care unit: How we did it? A prospective observational study. *Progress in Palliative Care, 29*(6), 342-351. https://doi.org/10.1080/09699260.2020.1852655

Silviera, M. J. (2023). *Advance care planning and advance directives*. UpToDate. https://www.uptodate.com/contents/advance-care-planning-and-advance-directives#H23369035

Vaughn, L., & Salas, A. S. (2022). Barriers and facilitators in the provision of palliative care in critical care: A qualitative descriptive study of nurses' perspectives. *Canadian Journal of Critical Care Nursing, 33*(1), 14-20. https://web.p.ebscohost.com/ehost/detail/detail?vid=0&sid=d56e9cea-5061-4ed9-ac58-bcbac1faa0e8%40redis&bdata=JkF1dGhUeXBlPWNvb2tpZSxzaGliJmF1dGh0eXBlPXNoaWImc2l0ZT1laG9zdC1saXZlJnNjb3BlPXNpdGU%3d#AN=155439019&db=rzh

Walia, A., Sharma, K. K., Garg, R., & Das, S. (2020). A descriptive study to assess knowledge, attitude, practices, perceived barriers, and support regarding palliative care and end-of-life care among critical care nurses of tertiary care medical institute. *Indian Journal of Palliative Care, 26*(4), 479-489. https://doi/org/10.4103/IJPC.IJPC_227_19

Wolf, A. T., White, K. R., Epstein, K. G., & Enfield, K. B. Palliative care and moral distress: An institutional survey of critical care nurses. *Critical Care Nurse, 39*(5), 38-49. https://doi.org/10.4037/ccn2019645

World Health Organization. (2020). *Palliative care*. World Health Organization. https://www.who.int/news-room/fact-sheets/detail/palliative-care